Article

Impact of a Caregiver Collective

by

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Abstract

Background. Caregivers of children with disabilities in Tanzania often face poverty, social exclusion, and mental health problems, which are compounded by stigma and limited formal support. In response, the Uhuru Mama Collective (UMC) was established in 2023 as a school-based initiative combining income generation, peer support, and collective empowerment.

Aims. This study examined the economic, social connectedness, and mental health impacts of participation in the UMC over 16 months on caregivers of children with disabilities, their children, and disability-related attitudes within the school community.

Methodology. A community-based participatory research design was employed, using a one-group, mixed-methods longitudinal approach. Thirty-three female caregivers were followed from baseline to 4, 12, and 16-month follow-ups, assessing economy and mental health. Focus groups and key informant interviews were conducted at 16 months to capture caregiver, teacher, and school perspectives on the impact of the collective.

Results. Substantial improvements in caregivers' financial stability, social inclusion, and mental health were demonstrated. Mean daily income more than doubled, the caregivers went from feeling isolated to active participants in a community, and depressive symptoms significantly reduced. Further, improvements in children's school attendance, peer relationships, and academic and life skills were reported. Finally, enhanced school–home communication and reduced stigma toward disability within the school community was reported.

Conclusion. Findings suggest that a school-based, caregiver-led collective can generate sustained economic, social, and mental health benefits for caregivers of children with disabilities, while also supporting child development, improving school–family relationships, and reducing stigma. The findings support the integration of caregiver interventions into disability, education, and social protection policies in low-resource settings.

Keywords: caregivers of children with disabilities; women's empowerment; peer support; community-based participatory research; health promotion

Background

Caregivers of children with disabilities in many African countries, including Tanzania, face economic hardship, social exclusion, and mental health problems (Mfilinge, 2022; Muzondo & Zvomuya, 2023; UNICEF, 2025; WHO, 2022). These burdens are compounded by stigma surrounding disability (Sæbjørnsen et al., 2023). Recent global reviews show that formal support programs for caregivers—such as cash-for-care schemes, personal assistance, respite services, and psychosocial interventions—are limited in scope across low- and middle-income countries (LMIC) and often face challenges of sustainability, cultural relevance, and low benefit levels (World Bank, 2025). Women, particularly mothers, are disproportionately affected due to their caregiving responsibilities and constrained income-generating opportunities (UNICEF, 2023a).

Caregivers' financial stability and mental health are closely linked to children's well-being and development (Knifton & Inglis, 2020; Magidigidi-Mathiso et al., 2025; Wen et al., 2023). Poverty restricts access to essentials such as adequate nutrition, healthcare, and education (Ridley et al., 2020). Caregiver mental health problems can limit responsive parenting and hinder children's healthy development (Bezerra et al., 2021; Brandt et al., 2022; Cooper, 2021; Honda et al., 2023). Research emphasizes that, in LMICs, strengthening caregivers' economic and mental health is essential for children's opportunities for learning, inclusion, and long-term development (UNICEF, 2025).

In Tanzania, an estimated 6.8% of children live with a disability, and their access to inclusive education and rehabilitation remains limited (UNICEF, 2021). Although national policies promote inclusion, implementation is constrained by poverty, stigma, and weak institutional support (UNICEF, 2023b).

Caregiver Support for Children with Disabilities

Peer support refers to help offered within social networks by people who share similar experiences, creating connection through shared circumstances (Lancaster et al., 2023). Peer support can strengthen confidence, reduce isolation, and help people navigate social and health-related challenges, and has been found particularly

effective for groups with limited access to formal services (Lessard et al., 2024). Studies indicate that peer-led group interventions can strengthen knowledge, attitudes, engagement, and social connectedness (Rajec et al., 2017). Peer-based support initiatives for parents of children with disabilities show promise in addressing both economic vulnerability and psychosocial stress in LMICs where formal infrastructures are lacking (He et al., 2024).

In Tanzanian culture, mutual support is often organized through collectives, where emotional care is intertwined with shared income-generating activities and everyday cooperation. This reflects a highly collectivist social orientation (Pelham et al., 2022). Studies of collectives in LMICs have found that peer-based interventions can reduce social isolation (Brody et al., 2015; Zuurmond et al., 2019), strengthen confidence and agency (Bellamy et al., 2017; Huis et al., 2017), and enhance caregivers' ability to navigate intertwined social and economic challenges (Banks et al., 2018; Teasdale et al., 2023). Various handcraft-based collectives in Africa, such as Neema Crafts in Tanzania, Muya in Ethiopia, and Gone Rural in Eswatini, highlight how income generation, well-being, and social cohesion can reinforce each other.

