Barriers Faced by Young Adults with Disabilities in Ulaanbaatar, Mongolia

Report of a Community-Based Emancipatory Disability Research (CB-EDR)

“ТЭГШ НИЙГЭМ ХОЛБОО”
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The 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 (EuropeAid/154970/DD/ACT/MN). This project was managed by Tegsh Niigem/Mongolia along with AIFO/Italy.

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Cover Picture credit: L. Turbat (Participants of the CB-EDR review meeting, Ulaanbataar, June 2019)

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Acronyms

AIFO	Italian Raoul Follereau Association
AP-CBID	Asia Pacific Community-Based Inclusive Development
AT	Assistive Technology
CB-EDR	Community-Based Emancipatory Disability Research
CBR	Community-Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
DAR	Disability & Rehabilitation team
DPO	Disabled People's Association
EDR	Emancipatory Disability Research
ER	Emancipatory Research
ICF	International Classification of Functioning and Disability
ILCM	Independent Living Centre Mongolia
MoLSP	Ministry of Labour and Social Protection
MoU	Memorandum of Understanding
NGO	Non-Governmental Organisation
SCI	Spinal Cord Injury
TAG	Technical Advisory Group
UB	Ulaanbaatar
UN	United Nations
WHO	World Health Organisation

Foreword

Over the past one and half decades, our three organisations - Tegsh Niigem (Mongolia), Independent Living Centre (Mongolia) and AIFO (Italy) have collaborated in a number of programmes and activities aiming at strengthening of the rights of the persons with disabilities.

During 2018-2019, the three organisations came together to collaborate in the conduction of an Emancipatory Disability Research (EDR) as a part of funding from the European Union under the project “Closing the gap: a right -based approach towards independent living for people with disabilities (EIDHR/2017/392-819)”.

This research was aimed at understanding the barriers faced by different groups of persons with disabilities and thinking of strategies to overcome those barriers. At the same time, by involving a group of young persons with disabilities in a 18 months’ long process, the EDR aimed to prepare a group of empowered young leaders who understand the challenges faced by different groups of persons with disabilities, both men and women, and can contribute to the strengthening of Disabled People’s Organisations (DPOs) in Mongolia.

The EDR process initiated in May 2018 was completed in October 2019 and its results are presented in this report. As shown by the persons with disabilities who presented their work in EDR at the 4th Asia-Pacific Congress on Community-Based Inclusive Development (AP-CBID) in Mongolia in July 2019, this research has stimulated a number of significant changes in strengthening their participation and influenced new strategies to promote their inclusion.

Our deepest gratitude goes to the researchers of EDR, the young persons with disabilities, who participated in the process, shared their personal experiences and gathered information from the field and made this initiative possible.

We wish to thank the European Union and the Government of Mongolia for enabling and supporting the EDR process, which saw the participation of different institutions and organisations, both from Mongolia and international, including academic persons, professionals and DPOs. We express our appreciation for their contributions to this research.

We hope that this publication will help in further refining and strengthening the EDR methodology so that it can be more effective in promoting empowerment of persons with disabilities till they can fight for their own rights.

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Mongolia

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Acknowledgements

The idea of conducting an Emancipatory Research in Mongolia came from the interactions between some Mongolian DPOs and Tegsh Niigem, who asked for technical support from AIFO-Italy.

We wish to thank all the persons and organizations that participated in the initial definition of Mongolia EDR research protocol, especially all the members of the Technical Advisory Group (TAG) and their organizations/institutions. (Full list of TAG members in **Annex 2**).

We also wish to thank the different Mongolian DPOs which collaborated in the research and identified young persons with disabilities who participated as researchers and made this research possible, especially Independent Living Centre, Wheel-chair Users' Association and Blind Youth Association.

Our special thanks go to the persons with disabilities who became researchers, who collected information from the field regarding different themes and shared it during the theme meetings along with their own life-experiences, over a period of 18 months. Many of them had to make personal sacrifices and to overcome numerous barriers to continue to be a researcher. (**Annex 3** presents the list of researchers who took part in at least one research theme).

We are also grateful to the staff of Tegsh Niigem, National Federation of Independent Living Centres Mongolia and AIFO-Mongolia, for their inputs, collaboration and logistical support in organising different meetings. Our special thanks go to Ms. B.Galya, Ms. B.Lkhagvasuren, Ms. Yu.Tsolmon and Mr L. Turbat from Tegsh Niigem.

All the personal assistants for the different disabled persons played an indispensable role in ensuring their participation and smooth functioning of the research. We are grateful to all of them and would especially like to express our appreciation to them. A very special appreciation is expressed for Ms. B. Myadag who provided sign language translation for the different meetings.

Ms. B. Battsetseg collaborated with this research as its rapporteur and prepared the meeting minutes in Mongolian and English. Her contribution to the successful completion of this research was fundamental and is gratefully acknowledged.

Lastly, we would like to thank European Union for believing in this project and supporting it.

Executive Summary

Overview: An Emancipatory Disability Research in Mongolia was carried out as part of a project aimed at promoting independent living among young adults with disabilities living in the national capital Ulaanbaatar (UB). It was focused on young adults with disabilities living in the 9 districts of UB and was seen as a part of the process which provides information and skills to persons for independent living. It was based on the social model of disability - it looked at the different ways in which the society creates disabling barriers which block or make difficult the participation of persons with disabilities in the different domains of life.

The idea of conducting the emancipatory research came from an interaction between some Mongolian DPOs and Tegsh Niigem, a Mongolian NGO active in the areas of rehabilitation, who then asked AIFO-Italy for technical support to conduct it.

EDR in Mongolia was implemented through a new approach called a "Community-Based Emancipatory Disability Research" (CB-EDR). A group of young persons with different disabilities were identified as volunteer-researchers by their DPOs, trained and then supported to carry out research in 12 broad areas which they had identified, over a period of 18 months. The researchers, individually or in small groups, carried out research on one theme at a time by collecting information about it from the field. They met periodically to share and discuss the findings of their research and to build a common understanding about the key issues related to the selected theme, and what could they do to overcome the barriers they had identified.

The research was supported by a Technical Advisory Group (TAG) of experts, academic researchers and DPO representatives, which provided advice and guidance to the researchers. The majority of TAG members were from Mongolia and were persons with disabilities themselves.

The key assumption underlying the CB-EDR approach was that understanding the barriers and collectively reflecting on them and discussing actions to overcome them, will lead to conscientization and empowerment. National DPOs and Federations of DPOs in Mongolia were informed about the basic idea of the research and asked to propose the names of persons with disabilities of 18 to 35 years of age, who were willing to commit themselves to participation in the initial 5-days long training course, followed by a 18 months long research process. A rapporteur for the research was engaged.

Initially 34 persons with moderate to severe disabilities were identified by the DPOs, who took part in the researchers' initial training in May 2018. During the training, the research implementation methodology was discussed. It was decided that the research will be carried out through periods for conducting field research followed by two-days' long meetings to discuss the information collected and to plan the next area of the research. Each meeting was supposed to focus on one specific theme decided by the researchers.

Research Implementation: During the initial training, 12 broad research themes were identified - independent living, livelihood opportunities, accessible technology, education, status in society, personal assistance, discrimination, sexuality, access to public transport, social welfare, persons living in the ger districts, and personal empowerment. It was agreed that as the research will progress, the researchers can review this list and can modify the list of the remaining themes.

Research on the first theme (barriers faced by persons living in the ger/tent districts) started immediately after the training and the first theme meeting to share the research findings was held around the end of July 2018. From then till beginning of November 2018, research was carried out on 4 themes. This was followed by a suspension of research activities for issues related to the project funding. The CB-EDR activities were restarted in March and concluded in September 2019, for a total of about 18 months.

For each theme, the researchers were supposed to go out and gather information regarding the theme of the research by verifying the different kinds of barriers, by interviewing other persons with disabilities and by talking to experts and service-providers. Sometimes, the small groups of researchers made joint plans while most of them collected information individually. Sometimes, as part of the information collection, they took pictures or recorded videos.

To share the research findings and to discuss their significance and to plan action to overcome the identified barriers, a 2-day meeting was organised for each theme. During these meetings, they planned how to conduct the research on the next theme. For each theme meeting, detailed meeting minutes were prepared in Mongolian and translated into English. From the minutes an official report of the meeting was prepared and shared with the researchers and TAG members. The meeting minutes were coded for different kinds of barriers and were analysed by the researchers to identify the main kinds of barriers which influenced people's lives in different thematic areas.

Findings: The discussions on the 12 selected themes brought out a great richness of details about how different barriers influence and affect different life-domains. The importance of different kinds of barriers changed for each domain. The broad themes meant that each researcher was free to choose and focus on a specific area, with the advantage that different researchers could focus on different areas and bring in different kinds of information about the themes. However, at the same time, this meant that all the different aspects of themes were not covered in the research.

On the other hand, as the research progressed over a period of about 18 months, the researchers had initiated different actions to overcome or at least reduce the impact of the barriers they were studying. These actions were not always well documented in the research reports as these often took place after the theme meetings. Information about these actions was known to the researchers but was documented partially during the first review meeting in June 2019, which showed remarkable impact of the research in influencing positive changes.

At the same time, the EDR process contributed to the empowerment of persons with disabilities who took part as researchers. Both the qualitative analysis and quantitative measurement of empowerment among the researchers confirmed this.

At the end of the research process, all the English translations of the meeting minutes were coded for different kinds of barriers and analysed by the international coordinator, for the preparation of this report. This analysis shows that the research carried out through the CB-EDR approach does not have the characteristics of a good academic research – on each theme, some issues are looked at and discussed in detail, while others are discussed superficially or ignored. In spite of its limitations, the analysis shows that the research has provided hitherto undocumented details regarding the different ways in which different kinds of barriers create hurdles the daily lives of persons with different disabilities in an urban and semi-urban context in Mongolia.

At the same time, CB-EDR poses some fundamental questions about what is research, what are its objectives and for whom it is done. Normally research is something done by persons with suitable academic training to understand issues and to find solutions to problems, though transferring the new knowledge and understandings into practical action is not always easy and takes time. In CB-EDR, the research was done by persons without academic training and was not documented properly during all its phases. Though the information they discovered was new for them, it may not be completely new for academics. However, its translation into practical action was sometimes swift, and though it was not always immediately effective, it did start a process of change. For the researchers of CB-EDR, their own empowerment was a key goal which they felt that they had achieved.

Conclusion: CB-EDR approach cannot answer all the different research needs related to disability, rehabilitation, inclusion and participation but the experience in Mongolia shows that it should be considered as one of the research strategies alongside academic ER and conventional qualitative and quantitative research, in understanding different aspect of the disability experience.

Introduction

The Community-based Emancipatory Disability Research (CB-EDR) was carried out over a period of 18 months by a group of young persons with moderate to severe disabilities living in Ulaanbataar, the capital of Mongolia. This research was rooted in the social and human rights models of disability and its principal inspiration was the international Convention on the Rights of Persons with Disabilities (CRPD) approved by the General Assembly of United Nations in December 2006.

The overarching theme of this research was looking at the factors which challenge or facilitate the daily lives of young persons, both men and women, of diverse socio-economic backgrounds and with different kinds of disabilities. It focused on 12 inter-connected specific themes.

This research has generated a huge amount of information - it has provided a richness of details and depth of understandings about the different barriers faced by young persons (19 to 35 years old) in the Mongolian urban and semi-urban context, which was missing so far. At the same time, it has helped to initiate practical actions to change and dismantle those barriers in different ways.

This report is an endeavour to present some of learnings from this initiative, which saw a dedicated involvement and participation from a large number of stakeholders, especially the persons with disabilities who volunteered to be the researchers and their organisations. Documenting this research was a huge challenge and in spite of so much efforts, some of the information collected during the research remains undocumented.

In this report the terms “emancipatory research” (ER), “emancipatory disability research” (EDR) and “community-based emancipatory disability research” (CB-EDR) have used in different places to characterise it or to place emphasis on the different aspects of the research. The report mostly uses the term “persons with disabilities”. However, at places, for improving its readability, the term “disabled persons” has been used, as understood through the social model (that is, persons disabled by the barriers).

The main report is divided into 2 parts – part 1 dealing with concepts and methods; and part 2 dealing with research findings and their significance.

CB-EDR is a people’s research – a research done by persons in the communities to answer questions which matter to them. The research process lasted for 18 months, during which the persons with disabilities collected information, discussed and analysed it and looked for solutions to the problems they were identifying. This report presents some of the information about that process and its results. It recognises that this research methodology is still developing and its process documentation was partial. To ensure that this report is accessible to the researchers themselves, it has been written in simple language and has tried to avoid jargon.

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 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. One problem was that meetings were too short, one day was not enough for everyone to share everything. There are differences among us and there was some discrimination among us, which was not easy to overcome. The two groups of the researchers, persons with cerebral palsy (CP) and the wheel-chair (WC) users, they were big and they dominated the discussions. While the CP persons were friendly, the WC users were less friendly, they talked in their own group and did not mix so much with the others.

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 I didn't say anything. Then slowly, I came out of my shell. Now, I always share my ideas and feelings, and I think that 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. In my school and in my class, other girls used to look at me strangely, because I did not understand what they were talking about. Now I understand them and I can talk back to them.

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, I didn't understand who was going to be the researcher, and when they said that I will be the researcher, I thought that I didn't know anything and 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. For the first theme research about people living in the Ger districts, I decided to go and visit a person I knew a little bit, who lived in a ger district. It was my first visit to such a place and I understood the kind of challenges he was facing.

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. Before I was silent, now I can express myself.

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. My mother looked after all the financial problems, she was solving them for me. 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.

PART 1

BACKGROUND, THEORETICAL INSIGHTS & METHODOLOGY

Chapter 1 - Background and Theoretical Insights

1.1 BACKGROUND

An Emancipatory Disability Research (EDR) was carried out under the project "*Closing the gap: a right-based approach towards independent living for people with disabilities*" (EuropeAid/154970/DD/ACT/MN). This project focused on the strengthening of Civil Society Organisations (CSOs) and Disabled People's Organisations (DPOs) in Mongolia at provincial and district levels, especially in terms of human rights. A key aim of this project was to promote empowerment of the persons with disabilities through the CSOs and DPOs.

