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## A Study of Nigerian Families Who Have a Family Member with Down Syndrome

### Abstract

*The Family Quality of Life Survey (FQOLS) (Brown et al., 2006), was administered to a group of 31 families who have children with Down syndrome enrolled at a community-based centre in Nigeria. Ideas on how families perceive services for their children, and the extent to which families are coping, are discussed. Suggestions are made for effective policy and practice and for enhanced understanding of disabilities by the society.*

This research project focuses on an exploration of quality of life of families that have children with Down syndrome (DS) in Nigeria, using the Family Quality of Life Survey (Brown et al., 2006). Although this instrument has been widely applied to the measurement of family satisfaction and well-being in some Western countries, the utilisation of the instrument is just now beginning to be employed not only as a research method, but also as an approach to understanding disabilities and family dynamics in a developing country like Nigeria (Ajuwon & Brown, 2012).

In the study to be reported, the FQOLS was utilized to assess several domains and dimensions reflecting the major components and characteristics of family quality of life of 31 families who have children at the Down Syndrome Foundation of Nigeria (DSFN). The DSFN, established in 2001, is a privately-operated community-based centre in Lagos, Nigeria. It is the only centre of its kind in Lagos for educating learners, most of whom have been diagnosed with DS (see <http://www.dsanigeria.org>). This study aims to provide a thematic analysis of the qualitative comments supporting the quantitatively measured domains and dimensions of the survey and to explore their relationships to one another.

### Method

#### Instrumentation

The FQOLS is a comprehensive tool for examining family quality of life, and is used to gather both quantitative and qualitative information. The survey tool consists of a section requesting details about the family, and nine domains: Health of the Family, Financial Well-Being, Family Relationships, Support from Others, Support from Disability-Related Services, Influence of Values, Careers/Preparing for Careers, Leisure and Recreation, and Community/Civic Interaction.

Each domain contains questions related to six key dimensions: Importance, Opportunities, Initiative, Attainment, Stability, and Satisfaction. The questionnaire has now been used in research in 20 countries. For a detailed description of the components of the survey, see Brown et al. (2006); Brown, Anand, Fung, Isaacs, and Baum (2003); Isaacs, Brown, Brown, et al. (2007); and Werner, Edwards, Baum, Brown, Brown, and Isaacs (2009).

## Procedures and Respondents

The researcher obtained formal approval from his university in the United States to conduct the study. On his arrival in Nigeria, the researcher convened a meeting with the management of the Down Syndrome Foundation of Nigeria. Approval was obtained to invite willing parents to the centre for a meeting at which the nature and scope of the study were explained, and one participant from each household was subsequently recruited for the project. These participants represented families with diverse socio-economic and educational backgrounds. Since English is the lingua franca in Nigeria, study participants had no difficulty in understanding and/or answering the questionnaire items. A clerical worker at the centre was identified and trained to assist with the administration of the instrument. The survey was completed by the volunteer respondents in small groups at the centre over a five-day period. From a standpoint of transportation and organizational efficiency, it was more effective to have the parents complete the survey when they brought their children to the centre in the morning, and/or returned them home in the afternoon.

A total of 31 out of 45 parents having a family member with DS completed the survey. Respondents were nearly evenly split between male and female (15 vs. 16). The majority of male respondents (8) were the father of the DS family member. Likewise, most female respondents were the mother of the DS family member. Seventy-four percent (23) of the 31 respondents reported belonging to an immediate family with two parents.

## Characteristics of Household Members and Caregiving Responsibilities

In one family, there was a pair of 8-year-old twin girls with DS, bringing the total number of DS family members in the study to 32. More

than half of the DS family members were male (56%). Their ages ranged from 1 to 40; 56% were minors under the age of 18. Only one DS family member was not living at home, specifically, a 24 year-old female.

With regard to caregiving roles, most families (29 or 94%) included the biological mother of the family member with DS. A majority of these mothers (83%) both lived in the home and were caregivers. They ranged in age from 28 to 72, with a mean of 46.7. Most families (23 or 74%) also included the biological father of the DS family member, 65% of whom both lived in the home and were caregivers. Their age range was 35 to 69, with a mean of 48.6. Thirty-five percent of respondents reported the presence of one or more siblings of the DS family member living at home and acting as caregivers. These 22 siblings ranged in age from 7 to 35. The mean age of the 10 male siblings was 21.1, while the mean age of the 12 female siblings was 23.25.

Involvement in family life appeared to be distributed across all family members. Respondents were asked which family member(s) was the most involved with the daily life of the DS family member. Mothers (alone) were named most frequently (18 or 58%), followed by a combination of parents and/or other family members (12 or 39%); only one father (alone) was named. With regard to the amount of personal responsibility that the respondent had for the family member with DS, responses were almost evenly divided into thirds as follows: 32% (10) indicated they had either "less' or 'about the amount of' responsibility that I like," 32% (10) indicated they had "more responsibility than I would like," and 36% (11) indicated they had "much more responsibility than I would like."

