

Influence of Capacity of Caregivers in Support of Children with Disabilities

Njeri S. Ngacha ^{1,*}, Ronnie Abukhalaf ², and Jason Powell ²

ABSTRACT

This study aimed to triangulate the critical variable of caregiver support that influences social service accessibility by understanding the roles of caregivers in supporting children with disabilities within the informal settlements of Kenya's sub-county of Kasarani. The primary target population includes caregivers, often parents, of children with disabilities, and the secondary target is stakeholders, funding agencies, and community-based humanitarian organizations within Kasarani. A questionnaire was provided to 200 prospective participants, with 157 responding. The resulting data was encoded and analyzed using SPSS to reveal descriptive statistics and a regression analysis model to determine relationships between the dependent and independent variables. The results show that social service accessibility in Kasarani is influenced by the four identified targets of this study. Specifically, a one-unit increase in caregiver participation provides a 0.231-unit increase in accessibility of social services. The findings suggest that increasing home care for children with disabilities is vital; therefore, it is recommended that the government use policies to establish additional homes for disabled children and expand funding for home care and local-based community organizations to improve the lives of those with disabilities.

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¹ Assistant Professor, School of Business, Northwestern State University, USA.

² Associate Professor, School of Business, Northwestern State University, USA.

* Corresponding Author:
e-mail: njeris@nsula.edu

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1. INTRODUCTION

According to the United Nations estimates, the world population was 8 billion at the end of 2022 (Worldometer, n.d.). In 2023, the World Health Organization (WHO) estimated that 16% of the world's population lives with significant disabilities and expects that number to rise as the population ages (WHO, 2023).

In the United States, an economically developed nation, a 2013 study reported functional disabilities in 22.2% of adults, including limited mobility, impaired cognitive disability, independent living and self-care, and vision (Courtney-Long *et al.*, 2015). Furthermore, a 2018 study reported that in 2016, 25.7% of noninstitutionalized adults had a disability (Okoro *et al.*, 2018). The following year, Zhao *et al.* (2019) reported that one out of three adults in rural US communities had a disability, and one out of twelve with a disability reported three or more. The overall trend was that all socio-demographic subgroups experienced an increase in adult disabilities inversely proportional to population size from large metropolitan counties down to noncore counties, except for Hispanics and adults over 65 (Zhao *et al.*, 2019).

Furthermore, Paul *et al.* (2021) reported that the 2015–2019 American Community Survey on civilian noninstitutional population found that within the more rural areas of the US, 18.0% of people reported having a disability. Those disabilities affected almost half of those 18 to 64 years old (49.4%) and 65 years and older (49.4%). Two years later, Paul *et al.* (2023) reported consistent findings from the updated 2016–2020 American Community Survey, with 17.8% in more rural areas reporting a disability, affecting 48.8% of adults 18% to 64% and 44.7% over 65%.

The United Nations Development Programme (UNDP) estimates that 80% of disabled people live in developing nations (UNDESA, 2022), and the World Bank (1975) estimates that 20% of the poorest



people are disabled. These individuals are often considered to have the most disadvantages within their community (UNDESA, 2022).

The number of people living with a disability is increasing in Africa because of increased violence, HIV/AIDS, poverty, malnutrition, and environmental degradation. In 2006, the World Health Organization estimated that, in developing countries, 150 million children aged 15 years and below had a disability and that only 3% were enrolled in special needs education (WHO, 2011). Nair (2010) reported that, in developing countries, approximately 98% of children with physical and intellectual disabilities were not enrolled in school, and less than 10% of all children with disabilities did not attend school. Furthermore, Amnesty International identified that two decades of civil strife in Somalia had left many disabled children at the mercy of extremists.

In Kenya, an estimated 10% (approximately 3.9 million) people have disabilities, 1.6% (about 554,000) have a physical disability, and only 2% of children with disabilities have access to education (APDK, 1999). Furthermore, in 2004, only 26,000 of an estimated 750,000 children were enrolled in special needs education (APDK, 1999). Schools exacerbate the problem by refusing to enroll children with disabilities due to their unique needs. These students typically have two choices: find an integrated school or a specialized school; however, poverty and discrimination prevent caregivers from affording the schools, and thus, children remain at home, denying them an opportunity at education, which is contrary to the Constitution of Kenya that guarantees the right to social services (Republic of Kenya, 2010).

