

Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh

A project implemented in partnership by
Carers Worldwide and the Centre for Disability in Development

Funded by the CareTech Foundation and the Rangoonwala Foundation



Meeting of the Kalinagar carers group

Photo by Ruma Akter

Final Evaluation Report by Md. Anisuzzaman

September 2024



Table of Contents

<i>Abbreviations and Acronyms</i>	4
<i>Acknowledgements and thanks</i>	5
<i>Executive Summary</i>	6
1. Introduction	8
1.1. Background.....	8
1.2. Project location	8
1.3. The issues facing family carers – a brief literature review	9
1.3a. Caring for children with disabilities or chronic illnesses.....	9
1.3b. Characteristics of Unpaid Carers	9
1.3c. Stigma.....	10
1.3d. Health Impacts of Caring for Children with Disabilities.....	10
1.3e. Socio-economic Status and Socio-cultural Norms	11
1.4. Objectives of the Final Evaluation	12
1.5. Scopes and Limitations	12
2. Evaluation Methodology	12
2.1. Desk Research.....	12
2.2. Sample Techniques.....	12
2.3. Sample Size for Qualitative Research	12
2.4. Areas of Evaluation.....	13
2.5. Data Analysis.....	13
3. Major achievements against Indicators	13
3.1. Project outputs, outcomes and achievements	13
Summary of results	16
3.2 Project end line survey	16
3.2.1 Support for the role of being a carer	16
3.2.2 Emotional and mental wellbeing	17
3.2.3 Physical wellbeing.....	18
3.2.4 Respite from caring.....	18
3.2.5 Financial wellbeing	19
3.2.6 Feeling valued as a carer.....	21
3.2.7. Confidence to claim rights and advocate	22
3.3. Related Policies, Laws, and Acts Review	24
3.4. Findings from Qualitative Research.....	25
4. Key Achievements, Challenges, and Lessons Learned	29
5. Recommendations	31
6. Conclusion	32
References	32

Annexes..... 36

Annex I: Lessons Learned (reported by the CDD Project Team)..... 36

Annex II: Focus Group Discussion (FGD) format for Final Evaluation..... 39

Annex III: Key Informant Interview (KII) format..... 43

Annex IV: IDI Guide for End Evaluation for CDD Project Team..... 46

Annex V: Case Study Checklist for Unpaid Family Carers 47

Annex VI. Observation Checklist of Family Members..... 49

Abbreviations and Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CCC	Community Caring Centre
CDD	Centre for Disability in Development
DD	Developmental Disability
DSS	Department of Social Services
FGDs	Focus Group Discussion
IDIs	In-Depth Interview
IACO	International Alliance of Carer Organizations
KIIs	Key Informant Interview
MP	Member of Parliament
MoHFP	Ministry of Health and Family Planning
MoLJPA	Ministry of Law Justice and Parliamentary Affairs
MoSW	Ministry of Social Welfare
NGO	Non-Governmental Organisation
HRQoL	Health-Related Quality of Life
QoL	Quality of Life
UHFPO	Upazilla Health and Family Welfare Officer
UP	Union Parishad
USSO	Upazilla Social Services Officer

Acknowledgements and thanks

This independent evaluation report reflects the collaboration between Carers Worldwide and the Centre for Disability in Development (CDD), Bangladesh, to support unpaid family carers of people with disabilities.

I would like to thank the unpaid family carers who put their trust in us and participated in the project over the last three years. Thanks also go to the carers who participated in this final evaluation, sharing the changes in their lives via the end of project survey and their insights on the project as a whole through focus group discussions. Their involvement has provided valuable perspectives on the challenges they face and the positive changes they have experienced within their families and communities.

I also extend my gratitude to Mr. Md. Moinul Islam, Senior Co-ordinator at CDD and all the project team members for their commitment and their enthusiasm in implementing the Carers Worldwide model, which has led to significant outcomes.

I am grateful to Mr. A. H. M. Noman Khan, Executive Director, and Mr. Nazmul Bari, Director of CDD, for their leadership and support in helping make this project a success.

The support from the Union Parishad, health professionals, and the Savar Government health facilities in implementing the Carers Worldwide model is much appreciated.

I would also like to thank the Carers Association Savar, Carers Alliance Bangladesh, and the Neuro-Developmental Disabilities Protection Trust for their steadfast support of unpaid family carers.

Special thanks go to Dr. Anisuzzaman for carrying out the independent evaluation, conducting interviews, completing the literature review, compiling this report and offering thoughtful recommendations that will shape future initiatives.

I would also like to recognize Ruth Patil for her valuable contributions to the project and her assistance in producing the report.

Lastly, but no means least, I extend my appreciation to the Rangoonwala Foundation and the CareTech Foundation for their generous funding and their belief in Carers Worldwide, which made this work possible.

I hope this report serves as a source of inspiration and a reflection of the progress we have made together over the past three years.

Dr. Anil K Patil
Founder and Executive Director
Carers Worldwide

Executive Summary

Introduction

The project "Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh" aimed to enhance the health and socioeconomic wellbeing of 1,002 carers of persons with disabilities (93% of whom were women and girls) in Savar, Bangladesh through the Carers Worldwide model. This model addresses carers' social inclusion, physical and mental health, employment, education, and advocacy needs.

The aim of this independent final evaluation was to:

- Assess the extent to which the project's outcomes and outputs were achieved
- Identify the impact of the project and the likelihood of sustaining this impact
- Identify key achievements, challenges, and lessons learned from the project
- Make recommendations for future projects involving Carers Worldwide, CDD, other Carers Worldwide partners, and other organizations

Methodology

The evaluation employed both desk and qualitative research methods, including Focus Group Discussions (FGDs), In-Depth Interviews (IDIs), and Key Informant Interviews (KIIs). It involved a comprehensive review of project documents like the proposal, baseline study, logframe, monitoring reports, and carers' data, supplemented by a literature search. The FGDs included seven groups of 15-20 carers, ensuring diverse representation by socio-economic status, involvement with different aspects of the project, and the type and severity of disabilities of their family members. IDIs were conducted with three project team members to gain deeper insights, while KIIs engaged four stakeholders, including doctors, local government officials, and CDD management, for broader perspectives on the project's effectiveness and sustainability. Two case studies provided detailed narratives on the project's impact on individual carers. Data from these activities were analyzed to identify key themes aligned with the evaluation objectives.

Findings

The project successfully addressed carers' needs through initiatives like forming 25 new Carers Support Groups (making a total of 50 in the project area), 4 new cluster level committees (making a total of 8), 1 carers association, and a national Carers Alliance. Monthly meetings of these groups facilitated discussions on financial needs, leading to small entrepreneurship plans. A significant 98% of carers reported improvements in mental and/or physical health. Over 70% received training and became self-employed in areas like homestead agriculture, poultry, goat and cow rearing, and small shops. Additionally, four community caring centres provided care for disabled children, giving carers respite.

Effectiveness

The project achieved and exceeded its targets, reducing loneliness and isolation among carers through support groups. It improved access to health services, identified health conditions, and provided emotional support through trained counsellors. The tailored training and employment opportunities, along with respite services, supported carers' mental health and wellbeing as well as their economic inclusion. Advocacy efforts enhanced the recognition of carers' needs at various levels.

Sustainability

The project's benefits are expected to continue beyond the funding period due to established structures like Carers Support Groups and community caring centres. Sustainability measures included building the capacity of CDD staff, engaging local authorities, and integrating project activities into community frameworks.

Impact

Carers experienced notable improvements in physical and mental health due to better access to health services and support groups. The project's economic interventions enhanced carers' financial wellbeing. Carers also reported increased confidence, greater participation in community activities, and reduced social isolation. The project's advocacy efforts empowered carers to actively participate in local advocacy initiatives.

Recommendations

Recommendations for future projects include enhancing community sensitization through Social Communication initiatives and developing social and behaviour change communication materials to promote awareness and acceptance of family carers. The training of volunteers at community caring centres should focus more on community counselling and special education principles. The centres should also be equipped with more educational materials and resources to support non-formal education for children with disabilities. Leadership training and follow-up interventions are recommended to ensure continuous capacity building.

Further recommendations include the increased use of technology to overcome inclusion barriers, documentation of project outcomes for replication, and strengthening monitoring and evaluation frameworks. Future project designs should incorporate savings plans for carers' groups from the start and expand stakeholder engagement. Identifying additional employment opportunities, such as in beauty parlours, IT, and electronics, is suggested, along with more comprehensive health screenings and the introduction of telemedicine services. A greater focus on co-carers could provide more respite opportunities.

For Carers Worldwide and CDD and future funders, continued capacity building for carers' group members and stakeholders is crucial for sustainability. Expanding advocacy efforts to achieve broader policy changes at the national level, exploring additional income-generating opportunities, and advocating for high-level policy changes based on evidence are also recommended. The latter is being addressed through the formation of the Carers Alliance Bangladesh, which has been facilitated by the project, and its work needs to be further supported and expanded.

1. Introduction

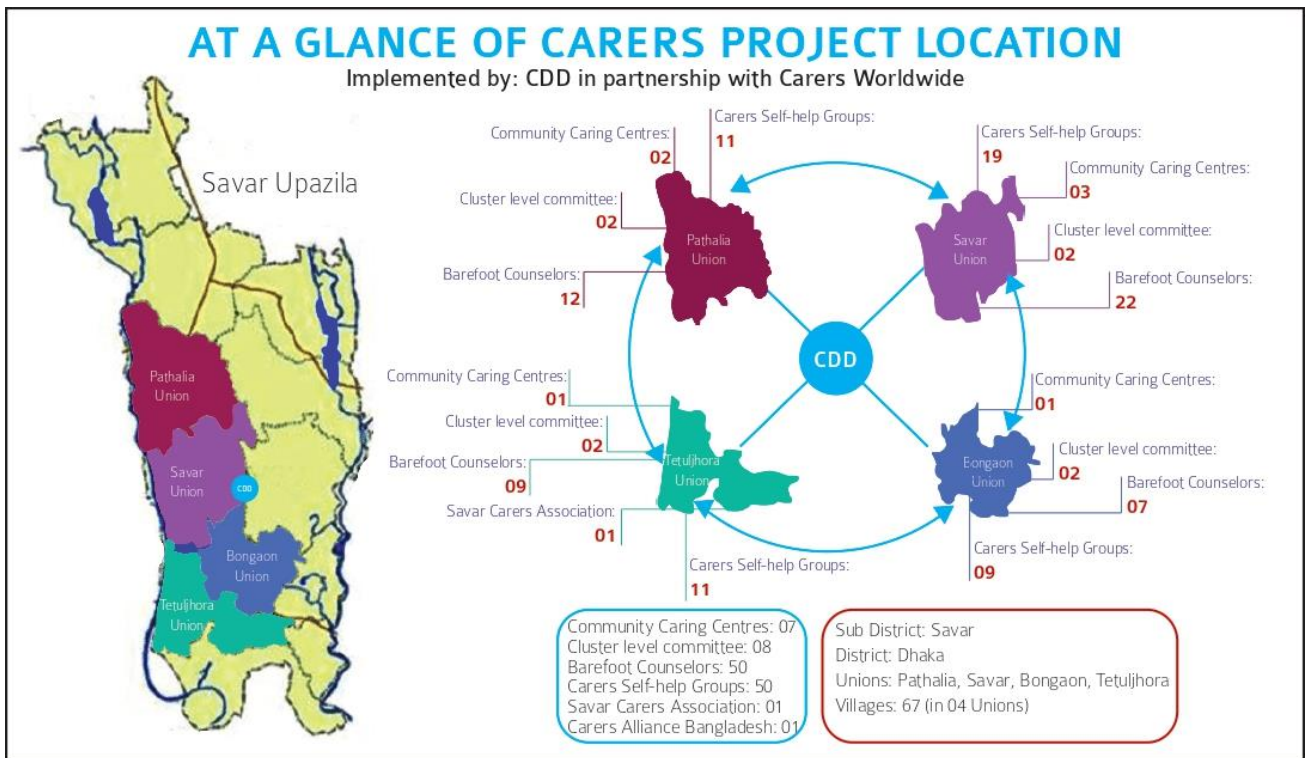
1.1. Background

Carers Worldwide, a UK-based international NGO founded in 2012, partnered with the Centre for Disability in Development (CDD), a leading Bangladeshi NGO founded in 1996. Carers Worldwide takes a holistic approach to transform the lives of carers, using the Carers Worldwide model which consists of five core elements: 'Carers Support Groups' reducing loneliness and isolation, creating social networks and supporting emotional wellbeing; 'Health Services' providing access to physical and mental health services, including locally available counselling; 'Employment, Training and Education' facilitating access to employment, training or education, tailored as appropriate to co-exist with caring responsibilities; 'Respite and Short Breaks' offering a break from caring responsibilities along with the development of alternative high-quality care options such as Community Caring Centres; and 'Advocacy' strengthening the collective voice of carers to advocate for their needs and the provisions they require at community, regional, and national level, leading to changes in policy and practice. As well as working directly with carers, Carers Worldwide works closely with local government authorities to promote the rights of carers and ultimately achieve changes at the level of policy. Carers Worldwide is currently active in India, Nepal and Bangladesh, working through local organisations and transforming the lives of over 180,000 carers, cared for individuals and their family members to date.

Carers Worldwide focuses on unpaid family carers in low- and middle-income countries, while CDD has impacted over 250,000 lives through its extensive network across Bangladesh. This partnership, established in 2018, has been pivotal in transforming the lives of carers and their families in Savar. The project "Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh" aimed to improve the health and socioeconomic wellbeing of 1,002 carers of persons with disabilities in Savar, Bangladesh. Building on a pilot project funded by the UK government's UK AID programme that supported 502 family carers, this initiative sought to identify and support an additional 500 carers through the Carers Worldwide model, which addresses carers' social inclusion, physical and mental health, employment, education, and advocacy needs.

1.2. Project location

The project "Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh" focused on enhancing the health and socioeconomic wellbeing of 1,002 carers of persons with disabilities. Savar, located on the outskirts of Dhaka, is a rapidly urbanizing area with diverse socioeconomic conditions and a growing population. The project builds on the success of a previous initiative that supported 502 family carers, aiming to extend this support to an additional 500 carers. The project leveraged the Carers Worldwide model, which offers a comprehensive approach to addressing the social inclusion, physical and mental health, employment, education, and advocacy needs of carers. This model was implemented in several locations across Savar, ensuring a broad and inclusive reach within the community. The project's expansion was designed to cater to a diverse group of carers, considering different types of disabilities and varying levels of socioeconomic status, thereby providing tailored support that is both accessible and impactful. The following maps detail the specific project locations where the initiative was implemented, highlighting the areas targeted for intervention and support.



