

Transforming Lives

Rehabilitation and Inclusion of
People with Disabilities in District
Skardu, Gilgit-Baltistan

2012

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PREAMBLE

“The caged bird sings
with a fearful trill,
Of things unknown
but longed for still,
And his tune is heard
on the distant hill,
For the caged bird
sings of freedom”

The quatrain above is an extract from Maya Angelou’s classic poem “I Know Why the Caged Bird Sings”. An African-American in the 1960s, Maya lived in Arkansas, America in a society so completely segregated that Maya believed white people to be a myth: imaginary and non-existent. As Maya grew up, she experienced racism at the hands of the white population of the state so much so that she assimilated the idea that blonde hair is beautiful and her black skin was a curse.

The verses above encapsulate her feelings; the bird represents Maya and the cage, the trap that she had gotten stuck in as a child. While racism and disability are two mutually exclusive concepts, they overlap at one significant aspect: societal exclusion. Ostracized by society, persons with disabilities bear much similarity to Maya’s caged bird, waiting to be freed from the societal and personal cages built around them.

The social segregation between persons with disabilities and those deemed to be ‘normal’ has a two-fold impact. This isolation from society forces them to remain within the confines of their comfort zones: their homes. These restrictions further shatter their self-confidence inhibiting them from putting their skills and talents to good use. It is overcoming this lack of confidence rather than the disability which is a major obstacle for them.

This set of case studies have been written as part of Rehabilitation and Inclusion of People with Disability project and provide a snapshot into the struggles and successes of persons with disabilities in district Skardu, Gilgit-Baltistan. The stories of each of these individuals represents the growing need for an understanding of the mobility and accessibility issues experienced by persons with disabilities.

It is undeniable that each person with disability that forms part of this booklet is an asset to society with untapped potential, a caged bird singing of freedom, waiting to be released from its captivity. The studies illustrate that alongside helping persons with disabilities, there is a great need to change societal attitudes. It is important for the society to empathize with these people, treat them as a part of the society and assist in their inclusion.

Then only can the caged bird truly taste freedom.

LIVELIHOOD FIGHTING FOR WORTH

Set in Thorgu Pine, Hussainabad, Fatima is seen stumbling across the house struggling to complete her daily chores. She looks out of the small window above the stove to where her husband, Haji Yusuf, is working on the one-kanal strip of land

growing potatoes which would later be cooked for dinner. He looks up at her their gaze meeting for a split-second, heaves a sigh, shakes his head and goes back to work. Fatima looks away, the familiar bitter feeling of worthlessness setting in.

| Fatima Yusuf | |
|----------------------|---|
| Village | Thorgu Pine, Hussainabad |
| Gender | Female |
| Age | 45 |
| Disability | Muscular Dystrophy |
| Interventions | Medical assessment; disability certificate; walking frame; accessible washroom; enterprise. |

Fatima was hit by muscular dystrophy at 18 which had managed to wear her down both physically and emotionally. With a waddling gait, poor balance and frequent falls, Fatima had struggled through life to satisfy even her most basic needs. The six-step wooden staircase in her house leading to the squat latrine posed a constant challenge, one which she could not afford a solution for. The Rs. 4,000 pension her husband earned was hardly enough to make ends meet.

Her disabling condition and economic worries had added wrinkles to her face that deceived her age. At 45, Fatima looked and felt much older. Even her husband did not have much solace to give to her. He said, "She would walk like a goat. We had never thought she was worth anything else." When CHIP had identified her through the local organisation Development and Welfare Association (DAWA), she could not have fathomed exactly how much she could accomplish with just a little assistance.

After a few assessments of her health conditions and disability, CHIP provided her with physiotherapy services and as her condition improved, with a walking frame. CHIP also built her an easy to use toilet for Rs. 47,000, with Yusuf contributing partially towards the money required for construction works. CHIP knew that that the interventions had been successful when a gleeful Fatima commented, "I was so eased by the new toilet! You know how difficult it was for me before."

But Fatima's success story does not end here. So far CHIP had only given her a fish to eat; the actual fishing lesson had not even begun. This was crucial if she was to be able to rise above those feelings of worthlessness and attain financial independence. For this end, CHIP orientated her in basic hygiene and accountancy skills and provided her with Rs. 10,000 while she pitched in Rs. 2,500 to set up a retail shop mostly selling children's goods. Fatima has been running the shop for the last one year.