## Results

The following results are responses from the family respondents. As such they are their perceptions of the quality of life of their family. Others may have differing perceptions, but since the primary carer is making the responses, they are likely to be views which play an important role in driving the family behaviours and actions.

## Developmental and Health Issues Associated with Down Syndrome

As in other countries, the well-being of many Nigerian children and adults with DS is negatively impacted by multiple developmental and health issues. Table 1 summarizes the open-ended comments made by the respondents when asked to describe the physical, mental, or behavioural conditions that they had identified.

Over three-fourths of respondents cited speech or language difficulties and delays, including receptive and expressive language, mutism, and incoherent speech as primary concerns to providing effective care. Behavioural problems involving poor coordination, restlessness, inattention, and inability to follow directions were discussed by 29%, followed by developmental delays related to physical growth, feeding, toileting, and cognition by 19%. Fewer remarks were made regarding physical and mental health problems.

Overall, the open-ended comments from respondents to this last question, together with the question "Is there anything else you would like to tell us about your family member(s) with an intellectual or developmental disability?" yielded a variety of interesting insights. For example, ten respondents indicated that their DS family member's well-being was inhibited by poor social skills and a tendency to social timidity in new situations. These children with DS often required constant parental supervision to interact with the wider community. Conversely,

two parents noted that their experiences were enhanced for themselves and their child with DS because she/he had a generally happy disposition or a desire to learn new things.

## Daily Caregiving Experience with a Family Member with Down Syndrome

Over a third of respondents (12) identified caregiver burden as the primary stressor in their life. The daily burden was physically and financially overpowering for these caregivers and their families, because for most families "home care assistance" was unavailable. This daily burden resulted in loss of other normative activities for caregivers – from social activities to loss of employment and independence for mothers, who were most often the primary caregiver.

Six respondents expressed specific concerns about the future well-being of their DS family member. These concerns were rooted in a lack of services that kept the adult child with the family and dependent on the family. For parents, the caregiver burden increased with age because disability-specific services were even less accessible when their child transitioned to adulthood. At the same time, individuals with DS had very limited access to vocational education and self-help training that would promote even basic independence in adulthood. In one of the interview sessions, an exasperated mother of a teenage daughter with DS remarked thus: "I'm not sure what will become of my daughter now that she is getting to that age, when other teen-

Table 1. Summary of Qualitative Descriptions of Physical, Mental, or Behavioural Condition

Condition	N	Percent
Speech or language difficulties and delays <sup>1</sup>	24	78.4
Behavioural problems <sup>2</sup>	9	29.0
Developmental delays <sup>3</sup>	6	19.4
Physical health problems <sup>4</sup>	4	12.9
Mental health problems <sup>5</sup>	2	6.5

<sup>1</sup> Receptive and expressive language, mutism, and incoherent speech

<sup>2</sup> Poor coordination, restlessness, inattention, inability to follow directions

<sup>3</sup> Physical growth, feeding, toileting, cognition

<sup>4</sup> Heart condition, poor vision and/or hearing, chronic digestive problems

<sup>5</sup> Mood or anxiety disorders (including schizophrenia) and anger

age girls without disability are doing some type of work, or engaging in social activities with boys, and looking ahead to possible relationship and marriage. Frankly speaking, I do not know how to handle the situation, and I am not going to be around forever to look after her!"

A number of caregivers (41.9%) indicated that personal and family attitudes enhanced their caregiving experience. These attitudes were captured in three broad themes: first, caregiving was a family commitment; second, they accepted the DS family member's condition and the primacy of the caregiving role; and third, their family member with DS brought a special joy and love to their entire family, in spite of negative experiences they sometimes encounter in society.

### Health Care Issues for Affected Families

Adequate health care is a luxury for most Nigerians, and barriers to health care services were broadly themed as: affordability, accessibility, and public attitude. It was revealed by most families (54.8%) during group interviews that affordability was the primary issue. Factors included the poor state of the Nigerian economy, low personal and family incomes, the high cost of good private health care, the high cost of healthy food, and the need for ongoing care for some individuals with DS. Respondents linked the high cost of medical care to potential health risks. Since medical care and prescription drugs were unaffordable for at least 50% of participants, many families relied on unregulated herbal remedies from traditional healers for many ailments. These products and practices come with unknown risks and side effects. First, traditional healing practices may not be effective with developmental conditions like Down syndrome and associated behaviours (although some herbalists are known to lay claim to such a "remedy"). Second, unregulated herbal medicines may have unknown side effects, especially when prescribed for special needs populations.

