

SOCIAL INCLUSION OF PERSONS WITH DISABILITIES IN THE NORTHERN CHARs (RIVER ISLANDS) IN BANGLADESH: FRIENDSHIP'S EXPERIENCE

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Abstract

The riverine northern 'Chars' (river islands) of Bangladesh are not static & have minimal connectivity with mainland areas. Superstition, lack of education, lack of infrastructure and adverse climatic conditions make life difficult for the inhabitants in these hard to reach areas where persons with disabilities are far behind to get their citizen rights and live a dignified life. Still they are excluded from mainstream activities and basic services due to remoteness, such as – health, education, livelihood, empowerment, social safety schemes etc. offered by the government and other non-government service providers. With the aim to improve the living condition of persons with disabilities in chars, Friendship Inclusive Citizenship launched a pilot project with support from the Ineke Feitz Stitching & Friendship Netherlands in 15 chars of Gaibandha and Kurigram in 2020. Friendship is implementing the 'Community Based Rehabilitation (CBR)' approach through sensitization, need-based therapeutic interventions, assistive devices, build capacities of caregivers/community volunteers/staff, form self-help groups (SHG) of persons with disabilities, inclusive education, livelihood training, referral and advocacy with local and national level stakeholders. Positive changes started to get visible around awareness among communities to realize their roles/responsibilities towards persons with disabilities, rights and available services for persons with disabilities etc. Persons with disabilities are receiving disability cards, allowances, assistive devices and therapies at government disability service centers with support from Friendship. Children with disabilities are enrolling in mainstream schools, SHGs are learning advocacy & leadership skills and govt. authorities are realizing their roles to serve these people in chars. These interventions are empowering persons with disabilities in remote chars to get their rights and services through concept of "Reaching the unreached" and "Leave no one behind".

Keywords: inclusion, CBR, disability, mainstream, hard to reach, rights.

Introduction

In the riverine northern region of Bangladesh, the 'Chars' (river islands) stand as witnesses to the intricate tapestry of challenges faced by communities residing in these isolated realms. One billion people, or 15% of the world's population, experience some form of disability and disability

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prevalence is higher for developing countries. In Bangladesh, 4.62 million people, which is 2.8% of the total population, have at least one disability (Ref: Preliminary report of the “National Survey on Persons with Disabilities (NSPD) 2021” Published in June 2022 by Bangladesh Bureau of Statistics (BBS)). According to the survey, Persons with Disabilities have fallen behind at alarming rates in access to health care, education and employment. In the present scenario, the number of persons with disabilities seems to grow and so the Government has also started encouraging NGOs like Friendship that plays a proactive role in offering the necessary opportunities in empowering this nascent group.

This paper delves into the multifaceted intersectionality of climate impact, geographical remoteness, and disability-related issues within the context of Bangladesh. Specifically, we explore the complex nexus of adversities faced by marginalized communities residing in the Chars and the glaring disparities in the provision of essential services, particularly for persons with disabilities. This paper highlights the specific interventions of Friendship NGO to improve the lives of persons with disabilities with a specific focus on safeguarding the rights of persons with disabilities as active citizens of the nation.

The Chars, characterized by their dynamic nature and minimal connectivity with the mainland, present a unique set of challenges that extend beyond the conventional scope of development interventions. Superstitions entrenched in local beliefs, limited educational opportunities, insufficient infrastructure, and the harsh reality of adverse climatic conditions collectively contribute to an arduous existence for the inhabitants of these hard-to-reach areas.

This paper sheds light on the pervasive marginalization experienced by persons with disabilities in these riverine communities. Despite the global discourse on disability rights and inclusivity, individuals with disabilities in the Chars are confronted with substantial obstacles in realizing their fundamental rights and leading dignified lives. The remoteness of these areas acts as a formidable barrier, impeding access to essential services such as healthcare, education, livelihood opportunities, empowerment initiatives, and social safety schemes provided by both governmental and non-governmental entities.

Our exploration emphasizes the urgent need to bridge the existing gaps and rectify the systemic neglect that perpetuates the exclusion of persons with disabilities from mainstream activities. As we navigate the complex interplay of climate change, geographical isolation, and disability-related challenges, we aim to illuminate pathways towards more inclusive policies, comprehensive support systems, and targeted interventions that can uplift and empower the marginalized communities inhabiting the river islands of Bangladesh. Through this conference proceeding, we aspire to

contribute to a nuanced understanding of the intricacies involved and advocate for transformative initiatives that strengthen resilience, inclusivity, and dignity for all, irrespective of geographical constraints and physical abilities.

