Effect of Economic Costs of Caring for Children with Intellectual Disability on Family Well-Being in Nakuru Municipality, Nakuru County, Kenya

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Abstract

Taking care of children with intellectual disability (ID) comes with numerous demands and responsibilities. Unfortunately, there has been scanty documentation, especially from a sociological perspective on the economic implications to families of children with intellectual disability in the society and how it affects the wellbeing of the family. The objective of this study was to determine the effect of economic costs of caring for children with ID on the well-being of families in Nakuru Municipality, Nakuru County, Kenya. Family system theory underpinned this investigation. It used a descriptive research approach in which semi-structured interviews were used to examine how families of children with intellectual disabilities experienced life. A multi-stage sampling strategy combining proportionate cluster sampling and purposive sampling methods were used to choose a sample of 84 households from the 503 families of children enrolled in eight special schools for children with ID. The collected data was analysed using thematic content analysis, descriptive statistics, and inferential statistics, and the results were presented in the form of tables, figures, and illustrative quotes. According to the findings, 42.9% of families with children who have intellectual disabilities in Nakuru Municipality are not doing well. The cost of care and the disruption of carers' work have a big impact on how well the families are doing. The study suggests that, in order to improve the welfare of families with children with ID, policymakers at the State Department for Social Protection should strengthen programmes like the Cash Transfer for People with Disability that address the financial burden of caring for children with ID.

***Keywords*: Economics, Intellectual, Disability, Family, Well-Being, Nakuru, Kenya**

Introduction

The World Health Organization (WHO) (2023) estimates that globally, about 1.3 billion persons suffer from severe disability. As the frequency of chronic diseases like cancer and diabetes rises, including in the developing world, the prevalence of disability is also rising (Yokota et al., 2015). Almost 80% of the 200 million people with disabilities are children and adolescents and live in the developing world (UN Department of Economic and Social Affairs, 2018). A prevalent type of impairment worldwide is intellectual disability (ID). According to Zablotsky et al. (2017), the prevalence of ID was 6.99% in the population of all children aged 3 to 17 in the United States (U.S.), compared to 10.5 per 1000 in India (Lakhan et al., 2015). However, at independence the post- colonial state embarked on ambitious efforts to expand electricity access to the rural areas in Kenya. Arguably, it was a temporary break from the colonial electrification policies. This was a period when a wave of nationalist euphoria swept across the African continent. During this time, the nationalist leaders attempted to fulfill the pledges they made at the eve of the 1963 election campaign (Cooper, 2002). In a context of high commodity prices for coffee and tea, the post- colonial state launched the first rural electrification programme in 1973. Under this first initiative, a few district headquarters in the country were connected to electricity. Finally, the much vaunted commodity began to penetrate to majority of rural areas in Kenya.

In Kenya, the 2019 National Population and Housing census established that there were 210,000 people living with ID in Kenya (Kenya National Bureau of Statistics, 2019). This number translates to a prevalence of 0.4% of the total population, which is lower than the global prevalence of 1%. The prevalence of ID in Nakuru County stood at 0.4% in the 2019 Census. The prevalence in Kenya may be higher than what was reported during the census as some families might have failed to disclose due to the stigma associated with intellectual disability (Development Initiative, 2020). Since children with ID make up a notable section of the Kenyan population, their wellbeing and that of their family is essential to the development of communities as well as Kenya as country.

There is growing concern regarding the burden of intellectual disability (ID) to caregivers who are usually mothers of the child with ID, elderly members of the family, or the unemployed members of the family, who are not usually prepared for the caregiver’s role (Kuria & Ndetei, 2013). The health and social service systems benefit greatly from the unpaid care and assistance given by families, which would be highly expensive to replace with paid official service. The members of these families, however, do not intend to be carers; they merely find themselves in such unfortunate situations. Their long-term financial stability, relationship quality, and health and well-being are all impacted by this. In order to support carers, such intricacies must be addressed in policy and practice.

The study by Makumi *et al.* (2021) found that most individuals with ID in Kenya find it difficult to transition from school to employment. As results, the individuals remain dependent on their families even in their adult years. The primary caregiver of a child with ID is not the only one who is impacted; other family members and the family's functioning as a whole are also affected. One of the most replicated findings in household research is that family well-being is lower when children exhibit more maladaptive behaviour (McConnell & Savage, 2015). Unfortunately, none of the investigations that have been examined to date were carried out in Kenya. As a result, little is known about the particular difficulties faced by families of children with ID throughout the nation.

Literature Review

Economic Costs of Caregiving and Family Well-Being

There are studies that have looked at the direct expenses of care and the indirect effects on families' financial situation, even though there hasn't been much written about the economic costs of caring for a kid with a disability. Families with children who have mental health issues have reported expensive treatment expenditures (Mitra et al., 2017). The majority of the families' expenses are for outpatient care. The study by Plamer and Nguyen (2012) revealed that disability increased the cost of outpatient care US $105 and inpatient care expenditure by USD 15. The study further found that the out of pocket expenditure for outpatient care ranged from USD 228 to USD 1,441 depending on the severity of the child's condition. The study by Palmer and Nguyen (2012) however focused on families of children with disability in Vietnam and thus results may not reflect the situation in Kenya. The study did not also explore how these expenditure influence the well-being of families of children with intellectual disability.