Financial issues were identified in a broader context, that is, financial need and long work hours generally impeded families from pursuing healthy lifestyle choices like regular exer-

cise. Respondents indicated access to basic health care services was problematic for most families and most problematic for persons with a developmental disability. Key inhibitors were systemic: scarcity of publicly funded health services, unaffordable private care, absence of governmental support for low-income families, and poor economic conditions. Consequently, public health facilities were under-funded, poorly equipped, and lacked specialists having disability-specific skills or knowledge. This point was reinforced by one male participant, thus: "When our baby son with DS was born in the public hospital, the doctors and nurses were not of much help. We spent our meager savings on searching for a "cure" from traditional healers. Luckily, through the DSN, the Kanu Heart Foundation provided us with financial support to go to India for three months where successful open heart surgery was done. Today, our baby is doing well physically, although he still requires help in feeding and other social skills."

Feeling neglected was a major theme expressed by respondents. An underfunded public health care system, along with poor attitudes of health professionals towards persons with disabilities, little or no early intervention, and poor dissemination of knowledge to patients were key issues raised by respondents. One frustrated mother of 8-year-old twin daughters with DS angrily stated: "When I was carrying the pregnancy, the hospital staff either did not do proper pre-natal testing or failed to inform me of their conditions. If I had been told, I would have chosen to terminate the pregnancy. Six months after the twins were delivered, my husband ran away, and I've since been left alone to look after them. But, I owe a lot to the DSN where the girls are now enrolled and where I also work as a teacher."

Still, there is increasing public awareness of health care needs and a growing expectation of access to services in Nigeria. This shift in public attitude and health knowledge is driven by media access, mainly radio and television, but also newspapers and magazines. This is leading to increased levels of frustration because families cannot access modern services they know will improve their health and well-being, because of the high cost of obtaining such health-related services. This declining situation has led some observers to believe that



Nigeria may be unable to meet the health-related Millennium Development Goals (MDGs) by 2015, which mandates each country to spend 15 percent of their yearly national budget on health. Nigeria currently spends less than seven percent annually (<http://www.nigerianbestforum.com/generaltopics/?p=85074>).

Respondents also described enhancers and inhibitors to health care access. Geographic location, along with personal behaviours and attitudes, were prominent themes that respondents identified as enhancing health outcomes. In spite of concerns about transportation and cost, residents of large urban centres had much better access to care.

Personal behaviours were the primary means for most respondents to maintain health. They indicated that eating well or improving their diet, getting regular exercise, improving their knowledge of what is required to maintain good health, and trying to access appropriate services were major contributors to well-being. Personal attitudes strongly linked to positive health behaviours included having an optimistic outlook on daily life; contentment with life situation; and a desire for better health. These attitudes were often integrated into their faith and daily religious practices.

### **Financial Well-Being of Families**

Three-quarters of participants expressed dissatisfaction with galloping inflation, general insecurity in their communities, the widespread degradation of the environment occasioned by traffic congestion, toxic wastes, air pollution, frequent power outages, constant noise from generating plants, and incessant flooding of urban centres that lack poor drainage systems. They cited ineffective social support programmes for persons with disabilities and their families. Almost all respondents commented on lack of access to basic amenities and infrastructures for good quality of life. It was obvious that chronic daily struggle to survive when raising a child with a disability intensified with the poor state of the economy.

Slightly over two-thirds of respondents (67.7%) indicated a declining financial position. Some experienced long-term unemployment; many were underemployed and worked long hours

to keep their jobs. Chronic unemployment was also a reality for many young adults with no disability who were graduates of post-secondary institutions and still living at home several years after graduation.

Three prominent themes emerged that related to poor future financial outcomes for families. First, family financial well-being was negatively impacted by inflation that dominates the economy. Second, aging and retirement issues were of concern for older caregivers. Many indicated poor earnings over their life course would be compounded by poor-quality pensions that are not paid on a regular schedule. Retirement would mean less income and less stable income, but not less caregiving responsibility. Third, a majority of respondents (80.6%) lamented the pervasive corruption at national, state, and local levels. Such corruption was seen as contributing immensely to the high levels of social and economic instability in the country (Dike, 2008; Sulaiman, 2008).

However, some respondents indicated their financial situation was improving. A few reported good financial management and good-performing investments, while others indicated job promotion or new business opportunities had enhanced family finances. Generally, respondents indicated that employed young adult children with no disability still living at home enhanced the financial well-being of the family. Some indicated membership in cooperative societies enabled them to access additional resources for meeting needs. As with many other aspects of family life in Nigeria, respondents indicated personal effort and faith, which, along with a positive attitude that things will get better, was central to current and future well-being.

### **Building and Maintaining Family Relationships**

Ninety percent of respondents described strong, positive social and emotional relationships with nuclear and extended family members. These relationships were enhanced in families that followed traditional, cultural values and actively practised their religious faith. Caregivers often received important emotional and instrumental support from adult children,

extended family, and their religious community. Satisfaction with family relationships was multi-dimensional. Some caregivers associated family satisfaction with personal growth and the ability to access training and continuing education. Most suggested satisfaction with family was related to mature personal attitudes. For older caregivers, family attitudes that valued the elderly and sought out their advice on important matters greatly added to satisfaction in this domain.