Materials and Methods

The innovative interventions

The riverine northern Chars of Bangladesh are characterized by their dynamic nature and limited connectivity with mainland areas. Life in these regions is compounded by superstitions, a lack of education, and adverse climatic conditions, creating formidable challenges for the inhabitants. Unfortunately, individuals with disabilities find themselves particularly disadvantaged, often perceived as burdens and facing ostracization, making the maintenance of dignified livelihoods an ongoing struggle. Recognizing these hardships, Friendship has undertaken a commitment to enhance the lives of people with disabilities in the Northern Chars.

In June 2020, the Friendship Inclusive Citizenship (IC) sector initiated the project, "Improving the Lives of Persons with Disabilities in the Northern Chars of Bangladesh" in the Char areas of Gaibandha and Kurigram districts. With support from Ineke Feitz Stichting (a Dutch donor agency) and Friendship Nederlands, the project aims to elevate living conditions, alter community behaviors towards persons with disabilities, and, crucially, bolster the self-confidence of individuals facing disabilities. Despite the challenges posed by the devastating COVID-19 pandemic, various activities have been introduced in the project areas.

The nationwide lockdown, implemented by the Government from mid-March 2020 and extended in phases until March 2022, significantly impeded project activities and service delivery to the community. However, the project team perseveres in its relentless efforts to enhance the integration of persons with disabilities in society and transform negative attitudes within the community. The team firmly believes that the project's activities will enhance the quality of life for people with disabilities, spanning education, employment, health, housing, and social inclusion.

To realize the project objectives, the team has adopted a community-based rehabilitation and community-based inclusive development approach. Tailored to the needs in health, education, livelihood, information accessibility, safety schemes, policies/acts of government, local government circulars/orders, referral services, awareness, and self-advocacy of self-help groups, the project seeks to bridge gaps and offer need-based solutions for persons with disabilities who often face neglect in receiving inclusive services in the Chars.

Simultaneously, the project employs a twin-track approach of community-based rehabilitation, emphasizing the value of lived experiences, participation, and capacity building in mainstream socio-economic activities to empower vulnerable individuals with disabilities in the Char areas. Friendship strives to create pathways towards inclusivity, acknowledging the unique challenges faced by persons with disabilities in these neglected regions.

The project design is intricately aligned with the principles of Community-Based Rehabilitation (CBR), a framework introduced by the World Health Organization (WHO) in 1978. This approach serves as the cornerstone to uphold and safeguard the rights of persons with disabilities, ensuring their active participation and inclusion within the community. In consonance with the international standards, particularly the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the project design places a paramount emphasis on promoting the inherent rights, dignity, and full participation of individuals with disabilities.

Furthermore, the project aligns itself with the Rights and Protection Act of Persons with Disabilities 2013, a pivotal legal framework in Bangladesh that sets out to protect and promote the rights of individuals with disabilities. Acknowledging the diverse needs within the disabled community, the project also adheres to the Rights and Protection Act of Persons with Neuro-developmental Disabilities 2013 in Bangladesh. This inclusive approach underscores the commitment to addressing the unique challenges faced by individuals with neuro-developmental disabilities and ensuring that they receive the necessary support and protection mandated by the legal framework.

By integrating these international and national standards into its design, the project aims to create a comprehensive and inclusive model that not only respects the rights of persons with disabilities but actively works towards their empowerment, social integration, and overall well-being. This alignment with established frameworks reflects a commitment to a holistic and rights-based approach, enhancing an environment that promotes equality, inclusivity, and the full realization of human potential for all individuals, irrespective of their abilities. The objectives of the project are:

1. To sensitize and aware persons with disabilities, family members/caregivers, communities, local level government and other stakeholders.
2. To build the capacity of persons with disabilities, family members and caregivers, community volunteers and project staff on social inclusion of persons with disabilities, community-based rehabilitation approach.

