



Community members in Jharkhand meet with CBM and local partner CSS. Participants include a fathers group recently formed thanks to the advocacy efforts of local women.

DISABILITY AND UNPAID CARE WORK

Unpaid care work is work undertaken without any monetary compensation, to provide household services, such as cooking and cleaning, and direct care for others. Gender inequality in the division of unpaid care work is pervasive across the globe and is present in every society. While social norms around paid work are shifting, women are still spending one to three hours more each day on housework, and two to ten times as much time on caring for a child, older person or person with a disability¹. Goal 5 of the Sustainable Development Goals includes a target to recognise and value unpaid care work; this highlights growing recognition of its relevance to the international development agenda.

¹ World Bank, *World Report on Disability* (2011).

The unequal distribution, intensity and lack of recognition of care work undermines the rights of many women. It is a barrier to meaningful participation in public and private life, as well as education and livelihood opportunities. It leaves women, particularly women and girls with disabilities who often both depend on others for care and are caregivers themselves, at increased risk of poverty². This leads to a further economic burden for families of people with disabilities, given that they already often face higher costs of living³.

Unpaid care work can have a significant impact on women's physical and mental health⁴, particularly for mothers of children with disabilities. According to the World Health Organisation, "[t]here is strong evidence that mothers ... of children with intellectual disabilities are at increased risk of poor physical and mental health when compared to parents of typically developing children."⁵

When caregivers become overburdened with unpaid care work the quality of the care they are able to provide is also affected. This means that the rights of people with disabilities who rely on others for care are also violated when unpaid care work is not adequately recognised or supported⁶.

In CBM, we need to be careful that our programs don't increase unpaid care work for mothers of children with disabilities. In the work that CBM supports, women are usually the ones caring for children, including children with disabilities. Home based rehabilitation and education is often a useful approach for supporting people with disabilities in resource-poor communities. However when programs focus on getting women (and not men) to train and provide this support for a family or community member they are often asking women to do even more with their limited time. This means programs may unintentionally block women's opportunities for finding work, engaging socially or becoming leaders in their communities.

Many children with disabilities live in female-headed households, and we need to make sure that our programs reach them. In some contexts households that include a child with a disability are disproportionately female-headed⁷. This is often due to fathers seeking work further from home in order to cover the additional costs associated with disabilities. In other cases, it is because fathers have abandoned the household entirely, as a result of the stigma surrounding disability; women may be blamed for giving birth to a child with a disability. This means that the responsibility of caring not only increases but is less easily distributed than in a traditional household. Where government social protection measures are non-existent or inaccessible this results in a vicious cycle; women caregivers become even more time-poor and unable to work or represent their interests in their communities. Often programs are

² UN Women, *Why We Care About Care? A Collection of Essays in English on Care Economy* (2016).

³ United Nations Children's Fund (UNICEF), *The State of the World's Children 2013: Children with Disabilities* (2013).

⁴ Magdalena Sepulveda, *Report of the Special Rapporteur on extreme poverty and human rights*, Special Rapporteur report (2013).

⁵ WHO, *Better Health, Better Lives: Research Priorities* (2012).

