Barriers Faced by Young Adults with Disabilities in Ulaanbaatar, Mongolia

A Community-Based
Emancipatory Disability Research

SUMMARY REPORT

"ТЭГШ НИЙГЭМ ХОЛБОО"
ТӨРИЙН БУС БАЙГУУЛЛАГА

AIFO
dal 1961 con gli ultimi

An Emancipatory Disability Research focusing on a group of young persons with disabilities from Ulaanbaatar in Mongolia, was carried out in 2018-19 as a part of the project "*Closing the gap: a right-based approach towards independent living for people with disabilities*", co-funded by EIDHR country schemes of European Commission (EIDHR/2017/392-819). This project was managed by Tegsh Niigem/Mongolia along with AIFO/Italy.

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FOREWORD

During 2018-19, an Emancipatory Disability Research (EDR) was conducted by a group of persons with disabilities in Ulaanbaatar, the capital of Mongolia. This research was a part the project "*Closing the gap: a right -based approach towards independent living for people with disabilities*" funded by European Union (EIDHR/2017/392-819).

Three organisations - Tegsh Niigem (Mongolia), Independent Living Centre (Mongolia) and AIFO (Italy), with support from different Mongolian organisations of persons with disabilities (DPOs) collaborated for the implementation of this research.

This research focused on identifying the barriers faced by different groups of persons with disabilities and strategies to overcome those barriers. This report presents the main findings from this research.

Our thanks to the young persons with disabilities and their organisations, who were involved in this research and to all the experts of the Technical Advisory Group who guided it. We also wish to thank the European Union and the Government of Mongolia for enabling and supporting the research process.

Tegsh Niigem Mongolia	Independent Living Centre, Mongolia	Italian association R. Follereau

1. INTRODUCTION

An Emancipatory Disability Research was organised in Ulaanbaatar, the capital of Mongolia, during 2018-19. It was conducted entirely by young persons (18-36 years old) with moderate to severe disabilities. It was community-based research as it was conducted by persons from local communities. This report presents the key findings from this research.

1.1 RESEARCHERS

34 persons with moderate to severe disabilities were identified to be the researchers with the help of national DPOs in Mongolia. They participated in a 5-days long training on conducting qualitative research.

52% of them were females and 48% males. Around 75% were unmarried. Around one-third of them came from the poorer Ger districts located in the periphery of the city. Their education varied from 6% who had no education to 37% with university education.

They represented all the different kinds of disabilities, including 42% of persons with speech and communication difficulties, around 50% were wheel-chair users and 58% needed assistance for daily living activities.

Of the 34 persons trained initially, some dropped out during the research process, while new persons joined, who were trained by the older researchers. Globally, a total of 42 persons with disabilities were involved in conducting the research.

Annex 1 provides a list of all the researchers.

1.2 TECHNICAL ADVISORY GROUP

A Technical Advisory Group (TAG) composed of disability activists, academics, specialists and research experts was created to support the research. It had 15 members, including 13 persons from Mongolia and 2 international members. Among them 60% were women and 53% were persons with disabilities.

The TAG met three times during the research – in the beginning to finalise the research protocol, in the middle and at the end of the research process to review the research progress and results. Some Group members also participated in specific activities of the research as observers.

Ms. B. Battsetseg, the rapporteur of the research, provided secretarial support to the TAG.

Annex 2 presents a list of the Technical Advisory Group members.

1.3 RESEARCH OBJECTIVES

The main objective of the research was to identify and understand the different barriers faced by persons with different disabilities living in Ulaanbaatar.

Secondary objectives of the research were:

- To discuss and identify possible strategies for overcoming those barriers;
- To reflect on the mechanisms underlying the creation of barriers and to promote self-empowerment.

1.4 RESEARCH METHODOLOGY

Through a participatory approach, the researchers identified 12 broad thematic areas for collecting information about the barriers. The thematic research areas included independent living, livelihood, education, health, discrimination, public transport, social welfare, assistive products, personal assistants and sexuality.

The following process was used to conduct the research:

- For each thematic research, the researchers met to collectively discuss the key issues associated with that theme and the directions of their enquiries.
- The researchers went out in the field individually or in small groups to gather information regarding the theme and its related barriers by interviewing individuals, families, service providers and authorities. Some researchers also searched for existing reports and researches on that theme.

- After a period of 4-5 weeks, the researchers met again to share their findings, to identify the key issues, to reflect on the mechanisms causing those barriers and to discuss possible strategies for overcoming them. Decision-makers and relevant authorities were sometimes invited to these meetings.
- The rapporteur prepared a draft report of the theme meeting, which was circulated to the researchers and Technical Advisory Group members before being finalised.

1.5 DATA AND INFORMATION ANALYSIS

On an average, 20 researchers took part in each of the 12 theme-researches. For every theme research, each researcher spoke to or interviewed an average of 5 individuals. Thus, globally the research involved more than 1000 persons for information collection.

There were 3 levels of analysis and reflection on the data and information collected during the research:

- While collecting information in the field, the researchers reflected on them individually or in small groups. Often, they also discussed the related issues with other members of their DPOs.
- During the theme meetings, the researchers came together for a collective analysis and reflection on the collected information and for discussing potential strategies for fighting those barriers.
- All the 12 formal theme reports, originally prepared by the rapporteur in Mongolian, were translated into English and

analysed though coding and grouping of the barriers. This report is based on that analysis.

Based upon the barriers identified in ICF - the International Classification of Functioning and Disability (WHO, 2001) and in the Craig Hospital Inventory of Environmental Factors (CHIEF, 2001), 6 possible categories of barriers were identified. These 6 categories were then used for analysis of the theme reports and for the preparation of this report. **Annex 3** presents this classification of barriers.

This document presents a global analysis of those 12 theme reports, as the main research findings.

2. RESEARCH RESULTS

2.1 INTRODUCTION

The Community-Based Emancipatory Disability Research (CB-EDR) in Mongolia was implemented through 12 theme-researches. For each theme research a report was prepared and analysed to identify the key barriers related to that theme faced by persons with disabilities. The main findings from those 12 theme-research reports have been summarised for this global analysis.