Italian Association Amici di R. Follereau (AIFO) has been active in Mongolia since early 1990s, when the national CBR programme called 'Tegsh Duren' (Full Equality) was started in collaboration with the Ministry of Health, with technical support from the Disability & Rehabilitation team of the World Health Organisation (WHO/DAR). From the beginning of the program in 6 provinces of Mongolia in 1992, Tegsh Duren CBR program gradually expanded to other provinces and in 2011 it became a national programme of the Government of Mongolia.

Around 15 years ago, a key partnership was forged between AIFO and Tegsh Niigem, a Mongolian NGO, active in the areas of livelihood, social participation and empowerment. Since then, they have been working together in close cooperation with different Disabled Peoples' Organisations (DPOs) and DPO-Federations of Mongolia. In 2018, Tegsh Niigem signed a Memorandum of Understanding (MoU) with the National Commission of Human Rights in 2018 for strengthening the rights of persons with disabilities and to assist the Commission in identifying any violations of those rights.

The idea of carrying out an EDR came from interactions between some DPOs and Tegsh Niigem, and it was included in a project proposal, which was approved by the European Union. It was seen as a key activity for understanding the most significant barriers facing persons with disabilities in different life-domains in Mongolia. At the same time, it was felt that it will inform and sensitize the DPOs and other stakeholders regarding those barriers and will help in initiating grassroots level action for overcoming them. It was decided to focus on young persons with different disabilities (18 to 35 years) so that a group of young future DPO leaders can be prepared, who understand the different challenges facing disabled persons in Mongolia and fight for their rights.

The idea of the research was proposed to the national DPOs of Mongolia. Some of them agreed to participate in the research by mobilising their members to volunteer for the role of researchers. The disability department of the Ministry of Labour and Social Protection (MoLSP) also decided to collaborate by authorising a person with disability working in that department to be one of the researchers. Different other academic institutions of Mongolia were also informed about the research and they agreed to delegate their representatives to be a part of the Technical Advisory Group (TAG) which provided external support to the research. Thus, this emancipatory research initiative was a joint effort involving DPOs, NGOs and some public and private institutions.

1.1.1 General Information About Mongolia

Mongolia is a large and sparsely populated, landlocked country in eastern Asia, south of Russia, north of China and east of Kazakhstan. The roughly oval shaped country covers an area of 1,564,100 km². Mongolia has a population of just over 3 million people (2016), making it one of the least densely populated countries in the world.

Mongolia won its independence from China in 1921. A communist regime was installed in 1924. During the early 1990s, the ex-communist Mongolian People's Party gradually yielded its monopoly on power. In 1996, the Democratic party won the national elections. Since then different political parties have been alternating in the national parliament. Today the country is a semi-presidential representative democratic republic with a multi-party system. President is the chief-of-state with mostly a ceremonial role. Prime Minister, elected by the parliament called State Great Khural, is the head of the government.

The capital city of Ulaanbaatar and the northern city of Darkhan support the highest population densities, while around 40% of the country's workforce is nomadic, herding livestock in the extensive pasturelands. About one-third of the total population lives in Ulaanbaatar (UB). The country is characterized by vast semidesert and desert plains, grassy steppe, mountains in west and southwest, and, Gobi Desert in south-central parts.

The whole of Mongolia is considered to be a part of the Mongolian Plateau. The highest point in Mongolia is the Khüiten Peak in the Tavan bogd massif located in the far west part of the country at 4,374 m (14,350 ft). The Uvs Lake basin in the north-west, bordering with Tuva area in Russia, is a natural World Heritage Site.

Mongolia is divided into 21 provinces (Aimags) and subdivided into 329 rural districts (Sums or Somons). The somons are subdivided into sub-districts (Horoo), while the smallest administrative units are called “Bags” (roughly translated into communities or villages, though they can cover more a few hundred kms and have a tiny, scattered human population with a large number of domestic animals).

The capital Ulaanbaatar (UB) is administrated separately as a capital city and is divided into 9 urban districts. In the reports, usually the term “district” is reserved only for city districts of UB, while the rural districts in the provinces (aimags) are called ‘somon’.

Ministry of Health (MoH) reaches the peripheral administrative units, Bags, through the community-health workers known as Feldscher. In case of need, the feldschers can refer persons to the most peripheral health units, usually located in Horoo or Somon-centres. Ministry of Labour and Social Protection (MoLSP) which deals with social welfare and social protection activities related to persons with disabilities and elderly persons, has its lowest level of functionaries at the Somon level. Similarly, Ministry of Education (MoE) also reaches down up to the Somon level.

1.1.2 Demographic information

This information was taken from the ‘Statistical Yearbook 2018’ of the Ministry of Labour and Social Protection (MoLSP).

The estimated resident population of Mongolia in 2018 was 3,188,347 (M 49.3%, F 50.7%); 67.4% of the population was urban. Average life expectancy was 70.2 years (M 66.1 Yrs, F 75.8 Yrs). Around 32% of the population had less than 18 years.

Working age population was 1,358,637 (M 53.8% & F 46.2%), out of which the unemployed were 7.78% (M 57.7%, F 42.3%). Out of the unemployed, 24,964 persons were registered with employment services and included only 437 persons with disabilities (1.75% of the registered unemployed). This means that majority of persons with disabilities of working age in Mongolia, who are unemployed, are not registered with the employment services.

The population growth rate in Mongolia has been decreasing in recent years: in 2014 it was estimated to be 2.3 while in 2018, it was estimated to be 1.7. Keeping in mind these trends, the population is expected to reach 3,817224 by 2030 and to be 4,920,406 persons by 2050.

The number of old persons living alone in 2018 was only 1.24%, that is 39,620 (M 26.1%, F 73.9%). The number of elderly persons and old persons living alone, is also expected to increase in the coming years.

1.1.3 Persons with Disabilities in Mongolia

The data regarding persons with disabilities and elderly persons in the MoLSP Year Book is based upon persons registered to receive disability pension and old age pension respectively. Total number of persons with disabilities was 105,730 (43.5% females and 56.5% males), about 3.3% of the total population. About 33.7% of all the persons with disabilities in Mongolia were in the national capital Ulaanbaatar, while the remaining 66.3% were in the provinces.

According to the National Statistic Institute of Mongolia (2018), the total population of UB was 1,417,000 persons, out of which 797,000 persons (56% of the city population) were living in the ger districts, named because of the ger (tent) houses. Ger districts are areas where immigrants coming from the countryside first settle and where city infrastructures such as roads, public transport, potable water supply and sanitary network are lacking and where public services such as health centres and schools are limited. Life in the ger districts is difficult for all inhabitants, even more so for persons with disabilities.

1.1.4 Previous Research on Barriers Faced by Persons with Disabilities in Mongolia

There is little published research in English regarding persons with disabilities in Mongolia. Most of the identified papers were related to presentations made at the CBR conferences, especially at the Asia-Pacific Community-Based Inclusive Development (AP-CBID) conference held in Mongolia in July 2019. Most of these papers were related to impact of specific interventions in the areas of health, education or income generation. No papers could be identified regarding social model of disability and the barriers faced by persons with disabilities, except for three papers presented by the researchers of the EDR.

Only one other research paper on barriers faced by disabled persons in Mongolia was identified, dealing with a research on the environmental barriers faced by persons with spinal cord injury (SCI) in Mongolia. (Dorjbal D., et al., 2019) In this research, 16 persons with SCI were interviewed to identify the barriers they encountered in their daily lives. The main barriers were – physical environment, absence of wheelchair-friendly transportation, negative societal attitudes, inadequate health and rehabilitation services, lack of access to assistive devices and medicines, limited financial resources for healthcare, and inaccurate categorization of disabilities in national laws.

1.2 THEORETICAL INSIGHTS: SOCIAL MODEL OF DISABILITY, EDR & EMPOWERMENT

Mike Oliver who coined the term "emancipatory research" in 1990, explained the limitations of conventional research on disability: "*Research has essentially failed disabled people on at least three counts. Firstly, it has failed to accurately capture and reflect the experience of disability from the perspective of disabled people themselves. Secondly, it has failed to provide information that has been useful to the policy making process and has contributed little to improving the material conditions under which disabled people live. Thirdly, it has failed to acknowledge the struggles of disabled people themselves and to recognise that disability is not simply a medical or welfare issue, but a political one as well.*" He proposed that persons with disabilities themselves should be involved as researchers on disability issues. He also underlined the need for producing "*collective accounts of collective experience*" in the emancipatory research. (Oliver M., 2002, p. 4)

Today the term "emancipatory research" is being used in diverse ways by persons working with different vulnerable and marginalised population groups. "*It is an umbrella term that can include many streams of critical theory based research such* *as feminist, disability, race and gender theory*."(Noel L., 2016) Academics conducting research involving different marginalised or vulnerable population groups, use this term. For example, a systematic review of emancipatory research looked at 45 articles related to education sector (Behar-Horen-Stein L. & Feng X., 2015), and it was not related to disability issues.

Therefore, for each emancipatory research, it is important to indicate the specific marginalised population group which is leading the process. This is necessary because the issues, problems and barriers facing each group of marginalised persons can be very different. For example, the problems faced by a group of persons with disabilities can be very different from those faced by a group of sex workers.

In future it would be worthwhile to study, analyse and compare emancipatory researches carried out among different marginalised groups to see their similarities and differences. For this reason, in this report the term "emancipatory disability research" has been used to distinguish it from emancipatory approaches used with other marginalised groups.

EDR methodology used in Mongolia incorporated elements from the participatory research methodologies and ideas of Brazilian pedagogist Paulo Freire, developed in the 1960s and 1970s. A brief review of theoretical underpinnings about different ways of understanding disabilities, the evolution of social model of disability, development of EDR approach, its role in promoting empowerment and its links with the international Convention on the Rights of Persons with Disabilities (CRPD) is presented here.

1.2.1 Impairments and Disabilities

According to the CRPD (UN, 2006), persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. The Preamble to the CRPD acknowledges that disability is "*an evolving concept*", but also stresses that "*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others*".

According to the World Disability Report (WHO & WB, 2011, pp.3-4), disability is a part of human condition and almost everyone will be temporarily or permanently impaired at some point in life, while those who survive to old age will experience increasing difficulties in functioning. This report looks at disability as complex, dynamic, multidimensional, and contested.

The World Report used the International Classification of Functioning and Disability (ICF) as its basic conceptual framework, according to which, functioning and disability are seen as a dynamic interaction between health conditions and contextual factors, both personal and environmental. (WHO, 2001) The health conditions related to disabilities can be visible or invisible, chronic or temporary. According to ICF, certain groups of persons with disabilities face greater disadvantages. For example, women with disabilities face disadvantages associated with gender as well as with disability.

Similarly, persons with mental health conditions and intellectual impairments face greater disadvantages compared to other groups of disabled persons. (pp. 6-7)

Both, the CRPD and the World Report on Disability use the words ‘impairment’ and ‘disability’. These two terms can be seen as part of a continuum, or different aspects of a single experience and it is difficult to determine where impairment ends and disability starts. “*Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision*”. (Shakespeare T. & Watson N., 2002).

1.2.2 Social Model of Disability

Professionals had seen disability mainly as a medical issue, a problem of the individual, who has to be treated and if possible, “normalised”. The conceptualisation of the Social Model, which identified society as the cause of disability by isolating and excluding persons with impairments, turned the understanding of disability completely on its head. It argued that it was not the impairment that was the main cause of the social exclusion of disabled people but the way society responded to people with impairments. (Oliver M., 2004)

As explained above, ICF (WHO, 2001) took account of the social model by incorporating the influence of environmental and personal factors on participation of disabled persons. The transition from an individual, medical perspective to a structural, social perspective has been described as the shift from a ‘medical model’ to a ‘social model’ in which people are viewed as being disabled by society rather than by their bodies. The medical model and the social model are often presented as dichotomous, but disability should be viewed neither as purely medical nor as purely social: persons with disabilities can often experience problems arising from their health condition. Thus, the World Report on Disability suggests a balanced approach, by giving appropriate weight to the different aspects of disability. (WHO & WB, 2011, p. 4)

1.2.3 CRPD and Emancipatory Research

The approval of the International Convention on the Rights of Persons with Disabilities (CRPD) in December 2006, stimulated a review of existing laws and services related to disabled persons across the world, emphasising that the condition of persons with disabilities is a human rights issue. Thus, the links between personal characteristics, environment and social behaviour presented in ICF, necessitate a commitment from the countries implementing CRPD to remove barriers, obstacles and discriminations for guaranteeing the full and effective participation of disabled persons in the society, equal to everyone else.

At the same time, CRPD has identified and strengthened the role of persons with disabilities and their organisations (Disabled People’s Organisations – DPOs), and asks countries to include DPO representatives in all aspects of disability-related activities (Art. 4 par. 3 of CRPD). In this sense, EDR can be seen as a part of collecting qualitative information about barriers in the countries, which can be included in the reports about progress of CRPD implementation (Art.35 of CRPD).

Point 2 of Art. 31 of CRPD, specifically asks the Governments to collect appropriate and disaggregated information which will help to identify and address the barriers faced by persons with disabilities in exercising their rights. EDR by focusing on the barriers experienced by persons with disabilities can contribute to these efforts and provide tools to the organisations of persons with disabilities to advocate for efforts to mitigate and dismantle those barriers.

1.2.4 Participatory Research & Paulo Freire

As mentioned above, the EDR implementation in Mongolia had some elements from Participatory Research approach and the ideas of Paulo Freire from Brazil. "*Changing the power-relationships between the researchers and the researched is a key aspect of this approach.*" (Chambers R., 1983)

Conventional research is a systematic process of inquiry about a subject or a problem, to create new knowledge and understanding about it. It usually does not involve the individuals related to the research subject/problem in any active roles except to answer questions and provide information. They have no role in the way the new knowledge is produced, used and disseminated. Participatory research (PR) approach evolved as an alternative system of knowledge production and sought their active participation. (Pant M., 2007)

This approach grew from the experiences of persons working with poor communities, especially in development and education programmes. (Traina I., 2015) Paulo Freire, a Brazilian philosopher and pedagogist in the 20th century, had an important impact on the development of participatory research methodologies. He proposed a research process through an ongoing non-hierarchical dialogue between the researchers and the community members in which all participating partners are equally important as problem-solvers, thinkers and learners. (Glassman M. & Erdem G., 2014)

Participatory research is a systematic collection and analysis of data for the purpose of taking action and making change by generating practical knowledge. (Macdonald C., 2012) Thus, in this approach, information collection is closely linked to practical action and producing a change.