Another economic cost associated with taking care of a child with ID is the cost of providing personal care to the child. Children with intellectual disability require exceptional level of care. Ordinarily, families of CWD can take two courses of action with respect to their mentally impaired child. The first course of action is to help the child at home where family members act as caregivers (Anderson *et al.*, 2012). The second course of action is to institutionalize the child so that he or she can receive care from professionals. In Kenya, many families of CWD follow the first course of action given that social institutions for taking care of mentally handicapped people are not well developed within the country (Mbugua *et al.*, 2011). Many families said that the associated expenditures were exorbitant in a study by McConachie et al. (2000) in Bangladeshi on what barriers families have when bringing their children with cerebral palsy for early intervention therapy. The cost of transportation was mentioned as the key issue. This study further emphasized the rural-urban divide, revealing that, overall, rural households parenting disabled children were younger, poorer, and less educated than urban families.

Families remain the most important source of long-term care and assistance for mentally handicapped children not only in Kenya, but in most developing countries. In their phenomenological study involving 17 parents raising children with ID in Zambia, Nyoni and Serpell (2011) found that the services offered by professionals to families with ID children was inadequate due to shortage of staff, bureaucracy, and red tape tendencies in hospitals. The services were found to be insensitive and manifested inconsistent opinion. Access to quality remedial services was also limited. Accessibility of quality care for mentally handicapped children has an impact of well-being of families. Mitchell and Hauser-Cram (2008) found that parents of children with development disabilities were more likely to experience depression and stress when they are not satisfied with the quality of care available to their children with ID.

It has been reported that families that care for CWD often find themselves slithering towards a life of poverty. A study conducted by Anderson *et al.* (2011) in the U.S.A. revealed that most families of CWD were more likely to have one working spouse as the partner is compelled to remain at home so as to meet their child's needs. In addition, it was found that parents of CWD required more time off work leading to reduced work hours; hence, resulting in low wages. Consequently, such families had low household income, which affected their quality of housing, nutrition, health, and education.

In their study, Hidangmayum and Khadi (2012) found that parents of CWD give more of their life to meet their children's need than they ever expected. This not only increased the level of parenting stress, but diminished the time available for these parents to engage in economic activities. This study involved 30 parents of CWD and 60 parents of normal children in Hubli-Dharwad City of India. The study also found that CWD took longer time to get used to new things; hence, they needed more help from their parents as compared to children without disability. The severity of the impairment was a significant predictor of the level of disruption to parents' life. Although Hidangmayum and Khadi's study highlight some of the issues that the researcher intended to explore within the current study, their study was conducted in India; hence, its findings may not be applicable to the Kenyan context.

In another study, Mulroy *et al.* (2007) found that caring for children with intellectual disability presented disadvantages to siblings such as limited parental and personal time, burden of helping, and relationship and socialization restrictions. According to these findings, caring for ID children not only pose economic challenges to the family, but also has social implications. Findings also revealed that smaller families were more likely to report these disadvantages than large families. The socioeconomic status of the family also predicted the extent to which caring for an ID child affected siblings. The study was conducted among 186 Western Australian families of children with ID. The study provides essential insights on how caring for children with ID affects the social well-being of the family, but, has not highlighted effects on the economic and material well-being of the family. Similarly, the study has been conducted in a context that is significantly different from the Kenyan context and thus the need for the current study.

In a study involving 111 parents of children with ID and 324 parents of children without any disability, Olsson and Hwang (2008) examined how socioeconomic status of families moderate the relationship between caring for children with ID and well-being of parents. Findings showed that parents of children with disabilities from families with low socioeconomic status had lower levels of well-being than parents of children with ID from families with high socioeconomic status. The findings showed that there was a relationship between socioeconomic status, caring for children with ID, and well-being of parents. However, Olsson and Hwang's study is slightly different from the current study since it explored the moderating effect of socioeconomic status rather than how the economic cost of caring for children with ID affects the well-being of the family. The study also focused on effect of caring for children with ID on parents rather than the family as whole.

In an earlier study by U.S.A. National Institute of Health (2006), it was found that the relationship between role occupancy and well-being of mothers of children with ID was mediated by socioeconomic status. In this study, the researcher sought to determine how roles of being married, being employed, or both affected the well-being of mothers of children with ID. Unlike in Olsson and Hwang (2008) where socioeconomic status played a moderating role, in this study, socioeconomic status played a mediating role. The U.S.A. National Institute of Health (2006) found that socioeconomic status explained the relationship between role occupancy and well-being of mothers of children with ID. Mothers who were married, or employed, or both, had higher levels of well-being because these roles enhanced their socioeconomic status. However, the study is still significantly different from the objective of the current study, which is to determine how the economic costs of caring for children with ID influence the well-being of families. The current study also focuses on the well-being of the family as whole rather than one members of the family.

In Australia, Doran *et al.* (2012) found that opportunity cost associated with lost jobs, absenteeism, and presenteeism accounted for 85 of all cost of caring for a child with intellectual disability. Doran *et al.* (2012) collected quantitative data from a sample of 90 families of children with ID. Results showed that opportunity cost ranged from $63,364 to $104,988 per annum. This is the amount of income that families in Australia lose due to the demands of caring for a child with ID. Doran *et al.* (2012) however observed that the impact of the economic loss on families was smothered by allowances paid by the government to families caring for children with ID. The allowances ranged from USD 4,464 per annum for a child with moderate ID to USD 6,698 for a child with severe ID. Although Doran *et al.* (2012) have quantified the cost of caring for children with disability, they did not link this cost with the wellbeing of the family. The current study fills this gap by testing how the costs incurred in caring for children with ID relate to the well-being of families. In addition, the present study provide data on the Kenya setting regarding the costs involved in caring for children with ID as well as whether families receive any support as their counterpart in Australia.