Disabilities and the lack of social services are significant problems within the Kasarani sub-county of Kenya. Many children in the informal settlement areas, like Korogocho, Kariobangi, and Mathare, are left alone because caregivers are busy working or searching for work. The lack of resources exposes these children to sexual and physical abuse that leads to dire circumstances that further compound the problem.

As a prominent global minority group, bringing people affected by disabilities into the discussions is vital because they have a unique perspective on resources that help harness their potential and improve their lives. Njeri and Smith (2023) introduced four variables that affect accessibility to social services in informal settlements of Kenya: stakeholder participation, funding agencies, caregivers, and local community-based organizations. That research focused on the stakeholder participation component of the regression analysis; here, we expand on the research by studying the caregiver component.

1.1. Problem Statement

The WHO estimates that 650 million people and 200 million children have a disability, which affects millions of families in developing countries. In 2008, the Kenya National Disability Survey found that 5% of Kenya's population has at least one disability and faces various handicapping situations depending on the type. Furthermore, those with disabilities face challenges in accessing infrastructure and services, including health, education, social support, and economic assistance, and the majority lack access to rehabilitation services and assistive technology aids.

The Nairobi Integrated Programme (NIP) area of coverage (Kasarani sub-county) has a disability prevalence rate of 5.3%, which is higher than the national figure of 4.6% according to the baseline survey conducted in the year 2013 by an independent consultant (Nyamu Consultants, 2013). This survey revealed that children with disability in the county did not receive the same treatment as their counterparts without disability. The survey further revealed that only one organization in the county works for the well-being of children with special needs (Nyamu Consultants, 2013). In addition, the survey indicated that the county lacked special units for children with Physical and Mental impairments in public primary and secondary schools. Furthermore, the existing special unit in the neighboring sub-counties charges exorbitant fees, which were not affordable to caregivers of these children owing to their poor economic status. The survey also revealed that children with special needs suffered neglect due to the economic status of their household (Nyamu Consultants, 2013).

This study employed social development theories of social learning and conflict theory to understand the success factors and criteria that play a pivotal role in increasing the accessibility of social services for people with disabilities.

1.2. Research Objective

The objective of the present study was to assess the capacity of caregivers of children with a disability in terms of the accessibility of social services in the informal settlement.

1.3. Theoretical Framework

The study was informed by two social theories: Social learning theory and Conflict theory. A theory is a general statement about the real world whose essential truth can be supported by evidence obtained through the scientific method, and it must explain in a provable way why something happens.

1.3.1. *Social Learning Theory*

Social learning theory (Bandura, 1977) posits that learning is a cognitive process that takes place in a social context and can occur purely through observation or direct instruction, even in the absence of motor reproduction or direct reinforcement. Social learning theory suggests that human behavior is learned as individuals interact with their environment. Problem behavior is maintained by positive or negative reinforcement. Learning theory explains behavior based on what organisms have learned from the environment. Methods that stem from this theory are the gradual shaping of new behavior through positive and negative reinforcement, modeling, stress management: biofeedback, relaxation techniques, cognitive restructuring, imagery, and systematic desensitization. Cognitive behavioral therapy looks at what role thoughts play in maintaining the problem. The emphasis is on changing dysfunctional thoughts that influence behavior.

1.3.2. *Conflict Theory by Karl Marx*

This theory draws attention to conflict, dominance, and oppression in social life. Groups and individuals try to advance their interests over the interests of others. Power is unequally divided, and some social groups dominate others. Social order is based on the manipulation and control of non-dominant groups by dominant groups. Social change is driven by conflict, and thus, lack of open conflict is a sign of exploitation, with periods of change interrupting long periods of stability. It is important to note that social workers use this theory to understand clients who are experiencing oppression in some form or another in our capitalist society.