1.2.5 Emancipatory Disability Research

Till the 1990s, social research on disability rarely involved disabled people in the research process. Moreover, the knowledge gained from the research was presented in complex technical terms and was not accessible to persons with disabilities and DPOs. (Barnes C., 2008)

Principles of Emancipatory Research: After Mike Oliver articulated the concept of emancipatory research in 1990, the idea of research on disability issues carried out by persons with disabilities themselves, was taken up by disability activists working in the academic institutions. Six principles of emancipatory research were proposed (Stone E. & Priestley M., 1996), including - the research should be rooted in the social model of disability, it should promote self-emancipation and empowerment along with removal of disabling barriers and use of plurality of methods for data collection and analysis according to the needs of disabled people involved in it.

Difference between Participatory and Emancipatory Research approaches: While both participatory and emancipatory approaches advocate for the participation of the subjects of the research in the research process, the emancipatory approach goes much further by giving the control of the decision-making process to them.

In conventional research, the information collected and the knowledge generated is owned by the researchers. In the participatory research, the information and knowledge are owned by both, the researchers and the researched. While in emancipatory research, these belong to the researched. (Swartz S. & Nyamnjoh A., 2018) However, just because a research on disability is being conducted by a person with disability does not mean that the research is based on emancipatory approach. In practice, a researcher who is also a person with disability, can conduct a research about disability issues involving other persons and not share information and knowledge with them. Thus, the issue of the 6 principles of emancipatory research are important. At the same time, in field conditions, it is possible that the boundaries between participatory and emancipatory research may be blurred.

Implementing Emancipatory research in the Field: An online search failed to identify any systematic reviews about the different kinds of marginalised population groups involved in emancipatory research. From a non-comprehensive analysis of research articles about emancipatory disability research, it seems that a majority of published articles are about theories, concepts, ethics and challenges of adopting this approach (Traina I., 2015; Chown N., et. al., 2017).

A search for articles about implementation of emancipatory disability research, showed 3 broad kinds of studies:

(1) Personal experiences of disabilities (mostly for student dissertations or Ph.D. thesis) – for example, a person who had experienced a mental health condition, or a person with mobility limitation, analysed their personal experiences (Mahipaul S., 2015; Sharma P., 2015).

(2) Inclusive research – The term “inclusive research” is used to denote mainstream research which is inclusive of persons with disabilities. (Klara M., 2014) This term has also been used for academic researchers collaborating with people with disabilities as co-researchers. The research topics are ones which are important for people with disabilities and the methods used take into account their support needs. It may be an evolutionary process in which those involved develop the skills necessary to carry out research together, and how incremental changes can bring about an increase in the direct involvement of people with disabilities in all the stages of the research process. There are some examples of inclusive research involving persons with autism and with intellectual disabilities. (Callus A.M., 2016; Chown N., et al., 2017)

(3) A research involving a small group of persons with disabilities or in a DPO (mostly for student dissertations or Ph.D. thesis) – for example, a person with a “mental disability” carried out a case study on a DPO called the African Youth with Disability Network (Kincaid K., 2013). Only a few examples of use of this approach in the field could be identified.

A search for DPOs or groups of ordinary persons with disabilities from developing countries, joining together to conduct a research without the presence of academic researchers, did not find any results, except for a research carried out by AIFO in India during 20010-11. (Deepak S., et al., 2014 A)

Difficulties of Implementing Emancipatory Research Approach in the Field: Right from the beginning when the emancipatory approach was proposed, researchers had started to raise concerns regarding difficulties of applying the 6 principles of emancipatory approach in the field conditions. (Stone E. & Priestley M., 1996)

Since then, other researchers have also described the difficulties in implementing emancipatory research. The social model advocates research agendas that are focused on the emancipation and empowerment of disabled people but, in reality, these are rarely achieved. For example, to be successful researchers need to engage with innovative and creative methodologies and to share their experiences of these within environments that welcome challenge and debate (Hodge N., 2008), which are difficult to achieve.

A key concern in emancipatory approach is about ensuring the quality of research. Skills such as selecting a research methodology, designing questionnaires, collecting information and analysing that information are all academic skills that cannot be ensured by excluding academic researchers from the emancipatory research process. The rigorous and expert application of the research skills are of vital importance if disability research is to avoid limiting the research to a mere ‘story-telling’ or ‘sharing of experiences’. Thus, academic researchers feel that emancipatory research should ensure academic rigour. (Stone E. and Priestley M., 1996)

1.2.6 Barriers Faced by Persons with Disabilities

Emancipatory Disability Research is rooted in the social model of disability and focuses on different kinds of barriers which create disablement.

The Preamble to the international Convention on the Rights of Persons with disabilities (CRPD) stresses that “*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others*”. Therefore, Art 31.2 of CRPD asks countries to collect disaggregated information about the different kinds of barriers which hinder persons with disabilities in their day to day lives and to address them to promote participation. (UN, 2006)

Thus, it is important to understand the different kinds of barriers that may be encountered by persons with different disabilities. International Classification of Functioning and Disabilities (ICF, 2001) grouped the environmental barriers in 3 groups - Services, Systems and Policies. It also mentioned the role of “personal factors” in dealing with barriers, but did not attempt to classify them. It took note that in some instances, a diverse collection of environmental factors may be expressed with a single concept such as poverty or social capital. It suggested that research was required to determine whether there were clear and consistent sets of environmental factors that constituted these terms.

There is a counter-side to the barriers – the facilitating factors. For any given limitation (i.e., potential disability), the amount of actual disability experienced by a person will depend on the nature of the environment, that is, whether the environment is positive and enabling (and serves to compensate for the condition, ameliorate the limitation, or facilitate one's functional activities) or negative and disabling (and serves to worsen the condition, enhance the limitation, or restrict one's functional activities). (IoM, 1997, p. 147)

The Different Categories of Barriers: There has been much more focus on identifying and categorising the different kinds of barriers compared to the efforts for identifying enabling factors. However, theoretically the opposite of a barrier is/can be an enabling factor. For example, if negative attitudes are a barrier, positive and encouraging attitudes are enabling; and if stairs are a barrier, lifts and ramps are enabling. Thus, the classification of barriers can also be applied to the enabling factors.

There have been many attempts to define and classify the barriers encountered by persons with disabilities. For example, the Craig Hospital Inventory of Environmental Factors (CHIEF, 2001) identified 5 kinds of barriers (accessibility, accommodation, resource availability, social support and equality). It measured disabilities/difficulties across 4 categories – mobility difficulties, self-care-ADL difficulties, communication difficulties and learning difficulties. It had a 2-step process: first asking how frequently did the person encounter the barrier; secondly asking, when a barrier was encountered, how big a problem it was for the person.

Other studies have suggested some variations to the CHIEF list. For example, in case studies on access to public health services in South Africa, four broad areas of barriers emerged from the participants' experiences: structural and environmental factors, systemic factors, activity limitations, and personal and cultural factors. (Gubela M., et al., 2017)

Defining and focusing on the concept of barriers is fundamental to the idea of emancipatory research since it aims at promoting empowerment through a collective research process among different marginalised population groups by identifying and then mobilising against those barriers. However, do different marginalised groups face same or similar barriers? Probably, the kind of barriers faced by different groups are same – attitudes, social-cultural, economic, education, physical, etc., though their relative importance may be perceived differently among different groups. No studies could be identified which compared the barriers between different marginalised population groups.

1.2.7 Empowerment & Its Measurement

Empowerment is not a new concept. Every society has local terms for autonomy, self-direction, self-confidence, self-worth. What is new is the effort to understand and measure it in a systematic way. (Biggeri M., et al., 2019)

Empowerment is broadly seen as increasing poor people's freedom of choice and action to shape their own lives. There are four key elements that can change power relations between marginalised people and powerful actors and thus promote empowerment - access to information, inclusion and participation, social accountability, and local organizational capacity. (Narayan D., 2005)

At the same time, persons involved in community development programmes point towards the complexity underlying the concept of empowerment. "*Empowerment is a contested concept and a moving target. It comprises complex, interrelated elements embracing values, knowledge, behaviour and relationships. The empowerment process is non-linear and depends largely on experience gained from opportunities to exercise rights that are inherently context specific. So, for example, people may become socially empowered but have limited political empowerment in one context, but may become relatively politically empowered with limited social empowerment in another.*" (Jupp D. & Ali S.I., 2010, p. 16) Thus, many activists and organisations working for decades with poor persons, landless peasants and women's rights, think that empowerment can be clearly defined or measured.

Therefore, a critical analysis of the different attempts to define and measure can be a useful starting point to see how others have tackled it. For example, Kabeer, who has worked on gender issues and women's empowerment, considers empowerment as a *process of change* through which those who have been denied the ability to make choices acquire the ability to do so. The 'ability to make choices' needs a possibility of alternatives to choose from. She also makes distinction between strategic life choices, such as choosing livelihood, getting married, and having children, and secondary life choices, which may be important for one's quality of life but do not constitute its defining parameters. (Kabeer N., 1999)

Empowerment has also been defined as "*the ability to imagine one's world differently and to realize this vision by changing power relations that have been keeping marginalized people in poverty*" (Eyben et al. 2008, 5). This definition gives precedence to a process of internal transformation, where the person learns to think and 'dream' in a different way.

Looking at activities carried out for promoting empowerment, can give an indirect view of understanding it. For example, a manual (WHO, 2013) on promoting community empowerment among the women sex workers for fighting HIV infection, suggested the following activities: bringing together the sex workers in a mutually supportive environment, removing barriers to full participation, letting them lead the process of identifying their priorities and context-appropriate strategies and strengthening their meaningful participation in programme design, implementation, management and evaluation.

Measuring Empowerment: There have been some attempts to measure empowerment in a systematic manner and two opposing approaches have been used for this purpose. One approach has been to identify different areas affecting empowerment and use these predefined categories for measurement. The other approach has been to ask persons to come up with examples of changes which they themselves perceive as significant and then, as a second step, try to categorise those examples.

A ‘Framework’ proposed in a World Bank document was one of the first comprehensive approaches towards proposed the measurement of empowerment. It had a complex structure with domains (state, market and society), a large number of sub-domains, levels (agency and opportunity structures) and grades (macro, intermediate and local). (Alsop R. & Heinsohn N., 2005) This was an example of using predefined categories to measure empowerment.

An example of the second approach comes from a development programme in Bangladesh. First the participants used drama, story-telling, songs, picture making, conversations and debate to generate statements which described their experience about empowerment. These were consolidated into categories through a participatory exercise, about which each of them expressed a score to indicate if they had achieved it or not. Then the results of the self-assessments were aggregated and processed by persons with technical expertise. The data was categorised and weighted to enable analysing trends, distributions and correlations. (Jupp D. & Ali S.I., 2010, p. 17)

Both the approaches suggest an index of areas, life-domains and activities for looking at empowerment, rather than using one specific indicator. For example, a manual on women’s empowerment, presents a 3-dimensional empowerment framework. It asks persons to choose some questions regarding their strategic life-choices from an index focussing on 4 themes - political and legal; income and entrepreneurship; socio-cultural; and, psycho-emotional. These 4 themes can be related to 3 areas – home, livelihood and community. Finally, it considers empowerment process at 4 levels – (i) gaining knowledge (ii) availability of material and non-material resources (iii) aspiring for a change, and (iv) taking actions. A Likert Scale is used to score if the persons agree or disagree with each statement. (Carr A., 2016)

Measuring if an intervention or an activity has brought about a change in the empowerment, would ideally require a comparison with a baseline. Ideally, there should also be a control group so that we can differentiate between changes due to specific interventions compared to other changes. However, having baseline information at the beginning of an emancipatory research process and involving control groups such as non-disabled persons, may not be easy.

However, none of approaches used for measuring empowerment have been standardised for use among persons with disabilities. A systematic review of the instruments used for measuring empowerment in persons with disabilities (Bakker L. & Van Brakel W.H., 2012) had concluded that none of the questionnaires were developed or validated in a developing country while the psychometric properties and equivalence criteria were not adequately described and measured in any of the reviewed article.

CONCLUSIONS

Emancipatory disability research is rooted in social model of disability, which focuses on the way the environment and the society create barriers around persons with disabilities. There is limited published EDR from developing countries and about young persons with disabilities, even less in Mongolia. Art. 31.2 of CRPD asks for collection of disaggregated data on barriers, so that action can be taken to increase participation.

Activists with a personal experience of disability, advocating for an emancipatory approach to research believe that an epistemological shift can be brought about by recognizing the importance of personal knowledge of disabled people and its transformative social potential through c*onscientization* or critical consciousness. (Miranda-Galarza, B., et al., 2013) However, there are limited examples of promoting such an approach among different groups of persons with disabilities in developing countries which lead to collective empowerment.

Another challenge is how to ensure a high quality of research in EDR among marginalised groups in developing countries, where participation of experienced and knowledgeable academic researchers is difficult and even if possible, needs to be evaluated carefully in the context of persons with disabilities without any research experience and with limited education. The models of emancipatory research developed so far, maintain some power imbalance between the researchers and the researched, even if both are persons with disabilities, and their impact in changing people's lives remains limited.

Another challenge is that of defining a way of measuring a change in empowerment among groups of persons with different disabilities in the context of developing countries. There are no standardised approaches to measuring a change in empowerment in the context of an emancipatory disability research.

Chapter 2 - Methodology

2.1 OVERVIEW

Emancipatory Disability Research (EDR) in Mongolia was carried out as part of a project aimed at promoting independent living among young adults with disabilities living in the national capital Ulaanbaatar (UB). Around 1/3rd of the total population of Mongolia lives in UB. The city is divided into 9 districts and includes urban districts (where persons live in apartments) and ger districts (where relatively poorer persons immigrating from the countryside live in tents or simpler houses). Thus, organising the EDR in Ulaanbataar, helped in focusing on barriers faced by a large number of persons with different disabilities living in urban area and semi-urban areas, and to work together with different national DPOs.

This research was focused on young adults with disabilities of 18 to 35 years living in the 9 districts of UB. It was planned as a part of the process which provides information and skills to persons for independent living. It was based on the social model of disability, and the researchers were asked to focus on understanding and identifying the different ways in which the society creates disabling barriers which block or make difficult the participation of persons with disabilities in the different domains of life.

It implemented a new model of EDR which had been tried over the past decade by the Italian non-governmental organisation AIFO in a few developing countries. The term "Community-Based Emancipatory Disability Research" (CB-EDR) is being used for this approach, which is substantially different from other approaches to EDR identified through the literature review. In CB-EDR, a group of young persons with different disabilities, without any formal qualifications for conducting research, is provided a brief training and facilitated to become researchers without any active role of persons with formal research expertise. Instead, the personal life experiences of the researchers represent their expertise.