1.3. The issues facing family carers – a brief literature review

1.3a. Caring for children with disabilities or chronic illnesses

A caregiver, or carer, is an unpaid individual such as a family member, friend, or neighbour who supports someone with a physical disability, cognitive condition, or chronic illness. The terms ‘carer’ and ‘caregiver’ are used interchangeably (IACO, 2024).

Caring for children with disabilities involves a wide range of responsibilities, including bathing, dressing, feeding, arranging education and social activities, managing finances, shopping, and providing transportation. This demanding role places significant strain on family carers, creating a public health concern that impacts millions of people.

Unpaid carers, who provide essential physical, psychological, spiritual, and emotional support, are vital to long-term home care. While caregiving can be fulfilling, it often leads to an increased risk of negative health outcomes, such as chronic illnesses and depression, while also limiting carers' ability to maintain a healthy lifestyle and access preventive healthcare. Deteriorating carer health has been associated with higher rates of child hospitalizations and out-of-home placements. A study by Murphy et al. (2007) emphasized carers' concerns that declining health could impair their capacity to care for their children, highlighting the importance of gaining a deeper understanding of the caregiving experience for children with disabilities (Elekanachi, R.U., Lajoie, A., Tavukcu, S. *et al*, 2024).

1.3b. Characteristics of Unpaid Carers

Raihan, Bidisha, and Jahan (2017) in their paper, "Unpacking Unpaid Labour in Bangladesh," analyzed key characteristics of unpaid workers using data from the national Labour Force Surveys (LFS) of 2005 and 2010. By examining changes over time, they identified socio-economic factors, such as the characteristics of household heads and the presence of older family members and children, that limit participation in the

formal labour market. Their economic analysis revealed that while men's unpaid work contributes minimally, women's unpaid labour accounts for up to 23 percent of total household self-employed income.

Tripathi, Azhar, and Zhai (2022) in their article, "Unpaid Care Work Among Women in South Asia: A Systematic Review," identified three key recurring themes across selected studies. First, women in South Asia overwhelmingly shoulder the burden of unpaid care work. Second, due to prevailing sociocultural norms, this work often goes unrecognized and undervalued, along with the women who perform it. Third, there is a notable lack of flexible working arrangements for women. They concluded that care work policies must take into account the distinct cultures, demographics, and labour markets of South Asian contexts. Although these studies are not exclusively focused on those caring for sick or disabled family members, the findings are highly relevant to this group.

Extensive research has demonstrated that raising a child with a developmental disability has a profound impact on family carers, particularly parents (Samuel, Rillotta, & Brown, 2012). The concept of chronic sorrow, introduced by Olshansky in 1962, has been explored relatively little in the literature (Phillips, 1991). It was initially developed to study the experiences of parents with severely mentally disabled children. Although the concept of chronic sorrow has developed over time, it remains clear that the economic, psychological, and social challenges of caring for a child with a developmental disability can greatly impact parents' quality of life. (Isa et al., 2016). Recognizing the crucial role families play in the well-being of children with disabilities, researchers, service providers, and policymakers stress the need to support these families and improve their quality of life. (Samuel et al., 2012; Werner and Shulman, 2013)

1.3c. Stigma

Researchers indicate that stigmatization is linked to a lower quality of life. However, there has been limited exploration into how family caregivers' internalization of stigma (affiliate stigma) affects their subjective well-being. Few studies have compared caregivers of individuals with various developmental disabilities or investigated psychosocial protective factors. Caring for a child with a developmental disability is associated with chronic sorrow and significant economic, psychological, and social impacts, all of which influence parents' quality of life. Given the vital role of families, it is essential to support them to enhance their quality of life (Samuel et al., 2012; Werner and Shulman, 2013).

Stigma encompasses prejudicial attitudes, stereotypes, discriminatory behaviors, and biased social structures that are upheld by a larger group against a smaller subgroup. It can manifest in various forms: public stigma (attitudes held by the general population), self-stigma (the internalization of negative views by individuals), and family stigma (the stigma experienced by those connected to stigmatized individuals). Mak and Cheung (2008) differentiate between public perceptions of family caregivers (family stigma) and internalized stigma (affiliate stigma). Research on affiliate stigma and subjective well-being is limited, with most studies concentrating on family stigma associated with mental illnesses. These studies indicate that greater awareness of stigma among family members of individuals with mental illnesses is linked to a lower quality of life (Werner and Shulman, 2013).

1.3d. Health Impacts of Caring for Children with Disabilities

The initial moment when parents discover their child's condition is intensely emotional and stressful (Hedov et al., 2002). Ongoing caregiving, frequently undertaken by parents, tends to increase parental stress and diminish well-being (Hedov et al., 2002; Hastings & Taunt, 2002).

Factors that contribute to increased parental stress and decreased well-being include lower socio-economic status, having more children, and the age of the child. Additional challenges such as behavioral issues, communication impairments, health problems, and the child's lack of self-sufficiency further negatively impact parental stress. Moreover, maladaptive coping strategies, lower optimism, strained marital relationships, and insufficient social support exacerbate these negative outcomes. To fully assess parental

functioning, health-related quality of life (HRQoL) is utilized, which includes physical, emotional, and intellectual functioning, as well as participation in valued activities. Parents of children with chronic conditions typically report lower HRQoL compared to parents of children without such conditions.

Raising a child with a developmental disability, such as autism or ADHD, can be highly stressful, and parents often encounter significant challenges. Research indicates that parents of children with developmental disabilities have a 10% higher rate of clinical depression compared to those with typically developing children. This heightened risk of depression can negatively affect parenting practices, family dynamics, and the overall wellbeing of the child. Experts are calling for greater recognition of carer health as a critical public health issue (Gallagher and Hannigan, 2014).

In addition to experiencing higher rates of depression and stress, parents of children with developmental disabilities also face poorer physical health, including issues such as back problems, migraines, ulcers, asthma, arthritis, and high blood pressure. Poor physical health is a known risk factor for depression (Moussavi et al., 2007), and recent research has found a positive association between poor physical health and depression among caregiving parents, suggesting a possible co-morbidity. The increased risk of depression in these parents may be partly due to poor physical health, rather than solely child or contextual factors. However, empirical studies have yet to control for physical health problems when examining depression in these parents, and the prevalence of co-morbidity remains unstudied (Gallagher and Hannigan, 2014).

Families caring for children with disabilities face distinct challenges compared to those caring for children without disabilities. Research indicates significant variation in how these caregivers adapt to the demands and stressors of their roles, leading to differing impacts on their health and well-being (Isa et al., 2016).

1.3e. Socio-economic Status and Socio-cultural Norms

Children with disabilities often require substantial healthcare resources and face multiple challenges beyond impaired motor function, including sensory, communicative, and intellectual impairments, and complex self-care limitations. While caregiving is a standard parental role, it becomes more complex when managing a child with significant functional limitations and potential long-term dependence. Parents must balance managing their child's chronic health issues with everyday responsibilities, making caregiving a particularly daunting task (Raina et al., 2005).

In contexts with limited resources and access to services, such as Bangladesh, the impact of disability on families is severe. Women, who are often the most disadvantaged and vulnerable, bear a disproportionate burden. Consequently, mothers of children with disabilities face compounded disadvantages in developing countries. Several studies explore the factors contributing to stress in mothers of children with severe physical disabilities, underscoring the importance of addressing these factors in planning services for both the child and the family.

The majority of children with disabilities reside in developing countries, where appropriate rehabilitation services are often limited. To maximize the benefits of the few available centre-based services, programmes frequently focus on training mothers in skills to support their child's development. However, economic and cultural barriers frequently hinder mothers' access to these services, and in some cases, attending such programmes may even increase their stress levels. Social factors such as land ownership and household income have also been found to negatively impact maternal stress. Caring for a child with a serious physical disability can steadily deplete a family's already limited resources, including costs for travel, medicine, and aids. Therefore, economic empowerment of these families may be crucial for successful interventions. In Bangladesh, innovative programmes such as small micro-credit initiatives have proven successful in empowering poor women.

1.4. Objectives of the Final Evaluation

The primary objectives of the final evaluation were to:

- Assess the extent to which the project's outcomes and outputs were achieved
- Identify the impact of the project and the likelihood of sustaining this impact
- Identify key achievements, challenges, and lessons learned from the project
- Make recommendations for future projects involving Carers Worldwide, CDD, other Carers Worldwide partners, and other organizations

1.5. Scopes and Limitations

The evaluation focused on changes in the social, emotional, mental, physical, and financial wellbeing of carers. It reviewed baseline information, the project logframe, and monitoring reports to measure the intended and unintended impacts, both positive and negative. Meetings and interviews with a range of project participants and stakeholders were also conducted.

Limitations of the evaluation include the following:

- Limited timeframe of the evaluation restricted for an in-depth review
- Potential biases in self-reported data from carers and their families

2. Evaluation Methodology

2.1. Desk Research

The evaluation reviewed all relevant documents, including the project proposal, baseline study, logframe, monitoring reports, and carers' data. A literature search was conducted by using various electronic databases, including PsychINFO, ScienceDirect, ProQuest, and MEDLINE and GoogleScholar using specific key terms, highlighting the importance of these factors to better understand the complex nature of stress processes and the carers' adaptations to their children's disabilities or long term health conditions.

2.2. Sample Techniques

The evaluation also followed qualitative research methods, including Focus Group Discussions (FGDs), In-Depth Interviews (IDIs), and Key Informant Interviews (KIIs). The evaluation was conducted following purposive sampling methods within project locations in Savar subdistrict within Dhaka district, Bangladesh.

2.3. Sample Size for Qualitative Research

- FGDs: Seven groups, each consisting of approximately 15- 20 carers, ensuring representation across socio-economic status, engagement with the community caring centres, and the type and severity of disability they are caring for.
- IDIs: Three groups, including project team members to gain deeper insights into the project impact.
- KIIs: Four stakeholders' representatives, including doctors, local government officials, CDD management, to gather diverse perspectives on the project's effectiveness and sustainability.
- Case Studies: Two detailed case studies of carers to understand individual stories and the impact of the project.

2.4. Areas of Evaluation

a) Relevance

- How well did the project address the needs of carers?
- Were the project activities aligned with the carers' requirements and priorities?

b) Effectiveness

- To what extent were the project outcomes and outputs achieved?
- What were the key factors that contributed to or hindered the achievement of these outcomes?

c) Sustainability

- Are the project's benefits likely to continue after the funding period?
- What measures have been taken to ensure the sustainability of the project outcomes?

d) Impact

- How has the project improved the physical and mental health of carers?
- What changes have occurred in the economic wellbeing of the carers' households?
- What level of carers' participation in family and community activities has been evident?
- To what extent has carers' confidence in advocating for their needs improved?

2.5. Data Analysis

Available data and statistics from project reports, the baseline and end of project reports were analyzed to measure changes and impact. Qualitative data from FGDs, IDIs, and KIIs were transcribed and coded. Themes were identified based on the objectives of the evaluation.

3. Major achievements against Indicators

3.1. Project outputs, outcomes and achievements

The project's activities, outputs and outcomes were designed around the stressors known to be experienced by carers, as identified by the earlier pilot project collaboration between Carers Worldwide and CDD along with the previous baseline research conducted with the project participants. This was a consultative process involving Carers Worldwide, CDD, a wide range of local civic and local government officials and a number of carers themselves.

These were the planned outputs and outcomes:

Outputs:

1: Carers groups and advocacy

- (a) 25 new carers groups formed
- (b) 50 carers groups meeting monthly, providing emotional support to reduce isolation, improve wellbeing and increase capacity to care
- (c) 4 new cluster level committees formed
- (d) 8 cluster level committees meeting quarterly
- (e) 1 Carers Association formed at district level
- (f) Carers Association meeting quarterly
- (g) 1 Bangladesh National Alliance of Carers formed, to facilitate recognition and interaction with the government and the NGO sector

2: Health

- (a) 25 community/carers representatives and 5 project staff trained/retrained in barefoot counselling
- (b) 25 community/carers representatives providing barefoot counselling to 1,002 carers
- (c) 10 government doctors and frontline health workers trained on carer health needs
- (d) Quarterly medical assessment camps held to facilitate immediate access to medical consultations and treatment for carers
- (e) 5 CDD staff trained in nutrition and effective hygiene practices to provide high quality and evidence based information to carers
- (f) 5 CDD staff trained in rehabilitation techniques

3: Livelihoods and alternative care

- (a) 425 carers trained in their chosen livelihood/income generation activity (IGA)
- (b) 425 carers provided with start up costs to enable them to initiate their livelihood/IGA
- (c) Establishment and operation of 2 community caring centres and continuation of 2 existing CCCs as alternative daycare solutions for children with disabilities

4: Local capacity strengthening

- (a) 5 local staff skilled and confident to implement the Carers Worldwide model

Outcomes:

1. A minimum of 85% of carers attending local self-help groups which means an increase in the number of carers participating in wider family and society activities.
2. A minimum of 75% of carers living above the poverty line
3. A minimum of 70% of carers reporting improved physical and/or mental health
4. A minimum of 40% of carers expressing confidence to advocate for their needs with government representatives

Results:

Output indicator	Target	Achieved
1. Carers groups and advocacy		
1a) 25 new carers groups formed	25	25
1b) 50 carers groups meeting monthly	50	50
1c) 4 new cluster level committees formed	4	4
1d) 8 cluster level committees meeting quarterly	8 CLCs	8 CLCs
1e) 1 Carers Association formed at district level	1 CA	1 CA
1f) Carers Association meeting quarterly	Quarterly meetings	Quarterly meetings
1g) 1 Bangladesh National Alliance of Carers formed, to facilitate recognition and interaction with the government and the NGO sector	1 Alliance formed	1 Alliance formed
2. Health		
2a) 25 community/carer representatives and 5 project staff trained/retrained in barefoot counselling	25 + 5	50 + 5
2b) 25 community/carer representatives providing barefoot counselling to 1,002 carers	30 1,002	50 1,008
2c) 10 government doctors and frontline health workers trained on carer health needs	10	18
2d) Quarterly medical assessment camps held to facilitate immediate access to medical consultations and treatment for carers	12	12
2e) 5 CDD staff trained in nutrition and effective hygiene practices to provide high quality and evidence based information to carers	5	17
2f) 5 CDD staff trained in rehabilitation techniques	5	15
3. Livelihoods and alternative care		
3a) 425 carers trained in their chosen livelihood/income generation activity	425	425
3b) 425 carers provided with start up costs to enable them to initiate their livelihood/income generation activity	425	474
3c) Establishment and operation of 2 community caring centres and continuation of 2 existing CCCs	4	4
4. Local capacity strengthening		
4a) 5 local staff skilled and confident to implement Carers Worldwide model	5	8
Outcome indicator		
A minimum of 85% of carers attending local self-help groups which means an increase in the number of carers participating in wider family and society activities	85%	87%
A minimum of 75% of carers living above the poverty line (results based on sample of 200 carers who took part in the project end line survey)	75%	77%
A minimum of 70% of carers reporting improved physical and/or mental health (results based on sample of 200 carers who took part in the project end line survey)	70%	99%
A minimum of 40% of carers expressing confidence to advocate for their needs with government representatives (results based on leadership indicators developed by project participants with guidance from staff)	40%	52%