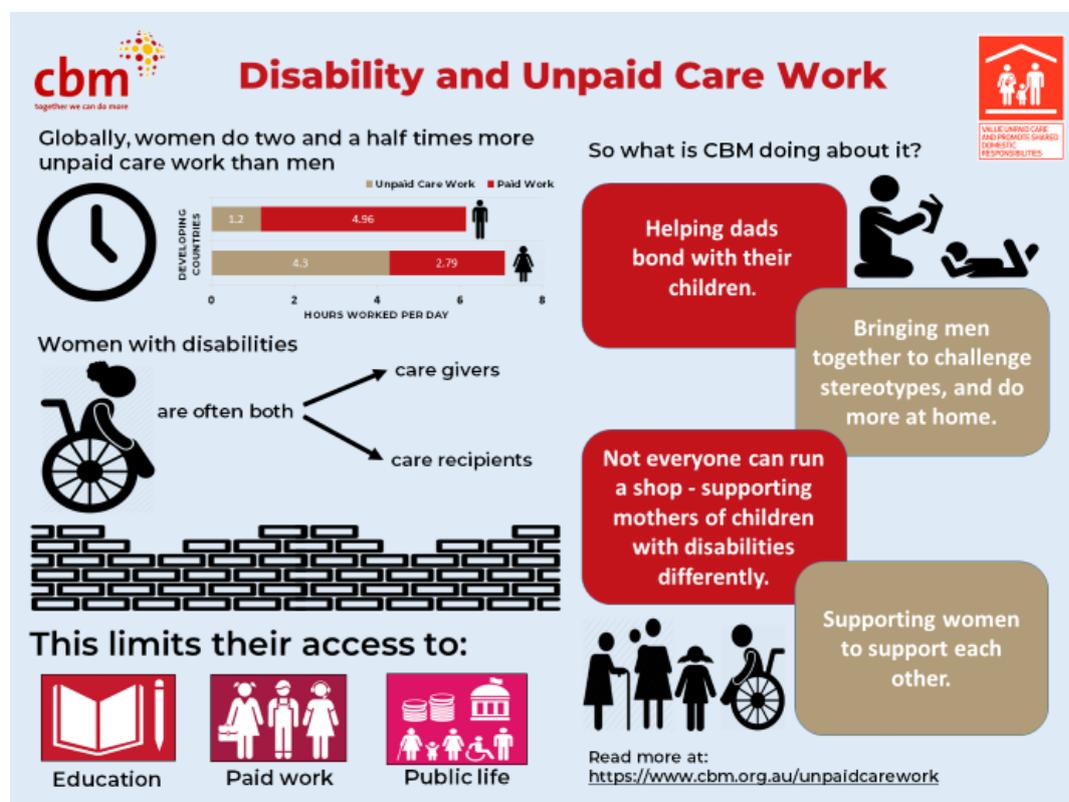
⁶ Sepulveda, (2013).

⁷ CBM Australia, *Leave No One Behind: Gender Equality, disability inclusion and leadership for sustainable development* (2018).

designed on the basis of traditional household structures that include a mother and a father and fail to take these additional considerations into account. For example, a livelihoods program might have an objective around women's economic empowerment, however women from these more vulnerable households are unable to participate due to their caring responsibilities.

Unpaid care work limits the participation of women with disabilities in our programs. While many women with disabilities remain single at rates disproportionate to other women⁸, when they do marry they face high expectations around unpaid care work, and their available time is severely limited. Often this stems from the perception that a married woman with a disability is not able to look outside the home for work, so even more caring responsibilities fall to her. This restricts their ability to find paid work or participate and lead in community work and advocacy, particularly through Disabled People's Organisations (DPOs). This is one reason why DPOs tend to be headed by men with disabilities, and where women with disabilities are in leadership positions, they are often single. This means that many married women with disabilities are not able to share their experiences and advocate for their own needs, including issues around family decision making and time use.

The following case studies from CBM's work in the Philippines, India and Ghana highlight the relationship between unpaid care work, disability and poverty and offer some simple strategies for combating these challenges. Some brief examples of how other organisations have addressed unpaid care work in health, livelihood and disaster risk response programming are also provided.



⁸ Human Rights Watch, *Women and Girls with Disabilities*. Available from <https://www.hrw.org/legacy/women/disabled.html>.

BUILDING AGENCY AND RELATIONSHIPS: A COMMUNITY

- The project is supporting the formation of women's collectives that support each other and **reduce** the burden of unpaid care work.
- It is also trying to **redistribute** care for children with disabilities more equally in families, by engaging fathers in care work and parents groups.

CONTEXT

Chotanagpur Sanskritik Sangh (CSS) is a non-government organisation and a CBM partner based in Jharkhand, India. They operate in some of the most rural and remote regions in India, with high poverty rates, severely limited resources and very conservative attitudes about women. Recognising the intersecting challenges of disability, gender and poverty, CSS ensures that both their rehabilitation and women's rights divisions (called 'MISSI', meaning 'sister' in local language), pool their respective resources and networks. By doing this they support women with disabilities to better understand the rights to which all women are entitled, undertake advocacy and access livelihoods and justice.