The CB-EDR process in Mongolia was supported externally by a technical group of experts, academic researchers and DPO representatives – Technical Advisory Group (TAG). It accompanied the research from the outside and provided some advice on demand. It had no role in the field research. The whole process was controlled entirely by persons with disabilities with varying qualifications, including some illiterate persons and was observed and documented with the help of a rapporteur.

From the outset, the discussions regarding the CB-EDR methodology had raised doubts about quality of its research findings. At the same time, it was felt that it would provide information which was not available through other more conventional approaches to research. In addition, its potential advantages were its rootedness in the civil society organisations and communities, with possibilities of influencing different stakeholders that can transfer the research findings into community action for improving the life and well-being of persons with disabilities.

This chapter presents details of the research methodology and the ideas behind selecting the CB-EDR model of research implementation.

2.2 COMMUNITY-BASED EMANCIPATORY DISABILITY RESEARCH (CB-EDR) APPROACH

The development of CB-EDR methodology can be understood in the context of the CBR programmes promoted by Italian Association Amici di R. Follereau (AIFO), which is an international non-governmental organisation, active in the area of disability and rehabilitation since late 1980s. It had been involved in community-based rehabilitation (CBR) programmes in different countries of Asia, Africa and South America, with a focus on simplification of rehabilitation knowledge and skills. It specialised in working with family and community resources, especially in urban peripheries and rural areas where there were few or no trained professionals. These programmes looked at disability and rehabilitation through a holistic lens, as exemplified by the CBR Matrix (WHO, UNICEF & ILO, 2010). Promoting self-help groups and helping them to organise themselves in organisations of persons with disabilities (DPOs) to fight for their rights, was a key component of these programmes.

The initial ideas of the CB-EDR methodology were developed during a brainstorming session by a small group of persons including disability activists, DPO representatives and persons working in an AIFO-supported CBR programmes in India. This resulted in a first CB-EDR initiative in a district CBR programme in Mandya (Karnataka, India) during 2010-12. (Deepak S., et al. 2011; Deepak S., 2012; Deepak S., et al. 2016). Since then, that approach has been adapted for other researches in different countries including India (Deepak S., et al, 2014), Palestine (Educaid, 2016) and Liberia (on-going).

The key concept of CB-EDR is to delegate full responsibility for conducting the research on persons with disabilities, even if they have limited research knowledge and skills. Thus, CB-EDR starts with an understanding that the quality of the research will be limited and cannot be compared to other approaches to emancipatory research and to other academic research. It accepts a democratisation of research conduction and places a value on the life experiences of persons with disabilities, their existing community networks and their advocacy capacities in translating the knowledge gained from this experience into actions for bringing a change.

Theory of Change approach was used to plan the research. There were 3 main pre-suppositions:

- The first pre-supposition was that persons with disabilities will gather details about the different kinds of barriers in ways which other persons without personal experiences of disability cannot do.
- The second pre-supposition was that facilitating collective reflections on different barriers among the researchers and asking them to think of community-based strategies for overcoming them, will lead to their empowerment.
- The third pre-supposition was that this will help their organisations to develop specific strategies and actions for fighting against those barriers and thus the CB-EDR will lead to practical action.

The research adopted a participatory qualitative approach for sharing life-experiences by the researchers and collecting information from the field on selected themes and then sharing them with other researchers to reflect on them and to build a common understanding about their causes and mechanisms. In terms of outcomes, this was expected to lead to building up a detailed map of barriers and facilitating factors encountered by the persons with disabilities living in UB in different life-domains.

Thus, the key assumption underlying the planned CB-EDR strategy was that understanding the issues and collectively reflecting on them, will lead to persons' conscientization and empowerment. Freire had suggested that oppressed and marginalised persons are conditioned to accept their situation as destiny, as objects of the larger society that dehumanises them. "*To empower them, the first task is to encourage them to engage in reflective action and challenge the unchallenged myths of their existence.*" (Kirylo J.D. & Boyd D., 2017, p. 80)

Reflecting upon the experiences gained from the EDR carried out in India, Palestine Liberia and Mongolia, it was felt that it is a distinct approach, different from other emancipatory approaches, and the term "Community-Based Emancipatory Disability Research" (CB-EDR) can be a useful way of describing it.

In all the different CB-EDR experiences completed so far, there were substantial differences in the way the basic idea was adapted in each research. The following steps summarise the implementation of CB-EDR approach in Mongolia:

- Identify 20-30 persons with disabilities who are willing to be researchers and can participate in periodic meetings over a period of 18 months. At least 50% of them should be women, and they should represent persons with different kinds of disabilities, different educational and socio-economic backgrounds and come from different districts of UB.
- Identify components of a Technical Advisory Group (TAG) which will provide external support to the researchers, whenever needed. TAG members can be academic researchers, disability experts and representatives of DPOs. Among the TAG members, a smaller Core Group was identified to deal with planning and logistics of different research activities.
- Organise a 5 days long training course for the selected persons with disabilities and provide basic skills in conducting qualitative research and a basic understanding about different concepts including social model of disability, respecting privacy, confidentiality of information and research ethics. During the final part of the training, the researchers identify the 12 broad themes around which they wish to conduct research.
- Identify a rapporteur who will accompany the whole process of CB-EDR and document all the formal meetings of the researchers. Also identify a team for providing logistic support for organising periodic meetings, including invitation of any guests to those meetings.
- Sharing all the meeting reports and field research reports with the researchers and TAG members.
- Organising review meetings with all the researchers and the TAG members to discuss the challenges and results of the research process at mid-point and end of the 18 months period.

- Analysing the English translations of the 12 research-theme reports by the international research coordinator and preparing a final report, which will be translated into Mongolian and shared with the researchers and the TAG members.

2.2 OBJECTIVES OF CB-EDR IN MONGOLIA

The *general objective* of CB-EDR in Mongolia was to understand the different ways in which the society and the environment create barriers to the participation of persons with different disabilities in different life-domains.

The *specific objectives* of the research were:

- To understand and map the different disabling barriers and enabling facilitating factors affecting the possibilities of independent living among young adults (18 to 35 years) with different disabilities living in Ulaanbaatar.
- To promote collective reflections on the identified barriers and to identify possible strategies for overcoming those barriers.
- To verify if the emancipatory research approach leads to empowerment of persons participating in it.

2.3 TECHNICAL ADVISORY GROUP (TAG)

An international Technical Advisory Group composed of 16 members including disability experts, academic researchers and persons with experience in community-based rehabilitation (CBR) programmes was created in June 2018. Only two of the TAG members were non-Mongolians. The members included 7 persons with disabilities and one family member of a disabled person. The work of TAG was assisted by the rapporteur for the EDR. It was coordinated by the International Research Coordinator, author of this report.

The research protocol was discussed with the TAG members and their suggestions were incorporated in the protocol. Among the key discussions of the TAG, there were issues of ethics, privacy and confidentiality in the EDR. For example, TAG had long discussions on the actions to be taken if during the research, a disabled person reported on-going domestic violence and yet does not wish any action to be taken. At the end, it was decided that all such issues emerging during the research will be brought to the attention of TAG.

TAG members were provided periodic information about the plans of research themes and asked to give advice regarding specific issues to be discussed. They were also asked to suggest specific persons with expertise or experience related to the research themes who could be invited to the meetings of the researchers. They were also provided all the theme research reports. Finally, they were expected to provide on-demand advice to the researchers according to their areas of expertise. They could also participate in the research meetings as observers. TAG members were asked to be gentle and constructive in their criticisms to the researchers.

Three meetings of TAG were organised – first at the beginning, a second review meeting after 12 months and third review meeting after 18 months, at the end of the research. For each meeting a report was prepared and shared with the members. Some of the TAG members, especially those representing the DPOs, were in closer contact with some researchers and had more opportunities to advise and to influence the research.

A core group of TAG was identified. It was composed of 5 persons, who followed the research more closely and played a more active role in planning the meetings, organising logistical support and if needed, in providing advice to the researchers. The members included the international research coordinator, the AIFO representative, a representative of a Mongolian DPO, a representative of an international DPO, and the president of Tegsh Niigem. The names of the TAG members are presented in **Annex 2**.

2.4 RESEARCHERS

The first ideas of organising CB-EDR came up during interactions between Tegsh Niigem and some DPO representatives. Subsequently, all the national DPOs and their federations were informed about the basic idea of the research. They were asked to propose the names of persons with disabilities as researchers. The researchers were supposed to be of 18 to 30 years of age, who were willing to commit themselves to participation in the initial 5-days long training course, followed by an 18 months long research process. During this process they were supposed to dedicate 5-7 days for conducting field research on each of the 12 research themes and then participate in the research-theme meetings.

The aim was to identify around 30-35 persons with disabilities, so that even if some of them were unable to participate in all the theme researches, around 20-25 persons would have been there for each theme research. There were no other pre-requisites for becoming an EDR researcher and the DPOs were encouraged to identify persons with different kinds of disabilities including persons with mental illness and intellectual disabilities.

However, following the initial communications, the DPOs and federations were unable to identify sufficient number of persons willing to be EDR-researchers. Thus, the age limit was increased to 35 years, and this helped in bringing more persons to the group.

Finally, 34 persons were identified as researchers who took part in the initial 5 days training course in May 2018 on conducting emancipatory research. 33 out of them agreed to provide general information about themselves. Demographic and general information about the researchers is provided in Chapter 3 (Results) of this report.

Following the training, some persons participated occasionally, while some others formally dropped out from EDR, after initial participation in one or few researches. Around 20 researchers took active role in conducting research and participating in most of the research meetings during the whole 18 months period. On the other hand, hearing about the research through their friends and peers, 8 new persons with disabilities joined as researchers. These received information regarding their roles from other researchers and the core group. Overall, there were 42 persons with disabilities who took part in at least one field research and one theme meeting.

No financial incentives or other reimbursements were provided to the researchers for the field research. Only the costs for their participation in the research meetings were covered from the research funds.

A list of the 42 persons with disabilities who participated as researchers in at least one theme research is given in **Annex 3**.

2.5 TRAINING OF RESEARCHERS

A 5-days training course for the researchers was carried out by the international Research Coordinator in the last week of May 2018 in an accessible location in UB. Around 34 persons with disabilities took part in the training (the number of participants varied on each day of the training with a daily average of 30 persons). A sign language translator facilitated the participation of persons with hearing impairments.

Among the participants, there were persons who needed travel assistance. Many had difficulty in sitting in one position for long periods. Some had difficulty in writing, while some had difficulties with memory and focusing attention. While these were challenges for the training, they were opportunities to create a sense of unity among the group and to promote greater understanding about the different needs of persons with disabilities.

The lessons on basics of research were adapted from a Health Systems Research manual (Varkevisser C.M., et al., 2003). They included participatory exercises on identification of difficulties faced by persons with disabilities in their daily lives and how each difficulty can have diverse primary and secondary causes. Different research approaches were explained in simple terms and the evolution of participatory to emancipatory research was discussed. This was linked to discussions about the different models of disability and their usefulness and limitations – traditional model, medical model and social model.

Some of the persons in the group had already completed “Disability Equality Training”. They shared their experiences and ideas from that training with the wider group.

There were discussions about the ethical aspects of the research to explain that discussions in the research meetings will be confidential and persons can leave the research at any point without any negative consequences. The discussions regarding ethics and respect of privacy were linked to signing of the consent forms. The group also discussed some related issues such as - the relative vulnerability of different groups of persons with disabilities, the concept of empowerment and how it can be promoted through the ER process.

Deciding the research methodology: During the training the different options for carrying out the research were discussed and decided through a consensus building approach. It was initially decided that the research will be carried out through field research followed by two-days long monthly meetings to share the findings. This will be carried out over a total period of 12 months (later extended to 18 months) and that each field research and meeting will focus on one priority theme, for a total of 12 themes.

It was also decided that each theme meeting will include testimonies from invited guests, experts as well as, persons with disabilities, who have some specific life experiences and skills related to the theme of the meeting. It will include sharing of a few life-stories by selected members of the group. It will also include group and plenary discussions around some key issues related to that theme.

Different ways of collecting information were discussed. It was decided that for each theme meeting, the group members will collect information about the issues by talking to other persons with disabilities in their local communities and collecting their experiences and views. They could prepare picture and/or video documentation regarding the theme from their local communities to share with other researchers. If they felt that it was important, they could suggest additional persons to invited as guests in specific theme meetings.

A key aspect of every theme meeting would have been discussing ways to overcome the challenges highlighted in the discussions. The researchers could propose actions to be taken by Government/State bodies, DPOs, NGOs and private organisations. However, the most important actions were those that they could make themselves.

2.6 DEFINING RESEARCH THEMES

12 broad thematic-areas were identified for the EDR through a participatory process: independent living, livelihood opportunities, accessible technology, education, status in society, personal assistance, discrimination, sexuality, access to public transport, social welfare, persons living in the ger districts, and personal empowerment. Before each of these theme research, the researchers would meet for a brain-storming session for identifying the key issues on which they wished to focus during the information collection from the field.

This selection of priority themes was provisional. Before the end of each theme meeting, the researchers would have to jointly decide the theme of the next research and the key issues they want to tackle regarding that theme. It was expected, that as they will proceed with different themes, they might wish to go into different directions with the research.

In fact, during the EDR process, the researchers did change some the themes of the research. The final list of themes on which research was carried out was as follows (dates of the theme meetings to share and discuss the collected information):

1. Barriers faced by persons living in the ger districts (28 June 2018)

2. Accessibility of Public transport (16 August 2018)

3. Accessing social welfare services for persons with disabilities (1 October 2018)

4. Barriers to Independent living (8 November 2018)

5. Barriers to expression of sexuality (16 March 2019)

6. Right to livelihood and barriers in exercising this right (7 April 2019)

7. Right to education for children and young adults (28 April 2019)

8. Discriminations faced by persons with disabilities (19 May 2019)

9. Personal assistance services in Mongolia (8 June 2019)

10. Barriers to empowerment (25 August 2019)

11. Barriers to health and well-being (13 September 2019)

12. Accessing assistive products (28 September 2019)

A summary report from each theme meeting is provided in **Annex 7**.