2.2 KEY BARRIERS PERCEIVED BY PERSONS WITH DISABILITIES IN MONGOLIA

The most important barriers identified during CB-EDR process in Mongolia are grouped in 6 categories:

2.2.1 Barriers Related to People’s Attitudes and Behaviours

The barriers related to people’s attitudes and behaviours was a vast area of enquiry and discussions throughout the research process. It ranged from family relationships, peer relationships, community interactions, and interactions with different service-providers including school teachers, health care workers, employers, and personal assistants. Internalised negative attitudes among persons with disabilities themselves were also a part of it. Negative impact of these barriers also had a large range, varying from being ignored and isolated, to being denied or discriminated, to being a target of emotional, physical and sexual abuse.

Another dimension of complexity in the barriers was related to the impact of “too much care”, “overprotection” and “lack of interaction with external world” in the family environment.

Occasionally, the same behaviour was perceived as positive or negative by different persons with disabilities. For example, in one testimony, the co-workers’ desire to be helpful, was perceived as their being discriminatory and patronising by one person with disability while another person appreciated it.

Experiences of negative attitudes in the families were mostly about taking too much care. Families were afraid that the person with disability would not be able to be autonomous, and would have to deal with negative attitudes of others. People used words like “loving too much”, “insisting on spoon feeding” and “over-protection” to describe family attitudes.

Negative attitudes were also a key issue in the families of their boyfriends/girlfriends, who did not see them as suitable companions for their disabled or non-disabled sons/daughters.

Negative attitudes in the communities included the beliefs of the religious persons (disability was a result of bad karma) and lack of understanding among general public, some of whom thought that disability was a contagious illness.

Sometimes, negative attitudes were linked with other considerations. For example, different persons explained that taxi drivers often refused to accept wheel-chair users because they felt that it would need extra work and time. Thus, they asked to be paid extra.

In the Ger districts there was a lack of sewage and waste disposal services and families often threw the kitchen and washing water in the streets outside their houses, and thus walking on the untarred streets became more difficult. During winters, this waste water froze, creating a slippery surface and causing further difficulties for everyone but more so for persons with disabilities.

Negative attitudes in families and communities towards the expression of sexuality of persons with disabilities was another significant area. Family and religious persons were usually the first sources of information on this theme but most of the time, they gave only negative information, by implying that sexual and affective life would not be possible or be even desirable for persons with disabilities.

Families also did not believe that persons with disabilities would be able to find a suitable companion and usually advised them to accept a life without a companion and without sex. A few families suggested to the young disabled women to have sex for having a child so that "*they would* *have someone who would love them and eventually look after them*". Other families were afraid that the relationship was just for some easy sex and then they will be left alone. There were also discussions about desirability of women with disability getting married to non-disabled men.

Young persons with disabilities also complained about lack of options for getting information about sexuality. A deaf girl said, "Going out with the deaf boys is not so easy, they can be very aggressive. You meet them for the first time and they want to have sex immediately. They have no idea about how to relate with a girl."

While the men with disabilities raised the possibility of receiving financial support for experiencing sex with sex-workers, the women shared information about use of vibrators and sex-toys.

Violence, abuse and sexual abuse were extreme forms of behaviour towards persons with disabilities in the families and communities and this issue was raised up mainly by women as well as by young adults with intellectual disabilities or with very severe disabilities. It was one of the most complex discussions in the research as the issues varied from the subject of violence against persons with disabilities and especially against women with disabilities to the need for sexual expression among young adults for which there were no socially sanctioned solutions.

Sexual abuse was a common theme in many stories told by the women with disabilities, where neighbours, strangers and especially, taxi drivers, touched them inappropriately, asked them if they wanted sex or tried to force them into sex. The women who were not completely self-sufficient faced greater risk of facing sexual violence. Sometimes the men provoking this violence expected to be seen as doing a favour "*because who else is ever going to have sex with her*". A deaf woman sex worker explained that she got paid much less than other sex workers and if she tried to ask for more, the men became very angry, as if they were doing her a favour.

On the other hand, expression of sexuality among young adults with disabilities was seen as a problem for the families. There were different testimonies of family women helping the young adult males with disabilities to get sexual release and one testimony of a father having sex with his wheel-chair using daughter.

This discussion also had another side – sometimes family members were the victims. In some stories, sisters and mothers in the families, were afraid of being assaulted by their sexually frustrated disabled male young adults.

Negative attitudes among teachers and peers affected access to education. They did not understand the different barriers faced by persons with disabilities and sometimes contributed to those barriers. They were ignorant about specific needs of persons with disabilities or had stereotypical views about them. Lack of specific skills such as sign language knowledge added to those barriers.

Talking to the teachers and peers, and explaining about their difficulties was an important part of overcoming some of these barriers. For example, a girl with cerebral palsy explained that she had to rewrite her notes and do the home assignments at night because she could not write fast. She said: "*I spoke to my teachers and they understood my problems. Now they give me their lecture notes one day earlier, so I don't need to remain awake and work at night.*"

Negative attitudes among health professionals were identified as key barriers in accessing health services during the research. Different persons explained how the health workers did not speak directly to them and instead talked only to their family members. They also demonstrated a lack of understanding about different disabilities. For example, one person explained the experience of taking her 4 years-old son to a doctor, "*The doctor just took over, he did not allow me to tell about and show him my son. I felt discriminated.*" Another person said, "*The doctor didn't talk to me, he just talked to my parents. I tried to speak, but he ignored me.*"

Another issue in the health services was the mismatch between the information persons expected from the services and what they actually received, because professionals did not discuss the expected results of the therapies with them. For example, a person explained that he had spent a big amount of money for 3 years to pay for rehabilitation therapies because he had hoped that his disability would go away. He said, "*Now I have accepted my disability, I am not wasting any more money. I want an independent life,*" he said.

Sometimes, health professionals did not know how to provide service to persons with disabilities. For example, one person said, "*Dentists are afraid of me. They insist that I need to get total anaesthesia for any intervention on my teeth.*" Another person, who has cerebral palsy, said, "*I told the doctor that I wanted to have a child, but she advised me not to become pregnant because I am disabled. I decided to have the child anyway, now I have my daughter and I am very happy.*"

Regarding the role of personal assistants there was some debate on the dependence upon family care. While there was some confusion regarding the meaning of term "personal assistants", most persons felt that as they grow up, it is better to have the support of a personal assistant. Family care can be a big burden for some families. A person with severe cerebral palsy explained that her mother took care of her for 20 years, stayed at home, was isolated and had no social protection contributions for pension. A wheel-chair user said, "*When I ask for assistance from my family, sometimes they get upset or they say, I am not your servant*."