MISSI has had a strong presence in Jharkhand since 1995, promoting the rights of women and eliminating discrimination against them. It has built considerable goodwill at the community level, where it advocates for the inclusion of women in decision making processes as well as access to their entitlements as provided under government schemes. Men and women alike know and trust MISSI's work, which is particularly critical when it comes to challenging gender perceptions in a community. MISSI also played an important role in advocating at state level for the *Prevention of Women from Domestic Violence Act, 2005* and formation of the Jharkhand Women's Commission.

THE CHALLENGE

As is the case in many developing communities, mothers in Jharkhand are almost entirely responsible for caring for children, including children with disabilities. CSS realised that this needed to change so that all family members support children with disabilities. They work to change perceptions by actively engaging fathers, mothers-in-law and other family members in issues that would otherwise fall to mothers. They also bring women together to support each other in care work: by forming collectives women are able to provide informal mechanisms for child care. These strategies are seen as essential for enabling more choice for women: choice to find employment opportunities, choice to participate in community decision making, or indeed choice to participate in unpaid care work. It's about women's rights, empowerment and redistribution, rather than simply supporting caregivers according to the status quo.

COLLECTIVE AGENCY: SUPPORT THROUGH THE SISTERHOOD

MISSI has many members in villages across Jharkhand, and it is through this network that local women are identified and engaged in their work. It provides them with leadership and training according to existing interests and skill sets. Once trained, MISSI facilitate links with vocational training institutes and options for income generation. Women work together in collectives, which not only

enhances their confidence and bargaining power for attaining bank loans, but also enables women to support each other with informal caregiving options. By pooling resources in this way the women's collectives are able to reduce the burden of unpaid care work. This means that mothers are still able to participate in and benefit from economic empowerment activities and inequality is not perpetuated in communities.

Through this work MISSI has learned that there is a positive cycle between building the confidence and initiative of individuals and building the confidence and initiative of groups. By training women, including women with disabilities, according to individual needs and interests and then bringing them together, MISSI believes that collectives are able to influence decision-making at household and community levels.

RELATIONSHIPS: WORKING WITH MEN AND FAMILIES TO CHANGE PERCEPTIONS ON CARE AND GENDER ROLES

MISSI's work with men came about indirectly at first, as a consequence of husbands of MISSI members becoming aware of the need for sharing household chores. Noticing this, they saw the need to message this in a more intentional way, so that further change might be seen at community level. As a result "Fathers Groups" were formed. Initially these groups were largely made up of older men, as they had more time and were present in the village whereas younger men had left for work. However links with existing youth groups were formed and mentoring relationships formed between some of the younger and older men. Experiences are shared on how care work is shared within households and the benefits of this. As a result, men in these communities do not encounter the same levels of stigma around caregiving, and are contributing more to unpaid care work in their homes.

"During a meeting with a Fathers Group men spoke openly of the impact that their wives, who are MISSI members, have had on their own lives. This has led to a redistribution of household chores: cutting vegetables, assisting in food preparation, equal contributions in raising children – which in turn has led to men having more positive relationships with their children." - CBM Australia Project Visit Report

From this approach MISSI has learned that changing embedded social norms takes a long time. Older men who have been around longer often have a greater understanding of the benefits of their wives being MISSI members.

NEXT STEPS

While there appears to be considerable social change as a result of MISSI's village level initiatives these have largely been reported on an ad hoc basis. A more systematic approach to collecting these stories of change would be useful for capturing MISSI's experience and sharing learning with other partners.

MISSI has helped women support each other through collectives, and encouraged redistribution of care work within households, however structural change could be promoted through further advocacy. For example state level advocacy could be undertaken to encourage government support for stronger social protection measures.

ENGAGING MEN AS CARE ADVOCATES IN THE PHILIPPINES

- The project is trying to **redistribute** care for children with disabilities more equally in families, by engaging fathers in care work and parents groups.

CONTEXT

Since 2013 NORFIL has worked on a model of Community Based Inclusive Development that ensures that children with disabilities access the services they need and the same opportunities as their peers. It also supports sustainable, empowered parents groups that engage with local government so that they are aware and do more to support people with disabilities. So far, it has worked in three locations, each for five years, with a clear plan for phase out that aims to leave behind an active parents association and a more disability-inclusive local government.