2.7 FIELD RESEARCH

For each theme, the researchers were supposed to go out and gather information regarding the theme of the research. Sometimes, the small groups of researchers made joint plans while most of them collected information individually. They went to visit other persons with disabilities or authorities responsible for providing services or related institutions. This provided opportunities for the researchers to go out of their familiar surroundings and experiment activities which they had never tried before.

For example, one researcher went out to a Ger district to see how people live in these areas and what are the different services available to them. Another researcher, decided to test the accessibility of the public transport system by going out and walking on sidewalks and trying to use the public buses. Some of the researchers even went to other nearby aimags (provinces) to see the living conditions of persons with disabilities outside the capital.

Sometimes the researchers used their mobile phones to take pictures or short videos to illustrate specific aspects of barriers. These were used during their presentations during the theme meetings. These were not shared with other persons and have not been used for the preparation of this report.

There were no fixed guidelines for gathering information around a theme. Individual researchers were free to decide the specific aspects on which they focused their attention. This meant that sometimes there was no information gathered regarding some specific aspects of a research theme while for other aspects, different persons had gathered similar information. Thus, each researcher was free to follow his/her own paths in terms of their own personal interests.

There were no interview guidelines or questionnaires for information collection. Some researchers did collect information on specific themes through interviews of variable quality. None of them had transcribed details of the interviews. Sometimes, the information they collected was wide, touching areas outside the specific research theme.

Viewed in terms of academic research, the information gathering on specific themes in CB-EDR was chaotic and incomplete.

2.8 RESEARCH MEETINGS AND REPORTS

For each of the 12 themes, the research was organised in the following way:

- A half day meeting to discuss the key issues related to the research theme and discussions on how to collect information regarding those issues. Some researchers also made joint plans for going out for field visits. They also discussed if specific persons related to the theme could be invited for talking about that theme.
- The researchers had one to one-and-a-half months' period for the information collection on the selected theme and preparations of power-point or text for the presentations.
- A full day meeting was organised for presenting the information gathered by the researchers on the theme, and listening to the testimonials of invited persons. After all the presentations the researchers had group discussions to identify the significant barriers affecting the lives of different groups of persons with disabilities and strategies for overcoming those barriers. Apart from discussing what should be done by the Government, NGOs and DPOs, they also discussed what they had already done and could do themselves to fight those barriers.
- Following each meeting, the rapporteur prepared the minutes and a meeting report in Mongolian, which was translated into English and finalised. The reports in Mongolian were shared with all the researchers and the TAG members.
- All the reports in English were analysed and used for mid-term review meeting in June 2019 and a final meeting at the end of September 2019. TAG members and the researchers participated in these meetings. Those same theme meeting reports and review meetings reports have also been analysed to prepare the present report.
- There were a few grey areas in terms of confidentiality of information, for the preparation of the theme meeting research reports. There were discussions if the names of individual researchers should be mentioned in relation to their specific research work in these reports. It was decided to acknowledge the names of the individual researchers who had made formal presentations during the theme meetings, unless their presentations were about sharing of their personal life experiences. For all the other discussions during the theme meetings, specific names were not used in the formal reports distributed outside the researchers' group. This same principle has been followed for the theme meeting reports presented in **Annex 7** of this report.

2.9 REPORT ANALYSIS AND UNDERSTANDING THE BARRIERS

There were 2 levels of research analysis and understanding of the barriers:

- The first level of analysis was during the 12 theme meetings during which the researchers themselves analysed the information they had collected and discussed the different barriers. This first level of analysis led to practical action in relation to specific themes.
- The second level of analysis is this report, which collectively reviews all the theme meeting reports translated into English from Mongolian. This second analysis has been translated into Mongolian and shared with all the researchers.

From a literature search on different kinds of barriers experienced by persons with disabilities, a list of kinds of barriers/facilitating factors was prepared, shared with the researchers and some TAG members, and finalised (**Annex 4**). This list of different kinds of barriers-facilitating factors was used to analyse the 12 theme meeting reports of the CB-EDR in Mongolia.

The following main categories of barriers affecting the lives of persons with disabilities were identified - People's Attitudes, Beliefs & Behaviour (including cultural & social factors), environment, Policies, Systems affecting Service-Provision, information & communication, economic factors, and products & technology. Each category had different sub-categories. Annex 4 provides details of this classification.

For the preparation of this document, all the theme meeting reports and review meetings reports were analysed and all the experiences regarding the barriers were coded according to the list of barriers. From each theme-report, all the barriers were grouped in different categories to identify the most significant barriers for that theme. Thus, while the theme reports provided a panorama of qualitative information regarding different barriers and facilitating factors, the analysis provides a quantitative idea of their importance.

2.10 EMPOWERMENT AND ITS MEASUREMENT

The possible impact of EDR on the empowerment of the researchers was measured both qualitatively and quantitatively:

(i) Qualitative review of influence of CB-EDR on empowerment of individual researchers: There were 4 specific moments touching on qualitative understanding of empowerment among the researchers during the EDR process.

An open discussion with the researchers on the meanings of empowerment for them and the influence of the research process on their individual lives was organised after 12 and 18 months of EDR. In addition, there were 2 additional qualitative inputs of the researchers on the subject of empowerment:

- The first was at the beginning of the EDR process, when different definitions of empowerment were explained during the initial training course and researchers were asked about their own understandings of the term.
- The second input had come at the end of August 2019, when the researchers had discussed the barriers to empowerment during a theme meeting focusing on this theme.

All the qualitative information regarding empowerment from these 4 moments has been analysed together.

(ii) Quantitative measurement of empowerment: There were 2 attempts at measurement of perceived change in empowerment through participation in CB-EDR.

The first attempt focused on measuring perceived changes in empowerment in 5 broad categories for a quantitative understanding after 12 months of EDR (during mid-term review). An index of 5 broad life-domains was used for this purpose – family relationships, friends and peer relationships, at school/university/work places, use of public transport system and awareness about rights. Scores were measured on Likert scale (0-7) for each of these 5 domains. **Annex 5** presents the questionnaire used for this measurement.

The second attempt on measurement of empowerment focused on measuring perceived changes through more specific questions related to 4 broad areas and was conducted at the end of the EDR process (during the final review after 18 months). The specific areas of inquiry for the second attempt were defined through a participatory process, which took into account the limitations of the first questionnaire.

Based on the 3-dimensional empowerment framework defined by the Commonwealth of Learning, the following 4 areas/domains of empowerment measurement were identified for the EDR in consultation with the researchers –

- Family (personal decision making and family decision making, talking about personal experiences to others);
- Community (participation and fighting for rights, advocacy for changing attitudes of different professionals and service providers);
- Disability (understanding about different kinds of disabilities and barriers faced by them, informing other children and adults with disabilities);
- DPO (participation and ability to intervene and express opinions).

A questionnaire with questions related to these 4 domains was prepared with a Likert scale of 1-6 and pilot tested among 2 persons, and then compiled by all the researchers. The questionnaire used for this second attempt is presented in **Annex 6**.

It was felt that since there were no standardised approaches to measurement of empowerment among persons with disabilities participating in an EDR process, looking at it through different lenses, both qualitative and quantitative, could have been useful in defining such an instrument in future.

2.11 LIMITATIONS AND CONSTRAINTS

The chief limitation of the CB-EDR approach was the lack of academic-quality research, as it did not involve any persons with research expertise in the field research. All the decisions about research themes, which information to collect, from whom, which questions to ask, how to ask them, how to record the answers and how to share that information for the documentation, were all made by persons with disabilities who had received a short 5-days' training about research but who lacked academic research skills. However, this limit should be considered as a trade-off, as the researchers brought in a wealth of life experiences, both personal and of their peers and friends, to the research. At the same time, they had a privileged access to opinions and ideas of other persons with disabilities, through the DPO networks, that would not be available to non-disabled persons.

Another limitation of the EDR was the lack of adequate literature search on different themes on which research was undertaken by the researchers. During the initial training, the importance of looking at the existing studies and published reports and papers about the theme before going out in the field to collect information was discussed. However, it was clear that the researchers did not have the skills to read academic articles and, in any case, there was very little available information in Mongolian language.

The research analysis was carried out at two parallel levels – at field level in Mongolia, by the researchers; and at international level by the international research coordinator in collaboration with some TAG members, who reviewed and analysed the reports of the theme meetings and provided some feedback to the researchers. At the field level, the researchers were almost on their own and had the freedom to decide the research themes, which aspects to focus on and how to collect information regarding those aspects.

Having these two parallel levels of research, with few spaces for interaction meant that the researchers had their own understanding of the issues they were looking at, which was different from the analysis presented in this report. The authors of this report and some TAG members participated in the review meetings and interacted with the researchers, but these were aimed more at understanding the researchers' point of views and not so much to share or explain the kind of formal analysis carried out in this report. The Mongolian translation of this report was shared with the researchers and their comments were solicited. While a few of the researchers who have a university degree, could probably understand and appreciate the analysis presented in this report, for majority of them, it would have been difficult to understand and probably it was of limited interest.

Another limitation of the CB-EDR approach was the difficulty in documenting different aspects of field level activities and the actions taken by the researchers to address some of the challenges identified during the research. The researchers gathered information on different themes individually or in small groups. As shown in the voices of the stakeholders later in this report, often they involved other persons from the DPOs in the field research. Some of them prepared formal presentations to share what they had learnt for the theme meetings. Some others prepared some notes and shared them during the meetings, while others, mainly listened to the others. During the one-day meetings, there was not enough time for each researcher to present and express their findings through presentations. It is likely that at least some of the researchers had doubts about the usefulness of the information they had collected or could have wanted to share and did not intervene during the meetings. The rapporteur could only document the formal presentations and plenary discussions made during the theme meetings and probably much of the information gathered by individual researchers remained undocumented.

This lack of documentation was especially true for the community actions initiated to tackle the challenges identified by the researchers about specific themes. For example, one researcher who had made a presentation regarding CB-EDR at an international conference, in response to question from the audience explained that following the research theme meeting on sexuality, the research report was discussed in the disability department of the Ministry of Labour and Social Protection, which had decided to start an information service on sexual and reproductive health for persons with disabilities to address the issues highlighted in the report. This information was missing from the formal reports of the research. It is possible that other similar information regarding specific actions were not always documented in the research reports.

During the review meetings, such missing information was sought from the researchers but it is likely that even then most such information was missed because those meetings had limited time, needed translation, and also because probably some of those actions were considered as unimportant by the researchers.

Finally, another limitation was not having a quantitative measurement of the empowerment level of the researchers in the beginning of CB-EDR process which could have been used as a baseline. While empowerment was measured quantitatively after 1 year and 1.5 years, these questionnaires were developed on the basis of discussions with the researchers on what was the meaning of empowerment for them and how did it express in their daily lives. It could have been useful to conduct such a participatory exercise to prepare a questionnaire also at the beginning of the process.

2.12 CONCLUSIONS

In conclusion, the CB-EDR approach methodology implemented in Mongolia had many limitations, the most significant being related to the quality of documentation of the research process and the quality of information gathering. However, this limitation is inherent in the kind of approach selected and will always be there, even if the whole process is accompanied by a trained local researcher.

Another limitation was about its impact, in terms of lack of standardised instrument to measure the empowerment of individual researchers and their DPOs, and the changes it can produce in the communities and society.

In spite of the above limitations, the CB-EDR approach is interesting since it chooses an alternative path, more in line with the spirit of ideas of persons like Paulo Freire and Richard Chambers, by focusing on conscientisation and by putting the last first. At the same time, CB-EDR approach satisfied all the six principles of emancipatory research –

- choosing an epistemology in line with social model of disability;
- surrendering the ideas of objectivity and highlighting the subjectivity of the researchers;
- focusing on changes desired by disabled persons themselves;
- turning upside down the power-relations by blurring the boundaries between the researchers and the researched;
- by politicising the personal experiences by using them to drive the change;
- collecting both qualitative and quantitative data.

It is also interesting because it links the desire for changes to collective actions to start those changes and to challenge the barriers persons have identified. Through its links with the DPOs and national federations, it has the potential to drive changes far beyond the duration of the research process – it would be interesting to look at the impact of CB-EDR process after a gap of a few years.

PART 2

RESEARCH FINDINGS & THEIR SIGNIFICANCE

Chapter 3 - Research Findings

3.1 INTRODUCTION

This chapter starts with general and demographic information about the researchers as they were also the first subjects of the research. Their personal life experiences were part of the research findings and were the starting point for information gathering from the community regarding the specific research themes.

Then, a summary of the key findings from the 12 theme researches & meetings and their significance are presented. For each theme, the researchers made collective plans, discussing the major issues and deciding which kind of information to collect and how to do it. Sometimes, they went out in small groups, others worked individually, to visit places and persons, to interview individuals with disabilities, their families or the service providers. More details about individual theme meetings can be found in **Annex 7**. During the theme meetings, the researchers shared their personal experiences and the information they had collected in the field. Some of them made formal presentations regarding their information collection and shared images of their findings. After these presentations they discussed the issues emerging from their information collection. The discussions included the actions needed to overcome those barriers.

Sometimes, the theme discussions were followed by practical actions against the barriers, including some which started during the theme meetings. These actions were initiated by the researchers. Some of them were successful and produced some results. The final part of this chapter presents findings related to actions resulting from the theme research under 2 sub-headings – (i) the understandings regarding the barriers faced by persons with disabilities in different life-domains; and (ii) the impact of the research on the barriers.

3.2 GENERAL & DEMOGRAPHIC INFORMATION ABOUT THE RESEARCHERS

The research started with 34 persons with disabilities who were selected as researchers and who participated in the first day of training. However, these 34 persons were not present on all the 5 days of training, during which average daily number of participants was 30. Many researchers were not used to sitting up for long periods required for the training and some of them had to lie down. Some were too tired after the first day and needed rest. Some had come out of homes for such an initiative for the first time and felt overwhelmed.

After the training, around 20-22 researchers participated in each research theme meeting. Some persons who had taken part in the field research were unable to come to all the theme meetings and some of them shared their findings through their friends and colleagues. Some others decided to drop out, as the participation was difficult for them due to ill health or other reasons. Some other persons who had not participated in the initial training, decided to become part of the research. Globally, 42 persons with disabilities took part in EDR as researchers by participating in at least one theme research & meeting. It required some effort to keep track of who had participated in how many field researches and theme meetings. **Annex 3** presents a summary of names, gender and main disabilities of the 42 researchers.