In Kenya, the study by Banks *et al.* (2021) found that persons living with disabilities and their household incur direct costs including cost of health care, transportation, acquisition assistive devices, and accommodation at school or work. These individuals also encounter indirect economic costs such as unemployment, underemployment or lower salaries. The study was based on in-depth interviews with 42 individuals with disability. This study provides evidence that shows that even in Kenya, families of persons with disability incur economic costs that affect their material and financial well-being. However, the study interrogated persons with different forms of disabilities and; therefore, its findings may not accurately capture the specific challenges encountered by families of children with ID. The current study sought to fill this gap.

Theoretical Framework

Family systems theory underpinned the current investigation. A theory that aims to describe how families function is the family systems theory. According to this viewpoint, the family is a system made up of various parts and their interactions. Murray Bowen created the theory in 1980 utilizing ideas from Ludwig von Bertalanffy's General Systems Theory (Brown, 2008). This theory is based in part on the idea that how each family member functions affects how the family system as a whole functions. This theory acknowledges the interconnectedness and interaction between various family members as well as the family as a whole. It implies that each family member's wellbeing is reliant upon and connected to that of the other members (Haefner, 2014). For instance, the entire family would be impacted if one of the partners was unable to find employment because they had to care for the mentally disabled child.

The interaction between family members is another idea that forms the basis of the family system theory. Systems theory emphasizes the interaction between family members as well as feedback processes and causal chains, rather than just the involvement of individual members (Brown, 2008). As a result of the interaction between family members, it is implied that the functioning of the family system as a whole is not equal to the sum of the functioning of its individual members. The theory also discusses the concept of family borders and its permeability (Haefner, 2014). It contends that because these borders are permeable, the health of the family is influenced not only by the performance of individual members but also by the connections that the family has with other systems like the neighbourhood, the school, and the place of employment of the parents.

Method

The descriptive research design was used for the present investigation. With regard to the financial impact of treating the condition, this design involved evaluating the current circumstances in the homes of children with intellectual impairment. This study strategy blended quantitative and qualitative techniques. The investigation was conducted in the municipality of Nakuru.

Families of children with intellectual disabilities living in Nakuru Municipality made up the study's population. The Nakuru municipality's special schools for the mentally challenged served as the sampling frame. There are eight special schools for the mentally handicapped in Nakuru Municipality, according to data from the Ministry of Education offices in Nakuru County, with a combined enrolment of 503 students.

Because families of children with ID are a relatively hidden population that is challenging to identify, the schools served as the most suitable sample frame. Accessing this population was made simple by the schools. The Nassiuma (2000) sample size calculation was used to determine the study's sample size.

$$n = \frac{NC^2}{C^2 + (N-1)e^2}$$

Where n= sample size, N= target population (503 for this study), C= coefficient of variation (30% for this study), e= margin of error (3% for this study). Using this formula, the appropriate sample size will be:

$$n = \frac{503 * 0.3^2}{0.3^2 + (503-1)0.03^2}$$

$$n = 83.6 \approx 84 \text{ families}$$

Table 1: Sampling Plan

SCHOOL	NUMBER OF STUDENTS	NUMBER OF PARTICIPANTS
Menengai Special School	38	6
Hill Special School	180	30
Our lady Fatima Special School	15	3
Our Lady Mercy Special School	10	2
Our Lady Victoria Special School	36	6
Nakuru North Special School	19	3
Muriundu Special School	25	4
Pangani Special School	180	30
TOTAL	**503**	**84**

Using the proportionate cluster sampling technique, 84 families were chosen as a sample from the 503 student families. According to the proportion of each cluster's population to the study's overall population, respondents were chosen from each cluster after the population was divided into parts known as clusters. In Nakuru Municipality, there are eight special schools that were handled as clusters. By guaranteeing that participants are selected from all schools, this sampling technique boosted the sample's representativeness.

The respondents in each school were chosen using the purposive sampling method. According on the researchers' assessment of the respondents' capacity to supply the required information, respondents were chosen using this manner. The following were the requirements for inclusion in the study: (1) the student's family must reside in the Nakuru Municipality; (2) the family must have had the impaired child in their care for at least five years; and (3) the family must agree to participate in the study. The researcher extensively collaborated with the eight schools' teachers to pinpoint pupils whose families fit these requirements.

Data Collection Methods

The primary caregivers to child with ID within 84 homes were interviewed. There were both open-ended and closed-ended questions in the interview guide. To increase validity by making sure all study factors are sufficiently addressed, it was separated into six portions in accordance with the variables of the study. The majority of the interviews took place in a school setting, where the researchers arranged for the right date and time of the interview with the teacher and caregiver. Because some caregivers couldn't find the time to travel to school, some interviews were held at the homes of the families. The caretakers were chosen, and the researcher asked them to participate in the study after explaining it to them. If you consented, you were required to sign a written consent form (Appendix 1). Forty five to 60 minutes were allotted for each interview.

Data Analysis Methods

The replies to the closed-ended questions were evaluated using descriptive statistics and the chi-square test. The Statistical Software for Social Sciences (SPSS) version 25 was used to code these questions and analyse them using percentages and frequencies. In order to describe the current situation with families of children with ID in terms of family well-being, socio-cultural implications of caring for a kid with ID, economic cost, and coping strategy, descriptive statistics were utilized. The chi-square test was used to determine whether there is a correlation between the four independent variables and the happiness of the family. The test's results were analysed at a significance level of 0.05.

Responses to the open-ended questions were analysed using a thematic content analysis. This method was centred on recognizing recurring themes in the participants' responses and creating patterns using those themes (Percy et al., 2015). In order to find themes, the researcher read over each interview's transcript. Both established and newly emergent concepts were highlighted. In order to create patterns that are crucial for defining the phenomenon of interests, the researcher incorporated topics from each of the 84 interviews.