On the other hand, satisfaction with family relationships was inhibited by chronic stressors related to urban life, financial hardship, and long hours of work that reduced contact between members. For some caregivers, satisfaction decreased when they had employed adult children struggling to make ends meet in their own families and unable to offer support to their siblings with DS or to aging caregiving parents. These employed adult children were employed in jobs that paid considerably less than their qualifications; yet, a great proportion of their monthly income was spent on transportation to and from worksites.

### Accessing Community Support

Most participants (58%) indicated access to community supports was largely inhibited by a lack of economic resources, along with the time burden of daily household duties and child care responsibilities. Additional caregiving for the family member with DS exacerbated this social isolation. Some identified work responsibilities and the lack of encouragement from others as key factors that limited access to community supports. Three respondents mentioned self-imposed isolation because they feared those outside their religion or immediate family. The general economic turmoil in the country contributed to social isolation of some participants. Poverty, lack of job security, and a daily struggle to survive can create an environment in which people do not support others outside their immediate family. This is especially true in large urban areas, where the influence of Western society has challenged complex social relationships present in traditional Nigerian cultural roles and eroded traditional family values.

Satisfaction with community support was enhanced by individual desire to socialize and ability to achieve balance between work, personal and domestic needs. Respondents globally indicated that receiving emotional and instrumental support, the presence of religious faith and traditional family values, and the growing independence of the DS family member improved satisfaction in this domain. Caregivers noted that community visibility – engaging in community activities with their affected child – resulted in improved social awareness and acceptance of disability. One parent described her experience as ... “Interaction with the community can go a long way towards showing them that we love our daughter with a disability. This will be a way to tell others in a similar situation to accept their offspring who may have a similar disability.”

In turn, improved community understanding of disability resulted in greater social acceptance of persons with disabilities and their families as integral members of the community. In the words of one caregiver ... “The best approach to getting the community informed about disability is for the families of the disabled to continue to involve their children in community-based programmes. That way, the public will gradually become more enlightened about their abilities and needs.”

### Accessing Support Services

Caregivers identified three specific categories of disability-related support services. These are summarized thus:

#### A. *Professional services:*

1. Speech and language therapy, occupational therapy, and audiology services
2. Behaviour therapy
3. Specialized pediatric services and medical services for persons with disabilities
4. Sexuality training for adolescents and young adults with DS

#### B. *Community-based services:*

1. Vocational training, including adapted computer programmes
2. Advocacy training for parents

3. Nutritional services/counselling for family
4. Psychological counselling and self-help skills training for individuals with DS
5. Adapted recreation activities
6. Specialized transportation

*C. Home-based services:*

1. Specialized health care services
2. Social workers
3. Respite care and related home support services

The major barriers to support services are summarized as being the following: the high cost for private school and specialized services and training; the limited number of government-supported schools for the disabled that are not well-staffed or equipped; and poor economic conditions that eroded family incomes and prevented them from purchasing private services. It was noted by a small number of participants (19.3%) that access to these services was enhanced by: sufficient personal income to purchase private services; proximity to private schools and services; and the presence of philanthropists or organizations funding special education and rehabilitation programmes.

However, for a number of caregivers (12.9%), access to advanced education or community-based services decreased even further with transition to adulthood, and there was no vocational training for the disabled adult population. Service access was further inhibited by lack of finances for some parents to purchase their own car and the poor public transportation systems in some neighbourhoods. This situation has forced two parents to resort to using the "Okada" (the local motor cycle) to bring their child with DS to and from the Centre each day. Underlying the access problem was a lack of national interest or policy to develop a transportation-friendly programme, especially in urban centres of the country. As one parent noted: "The government would be improving the quality of training if it can set up a special transportation programme for children and youth who are disabled. Such a service would greatly relieve the burden of parents who spend several hours in the traffic each day as they bring their child to and from school."

## **Influence of Values**

Personal and community world views were strongly influenced by formal religious values, strong religious faith, and traditional cultural values. Caregivers noted that traditional superstitions associated with any form of disability were problematic and must be replaced with a modern understanding of disability. They identified religious and cultural leaders as the key to this shift in knowledge and practice. While many leaders did not promote disability awareness in their everyday dialog and actions, places of worship among Moslems, Christians, and traditional believers were viewed as appropriate venues to educate the broader public on disability-related issues, given the extreme religiosity of the people. It was suggested that professionally trained special educators and counsellors should work closely with such religious leaders to increase their knowledge and awareness, as well as enhance the integration into religious activities of members with disabilities.

Indeed, religious values can be seen to have strong protective effects for individuals and families, reducing the negative impacts of daily life stressors and challenges associated with raising a child with a disability. The influence of religious beliefs and traditional cultural values can therefore be translated into greater personal and family worth and dignity and a sense that each person is valued for who they are, with special "compassion and love for the disabled."