Research on peer support, caregiver groups, and community-based disability initiatives in LMICs suggests that sustained impact is more likely when interventions strengthen caregivers' practical skills, self-confidence, and opportunities for social and economic participation while being grounded in local leadership and culture (Bannink Mbazzi et al., 2020; Brody et al., 2015; Campbell & Jovchelovitch, 2000; Huis et al., 2017; Nalugya et al., 2023; Zuurmond et al., 2019).

The Uhuru Mama Intervention

The Uhuru Mama Collective (UMC) was established in July 2023 at a public primary school in Ilala District in Dar es Salaam—a densely populated low-income area. The collective brings together 33 female caregivers of children with disabilities who meet three days per week during school hours. The school-based location is central to the model: while children attend school, caregivers can participate without additional childcare or transport costs. In the first year, the caregivers worked in the shade of a tree before being given a small stand-alone workshop space in the schoolyard.

The intervention combines three interrelated components. First, caregivers receive training in craftwork using locally available natural materials, particularly grasses and palm leaves, as well as in tailoring and beadwork. They produce items such as woven bowls, baskets, flowerpots, stuffed animals, and sewn clothes for sale in local and international markets. Income from sales is managed collectively and provides participants with a modest but regular source of earnings.

Second, shared craft production creates opportunities for informal peer support. Activities such as grass weaving allow caregivers to talk while working, exchange practical advice, discuss caregiving challenges, and share emotional support. Participants frequently described these everyday interactions as a source of belonging and reduced isolation.

Third, regular psychosocial sessions combine open discussion with culturally adapted cognitive-behavioural tools. These sessions focus on emotional awareness, coping, problem-solving, and mutual support, offering a structured space for caregivers to reflect on their experiences and everyday challenges.

The UMC was initiated by Dr. Mariana Makuu (a Tanzanian social worker) and Dr. Solfrid Raknes (a Norwegian psychologist), with translation support from a Tanzanian social work student. None of the initiators had financial interests in the collective. A caregiver leadership group, consisting of a chairperson, treasurer, and secretary, was elected at the founding meeting and remained in place throughout the study period. During the first 16 months, the UMC registered as a Tanzanian NGO, opened a bank account, received approximately USD 4,500 through fundraising, and sold products for approximately USD 4,530 through local and international handicraft markets.

Theoretical Framing

For caregivers of children with disabilities, exclusion, stigma, and economic marginalization are often embedded within broader social and structural inequalities. This study uses empowerment as an analytical lens to examine how caregivers may gain agency, voice, recognition, and practical capacity to shape their everyday lives.

Drawing on Freire, empowerment is understood as a collective process through which marginalized groups develop critical awareness and act together to change their conditions (Freire, 1970). Building on Freire, Kabeer (1999) highlights the links between resources, agency, and achievements, while Cornwall (2016) emphasizes that empowerment must be grounded in lived experience, local context, and unequal power relations.

This relational understanding of empowerment resonates with Ubuntu, which is an African philosophy that understands personhood and well-being as inherently collective—"being self through others" (Mugumbate & Nyanguru, 2015). In caregiving contexts, Ubuntu emphasizes mutual care, shared responsibility, acceptance, and collective support, particularly for children and families in vulnerable situations (Chitereka, 2023; Muzondo & Zvomuya, 2023).

An ecological perspective further situates empowerment within the systems that shape caregivers' and children's everyday lives. Bronfenbrenner's ecological theory provides the main framework for understanding development and well-being as shaped by interactions between individuals, families, schools, communities, and wider social contexts (Bronfenbrenner, 1979). Ungar's social-ecological understanding of resilience adds attention to whether people facing adversity can access resources that are meaningful and usable in their own cultural and social contexts (Ungar, 2011).

Research Aims and Questions

This study evaluates impacts of the UMC over a 16-month period on the economy, social inclusion, and mental health. The following questions were addressed:

1. What was the economic, social, and mental health impact of participating in the UMC on caregivers of children with disabilities?
2. How did the UMC influence caregivers' children with disabilities?
3. How did the UMC shape school–family collaboration and community attitudes toward disability?

By integrating longitudinal mixed-methods data, the study examines how a caregiver-led collective functions in practice, and explores the potential of such collectives as a sustainable, community-driven approach to empowerment for families of children with disabilities.