THE CHALLENGE

NORFIL's work aims to improve the quality of life of children and youth with disability through full enjoyment of their rights, on an equal basis with others. However project staff realised that many of the responsibilities relating to raising a child with a disability fell to mothers. They noticed that there were more women volunteers in the project and that mothers were usually the ones attending village level meetings and rehabilitation training courses. By contrast the formalised parents' organisation that advocates to government at district level had significantly more males representing their household. This is in line with traditional gender norms in the project area: the father is typically head of household and main breadwinner, while the mother is prime caregiver, in charge of housework, and usually prioritises the family needs before their own. By reinforcing these norms, the project was unintentionally creating additional workloads for mothers, and reinforcing the idea that men were better placed to represent the interests of the family in the public sphere.

ENGAGING FATHERS AND SIBLINGS IN CARE WORK

NORFIL devised a gender strategy to challenge these norms and advocate for the shared responsibility of mothers and fathers, in matters of child rearing, responsible parenthood and rehabilitation of children with disabilities. Two main activities towards this are:

- Requiring that both parents to be present in family conference to discuss their role in the rehabilitation of their child with a disability.
- Conducting training with fathers, and training with siblings, to help support and enrich relationships between children with disabilities and their fathers and siblings.

The fathers' training was arranged on weekends, as a way of reinforcing the idea that caring for a child with a disability was not just a mother's role. NORFIL has found that these 'dad's only' weekends work well because they provide an opportunity for men to express sadness and uncertainty about their child with

other fathers in a supportive environment, outside a family context where males are expected to be strong and not show emotion.

This also appears to be having some longer term impacts: a recent mid-term review of the NORFIL project found that the specific fathers and sibling training was increasing contributions to home based rehabilitation and household work.

Fathers who participated in the training have reported an increased understanding of their role as a parent, increased participation in household activities such as bathing children and cooking. What was less expected is the positive impact this is having on relationships: between husbands and wives and fathers and their children. One father explained that "*I now love my son more*" and two fathers mentioned their pride in the things their child is learning to do and participating in.

INCREASING CAREGIVER PARTICIPATION AND OPPORTUNITY

Because fathers are taking on more household and care work, mothers are now finding the time to represent their interests and participate in community advocacy and decision making. One mother who is on the board of a parents group was able to participate in the country level parents convention in Cebu. This was because her husband had attended the training and was more confident to care for their son with a disability.

The main challenges in our family is when there is an activity I have to attend and there is no one who can take care for my child since my husband is the one earning for our daily needs. While my husband had been called for the new job...we have to decide if I will attend for the [parents] convention or my husband will not go for the call of his application. My husband give the opportunity for me to attend for the convention and not on his applied work, he said if that is for me, I can re-apply for the job. – CBM Australia Mid-Term Review

NEXT STEPS

While NORFIL have trialled some innovative approaches to father engagement with considerable success at household level, there is still room for progress in terms of engaging fathers in local parents groups and encouraging fathers to see that their contributions are important here as well. This is likely the result of cultural and social norms where men are seen as the breadwinners of the family and women as the caregivers. Consideration of elements such parent group meeting times are areas for future exploration, as this could likely be a contributing factor to fathers not being present, if meetings are held during working hours.

RECOGNISING AND SUPPORTING CAREGIVERS IN GHANA

- The program is **recognising** the value of carers by directly supporting and measuring their quality of life, as well as that of the child with a disability and the broader household.
- It also recognises the challenges to **redistribution** of care work (and the impact on livelihoods) when there is no one to redistribute to. This is being addressed by linking families, especially single parent/female headed households, to social safety nets.

CONTEXT

Cerebral palsy is the most common cause of physical disability in children worldwide, and yet in most low resource settings there are few services available to support children with cerebral palsy or their families. In Ghana there are only an estimated 150 physiotherapists across the country and its first cohort of speech and language therapists and occupational therapists have recently begun training. In this extremely resource poor setting home and community based interventions are critical.

CBM's partner organisation, the Presbyterian Church of Ghana, runs community based rehabilitation and inclusive primary health care programs across the country. They chose eight existing sites to implement "*Getting to know cerebral palsy*", a community based program that aims to improve care and support for children with cerebral palsy in a way that is empowering for caregivers. The program consists of once a month caregiver support group training for three hours, and a monthly home visit. In addition to support for the child, the training focused on bringing caregivers together to share their experiences, build social inclusion, and also identify livelihood options.