Fatima initially expressed anticipation over the running of the shop but her business womanly attitude and assistance from her husband has allowed her to reap back Rs. 100 in profit every day. Her husband buys merchandise from Skardu city wholesale market. Fatima has been reinvesting the savings back into the shop claiming that the more items she has to sell, the better. The shop walls have been lined with health posters made by her daughter Maryam. CHIP has trained her as an on-call birth attendant. She has performed four deliveries and holds three health sessions a month for women of the area.

LIVELIHOOD COLOURFUL OBLIVION

It is said that the worst nightmares are those that you cannot wake up from. Nargis sits on a frayed charpoy staring blankly into a permanent oblivion reminiscing the last time she saw colour in her life. Chirpy

laughter, clanking of metal pots, the slither of sparks, a scream and she snaps to life. But even though the nightmare is just a part of her memory, its effects, unfortunately, are to last a lifetime. The sparks from the stove fire, forty years ago, have left her blinded for life.

As a fifty year old woman, Nargis had resigned to a squalid room in Hussainabad completely giving in to her disability. Even though the 700-household village that she called home had been installed with water supply and sanitation systems, the quality of life that Nargis lived was appalling. That is, until CHIP identified her through the local organisation Development and Welfare Association (DAWA).

CHIP worked to improve both: her quality of life in terms of health and hygiene; and her economic standing. After orientating her in basic personal hygiene, she was taught how to walk with a cane so that she as to integrate her into the society around her. CHIP also helped her to set up her own Nargis Poultry Shop which is fully run by her and provides a regular source of income for her family.

The shop, albeit a small mud-block facility, is well maintained with good hygienic standards. It has a capacity of 20 birds which are all reared and fed by Nargis herself. A male community mobilise regularly visits the shops to check if there are any problems being faced in the general running of the shop. The community mobiliser is also responsible for arranging a poultry doctor's consultation appointment.

What is even more commendable is that she can now recognise the denominations of the currency notes and can count them easily. Therefore, whether it involves storing or selling eggs or calculating her costs and profits, Nargis now refuses to let her disability to hamper her from making her small business a success.

Overcoming her disability has instilled a sense of pride in Nargis. Her voice emanated a new found confidence when she said, "I am able to sell about four dozen eggs a week. On average I earn about five hundred rupees a week. Isn't it better than being glued to my charpoy?"

It really is, Nargis. It really is.

| Nargis | |
|----------------------|--|
| Village | Hussainabad |
| Gender | Female |
| Age | 44 |
| Disability | Permanent visual impairment |
| Interventions | Orientation in basic health and hygiene; walking cane; poultry shop. |

LIVELIHOOD STITCHING BACK THE PIECES

As a child hit with polio, Zaheer Ali wished he could leave the confines of his house in Astana Bala and go out and play. As an 18 year old, things had not changed; his condition was so severe he had to rely on other people to move around. To add to his physical woes, his tailor father was wracked with financial worries. His inability to contribute to the running of the household would only serve to aggravate his frustration.

| Zaheer Ali | |
|----------------------|--|
| Village | Astana Bala |
| Gender | Male |
| Age | 22 |
| Disability | Poliomyelitis |
| Interventions | Medical assessment; disability certificate; wheel chair; washroom, house and street made accessible; self help group; community based organisation member. |

“It was so belittling to be so dependent on others around me for even the smallest of things. It was depressing; my confidence was shattered; I had given up hope. Little did I know, things were about to change!” Zaheer commented with the slight slouch in his posture as he reminisced about his past struggles. It seemed as if as if simply thinking about them upset him. But as the saying goes, all’s well that ends well.

CHIP identified Zaheer through a social welfare society based in Kushmarah Gondh. After a medical assessment was provided with a wheel chair and his washroom, house and street were made accessible for him. These measures allowed him to move freely without being dependent on others. He was also given a disability certificate to allow for social inclusion. These were one of his first steps towards achieving self-confidence.

As a part of the social inclusion programme, Zaheer was made part of a self help group and a member of a community based organisation. This helped him regain his lost confidence as he interacted with others like him and voiced his opinion in communal decisions. But the main reason Ali gained credence in society was because of his tailoring skills.

Falling into his father’s footsteps, Zaheer was trained in tailoring and CHIP helped him set up a shop in the Clifton Market which is the main shopping area in village. The fact that he is now capable of running the house himself without his father exerting himself is a great boost to Zaheer’s self-esteem. His success is evident with the progress he has made: he is able to save Rs. 400 a day and has only recently married off his sister.

It is morning; Zaheer can be seen riding his tricycle to work, only about half a kilometre from home. Unknown to those who wave at him, he is thinking of the time when he would be locked at home waiting for the time when he would be able to move out of the house without asking one of his three brothers to support him. But he quickly brushes aside any such thoughts, straightens his back and enjoys the morning breeze as he cycles to his newly found independence.