## **Career Development**

Respondents indicated that career development was influenced by personal and structural factors. Individuals needed an enthusiastic attitude to learn, along with specific educational goals that focused on completing higher education or vocational training opportunities. One family succinctly characterized this philosophy thus: "Education is the passport to prosperity."

In the majority of cases (52%), of participants stated that access to scholarships for education was crucial to success. However, such scholarships are becoming limited, due to reduced education funds at both federal and state levels. To compound the situation, parents were frustrated with frequent strikes by lecturers in government-owned post-secondary institutions

agitating for better learning climate, as well as improved salaries. Indeed, such instability in higher education imposed serious limitations on opportunities for most students, and this in turn negatively impacted their career prospects.

In addition to the high cost of education, it was observed that the curricula in the post-secondary institutions failed to inculcate in students the knowledge and skills needed for self-employment. The outcome was labour instability with high unemployment rates in general, and for new graduates in particular. There were even fewer work opportunities for older workers and individuals with any identifiable disability. Some employed family members observed that their employers made little or no provision for advanced training on the job. Other inhibitors to career development included the depressed economy and the absence of effective policy to support education, training, and employment.

### Leisure and Recreation Pursuits

In the home, joint leisure and recreation for families with DS focused on watching TV and movies together, listening to music, and reading. Other home-based pursuits included entertaining visitors and cooking. Two-thirds of respondents commented they lack the funds to purchase computer and computer games for their children with ID. In addition, these parents decried their inability to teach basic specialized computer literacy skills. Yet they feel that access to home-based computers and toys can supplement the school learning activities of their children with DS, and promote interaction with siblings and friends.

A majority of families (85%) indicated their community activities were centred on religious-based events. However, a small percentage of respondents (19.3%) also spoke of going on family vacations, visiting friends and extended family members in the village, shopping, picnics, and outdoor sports as favorite pastimes.

Most caregivers (81%) expressed an understanding that leisure pursuits contributed to physical and emotional well-being. They indicated that their leisure choices were based on activities that helped the family to relax, but inclusivity was a factor and the activity was selected to include the member with DS.

Thirty-nine percent of caregivers described the poor availability and high cost of organized recreational activities in large urban areas. Lack of structured activities for individuals with any form of disability was problematic for all families and reflected the low value placed on disability-related services by society and the government. Low personal and family incomes and the high cost of public transportation further impeded family participation in many formal activities. For some families, caregiving burden and general family demands left no time for leisure and recreation.

### Community Interaction

Respondents indicated that much of their community interaction involved faith based activities – participating in choirs, or doing volunteer activities. They also relied on social interactions with extended family members. Many families were members of the Centre, and service clubs like the YWCA. It was noted by some participants that the Centre periodically organizes community-based events that positively promote the aims of the centre. Such activities included: walkathons, running, and soccer matches.

### Analysis of Domains and Dimensions

Table 2 provides the means and standard deviations of the Family Quality of Life Survey measures by the six dimensions (Importance, Opportunities, Initiative, Attainment, Stability, and Satisfaction) within each of the nine domains (Health of the family, Financial well-being, Family relationships, Support from others, Support from services, Influence of values, Careers or preparing for careers, Leisure and recreation, and Community interaction). In addition, the last two columns display the mean and standard deviation for each Domain Score, that is, the arithmetic mean of the six dimension measures within each domain.

On average, families gave the least importance to the domains of Support from others (mean response on a scale of 1 to 5=3.55) and Leisure and recreation (3.81), and the most importance to financial well-being (4.87) and Health of family (4.90). The fewest opportunities were associated with Support from services (1.84)



Table 2. Means and Standard Deviations of FQOLS Responses by Six Dimensions and Nine Domains

	Importance		Oppor- tunities		Initiative		Attainment		Stability		Satisfaction		Domain Score	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Health of family	4.90	0.40	2.06	0.89	3.61	1.28	3.55	1.03	3.65	0.98	3.32	1.14	3.52	0.56
Financial well-being	4.87	0.34	2.39	0.84	4.32	0.94	3.16	1.10	3.48	1.24	3.06	1.18	3.55	0.66
Family relationships	4.65	0.80	4.39	0.62	4.68	0.65	4.48	0.85	4.19	0.91	4.29	1.04	4.45	0.59
Support from others	3.55	1.21	2.33	0.88	2.68	1.17	2.35	0.76	3.19	0.54	3.00	0.89	2.83	0.59
Support from services	4.61	0.62	1.84	0.82	3.97	1.20	2.10	0.94	3.10	0.79	2.84	1.10	3.08	0.54
Influence of values	4.61	0.67	4.13	0.96	4.45	0.77	4.48	0.85	4.23	0.84	4.06	0.96	4.33	0.70
Careers/ preparing for careers	4.77	0.50	2.63	1.19	4.43	0.82	3.86	1.16	3.48	1.06	3.29	0.94	3.75	0.67
Leisure and recreation	3.81	0.98	2.90	0.94	3.52	0.93	3.45	0.96	3.55	0.89	3.29	1.04	3.42	0.76
Community/ civic interaction	3.84	1.00	3.35	0.92	3.35	1.08	3.23	0.92	3.45	0.81	3.52	1.03	3.46	0.77

and Health of family (2.06), while the most opportunities were associated with Influence of values (4.13) and Family relationships (4.39).