THE CHALLENGE

The program seemed to be making some good progress in terms of improvements in child health, however, there was no formal evidence to show whether the training material used by this program had an impact on caregivers specifically. A 2 year study was commissioned and through this the program learned about the complex and challenging links between caregiving, economic empowerment, gender, disability and poverty. It highlighted the importance of recognising the impact that disability, and disability inclusive programming, has on caregivers.

CARING ABOUT CAREGIVERS: VALUING AND MEASURING THEIR QUALITY OF LIFE

The program looked at whether the focus on empowering caregivers had led to any improvements to their quality of life. They found there were significant improvements in terms of knowledge and confidence in caring for their child, attitudes towards and patience with their child, and self-esteem and dignity; caregivers felt for the first time that they and their child were valued. The support group was key to this change as it helped caregivers realise that they

were not on their own, helped address issues of stigma and provided a safe space to share experience and learning.

Mother: At first my mum (grandmother) and I used to weep. I thought I was the only one with this problem but when I saw my colleague women with similar problems, I realized that I wasn't the only one. [And how does that help you knowing the other women?] I now know that there are other women like me with the same situation, so I have other mothers that I can share my problems with each time I go for meetings. – London School of Hygiene and Tropical Medicine, University of Ghana and CBM Program Evaluation

ABSENT FATHERS, POVERTY AND SOCIAL PROTECTION

Unfortunately, while the program has had a positive impact on caregivers themselves, complex family situations mean that many caregivers do not feel supported in caring for their child. There was little change in family attitudes over time for caregivers living with their husband's family, where blame for bringing a disability into the family is often attributed to the mother. They found that 51% of all participating families reported that the father no longer lived at home. The child's disability was a common reason given for a father's departure.

...Although Monica reflects on all these positive improvements, her own home situation deteriorates over the year. Her husband moves out of their room in the house and she is left on her own with the child. The mother-in-law is looking for a new wife for her son. His increasing lack of support means that she also now struggles financially to pay for health care for the child, such as a follow up hearing test, because the husband is no longer willing to contribute to this. – London School of Hygiene and Tropical Medicine, University of Ghana and CBM Program Evaluation

This pervasive stigma around disability that impacts both mothers and children with disabilities isolates caregivers from families and communities. The lack of support also restricts the time available for earning a living, particularly in cases where the child is not in school and childcare is not available. Sixty five percent of the caregivers participating in the program did not have a way to earn a living due to childcare and housework. This pushes many female-headed households further into poverty and further limits access to health care.

NEXT STEPS

The program has made a valuable contribution to improving the quality of life of caregivers and their children, particularly in terms of creating local support networks in communities where they often felt socially excluded. They have recognised the importance of considering the impact of our programs on caregivers as well as care recipients.

In spite of these positive changes, there is still an urgent need to address the extremely high levels of stigma and discrimination towards children with cerebral palsy and their caregivers, which is a major barrier to accessing services and wider community support. More specific engagement with fathers and other family members would go some way towards this.

GOOD PRACTICE

HEALTH

- Unpaid care work may affect women's physical and mental health due to its often physically and emotionally demanding nature.
- Women may not be able to access health services due to lack of time or money, due to unpaid care work responsibilities.
- This may in turn have a negative impact for recipients of care who rely on caregivers.

Involve fathers as early as possible - from prenatal period on. The organisation MenCare leads a global campaign for engaging fathers focus on fatherhood as a key entry point for challenging gender norms around household work, care for children and equitable relationships. They have developed a resource called 'Program P' that primarily trains healthcare providers in how to engage men in prenatal consultations – a key time for creating new caregiving behaviours. They are also supported to educate the public on issues around caregiving, parenting and gender roles. There are also tools and resources for working more generally with men as caregiver and fathers to prevent violence against children and women and to promote gender equality.