Results

Response Rate

The fact that the researcher delivered the questionnaire on the spot as soon as the respondents decided to participate is a major factor in the study's 100% response rate. This lessened the possibility of misplaced surveys or questionnaires being returned with a large number of unanswered questions. The researcher had complete discretion to choose responders at any point up until the target sample size was obtained thanks to the sampling technique that was used.

Respondents and Family Background Information

To ascertain the sample's representativeness and support the generalizability of the findings, the characteristics of the respondents and families that participated in the study were analysed. Table 2 provides a summary of these traits.

Table 2: Respondents and Family Background Information

VARIABLE	CATEGORIES	STATISTICS
Gender of Respondent	Male	39.3%
	Female	60.7%
Age of Respondent	Mean	41.67 years
	Minimum	24 years
	Maximum	71 years
Marital Status of the Respondent	Single	22.6%
	Married	57.1%
	Divorced/ Separated	7.2%
	Widow/ Widower	13.1%
Respondent's Relationship with the child with ID	Parent	73.8%
	Sibling	10.7%
	Uncle/ Aunt	15.5%
Family Size	Mean	4.1 members
	Minimum	2 members
	Maximum	9 members
Age of the Child with ID	Mean	13.83 years
	Minimum	4 years
	Maximum	18 years

According to findings in Table 2, women made up 60.7% of the respondents, while men made up the remaining 39.3%. This gender distribution is largely explained by the fact that the study focused on the family's primary caregiver in order to gather data on the family's experiences. WHO (2018) found that the majority of the responsibility for raising disabled children falls on women, particularly mothers. This suggests that the respondents' gender distribution is consistent with the gender distribution of caregivers for children with disabilities.

With the youngest respondent being 24 years old and the oldest being 71 years old, the respondents' average age was 41.67 years. The results show that the sample had a wide range of ages even though the majority of the respondents were middle-aged or older. Given that the majority of respondents (57.1%) were married, this indicates that dual parent families care for the majority of children with ID in Nakuru Municipality. The family's well-being is affected by this family setup since dual parents can divide up the duties of caring for the family's other children and the child with ID (Allred, 2013). Although 7.2% of respondents were divorced or separated, 13.1% of respondents were widows or widowers, and 22.6% of respondents were single. These families are especially susceptible to the strain and responsibility of caring for an ID child.

The bulk of responders (73.8%) were the parents of the ID-carrying child, followed by siblings (10.7%) and uncles and aunts (15.5%). According to Chambers and Chambers (2015), the experiences and wellbeing of the family are influenced by the caregivers' interaction with the child who has an ID. The impact of caregiving on the social and psychological wellbeing of the family members is frequently minimized where there is a strong and close bond between the ID child and the family providing care. When this bond exists, family members are frequently willing to accommodate the demands of caring for the child. Approximately 10.7% of the respondents claimed to be the ID-holding child's siblings, while 15.5% claimed to be either the ID-holding child's uncle or aunt.

The average number of members per family in the study was 4.1. This family size is comparable to the national average, which according to the 2019 National Population and Housing Census, was 3.9 people per family (Kenyan National Bureau of Statistics, 2019). A small family size may benefit the family's well-being since it may lower the family's financial demands, allowing the family to allocate some of its resources to the care of the ID child.

Fewer children mean less children for parents to care of in addition to the child with ID, which minimizes their responsibility. The youngest child with ID was 4 years old, and the oldest was 18 years old. The average age of the child with ID was 13.83 years. The age of the child, which influences how much care they will require, is assumed to have an impact on the wellbeing of the family in the study. Compared to older children, smaller children require more constant attention.

Family Well-Being

Family well-being served as the study's dependent variable. The primary caregivers were asked a series of 10 questions about various areas of family well-being in order to evaluate this topic, to which they were asked to provide a "Yes" or "No" response. The number and percentage of respondents who responded positively (Yes), indicating that their family possessed that specific characteristic of family well-being, are shown in Table 3.

Table 3: Respondents Views on different Aspects of Family Well-Being

S/N	QUESTION	YES [N (%)]
1	Do your family members enjoy spending time together	72 (85.7)
2	Do your family members have friends who provide support	50 (59.5)
3	Do your family members have time to pursue their own interest	57 (67.9)
4	Do all family members get medical care when needed	29 (34.5)
5	Do you find it easy to take care of family expenses	2 (2.4)
6	Do you feel safe and comfortable at home	70 (83.3)
7	Do your family members support each other to accomplish goals	75 (89.3)
8	Do you often solve issues together as a family	71 (84.5)
9	Do all family members get adequate and balanced diet	33 (39.3)
10	Do family members have adequate access to transportation services	38 (45.2)

According to results in Table 3, 85.7% of respondents said that they and their family members like being together. This question was designed to evaluate family relationships, which are a key sign of a healthy family (Noor et al., 2012). The majority of families who care for children with ID, according to the results, have healthy family dynamics. The conclusion also suggests that the bond between family members has not been harmed by raising the child with ID. This assertion is supported further by responses to questions 6 and 7, which revealed that 83.3% of respondents felt safe and at ease at home, 89.3% of respondents said that their family members support one another in achieving goals, and 84.5% of respondents said that they frequently resolve disputes as a family.