There were many testimonies about the positive impact of having a personal assistant on the quality of life. For example, one person said, "*The best thing is that I can make decisions independently. Personal assistants help me to live like others*." Another person said, "*I have a personal assistant for 2 hours a day. Thus, I need to do everything within those 2 hours*."

Many persons had questions about what kind of support can be provided by a personal assistant. One person wanted to know if he could ask his personal assistant to go and bring water as he cannot carry it. Another person expressed worry about personal assistants sharing intimate information about him with others. Some persons, who were not self-sufficient, raised the issue of how to deal with their personal assistants when they wanted to have sex and if they could ask for support from their assistants.

Internalised negative attitudes among persons with disabilities themselves was another major barrier. Some persons felt that overprotection and fear of their families created loss of self-confidence and internalised negative attitudes.

Many testimonies touched upon years passed in isolation in the house, feeling afraid of going out, feeling ashamed of others' negative reactions, thinking that others will pity them. Sometimes, these feelings were accompanied with depression and ideas of committing suicide.

One person spoke of loss of social role due to disability, which contributed to his negative self-image. He explained that cutting the wood and bringing water containers from the common well, required strength and are seen as a son’s duty. After an accident, due to his disability, he was unable to carry out these activities while his old and sick father had to do these, which made him feel like a failure as a son.

The group also discussed the *strategies for overcoming negative attitudes* and behaviours. They felt that talking to people and creating awareness was important. Involvement of supportive friends, peers, co-workers and classmates in such situations was equally important. Finally, not accepting discrimination and raising their voices was important.

Overcoming the internalised negative attitudes by going out of the homes was seen as the necessary first step to breakout and challenge these barriers. Sometimes, the decision to go out was inspired by something seen on the TV but most of the time, it was not clear what made them to take this first step.

Going out and finding that other persons with disabilities similar to you or with even more severe disabilities, were out working, making friends, and living their lives was liberating. Others felt that getting a personal assistant was a key factor important for independent living.

2.2.2 Barriers Related to Environment

Unbuilt (natural) and built environment played an important role in creating barriers, even more so in the Ger districts, which are peripheral areas around the city, usually located in hilly areas and which lack the infra-structures and public services.

Barriers related to urban homes: Most of the urban housing in UB were composed of multi-story apartment buildings and these often lacked lifts. Thus, persons with mobility disabilities had difficulties going up and down and needed help. Narrow doors and inaccessible toilets inside the homes were an additional barrier, which required additional resources for repairs and adaptations.

Barriers related to urban buildings: Most supermarkets, restaurants, cinemas and other public use buildings usually lacked accessibility, creating a barrier especially for persons with mobility difficulties.

Barriers related to the public transport: Difficulties in using public transport services was seen as a major barrier. Public buses were the most cost-economic medium of transport for persons with disabilities. UB transport services had bought some buses with platform for the accessibility of wheel-chairs but, in spite of them, the challenges were many.

The way the bus stops were designed was a problem as the areas around the bus stands were occupied by kiosks, vehicles, poles, publicity boards and other barriers. Buses, which were full, often stopped before or after the bus stop and drivers were in a hurry. Bus numbers and destinations were not always easy to read. There were no handles to hold on for getting in the buses. Once inside, there were few seats reserved for persons with disabilities and they were often occupied by elderly persons. The drivers did not wait for the disabled person to sit down, when they moved. There were no announcements and no electronic boards showing the names of the bus stops. Getting up in a moving bus and getting down were both problematic. The accessible buses were often not working, or their platforms do not work or the bus drivers do not wish to spend time using them.

Similar issues were applicable to trains, which also had steps, narrow corridors and inaccessible toilets. Taxis were costly, they refused to carry persons with disabilities or asked for extra payment and were often rude, especially to women with disabilities.

Barriers in educational institutions: Lack of accessible educational buildings and services was a major environmental barrier. For example, one researcher said that his brother had to stay with him in the university to carry him on his shoulders, from one class to another because of the stairs. Another researcher said that when he spoke to his professor about the physical inaccessibility of the university building, he was told that they would allow him to follow most lessons from home. Researchers felt that such helpful attitudes by professors, actually helped their institutions to remain inaccessible.

Researchers also shared their experiences in which sometimes schools had specific services such as accessible toilets and ramps, but these were kept locked and could not be used. One of the researchers with a spinal cord injury who used a wheelchair, shared his own experience in the university: "*Even though there was an accessible toilet at my university, it was locked all the time. Therefore, I couldn't drink anything at my school, and during the 3 years of my studies, I never used the university toilet.*"

Barriers in health institutions: General accessibility of hospitals and health centres was another critical area of environmental barriers. Often there were no lifts or they had narrow doors so wheel-chairs could not go in. There were no accessible toilets, beds and specific equipment for providing health care to persons with disabilities and there were no sign language translators. Women with disabilities complained about lack of suitable beds for child-birth. A person with mobility difficulty said, "*I have only visited our health centre twice to see my family doctor, because someone has to carry me up, as his room is on the second floor*."

Another researcher explained, "*After my accident there was no one to explain and give me advice about my disability. I developed complications, like pressure sores because I did not know how to use the wheel chair properly*."

Additional environmental barriers faced by persons in the Ger districts: Gers are the round tents used as homes by Mongolians in rural areas. All around UB, on the surrounding hills, there are areas where people migrating from rural areas set up a ger because they do not have the resources to rent or buy a house in the city. These areas are called "Ger districts" and they lack public services like roads, water supply, central heating, sewage disposal, and transport. It is estimated that more than 60% of population of Ulaanbaatar lived in the Ger districts, so a large number of persons of disabilities were there among them.

The hilly areas without proper roads and sidewalks, created barriers for persons with mobility and vision disabilities, similar to the barriers faced by persons living in rural areas. Tents where people lived were usually surrounded by rough terrain and toilets were built away from the tents as temporary structures, as they have to be shifted when the hole below it gets full. Coming out of the tent and entering toilet, both were difficult activities.