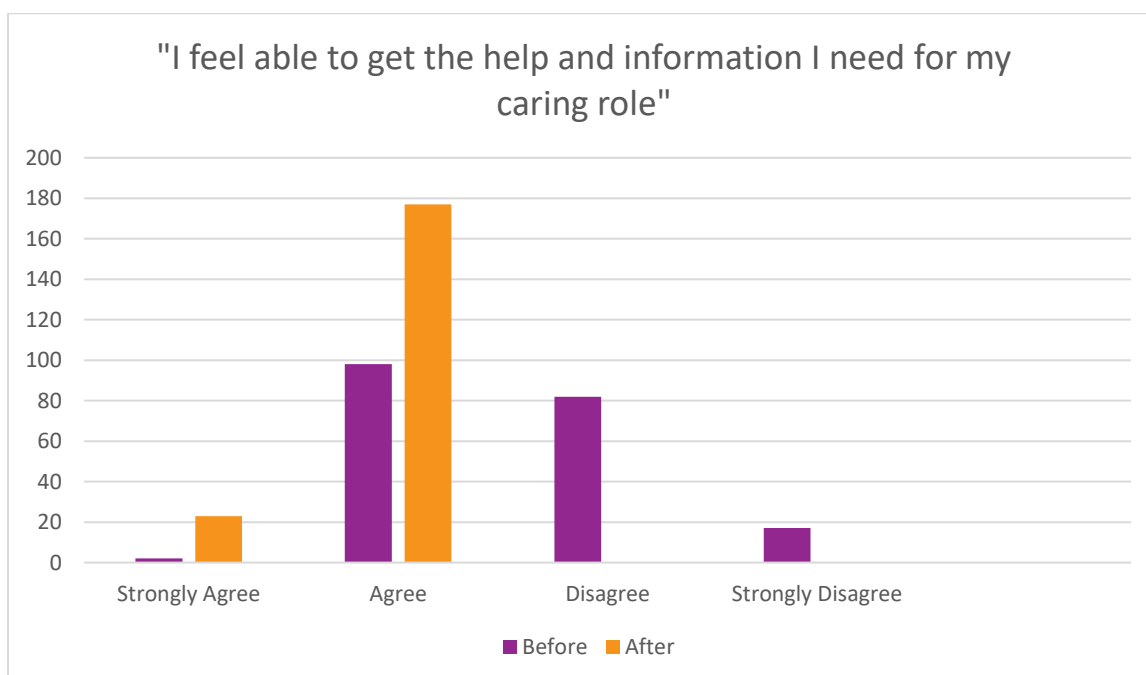
Summary of results

Data obtained from quarterly monitoring throughout the three years of the project and from the project end survey reveals that the project successfully met its goals, achieving significant outputs and outcomes that have positively impacted the lives of carers and their families. The formation of carers' groups, advocacy initiatives, and health support services addressed the key stressors identified in baseline survey. The project provided crucial training on basic counselling and various livelihood skills, leading to improved mental and physical health, economic stability, and enhanced community participation among carers. The establishment of community caring centres offered essential respite care, and the creation of a Carers Association facilitated stronger advocacy efforts. Overall, the project's comprehensive approach has empowered carers, reduced poverty, and increased their confidence to advocate for their rights and needs. The achievements underscore the effectiveness of the Carers Worldwide model and the importance of continued support and capacity building to sustain these positive changes.

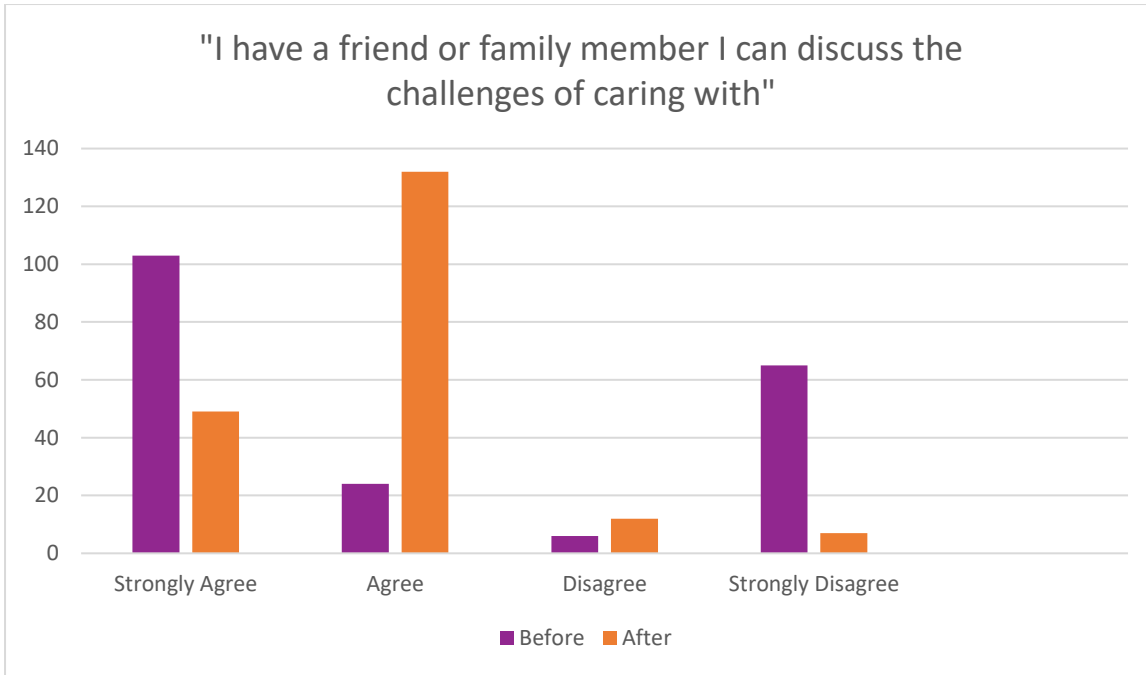
3.2 Project end line survey

The following results are based on the responses of a cohort of 200 carers (95% women and girls) to the baseline survey conducted at the start of the project and to the endline survey conducted at the end of the project's three years.

3.2.1 Support for the role of being a carer

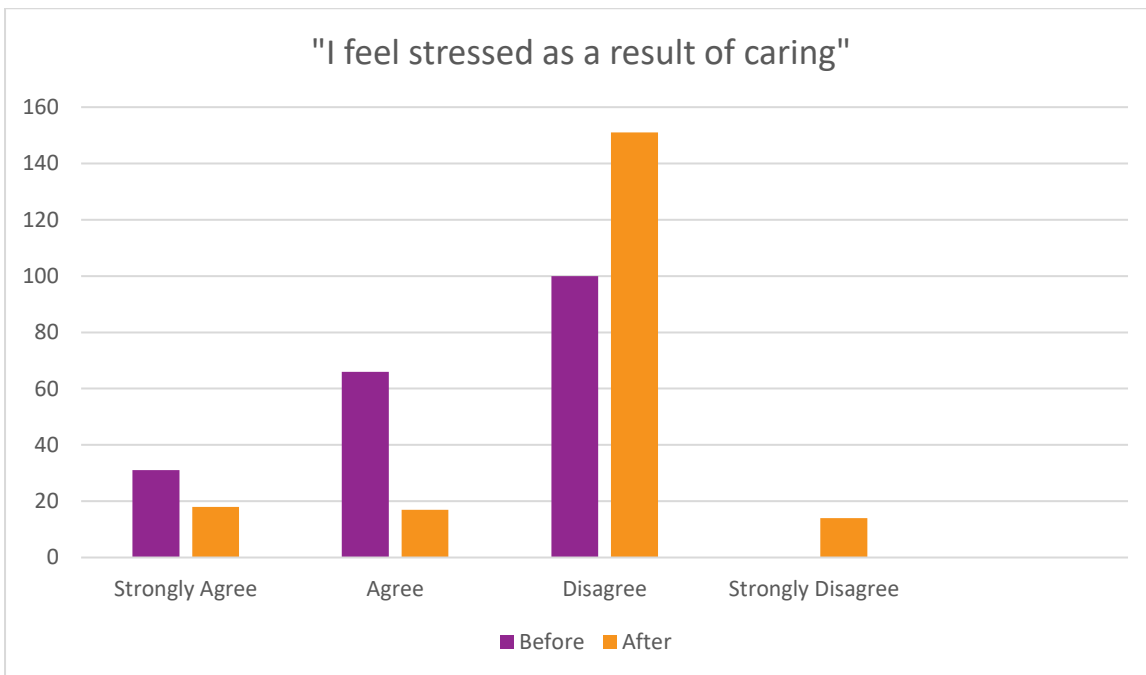


All respondents reported that the project has enabled them to access better support and assistance necessary for their caregiving responsibilities. This is in contrast to only 50% of carers feeling adequately informed at the start of the project.



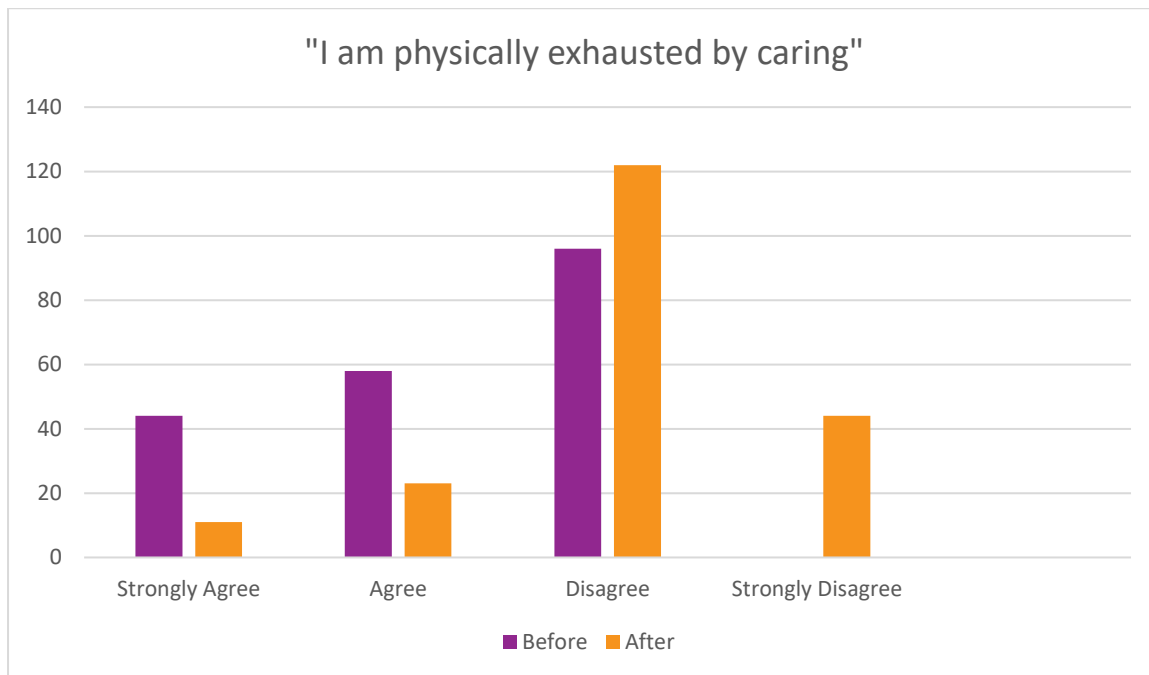
Having someone to talk to is critical to being able to cope with a caring role. 36% of carers had nobody to talk to at the start of the project and this figure has now reduced to 9%, with 91% of carers having someone to turn to.

3.2.2 Emotional and mental wellbeing



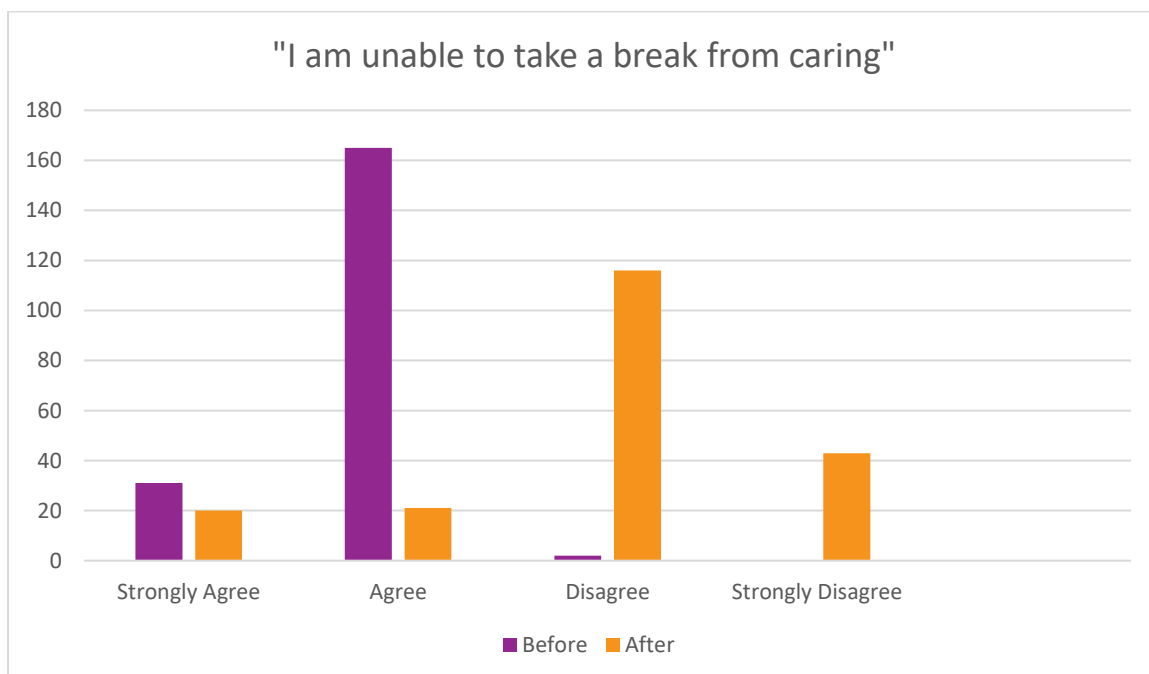
At the start of the project, 49% of carers reported feeling stressed as a result of caring. By the end of the project, this figure had reduced to only 18%, with 82% reporting that caring was not causing them to feel stressed.