3. To facilitate advocacy initiatives at local level and national level to promote services for persons with disabilities at hard-to-reach climate impacted chars.
4. To provide need-based physiotherapy, medical treatment, therapeutic interventions and assistive devices to the children and persons with disabilities.
5. To execute smooth operation and implementation of this project through appropriate monitoring and supervision

Situation Analysis

To explore the actual number of persons with disabilities in the northern river islands (chars) of the Friendship Inclusive Citizenship sector's working areas (79 selected chars of Gaibandha and Kurigram districts in Bangladesh), a comprehensive household survey was conducted during the reporting period from July 1, 2020, to December 31, 2022 under the disability inclusion project. The survey covered a total of 20,997 households across 79 chars, providing a detailed snapshot of the socio-demographic landscape. Within this extensive survey, 3,397 persons with disabilities were identified, including 819 children with disabilities. The project aimed to deliver inclusive services tailored to the specific needs of these individuals, and throughout the pilot phase, approximately 41,250 people (direct and indirect beneficiaries) in total received such services.

During the initial household listing phase, 3397 people were identified as having different types of disabilities. However, a crucial refinement occurred when the project team, comprising physiotherapists and trained community volunteers, conducted a community-based individual screening of disabilities. This screening revealed that some individuals had minor issues not qualifying as disability conditions (254), while others, previously unidentified, were found to have actual disabilities, particularly among children and the elderly (153).

The methodology employed in this survey not only aimed at quantitative data collection but also sought to capture the nuanced realities of disability within the community. Through this meticulous approach, the project strived to create a more accurate and comprehensive understanding of the prevalence and nature of disabilities in the Char areas. The survey results form a crucial foundation for evaluating the project's impact on the lives of persons with disabilities and will contribute valuable insights to the ongoing efforts to enhance inclusivity, dignity, and hope in these marginalized communities. The collaborative support from both the Government and local communities has been instrumental in the successful implementation of this methodology. The project embraced a Community-Based Rehabilitation (CBR) approach (of World Health Organization, 1978), engaging

the community in addressing the diverse needs of persons with disabilities. By promoting inclusivity, enhancing awareness, and fostering self-help groups, CBR served as the cornerstone for empowering individuals and creating a supportive environment. This methodology prioritized a grassroots perspective, ensuring sustainable development and lasting impact within the riverine communities of the Chars.

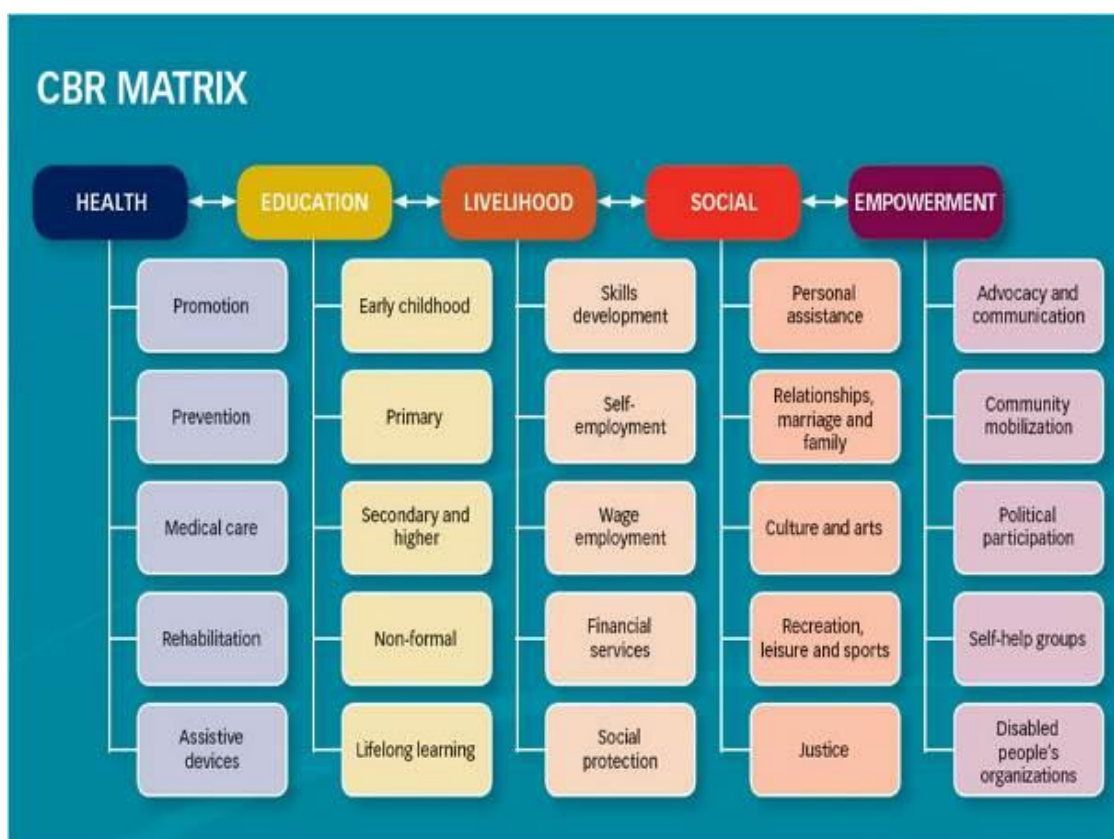


Figure 1: CBR matrix (WHO 1978)