The least initiative, on average, was taken by families with respect to Support from others (2.68) and Community or civic interaction (3.35), and the most initiative was taken with respect to Influence of values (4.45) and Family relationships (4.68). Support from services (2.10) and Support from others (2.35) were rated the lowest domains for attainment, while Family relationships (4.48) and Influence of values (4.48) were rated the highest.

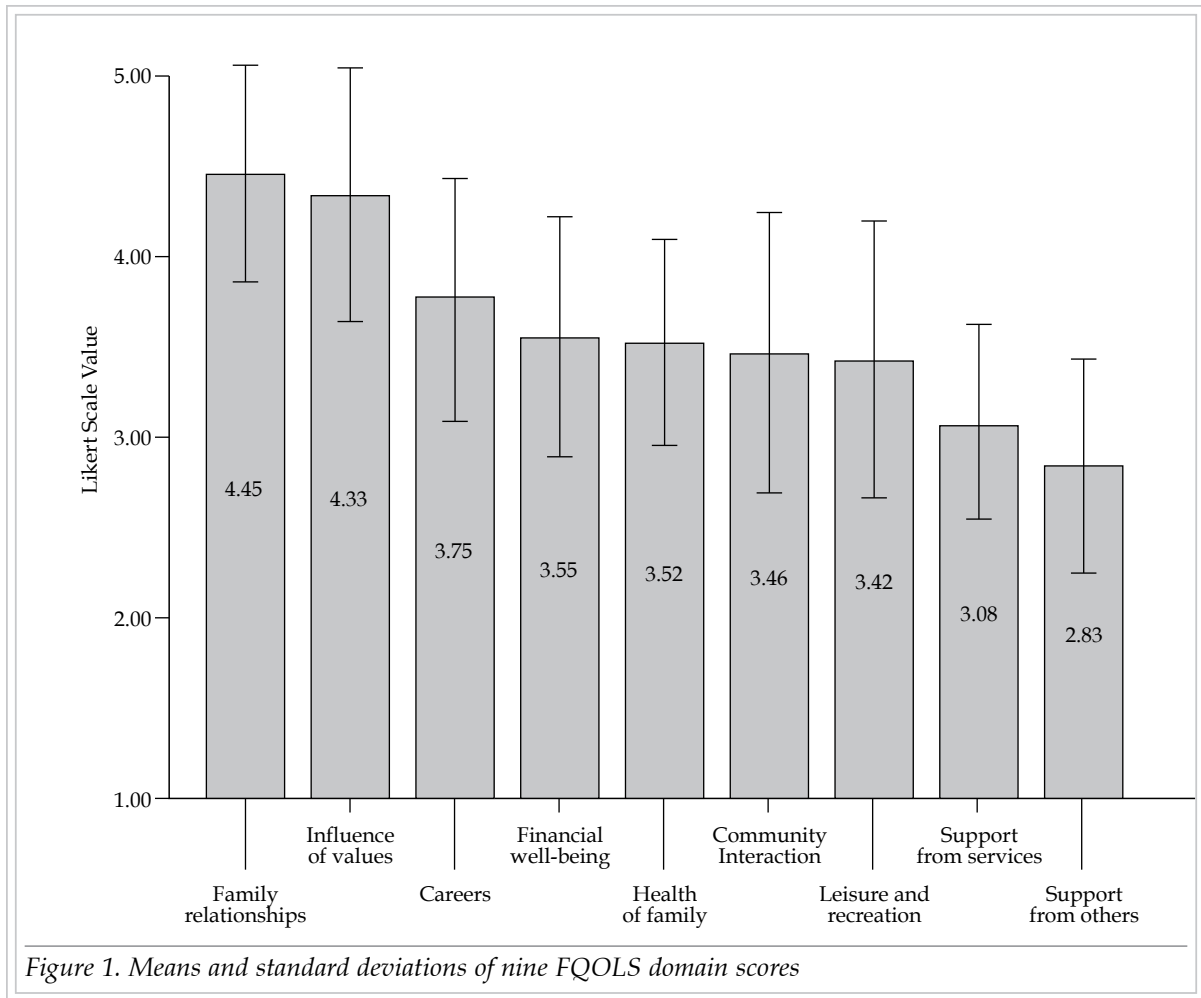
Support from services (3.10) and Support from others (3.19) were perceived to be the least stable domains, and Family relationships (4.19) and Influence of values (4.23) were perceived to be the most stable domains. The least satisfaction was associated with the domains Support

from services (2.84) and Support from others (3.00), while the most satisfaction was associated with Influence of values (4.06) and Family relationships (4.29).