Table 4 also reveals that, in response to question 2, 59.5% of the respondents indicated that their family members have friends who can offer help. This question was designed to evaluate the social connections and community involvement of people who are a part of families who care for children with ID. The question was based on the assumption that families caring for disabled children experience social stigma, which prevents them from forming positive relationships with other community members. The results of this survey indicate that most families that care for children with ID in Nakuru Municipality do not fall into this category. The results demonstrate that majority of these families' family members have been successful in overcoming stigma and forging connections with other community members. However, a sizable majority of respondents (40.5) provided a negative response, indicating that they believe their family members are unable to form strong bonds and connections with other members of their community.

Similar to question 2, 67.9% of respondents indicated that their family members have time to pursue their own interests in their assenting response to question 3. This question evaluated the aspect of life achievement, which Noor et al. (2012) identified as another sign of family well-being. The idea behind the question was that caring for a disabled child might inhibit family members from pursuing their own interests and, as a result, from accomplishing their life goals. According to recent findings, families in Nakuru Municipality who care for children with ID have not experienced this. According to the data that is currently available, individuals in more than two-thirds of the sampled households have the freedom to pursue their own interests, which improves their chances of succeeding in life.

Less than half of those who responded (34.5%) to question 3 said that all of their family members receive medical care when necessary. This inquiry aimed to gauge the wellbeing of those in families who care for children with ID. It was based on the idea that having to take care of a child with ID would make it more difficult for families to care for their other members. The results of the current study support this idea because most of the respondents claimed that their family members do not receive necessary medical care. The health of the family members is negatively impacted by limited access to medical care. The access to a sufficient and balanced food by members of families of children with ID was evaluated in question 9, which also addressed the topic of health. According to this, only 39.3% of respondents claimed to be able to have a sufficient and balanced diet.

Only 2.4% of those surveyed answered "Yes" to question 5, which inquired about the families' capacity to pay for household bills. According to this finding, the majority of families in Nakuru Municipality who care for children with ID struggle to provide for their basic necessities. Less than half of respondents (45.2%) to question 10 indicated that family members have adequate access to transportation services, which supports the finding. These results demonstrate that one of the fundamental necessities that most families with children in ID struggle to achieve is transportation. Findings imply that the majority of these families are having trouble meeting other fundamental demands, and that this circumstance is detrimental to their wellbeing.

The majority of families in Nakuru municipality who are raising children with ID have reported that their condition has had an impact on their social wellbeing, according to the findings in Table 3. The majority of these families have been able to preserve positive relationships both inside the family and with other members of the community. This may signify greater enlightenment of communities in Nakuru municipality on ID leading to diminished stigmatization of families of children with ID. Nonetheless, the economic well-being of these families has been negatively impacted, as seen by challenges in accessing services including decent nourishment, healthcare, and transportation. The replies to an open-ended follow-up question that asked participants to describe how life in their families has changed since they began caring for the child with ID provided qualitative evidence that further supports the quantitative conclusion. In response to the inquiry, 72.6% of respondents cited concerns that allude to money problems. Two of the respondents provided the following responses:

"Life has been a bit challenging. My child requires expensive medication and complex treatment procedures, which has really affected us financially. When money is not available, the child goes without medication making his condition worse." **(Respondent 13, female, 36 years old)**

"Our life has drastically changed. The child requires a lot of attention since she cannot do most of the things that children do. We have been unable to get a house help who can withstand the demand of taking care of the child. Many stay for a few weeks and leave. Eventually, my wife had to leave her job and take care of the child. This has really hit us hard, financially." **(Respondent 62, male, 44 years old)**

The aforementioned narration makes it abundantly evident that most families with children with ID are finding it difficult to meet the financial demands of caring for a child with ID. Due to the added costs of treating and caring for the child with ID, many families have had to make adjustments. In some families, one parent has been made to care for the child at home while the other parent is left to earn a living.

Data for all 10 items in Table 4.3 were combined to create a single family well-being score in order to permit additional analysis on how socio-cultural factors, economic cost, and coping mechanisms influence the well-being of families of children with ID. An aggregate well-being scale that ranged from 0 (for respondents who gave a "No" response to all ten questions) to 10 (from respondents who gave a "Yes" response to all ten questions) was created by aggregating all "No" replies as 0 and all "Yes" responses as 1. Hence, a higher score indicates greater family well-being.

The aggregate data on family well-being was converted into category data by classifying the families that had scores of 5 and below as having low well-being and those that had scores of 6 and above as having high well-being because the study intended to use the chi-square test to evaluate the relationship between the independent variable and family well-being. Figure 1 displays how the 84 study-involved families were distributed across the two well-being categories.

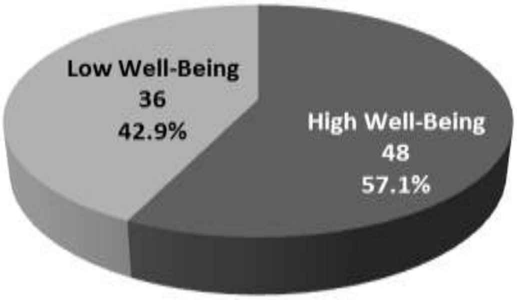

Figure 1: Distribution of Families according to their State of Well-being

The majority of the families (57.1%) experienced great well-being, as shown in Figure 1. This indicates that these families' overall well-being scores were 6 or higher. According to the respondents, it appears that most of the 10 well-being indicators listed in Table 4.3 are present in the families. However as shown in Figure 4.1, more than a third (42.9%) of the families have low levels of well-being when it comes to their financial situation, their relationship as a family, and their social and community connections.

Influence of Economic Cost on Family Well-being

The second objective of the study was to examine the effect of economic cost of caring for children with ID on family well-being. The study focused on assessing the influence of three main economic factors namely: expenditure on care, disruption in caregivers’ work, and material support.