3.2.1 General and demographic information about the persons initially trained as researchers: The 34 persons who had come to the EDR training on the first day were asked to provide general and demographic information. A total of thirty-three (33) persons compiled the forms and provided this information which is summarized below.

Gender and age: Among them there were 16 male (48%) and 18 females (52%). Their average age was 26 years. The youngest participant was 19 years old while the oldest participant was 36 years.

Marital status: Among them the majority of persons (76%) were unmarried, while 5 were married (15%) and 3 were divorced (9%).

Residence: 32 persons (97%) were from Ulaanbaatar while 1 person was from another city called Erdenet, about 300 km away. Among the persons from Ulaanbaatar, majority of persons were from the urban districts (69%) while 11 persons (31%) were from the peripheral ger districts where services are limited and persons are poorer.

Education: 2 persons (6%) had no school education, 4 persons (12%) had studied till middle school, 7 had completed high school (21%), 8 persons (24%) had done technical education college and 12 persons (37%) had university level education.

Participation in Self-help groups (SHGs) and organisations of persons with disabilities (DPOs): Among the researchers, 9 persons (28%), almost all women, were members of SHGs.

26 persons (79%) were members of DPOs, including 6 persons who were active in DPOs for more than 5 years.

Kinds of disabilities: 11 persons (33%) had vision related disabilities – among them, 1 participant was blind and 10 persons had low vision. Among the persons with low vision, only 4 used eye-glasses.

5 persons (15%) reported hearing related disabilities – among them 2 were deaf while 3 persons were hard of hearing. Among the hard of hearing persons, only one was using a hearing aid.

14 persons (42%) reported speech related disabilities – among them, 2 could not speak and 12 persons had speaking difficulty. Among the persons with speaking difficulties, 3 persons used a technical aid for communication.

20 persons (60%) reported mobility related disabilities – among them, 17 persons were using a technical appliance for mobility (mostly wheel chairs, only 2 persons were using crutches).

10 persons (30%) reported difficulties related to memory and concentration – among them 1 person reported serious difficulties in remembering and focusing attention.

2 persons (6%) reported having convulsions and both of them were taking anti-convulsion medication. Among them, one person reported having frequent convulsions in spite of the medications.

17 persons (58%) reported difficulties in activities of daily living such as washing and dressing. Among them 11 persons had severe difficulties and needed assistance for their daily living activities.

Globally 24 persons (72%) reported more than one kind of disabilities. Among them most were persons with moderate to severe level of disabilities including one person with quadriplegia, 7 persons with paraplegia, 2 persons with amputations, and 17 persons with cerebral palsy.

Age at becoming disabled: 19 persons had disabilities since birth (58%), another 7 persons (21%) became disabled in early childhood while the remaining 7 persons (21%) became disabled after adolescence.

Personal experiences of stigma and discrimination: For 7 persons (21%) stigma and discrimination continue to be a big issue in their lives. 19 persons (58%) said that they had occasionally faced stigma and discrimination while the remaining 7 persons (21%) said that stigma and discrimination were not an issue for them.

3.2.2 Information regarding researchers at the end of CB-EDR

As explained above, there was some turn-over of researchers during the 18 months of the research. Some persons dropped out and some new persons join in. Overall, 42 persons with disabilities took part in at least one field research and one research theme meeting.

Among these 42 persons, 23 were males (55%) and 19 females (45%). Among them, there were 2 big groups – 18 persons with cerebral palsy and 10 persons with spinal cord injury. Together these 2 groups constituted 2/3rds of all the researchers.

3.2.3 Comments about composition of the researchers: Researchers represented both men and women, of different educational and socio-economic backgrounds and with a wide representation of different kinds of impairments, majority of them with moderate to severe disabilities. They came from all the different districts of UB.

Except for persons with chronic mental health conditions and persons with significant intellectual disabilities, all other groups of persons with disabilities in Mongolia were represented in the researchers.

As the above analysis shows, a large number of researchers had multiple and different kinds of disabilities. However, the group was dominated by persons with 2 kinds of primary disabilities – persons with cerebral palsy and persons with spinal cord injury, who together represented two-thirds of all the researchers.

3.3 BARRIERS FACED BY PERSONS WITH DISABILITIES

The researchers had initially identified 12 broad thematic areas for the research. During the 18 months of the CB-EDR process, some of these themes were changed. A summary of the key findings on each thematic area is presented below while the individual reports of the theme meetings are presented in **Annex 7**.

3.3.1 Barriers faced by Persons with Disabilities in the Ger districts (Meeting 01): Ulaanbaatar (UB), the capital of Mongolia includes 2 kinds of residential areas – (i) the planned residential areas with apartment buildings where residents have all the public services, and (ii) the Ger (the round shaped Mongolian tent) districts on the slopes of the hills surrounding the city, where persons coming from rural areas of the country establish their homes and where they lack basic public services such as drinking water, sewage system, central heating, roads and public transport.

At least one third of all Mongolians live in UB. Among them, between 60 to 70% of UB's population lives in the Ger districts. It is estimated that around 750,000 Mongolians live in the Ger districts, which poses specific challenges to persons with disabilities.

31% of the EDR researchers lived in the Ger districts. Other visited some Ger areas for the research and spoke to persons with different disabilities. They collected a total of 61 examples of barriers and facilitating factors – 52 examples of barriers and 9 facilitating factors.

About 56% of the barriers were related to environmental issues and another 17% to the lack of public services. The remaining 27% of the barriers were related to other life-domains - economic barriers, personal characteristics of persons with disabilities, technology and products, negative attitudes and difficulties in accessing education. There were only a few testimonies regarding facilitating factors - these were almost equally divided between - public services, attitudes, economic factors and technology & products.

Environmental barriers & Lack of public Services: These two combined to create the most significant barriers perceived by the persons with disabilities living in the Ger districts. These included issues related to the unbuilt terrain - these are hilly areas which lack roads and sidewalks, so that persons with mobility and vision disabilities face difficulties in navigating them. Another subgroup of issues was related to the lack of public services – no street lights, no signage, no water supply, no sewage system and no public transport services. The two kinds of barriers, unbuilt terrain and lack of services, interacted to worsen their impact on people's lives.

For example, lack of sewage and waste disposal services result in kitchen and washing water being poured in the open, which made walking on the untarred streets more difficult. During winters, that waste water freezes, creating further difficulties, not only for persons with disabilities.

Barriers related to built areas – buildings of public use such as shops and bath-houses, as well as, buildings for personal/family use such as homes/gers and toilets, all posed obstacles due to physical barriers such as stairs without ramps, wooden planks at the bottom of entrance gates and ger doors. Toilets pose a specific challenge, as they are located in courtyards, have narrow entrance and are usually temporary wooden structures built over holes in the ground, as there are no sewage lines.

Even inside the tents or homes, lack of central heating means that persons need to use wood stoves, which require splitting and carrying the wood, placing it in stoves, cleaning the ash, etc., all tasks difficult or impossible for some groups of persons with disabilities. On the other hand, lack of water supply means that persons need to go to water supply points and bring water containers to their homes, which again creates barriers for persons with disabilities. There is hardly any aspect of life of persons with disabilities which remains unaffected by the environmental barriers in the ger districts.

Economic barriers: 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, were raised in a few testimonies.

Negative attitudes: There were only a few examples of negative attitudes in the testimonies and were mainly related to taxi drivers, who did not want to carry the persons on wheel-chairs because they feel that these persons need extra work and take more time.

Even the internalised negative attitudes among persons with disabilities resulting in low self-esteem or lack of confidence, emerged only in a couple of testimonies. One possible reason for this could be that the other environmental, service related and economic barriers are so overwhelming that when persons with disabilities do get an opportunity for participation, they have an incentive to use that opportunity.

One testimony, of a young man who had become paraplegic after an accident, brought out a specific facet of the impact of barriers – that of loss of social role. He explained that cutting the wood, bringing water containers from the common well, all these require hard work and are a son's duty. After an accident, due to his disability, he was unable to carry out these activities and his old and sick father had to do these, which made him feel like a failure in the role of a son.

Facilitating factors: Having a ramp at home, using electric heater instead of wood stove, and having subsidized university education were cited as facilitating factors. However, often persons noted that something which was supposed to be facilitating, also had a negative side to it. For example, one person told about his visit to his university professor to talk about the physical inaccessibility of the university building and was told that he could follow many lessons from home. Thus, he felt that while the professor was facilitating his studies, at the same time, this solution was not having any impact on the removal of physical barriers in the university buildings and other students were not even aware of the difficulties faced by disabled students.

Similarly, some persons felt that their families tried to help them and protect them, which was supposed to facilitate their lives but that same help and protection became barriers because they did not have any impact on the barriers and persons had less self-confidence to go out and deal with the challenges.

In conclusion, for persons living in the Ger districts, barriers related to environmental factors and lack of civic services are perceived as most important. The impact of these is so dominating in their lives that in comparison, all other barriers are perceived less.

3.3.2 Barriers Related to Public Transport (Meeting 02): For understanding the barriers related to public transport, some researchers used public transport for the first time. Others who already use public transport, shared their daily experiences. Some persons spoke to other persons with disabilities to understand their difficulties. They collected a total of 56 examples of barriers and facilitating factors – 52 examples of barriers and 4 of facilitating factors.

Barriers about Physical Infrastructure of Public Transport: The biggest number of barriers (44%) emerging from people's stories were related to the physical infrastructure of the public transport. These related to inaccessibility of the transport due to presence of steps, narrow doors, lack of handles inside the doors, narrowness of corridors, etc. in accessing the public buses. There were a couple of examples of similar issues in trains which also have steps, narrow corridors and inaccessible toilets.

There were accessibility issues regarding the bus stops as well, where the presence of obstacles like poles and kiosks, makes it difficult for persons with mobility and vision disabilities to navigate them. The bus stops are small and narrow, so buses do not enter properly and therefore, even when they are accessible, they cannot align properly with the kerb and thus persons with wheelchairs cannot use them.

Once persons overcome all these barriers, inside the buses and trains, there are other barriers. Frequently there are no announcements regarding bus stops and destinations and there are no display boards with such information. Sometimes, buses have possibility of making announcements but the system is broken or drivers forget to switch them on. Often the display boards are located only in the front or the back and thus not easily visible. Other times, the display font is very small or it is located outside the window and difficult to read. While travelling, bus windows may be covered with stickers so it may not be easy to look out and see the location.

Barriers related to organisation of public transport services (17%): There are many persons who wish to take the bus and the buses are not frequent, thus they are full and persons with disabilities are left out, especially at peak hours. This creates significant problems for those disabled persons who have jobs. The buses are crowded and the drivers are in a hurry, they stop for a very short time. Thus, persons with disabilities do not enough time to get in or to get down. There are not enough reserved seats for persons with disabilities in the buses. Sometimes, the reserved seats are not well-marked, or elderly persons may occupy them, so persons with disabilities do not get a seat.

Barriers due to attitudes of the bus drivers (17%): The researchers felt that bus drivers look at them negatively and do not wish them to get in their buses, because they are too slow or they occupy too much space. When they see a person with disability they do not stop or stop at a long distance from the bus-stop (this also happens because the bus-stops are short and narrow). When the disabled persons get in the bus, the bus starts moving before they have the time to sit down thus, they risk falling down and getting injured.

Other barriers (22%): The other barriers were linked with private transport such as taxi and micro-bus (do not accept persons with disabilities or want to be paid extra), economic difficulties (high cost of private transport), lack of transport services in certain areas (near Ger districts and in countryside) and lack of accessible information (sign language or braille).

A deaf person mentioned the difficulties of those with invisible disabilities so that people look with suspicion when they use the card for subsidized transport or when they sit in place reserved for disabled person.

Facilitating factors: The examples of facilitating factors were all related to the helpfulness of other passengers, who are willing to make space in taxi or help getting in the bus. However, as persons are not aware of the different needs of persons with disabilities, even as they try to help they may cause the disabled persons to fall down or hurt themselves.

3.3.3 Barriers related to Social Welfare Services (Meeting 3): Discussions related to this research were extremely limited. Only a small number of researchers spoke about this theme and most of them shared their own life experiences. Some of the issues raised during this meeting were not pertinent to the theme (such as those related to school education for children with disabilities and those about the attitudes of employers towards potential employees who have disabilities). Considering only the issues related to social welfare services, only 9 examples of barriers were raised and the most common were those related to the criteria used for disability assessment and its implications.

Persons with severe difficulty in a body function, such as blind persons, deaf persons and wheel-chair users, are classified as "high percentage of disability" in their assessment and become eligible for disability pension. At the same time, this automatically classifies them as "unable to work" and thus they cannot use the job-reservation quota (every company having 25 employees must employ a person with disability) to find job and cannot pay the social insurance. Thus, the researchers asked to review the disability assessment system and to find another way of classifying their disability which does not automatically assume that because they have severe limitation in one body function, they are not fit for work.

The other barriers mentioned during the meeting included – increase of job reservation quota, increase of amount of disability pension and giving more incentives such as tax breaks to employers who accept employees with disabilities. One person mentioned the lack of resources to buy house by the persons with disabilities. Finally, one facilitating factor was mentioned – the subsidy given by social welfare services for the house rent and electricity expenses.

This theme meeting had limited participation and discussions. The researchers did not have much idea of the different activities which come under social welfare and how these impacted the lives of persons with disabilities.

3.3.4 Barriers to Independent Living of Persons with Disabilities (Meeting 4): During these discussions there were only a few presentations about information collected from other persons with disabilities, most researchers shared their own life experiences. This was also the theme on which there were a large number of examples of facilitating factors which help in overcoming barriers. A total of 69 examples of barriers and facilitating factors were presented, among which 32 (46%) were examples of facilitating factors.

Barriers related to Negative Attitudes and Beliefs among Persons with disabilities themselves: Out of the 37 examples of barriers, more than 50% were related to negative attitudes and beliefs. More than one fourth (27%) were related to internalized negative attitudes and beliefs among persons with disabilities. Almost all the stories recounted of event which had led to their disability, such an accident or an injury, and the years passed in isolation in the house, fearful of going out, afraid and ashamed of reaction of others, thinking that others feel pity towards them and sometimes, accompanied with depression and ideas of committing suicide.

Negative attitudes among family members and service providers: Another 24% of the barriers were related to negative attitudes and beliefs or lack of information in family and among professionals. These included not being allowed to go to school, being taken to the temple where their disability was told to be a result of bad karma, thinking that disability is contagious and thinking that disability is a kind of sickness.