3.2.3 Physical wellbeing



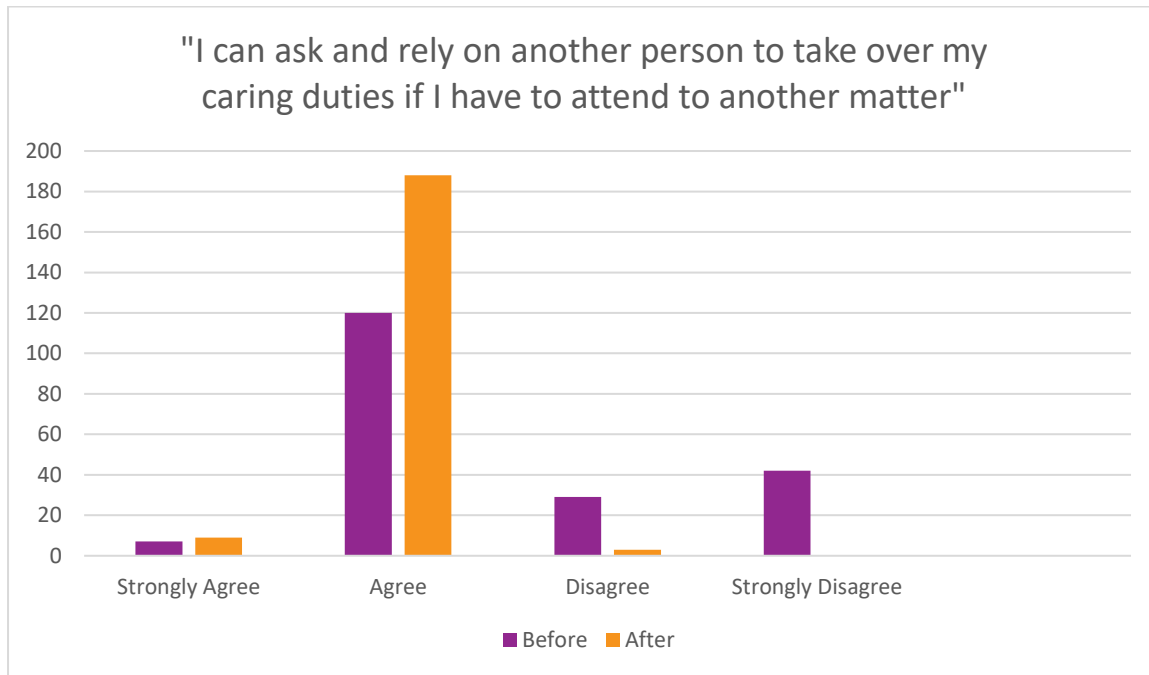
51% of carers surveyed at the start of the project reported being physically exhausted by caring. By the end of the project, this figure had reduced to 17%. Caring and all that it entails is always going to be tiring, but a reduction in levels of exhaustion to this extent is an important achievement.

3.2.4 Respite from caring



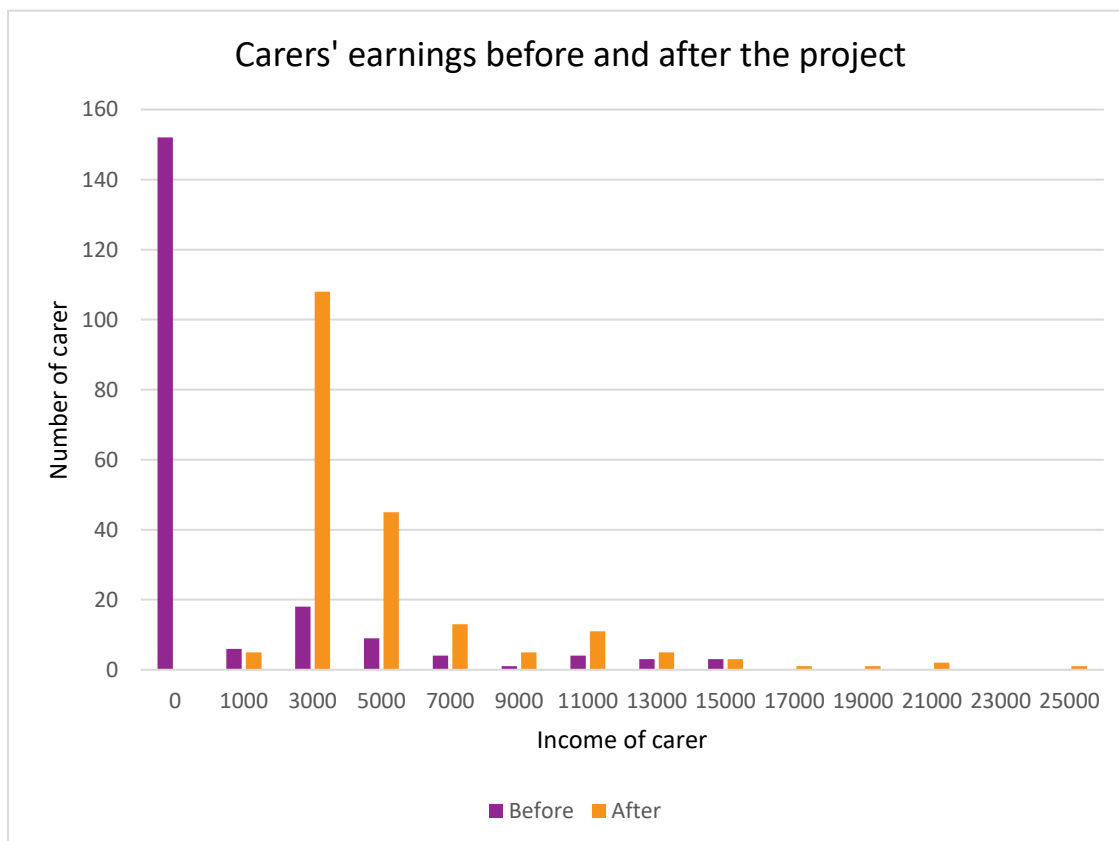
At the start of the project, 98% of carers reported that they were unable to take a break from their caring responsibilities. Carers need to be able to take a break if they are to preserve their own mental and physical health. At the end of the project, this situation had been transformed with 79.5% of carers now able to

access periods of respite from caring. This respite allows them to have more control over their lives, giving them time and energy to focus on personal needs and activities outside of their caring responsibilities.

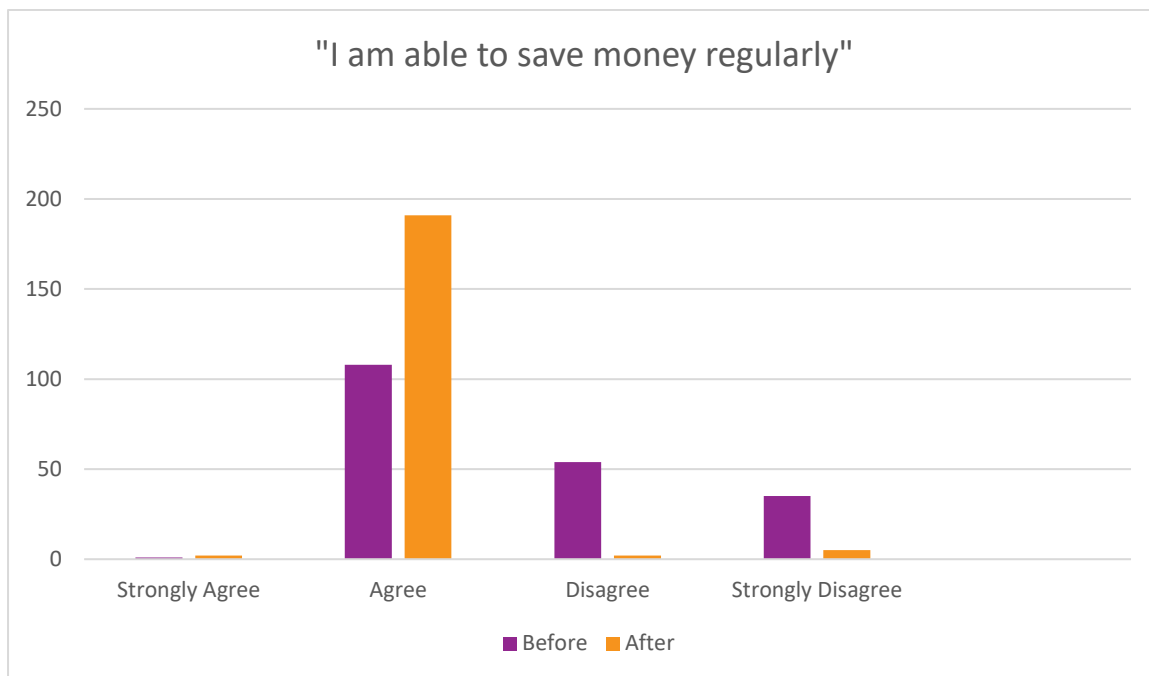


From a baseline figure of 63%, 98% of carers now report being able to call on another person to take over care in the case of an emergency.

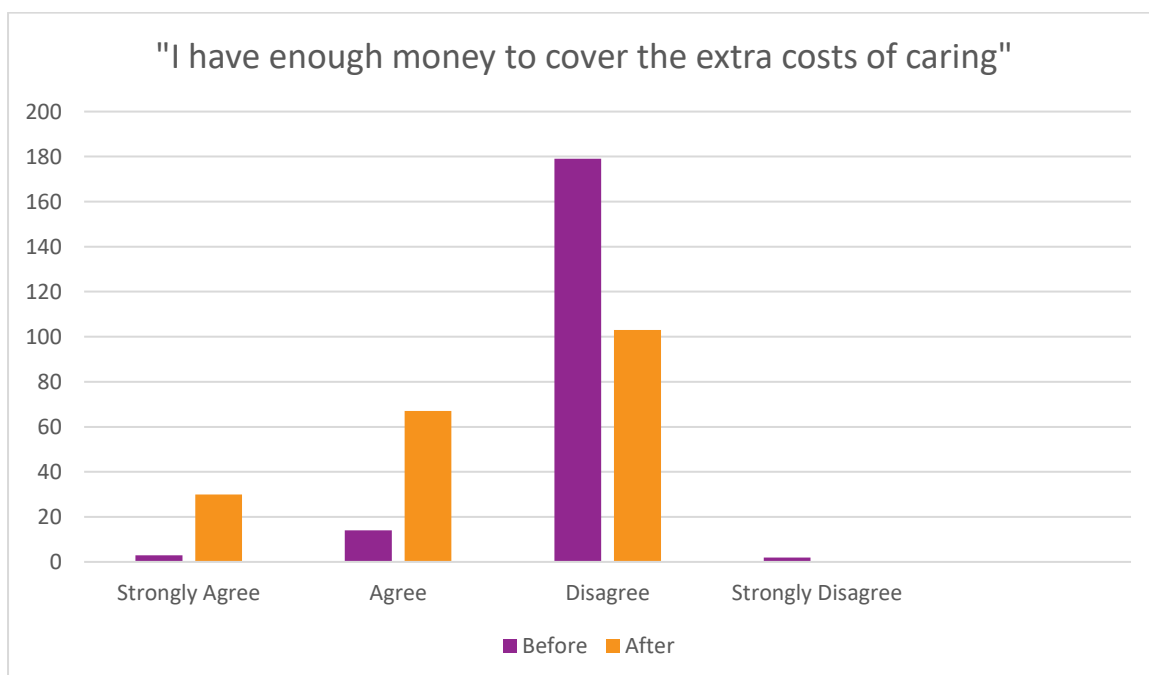
3.2.5 Financial wellbeing



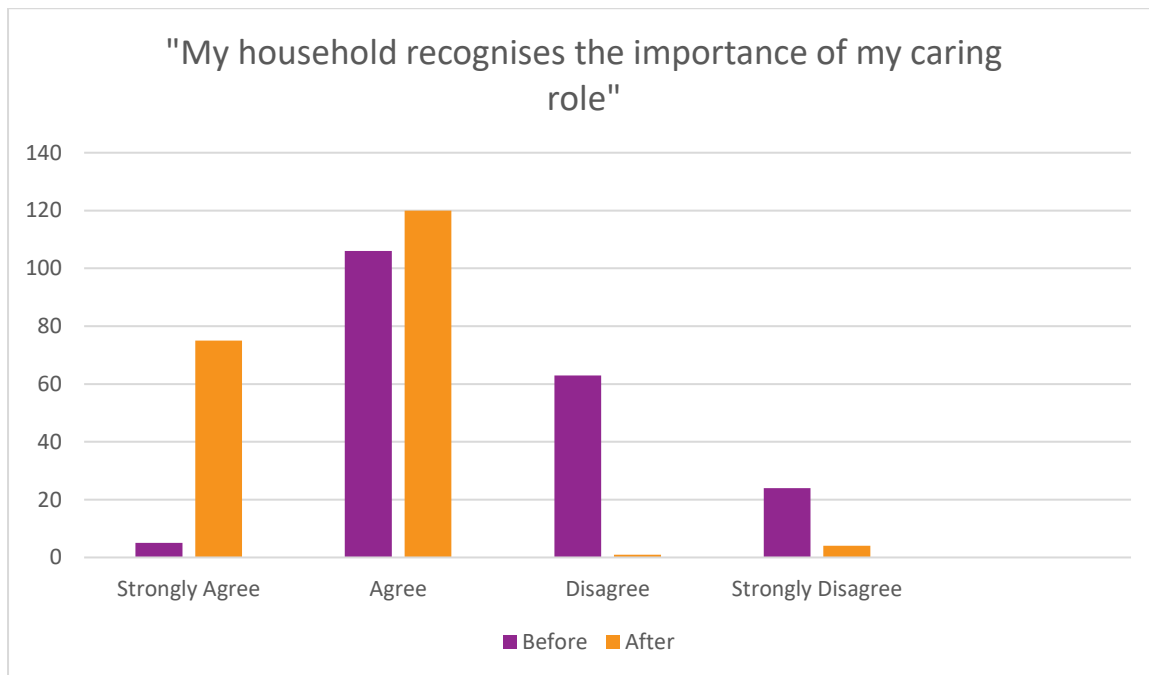
Before the project, 76% of the carers surveyed were unable to earn an income. The majority of those who were able to earn, were only able to do so at a minimal level. After the project, the economic situation of this group of carers has changed radically with all of them now earning a consistent income and therefore in a position to contribute to their household income. This change not only promotes financial security but also contributes to positive mental health and community inclusion.