Expenditure on Care and Family Well-Being

The study sought to establish how much the families of children with ID in Nakuru Municipality spend in taking care of their child as well as how the cost of care influences their well-being. It was founded on the rationale that different families incur varying cost depending on severity of the child disability, age of the child, and access to health insurance among other factors. To assess this issue, respondents were asked to indicate the average amount that they spend in a month in providing care to the child with ID. This was a structured question that gave respondents four categories of expenditure to choose from. Results are summarized in Table 4.

Table 4: Distribution of Families based on Expenditure on Care

EXPENDITURE CATEGORY (KSHS.)	FREQUENCY	PERCENT
Less than 10,000	26	30.9
10,000- 50,000	43	51.2
51,000- 100,000	11	13.1
Above 100,000	4	4.8
Total	84	100

Table 4 shows that the majority of the sampled families (51.2%) spend between Kshs 10,000 and Kshs. 50,000 per month in providing care to the child with ID. This is quite a significant amount for an average family to part with and thus may have a major impact on the well-being of the family. About 30.9% spend less than Kshs 10,000 on care. These are probably families whose child has less severe case of ID or are compelled to reduce expenditure by their economic circumstances. About 13.1% spend Kshs. 51,000 – 100,000 per month while 4.8% spend over Kshs. 100,000. The expenditure in these categories is on the higher side and may reflect family preferences. It is most probable that families that spend these high amounts are affluent families. The 2013 inequality report showed only 13.5% of households in Nakuru County spends more than Kshs 7,500 per person in a month (Kenya National Bureau of Statistics, 2013). The subject of expenditure on care was interrogated further by asking respondents to share on some of the items that their families were spending on in caring for the child with ID. The question was specific to only the expenditures items go directly towards addressing the child with ID. These are expenditures that would otherwise not be incurred if the family did not have a child with ID. Respondents were presented with several options and asked to tick all that applied. Results are summarized in Figure 2.

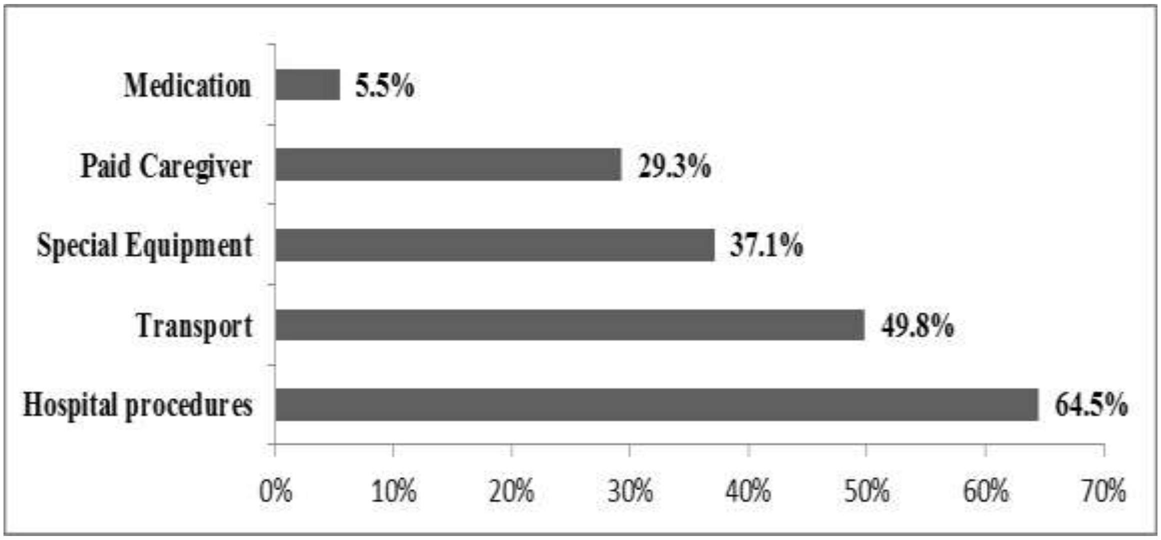

Figure 2: Expenditure Items for Families of Children with ID

Figure 2 illustrates that hospital procedures were the most common expenditure items among the families of children with ID in Nakuru Municipality having been mentioned by 64.5% of the respondents. Respondents mentioned spending money on procedures such as speech therapy, physiotherapy, occupational therapy, counselling, and paediatric care. Transport was the second most frequently mentioned expenditure item having been cited by 49.8% of the respondents. Some respondents narrated that they incur a lot in transportation to and from hospital and school given that the families have to hire special transport means because the children cannot use public means without a person accompanying them.

About 37.1% of the respondent mentioned that they usually spend a significant amount of special equipment such as wheel chair, pressure relief cushion, audio books, and communication boards. These assistive technologies help to improve learning and the daily functioning of the children with ID. About 29.3% of the respondents said that their families incur expenses in hiring caregivers to take care of the child. These are probably the families that hire people to specifically look after the child with ID mainly because most members of the families are committed elsewhere or are unable to provide appropriate care.

About 5.5% of the respondents said that their families incur expenses on medication that are often used to manage challenging behaviour in the children with ID. The fact that only a small section of the respondents reported the expenditure on medication suggests that most of the children with ID do require medication. The influence of these expenditures on family well-being tested by cross-tabulating the data on family expenditure on care (Table 4.7) with the data on family well-being. The last category in Table 4.7 (expenditure of Above 100,000) was merged with the third category (51,000-100,000) because it had only four individuals, which could have skewed the analysis. Table 5 presents the results of the cross-tabulation.