EMPOWERMENT CRIPPLING THE DYSTROPHY

Out in the early hours of the morning, the sky is still pink when Jaafar Ali, 18, can be seen boarding the public minibus from his house in Hasan Colony. A few minutes later, he steps off the bus and makes his way on foot to his office. He works hard in a government office and returns home by afternoon with his daily wages in hand. He spends the rest of his day either studying or reading for leisure.

| Jaafar Ali | |
|----------------------|---|
| Village | Hasan Colony |
| Gender | Male |
| Age | 18 |
| Disability | Poliomyelitis |
| Interventions | Medical assessment; disability certificate; assistive device; computer skills; self help group member; Disabled Persons Organisation executive body member. |

It all seems like a snapshot of the life of an ordinary man but alas, that is not the case. Jaafar was struck with polio as a child when he lived with his family in Karachi. With his own determination and his family's support, Jaafar continued to attend school. The financial difficulties his labourer father had to face in educating Jaafar and his siblings only added to the family's miseries.

But the story is not all bleak. CHIP identified Jaafar through a community based organisation. A community used to visit him four times a week to orientate on hygiene. The community mobiliser also served to act as his counsellor, boosting his morale and encouraging him to pursue his education. To ease the pain of his disabling condition, Jaafar was given an assistive device and a toilet chair.

Furthermore, to boost his employability, CHIP trained him in computer training. CHIP's successful efforts are evident in the manner in which Jaafar speaks about his future plans. "I am inspired. I feel like there is hope again and this time, my disability will not bring me down. I will continue my education and work hard," he said, his words emanating a fervour and confidence that had not existed before.

Jaafar has also decided to use his experiences and help other disabled people as well. He is an executive body member of a local Disabled Persons Organisation. The DPO is registered with Nawabshah Disability Forum. Jaafar acknowledges that there have been frequent polio vaccination campaigns in his area. He hopes the anti-polio drives will result in reduction of the incidence of the crippling disease.

It is remarkable how Jaafar has managed to normalise his life despite his crippling condition. He serves as a model of determination for all those disabled individuals who have lost hope.

According to Islamic principles, it is prohibited to eat with your left hand.

In a society steeped in dogmas and tradition where Islam is used as an excuse to point fingers at others rather than to improve our own way of life, it was absolutely unacceptable that Ghulam Nabi would eat

with his left hand. It went completely unnoticed that Ghulam Nabi's disability had left him paralysed in his right hand and foot. Thus, it comes as no surprise that people in Chundah were offended by Ghulam Nabi's blasphemous ways.

"I had little value in society; people just did not bother to acknowledge my presence," Ghulam Nabi recalls. He was hit with polio at a tender age and despite having matriculated had no job. CHIP identified him through a local organisation Anjuman-i-Falah-i-Aama Haidaria and after a medical assessment helped him acquire a disability certificate. He was further given training in hygiene, sign language, record keeping and inclusive teaching methodology.

CHIP also helped him open a tuck shop which provides a regular source of income for his family including his wife and child. With his determination, it is not surprising that he managed to pass his FA exams and as a 27 year old, is working as a community teacher as well. Describing his job he says, "I teach people how to keep themselves clean and healthy and make them realise how important it is to cooperate with others and make them feel welcome," his passion for his work emanating in his voice.

Alongside pursuing his education and a stable career, Ghulam Nabi is also doing much to further support for people with impairments. He is an executive body member of the local organisation through which he was identified, the vice president of an organisation for people with disabilities and president of the health committee under CHIP's Health Strengthening Project.

It is amazing that his list of community development activities and achievements does not end here. Having been socially ostracised most of his life, Ghulam Nabi is trying his best to ensure that others with his condition do not suffer the same fate. Despite his crippling condition, he is a member of a cricket team and also a member of the group that arranges theatre performances for creating awareness among people about the importance of inclusivity.

| Ghulam Nabi | |
|----------------------|--|
| Village | Chundah |
| Gender | Male |
| Age | 27 |
| Disability | Poliomyelitis |
| Interventions | Medical assessment; disability certificate; tuck shop; teaching job; community based organisation executive body member; self help group member; Disabled Persons Organisation vice president. |

EMPOWERMENT**GIVING BACK**

“Life takes some strange turns doesn’t it? I had always been very active and my disease came as a huge shock for me and my family. I was depressed and smoking provided a leeway for me to while away the foreboding sense of helplessness that had overcome me. It was a difficult time for me, especially the initial years. It was difficult to register that something like this could happen. I could see the disbelief in my father’s eyes too,” Akbar Ali said.