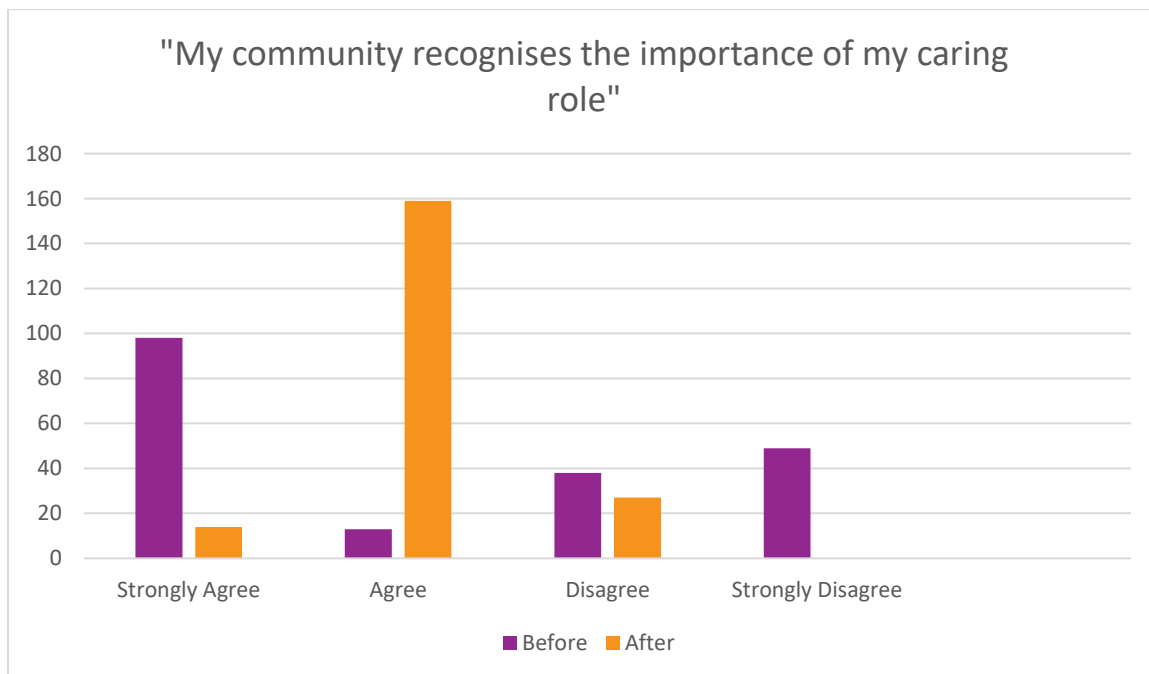
97.5% of carers are now able to save regularly, in contrast to 54.5% at the start of the project. The project has promoted savings activities within the carers groups, access to government allowances and the taking up of new income generation activities, all of which have contributed to greater financial security for carers and their families. The additional costs associated with caring are many and place significant financial pressure on families. Carers are still expressing concern about not having enough money to cover the extra costs of caring but the figure has reduced from 91% to 51.5% during the lifetime of the project.



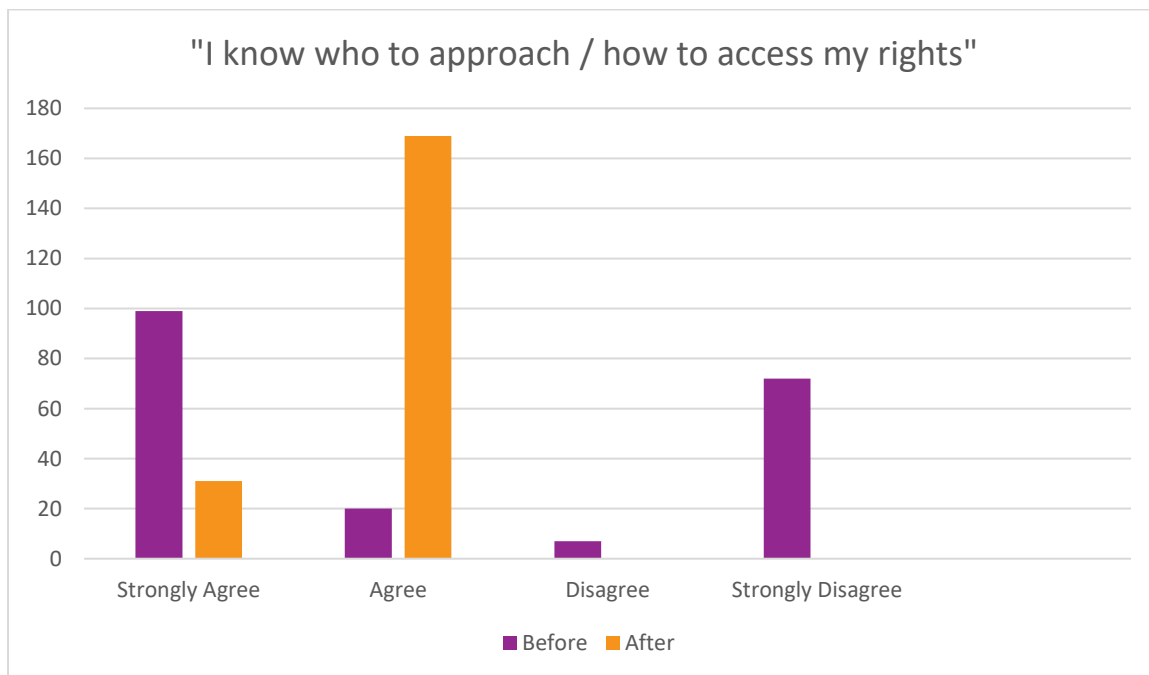
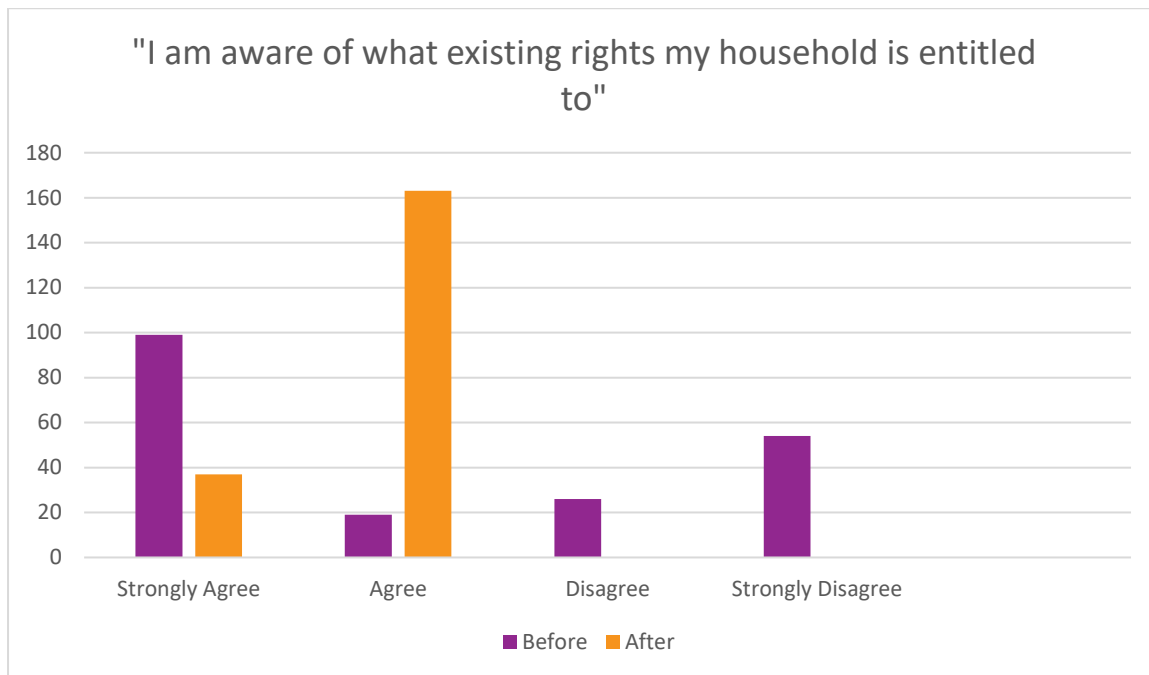
3.2.6 Feeling valued as a carer



Feeling valued as a carer by family and community is critical to maintaining self esteem and emotional wellbeing, as well as to receiving practical assistance. Before the project, 55.5% of carers felt valued for their caring role by their household members and by the local community. By the end of the project, this figure had increased to 97.5% at the family level and 86.5% at the community level. Increasing the visibility of carers and recognition of their vital role had been a key objective of the project.

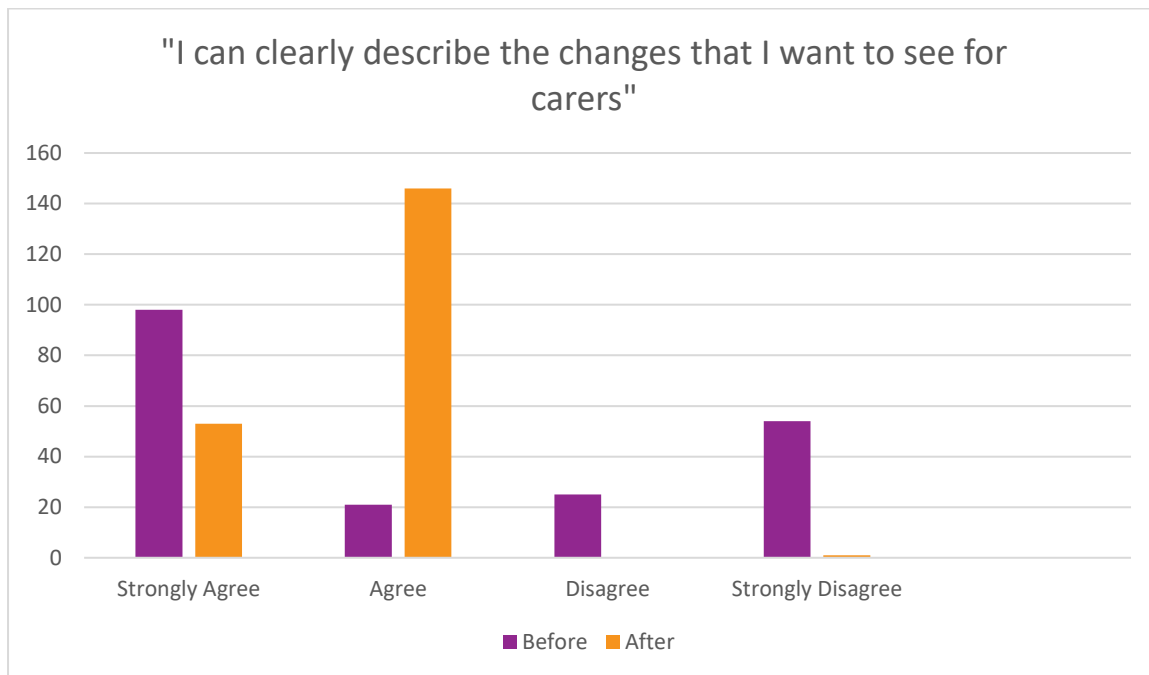


3.2.7. Confidence to claim rights and advocate

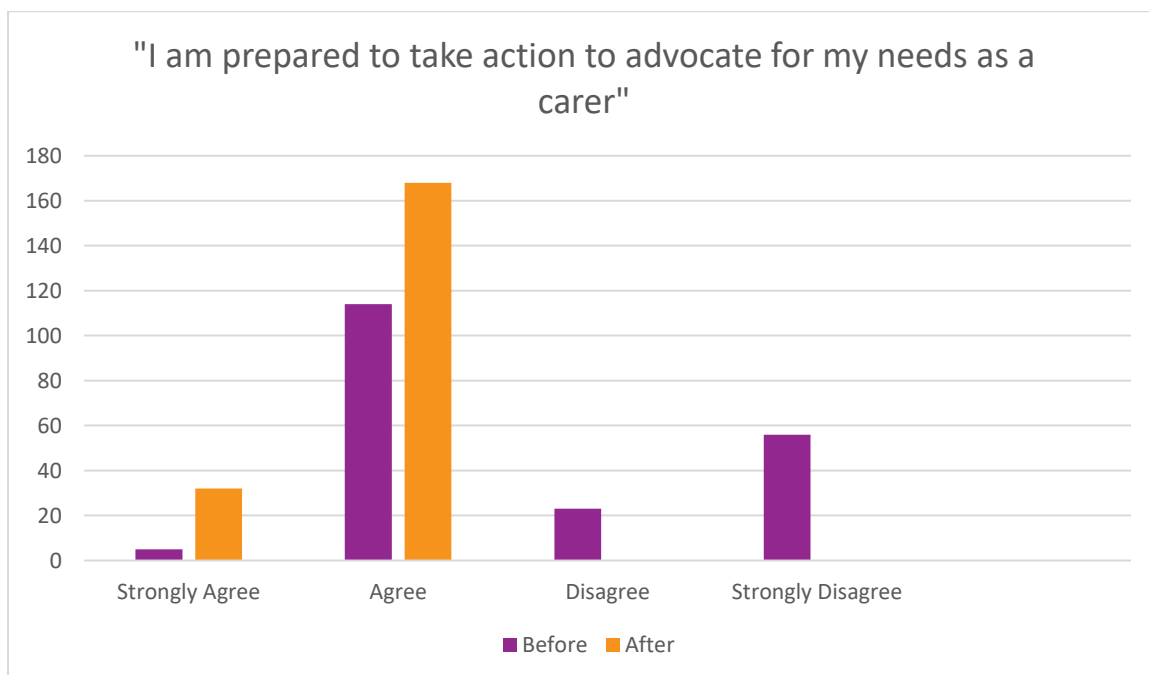


At the start of the project, only 59% of carers were aware of the rights their household were entitled to and how to access those entitlements. Now, all the carers surveyed know what they are entitled to and how to access those rights. This is a significant achievement as embedding that knowledge amongst the carer community will lead to other carers and disabled people becoming aware of their rights as well.

Moving on from existing rights, carers have also become empowered to advocate for change in the future, as demonstrated below:



99.5% of carers now feel confident to describe a positive future vision for carers and how to reach that, as compared to 59.5% at the start of the project. They are all now prepared to take action to advocate for their needs as a carer, in contrast to only 59.5% having this knowledge and confidence at the start of the project. This change can be attributed to the power of the carers groups, cluster level committees and Carers Association, which have instilled the knowledge, skills and confidence necessary to represent themselves and their dependents. In other words, the project has successfully helped carers develop the ability to speak out and assert their needs more effectively.