Mongolians also have a cultural tradition of fixing a strip of wood on the ground at the entrance of the household and the tent. These wooden strips created barrier for wheel-chairs, rollators and walkers.

Lack of central heating in the Ger districts meant that persons needed to use wood stoves, which required buying, carrying and splitting the wood pieces, putting them in the stoves, and regularly cleaning the ash from the stoves. All these tasks created barriers for persons with disabilities.

Similarly, lack of centralised water supply meant that persons needed to go to the common wells and water supply points, fill buckets and containers and carry them to their homes, which created barriers for persons with disabilities.

Buildings for public use in the Ger districts such as shops and bath-houses usually had stairs and there were no ramps.

2.2.3 Barriers Related to Policies, Laws and Programmes

The challenges faced by persons with disabilities linked to specific policies, strategies, laws, norms and specific programmes of the Government of Mongolia were raised up in some theme researches. A summary of such issues is presented below.

Disability Certification System in Mongolia: Issues related to the disability certification system came up during discussions numerous times during the EDR. There were 2 main challenges in this regard –

(1) The way the disability certificates described the persons with severe difficulty in a body function (such as blind persons, deaf persons and wheel-chair users) was seen as problematic. They are described as "*persons with high percentage of disability which means that they are unable to work*". The high percentage of disability allowed them to become eligible for disability pension. On the other hand, "unable to work" meant that they could not apply for any jobs under the job-reservation quota (every company having 25 employees must employ a person with disability).

Thus, the disabled persons asked for a review of the description in disability assessment system so that it does not automatically assume that because they have severe limitation in one body function, they are not fit for work.

(2) The need to renew the disability certificates every year or every few years even when the doctors know that it is a chronic disability and it is not going to get better. The researchers agreed that sometimes people could have a temporary disability, such as a fracture or after an operation and these persons need to renew their disability certificate every year. However, persons with lifelong disabilities felt that yearly certification created an additional burden on them and their families.

For example, a person who was operated for a spinal cord tumour and had paraplegia said, "*It is a problem for me to go to Disability Certification Committee every year. It is obvious that my spine is damaged and it is not going to change. But every year, I need to get an MRI test of my spine and pay more than 400 thousand tugriks to get all the tests to show to them. So financially and psychologically it is a big pressure on me and it is unnecessary*."

Right to have a personal assistance: According to the disability law, personal assistants were allowed only if the disability was assessed to be more than 80%. However, some researchers felt that this system should have some flexibility. For example, one woman who was without an arm and whose disability has been assessed at 70%, said: "*I am self-sufficient most of the time but there were occasions when I needed a personal assistant. Like when my baby was small and I had to breast feed her, I needed the help of a personal assistant*."

Challenges linked to the public transport policies: Many persons with disabilities felt that bus drivers were not helpful to them and did not allow them to board the buses properly. It was pointed out that this was caused by strict running time for each bus trip and bus drivers did not want to get penalised.

Another issue was that there were few reserved seats for persons with disabilities in the buses and they were not marked properly.

There were other challenges associated with the use of taxi and micro-bus services including refusal to accept persons with disabilities or asking to be paid extra, high cost of private transport and lack of transport services in Ger districts.

Barriers related to livelihood policies: On one hand, persons with disabilities felt that job-reservation quota should be increased. At the same time, they asked to increase the penalty costs for employers who did not follow the job reservation quota, as they preferred to pay the penalty instead of employing a disabled person. Another suggestion was to provide more incentives to employers who accept employees with disabilities, such as tax breaks.

At the same time, some persons with disabilities felt that they needed more flexible working environments. Examples were given of laws about rigid working hours which did not allow the persons to work for shorter periods.

Barriers related to education policies: Many persons with disabilities spoke against education in special schools and asked for inclusive education. They felt that the special schools did not provide adequate skills to the students, their quality of education was poor and often the teachers did not know how to teach children with disabilities. They also felt that students in special schools did not learn how to live and work outside the special school environment.

All the special schools were based in UB and each of them decided their own teaching curriculums for their children, which sometimes excluded specific subjects such as physics. Therefore, at the end of the studies, the students of these schools did not get a high school certificate, they only received a special school certificate.

Lack of sufficient learning materials and specific teaching equipment for children with disabilities was another area of concern. One researcher shared her experience of visiting to a primary school in a province, where in a separate class for children with disabilities they had 24 children, but only 2 old books for learning alphabets.

There were repeated and specific criticisms of the education system from the deaf students, who asked the Government to decide about the Mongolian sign language so that teachers could be trained properly. Lack of a national sign language was identified as a major barrier by deaf persons and their organisations.

Barriers related to health policies: Many negative experiences were about service-related barriers such as long queues which do not take into account the difficulties of persons with disabilities.

Another area of concern was the privatization policies of the health services, which created many limitations. For example, it meant that the hospital stay had to be very short, and even if a person needed a longer stay, they were sent home.

2.2.4 Communication Barriers

The challenges relation to communication difficulties focused on three areas – (a) receiving information from professionals and service providers; (b) information about public transport; and, (c) the impact of communication difficulties on inter-personal relationships.

Communication barriers related to receiving information: Most of these issues emerged during the meeting on sexuality, when men and women with different disabilities pointed out that there were many things about their bodies and body-functions, which no one had ever explained to them.

They also felt that the health and rehabilitation professionals did not know how to explain about sexuality and reproductive health to persons with disabilities. They often seemed to imply that as persons with severe disabilities, they should not even think of sex.

Deaf persons faced even bigger barriers in learning about their bodies and sex. Even when someone wrote down the information for them, they did not always understand it completely. Many of them lacked basic knowledge about human anatomy of the opposite sex and did not understand how their own bodies work.

For persons with disabilities the two main sources of information were friends and internet, though both were sometimes not able to provide the required information.

Communication barriers related to public transport: Persons with vision disabilities complained that frequently there were no announcements regarding bus stops and destinations, so sometimes they missed their bus-stop.