Other Barriers: Among the remaining 50% of the barriers, the two most important groups of barriers were – barriers related to finding a job and becoming financially independent (22%); and barriers related to accessibility of information (19%).

Barriers related to work-places: The job-related barriers included lack of ramps and accessible toilets in workplaces, belief of employers that disabled persons can't work and the penalty for not respecting the law (companies having 50 or more employees must have 3% of workforce as persons with disabilities) is low so that they prefer paying the penalty.

Barriers related to communication: Lack of sign language and not to be able to communicate with others was other area of barriers. Another person explained that he can't go out in evening to meet friends because he can't understand where they are planning to meet and how to get there. A deaf girl said, "I can't make myself understand to the doctor or to the policeman, they talk to others and not to me. No one tells me about family planning and how not to get pregnant."

Barriers related to lack of personal assistants: About 10% of barriers were linked to inability to have a personal assistant due to lack of resources. One person explained that personal assistants are allowed only if the disability is assessed to be more than 80%, while she is without an arm and has been assessed at 70%, while there are occasions when she needs a personal assistant (for example, when she has to be breast-feed her baby).

Facilitating factors: On the other hand, the factors which facilitated independent living were mainly related to going out of the house at some point in their lives, meeting other persons with disabilities and understanding that they can be independent. Sometimes, the decision to go out can be inspired by someone seen on TV but most of the time, it was not clear what made them to take that first step of going out of home. For example, one girl said, "Till I was 17, I was closed in home. Then one day, I decided to go out, I took a bus. My family was so worried. After that there was no stopping me."

Going out and finding that other persons with disabilities similar to you or even more severe disabilities, are going out, working, making friends, can be liberating. Getting a personal assistant is a key factor in the passage from a life at home to independent living.

Talking to others and explaining about their difficulties is important. A girl with cerebral palsy explained that she had to rewrite her notes and do the home assignments at night because she can't write fast. She said: "I spoke to my lecturers, they understood my problems. Now they give me their lecture notes one day earlier, so I need to remain awake and work at night."

One researcher, a person with cerebral palsy, shared her story about the negative beliefs of professionals. She told her doctor that she wanted to have a child, but the doctor advised her not to do it. "I decided to have the child anyway, now I have my daughter and I am very happy." Another person explained that he spent a big amount of money for 3 years to pay for rehabilitation therapies because he hoped that his disability will go away. "Now I have accepted my disability, I am not wasting any more money, I meet with others, I want an independent life" he said.

However, not all barriers were external and could be overcome. A young mother whose arm is amputated, said, "Before the accident, I wanted to be a hairdresser. Now, without my arm, I know that I cannot do it. Still I dream of one day styling my own hair, but I can't do it with my one hand."

3.3.5 Barriers related to Sexuality (Meeting 5): The meeting on this theme was held separately for men and women. However, many of the issues which emerged in these meetings were common and some males shared experiences about their female friends, while some females shared experienced about their male friends.

The discussions touched on different areas and the researchers shared their personal experiences as well as those of their friends. Among there were three prominent areas of barriers in these discussions – (i) How and where to get information about sexuality and reproductive health; (ii) Family and community attitudes; and, (iii) the risk of sexual abuse.

Lack of information: When you get a serious disability, such as paraplegia, can you still have sex? Can you have children? How do you deal with a urinary catheter when you want to have sex? How do you avoid becoming pregnant? Do you have sex with your prosthesis on or you remove it? Persons with disabilities raised all kinds of questions and said that there is no one to whom you can talk and ask these questions, except to your friends. The specialists do not know that persons with disabilities have these questions and may be, don't know how to answer them. They often seem to imply that as a person with severe disability one should not think of sex.

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

Friends and internet were the two main sources of information, though both were sometimes not able to provide the required information. Family and religious persons were also sources of information but most of the time, they gave only negative information, by implying that sexual and affective life is not possible or even desirable for persons with disabilities.

Family and community attitudes: Families and friends may think that because persons are disabled and because they don't talk about a taboo subject in the family, they have no sexual desires. If they start showing interest in having a relationship, family persons do not believe that someone can really love them and they are fearful that relationship is just for some easy sex and then they will be left alone. Sometimes, families involve religious persons like monks in these discussions, who also suggest that having love, sex and family are not for them and they should suppress their desires.

The negative attitudes of families and communities were also internalised by the persons with disabilities who sometimes felt that they needed hormones or treatments which could suppress their sexual desires. For most of them, the question "what will my family say" was the key question in their relationships, which were often kept hidden. One woman explained, "I hide my relationship from my mother. May be when I will have a job and I can be independent, then I can tell her."

There was one testimony which was different – the young woman said that her mother encouraged her to have sex and get pregnant, so that her child can look after her when her parents will die.

There was another aspect related to families of young adults with intellectual disabilities or very severe disabilities. In some stories, women of the families, sisters and mothers, were afraid of being assaulted by their sexually frustrated disabled male young adults.

In one example, a young woman with intellectual impairment would take off her clothes and run out in the street, while her mother had no idea what to do for her daughter. There were different examples of family women helping the young adult males with disabilities to get sexual release and one example of a father having sex with his wheel chair using daughter. Some researchers felt that there was danger of sexual abuse in the family.

There were also discussions about desirability of women with disability getting married to non-disabled men. Similar concerns regarding men with disability getting married to non-disabled women were not raised in the men's meeting.

Risk of sexual abuse: This 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 risks were greater among women who were not completely self-sufficient.

A deaf girl said, "The deaf boys can be very aggressive. You meet them for the first time and they want to have sex immediately." In another testimony, 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.

Other barriers: Three persons raised the issue of how to deal with their personal assistants when they want to have sex. Three persons raised the issue of privacy because they are not self-sufficient.

Two women with disabilities who had children said that friends and guests sometimes praise their husbands for having married them in spite of their disabilities and this was hurtful to them.

Facilitating factors: In spite of all the barriers, different persons shared positive experiences, including those of masturbation and using pornography in their relationships. While the men with disabilities raised the possibility of having sex with sex-workers and the need for covering this expense from social welfare, the women shared information about vibrators and sex-toys.

One woman told that her mother who is a gynaecologist, had given her good advice regarding use of protection during sex. Another shared experience of having sex with a friend and wondered if it was all right for women to tell the men that they wanted some sex.

A blind person said that he can enjoy porn videos, even if he can't see them. Another told about a couple, both of whom have severe disabilities, who live together and love each other, even if they can't have sex.

Additional issues: Some issues raised in this meeting challenged the social model of disability. Story about the young man attacking his sisters/mother or the young lady who removes her clothes and runs out in the street, could not be fitted in the binary discussions of barriers/facilitating factors. Families, especially mothers, seem to have the responsibility of helping their sons find sexual release while there was one story of a father having sex with his daughter, for similar reasons.

Similarly, when the stories mention physical abuse, violence or sexual abuse, what kind of barrier is that? Lack of attention/care/love from the family is another kind of abuse? Where do these fit in with medical model or social model?

Discussions about mixed couples (in which only one partner has a disability) and both have to be disabled are about community beliefs. They say that persons should be free to decide whichever they prefer, but these ideas invariably encounter the negative stereotypes prevalent in the society.

The participants also discussed the lack of a specific clause on sexuality at the CRPD though articles 16 and 25 mention sexual abuse and health. In the Mongolian law on rights of persons with disabilities, article 6.3.5 (about discrimination) and article 29 (about women with disabilities) touch on reproductive health and sexual abuse. They concluded that in CRPD and the national law, the sexuality of persons with disabilities is hidden, and is seen only in terms of sexual abuse and reproduction. They proposed to promote public awareness for amending the national legislation, specifically, in the article 25.1 which mentions their right to sufficient income to cover their basic needs, to add reference to their "biological and social needs". Another suggestion was for social welfare subsidies to cover expenses related to medicines like Viagra, sex toys and access to sex-workers.

3.3.6 Barriers to Work & Employment (Meeting 6): The presentations and discussions about the barriers faced in finding and keeping work, brought out 32 kinds of examples of barriers. The most significant barriers which were repeated by most participants (60%) were those related to laws, policies and systems of the Government, especially those of Labour and Social Protection and Education ministries.

Lack of labour skills: Persons felt that they lacked labour skills, they had no specific vocational skills, while the labour market lacks flexibility. They felt that cooperatives or protected workshops can be one answer. Examples were given of laws about working hours which are rigid and do not allow for persons who can work for shorter periods. One person explained her need of frequent leave for health care and that her employment did not allow it. They also talked about lack of work place adaptations and the inadequacy of penalties for employers who do not comply with the law requiring obligatory employment for persons with disabilities. Lack of provision of personal assistants was cited as another barrier.

In terms of education, persons felt that the special schools do not provide skills, the quality of education is poor and the teachers do not know how to teach children with disabilities. They proposed that inclusive education would make it easier for persons to learn to live and work with others. There were specific criticisms of the education system from the deaf persons, who felt that the country lacks proper sign language system and teachers who can teach in sign language. An additional difficulty for deaf persons was their understanding of the abstract concepts.

Issues related to Disability Certification System: The disability certification system was also cited as being unhelpful since it declares persons with severe disabilities such as deafness or blindness to be incapable of work. This was an area of repeated discussions throughout the research. Some researchers raised it during discussions on different themes as influenced and created many barriers for different groups of persons with severe disabilities. Some persons raised the issue of yearly certification, which creates additional burdens on them and their families, even if they have lifelong disabilities.

Negative attitudes at the workplace: The second significant area of barriers in terms of work opportunities was that of negative attitudes, raised up by about 26% of the participants. Persons mentioned negative attitudes in the family, in the communities and among co-workers at the work places, as well as, the internalised negative attitudes among persons with disabilities themselves due to lack of self-confidence and motivation.

Other environmental barriers: Barriers related to the environment (physical and transport related barriers) were raised up by only 9% of the participants. Similarly lack of information was raised by a small number of persons.

Facilitating factors: The facilitating factors mentioned by the participants included the reservation system of the Government with penalties for employers who do not respect it. One person cited a survey which had shown high level of awareness (46%) among persons with disabilities about the need for workplace adaptations.

The researchers identified 3 priority areas for action by the Government to promote employment of persons with disabilities – resolving the issues related to disability certification, promoting inclusive education and strengthening job reservation-employers penalty system.

The deaf persons asked for better teachers who know sign language, positive role models and development of software which can convert text into sign language.

3.3.7 Barriers related to Education (meeting 7): During the meeting on the barriers related to education, the researchers shared their own experiences and also shared information about their discussions with some children with disabilities and their families. During the presentations and discussions, 43 kinds of examples of barriers were raised and discussed.

Barriers related to laws and policies: The most frequent barriers mentioned by the researchers were those related to laws, policies and systems of education ministry. These included different issues related to school teachers who had no training about how to teach different groups of children with disabilities and who felt overburdened, and thus gave little or no attention to disabled children in their classes. One researcher shared an interview with the mother of child, who had told that though her daughter goes to 6th standard in the school, she still does not know how to read or write.

Another area was the policy of sending children to special schools. These schools are all based in UB and these develop their own teaching curriculums for their children, which might exclude subjects like physics, so that at the end of the studies, the students of these schools do not get a high school certificate. While there was appreciation for child-centred flexible approach to education, it was frustrating for them to not receive a school completion certificate. The researchers felt that country needs to implement inclusive education.

Barriers related to specific teaching and learning equipment and products: Lack of sufficient learning materials and specific 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 they had a separate class for children with disabilities. For 24 children, they had only 2 books (both from 1975) for learning alphabets. Deaf and hard of hearing persons spoke about lack of teachers who know sign language and noisy classrooms. Blind and low vision persons spoke about lack of simple things like magnifying glasses.

Barriers related to negative attitudes: The second most frequent kinds of barriers which came in their discussions were those related to negative attitudes (23%), of the families, school teachers, community members, and of other children in the school. The researchers felt that personal characteristics of the persons with disabilities, in terms of self-confidence and motivation, are key elements. They also felt that underneath the issue of negative attitudes of the family, there is lack of understanding about different opportunities of education for children with disabilities and how it can affect their lives. Thus, they stressed on the importance of providing counselling to the families.

Environmental barriers: The third significant area of barriers was that of environmental barriers, especially those related to physical accessibility. Researchers shared their experiences where schools have specific services such as accessible toilets and ramps, but are kept locked and can't be used. One of the researcher with spinal cord injury shared his own experience in the university: "*Even though there was accessible toilet at my university, it locked all the time. Therefore, I couldn't drink anything at my school, and I have never used toilet for 3 years during my study*."

The environmental barriers placed additional burden on the families, as they have to find ways to overcome them. One researcher told that his brother stayed with him in the university to carry him on his shoulders, from one class to another.

Some researchers shared positive experiences of understanding and support from their university professors, such as getting extra time to write answers in the exams.

3.3.8 Barriers and Discrimination (meeting 8): Discrimination is one of the barriers faced by persons with disabilities. The researchers had decided to focus one of their researches on the theme of discrimination. Their discussions while sharing the results of this research underlined the conceptual confusion between discrimination and other barriers among the researchers. The boundaries between discrimination and a group of other concepts (such as fear, ignorance, stigma, stereotypes, dependency and lack of accountability) were often blurred in those discussions.

Another area of blurred boundaries was between the peer and co-workers' desire to help and support, and their being patronising or at least "behaving differently" and thus discriminating. On one hand, some persons felt that special schools and segregated classes in ordinary schools were discriminating, on another, they felt that in mixed classes in ordinary schools, "dividing students between those who can read fluently and those who can't" was discriminating.

Negative attitudes in families as discrimination: The researchers came up with 20 examples of discriminating barriers and a vast majority of these (85%) were about people's attitudes – especially in their own families (loving too much, spoon feeding and over-protection does not let a person become autonomous). Negative attitudes were also a key issue in the families of their boyfriends/girlfriends, who did not see them as suitable companions for their sons/daughters. Their own families did not believe that they would find a suitable companion and advised them to accept a life without a companion or even to aim for having a child outside marriage or through adoption, who can love them.

Negative attitudes in schools and work places: The second group of persons whose negative attitudes were a significant barrier, was those related to education and work, including co-workers, classmates, teachers and employers, who did not understand the different barriers faced by persons with disabilities and sometimes contributed to those barriers. Employers and teachers were ignorant about specific needs of persons with disabilities or had stereotypical views about them. Two deaf persons felt that lack of knowledge of sign language among the teachers was discriminating.