3.3. Related Policies, Laws, and Acts Review

As part of the advocacy related activities of the project, a comprehensive review of plans and policies of the Government of Bangladesh as they relate to unpaid family carers and their disabled family members was carried out. This evaluation also reviewed all the related policies. The following table summarises the findings. Recommendations for future action are also included:

Title and Year	Areas Covered	Gaps Identified	Recommendations for Advocacy focus
Eighth Five Year Plan, July 2020- June 2025	Social services, health, education, employment, economic services	Lack of specific provisions for unpaid family carers of persons with disabilities.	Include targeted programmes and support services for unpaid family carers, allocate specific budgetary provisions.
Rights and Protection of the Persons with Disabilities Act, 2013	Rights, protection, accessibility, inclusion	Implementation gaps, inadequate enforcement mechanisms.	Strengthen enforcement mechanisms, improve accessibility standards, enhance awareness programs.
National Mental Health Policy, 2022	Mental health services, support systems	Limited provisions for family carers' mental health support.	Introduce carer support programmes, integrate family support in mental health services planning.
Protection of Persons with Neuro-developmental Disability Trust Act, 2013	Rights, protection, support systems	Limited coverage of family carers' needs and rights.	Amend to include provisions for family carers, establish carer support networks.
National Strategic Plan for Neurodevelopmental Disorder, 2016-2021	Health, education, support services	Lack of specific support for family carers.	Develop carer training programmes, integrate carer needs in disorder-specific services.
Labour Act, 2006	Employment rights, working conditions	Limited provisions for flexible working arrangements for carers.	Amend to include carer-friendly workplace policies, promote flexible working options.
National Skill Development Policy, 2011	Skill training, employment opportunities	Insufficient focus on skills training for carers.	Develop carer-specific skill development programmes, integrate carer roles in vocational training.
National Education Policy, 2010	Education rights, inclusive education	Limited provisions for support to carers managing educational needs.	Establish support mechanisms for carers of students with disabilities, promote inclusive education practices.
National Children Policy, 2011	Child welfare, protection	Lack of specific provisions for children with disabilities and their carers.	Include carer support in child protection strategies,

Title and Year	Areas Covered	Gaps Identified	Recommendations for Advocacy focus
			ensure inclusive policies for children with disabilities.
Action Plan For Implementation of National Social Security Strategy (NSSS) of Bangladesh	Social protection, welfare	Inadequate coverage of carer rights and support. the female carer of children with disabilities is preferred as the recipient for delivery of the Child Benefit Allowance. The income of the household is considered (yearly Tk. 36,000)	Introduce carer allowance or benefits, enhance social security coverage for carers of persons with disabilities and remove all barriers to access.

3.4. Findings from Qualitative Research

Relevance

The project effectively addressed the needs of carers by providing tailored support through 50 Carers Support Groups, 8 cluster level committees, 1 Carers Association and 1 national Carers Alliance, which were formed and continued.

Carers groups were organized with enormous passion. Members reported to be meeting once in a month to exchange information, discuss on financial needs, to allocate and disburse funds to run small entrepreneurship based on their plans, as per availability.

'We were confined at home. Our group created access to socialization, especially learning from other carers in the society.' Carers group member from Sadapur, Savar

The evaluation revealed that the project was successful in organising respite and short break opportunities for carers.

'Our centre gave us respite and short break opportunity from our day to day activities, including taking care of children with disabilities, taking care of mother in law and cooking for family.' Carer benefiting from the Community Caring Centre provision

During the evaluation, it was reported that the project created access for carers' group members to health services. Representatives of the Carers Association were found to be instrumental in organizing health screening and medication camps in the Savar project area.

'If it is possible to arrange an identity card for unpaid carers, we can offer specialized and one stop services. We will offer strategic support as we have the same goal to achieve.' Upazilla Health and Family Welfare Officer, Savar

The project also took systemic initiatives for skills development of carers group members on local level advocacy to promote the rights of unpaid family carers.

'Carers can be a part of project implementation. They can be trained up on any relevant topic so that they can contribute in the project implementation, monitoring and follow up of interventions. They can be trained as local service providers, as paid community resource persons. They also get access to financial resources.' CDD Executive Director

The evaluation revealed that during the project more than 70% of carers' got access to skills training and got self-employed as an outcome of the project's interventions. The majority of the carers were found to be earning from the homestead agriculture, poultry, goat rearing, cow rearing, small shops. Around 50% of the respondents received a grant as credit ranging from BDT 10,000 to 20,000.

'After attending training and obtaining financial support as a grant, I invested in my grocery shop. I have items amounting BDT 800,000.00 in my shop and we are successfully continuing our business.' Carer

'I invested in buying an autorickshaw and my husband is earning BDT 20,000.00 per month. We have no problem to maintain our family expenses now.' Carer

'I bought some goats after receiving training and a grant of BDT 20,000.00. I invested on buying cows after selling those goats. Now we have a good earning from selling cow milk.' Carer

The project activities were well-aligned with carers' requirements and priorities, as indicated by high participation and satisfaction levels reported during FGDs, KIIs and IDIs.

'Offering economic support for the carers is the most relevant part of the project.' Upazilla Health and Family Welfare Officer, Savar

Effectiveness

The project achieved significant outcomes and outputs. Formation and strengthening of Carers Support Groups facilitated the carers in reducing loneliness and isolation.

'We were victims of social stigma and bullying in the society. When we got the opportunity to be involved in groups, we got relieved from all those social barriers.' Carer

'Economic development and social inclusion are the most notable outcomes of the project.' Upazilla Social Services Officer, Savar

The majority of carers reported improved access to physical and mental health services. Health screening and tests helped the carers to reduce their stress and identify any ophthalmological, gynecological or general health conditions. After diagnosis and obtaining medications, spectacles and so on they felt relieved of general anxiety and stress. Further the trained community counsellors' support was reported to be effective to the carers.

'When I got the opportunity to express my concerns to the community counsellor, I felt relieved from my stresses.' Carer

The evaluation identified that training and employment opportunities were tailored to carers' circumstances. While taking case studies, some of the respondents shared their initial struggles and how they overcame those challenges through the support of the project.

'I invested in agricultural work in my family and leased lands. I can take care of my family and at the same time engage in my work. I can earn my livelihood with dignity due to my economic wellbeing. I start my day early and accomplish all tasks of the day accordingly.' Carer and community caring centre volunteer

It was reported by the majority of the carers that provision of respite and short breaks helped to maintain their mental health and overall wellbeing.

'We get the opportunity for sharing and exchange of our concerns and experiences, which has created a social bonding. We get moral support from this community caring centre. We feel relieved from our monotonous life. We also participate in the annual picnic and indoor games. We receive physical therapy on a periodical basis.' Carer benefiting from the Community Caring Centre provision

Increased advocacy efforts resulted in greater recognition of carers' needs at the local and national levels. The evaluation revealed that carers realized their rights and entitlements after getting enrolled in the support groups. As an innovative idea initiated by the project to influence the process, the Carers Worldwide model helped to improve nutrition, leadership management, physical and mental health of carers.

'This project needs further continuation. Orientation and capacity development of Government officials, MPs, Union Parishad chairman and counsellors need to be included in the project interventions.' Upazilla Health and Family Welfare Officer, Savar

The Carers Association, promoted by the project, helped the unpaid family carers to enjoy dignity and respect within family and society and access to the rights and entitlements from the duty bearers in the country.

'Now we get access to social security benefits at the Union Parishad, mother and child care from the Upazilla health complex, and support from the department of youth development.' Member of Savar Carers Association

Key factors contributing to these achievements included strong collaboration between Carers Worldwide and CDD, effective community engagement, and responsive project management.

'We assess the needs and prioritize our problems in the carers support group and cluster level meetings. We conveyed our demands to the policy makers representing healthcare, social protection, insurance, etc. in the national level advocacy meetings.' President of Savar Carers' Association

Challenges included limited resources and logistical constraints in reaching all targeted carers. Lack of skills on marketing and access to market linkages obstructed the growth of business plans of some carers.

'Around 50% of the group members received grant support as a start-up capital. Access to financial services needs to be increased in future.' CDD Project Team, Savar

Sustainability

The project's benefits are likely to continue beyond the funding period due to the establishment of sustainable support structures, such as Carers Support Groups and Community Caring Centres.

'The project needs to be implemented at least another five years to achieve mainstreaming into the development agenda.' Upazilla Social Services Officer, Savar

'Disabled persons and their carers need to get more attention from society. The community needs to be aware about the interventions of the carers support groups. The carers' programme is an innovative project.' Union Parishad secretary

'Once we sign a Memorandum of Agreement, health services will be more available for all carers' at the door step.' Upazilla Health and Family Welfare Officer, Savar

Measures taken to ensure sustainability included capacity building of CDD staff, engagement with local government authorities, and integration of project activities into existing community frameworks.

'I think institute based services are difficult for carers. Community based services for the support of carers is very helpful. These carers' services are really very remarkable.' Upazilla Health and Family Welfare Officer, Savar

'A helpdesk from the department of Social Services at the Union Parishads may offer need based support to the carers support groups, cluster level committees and Carers Association at the Union levels.' Upazilla Social Services Officer, Savar

'Carers may be trained as community resource persons.' CDD Executive Director

Impact

Health Improvements: Carers reported substantial improvements in physical and mental health, attributed to access to health services and support groups. Related stakeholders reported that they found the health initiatives of the project significant and impactful.

'There is a sustaining impact on access to the health services.' CDD Project team

'Now we visit the Upazilla health complex on our own. We are also capable to visit any referred hospitals in Dhaka. We did not know about these before getting enrolled in the carers support group.' Carer

'Creating access to health services is a significant impact of the project.' Upazilla Social Services Officer, Savar

'It is necessary to conduct a needs assessment of required services and assistive devices for persons with disabilities and carers, which need to be followed-up and monitored. More coordination and trust needs to be established among related stakeholders at the community levels.' Union Parishad secretary

'The intervention of community level counselling was effective to manage stress among carers. Mental health services could be offered by professional counsellors, periodically or using a virtual platform.' Mental Health and Psychosocial Support professional

Economic Wellbeing: The end of project survey and the evaluation revealed that the majority of carers experienced enhanced economic wellbeing through employment opportunities and financial training provided by the project.

'After receiving a grant amounting BDT 20,000.00 I bought sewing machines and necessary equipment. I am capable to maintain my family expenses.' Carer

'The grant amount needs to be increased in order to sustain the economic wellbeing of the carers.' Upazilla Social Services Officer, Savar

Community Participation: Increased participation in family and community activities was evident, with carers expressing greater confidence and reduced social isolation.

'We are getting increased opportunities to associate in the society after getting enrolled to the carers group and visiting the community caring centre. Our children are also getting ample opportunity to socialize. It could be better to have more therapeutic care for us and more education opportunities for our children with disabilities.' Carer

'Social communication materials need to be developed.' CDD project team

Advocacy: Carers' confidence in advocating for their needs significantly improved, as demonstrated by their active involvement in local advocacy initiatives.

'We have presented the demand for issuance of an identity card to the high level government officials. We have also been able to access social, health, training, employment and financial services at the local level. We hope to continue our efforts and replicate at the national level.' Carers Association member, Savar

'The day will come when carers groups will be able to ensure the salary of the resource person. Carers groups will offer services at the local level. Each Carers Association may take care of 50 carer groups.' CDD Executive Director

'A new era has been established through this project. If the government get involved, the project will replicate the model of Carers Worldwide.' CDD project team

'Partners of CDD and branches of SWID Bangladesh are capable to support the project. The Neurodevelopmental Disability Trust, the National Forum of Organisations working with the Disabled, the Department of Education, hospitals, and more need to play an active role.' Carers Alliance members

4. Key Achievements, Challenges, and Lessons Learned

Key Achievements

- Each of the local-level **carers' groups** met formally in monthly meetings, provided **emotional support to reduce isolation**, and contributed to improving **wellbeing** and increasing **capacity to care**.
- All target (08) Cluster Level Committees were formed and were operational.
- A federated Carers Association was formed in Savar and enhanced advocacy efforts leading to **greater recognition of carers' needs**.
- More than 50% of carers were able to access **appropriate, high quality and timely medical advice** and more than 80% received **community counselling** care services. Most of the carers became more aware of the **importance of mental health**.
- The majority of the carers' group members became **able to express their health needs**.

- **87% of carers were attending local carers groups**, indicating a significant increase in the number of carers participating in wider family and society activities.
- Access to **financial resources improved**. More than 70% carers were trained and supported to initiate a new income generation activity (IGA) and were engaging in that livelihood.
- **4 community caring centres** were operational throughout the project lifetime, providing support to 129 disabled children and 125 carers.
- 1 Bangladesh Carers Alliance was formed to facilitate **recognition and interaction with the government and the NGO sector**.
- All of the project staff were found to be **confident in working with carers**, identifying their needs, and facilitating techniques to meet those needs.
- **Engagement of secondary stakeholders** was ensured from the initiation of the project. Stakeholders such as doctors, Union Parishad officials and the Department of Social Services took part in various interventions from the beginning of the project.

Challenges

- More initiatives would even better equip carers to face family, community and society.
- During the initial stage of the implementation phase, the project faced challenges to obtain social, health and other data.
- Logistical constraints meant reaching all targeted carers in line with individual requirements was challenging.
- Socio-economic prerequisites from some community members restricted their active participation.
- Capacity development initiatives of carers needed to be documented to improve knowledge management for future projects.
- Support from family members and community members were needed to support the project interventions.
- Participatory monitoring efforts to track the progress of the project could be strengthened.
- The Carers Alliance could have been launched earlier to achieve greater policy gains.
- Establishing long term relations and linkages with related stakeholders are needed to address the unmet needs of the carers.
- Potential biases in self-reported data affecting the accuracy of impact assessment.

Lessons Learned

- Strong community engagement and close collaboration with local organisations are crucial for project success.
- Establishing a steering structure is important for sustaining the achievements of the project.
- Carers from carers group to Carers Association level need to take co-ordinated initiatives to achieve even more outcome and impact from the project outputs.
- Transmission of the project implementation process at the grassroots level is important for achieving the project indicators.
- Fostering collaboration with elected representatives, health, training, social and financial service providers is crucial for long term relations and increased outcomes of the targets.
- Tailored support that addresses diverse needs of carers leads to better outcomes.

- Techniques to manage people with mental disorders leading to disability may be useful for carers who need this skill.
- Involvement of alternative carers, as and where possible, is beneficial to ensure greater success of the project interventions.
- Sustainable impact requires local capacity strengthening and integrating project activities into existing frameworks.
- Flexibility in project implementation allows for adjustments based on community feedback and emerging challenges.
- Enhanced knowledge management and dissemination of innovation and learning is required to attract related stakeholders on the needs of unpaid family carers.
- Efforts of the Carers Association as well as the Carers Alliance in following a long term advocacy strategy is mandatory to reach out to the policy makers for further policy gains.