The bar chart in Figure 1 graphically displays the mean and standard deviation for each of the nine computed Domain Scores in descending order by mean value. As shown, the two highest means are for Family relationships (4.45) and Influence of values (4.33), while the two lowest means are for Support from services (3.08) and Support from others (2.83).

## Discussion

Living with a child with disability in the Nigerian society can have profound effects on the entire family dynamics. In this study, respondents expressed their perspectives as



they provide meaningfully for their children with DS. Table 2 and Figure 1 data are reasonably comparable with other studies (Brown, 2010; Cagron, Schmidt, & Brown, 2011; Clark, Brown, & Karrapaya, 2012; Werner, Edwards, Baum, et al., 2009). As Brown (2010) points out in a comparison of data from different countries using the same survey in terms of satisfaction and attainment dimensions, for example, the Nigerian data (Ajuwon & Brown, 2012) shows the lowest rating in Support from Others, and Support from Services and, again in terms of consistency with other countries, Family Relations and Health of Family were rated highly, and this is also true of the sub-set of Down data in the present study. However, there are differences, and in the present study values were consistently high on all dimensions which, as pointed out by Brown (2010), may have reflected the importance of religious and spiritual beliefs. Although there were often lev-

els of variation between higher and lower economic countries, similar domain patterns tend to exist though complicated by family attitudes and societal values (see Brown, Hong, Shearer, Wang, & Wang, 2011).

Discussion also needs to reflect on the variations within domains and dimensions within a country. An average rating below 4 for any domain or dimension suggests that many of the families perceived themselves as having low family scores. Where the scores are below 3, most families fell in this negative range. For example, all of the dimensions associated with the domains covering Support from Others and Support from Services represent aspects that require particular attention both in planning and practical support (Brown, Hong, Shearer, Wang, & Wang, 2011; Wang & Brown, 2009), and this issue is further illustrated in the qualitative information above.

It appears that only one other FQOL study has been carried out with families having children with Down syndrome as a separate group (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). Again, the pattern of results appears reasonably comparable to the present study. However, it would be interesting to know whether in the current study Down families gained higher domain scores in otherwise vulnerable areas in other groups of families where there are multiple disabilities and/or behavioural challenges. It seems possible that social attitudes and environmental opportunities may be important variables in this context.

Some of the qualitative comments point to the implications of not having in place concrete special education, health and social policies. This gap in service has impeded overall development and community integration of their children, leading to a decline in most family members' life satisfaction and well-being. One participant noted: "This is not the kind of lifestyle I wish for members of my household or anyone for that matter ... Nigeria has abundant natural resources that can be used to benefit the masses ... yet most of its citizens live in poverty because of corruption on the part of some government officials. These officials visit the advanced countries where they see good social programmes in place. But they refuse to see anything good in bringing such practical social ideas to our own land."

Nonetheless, a handful of participants took their son or daughter with DS with them to places of worship, social gatherings, or to the market place. However, teasing of children with DS and accompanying family members when in the public like the market-place or even the neighbourhood water bore-hole was not an isolated event. A number of participants mentioned social isolation because other people avoided them in these public places. A few respondents described denial of retail services because they brought their child with DS to the market-place. Thus, based on such prevailing myths, a vendor of foodstuffs or shoes may view selling her/his merchandise to a buyer accompanied by a child with DS as ill-luck, especially if the transaction was the first to occur that day. Similarly, a commercial bus operator may disallow passengers with DS the opportunity to ride in the bus, because of the

discomfort the presence of the child with DS might cause the passengers. Even at church, one mother observed the uneasiness of other members the first time she went to service with her daughter with DS. The mother noted: "After service that day, I met with the Pastor to talk about my daughter, and the need to include aspects of the condition in future sermons ... and as time progressed, and my daughter also began to show improved behaviours, I could see changes in the attitudes and behaviours of the people."

Most Nigerian parents recognized that these negative attitudes stem from superstitions that are rooted in traditional beliefs about disability in some communities (Okoh, 1987), a pressing issue in a number of other countries (Brown, 2010). These superstitions point towards better education about disabilities, and also indicate that positive changes can be made with family members who are willing to assume advocacy roles.

From the current FQOLS study, levels of unmet needs were found in relation to health, financial well-being, disability-specific support, careers, and community interaction, and this resulted in caregiver burden for most participants. The daily care situation often prevented family members (especially mothers) from independently engaging in social activities.

Excessive care burden resulted in long-term effects of chronic stress on the health status of other family members. Thus, several respondents were concerned about their own future well-being and that of their adult family members with DS. But the positive attitudes of some respondents continue to inspire them to seek training for their children, in spite of the high costs of transportation, health care, and special education from privately operated schools. These families feel that providing meaningful special education to their children with DS is a worthwhile investment, because they view caregiving as a family commitment, and a way to show special joy and love for their children with DS.