Further info: [Program P Manual](#)

Interactive activities help internalise behaviours. In Niger, the UNFPA's 'School for Husbands' are formed when UNFPA staff and community leaders convene with village chiefs to identify 8 to 10 "model husbands" – respected men in the village who are willing and have progressive views regarding family planning and gender based violence. Once they have participated in an initial three day training program on gender equality and discrimination, they meet twice a month to discuss specific areas of reproductive health and seek community-appropriate solutions to problems. Ideally this brings other men in the village on board. Couples whose husbands participated in the groups have reported several positive changes in attitude and behaviour, including more open communication on maternal health. Perhaps more significantly, there were also reported changes in the number of births attended by a skilled health professional, by women whose partners were involved in the groups. The initiative has spread to other regions and countries.

Further info: ['Schools for Husbands', Niger](#)

LIVELIHOODS

- When a caregiving parent or child has a disability there can be increased time demands and less opportunity to seek paid work. Combined with the higher costs of living faced by many families of people with disabilities this can lead to greater risk of poverty.
- Families of children with disabilities are more likely to become single parent/female headed households, which further reduces time available for livelihood opportunities.
- Women who work outside the home often still undertake the bulk of unpaid care work in the home, reducing time for rest and other opportunities.

Additional training for Village Saving and Loan (VSL) groups CARE and Promundo support women's economic empowerment activities in Rwanda. As part of this they have developed a curriculum and provide training for husbands on business skills, couples' decision making processes, health and well-being and laws and policies relating to gender based violence.

Start small in existing program, compare results. The program started with additional training for husbands of 30 women they were working with, over 16 weeks. The other female beneficiaries continued with the traditional programming and their husbands did not undertake additional training. The program found that involving men resulted in increased income, as well as greater participation of men in childcare and reduced conflict between couples.

Further info: [Journeys of Transformation, CARE and Promundo, Rwanda](#)

Engaging men and boys through CARE Farmer Field and Business School. The model uses a focus on increasing productivity and marketing to work with men and leaders who can facilitate positive changes for women farmers. They are trained in modules designed to create awareness on workload burden/time-use, access/ownership of resources, household decision making and gender based violence.

Further info: [Pathways to Secure Livelihood Program, CARE, Bangladesh, India, Malawai, Tanzania, Mali and Ghana](#)

Careful sensitisation and timing considerations. ActionAid ran a women's economic empowerment program in Malawi and started by holding sensitisation meetings in the community, engaging community leaders and men who learn about the planned activities. They only approached women directly *after* the whole community was aware. As a result men felt comfortable with their wives participating. In order to fit the activities around women's unpaid care work, the meetings were held in the afternoon at a time best suited to the women, and only took place weekly for about two hours, so that only limited additional time was required of women.

Further info: [ActionAid, Women's Economic Empowerment in Malawi](#)

DISASTER RISK REDUCTION

- Unpaid care work has a disproportionate impact on the time women have available to lead their communities in reducing disaster risks and building resilience. These time limitations may be increased when a caregiver or their child has a disability.
- Where women, including women with disabilities, are included in DRR efforts they are often limited to caregiving and other stereotypical roles.

Enabling women's leadership in disaster risk reduction.

ActionAid has found that unpaid care work is one of the most significant barriers to women's participation and leadership in disaster risk reduction activities. Part of their work addressing this includes raising awareness in communities by helping women and men create and share 'time diaries' and encouraging dialogue between women and men including with traditional community leaders. A number of case studies are available with practical examples of how this might be done in different settings.

Further info: [Actionaid, DRR and women's leadership in Bangladesh, Nigeria, Malawi, Nepal, Vietnam](#)

Engaging men as ambassadors – using drama to engage other men, leaders, law makers, government officials. ActionAid mobilises women farmers in Malawi to form groups advocating for policy and resources that address the hazards they face as a result of climate change. Through some reflective work, one group realised that climate change was increasing the burden of unpaid care work: water points drying up meant that women had to walk further and increased hunger was increasing violence against women in households.

Rather than advocate alone, the group joined with a group of men who agreed to be ambassadors, championing the freedoms of women and challenging unpaid care burdens. The men used drama to interact with fellow men, boys, traditional leaders, law makers and government officials. Traditional leaders were also engaged, ensuring that the cultural and traditional belief enshrining women's roles change.

Further info: [ActionAid, Working Alongside Men in Malawi](#)

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