| Akbar Ali | |
|----------------------|--|
| Village | Shot Qumrah |
| Gender | Male |
| Age | 40 |
| Disability | Rheumatoid Arthritis |
| Interventions | Washroom and house made accessible; self help group member; Disabled Persons Organisation president. |

It is strange, indeed. At 40, Akbar Ali seems like the last person that could be diagnosed with rheumatoid arthritis. After completing his graduation, he started working as a sub inspector with the Airport Security Force. It was then that he started experiencing bouts of pain in his joints. He began to walk stiffly and the aches and swellings he experienced returned and subsided. He tried to work his way through it but as the pain became unbearable he consulted therapists and he was eventually diagnosed with the disease.

Upon identification, CHIP wanted to channel Akbar’s skills in the right direction. It encouraged him to put his education to use instead of wasting his capabilities. To improve Akbar’s accessibility, CHIP built him a ramp so as to allow him to easily drive his wheelchair in and out of his home in Shot Qumrah. A special toilet was also built for him at his home.

Currently, Akbar Ali is the president of the Karakoram Disability Forum in Gilgit-Baltistan, an organisation addressing the needs of disabled people. The organisation is composed of 36 members of whom 12 are women. Akbar contends that he has been invited by the CHIP team to attend programs and has trained his organisation in making project proposals and writing reports of the activities.

For Akbar, Disability Forum has helped him in regaining his lost confidence and sense of purpose. The confidence emanates from his voice as he lists out the achievements and breakthroughs his organisation has made, “We have been campaigning with different government departments to have the persons with disability hired on their two percent quota in jobs. The police department has given jobs to three persons with impairments. The health officials have promised us to sign up at least one person with disability. The Gilgit-Baltistan chief minister has sanctioned Rs 50,000 for our organisation.”

But it became absolutely crystal that CHIP’s efforts had hit home when Akbar beamed, “Thanks to CHIP, I don’t consider myself disabled anymore.”

The theatrical performance organized by CHIP in the village of Astana Bala ended at twilight with a thunderous applause. Amidst the audience, Muddassir Rafiq sat with his two brothers and a small smile on his face. The play with its disabled friendly ramp had made him feel welcomed and he was to leave now with a sense of purpose.

Like light at the end of the tunnel, he had found an avenue to help him fulfil his desire for education.

As a 22 year old, Muddassir's life seems fraught with difficulties. Orphaned at a young age and seemingly fated only to awkwardly stitched clothes due to his polio, Muddassir is unable to recall many happy childhood memories. But for him, education was of utmost important and it was this crutch that helped him get back up on his own two feet and regain his lost confidence.

After a medical assessment, CHIP facilitated Muddassir in obtaining a disability certificate and provided him with a wheel chair and a purpose built motorbike which he used to drive into school. Accessibility was also improved by making the washroom and house more disability friendly. His school was also made accessible and a ramp and bathroom for disabled individuals was constructed. CHIP also provided the school with swings for disabled children and teachers were trained in sign language so as to facilitate children with hearing and speaking impairment.

To further facilitate his integration into society, Muddassir was made a part of a self-help group and is currently working for others with disability as a joint secretary of the DPO alongside his studies. With his thirst for knowledge, it is not surprising that he also goes to a language centre to learn English. His resolve to complete his education stems from his longer term goals of becoming a citizen who could contribute to society.

With such determination, Muddassir will undoubtedly go a long way to fulfill all his goals.

| Muddassir Rafiq | |
|----------------------|---|
| Village | Astana Bala |
| Gender | Male |
| Age | 22 |
| Disability | Poliomyelitis |
| Interventions | Medical assessment; disability certificate; wheelchair; purpose built motorbike; washroom, house and school made accessible; self help group member; Disabled Persons Organisation joint secretary. |

Abida did not like playing with other children or going to school. She tiptoed around the house not daring to stray away from her comfort zone. What if she fell? Would the other children laugh at her? What if no one would come to help her pick her up? Little did she know that her main obstacle was not her disabling condition, it was her lack of self-confidence.

| Abida | |
|----------------------|--|
| Village | Shot Qumrah |
| Gender | Female |
| Age | 12 |
| Disability | Muscular Dystrophy |
| Interventions | Medical assessment; house and school made accessible; physiotherapy. |

Aged 12, Abida had inherited muscular dystrophy from her family. She was forced to walk on her toes as this was the only way to ease her pain and allow her to walk easily. Till about three years ago, her home in Shot Qumrah was her cocoon and she did not dare break out of it. CHIP identified her through a local society Qasimia Welfare Organisation which organised religious lectures and theatre performances to promote inclusion of the disabled in society.