Table 5: Cross-Tabulation of Expenditure on Care with Family Well-Being Data

		FAMILY WELL-BEING CATEGORIES		
		Low Well-Being	High-Well-being	Total
Expenditure Categories	Less than 10,000	8 (30.8%)	18 (69.2%)	26 (100%)
	10,000- 50,000	24 (55.8%)	19 (44.2%)	43 (100%)
	Above 50,000	4 (26.7%)	11 (73.3%)	15 (100%)
Total		36 (42.9%)	48 (57.1%)	**84 (100%)**
Chi-square X2 = 3.794, d.f. = 2, sig. = 0.029				

Table 5 illustrates, the majority of the families (69.2%) in the category that spend less than Kshs. 10,000 have high well-being. In the category of families that spend Kshs. 10,000- 50,000, most families (55.8%) have low state of well-being while in the category that spends above Kshs. 50,000, the largest proportion of families (73.3%) have high well-being. The chi-square test showed that the differences in proportion of families with low or high well-being across the three categories of expenditure are statistically significant at the 0.05 significance level (X^2= 3.794, p<.05). These finding imply that expenditure on care has a significant influence on the well-being of families of children with ID in Nakuru Municipality.

The findings do not however clarify the direction of the relationship between expenditure on care and family well-being. There is no clear pattern as the proportion of families with low well-being increases from 30.8% to 55.8% when expenditure on care increases from less than 10,000 to the 10,000-50,000 category, but then the proportion declines to 26.7% when expenditure increases to above 50,000. The lack of a clear pattern between expenditure on care and family well-being is probably because many other factors have the potential of affecting this relationship key among them being family income. High household income may encourage a family to spend more on providing care to the child with ID without this expenditure taking a toll on the well-being of the family. Similarly, high income may cushion a family that is required to spend more in providing care to the child with ID. Another factor that has the potential of affecting this relationship is financial and material support provided to the families.

Disruption in Caregivers' Work and Family Well-Being

The study sought to establish the opportunity cost that families in Nakuru Municipality incur for taking care of a child with ID. This analysis was founded on the rationale that in some families, caregivers of children with ID are often compelled to quit their job or take up jobs that are less involving in order to provide care for the child. As a results, the family losses the opportunity to earn extra income that could have improved their standards of living. To assess this issue, respondents were asked to indicate whether taking care of the child with ID has affected their work and that of other family members using a "Yes" or "No" response. Figure 3 summarizes the findings.

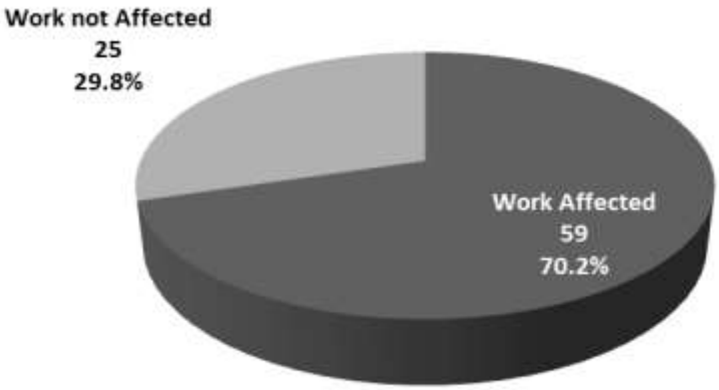

Figure 3: Families Distribution based on Disruption in Caregivers Work

Figure 3 exemplifies that the majority of the families (70.2%) have a family member whose work has been disrupted by the responsibilities of taking care of the child with ID. This implies the opportunity cost of taking care of a child with ID is quite high among families in Nakuru Municipality. About 30% of the respondents however said that work of family members has not been disrupted. These are most likely families that have hired a paid caregiver to take care of the child with ID so as to enable family members to undertake their work responsibilities. Respondents who indicated that the work of family members had been disrupted were asked to share how caring for the child with ID has disrupted the work of family members. It emerged that in about 26% of the families, the primary caregiver has been compelled to stop working in order to take care of the child with ID. In other families, the responsibilities of taking care of a child with ID have led to high rates of absenteeism from work, lateness, and presenteeism. Some respondents narrated as follows:

*"I run a small business and most of the time I open late and close early in order to take care of the child. When it is times to go for therapy, I am forced to close my business for the whole day. This leads to many losses." **(Respondent7, Female, 41 years old)***

*"I had a thriving tailoring business before this child came. Now, the business has really gone down because I am not able to open every day. Even when I open, I am not able to work as well as in past because I keep worrying about my child. There are many days when I am forced to take the child with me to my workshop, which keeps distracting me when I am working. I have lost many customers because of not completing their clothes on time." **(Respondent 43, female, 39 years old)***

*"As I explained early, my wife had to leave her job in order to take care of this child because we could not get a hired person who could withstand the huge responsibilities involved. This has really affected our income as a family." **(Respondent 62, male, 44 years old)***

The first account illustrates how caring for the child with ID has caused high rate of work absenteeism among the primary caregivers leading to decline in family income. The second account illustrates how caring for a child with ID has led to work absenteeism as well as presenteeism. Lack (2011) defines presenteeism as being present at work but unable to fully engage in the work duties. The respondent explains that there are days when she goes to work but find it difficult to work because she keeps thinking about the child with ID. In the last narration, the respondent's wife had to quit her job in order to assist in taking care of the child with ID. The influence of disruption on family well-being was tested by cross-tabulating the data on family distribution based on disruption in caregivers work with the data on family well-being. Table 6 presents the results.