1.4. *The Capacity of Caregivers of Children with Disability on the Accessibility of Social Services in the Informal Settlement*

Caring for a child with a disability can be one of the most heart-wrenching experiences a parent can go through, but at the same time, it can also be very rewarding. It is important to never undermine the stress faced on a daily basis by the caregiver of a disabled child. Everyday tasks such as feeding, grooming, toileting, and bedtime routines can be extremely challenging, especially if the child requires complex care. Many people in this situation will no longer be able to work, as caring for the child may be a full-time responsibility. Home-based care has been recommended, and increasingly, anyone who is suffering from any health conditions in the hospital is being discharged from the hospital as soon as possible to continue their rehabilitation at home (Bonita & Beaglehole, 1988).

In some cases, the child may suffer from a lifelong disability that involves ongoing assistance with activities of daily living. This type of situation prohibits the child's ability to grow into an independent person who takes care of their own needs. Therefore, a continuous caregiver is always needed, and when the parent is the caregiver, this will dramatically change not only their life but the lives of the entire family as well. Especially when other children live in the home, they may feel like their needs are not being met or that not enough time and attention are being spent with them. Likewise, the husband-and-wife relationship may suffer as one spouse spends a lot of time with the disabled child and not as much time in the relationship. Caregivers of children with disabilities describe negative physical, emotional, and functional health consequences of long-term, informal caregiving. They have important insights regarding those aspects of caregiving that have positive and negative influences on their health. Interventions that address these issues may have the potential to positively impact caregiver health.

The caregiver can also provide respite and emotional care for the parents and other family members who are involved in the care. Many studies have involved pet visitation to nursing homes to counteract the boredom and lack of social stimulation these children face. The specific long-lasting effects of these caregiver services are difficult to define, particularly since many of these children suffer from senility and other severe medical problems that limit functioning, and they cannot be rehabilitated (Beck & Katcher, 1984). The caregiver can run errands, complete housekeeping, do laundry, and prepare meals while the parents rest or complete other tasks. A caregiver who is trained to work with special needs children and their families can also provide a comforting shoulder for the parents to lean on whenever they begin to feel overwhelmed and stressed. The vast demands and responsibilities that accompany caring for a child with special needs can be difficult for family members to handle on their own. Although the family unit is a supportive structure, a special needs caregiver can reinforce the structure with competent and professional outside help.

1.5. *Conceptual Framework*

The conceptual framework resulting from the relationships between the study variables is depicted in Fig. 1.

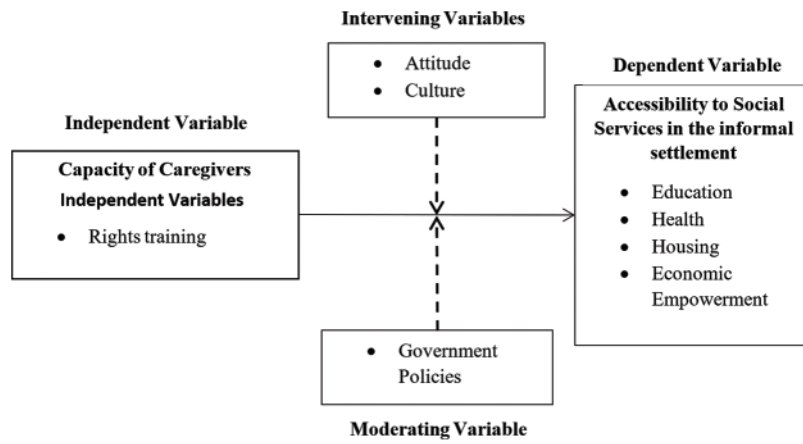


Fig. 1. The conceptual framework.