Methodology

Ethics, Research Design, and Study Context

The study employed a community-based participatory research (CBPR) design, using a one-group, mixed-methods longitudinal approach. Specific research clearance for this study was approved under Reference No: MOU 18.11.22– 18.11.27. Informed oral consent was obtained from all participants after providing clear explanations of the study's purpose, procedures, risks, and rights. Participants were free to withdraw at any time without consequences and could skip any questions they found uncomfortable.

The study was conducted within an already established Global North–South collaboration, where universities in Norway exchange students and staff with a Tanzanian university and teaching school. These frames introduced potential power asymmetries related to differences in resources, mobility, education, and institutional status. Additionally, the first and last authors held dual roles as facilitators of the Uhuru Mama Collective (UMC) and researchers, while the second author was part of the UMC leadership and without previous experience with research. In line with a community-based co-researcher methodology, the UMC leaders were actively involved throughout the research process, contributing through their lived experience, community insight, and ongoing engagement with the collective. The three UMC leaders received basic research training and supported data collection to help reduce power imbalances and enhance contextual relevance (Pratt, 2019).

Consistent with CBPR principles, community partners contributed to refining research questions, interpreting findings, and reviewing emerging themes to ensure that study conclusions reflected local experiences and priorities. This participatory approach positioned caregivers not only as participants but also as contributors to knowledge generation and collective development. The use of longitudinal, mixed methods was

chosen for comprehensive assessment of impact at several levels and domains over time (Creswell & Plano Clark, 2011).

The collective is identified in this paper by name because it is a publicly recognized and registered community organization whose activities are intentionally visible within the local community. This decision was discussed with the collective's leadership and aligned with participants' preference that their work and achievements be acknowledged rather than rendered invisible through anonymization. Although the collective is named, all individual participants remain anonymized, and quotations are presented without identifying information.

Sample Characteristics and Description of the Intervention

The sample for the quantitative data included 33 female caregivers (mean age 42, range 28–57), all of whom were members of the UMC. These were mostly biological mothers, with some being adoptive or other maternal caregivers. Most (78%) lived with the child's father. All children had intellectual disabilities, while some also had physical disabilities. About 24% of households lacked reliable access to food and water. Most participants had limited formal education, primarily at primary level or below, reflecting structural and socio-economic barriers to sustained education. See further descriptions in Table 1.

Table 1. Descriptive Statistics, 16 Months into the Collective

Variable	M (SD)	Min	Max
Age	42.45 (6.63)	28	56
Household size	5.67 (2.38)	3	12
Number of children	2.94 (1.35)	1	6
Household income (TZS)	13.469 (6.727)	1,500	30,000

For the qualitative data—the sample for the focus groups for caregivers (n=8), teachers (n=8), and key informant interviews (KII) (n=5: head teacher, assistant head teacher, 2 special needs unit staff, and school matron)—participants were recruited pragmatically via the school using purposive sampling to ensure heterogeneity across roles, caregiving experiences, and levels of engagement with the collective and school activities.

Data Collection

Quantitative data were collected at baseline and at 4, 12, and 16 months; qualitative data were collected at 16 months. All data were collected in Swahili, then translated to English.

Quantitative data were collected using a structured questionnaire comprising six thematic sections: Demographic and Household Information. Age, education level, household size, daily household income, Swahili/English literacy, tribal identity, child's disability, and cohabitation with the child's father. Economic and Collective Participation. Frequency of participation in collective activities, types of handicrafts produced, perceived impact of work on well-being, and self-assessed changes in financial situation and confidence. Mental Health. The level of depression was assessed by using a standardized and normed scale validated for use among adults in Tanzania (Fawzi et al., 2019): Patient Health Questionnaire-9 (PHQ-9) (Kroenke et al., 2001). Depression scores on the PHQ-9 are highly correlated with general mental health indicators, making it a reliable measure for assessing mental health in this population (Beard et al., 2016). Social Connectedness. To assess caregivers' perceived sense of social belonging, a locally adapted version of the Social Connectedness Scale (SCS) developed by Lee and Robbins (1995) was used. In this study, the scale was translated into Swahili. Child Development and Family Relationships. Caregivers were asked to assess changes in their child's independence, communication, behavior, and their own skills and relationship with the child since joining the collective. Teacher Attitudes and School Support. Respondents reported perceived changes in teachers' understanding, support, and respect toward families with children with disabilities since the collective was established.

Qualitative data. The third author conducted the two focus group discussions (one with caregivers and one with teachers), while the last author conducted five key informant interviews with school staff. For interview guides, see appendix.