Persons with hearing disabilities said that buses lacked display boards or their display boards were non-functioning. Often the display boards were located only in the front or the back of the bus. Sometimes, the display font was very small or it was located outside the bus window and difficult to read. The bus windows were sometimes covered with stickers so persons could not look out to see the location.

Lack of display boards and announcements also caused problems to persons with mobility difficulties, who needed to get up from the seats and come near the exit before the bus stop, otherwise they risked missing their stop.

Communication barriers related to inter-personal relationships: This issue was raised mainly by persons with hearing difficulties. For example, one person explained that he could not go out in evenings to meet friends because he could not understand where they are planning to meet and how to get there. They felt that development of a software which could convert text into sign language would be useful for them.

2.2.5 Economic Barriers

There were few discussions about economic barriers during the research. They mainly focused on increasing the amount of disability pension from the Government.

Some persons from Ger districts complained of not having enough resources for basic necessities, not having funds to cover health-care expenses and not being able to pay for a carer or a personal assistant.

Some persons asked for an increase in the subsidy given by social welfare services for paying the house rent and electricity expenses.

The issue of economic barriers was also raised regarding access to better quality assistive products. For example, persons with paraplegia and tetraplegia, who needed diapers and urine bags, said that they needed big quantities and the amount provided by the Social Welfare was insufficient.

2.2.6 Products and Technology Barriers

Discussions about barriers related to products and technology also focused mainly on access to assistive products through the Social Welfare services of the Government.

Many persons complained about the poor quality of some products, such as wheel chairs and hearing aids, as these came in limited standard sizes/models, were heavy and old fashioned, lacked essential components such as cushions and could not be adapted to the needs of individual users.

At the same time, there were complaints that there was no training given to the persons about the proper use and maintenance of the assistive products such as wheel-chairs and other products. Sometimes this resulted in injuries, wounds and complications in the users.

If persons want better quality products, they needed to pay for it additional amounts, which was possible only for persons with more economic resources.

A second area of discussion was about innovative technologies and difficulties in accessing these in Mongolia. For example, persons mentioned lack of specific products such as Text-to-Voice software for blind and low vision persons in Mongolian language. These barriers also applied to digital Apps for the mobile phones.

2.2.7 Additional Comments Regarding the Barriers

Most discussions on barriers were related to 3 categories – (i) negative attitudes and behaviours, (ii) environment and (iii) the Government laws and policies. In comparison, discussions related to the barriers in other 3 categories (communication, economic and products-technology) were less common.

Many times, people's stories showed the links between different categories of barriers. For example, discussions about the barriers faced by disabled persons in the Ger districts due to lack of services such as proper roads were worsened by people's negative attitudes and their socio-cultural practices.

Thus, the sub-division of the barriers in the 6 categories, was seen as an attempt for facilitating understanding and fixing responsibilities, but they were not rigid and separate blocks. This meant that strategies to remove or lessen the barriers had to be multi-directional to be successful.

Finally, the researchers felt that some issues raised in this research were difficult to discuss only in terms of social model of disability. For example, the testimonies about the fear of the family women about the sexually frustrated young men with disabilities were difficult to discuss only in terms of barriers. Similarly, they felt that difficulties in finding marriage-partners was a complicated issue that could not be explained only in terms of barriers.

3. PARTICIPATING IN EDR: VOICES OF THE RESEARCHERS

Mr. Tamirkhuu Narangerel: For me the biggest impact of being a researcher has been that now I can see the problems from different angles. Another change is that now we do not talk about problems just for talking, we also search for solutions.

At a more personal level, I have become more self-confident. I know about my rights, and I have many more friends. I have become much better in working as a team. I am also less ashamed of going out with my wife and son.

Ms Boloroo Buyanjargal: I had difficulties in communicating in the beginning. I am so much better in communicating now because I am less ashamed of the way I speak. I like that we can be honest with each other and talk about things which really concern us.

Some of the other persons in our group have also changed. Earlier, they were silent but slowly they started to speak and now they are active. For me the best part of the theme meetings was in the afternoons, when we had free discussions and we talked about finding solutions.

Ms Selenge Demberel and **Ms Khulan Magnaidavaa**: When we started discussing a theme, it didn't look so interesting and we thought what are going to do in this theme? But once we started talking about it, we found that there was so much to discover and it became interesting. However, we wish to point out some of the negative aspects of our group-work. There are differences among us and there was some discrimination among us, which was not easy to overcome.

Ms Gantsetseg Ganbaatar: For some period, I was the only deaf person in the group of researchers. I was not used to communicating with others. Before I joined the research, I was very closed. In the beginning, in some meetings, I came and listened to others, but didn't say anything. Then slowly, I came out of my shell. Now, I always share my ideas and feelings. Now I have become a good contributor to the group discussions.

Ms Bayartsetseg Gantogtokh: For me the meetings on sexuality and education were very important. They helped me to understand so many things. Before this research, I didn't understand much about my body, because we never talked about it to anyone or to our parents, and we didn't know about our sexuality.

Mr Bilegsaihan Enkhbayar: Before coming to this research, I didn't understand the challenges faced by persons with other disabilities, I knew only about my own issues as a person with cerebral palsy. Now I understand their difficulties and I know how environment affects us in different ways. Every theme has been a journey of discovery of new things. I understand myself better and now I know what do I want from life.

I have joined university and I want to become an English language translator. I have learned to speak in front of others, I communicate better. I think that my movements are more controlled.

Ms. Misheel Bold: When I came to the first meeting, and when they said that I will be the researcher, I thought that I didn't know anything and wondered how was I going to do it. Now after going on with the research for one year, I have understood that I can be a researcher and anyone can be a researcher.

I have difficulty in communicating and usually people do not listen to me, so I used to speak without listening to others. Being a part of the research has taught me to listen to others and respect others. I think that this is also empowerment.

Mr. Otgonbayar Erdenechimeg: One year ago, I could not go out on the street. Family members used to buy my clothes, it did not matter if I liked them or not, if they were small or big. They bought what they liked.

Now, after one year of joining the research, I go out myself to buy my clothes. I can use the public transport and if needed, I can even quarrel with the driver.

Mr. Nyam-Ochir Byambadorj: All of us have changed as individuals. It was not only because of the research but there were other things which also contributed to our empowerment.