Project Beneficiaries

In this project, the Friendship Inclusive Citizenship sector has considered all types of persons with disabilities to contribute to the Sustainable Development Goals (SDG) which is “No one lives behind” while providing need-based services to all types of persons with disabilities (regarding age, gender, socio-economic condition, religious believes, geographical vulnerabilities to consider hard to reach areas and hard to reach people). The project beneficiaries are: a) Primary beneficiaries: Children and adolescents with disabilities, Adults with disabilities and Self-help groups (SHG) of persons with disabilities (52 groups); b) Secondary beneficiaries: Parents, Family members/caregivers, Youth groups, community people (teachers, elderly people, religious leader, char people) and Local

government and other stakeholders, such as local Union Parishad members (smallest unit of local government), Officials of national foundation of Disabled Development under the Ministry of Social Welfare, Social services office, officials of education office, others service provider/referral agencies etc.

Specific Interventions in Details

Through this project, we endeavor to create an enabling environment that nurtures individuals with disabilities, self-help groups comprising persons with disabilities and their family members. This initiative aims to address common problems, correct misperceptions, and enhance individual strengths, ultimately nurturing a life filled with dignity and hope while improving overall quality of life. The pilot phase of the project has covered the reporting period from July 1, 2020, to December 31, 2022, and has garnered substantial support from both the Government and local communities. Notably, several innovations were implemented in response to popular demand and Government suggestions during this reporting period, amplifying the project's impact. A noteworthy example is the establishment of a Disability-Friendly Corner at the Government's Disability Service Centre in Gaibandha and Kurigram. Under this pilot phase, Friendship has undertaken various activities to fulfill the project's targets:

- **Self-help Group Sessions:** A total of 53 groups are functioning and conducted 1,002 fortnightly sessions with the support of persons with disabilities and their caregivers. Most of the implementing char areas are not static and change the geographical pattern in every flash flood. This is one of the obstacles in providing smooth quality services to persons with disabilities due to mobility issues. It is also difficult to gather people with disabilities and their caregivers in one place considering their time and access. However, for this project, it is important to gather persons with disabilities and their caregivers to disseminate awareness and rights related information for living dignified life. Keeping that in mind, the team formed a special group for persons with disabilities named "Self-help Group" (SHG), aiming to resolve common problems, enhance their strengths, and access their rights from the state and other concerned places. Initially, the project team developed one group with the support of all selected persons with disabilities and their caregivers at each char, but the members' presence in the group meetings was not up to the mark. The project team figured out that if they consider more groups instead of one group in a large char, then it will create more impact as it will give more access of persons with disabilities to be regular in the SHG meetings and they can easily come to the nearest groups. Based on this concept the team members formed 4-5 groups per char with at least 5-7 members so that the persons with disabilities do not have to take the trouble of regular movement. This was a good

idea which is properly working. The project team regularly reformed the groups based on their demand and now 53 groups are functioning at 15 chars.

The topics shared within the SHG group sessions are:

- i. Demonstration of disability issues and optimal behavior towards them.
 - ii. The treatments and care for persons with disabilities.
 - iii. Discussion on the precautions during pregnancy so the child will not get harmed during or after the delivery.
 - iv. Educate the group members on the available services from the Government and other institutions.
 - v. Disseminate knowledge and skills that enable them to become contributors to their families and communities.
 - vi. Engage the group members in a participatory way - getting help, sharing knowledge and experience, giving support, and learning to help oneself.
 - vii. Enabling the environment related to inclusiveness among the family members and the community.
 - viii. Highlight the importance of personal hygiene and living conditions for persons with disabilities.
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- **Friendship Community Youth Group (FCYG):** A total of 225 members are active under 15 groups and participated in the 284 sessions, mobilized to raise awareness for sustained bottom-up development in the coming days.
 - **Civil Society Groups:** Friendship has set up Civil Society groups playing a guardian role at the community level and conducted 203 sessions on the rights of persons with disabilities that have helped improve the environment for them at community level.
 - **Community Volunteer activities:** Community volunteers have been selected from each community and 15 members were active during pilot phase. They are working on distributing information, education, and communication materials. Friendship connects and brings together persons with disabilities and their caregivers to learn and grow as self-sufficient people. Through disseminating behavioral change communication materials, Friendship creates awareness in the communities to alter approaches toward persons with disabilities for the better. The community volunteers have been prepared and mobilized for regular household visits on personal hygiene, social safety, and better inclusion in the family unit for disabled persons through 8929 visits.
 - **Char Theatre Activities:** Two Char Theatre teams performed in 164 shows at the community level. During the COVID-19 pandemic situation team also short drama 8-10 minutes duration and

the duration of regular drama is 40-45 minutes. The char theater concept has created mass awareness among the char communities towards the rights of persons with disabilities among their families, communities and awaken the community and local level government authorities towards their roles and responsibilities to establish the rights of persons with disabilities within their community level.

- **Government Disability Identification Cards for Persons with Disabilities:** A total of 293 registration processes were completed for the "Shoborna Nagoric Card" (Golden Citizen Card provided to the persons with disabilities by the Ministry of Social Welfare) - a card issued by the Government providing a monthly allowance is BDT 850 per persons with disability under the Social Safety Net Programs of the Government of Bangladesh. In this project, a total of 96 persons with disabilities living in the disconnected chars (river islands) are receiving disability allowance per month from the government by the initiatives of this project.
- **Adult Learners' Group formation:** This group is formed at community level. Each char has 100 members in these groups, and they arrange fortnightly sessions. During these sessions, the disability issues are discussed by the Disability project staff. During the project period, a total of 646 sessions were conducted where disability issues were discussed.
- **Information, Education and Communication (IEC) and Behaviour Change Communication (BCC) Materials:** The project developed two flip charts on disability issues and was regularly used during community sessions e.g. Self-help, youth group, adult group etc. Also, 10 billboards have been established in different prominent places in Gaibandha and Kurigram districts, such as the Social Welfare department office premises, District Disability Center, Balashi Ghat, Upazilla Office, Union Parishad Office, etc. where different target stakeholders can get the information about the rights of persons with disabilities living in the chars easily.
- **Sign Language Training:** As part of a comprehensive approach to such initiatives of the project towards persons with disabilities, Friendship has initiated sign language learning for hearing and speech impaired persons and their family members in the chars.
- **Physiotherapy services:** To help people with physical disabilities, Friendship offers physiotherapy services such as door-to-door physiotherapy, physiotherapy on referral, and distribution of assistive devices. Physiotherapist services paid a total of 2,702 door-to-door services.
- **Referral services:** 184 referrals have been forwarded with financial support, and 493 referrals have been managed without financial support e.g. regular physical checkup, customize assistive device, physiotherapy services, filaria treatment, eye treatment, medical certificate collection from government health complex, which required for disability card etc.

- **Arranged Assistive Devices:** A total of 51 customized assistive devices arranged for the persons with disabilities. Also collected another 23 assistive devices from government departments including wheel chairs, white cane etc.
- **Eye Treatment:** A total of 5 eye screening camps arranged with support of Friendship Health Sector and collaboration with other NOGs. A total of 478 people received the preliminary services and 183 patients directly received the advanced services including 54 free of cost cataract surgery.
- **Arranged Joint Physiotherapy Camps with the Support of Government Disability Service centres (National Foundation of the Disabled Development):** A total of 7 physiotherapy camps organized jointly by Friendship and the Government Disability Service Centres through their Mobile Physiotherapy Van at Kurigram districts where 453 patients from the chars received intensive services.
- **Inclusive Education:** The children with disabilities, after receiving need based therapies, some of them became capable to go to nearby schools (Friendship Education sector's schools) in disconnected chars. Whereas, in the chars which are connected to mainland, the children got enrolled in the nearby government primary schools. Altogether, 9 children with disabilities were enrolled in schools under this project.
- **Capacity Building Training:** 70 persons with disabilities/caregivers received capacity-building training on crafts making as a part to build their capacity on income generating activities from the project, so they can engage themselves in the income generation and earn by themselves and lead a quality life. The trainees have been connected to organizations that will be buying their handicrafts. These were the 15 days long training.
- **Establishment of Disability-friendly Toilets:** Friendship built disabled-friendly toilets in Friendship school premises and homes to address sanitation concerns of physically challenged persons and children at char Jatrapur in Kurigram district. These toilets are in school premises to motivate parents, teachers, other non-disabled school children and community people to be aware on the needs of adapted toilets and its usage. The project is working on to adapt more toilets which are under process of completion.
- **Government Collaboration:** Another landmark achievement of the project is the collaboration of Friendship with the Government of Bangladesh in setting up the Friendship disability corner at the premises of the Government Disability Services Centres of Gaibandha and Kurigram. These corners will provide therapeutic services to the beneficiaries with the needed physiotherapy and occupational therapies as well as speech therapy, play therapy etc.