Table 6: Cross Tabulation of Disruption of Caregivers' Work and Family Well-Being

		Family Well-Being Categories		
		Low Well-Being	High-Well-being	Total
Disruption in caregivers' work categories	Work Disrupted	31 (52.5%)	28 (47.5%)	59 (100%)
	Work not Disrupted	5 (20.0%)	20 (80.0%)	25 (100%)
Total		**36 (42.9%)**	**48 (57.1%)**	**84 (100%)**

Chi-square $X^2 = 6.328$, d.f. = 1, sig. = 0.000

Table 6 demonstrates that the proportion of families with low well-being was highest in the categories of families where caregivers' work had been disrupted at 52.5% as compared to 20.0% for families whose caregivers' work was not disrupted. These results indicate that disruption of caregivers' work has a negative influence on the well-being of the family of the child with ID. The chi-square test showed that the relationship between these two variables was statistically significant at the 0.01 level of significance (X^2= 6.328, p<.01). This result implies that disruption in caregivers' work has a noteworthy implication on the standard of living of families caring for a child with ID. The most obvious explanation is that work disruption reduces family income, which alters the family ability to meet its basic needs leading to poor state of well-being. In ability to meet basic needs may also diminish family members' life achievement. The financial strain caused by lost income may also diminish the quality of familial relationships.

Discussion and Conclusions

Mental health policies are least developed in many parts of the world because of the low priority given to mental health compared to other health areas. This study sought to highlight the economic implications of taking care of children with intellectual disabilities in Kenya with the view of informing policies, scaling up the provision of services, and strengthen other sectors that provide similar services such as churches, civil societies, and community organizations.

The majority of families with children with ID in the research region, according to the findings, are in a high level of well-being, as shown by their access to necessities of life, their relationships with family and other members of the community, and their success in life. However, more than 40% of families struggle to achieve these components of wellbeing. The study by McConnell and Savage (2015), which found that raising a kid with ID increases the likelihood of psychological, physical, and financial suffering among families and leads to family dysfunction, is consistent with our findings.

Regarding the influence of economic costs, the study has found that the majority of the families of children with ID spend between Kshs. 10,000 and Kshs. 50,000 in providing care to the child with ID. Hospital procedures were the largest expenditure items in most families. This finding is consistent with the study by Palmer and Nguyen (2012) who found that outpatient care accounted for the largest expenditure of families of children with ID in Vietnam. Other expenditure items among families of children with ID in Nakuru Municipality include transport, special equipment, and paid caregivers. Results showed that amount of expenses that the family incurs in providing care influences the well-being of the family in significant way, but data was not conclusive regarding the direction of this relationship.

Results further showed that disruption of caregivers' work by caring responsibility negatively influences the well-being of families by causing loss of income in the family. This finding is consistent with the study by Doran *et al.* (2012), which found that opportunity costs associated with lost jobs and work absenteeism accounted for 85% of losses that families of children with ID in Australia suffer. The findings also reinforce the view that families remain the most important source of long-term care and assistance for mentally handicapped children. This phenomenon is not limited to Kenya, but is evident in most developing countries. Nyoni and Serpell (2011) also observed that families were mainly responsible for providing personal care to children with with autism in Zambia. Family care tends to increase the opportunity cost involved when a family member is compelled to stay at home and look after the child with ID.

The findings highlight the need for policy and practice intervention aimed at addressing these economic costs. Findings reveal that most of the expenses by families of children on ID is incurred on hospital procedures. Despite this, literature shows that only 0.5% of the annual health budget in Kenya is allocated to mental health. There is a need to increase this budget. Most of the money allocated by the government is also used to provide treatment in hospitals reaching only those who have severe mental impairment. Few resources are made available for provision of services to patients living in community settings. This study has established that the cost of caring for children with ID are not limited to treatment but also encompass other items such as transport cost and provision of personal care for the child. The study has also established that over 70% of the families incur the opportunity cost of caring for the child with ID associated with quitting jobs, absenteeism, and presenteeism. There is need for policy and practice intervention for addressing this challenge. In particular, the study has established that providing material support to the family significantly improves family well-being.

The research also supports the family systems theory, which sees the family as a system made up of various parts and their interactions. According to the hypothesis, how one family member functions affects how the entire family system functions. It acknowledges the interdependence and interaction between various family members as well as the family's unity. According to the study, in some families with ID, one parent must stop their job or engage in less economic activities in order to care for the child with ID.

Policymakers at the National Parliament should expand the cash transfer for person with disability to ensure that it reaches a large number of families. Current findings show that only about a quarter of the families of children with ID in Nakuru municipality get this assistance. The amount of cash transfer should be increased from the current Kshs. 2,000 per month to a minimum of Kshs. 5,000 per month as current findings show that majority of the families spend Kshs. 10,000- 50,000 in providing care to children with ID. The allocation should vary according to the severity of disability and the socioeconomic status of a family.

The study also recommends that the legislator at the National Parliament should enact the bill that seek to create a special fund for remitting contributions to the NHIF on behalf of person with disabilities who cannot afford to pay their contribution. The bill has been pending in the Kenyan Senate since 2017. Actualizing this fund will enhance the well-being of families of children with ID as current findings have shown that hospital procedures are the largest expenditure item in these families.

Social organizations such as NGOs and churches should also consider providing material support to families of children with ID. Findings have shown that families that receive material support fare much better than those that do not receive material support. Extended families should also be enlightened of the economic cost of caring for children with ID and be encouraged to support their kin.

Families of children with ID in the Nakuru Municipality were the only participants in this study. The investigation should be repeated in other regions to support the generalization of these findings. Future research should focus in particular on how caring for children with ID affects the wellbeing of families in rural locations.

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