5. Recommendations

For Future Projects

- Enhance community sensitization through social communication initiatives and developing social and behaviour change communication materials to promote awareness and acceptance of family carers.
- Train volunteers of the Community Caring Centres (CCC) in more depth on the principles of community counselling.
- Train volunteers of the CCCs in more depth on special education.
- Equip CCCs with more educational materials and teaching and learning equipment to further develop the provision of special education/ non formal education for the children with disabilities and cater to their learning needs. Interested volunteers with a background in teaching or training can also volunteer in the special education initiative.
- Leadership training needs to be incorporated at various levels including carers groups, cluster level committees and the Carers Association with the provision of follow up interventions and refresher trainings.
- Increase the use of technology to overcome policy, social and environmental barriers of inclusion.
- Document outputs and lessons learned for demonstration and replication.
- Adopt innovative solutions to designing, implementing and monitoring of future projects.
- Strengthen monitoring and evaluation frameworks to capture more comprehensive data on project impact.
- Incorporate carers group savings plans in the project design.
- Stakeholder engagement (eg. with doctors, Union Parishad officials and the Department of Social Services) during planning, implementation and monitoring of interventions can be strengthened.
- More employment opportunities can be identified for the carers, including beauty parlour, computer, IT, maintenance of electrical and electronics equipment.
- The Department of Youth Development and the Upazilla Social Services Officer can be involved in training carers in other informal and formal trades.
- Provision for more screening of physical and mental health can be incorporated.
- Telemedicine and tele-counselling (one hotline number) can be introduced.
- Co- carers can be included to ensure more respite and short break for carers.
- The work of the Carers Alliance with the government, private sector and NGOs can be prioritized and strengthened.

For Carers Worldwide, CDD and future funders

- Continue capacity building of carers' group members, Association members and key stakeholders to ensure sustainability.
- Expand advocacy efforts to include broader policy changes at the national level.
- Explore additional income-generating opportunities for carers to further improve their economic stability.
- Initiate more evidence based advocacy for high level policy advocacy.

6. Conclusion

The project "Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh" successfully improved the health and socioeconomic wellbeing of 1,008 carers, 93% of whom were women and girls. The project's holistic approach and strong partnerships were key to its success. Moving forward, the project needs continued support to further promote and advocate for carers in order to sustain and expand these positive outcomes.



Shadhona and her daughter Sikha with their goats which they bought with a loan from the project

Photo by Farah Omar

References

- Elekanachi, R.U., Lajoie, A., Tavukcu, S. *et al.* The experience of caregiving for children with rare musculoskeletal conditions: a qualitative study in arthrogryposis multiplex congenita. *Orphanet J Rare Dis* 19, 235 (2024). <https://doi.org/10.1186/s13023-024-03224-8>
- Gallagher, S and Hannigan, A. Depression and chronic health conditions in parents of children with and without developmental disabilities: The growing up in Ireland cohort study. *Research in Developmental Disabilities*. Volume 35, Issue 2, February 2014, Pages 448-454 in the weblink < <https://www.sciencedirect.com/science/article/abs/pii/S089142221300543X?via%3Dihub>>
- Government of Bangladesh *Eighth Five Year Plan, July 2020- June 2025*. Dhaka: Ministry of Planning. <https://plancomm.gov.bd/site/files/8ec347dc-4926-4802-a839-7569897e1a7a/8th-Five-Year-Plan>, accessed on July 03, 2024
- Government of Bangladesh *Rights and Protection of Persons with Disabilities Act 2013 (in Bangla)*. Dhaka: MoLJPA. <http://bdlaws.minlaw.gov.bd/act-details-1126.html>. accessed on June 30, 2024
- Government of Bangladesh *National Mental Health Strategic Plan 2020- 2030*. Dhaka: MoHFW. <https://www.google.com/search?client=firefox-b-d&q=National+Mental+Health+Policy%2C+2022>, accessed on July 04, 2024
- Government of Bangladesh *National Mental Health Policy*. 2022. Dhaka: MoHFW. <https://www.google.com/url?sa=t&source=web&rct=j&opi=89978449&url=https://nimh.gov.bd/wp-content/uploads/2023/04/Bangladesh-National-Mental-Health-Policy-2022.pdf&ved=2ahUKewif4I-khZ2HAXUTr1YBHQZpBHEQFnoECBIQAQ&usq=AOvVaw0nXdYtDyrWMRgMGHMFNoKE>, accessed on July 05, 2024
- Government of Bangladesh *Neurodevelopmental Disability Trust Act 2013*. Dhaka: MoLJPA. [https://nddtrust.gov.bd/sites/default/files/files/nddtrust.portal.gov.bd/law/e1e1d066_36b3_45fc_a66b_392fbfb9852e/-%E0%A6%A1%E0%A7%87%E0%A6%AD%E0%A7%87%E0%A6%B2%E0%A6%AA%E0%A6%AE%E0%A7%87%E0%A6%A8%E0%A7%8D%E0%A6%9F%E0%A6%BE%E0%A6%B2%20%E0%A6%AA%E0%A7%8D%E0%A6%B0%E0%A6%A4%E0%A6%BF%E0%A6%AC%E0%A6%A8%E0%A7%8D%E0%A7%E0%A7%80%20%E0%A6%9F%E0%A7%8D%E0%A6%B0%E0%A6%BE%E0%A6%B8%E0%A7%8D%E0%A6%9F%20%E0%A6%86%E0%A6%87%E0%A6%A8,%20%E0%A7%A8%E0%A7%A6%E0%A7%A7%E0%A7%A9%20\(3\).pdf](https://nddtrust.gov.bd/sites/default/files/files/nddtrust.portal.gov.bd/law/e1e1d066_36b3_45fc_a66b_392fbfb9852e/-%E0%A6%A1%E0%A7%87%E0%A6%AD%E0%A7%87%E0%A6%B2%E0%A6%AA%E0%A6%AE%E0%A7%87%E0%A6%A8%E0%A7%8D%E0%A6%9F%E0%A6%BE%E0%A6%B2%20%E0%A6%AA%E0%A7%8D%E0%A6%B0%E0%A6%A4%E0%A6%BF%E0%A6%AC%E0%A6%A8%E0%A7%8D%E0%A7%E0%A7%80%20%E0%A6%9F%E0%A7%8D%E0%A6%B0%E0%A6%BE%E0%A6%B8%E0%A7%8D%E0%A6%9F%20%E0%A6%86%E0%A6%87%E0%A6%A8,%20%E0%A7%A8%E0%A7%A6%E0%A7%A7%E0%A7%A9%20(3).pdf), accessed on July 03, 2024
- Government of Bangladesh *Bangladesh Labour Act 2006*. Dhaka: MoLJPA. <http://bdlaws.minlaw.gov.bd/act-952.html>, Accessed on July 6, 2024
- Government of Bangladesh *National Skills Development Policy 2011*. Dhaka: NSDA. <https://www.google.com/search?client=firefox-b-d&q=national+skills+development+policy>, accessed on July 03, 2024
- Government of Bangladesh *National Skills Development Policy 2010*. Dhaka: MoE. <https://moedu.gov.bd/site/page/318a22d2-b400-48a7-8222-303ab11cc205/National-Education-Policy-2010>, Accessed on June 30, 2024

- Government of Bangladesh *National Children Policy 2011*. Dhaka, MoW&CA. <https://www.google.com/search?client=firefox-b-d&q=National+Children+Policy%2C+2011>, accessed on July 05, 2024
- Government of Bangladesh *Action Plan For Implementation of National Social Security Strategy (NSSS) of Bangladesh*. Dhaka: GED, Planning Commission. <https://gedkp.gov.bd/knowledge-archive/policy-strategy-docs/?cn=policy-strategy-docs>, accessed on July 04, 2024
- Hedov, G , Wikblad, K and Annerén, G. First information and support provided to parents of children with Down syndrome in Sweden: clinical goals and parental experiences. *Acta Paediatr.*2002, in the weblink <https://pubmed.ncbi.nlm.nih.gov/12578293/>
- Hastings, R. P and Taunt, H.M, Positive Perceptions in Families of Children With Developmental Disabilities, *Am J Ment Retard* (2002) 107 (2): 116–127. [https://doi.org/10.1352/0895-8017\(2002\)107<0116:PPIFOC>2.0.CO;2](https://doi.org/10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2) accessed on August 18, 2024
- Isa, S.N.I, Ishak, I., Rahman, AAB., Saat, NZM., Din. NC., Syarif Husin Lubis, Ismail, MFM. Health and quality of life among the caregivers of children with disabilities: A review of literature. *Asian Journal of Psychiatry*. Volume 23, October 2016, Pages 71-77. In the weblink <https://www.sciencedirect.com/science/article/abs/pii/S1876201816302994>
- IACO: Recognizing Carers. <https://internationalcarers.org/carer-facts/>, accessed on July 02, 2024
- Mak, W. S and Cheung, R. M. Affiliate Stigma Among Caregivers of People with Intellectual Disability or Mental Illness, *Journal of Applied Research in Intellectual Disabilities*, Volume 21, Issue 6 p. 532-545, 2008, <https://doi.org/10.1111/j.1468-3148.2008.00426.x>, cited in Werner, S. and Shulman, C. Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in Developmental Disabilities*. Volume 34, Issue 11, November 2013. Pages 4103-4114, <https://www.sciencedirect.com/science/article/abs/pii/S0891422213003715#preview-section-cited-by>. Accessed on July 01, 2024
- Moussavi S, Chatterji S, Verdes E, Tandon A, Patel V and Ustun B. Depression, chronic diseases, and decrements in health: results from the World Health surveys. *The Lancet* volume 370, issue 9590, p. 851-858, 2007 [Depression, chronic diseases, and decrements in health: results from the World Health Surveys - ScienceDirect](https://doi.org/10.1016/S0140-6736(07)61233-9)
- Murphy NA, Christian B, Caplin DA, Young PC. The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Dev.* 2007;33(2):180–7. Cited in Elekanachi, R.U., Lajoie, A., Tavukcu, S. *et al.* The experience of caregiving for children with rare musculoskeletal conditions: a qualitative study in arthrogryposis multiplex congenita. *Orphanet J Rare Dis* 19, 235 (2024). <https://doi.org/10.1186/s13023-024-03224-8>
- Phillips M, Chronic sorrow in mothers of chronically ill and disabled children. *Issues Compr Pediatr Nurs.* 1991. PMID: 1840407. in the weblink <https://pubmed.ncbi.nlm.nih.gov/1840407/>. accessed on August 18, 2024
- Raihan, S, Haque, S H and Jahan, I. "Unpacking unpaid labour in Bangladesh," *The Indian Journal of Labour Economics*, Springer; The Indian Society of Labour Economics (ISLE), vol. 60(4). pages 571-587, December, 2017. In the weblink

<https://www.researchgate.net/publication/326424813_Unpacking_unpaid_labour_in_Bangladesh/link/6132591dc69a4e487979c967/download> accessed on July 05, 2024

- Raina, P. O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russell, D., Swinton, M., Zhu, B., Wood, E. The health and well-being of caregivers of children with cerebral palsy, *Pediatrics* (2005) 115 (6): e626–e636. <<https://pubmed.ncbi.nlm.nih.gov/15930188/>>
- Samuel, P. S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research*, 56, 1–16. doi:10.1111/j.1365-2788.2011.01486, accessed on August 17, 2024
- Tripathi, S, Azhar, S and Fuhua Zhai, F. Unpaid care work among women in South Asia: A systematic review, 2022, in the weblonk <<https://onlinelibrary.wiley.com/authored-by/Tripathi/Saumya>>, Accessed on June 28, 2024
- Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education & Training in Mental Retardation & Developmental Disabilities*, 37(4), 410–420. In the weblink <https://www.google.com/url?sa=t&source=web&rct=j&opi=89978449&url=https://disabilitystudies.nl/sites/default/files/beeld/onderwijs/hastings2002-positive_perceptions_in_families_of_children_with-dd.pdf&ved=2ahUKEwj4INGS3PuHAXUvavUHHYHZKpQQFnoECCEQAQ&usg=AOvVaw1Ri9MgyyXLkHiPWjA7I3rV>
- Werner, S. and Shulman, C. Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables, *Research in Developmental Disabilities*, Volume 34, Issue 11, November 2013, Pages 4103-4114, <https://www.sciencedirect.com/science/article/abs/pii/S0891422213003715#preview-section-cited-by>. Accessed on July 01, 2024

Annexes

Annex I: Lessons Learned (reported by the CDD Project Team)

Lessons learned from working with carers:

Working with carers involves a complex interplay of skills, empathy, and understanding. Carers provide essential support to individuals who may not be able to fully care for themselves due to disability, age, illness, or other conditions. Listed below are some of the lessons the project team learned from working with carers .

Carers Support Groups

- Due to caring responsibility, most of the carer were distracted during the group meetings. It was necessary to identify an alternative carer from their family, to include him or her in the meeting to observe the carers group activities, so she/he could understand the group meeting value, and then involve him/her in providing care during future group meetings.
- Carers group leaders needed training for the records keeping, documents preparation and group management .
- Carers feel that the community level carers groups are the local level platform of the carers. Due to limitations in budget and project scope, it was not possible to include all carers into the groups. It is necessary to initiate a plan for how to include all carers.
- The financial support received from the group for livelihood activities was not enough so the groups started saving to further improve livelihood activities. Savings should start in all groups.
- It is not easy to provide Golden Citizen Card and Allowance to the persons with disabilities, but the carers groups took initiative successfully and ensured this safety net for their loved ones.
- Awareness sessions are part of the carers monthly group meetings, so carers-related IEC materials would help the carers' leaders to facilitate the meetings and make the information more understandable for all the group members.
- More time is needed to further support and mentor the groups that are not functioning as strongly.
- To develop the capacity of the existing carers groups, cluster level committees need to provide more time for group management.

Health Services

- The medicine prescribed for the carers at the health camps does not cover the required duration. In this situation, the linkages with the government hospitals are necessary to ensure their medicine support and continued health services.
- Psychiatrist support is needed at one in every two health camps to ensure mental health treatment is available for carers.
- Telemedicine for the carers will be more effective due to their caring responsibility.
- Central help desk for the carers on mental health related counselling and over the phone tertiary level counselling would be beneficial.

- Carers above 50 years need specialized health services such as assessment of non-communicable diseases including diabetes. This will play a role in ensuring the prevention and treatment of age related diseases.
- Regular follow up camps are needed and could take place at government community clinics to ensure healthcare for carers.

Respite and short breaks

- Carers are less stressed in the environment of the community caring centres. Monthly visits from a specialist counselor would support carers' mental health.
- Each community caring centre works intensively with 15-20 carers. The capacity of the CCCs should be increased, with the possibility of also running evening sessions.
- Training on self care for care carers will help them to support themselves as well as their loved ones.
- Assessment and regular input from a trained nutritionist would provide valuable support.

Employment, Training and Education

- Carers are currently trained and involved in the livelihood activities under five trades. More trades need to be included.
- Carers received training on their selected trade. Follow up and more in-depth training needs to be arranged.
- Livelihood training from local government and government officials enhances the capacity of the carers ongoing livelihood activities. Further linkages for regular training updates would be beneficial.
- Need to develop carers' capacity on marketing.