Some parents of children with DS provide care well in excess of that reported by other parents. They spend several hours on basic care of their children with DS in the evenings and/or week-

ends, and unable to access respite care services. This situation ultimately interferes with the ability of caregivers to work and contribute to the household income and/or provide quality care for other siblings, and to aged grandparents who live with them.

A number of currently-employed respondents commented that the skyrocketing inflation was impeding their ability to purchase their own housing and vehicles. One major concern was the families' constant struggle with high tuition fees for their other children enrolled in privately run tertiary institutions. Furthermore, some participants were dissatisfied that their trained family members could not secure employment after graduation from institutions of higher learning. These educated older siblings without disabilities continued to live at home, unable to augment the household income, further inhibiting the families' financial capacity to access quality specialized resources. Clearly, these situations severely limited choices for the families and their sons or daughters with DS. It is obvious that unless adequate social protections are established for these families and their children with disabilities, these families will continue to experience declining life satisfaction and well-being as their children grow up.

### **Limitations of the Project and Recommendations for Future Service**

One limitation of the current project relates to the samples selection. As previously noted, participants in this study were drawn from the Down Syndrome Foundation of Nigeria, a small centre in the city of Lagos. It should be emphasized that study participants consisted of mothers and fathers who had children with DS at the Centre; hence, the views expressed on family quality of life were those of the participants, and not necessarily those of the rest of the household. As such, the opinions of other family members should be explored in any future research.

Although the participants demonstrated sufficient awareness of the impact of DS on the family structure, a larger sample of families from the rest of the country would have provided a more representative data. Future research efforts aimed at exploring Nigerian families

and their children with DS should expand their focus to include a broader spectrum of the disability groups and their families.

## **Recommendations**

In light of the multiple needs expressed by families interviewed, and who also completed the Family Quality of Life survey, the following specific recommendations are made:

1. The DSFN should establish a variety of professional services that focus on developing speech and language skills, appropriate behaviours, specialized pediatric and health care services, and sexuality training of adolescents with DS. Provisions must also be made for in-home assistance including counselling of parents and the siblings of the child with DS.
2. The need for community-based vocational services and computer literacy training should be in the forefront of the Centres' curriculum planning efforts, especially for young adults. The focus should be to capitalize on indigenous customs that will be inclusive of the individuals with DS, and their families at school, home, and community events. This process should involve the utilization of local resources and manpower to sufficiently prepare trainees with DS for employment and community integration, in the public or private sector, or even as self-employed individuals.
3. Although participants in this study are a small fraction of the total number of parents of children with disabilities in Nigeria, they represent an exemplary group of advocates who are seeking for their children quality education that will guarantee for them a functional and independent living. In order to achieve this, these parents have demanded respite care to allow them to receive a break from care-giving. This is justifiable because raising a child with a disability is challenging, particularly in a society that has no social safety nets (Brown, Ajuwon, Wang, & Vahakuopus, 2009). As several parents have alluded to in this study, there are many demands placed on families in the process of adjusting to their children with DS, not the



least of which are: the number of appointments for medical and support services, challenges of learning how to provide and/or adapt home supports, and working with school personnel. These families are often over-stressed as they try to juggle medical appointments during work hours and care for the children with a disability and their siblings. Parents are tired and depressed, yet they continue to sacrifice their own health and well-being to meet care-giving obligations of their children.

4. Respondents commented positively on their religious values and how they participate with their daughter or son in activities organized by their worship centres.

In this regard, religious centres should capitalize on this and assume a major role in fostering greater acceptance of and respect for persons with disabilities and their families. This view is supported by a number of other studies that point out that meeting child and parent needs, particularly spiritual needs, helps some parents deal with their challenges (Kober, 2011). There are many ways leaders in these places of worship can accomplish this. They can give sermons that highlight the dignity and worth of people, including children, youth, and adults with disabilities. A mosque, a church or a shrine can sponsor the education of a child with DS. They can sponsor educational field-trips or sporting events like the Special Olympics. They can construct classrooms at these special schools, or even fund a child's medical treatment that is often beyond the means of the family. The ultimate goal would be to identify with, and provide moral support for, programmes appropriate for the chronological age of the special needs learners.

5. The themes describing family experiences that emerged from the participants' comments in this study indicate a strong need for the development of government disability policies, as well as greater initiatives to train family members or care-givers. In this regard, federal, state, and local authorities must set aside sufficient funds each year to implement new programmes. However, care must be taken to ensure that such programmes are planned and implemented

within the community, so members become more cognizant of the difficulties that children with disabilities face, and are empowered to challenge the stereotypes held by the public towards people with disabilities.

In conclusion, these recommendations will provide mutual support and joint action in advocating for the families and their offspring with DS that are aimed at improving their overall quality of life.

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