2. METHOD

The researcher used a descriptive survey research design. Descriptive design is used to obtain information concerning the current status of the phenomena to describe what exists concerning variables or conditions in a situation; it allows the researcher to describe, record, analyze, and report conditions that exist or exist (Kothari, 2005). It aims to discover “what is,” so observational and survey methods are frequently used to collect descriptive data (Borg & Gall, 1989; Kothari, 2005). It is mainly conducted when the researcher wants to gain a deeper understanding of a topic. It involves gathering data describing events and organizing, tabulating, depicting, and describing the data collected (Glass & Hopkins, 1984).

The researcher used quantitative research to check on the accessibility of social services in the informal settlement areas. Descriptive data was collected and categorized in the field using questionnaires. The major purpose of descriptive research design is to describe the current state of affairs as they exist (Kothari, 2005). Conclusions were drawn as the study progressed. The study also reviewed primary data obtained through questionnaires, individual and key informant interviews, secondary data referenced from journals, baseline/assessment research and strategy reports by different agencies, text and electronic books, and other related materials.

3. RESULTS

3.1. Response Rate

The study targeted a sample size of 200 respondents, of which 157 responded, constituting 78.5% (see Table I). This response rate was satisfactory for concluding the study. The response rate was representative. According to Mugenda and Mugenda (2003), a response rate of 50% is adequate for analysis and reporting; a rate of 60% is good, and a response rate of 70% and over is excellent. Based on the assertion, the response rate was considered to be excellent.

TABLE I: RESPONSE RATE

	Questionnaires administered	Questionnaires filled & returned	Percentage
Respondents	200	157	78.5

TABLE II: AGE DISTRIBUTION OF THE RESPONDENTS

Age bracket	N	Percentage
Below 18	21	13.38
Between 18–35	56	35.67
Between 36–49	43	27.39
50+	37	23.57

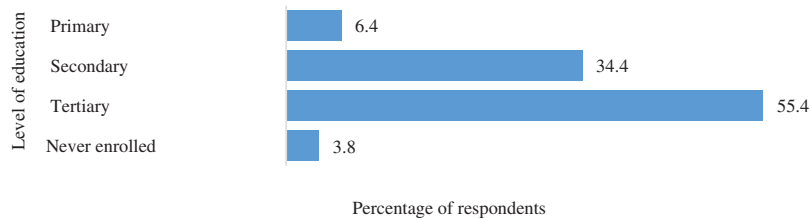


Fig. 2. Distribution of the respondents by their level of education.

3.2. Demographic Characteristics of the Respondents

This section analyzes the demographic information of the individual respondents and their respective agencies. The aim of doing this was to enhance understanding of the background information of the respondents and their personal ability to provide relevant data sought for this study.

3.2.1. Gender

From the findings, 68% of the respondents were female, while only 32% of the respondents were male. This implies that the majority of the respondents were female.

3.2.2. Age of the Respondents

The researcher also sought to determine the age bracket in which the respondents fell (see Table II). Regarding respondents' age categories, the study revealed that most of the respondents, as shown by 35.67%, were aged between 18 to 35 years, 27.39% of the respondents were aged between 36 to 49 years, and 23.57% were over 50 years. In contrast, only 13.38% of the respondents were under 18 years old. This implies that respondents were well distributed in terms of their age.

3.2.3. Level of Education

The respondents were asked to indicate their level of education. Fig. 2 summarizes the responses. According to the findings, most (55.4%) of the respondents indicated tertiary as their highest level of education, 34.4% indicated secondary, 6.4% held primary certificates, and 3.8% never enrolled in school. These findings imply that most of the respondents were academically qualified and, therefore, familiar with their duties.

3.2.4. Years of Experience

The researcher sought to determine the respondents' years of experience. Table III summarizes the responses.

From the findings, the majority (29.3%) of the respondents indicated that they had worked as caregivers and stakeholders of children with disabilities for 5 to 10 years, 28% had worked for 10–15 years, while 22.3% and 20.4% had worked for over 15 years and 1 to 5 years respectively. Productivity in jobs depends on knowledge acquired prior to entry into the labor market or early in the career. This implies that most of the respondents of this study had worked for an ample time. Thus, they were conversant with the information that the study sought on their organization.