Reflexivity and Researcher Positionality

As the study was conducted within a community-based participatory research framework, the research team included both academic researchers and members closely involved in the UMC. The first and fifth authors were involved in initiating and facilitating the collective, while the second author held a leadership role within UMC. These dual roles provided important contextual insight and supported trust, continuity, and local relevance. At the same time, they raised methodological and ethical considerations related to power relations, social desirability, and potential confirmation bias.

To strengthen transparency and reduce these risks, several strategies were used. Before and during data collection, participants were informed that their responses were confidential and would not affect their access to collective activities, income from sales, or external support. Quantitative questions were asked in a structured format. Focus group discussions were facilitated with support from the third author (a Tanzanian social work professional and translator) to strengthen linguistic and cultural sensitivity.

The involvement of UMC leaders as co-researchers was also sought to be handled reflexively and care, recognizing both the value as caretakers and local knowledge in general, and the methodological challenges linked to overlapping roles. Their role was not to conduct independent coding but to contribute contextual knowledge, assist with interpretation, and support member-checking. This helped ensure that the analysis was grounded in the everyday realities of the collective. At the same time, we acknowledge that these strategies cannot fully remove the possibility that participants may have emphasized positive experiences, or that the researchers' close involvement may have shaped interpretation. The findings should therefore be read as emerging from a relational and participatory research process, with both the strengths and limitations that such an approach entails.

Data Analysis

Quantitative analysis was conducted in SPSS v.29. Descriptive statistics (means, standard deviations (SDs), ranges) and frequencies were reported. Paired t-tests

measured changes over time in PHQ-9 scores. Regression models examined associations between depression, income, food security, and other covariates (age, household size, hours of participation).

Based om the translated data from the interviews, qualitative data were coded thematically following Braun and Clarke's (2006) six-step method by the first author, then reviewed and validated by the third and last author, then reviewed by the leadership group of UMC, which included the second author.

Results

Quantitative results

Impact on Caregivers

Daily household income at 16 months was TZS 13,469.70 (SD = 6,727.74), ranging from 1,500 to 30,000 per day. Most people reported making 15,000 per day, which has been stable since the 1-year follow-up M=TZS 14,166, a significant doubling from baseline (M=TZS 6,775; t=10.94, p<.001). Participants reported a positive (n=24, 72.7%) or significantly positive (n=9, 27.3%) impact of the collective on their financial situation.

Social connectedness average scores were 16.44 (SD=12.82, range: 8–48; Cronbach's alpha=.97). Social connectedness was not associated with mental health in models both unadjusted and adjusted for parent age, food/water security, household income, and reading/writing literacy levels.

Caregiver mental health. Many participants reported improvements in their personal well-being because of making handicrafts with the collective (n=18, 55%). Almost all participants (n=31, 94%) reported that participation in the collective had improved their confidence.

Mean depression scores on the PHQ-9 were 4.94 (SD=3.83), which was a significant improvement from baseline (M=6.33; SD=5.68; p<.05), although it was a slight average increase compared to 1-year follow-up (see Table 2). However, the Cronbach's alpha for the PHQ-9 is low (.53), questioning the scale's reliability. This

suggests the PHQ-9 may not be a reliable measure of mental well-being this wave. However, alpha for time 3 was satisfactory (.77), suggesting that the PHQ-9 was less reliable at the 16-month follow-up, possibly due to the sustained impact on well-being with only three PHQ-9 scores falling in a depressive range. This indicates that the intervention has helped to sustain mental well-being and reduce depression over the long term (16 months)**.** At 16-month follow-up, 90.9% of the sample (n=30) reported no or mild symptoms, and only n=3 parents (9.1%) reported moderate or severe depressive symptoms, which is an improvement compared to baseline (78%) and 3-month follow-up (80%). Social connectedness was higher in those with no/mild depression (M=16.97; SD=13.08) compared to those with moderate/severe depression (M=9; SD=1.00), although only three people had moderate/severe depression.