I travelled through parts of Mongolia with my wheel-chair for the Mongolia Try 2019 campaign to create awareness, and I went to Geneva to speak to the Human Rights Commission. Now we have to see how we can use our knowledge and strength to change the social attitudes in Mongolia.

Mr. Enhsanaa Baatar: I used to feel that I had no financial knowledge, so my mother looked after all the financial issues. One day I spoke with my mother, and told her that I wanted to try to manage my own finances. I felt that I could manage them, so now I am dealing with them myself.

4. IMPACT OF EDR

4.1 INTRODUCTION

There were 3 kinds of changes due to the EDR:

- Using the research findings to initiate practical action to overcome or remove the identified barriers;
- Empowerment of the individuals who took part in the research;
- Strengthening of the Organisations of Persons with Disabilities.

This chapter looks at the first 2 kinds of changes. The third aspect, the impact of the research on the DPOs is presented in the next chapter through some testimonies of the TAG members.

4.2 USING RESEARCH KNOWLEDGE TO PROMOTE CHANGE

Using the research findings for initiating practical action happened in 3 ways:

- During the theme researches, the researchers visited different stakeholders and posed questions focusing on barriers posed by their families, communities, institutions, services and programmes. This created critical awareness among the interviewees about their own roles in exclusion of persons with disabilities and sometimes stimulated a change.
- During the meetings organised at the end of each theme research, the key stakeholders including ministers and representatives of institutions were invited to listen to the findings of the researchers. They were asked what they could do to ameliorate the barriers. This sometimes stimulated a change.
- During and after the end of each theme research process, the researchers also took the discussions to their own organisations. This led advocacy campaigns and other DPO activities in asking for the change.

For example, during the mid-term review meeting held in June 2019, many researchers had commented that for them the most interesting part of the theme research meetings was in the afternoons, when they had discussed the action needed to challenge the different barriers they had identified during the research.

2 kinds of changes resulted from the research: There were numerous examples of actions started by researchers and their DPOs to remove or decrease the impact of the specific barriers. Two kinds of impacts of emancipatory research emerged from the discussions –

(i) Greater reciprocal understandings regarding the barriers faced by persons with different disabilities in different life-domains leading to greater collaboration between DPOs;

(ii) The impact of the research on the barriers through change in policies and services.

Understandings Regarding the Barriers Faced by Persons with Different Disabilities: Almost all the researchers agreed that before joining the research they had little understanding about the barriers faced by persons with other disabilities. Almost all of them agreed that this reciprocal understanding and building of solidarity across different kinds of disabilities was fundamental in their collective action to fight for their rights and to advocate for a change. Most researchers agreed that this kind of interaction was crucial for strengthening their organisations and federations.

Impact of the Research on the barriers: Some of the activities initiated during and following the research to address the identified barriers are explained below:

> *Reducing the barriers related to the Public Transport Services*: During the meeting on the public transport services, representatives from the Ministry of Road and Transport development were invited. During the meeting, they informed that they had created a Disability Committee within the ministry and they were working on an amendment of the national transport law. They said that their aim was to have 100% accessible public buses. They invited a representative of the researchers to join this Committee.
>
> *Barriers faced by the persons living in the ger districts*: The information from this theme-research was shared with the

Department of Disability in the department of Social Welfare, which organised a meeting with the Ministry of Construction and City Planning. They discussed the barriers identified during the research and proposed amendments to the law regarding provision of housing to the Ger residents.

Information Services on sexual and reproductive health: Meeting report on Sexuality was discussed with the Disability department of the Government, which then prepared a project on the theme of reproductive health and sexuality, so that more could be done about it. In the meantime, they have already set up a telephone line to provide information and advice to disabled persons on this theme.

Impact on the DPOs: The researchers took back the information from the research to their respective organisations. This led to specific advocacy activities, as well as, provided ideas about preparing new projects to present to the funding organisations. A DPO representative said that the researchers can play an important role in strengthening the cross-disability movement and bringing together different DPOs to fight together.

4.3 EMPOWERING THE RESEARCHERS AND THEIR ORGANISATIONS

One of the objectives of the research was to promote empowerment of the persons with disabilities participating in the EDR. Reflecting on how the research process was impacting the participants' perception of their empowerment, was a recurrent theme throughout the research process.

4.3.1 Understandings of “Empowerment” Among the Persons with disabilities in Mongolia: The emancipatory research provided different opportunities for discussing how the researchers understood the term “empowerment” and what led to their empowerment.

Meanings of empowerment: For many persons, empowerment was closely related to self-confidence, making one’s decisions and taking responsibility for oneself, including the responsibility for the mistakes. Some other characteristics of empowerment identified by the researchers were - active participation, education, learning to appreciate different point of views, respecting themselves and respecting others, expressing themselves and listening to others, having their own space, feeling free, understanding legal status, being honest.

Causes of Disempowerment: Disempowerment was seen as a result of interactions between the persons and the others, starting with the immediate family. It was influenced by the personal characteristics of the individuals and those of the persons and environments surrounding them, including - having low self-confidence, low level of education, being shy or afraid to share their opinions freely, underestimating themselves, having an emotional personality, staying at home, being too sensitive, expecting and asking for too much help, not taking responsibility for themselves, and not resisting/fighting when others made decisions for them.

Strategies for becoming empowered: Persons with disabilities themselves need to take the first step of wishing to become empowered. Knowing other persons with disabilities and seeing that they are active and independent helps in this understanding. Having accessible information, meeting other persons with disabilities and being part of DPOs, are important factors in promoting empowerment.

4.3.2 Empowering Impact of the Research on the Researchers

According to the researchers, the research process acted as an important stimulation to the group to reflect on the different meanings and understandings of empowerment. Different other factors, both personal and institutional, contributed to the changes they perceived in themselves.

The researchers identified the following changes in themselves due to their participation in the CB-EDR process – ability to see problems and issues from different angles and point of views; thinking about and searching for solutions to the barriers they have identified, having greater self-confidence, learning about laws and rights; having more friends, learning to work in teams, expressing opinions freely in front of others, exploring how to live independently, looking for work and feeling less ashamed of going out.