3.2.5. Capacity of Caregivers of Children with Disability on the Accessibility of Social Services in the Informal Settlement

The findings regarding the capacity of caregivers revealed that the majority (63.7%) of the respondents agreed that caregiver capacity influences the accessibility of social services for children with disability in Kasarani Sub County. In contrast, 36.3% of them disagreed.

The research examined the level at which respondents agreed on the above statements relating to the effect of the capacity of caregivers on the accessibility of social services for children with disability (see Tables IV and V). The majority agreed with all the statements as shown by their means: Caring

TABLE III: DISTRIBUTION OF THE RESPONDENTS BY THEIR YEARS OF EXPERIENCE

Years of experience	N	Percentage
1–5 years	32	20.4
5–10 years	46	29.3
10–15 years	44	28.0
15+ years	35	22.3

for a child with a disability is one of the most heart-wrenching experiences a parent can go through. This statement was supported by 4.11. The husband and wife relationship can suffer due to much time spent with the disabled child by one spouse, which was shown by a mean of 4.45. In contrast, the caregiver provides a comfortable shoulder for the parents to lean on whenever they feel overwhelmed and stressed, shown by a mean of 4.35.

The study further revealed that the caregiver provides respite and emotional care for the parents and other family members involved in the care, as shown by a mean of 4.05. The study findings are in line with those of Bonita and Beaglehole (1988). The caregiver provides respite and emotional care for the parents involved in the caretaking.

3.2.6. Regression Analysis

A multiple regression model was applied to identify the factors influencing the accessibility of social services in informal settlements. The study adopted the following regression equation to establish the relationship between variables:

$$Y = a + \beta_1 X_1 + \beta_2 X_2 + \beta_3 X_3 + \beta_4 X_4 + \varepsilon \tag{1}$$

where:

Y: Accessibility to social services in the informal settlement,

a: The constant of regression,

$\beta_1, \beta_2, \beta_3,$ and β_4 : the regression coefficients/weights of the following respective independent variables,

X₁: Stakeholder participation,

X₂: Funding agencies,

X₃: Capacity of caregivers,

X₄: Other local community-based organizations.

All four independent variables were measured using the responses on each of the variables obtained from the respondents. The results are shown in Tables VI and VII.

$$Y = 0.889 + (0.555)X_1 + (0.187)X_2 + (0.231)X_3 + (0.117)X_4 + \varepsilon \tag{2}$$

The regression equation given in Eq. (2) has established that holding all factors (stakeholder’s participation, funding agencies, capacity of caregivers, and other local community-based organizations) constant, other factors influencing the accessibility of social services in informal settlements will be 0.889. The findings also show that taking all other independent variables at zero, a unit increase in the capacity of caregivers will lead to a 0.231 increase in the accessibility of social services in the informal settlement.

The study used the R-squared. The R-squared value is called the coefficient of determination and tells us how the accessibility to social services in the informal settlement varied with stakeholder participation, funding agencies, the capacity of caregivers, and other local community-based organizations. The four independent variables studied explain 74.5% of the factors influencing accessibility of social services in informal settlements as represented by the R-squared value (i.e., coefficient of determinant). This, therefore, means that other factors not studied in this research contribute to 25.5% of the factors affecting the accessibility of social services in informal settlements. The results of this study concur with Clark (1996), who found that the capacity of caregivers plays a significant role in improving the accessibility of social services in informal settlements.

The study used ANOVA to establish the significance of the regression model from which a significance value of p less than 0.05 was established ($p = 0.011 < 0.05$; see Table VIII). The model is statistically significant in predicting how stakeholder’s participation, funding agencies, capacity of caregivers and other local community-based organizations affect accessibility to social services in the informal settlement. This shows that the regression model has a less than 0.05 likelihood (probability) of giving a wrong prediction. This means that the regression model has a confidence level of above 95%, hence, high reliability of the results. Using the F-test, the sample F value had a value of 3.662 with critical f value at $\alpha = 0.05$, 5 degrees of freedom for the numerator, and 7 degrees of freedom for the denominator; this implies that the regression model is statistically significant since $55.43 > 11.75$. According to this model can be used for estimating purposes.