Table 2. **Symptoms of Depression Over Time**

	Baseline	**Three-Month Follow-up**	**One-Year Follow-up**	**16-Month Follow-up**	**t (p-value)[a]**
PHQ-9 Total Score Mean (SD)	6.33 (5.68)	5.75 (4.00)	3.61 (3.91)	4.94 (3.83)	-3.99 (<.001)[a]
PHQ-9 Total Score Range (Min–Max)	0–19	0–16	0–18	0–16	
Depression Symptom Categories	**n, %**	**n, %**	**n, %**	**n, %**	
No depression (score 0–4)	10, 37%	8, 40%	21, 64%	16, 48.5%	
Mild depression (score 5–9)	11, 41%	8, 40%	10, 30%	14, 42.4%	
Moderate depression (score 10–14)	3, 11%	3, 15%	1, 3%	1, 3.0%	
Moderate to severe depression (score 15+)	3, 11%	1, 5%	1, 3%	2, 6.1%	

Table 2. Symptoms of depression, assessed by Patient Health Questionnaire (PHQ-9) *are presented as means and standard deviations (SD) and as frequencies. Higher scores indicate greater depressive symptom severity.*
[a] t-test of mean scores at baseline to one-year follow-up.
[b] t-test of mean scores at baseline to 16-month follow-up.

Impact on Children with Disabilities

Parent–Child Relationships. When asked how involvement with the collective has changed their relationship with their child, 93.9% of participants (n=31) believed their relationships had improved slightly (42.4%) or significantly (52.5%), while only 6.1% (n=2) felt it had remained the same.

Child Development. All 33 parents reported that there had been an improvement in their skills to support their child's development, that their child had become more independent with daily tasks (e.g., dressing, eating, organizing), and that they had observed noticeable improvements in their child's communication skills since joining the collective.

Impact on School–Family Collaboration and Attitudes

Parents reported that most teachers were somewhat understanding (n=10, 30.3%) or more understanding (n=20, 60.6%), though n=5 (15.2%) reported that their teacher was less understanding of families with children with disabilities. Parents similarly reported that teacher support for families with children with disabilities had improved (n=28, 85%), and n=5 (15.2%) again reported that they had become less supportive. Teachers' respect for caregivers of children with disabilities since the UMC was established improved for most (n=27, 82%).

Qualitative Results

Impact on Caregivers

Economic empowerment was reported as having taken place due to income generation, transferrable livelihood skills, and social participation through economic autonomy.

Greater social connectedness was reported, due to reduced social isolation and stigma through collective belonging, strengthening through unity, improved emotional well-being and self-efficacy, and reduced depression and anxiety.

Impact on Children with Disabilities

Positive changes in children's development and inclusion were reported, in the form of increased educational participation and learning, functional independence and general life skills, and improved social inclusion and peer relationships between the children both with and without disabilities.

Impact on School–Family Collaboration and Attitudes

Improved school–family collaboration was reported, due to improved economic stability enabling school participation, and increased caregiver presence at school.

Better school–home communication and stigma reduction was explained through increased caregiver confidence and visibility, and increased social dignity and community participation from the caregivers.

For further details, including the reported changes and associated quotes, see Table 3.

Table 3. Impact of the Uhuru Mama Collective on Caregivers, Based on Qualitative Data

Main Theme	Sub-Themes	Changes Reported	Quotes
1. Impact on Caregivers			
Economic empowerment	**Income generation**	Participation created regular income through craft production and sales	**KI-1, B.** *The partnership helped address the challenges of transportation costs, lack of school supplies, and medical expenses after the mothers could create and sell products, generating income to tackle economic challenges.* **KI-1, D.** *The financial benefits are evident in how they dress nicely, braid their hair, and engage in social matters, such as contributing to funerals.* **P, 6**. *The economic difference is very big for me. My independence has increased.*
	Transferable livelihood skills	Acquisition of transferable production and sales skills	**T, 4.** *Participation in the group has helped the women to learn life skills and acquire various kinds of knowledge. They now know how to sew clothes, weave baskets, and make decorations. These women have also learned techniques for selling their products.* **P, 3**. *The difference is due to the skills we have acquired. Even if we are at home, we can sew something and sell it. We have acquired skills that will last.*
	Social participation through economic autonomy	Ability to contribute to social obligations and events	**P, 2**. *Now we get cash support. For example, every Thursday when I get cash support, it helps. I can pay small contributions. I do not have to ask for everything, as I had to do previously.*
Social connectedness	**Reduced social isolation and stigma through collective belonging**	Normalization of shared experiences; mutual recognition	**P, 7.** *Through this partnership, we have been able to create trust and rely on each other because our closeness has increased.* **KI-2, K.** *We now see that the mothers comfort and support each other, and that they engage with teachers and other caregivers. The group has created unity.* **P, 6.** *The relationship between collective members has improved. For example, I receive calls from my fellow members when I am at home. Also, when I had a bereavement, they came to see me and contributed*