After a medical assessment, CHIP sought to ease the pain of her difficulties and enhance her accessibility. Ramps were built for Abida at home and after enrolment, at her school. An easy to use toilet was also constructed for her at home. She was also supplied with a school. Furthermore, despite there being no physiotherapy centre in the area, CHIP arranged for a physiotherapist so that the treatment would allow her to walk to and from school every day.

Abida's progress report was given by her teacher Najma Raza, who is in charge of the 103-student school. "Abida was confused in the beginning especially because she still found difficulties in walking. But now that she has been here for her third year, she has improved a lot. Walking is not as arduous a task for her as it was before and she can travel to and from school with a lot more ease now," Najma contends.

What is even more promising is that Abida has already begun to think long term. She has expressed her liking for studying in the school and her future desires of working as a teacher herself.

Forlorn and scrawny, Syed Ali Shah could be seen sitting in a corner hugging his knees. He could hear distant voices but he could clearly make out his mother's words, "Shah is sleeping right now. You can meet him later." He turned his gaze towards the barred window in his room and wondered for the millionth time why his parents would not let him play with his other cousins.

| Syed Ali Shah | |
|----------------------|---|
| Village | Katpana |
| Gender | Male |
| Age | 14 |
| Disability | Stunted Growth |
| Interventions | Medical assessment; assistive device; washroom and house made accessible; school kit; foot surgery. |

At age 14, Shah barely looks 9. His stunted growth is a direct consequence of malnutrition and poverty impairing his physical and cognitive development. CHIP had to make several visits to his home in Katpana village until they were allowed to see him. His parents would make an excuse and turn them away every single time until seven months ago when Shah's parents gave in to the advocacy.

Shah was medically assessed by the team and provided with an assistive device. To improve accessibility, his house and washroom were also made disability friendly. As a part of the social inclusion strategy, Shah was also enrolled in a school and given a school kit to assist him. To further make things easier for Shah, teachers were trained as to how to teach children with disability.

In order to physically improve Shah's condition, he was referred to the District Headquarters Hospital in Skardu for foot surgery. Successful surgery and continuous physiotherapy has allowed Shah to make a good recovery. He is able to visit his relatives and play football and cricket as well. Shah could barely contain his glee as he expressed his enthusiasm for bowling. His spirits were running particularly high for team Pakistan as they had only recently emerged as Asia Cup winners.

Shah's hands and feet are now performing quite well. He is all smiles as he explains, "I can hold my pencil properly now. The teachers think my hand writing is a lot neater now as well!" Shah's happiness seems to be emanating to his father who can be seen nodding proudly with his son in agreement. Shah's progress has even led to his father advocating CHIP's inclusive development message to others.

Disaster struck in 2010 when the flash floods triggered by heavy rains killed 43 people in Razia Kulsum's 450-household village Shot Qumrah. Her house was swept away and the tragedy left her husband a victim of post-traumatic stress disorder. Despite the efforts of an international organisation which provided the family with a makeshift home, the husband has been showing no signs of recovery and has been unable to work ever since.

| Razia Kulsum | |
|----------------------|---|
| Village | Shot Qumrah |
| Gender | Female |
| Age | 40 |
| Disability | Physically handicapped |
| Interventions | Medical assessment; disability certificate; tailoring shop. |

But the list of problems for Razia did not end here. To make the situation even more complex, Razia is also physically handicapped. Her disabling condition took root after a tumble in the early years of her life. Till about three years ago, Razia was housebound and preferred to stay that way. It would have been unimaginable for her and those around her to have fathomed that she, aged 40, would blossom into the independent woman she is today.

Qasimia Welfare Organisation, a local society, organised religious lectures and theatre performances to encourage the inclusion of disabled individuals into society. She was identified through a door-to-door survey by a team of the Qasimia Welfare Organisation. Upon discovery, CHIP performed medical assessments on her and facilitated her in obtaining a disability certificate.

Furthermore, CHIP trained her in tailoring as a part of the programme which aims at making individuals independent and reliable bread winners for their families. Upon obtaining a tailoring certificate CHIP helped her in setting up her own tailoring shop. This shop has become a source of income for her and her family alleviating her financial woes every since her husband stopped working.

"Ever since the tragedy [flash floods] my husband has been unable to work and the pressure was on me to my feed my daughter and husband. I didn't know anything about tailoring but now over the years I have learnt to sew quite well. For me, nothing serves my family's needs better than tailoring; at least I am earning bread for myself and family with this skill," a teary eyed Razia commented.