TABLE IV: CAPACITY OF CAREGIVERS

Responses	Frequency	Percentage
Yes	100	63.7
No	57	36.3

TABLE V: DISTRIBUTION OF RESPONSES FOR THE EFFECT OF THE CAPACITY OF CAREGIVERS STATEMENTS

Statements	Strongly disagree	Disagree	Moderate	Agree	Strongly agree	Mean	Std. deviation
Caring for a child with a disability is one of the most heart-wrenching experiences a parent can go through.	1	7	27	61	61	4.11	0.18
Husband and wife relationship can suffer due to much time spent with the disabled child by one spouse.	2	12	12	59	72	4.19	0.20
The caregiver provides respite and emotional care for the parents and other family members who are involved in the care.	4	5	14	90	44	4.05	0.23
The vast demands and responsibilities that accompany caring for a child with special needs are difficult for family members to handle on their own.	11	5	7	81	53	4.02	0.22
A caregiver provides a comfortable shoulder for the parents to lean on whenever they begin to feel overwhelmed and stressed.	5	6	2	71	73	4.28	0.24

TABLE VI: REGRESSION COEFFICIENTS

Variables in the regression model	Unstandardized coefficients		Standardized coefficients	t	p
	B	Std. error	Beta		
(Constant)	0.889	0.360		2.470	0.002
Stakeholder’s participation (X ₁)	0.555	0.216	0.444	2.546	0.003
Funding agencies (X ₂)	0.187	0.162	0.125	1.154	<0.001
Capacity of caregivers (X ₃)	0.231	0.128	0.333	1.804	0.001
Other local community-based organizations (X ₄)	0.117	0.111	0.345	1.054	<0.001

TABLE VII: REGRESSION MODEL SUMMARY

R	R-squared	Adjusted R-squared	Std. error of the estimate
0.863	0.745	0.722	0.05

TABLE VIII: ANOVA OF THE FACTORS INFLUENCING THE ACCESSIBILITY OF SOCIAL SERVICES IN INFORMAL SETTLEMENTS

Model	Sum of squares	df	Mean square	F	Sig.
Regression	675.56	4	168.89	55.43	0.011
Residual	463.24	152	3.047		
Total	1138.8	156			

4. DISCUSSION

The study revealed that the capacity of caregivers greatly influences the accessibility of social services for children with disabilities in Kasarani Sub County. It also established that a unit increase in the capacity of caregivers leads to an increase in the accessibility of Social Services in the informal settlement. These results coincide with those of Bandura (1977), who found that social change is driven by conflict, and thus, lack of open conflict is a sign of exploitation, with periods of change interrupting long periods of stability. Furthermore, Hussain et al. (2008) noted that the child may suffer from a lifelong disability that involves ongoing assistance with activities of daily living.

5. SUMMARY OF THE FINDINGS

The study revealed that the capacity of caregivers greatly influences the accessibility of social services for children with disabilities in Kasarani Sub County. Predictions from the regression model predicted that a unit increase in the capacity of caregivers will lead to an increase in accessibility of Social Services in the informal settlement. Also, the study established a significant relationship between the accessibility of Social Services in the informal settlement and the capacity of caregivers. Also, the study established that caring for a child with a disability is one of the most heart-wrenching experiences a

parent can go through, and therefore, the caregivers play an important role in providing emotional care for those parents and other family members who are involved in the care.

6. CONCLUSION

The study concludes that the capacity of caregivers influences the accessibility of social services for children with disabilities in Kasarani Sub County to a great extent. Also, it establishes that caring for a child with a disability is one of the most heart-wrenching experiences a parent can go through.

7. RECOMMENDATIONS

The study recommends more homecare to be established in the informal settlements in the country to help those children with disabilities. Additionally, the government should organize more training on caregiving, which will enable many people to acquire skills in care, hence enhancing the capacity of caregivers.

CONFLICT OF INTEREST

The authors declare that they do not have any conflict of interest.

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