One person explained the empowering role of group discussions, "*Talking in a group about how to overcome the problems was the best part of the meetings. It made us understand that we can also change things*." Talking about and understanding the International Convention on Rights of Persons with Disabilities (CRPD) in relation to different themes was another important empowering factor in their opinion.

Another person said that the changes they perceived in themselves were not uniform and they took time. She explained, "*Some persons did not take an active role in the discussions in the beginning. They were coming to the meetings but were not saying anything, only listening. But after 4-5 meetings, they slowly started to come out and share their opinions*."

Inviting and talking to key stakeholders during the different stake-holders during the research on different themes, such as the participation of the Minister of Transportation in the meeting on public transport, provided a better understanding of issues about the theme and increased self-confidence of researchers that they could bring about a change.

Being part of a group composed of persons with different disabilities was also empowering. One of the researchers, a person with cerebral palsy explained, "*I did not know what kinds of problems are faced by deaf persons, blind persons and persons with epilepsy. Now I understand that there are different kinds of barriers for different groups of persons, the same barriers affect us differently. It also means that I have more friends.*"

Discussing themes such as sexuality was appreciated by different persons. One person said, "*I didn't know my own body, I even did not know what is menstruation. We never talk about it to anyone, not even to my parents.*"

Looking at problems in a systematic way, collecting data and information, and understanding its implications was another skill gained through the EDR process. All the researchers had the opportunity to take part in the Asian-Pacific Community-Based Inclusive Development (AP-CBID) congress which was held in Mongolia in July 2019. They made a joint presentation in the congress to share their experiences in the research. Three (3) researchers also made individual presentations during the congress. They interacted with persons coming from different parts of the world. It was perceived as an empowering experience.

5. IMPACT OF THE RESEARCH: TAG

Different DPOs and academic institutions were partners in this emancipatory research. Some of their representatives were members of the Technical Advisory Group (TAG). TAG members provided additional information about the impact of the research.

Mr. Undrakhbayar (Independent Living Movement Mongolia): During the research process, the researchers received additional stimulations and opportunities for empowerment. For example, after the research started, we were involved in the preparation of the national shadow report on the implementation of CRPD. We also organised a long march of wheel-chair users across different provinces of the country under the “Mongolia Try 2019” initiative. So, there were multiple sources of empowerment for the researchers.

The hottest theme in this research was that on sexuality. It was clear that many researchers wanted to talk about it but were ashamed or shy. The discussions were difficult to initiate but once they started, it was clear that it was very important for them to talk about it and they had a lot of questions. Many of them had assumed that sex was not expected for them and had no idea about it. General information about it was not enough, many of them needed specific information linked with their disability.

For many researchers, social interaction with other researchers was very important. Before the research, many of them had been staying at home, going out only once or twice in a year for medical check-ups or to get disability certificate. A family member of one of the researchers, told me that her younger brother was a very quiet person. He was shy and hardly ever spoke anything. He did not go out. After becoming a researcher, he was completely changed, he has become talkative and his way of life had changed. That guy is not alone in the way he had changed. So many of these researchers come to our office, they have become more smiling and talkative persons.

Dr. Batdulam (head of Public Health Program at the School of Medicine of the Mongolia National University and mother of one of the researchers): Participation in the research has helped him to become more self-confident and active. The researchers have been lucky, it is as if they have been part of a one year long self-learning training course. When they were doing research on public transport, he wanted to know about travelling in bus. He had never been in a bus before. So, all our family, we went with him for a bus ride. He had never been to a Ger district and he joined the Mongolia Try march and thus travelled with other disabled persons on wheel chairs. He had never sat on a wheel chair before and since it is difficult for him to sit still, it was a difficult experience for him but it made him understand what it does it mean to be a wheel chair user. Another important theme for him was that of sexuality. We had never talked about it, but I hoped that he would get information from his companions. For the theme of independent living, he did a survey on ‘one day of my life’ to reflect critically on what things he could do or could not do if he had to live independently. He found that he could not go out alone and could not cook, but was able to able to manage everything else. Personal assistants helped him to understand how they can assist. His social interactions have improved. He has now an Instagram account, he writes and shares things about himself. He is more confident, he wants to get his degree and study more. This last one year has changed him.

Mr. Avirmed (founder-director of the Independent Living Movement Mongolia and chair-person of the TAG): Many of the researchers are from Independent Living Movement and so I got a lot of feedback from them. The researchers often talk to me asking for my advice regarding the research themes. I always encourage them to think and look for information. Their skills in searching for information and talking to others to collect information have improved. The change has been slow but now it can be made out clearly. One of the researchers, before the research, he did not want to come out of his house, now he is in our office every day, he has become an active member and wants to start something in relation to educational opportunities for other disabled persons.

Ms. Bolormaa (chair-person of the Blind Youth Association): As a psychologist, I feel that the research is an opportunity for these young people to meet and be together, talk to each other. Their peer group discussions are improving their capacities. They all gain different knowledge. The blind person in their group, now he knows the difficulties faced by other persons with disabilities. They will be better leaders of the DPOs and they can collaborate much better with other DPOs.

Ms. Oyuntsetseg (National Rehabilitation Centre): There is one deaf woman among the researchers. Earlier, she was very shy and introverted. She did not communicate much with others. Even her family was different, they were always checking on her, they were over-protective. Now she goes out alone, she can communicate better with her family. She feels that she can help others and this is building her self-confidence. Education is a problem among the deaf persons. Many of them think that it is enough for them to communicate with others through sign language and they do not give importance to reading and understanding. She has become more attentive towards reading and understanding, so being a researcher has helped her to become a better student. The meeting on sexuality, it had a very strong impact on her. Before that meeting, she had not thought of herself as a woman and about her right to sexuality. In the meeting, she learned about it from others.

Ms. S. Enhsaihan (Management Academy of Ulaanbataar): In 2015-16, I was involved in the evaluation of the national CBR program in Mongolia. During the first meeting of TAG I had taken part in selecting the themes for the research which were later discussed by the researchers. However, at that time I could not understand how the research was going to work and how persons with disabilities will be trained to become researchers. Then, over the past one year, I have read the different research reports and I admire the way they have conducted the research.