Main Theme	Sub-Themes	Changes Reported	Quotes
			money. I was very comforted. And even when a child is sick, they call to ask about the child's condition. Initially we used to meet at school, but we did not have personal closeness—we were just seeing each other but we did not know each other, nor did we help each other as we do now.
	Strengthening through unity	Members experienced increased mutual support and peer solidarity	**P, 3.** *As my fellow contributors have said, we receive a share of money every week, and when we face a challenge, the group members help us. We also discuss and exchange ideas about various topics, guiding each other on the best ways to resolve them. For example, we talk about parenting and the challenges our children face when they arise.* **P, 6**. *I really appreciate it because at first, these things were difficult for me; I didn't understand many things, and I felt restricted in talking to my neighbors or family.*
Mental health	**Improved emotional well-being and self-efficacy**	Being part of a larger supportive community elevated mothers' self-confidence and mental health	**P, 7.** *Now, my fear is decreasing because my self-confidence has increased. By sitting in the group, I've come to see that I'm not alone—there are many children with special needs. I've also seen how deeply other parents love their children, and that has taught me a lot. Now, I have great freedom with my child at home, and I am no longer as afraid as I used to be.* **T, 2.** *These women now appear livelier and show signs of happiness.* **T, 4.** *They have gained confidence in earning money to support themselves and their children. The project has made them more self-confident and closer to their families. I can also add that their families now respect them more because they can support themselves, unlike before. For example, previously, some women may have been seen as burdens by their families because they were asking for help, but now they take care of themselves, and that has restored their dignity.*

Main Theme	Sub-Themes	Changes Reported	Quotes
	Reduced depression and anxiety	A shift from despair to hope	**KI-1, D.** *The sense of hopelessness they had before has greatly diminished.* **KI-1, E.** *Regarding psychological support, I can say that bringing them together to engage in artistic activities has helped reduce their stress.* **P, 1.** *Depression was a problem for many mothers, but now, many are improving. The ability to speak and exchange ideas has become much better compared to before; when we meet now, we can talk and laugh freely.*
2. Impact on Children with Disabilities			
Child development and inclusion	**Educational participation and learning**	Gains in basic academic skills (literacy, communication)	**T, 8.** *This partnership has greatly helped the children of the women in the group to be livelier in the classroom, and even during sports activities.* **P, 8**. *My child now can speak and write, before he could not.* **P, 2**. *My child has been placed in an inclusive classroom. I did not expect at first that it would be possible, but I am very happy with his progress.*
	Functional independence and life skills	Improvements in children's ability to manage daily tasks	**P, 1.** *As we mentioned, the changes are significant for our children. My child is a living example, who now asks to help with household issues. She didn't have that ability before, but she observes how we cooperate and work together. A great deal of fear has disappeared.*
	Social inclusion and peer relationships	Children showed increased social interaction, forming friendships and participating more confidently in play and group activities with peers with and without disabilities	**T, 5:** *Many children with intellectual disabilities have become closer to other children with and without disabilities. This is evident during teatime, where these children are seen interacting enthusiastically with other children.* **P, 2.** *In the community, discrimination is high, but our children with intellectual disabilities possess the capacity to be confident and engage with others. We even observe that in inclusive classrooms, our children socialize and play with their peers who do not have disabilities.* **P, 8**. *My child has found many other friends among the children of parents*

Main Theme	Sub-Themes	Changes Reported	Quotes
			who are also part of the collective. They play together and they help each other, and closeness with other students without disabilities has increased. I am happy to see my child is becoming more cheerful.
3. Impact on School–Home Collaboration and Community Attitudes			
School–family collaboration	**Economic stability enabling school participation**	Improved and more consistent school attendance among children with disabilities	***T, 2.*** *Previously, women in the Uhuru Mama Collective faced numerous economic challenges. For example, some struggled to cover even the tuition fees to send their children to school, which led to their children being labeled truants. These women appeared very distressed and lacked enthusiasm. Now, school attendance among these children has greatly improved because, thanks to the income generated by their project, the women can afford transportation and essential needs.*
	Increased caregiver presence at school	More frequent interaction facilitating communication with teachers	***P, 6.*** *Our presence in the school environment makes it easier for me to participate in my child's academic journey.* ***T, 6.*** *The involvement of mothers with children who have intellectual disabilities in staying close to teachers and monitoring their children's progress has increased the closeness between teachers and children.*
Communication and stigma reduction	**Increased caregiver confidence and visibility**	More proactive communication with teachers and reduced fear of contact	***P, 4.*** *When I see a teacher is calling me, I am not afraid now, unlike before.* ***P, 5.*** *I see many parents in the collective following up with teachers to ask about their children's progress, and the teachers are very happy about this. They tell us it is very important. I feel very involved.* ***P, 1.*** *Regarding cooperation, it has increased greatly at school. Communication has improved significantly. We believe it will continue to improve.*
	Social dignity and community participation	Improved appearance, participation in social events, and	**KI-1, D.** *The financial benefits are evident in how the mothers dress nicely and braid their hair and engage in social matters, such as contributing to funerals.*