The rights-based approach and inclusion of persons with disabilities within their own community through implementation of the ‘Community Based Rehabilitation (CBR)’ is implemented at the most vulnerable, climate impacted marginalized chars of northern Bangladesh.

Results and Discussion

The project has resulted in a tangible and impactful transformation, adopting inclusive communities and significantly improving the lives of persons with disabilities in the Chars through targeted interventions, advocacy, and collaborative initiatives. The major result and impact are described here -

By implementing the above mentioned activities, the project has sensitized and created positive awareness among the char based communities and made them realize their roles and responsibilities towards the persons with disabilities living with them in their community, their rights, the services offered by the government for the persons with disabilities and how to get these services, how the community people and youths can come forward to support the persons with disabilities by pair to pair method, how they can support the SHGs so the inclusion of the persons with disabilities can be established within their community where no one will leave behind in any development initiatives. As a result of the awareness activities now parents/caregivers and society members are encouraged to enroll the children in the mainstream educational system e.g., Friendship and Government schools.

The project has established good rapport with local-level government agencies at district and sub-district level, with union parishads (the smallest unit of local government power structure) and enabled the collaborative approaches to work together by sharing and exchanging support to provide services for the persons with disabilities living in the chars. Now these people have started receiving services from the local government through the support of project staff and referral services. Persons with disabilities and their caregivers are now aware about safety support and receive information on how they can collect the support by themselves.

Through the above-mentioned activities, the capacity of persons with disabilities, family members/caregivers, community volunteers, char theater artists, project staff, and Friendship head office based project team were built and developed to strengthen the project implementation and monitoring appropriately following the concept of CBR and community-based inclusive development. The team still needs more training and information on different types of disabilities and innovations for better implementation of need based services at chars, such as – more concrete knowledge on different types of disabilities, how to support them in daily living activities and independent movement, how to organize SHGs, how to build leadership of the SHG leaders, sign language and

Braille, inclusive education, income generating activities of persons with disabilities/SHG/family members, support them in production and market linkage etc.

The project has provided need-based physiotherapy services, assistive devices, eye screening services for the char based children and persons with disabilities. Now people are willing to disclose their family members' disabilities or problems with project staff not only physiotherapists even discussed with community volunteers which was unusual before implementing the project activities. Also, family members want to share financial contributions for accessing the referral centers as well as. The family members and caregivers realized the benefit of treatment for persons with disabilities and this is the one of major changes of people's perceptions. Based on regular sessions the family members do their best to improve the living environment for the persons with disabilities. Still, there are limitations and challenges to providing all the need based services, which need to be addressed with more emphasis.

Conclusion

The project meticulously adhered to the comprehensive Community-Based Rehabilitation (CBR) framework, strategically integrating key components to address the holistic needs of persons with disabilities. In the realm of health, the initiative facilitated door-to-door physiotherapy services, eye screening camps, and specialized clinics, ensuring access to vital healthcare. Education initiatives were spearheaded through adult learners' groups, fostering regular discussions on disability issues, while livelihood advancements involved capacity-building training, skill development, and the arrangement of assistive devices.

Moreover, the project actively promoted social rights, orchestrating awareness campaigns, and securing government cards for persons with disabilities, thus ensuring their monthly allowances. The empowerment dimension was embodied through the establishment of self-help groups, Friendship Community Youth Groups, and Civil Society Groups, nurturing collective strength and advocating for sustained bottom-up development. By aligning with all facets of CBR, the project aimed not only to enhance the individual well-being of persons with disabilities but also to create enduring positive changes within the fabric of their communities in the riverine Chars of Bangladesh.

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