Advocacy

- Need to strengthen the capacity of the Carers Association and the Carers Alliance for securing the rights of carers.
- Training for the Government officials on the Carers Worldwide Model will promote a facilitating environment for the carers to talk about their rights.
- Carers now easily go to the different government offices and are able to share their needs.
- Carers are now strongly linked with the local government and as part of their advocacy work, they can access the local government financial assistance from the Union Parishad.

Besides the above, the following areas were also raised during the project team meeting:

- Effective communication is critical. Clear instructions, open dialogue, and regular updates help ensure that both the carer and the person being cared for understand what is expected and needed.
- Working with carers often requires a lot of patience, especially when working with the carers who are caring for individuals who have severe disabilities or chronic illnesses. It is important to recognise that progress can be slow and there will be setbacks. These carers typically experience more mental health issues and so mental health support needs to be planned with the condition of their relative in mind.

- Respect individual differences: every carer and the person they care for are unique. It is important to the family members and community people to respect individual preferences and personal boundaries to build a trusting and effective care relationship.
- Carers often experience high levels of stress and emotional fatigue. Providing them with emotional support and recognizing their efforts can make a significant difference in their well-being and performance.
- Continuous education and training in areas such as livelihoods, first aid, medical conditions, and care techniques can enhance carers' skills and confidence, leading to better care for those they support.
- The needs of the person being cared for can change rapidly, and carers must be able to adapt to new situations and requirements. Flexibility in scheduling and approach can greatly improve the effectiveness of care.
- Carers work as part of a frontline country resource team. Effective collaboration with doctors, nurses, social workers, and family members ensures a comprehensive approach to care that addresses all aspects of the individual's needs.
- Burnout is a common issue among carers due to the demanding nature of their work. Recognizing the signs of burnout and implementing strategies to address it, such as regular breaks, support groups, and counseling, is essential for sustainable care.
- Carers often have deep, practical knowledge about the needs and preferences of the person they care for. Valuing and incorporating their insights into care plans can lead to more personalized and effective care.

Annex II: Focus Group Discussion (FGD) format for Final Evaluation

*(The Focus Group Discussion is conducted after the **informed consent procedure** have been done)*

Respondent type _____
Date: _____
Place: _____
Facilitator: _____

Introduction:

The project "Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh" aims to improve the health and socioeconomic wellbeing of carers of persons with disabilities in Savar, Bangladesh.

Welcome and thank you for agreeing to participate in this focus group discussion. I am going to ask you some questions about the access of unpaid carers in Savar to the available services offered by the government facilities, NGOs and other stakeholders. I am going to focus not only availing the services but also quality of services, positive or negative impact on their living, including status of health, livelihood, social and empowerment of the unpaid carers. Your answers will be used to improve programs and services for unpaid carers at the neighbouring places of service and facilities. You have been selected to participate in this evaluation as you are familiar with the services offered by the project and related stakeholders in Savar. Since, this guideline is used with different types of stakeholders, you may not be aware of the answer to each item. If you are not familiar with any topic, please simply move to the next item of the same section. This evaluation intends to improve future programmes and services for unpaid carers who are seeking services. We want to ask you to use your own experience, and your knowledge and experience of other people like you, to answer these questions. We will also discuss how these could be improved.

The Facilitator will inform participants about the following issues as well:

- We do not have to speak in any particular order, but must allow everyone to participate if they wish to do so.
- Everyone is entitled to their own opinions and must respect each other's opinion.
- There are no right or wrong answers.
- Your identities will be kept confidential and their answers will not be attributable to them as named individuals.
- You feel free to ask for clarifications

The facilitator will also give special attention to the issue that the access to services can vary by gender (they might be higher for women with disabilities), so that facilitator will explore the issue whether there is any difference in each service due to any reason. Hence, what we want to talk about is the services available, access and barriers to the services for unpaid workers as well as their family members.

As I mentioned at the start, the purpose of this discussion is to learn more about how project interventions, process followed to promote access to services for unpaid family carers in Savar. The rest of the questions in this interview are to learn more about related topics.

- d) What role other committees played in the cluster during last one year and/or earlier? Did the unpaid carers of other committees face any difficulty?

Needs of Unpaid Family Carers:

- a) Are you aware of the major challenges faced by family carers like you?
b) How do you know challenges of other carers groups in the cluster? How did they overcome those challenges?
c) How did the project people support the committees? How well do you think the project addressed your needs as a carer?

Addressing the requirement of the unpaid family carers

- a) How well were the project activities aligned with your requirements and priorities?
b) Can you give examples of project activities that were particularly helpful or not helpful.
c) To what extent do you feel the project intervention(s) made positive changes in your individual, family and social life ?
d) According to you, which were the most important interventions considering your requirement to fulfil your health, livelihoods, think were the most successfully achieved?
e) What specific need(s) were not addressed by the project? How did you overcome those challenges?

Project Impact

- a) How has the project improved your physical and mental health as a carer?
b) Can you share specific examples of improvements in your health?
c) **Economic Wellbeing:**

What changes have occurred in the economic wellbeing of your household as a result of the project? Have there been any improvements in your financial situation? Please provide examples.

Factors Contributing to or Hindering Achievement:

- a) What were the key factors that contributed to the success of the project?
b) Which challenges or barriers impeded your access to specific project activities? How did you overcome those challenges?
c) What would you suggest for improvement in future projects?

Continuation of Project Interventions:

- a. What aspects of the project do you think are most likely to be persistent? (can you tell me more about that)
b. According to you how the positive impact of the project will continue after the funding period ends?
c. How many measures have been taken by the carers groups of different tier to ensure the sustainability of the project?
d. Are there any additional measures that you think should be taken to ensure sustainability?
e. What would you suggest for improvement in future projects?

Conclusion:

- Thank the participants for their time and valuable insights.
- Inform them about the next steps in the evaluation process and how their feedback will be used.
- Addressing final questions or concerns from the participants .

Annex III: Key Informant Interview (KII) format

Guide for Stakeholders (doctors, health workers, government officials, and community leaders):

Dear Sir/ Madam,

The project "Upscaling and Expanding a Successfully Tested Approach to Support Unpaid Family Carers in Savar, Bangladesh" aims to improve the health and socioeconomic wellbeing of carers of persons with disabilities in Savar, Bangladesh.

Welcome and thank you for agreeing to participate in this focus group discussion. I am going to ask you some questions about the access of unpaid carers in Savar to the available services offered by the government facilities, NGOs and other stakeholders. I am going to focus not only availing the services but also quality of services, positive or negative impact on their living, including status of health, livelihood, social and empowerment of the unpaid carers. Your answers will be used to improve programs and services for unpaid carers at the neighbouring places of service and facilities. You have been selected to participate in this evaluation as you are familiar with the services offered by the project and related stakeholders in Savar. Since, this guideline is used with different types of stakeholders, you may not be aware of the answer to each item. If you are not familiar with any topic, please simply move to the next item of the same section. This evaluation intends to improve future programmes and services for unpaid carers who are seeking services. We want to ask you to use your own experience, and your knowledge and experience of other people like you, to answer these questions. We will also discuss how these could be improved.

With this interview we would like to get your suggestions and recommendations for the project needed in your area. As such, the questions are prepared for public Institutions with the aims to collect information about your involvement in the project, as well as the extent to which they intervene in this field. It is also aimed to learn the efficient use of resources to plan, implement, and monitor the project's progress as per the initial project design and logical framework.

This questionnaire aims to gather comprehensive feedback from related stakeholders who directly or indirectly supported the implementation, monitoring of the project interventions. Your input will be invaluable in shaping future initiatives and improving outcomes for unpaid family carers and persons with disabilities in Savar, Bangladesh.

It would be great if you can devote 40 minutes of your time to answer our questions. Thank you in advance for your cooperation!

Consent Form

Within the scope of the evaluation, your answers will be kept completely confidential and anonymous. Your responses will not be shared with third parties under any circumstances. Your answers to the questions will be analysed and reported collectively after all the data are combined. We thank you for your time and interest in the project.

I agree to participate in this research voluntarily. Yes No

1. Project Implementation:

- a) Can you please introduce yourself and describe your role in relation to the project?
- b) How would you describe the overall implementation process of the project?
- c) What were the main challenges faced during the implementation, and how were they addressed?
- d) Can you provide examples of successful strategies or interventions used in the project?
- e) What aspects of the project do you find most significant or impactful?

2. Project Relevance and Effectiveness:

- a) In your opinion, how relevant is the project to the needs of unpaid family carers in Savar, Bangladesh?
- b) From your perspective, how effective have the project activities been in addressing the needs of unpaid family carers and persons with disabilities in Savar?

3. Project Outcome:

- a) In your opinion, what are the most notable outcomes of the project for unpaid family carers?
- b) How has the project influenced the well-being of the family carers involved?
- c) Can you please describe the process followed by the project in the implementation, monitoring and follow-up of the project.

4. Impact and Sustainability:

- a) Can you share any specific stories or examples regarding the impact of the project on the social, emotional, mental, physical, and financial wellbeing of unpaid family carers?
- b) How sustainable do you think the project's outputs and outcomes are beyond the funding period?
- c) What measures have been put in place to ensure the sustainability of the project's outcomes?
- d) How do you see the project evolving in the future?
- e) What additional support or resources might be needed to sustain and expand the project?

5. Challenges and Lessons Learned:

- a) What were the main challenges encountered during the implementation of the project?
- b) Are there any lessons learned from this project that could inform future initiatives in similar contexts?
- c) What key lessons have been learned from the project?
- d) Are there any practices or approaches from this project that could be applied to similar initiatives in other contexts?
- e) What would you recommend changing or improving in future projects of this nature?

6. Stakeholder Involvement:

- a) How were stakeholders, including family carers, engaged in the project planning and implementation?
- b) What role did the Centre for Disability in Development play in the project?
- c) How effective was the collaboration with the CareTech Foundation and the Rangoonwala Foundation?

7. Monitoring and Evaluation:

- a) How was the project's progress monitored and evaluated?
- b) What indicators were used to measure success, and how effective were they?
- c) Can you discuss any significant findings from the project's monitoring and evaluation reports?

8. Capacity Building:

- a) How did the project contribute to building the capacity of family carers and other stakeholders?
- b) What training or resources were provided, and how effective were they?
- c) How has the capacity building component of the project impacted its overall success?

9. Challenges and Barriers:

- a) What were the main barriers to achieving the project's objectives?
- b) How were these barriers addressed, and what challenges remain?
- c) Can you suggest ways to overcome these challenges in future projects?

10. Recommendations for Future Projects:

- a) Based on your experience, what recommendations would you make for future projects aimed at supporting unpaid family carers?
- b) Are there any particular areas that need more focus and/or resources?
- c) How can future projects better address the needs and challenges of unpaid family carers in similar contexts?

11. Recommendations:

- Based on your experience and observations, what recommendations would you propose for future projects involving Carers Worldwide, CDD, and other organizations?

Additional Comments:

- Is there anything else you would like to add that hasn't been covered in the interview?

Closing:

- Thank you for your time and insights. Is there any way we can follow up with you for further clarification or information?

Annex IV: IDI Guide for End Evaluation for CDD Project Team

Relevance:

1. How well did the project address the needs of carers in Savar, Bangladesh?
2. Were the project activities aligned with the carers' requirements and priorities as identified in the baseline study?
3. How did the project engage with local communities and stakeholders to ensure relevance and appropriateness?

Effectiveness:

4. To what extent were the project outcomes and outputs achieved within the specified timeline?
5. What were the key factors that contributed to the successful achievement of project outcomes?
6. Were there any challenges or barriers encountered during the implementation that hindered the achievement of desired outcomes? If so, please elaborate.

Sustainability:

7. Are the project's benefits likely to continue after the funding period? Please explain.
8. What measures have been taken to ensure the sustainability of the project outcomes beyond the project duration?
9. How has the project strengthened local capacities and systems to sustain the initiatives post-project?

Impact:

10. How has the project improved the physical and mental health of carers in Savar?
11. Can you elaborate on the changes observed in the economic wellbeing of the carers' households as a result of project interventions?
12. In what ways has the project empowered carers to advocate for their needs with local government representatives?

Additional Questions:

13. How has the partnership between Carers Worldwide and CDD contributed to the overall success of the project?
14. What lessons have been learned from this project that could inform future initiatives targeting carers in similar contexts?
15. How would you rate the overall effectiveness of project monitoring and evaluation mechanisms in capturing progress and impact?

Annex V: Case Study Checklist for Unpaid Family Carers

A. Personal Information:

- Name
- Age
- Gender
- Relationship to the person with a disability
- Type of disability cared for
- Duration of caregiving
- Socio-economic status
- Own health condition or disability (if any)

B. Carers Support Groups:

- Participation in support groups
- Frequency of attendance
- Activities engaged in during support group meetings
- Perceived benefits (e.g., reduced loneliness, improved emotional wellbeing)
- Challenges faced in attending support groups

C. Health Services:

- Access to physical health services
- Access to mental health services (e.g., counseling)
- Frequency of health service utilization
- Improvements in physical and mental health
- Barriers to accessing health services

D. Employment, Training, and Education:

- Participation in employment, training, or educational programs
- Type of employment or training received
- Compatibility of these activities with caregiving responsibilities
- Changes in financial status
- Skills or knowledge gained
- Challenges in balancing caregiving and employment/training/education

E. Respite and Short Breaks:

- Access to respite care or short breaks
- Types of respite care utilized (e.g., Community Caring Centres)
- Frequency and duration of breaks
- Impact of breaks on personal wellbeing and caregiving quality
- Barriers to accessing respite care

F. Advocacy:

- Involvement in advocacy activities
- Confidence in advocating for needs with local government representatives
- Successes in advocacy efforts

- Areas where advocacy is still needed
- Support received for advocacy activities

G. Impact on Carer's Wellbeing:

- Changes in social participation (family and community activities)
- Financial security and poverty status
- Physical health improvements
- Mental health improvements
- Overall wellbeing and life satisfaction

H. Impact on the Person with Disability:

- Changes in the quality of care received
- Improvements in quality of life
- Feedback from the person with disability

I. Household Wellbeing:

- Economic wellbeing of the household
- Overall family dynamics and relationships
- Perceived improvements in household functioning

J. Challenges and Recommendations:

- Main challenges faced during the project
- Lessons learned
- Suggestions for future projects

Annex VI. Observation Checklist of Family Members

A. Family Member Information:

- Name
- Age
- Gender
- Relationship to the carer and the person with disability

B. Participation in the Project:

- Involvement in project activities
- Types of support provided to the carer
- Changes in household responsibilities

C. Impact on Family Dynamics:

- Changes in family dynamics and relationships
- Observed improvements in carer's wellbeing
- Observed improvements in the person with disability's quality of life
- Economic changes in the household

D. Feedback on Project:

- Perceived benefits of the project
- Challenges faced by the family due to the project
- Suggestions for future improvements

E. Overall Household Wellbeing:

- Changes in household economic status
- Overall household functioning and harmony
- Support received from the community and local authorities