Main Theme	Sub-Themes	Changes Reported	Quotes
		reduced social marginalization	

Table 3 highlights the intervention´s impact on caregivers of children with disabilities, on their children, and on community attitudes on disability. Quotes from caregivers (P), teachers (T), and Key Informants (KI) illustrate the reported changes.

Discussion

The findings suggest that the UMC's impact lay not in income generation, peer support, or psychosocial support alone but in the way that these elements were embedded in a school-based, caregiver-led collective over time.

Economic Participation, Dignity, and Caregiver Agency

A doubling of household income over 16 months is notable in a context where many families live below the global poverty line. Beyond income itself, economic participation supported dignity, autonomy, and children's school attendance by helping caregivers to cover transport and related costs. These findings align with broader evidence that income generation can act as a catalyst for social connectedness and mental health in LMICs (Orton et al., 2016). Viewed through the empowerment and ecological framework, these findings add empirical support to arguments for rethinking disability-related care as more than unpaid private responsibility. Caregiving should also be understood as socially valuable work, shaped by access to resources, agency, recognition, and supportive institutional relationships (Bronfenbrenner, 1979; Kabeer, 1999; UNICEF, 2023b; 2025; World Bank, 2025).

From Isolation to Belonging: Peer Support and Mental Health

Although the social connectedness scores were low relative to Western reference samples, the qualitative data indicated substantial gains in peer support and reduced isolation. Caregivers described the UMC as a collective space where disability was normalized, shared experiences were validated, and emotional and practical support were exchanged. Our findings align with evidence from LMICs showing that peer-based interventions can reduce social isolation, strengthen agency, and support caregivers' capacity to navigate intertwined social and economic challenges (Brody et

al., 2015; Huis et al., 2017; Zuurmond et al., 2019). Our findings support the value of interventions that combine skill-building, economic engagement, and peer support, and that are locally led and embedded in existing social norms, as key mechanisms for sustained impact (Bannink Mbazzi et al., 2020; Campbell & Jovchelovitch, 2000; Nalugya et al., 2023).

The reduction in depressive symptoms over 16 months is notable given the chronic and cumulative stressors faced by caregivers of children with disabilities. Unlike time-limited psychosocial interventions—where benefits often diminish once structured support ends (Cuijpers et al., 2021)—the UMC provided ongoing peer engagement, shared routines, and practical collaboration over time. Our results are aligned with research showing that livelihood security can reduce psychological distress (Lund et al., 2018), and with research stating that peer support can strengthen coping, hope, and emotional regulation (Brody et al., 2015; He et al., 2024). Importantly, the embedding of mental health support within everyday economic and social activities at a school may have helped sustain mental health gains. This resonates with evidence that engagement in work, learning, and collective identity is protective against depression, particularly in contexts where formal mental health services are scarce (Patel et al., 2018; Sorensen et al., 2021).

From Caregiver Support to Child and School Inclusion

Teachers and caregivers reported positive changes among the children with disabilities, including improvements in school attendance, basic academic and communication skills, functional independence, and peer relationships. These outcomes align with emerging evidence that caregiver-focused interventions can indirectly benefit child development and inclusion (He et al., 2024). Importantly, the study moves beyond caregiver-reported outcomes by incorporating teacher perspectives, strengthening confidence in observed changes within school settings.

A key contribution of this study lies in its examination of how a caregiver collective can influence school–family relationships and disability-related stigma in a community. This shift appears to have altered interactional norms, making caregiver presence and communication with teachers more routine and socially accepted.

These findings align with research showing that community-based initiatives can reshape local norms around inclusion when material resources are paired with social recognition and collective identity (Shahali et al., 2024). Our findings illustrate how stigma reduction may occur through everyday practices that normalize participation, such as regular school presence, shared routines, and sustained engagement over time.