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LIST OF ANNEXES

Annex 1: List of researchers

Annex 2: Technical Advisory Group members

Annex 3: Different kinds of barriers for classification

Annex 1

CB-EDR RESEARCHERS

No	Surname	Name	Gender	Type of disability
1	Naranbaatar	Enkhsanaa	M	CP
2	Bold	Misheel	F	CP
3	Gankhuyag	Enkhmaa	F	CP
4	Davaa	Uyangasaikhan	F	CP
5	Enkhbayar	Bilegsaikhan	M	CP
6	Gelegpel	Erdenezul	F	Spinal cord injury
7	Ganbaatar	Gantsetseg	F	Deaf
8	Erdenechimeg	Otgonbayar	M	Poliomyelitis
9	Togtokhsuren	Sumiyakhuu	F	Spinal cord injury /light/
10	Byambajav	Altangerel	M	Osteoporosis
11	Byuyanjargal	Boloroo	F	CP
12	Batjargal	Byambadorj	M	Spinal cord injury
13	Magnadavaa	Khulan	F	Hydrocephalus
14	Sergelen	Namuuntsetseg	F	CP
15	Turukh	Urantugs	F	Spinal cord injury /severe, neck injury/
16	Gan-Ochir	Batdelger	M	Blind
17	Ganbalt	Gunjidmaa	F	CP
18	Byambadorj	Nyam-Ochir	M	Spinal cord injury /severe, neck injury/
19	Saikhanbayar	Sandag	M	CP
20	Narangerel	Tamirkhuu	M	Spinal cord injury /severe, neck injury/
21	Zorigt	Gansukh	M	Epilepsy
22	Nasanbat	Temuulen	M	CP
23	Jantsan	Bataa	M	CP

24	Erdenebileg	Misheel	F	CP
25	Bold	Bolor	F	CP
26	Aaraa	Myagmarsuen	M	CP
27	Erdenebaatar	Nomintsetseg	F	CP
28	Demberel	Selenge	F	Spinal cord injury
29	Ganbat	Altankhuyag	M	Low vision
30	Bayarmagnai	Elbegdorj	M	CP
31	Altankhuyag	Tsenguun	M	Hard of hearing
32	Gantogtoh	Bayartsetseg	F	Left arm amputation
33	Khandmaa	Otgondelger	M	CP
34	Gotov	Tsedendambaa	M	Spinal cord injury
35	Boldsaikhan	Bayarsaikhan	M	Deaf
36	Ser-Od	Saranchimeg	F	Poliomyelitis
37	Uul	Davaadorj	M	Spinal cord injury
38	Munkh-Erdene	Duulim	M	Epilepsy
39	Chinggis	Enkhsaikhan	F	CP
40	Enkhbayar	Khasar	M	Hemiplegia
41	Batnairamdal	Munkhbat	M	Spinal cord injury
42	Tugsdelger	Tugsjargal	F	Hard of hearing

Annex 2

TECHNICAL ADVISORY GROUP (TAG)

No	Name	Organization	Sex	Disability type
1.	Ya.Avirmed	Mongolian Federation of Independent living center	M	Moving (wheel chair user)
2.	Ch.Undrahbayar	Mongolian Federation of Independent living center	M	Moving (wheel chair user)
3.	B.Chuluundolgor	National Association of Wheel chair users	F	Moving (wheel chair user)
4.	D.Ganbold	Officer, Disability development department, Ministry of Labor and Social Protection	M	Moving (hand)
5.	Bolormaa	Chair, Blind youth association	F	Seeing (blind)
6.	Oyuntsetseg	National RHB Center	F	Hearing (deaf)
7.	Myagmarsuren	Lecturer, Mongolian Education University	F	-
8.	Erdenetsetseg	Lecturer, Nursing School, National University of Medical Science	F	-
9.	T.Batdulam	Executive director of AP CBR Networking	F	Mother of disabled person

10.	O.Ganchuluun	Exectuive director, National Center of Mental Health	F	-
11.	T.Altantsetseg	Sociology dept, Management Academy	F	-
12.	S.Enhsaihan	Management dept, Management Academy	F	-
13.	Sunil Deepak	International Research Coordinator	M	-
14.	Giampiero Griffo	RIDS & DPI Italy	M	Moving (wheel chair user)
15.	L.Enhbuyant	Tegsh Niigem NGO, Secretary	M	-
16.	B.Battsetseg	Rapporteur	F	-

Annex 3

Classification of Different Kinds of Barriers

People's Attitudes, Beliefs & Behaviour (including cultural & social factors)	Family	Close family
		Extended family
	Community	Friends
		Neighbours
		Formal & Informal leaders
		Others in community
	Service Providing Personnel (Govt., Private, Non-profit, all)	Health
		Education & Vocational Training
		Transport
		Livelihood
		Social welfare
		Justice
		DPOs
		Other services
	Persons with disabilities themselves	Lack of self-confidence, isolation ...
Environment	Natural	Terrain
		Water bodies (wells, ponds, rivers, lakes)
		Climate (heat, cold, snow ...)
	Built for Collectivity (Buildings)	Roads, sidewalks, crossings
		Public services (hospitals, schools, offices, courts, parks, markets, stadiums, cinema, toilets, airports, railway stations ...)
	Built for members (Buildings)	DPOs, clubs, associations
	Built for individuals (Buildings)	Homes
Policies, Systems affecting Service-Provision	Health	General health services
		Rehabilitation services

		Access to medicines
		Access to assistive technology
	Education	School education
		Higher education
		Professional courses
		Vocational & Technical training
	Social Welfare	Pension
		Personal assistance
		Access to assistive technology
		Disability certificate
		Other assistance such as for transport
	Labour	Job Reservations, incentives
		Work place adaptation
	Others	Such as legal support, inheritance rights, marriage and family rights
Information & Communication	Written	Font size, colour, contrast
		Easy to understand and use of illustrations/pictures
		Software (voice to text, text to voice)
	Spoken	Communication board or device
		Sign language
		Loop and transmission to hearing aids
		Subtitles
	Visual / Video	Sign language
		Subtitles
		Commentary for films and events
Economic	Financial resources	Additional costs of living for ADL
	Loss of income	For family care-givers
Products and Technology	Smartphones	
	Car modifications	

	Adapted cupboards, kitchen, etc.	
	Sexuality	
	Others	