Interpreting the Findings Through Empowerment and Ecological Perspectives

From an empowerment perspective, the findings illustrate the links between resources, agency, and achievements: caregivers gained access to income, skills, and recognition, and school-based relationships appeared to strengthen their capacity for everyday action (Kabeer, 1999; Cornwall, 2016).

The collective nature of these changes also resonates with Freire's view of empowerment as a process through which marginalized groups develop voice, shared awareness, and collective capacity to act on their circumstances (Freire, 1970). In the UMC, shared work, peer support, and psychosocial reflection created spaces where caregivers could reinterpret isolation and hardship as shared challenges rather than private burdens. This process also reflects Ubuntu-informed understandings of care, where dignity, well-being, and responsibility are relational and embedded in mutual support (Chitereka, 2023; Mugumbate & Nyanguru, 2015; Muzondo & Zvomuya, 2023).

From an ecological perspective, the UMC appears to have created change across interconnected levels. At the individual level, caregivers reported improved confidence, economic stability, and mental well-being. At the relational level, shared work and peer support reduced isolation and strengthened mutual care. At the institutional level, the school-based setting increased everyday contact between caregivers and teachers. At the community level, the visible presence of productive caregivers on school grounds may have contributed to more inclusive attitudes toward disability. This aligns with Bronfenbrenner's understanding of development as

shaped by reciprocal interactions between individuals and their surrounding systems over time (Bronfenbrenner, 1979).

Ungar's social-ecological understanding of resilience further helps interpret the UMC as a mechanism through which caregivers gained access to resources that were meaningful and usable in their everyday lives, including income, peer support, school contact, recognition, and shared problem-solving (Ungar, 2011). The first author's dual role as facilitator and researcher is also relevant in this regard. Her access to international networks, product ideas, fundraising, and consumer markets was not external to the intervention but part of the wider ecology that made the collective possible. At the same time, this introduced power asymmetries and possible bias. The findings should therefore be understood as emerging from a relational and co-created process in which local leadership, school infrastructure, caregiver participation, and external networks interacted to produce change, which is consistent with community-based participatory research approaches that emphasize collaboration, reflexivity, and local ownership (Israel et al., 2019; Jameson et al., 2023; Wallerstein et al., 2018).

Limitations and Strengths

A key strength of this study was the participatory design. Involving UMC leaders as community co-researchers increased contextual relevance, strengthened trust, and facilitated interpretation of findings from local perspectives. The longitudinal mixed-methods design was another strength, as it made it possible to examine changes over time and to capture economic, social, psychological, and school-related outcomes.

However, several limitations should be acknowledged. The study used a one-group design without a comparison group, so causal conclusions must be made cautiously. The sample was small and drawn from one school-based collective, which limits transferability. Some outcomes, particularly changes in children's development and community attitudes, were based on reports from caregivers, teachers, and school staff rather than direct measurement. Responses may also have been influenced by social desirability, given the close relationships between participants, UMC leaders,

and researchers. The dual roles of some researchers as both facilitators and researchers may have introduced confirmation bias, but reflexive discussion, structured data collection, and local review of emerging interpretations were used to reduce this risk. Such relational dynamics are also part of CBPR in low-resource settings, where trust and local ownership are central (Jameson et al., 2023).

Implications and Conclusion

For scalability, establishing and maintaining cultural collectives requires financing mechanisms that recognize social processes as well as measurable outcomes. For caregiver collectives, sustainability and scalability are therefore most likely when economic activities, leadership structures, and support mechanisms are co-developed with communities, reinforcing local ownership, dignity, and relational accountability rather than external dependency.

Implications for research. Future research should include comparison groups, longer follow-up periods, and cost-effectiveness analyses to better assess sustainability and scalability. Comparative studies are also needed to examine whether the core principles of the UMC model—caregiver-led income generation, peer support, school embeddedness, and collective ownership—could be adapted to high-income welfare contexts, such as Norway, where economic needs, service systems, and cultural expectations around caregiving differ substantially.

Implications for practice. Practitioners and services working with families of children with disabilities should consider community-embedded approaches that address livelihoods and social belonging alongside psychosocial support, rather than relying solely on time-limited counseling or education programs.

Implications for policy. Policymakers should consider supporting school-based caregiver interventions as part of social protection and inclusive education strategies. Investment mechanisms should recognize social processes—such as peer support, dignity, and community participation—alongside economic outcomes, to enable sustainable, locally led scale-up.

In conclusion, our findings support the integration of culturally grounded initiatives into disability, education, and social protection services and policies.

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