Negative attitudes in public spaces: One person gave the example of discrimination in a restaurant, where persons with disabilities were not served beer and when they asked for a police intervention citing discrimination, the police agreed with the restaurant owner. Another person gave an example of a dentist in a government hospital refusing to provide treatment and telling him to go to a private clinic.

Facilitating factors: The group felt that talking to different groups of persons, such as, employers and teachers and creating awareness was very important. Involvement of supportive co-workers and classmates could be important in such situations. They also felt that not accepting discrimination and raising their voices was equally important.

3.3.9 Role of Personal Assistants (meeting 9): Among the researchers, there were some, especially the wheel-chair users, who had experience of having personal assistants while the remaining persons had no personal experiences and depended upon their families for the support needed in their daily activities. This was reflected in this thematic research, which had two broad themes – the difficulties and limitations of the assistance provided by families and the issues related to having personal assistants.

Defining what is personal assistance and who is a personal assistant: There was also some confusion regarding the meaning of "personal assistants". For example, a deaf person said, "I need to communicate through writing when I am without a sign language interpreter. However, we can do whatever we want by ourselves. So, I think that a sign language interpreter is different from personal assistant." Another person said, "In Japan, everyone who are assisting the persons with disabilities are called personal assistant. In Mongolia, the Blind Federation says that guide dogs are not personal assistant and deaf people say that sign language interpreters are not personal assistant." Yet another person said, "I need someone who can help to carry water from a well, will that be the job of a personal assistant?"

Burden of personal assistance on the families: Persons not having a personal assistant explained the burden it puts on their families and the different challenges it can cause in their family relationships. A wheel-chair user said, "When I ask for assistance from my family, sometimes they get upset or says to they say, I am not your servant." Another wheel-chair user said, "When I started to study, my mom helped me to go to the university. When we asked my father for help in getting in or getting out of the car, sometimes he got annoyed. I was hurt by his reaction." 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.

Training and norms for personal assistants: Apart from the lack of definition of personal assistance services in the social welfare services, the researchers did not discuss the different barriers linked with them. One person pointed out the lack of adequate training for the personal assistants and said, "Sometimes, my personal assistants feel a bit embarrassed about me, when we are out." Another person said, "Personal assistants should be responsible and they must maintain the confidentiality of the private life of person with disabilities they are assisting. They know everything about us, including intimate things which other people don't know."

Positive impact of personal assistants: Persons who had experience with personal assistants were largely positive about their experience. One person said, "The best thing is that I can make decisions independently. When I Was living with my family, they were too protective. By living independently, I can learn from my mistakes. 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. Since I have a personal assistant my life has changed because before that, my family used to influence my decisions."

Some researchers pointed out that even persons with mild disabilities may sometimes need some personal assistance. A person with mild cerebral palsy said, "People see me as a person who has a slight disability yet I cannot do many things independently. I spent 4 years to learn how to write. If there was a personal assistance service at that time, I could have saved time and used it to study other things."

Finally, one person who is a wheel-chair user, raised the issue of "cultural need of a personal assistance": "When my wife's relatives visit us, they see me as a disrespectful person, because I don't do anything and my wife does all the household work. If I had a personal assistant, I could have some things for the guests. Therefore, the needs of personal assistance do not depend only on the severity of disability."

3.3.10 Barriers to empowerment (meeting 10): The research on the barriers to empowerment was mainly an opportunity for the researchers to look back critically at their own life experiences and try to understand the different barriers and facilitators to their own empowerment processes. They gave 41 examples of barriers and facilitating factors, focusing most of those examples (93%) on facilitating factors.

Empowering impact of the EDR: Around one fourth of the facilitating examples (24%) were related to researchers' participation in the emancipatory research, which provided insights about how they saw empowerment in different ways. For example, a deaf person said, "Before becoming a part of the researchers, I was communicating only with people with hearing difficulties and family members. It changed after becoming researcher." A person with cerebral palsy said, "I couldn't speak on behalf of other people. Now I can speak with others. I have learnt about other disabled people. I never knew about other people, how they live. I never asked any permission to speak by raising my hand, now I can raise my hand and speak." Another person with cerebral palsy said, "I tended to speak without listening others. But now I can listen to others and respect others."

Participation for empowerment: For 20% of the researchers, empowerment is a result of participation, when people take part actively in something, such as a training course, going for shopping or even using public transport. For example, a wheel chair user said, "One year ago I couldn't go out. My family used to buy my clothes, regardless of my likes or dislikes, big or small. Now I can go to the market, I buy my clothes. I can use public transport and I can even quarrel with the driver." A deaf person said, "I had no financial knowledge, my mother was solving my problems on my behalf. One day I spoke with her and explained I wanted to try. I tried to solve my financial problem and I felt that I could manage it."

Role of information in empowerment: For 18%, getting information and understanding how things work is a key factor. One person said, "Parents don't know many things and they face problem every day. Trained advisors are needed for parents, children and persons with disabilities.” Another 18% felt that it was important to express themselves and speak out, that facilitates empowerment.

Another important factor was to meet other persons with disabilities and understand about their lives. One person said, “I use a walker. I used to think that I am the only one who has a severe disability. Here, I learnt that there are other people who have severe disabilities and they are living their lives.”

Among the factors which act as barriers to empowerment, the participants mentioned negative family attitudes, their over-protection and lack of information.

3.3.11 Barriers to Health Services (meeting 11): The theme meeting to discuss the barriers to health services was one of the most participated, with presentation of 47 examples of barriers related to this theme.

Attitudes, specific knowledge and skills of health professionals: The largest number of examples (34%) referred to attitudes, knowledge and skills of health professionals towards persons with disabilities. Different persons explained how the professionals did not speak directly to persons with disabilities and talked to their family members, had specific ideas about what was desirable instead of listening to the persons with disabilities and in general demonstrated a lack of understanding about different disabilities. One researcher explained the experience of taking her 4 years old son to a doctor, “The doctor took over, he did not allow me to show him my son. I felt discriminated somehow.” Another person shared her experience of calling the telephone number for emergency services, “I dialled 103, they understood what I was saying. But the operator said to me that you don’t need to talk, give your phone to someone else.” Another person said, “The doctor didn’t talk to me, he just talked to my parents. I tried to speak, but he ignored me.”

Difficulties faced by persons with cerebral palsy in receiving dental care services was an important sub-group of persons who felt that health professionals did not know how to deal with persons with disabilities. One person said, “Dentists are afraid of us. They insist that we need to get whole body anaesthesia.” Another shared her experience, “10 years ago I had dental problem, but the dentist said that there was no technology. In the end, I had to get general anaesthesia, only then they took my teeth out. After that, I got acquaintance with another doctor who had graduated in Japan. He was very good in dealing with persons with disabilities.”

Accessibility of the health services: A second critical area of barriers (30%) was related to accessibility, including general accessibility of hospitals and health centres, having accessible toilets, beds and specific equipment for persons with disabilities and having sign language translators. One wheel-chair user said, “There is no accessible bed and toilet. They don’t have an accessible bed for medical check-up for the disabled women for gynaecology conditions.” Another person with mobility difficulty said, “I have never received medical service when I need it. I only went to my family doctor’s health centre twice, because someone has to carry me to reach it as it is on the second floor.” A deaf person said, “Health workers try not to communicate with us. They prescribe some medicine, but without proper diagnosis because they don’t try to understand. They don’t explain how to take the medicine. Sometimes we don’t take medicines due to economic difficulties, sometimes we don’t take treatment because of loss of heart.”

Barriers related to the health services organisation: About 17% of experiences were about service-related barriers such as long queues which do not take into account the difficulties of persons with disabilities and privatization policies so that the hospital stay has to be very short even if the persons need a longer stay. A key area of concern was related to disability certification system. For example, a person who was operated for a spinal cord tumour 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 go MRI and pay more than 400 thousand tugriks to get the tests to show to them. So financially and psychologically it is a big pressure on me.”

Other barriers: There were many other issues raised by the researchers such as costs of having a care-giver in the hospital, negative attitudes of other patients and lack of new technology. Some of these concerns could be due to a lack of coordination between the health services which come under the Ministry of Health and the rehabilitation services under Ministry of Labour and Social Protection. For example, one person explained, “Young people who become disabled, have no information about their body functions. After the accident there is no one to give good advice, so we get complications, such as pressure sore and not knowing how to use wheel chair properly. I have heard that in other countries during the hospitalization they teach the persons about how to use wheel chair and how to take care of yourself. Such a practice will be very helpful.”

Facilitating factors: There were two specific suggestions for improving the disability-understanding of the health professionals – to provide Disability Equality Training (DET) to them; to organise visits of undergraduate students to DPOs. One person shared his experience of a software on accessible design and collaborating with a group of architectures in designing an accessible health centre: “We made a website and an accessibility App for smart phones and piloted it in the Architecture school. We made a joint evaluation and planning. The students made the construction design including accessible ramps according to the international standards.” Another person shared information about setting up of an accessible health care service for women with disabilities at health centre number 10 in Bayanzurch district.

3.3.12 Barriers to Assistive Technology (meeting 12): Among the researchers, almost all of them use one or more assistive products (APs). For this theme, their research focused mainly on their own personal experiences. This theme was also a part of another research under the technical supervision of the World Health Organisation (WHO) carried out by an external consultant, thus the discussions were carried out over different days and were not limited to their one day of EDR meeting. A separate report has been prepared about this research.

Access to assistive products in Mongolia: Mongolia has an approved list of APs under the MoLSP. At present, it includes 80 products including some medical equipment such as talking thermometers and blood pressure measuring instruments, as well as some general equipment such as radio receivers. For each AP, the Ministry selects official suppliers and a maximum cost contribution.

Barriers related to access to assistive products: The barriers identified by the researchers focused on 2 main areas – poor quality of some APs, such as wheel chairs, as most APs are of limited standard sizes and cannot be adapted to single users and there is no training about its use; lack of some APs in the MoLSP list such as wheel chair cushions.

If persons want better quality products, they need to pay for it additional amounts, which creates economic barriers. The subsidized APs are given once in 3 years (some like wheel chairs, once in 5 years) and if they break down, there are no services for maintenance and repair.

Sometimes persons need specific products such as urine bags and catheters for persons with spinal cord injury, these may not be always available and the number covered are not sufficient for persons' needs, they need to pay commissions to the official APs suppliers so that funds released by MoLSP for other APs can be used to buy these other products from other private suppliers.

Lack of specific products such as Text to Voice software for blind and low vision persons in Mongolian language, was another difficulty. Lack of information regarding the availability and usefulness of different APs was cited as another important barrier, especially in the rural areas.

Facilitating factors: One of the DPOs, that working for blind persons, has a centralised system of conducting advocacy for as well as, for procuring and distributing specific APs to persons with vision problems. A couple of other DPOs are playing a role in access to better wheel chairs and their maintenance and repair. All researchers agreed that access to good APs had a tremendous impact on the quality of their lives and made it possible for them to live independently.

3.4 IMPACT OF CB-EDR

One of the objectives of CB-EDR was to promote the empowerment of the persons participating in it. This issue is tackled separately in the next chapter.

Another aspect of the impact of this research was the transfer of research findings into practical action to overcome or dismantle the barriers identified during the process related to the different themes. As explained earlier, in spite of different attempts to facilitate it, information regarding these actions stimulated by the research findings were not collected systematically during the research process. Information regarding these came indirectly, especially during the review meetings conducted at 12 months and 18 months from the start of CB-EDR.

Some of these actions are mentioned in relation to perceived changes in empowerment in the next chapter. Some others are mentioned under "Impact of CB-EDR: Voices of the Researchers" and "Impact of CB-EDR: Views of the Stakeholders" elsewhere in this report. Thus, while there is no complete list of different actions that were initiated to challenge and dismantle the barriers, there are different indications that this was a key part of the research process.

During the review meeting held in June 2019, many researchers had commented that for them the most interesting part of the theme meeting was in the afternoons, after they had finished listening to different presentations. During these discussion sessions they had talked about the action needed to challenge the different barriers they had identified during the research.

Two kinds of actions emerged from the discussions during the review meetings - (i) the understandings regarding the barriers faced by persons with disabilities in different life-domains; and (ii) the impact of the research on the barriers.

Understandings Regarding the Barriers Faced by Persons with Different Disabilities: Almost all the researchers brought this out this point at some point during the discussions that before coming to the CB-EDR process they had little understanding about the barriers faced by persons with other disabilities. Many of them had never really interacted with persons having 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. One of the researchers said that this interaction with others, made her see herself and her difficulties in a completely new light. Most researchers agreed that this kind of interaction was crucial for strengthening the DPO federations.

Impact of the Research on the barriers: Through invitations to major stakeholders involved in service provision to the specific theme meetings, and through their questions and sharing of personal experiences, the researchers initiated actions during the meetings. For example, inviting persons from Transport Ministry to the meeting on the difficulties in accessing public transport services, the researchers contributed to the discussions on how to manage the barriers related to it.

Actions were also initiated following the conclusion of the meetings. Many discussions from the meetings were reported and discussed in the DPOs and in the Government ministries. Sometimes, they led to initiation of new services, such as the information service for persons with disabilities on sexuality initiated under the Ministry of Labour and Social Protection. At other times, they joined some other on-going initiatives, such as the contributions of the researchers on the national survey on the assessment of Assistive Technology, which was carried out in 2019.

More examples about the different practical actions for mitigating the challenges posed by different barriers are scattered through the whole document.

3.5 CONCLUSIONS

The discussions on the 12 selected themes brought out a great richness of details about how different barriers influence and affect different life-domains. The relative importance of the different kinds of barriers changed for each domain. For example, for access to education, the most important perceived barriers were linked to national laws and policies, while for the access to the health services, these were linked to peoples' attitudes, and to the lack of specific knowledge and skills of the health professionals.

The themes selected by the researchers were very broad, such as "the barriers to social welfare" or "the barriers to the health services". They were asked to find out the relevant background information for each theme by searching for any existing information about the theme before conducting the research. However, this search of existing information and any previous studies, did not happen in a systematic way and thus, planning for the research was carried out mainly on the basis of researchers' personal experiences and any existing knowledge in their DPOs.

The broad themes also meant that each researcher was free to choose and focus on a specific area, with the advantage that different researchers could focus on different areas and bring in different kinds of information about the themes. However, at the same time, this meant that all the different aspects of some themes were not covered in the research.

Preparing the theme meeting reports by the rapporteur created some confusion regarding the confidentiality of the information. For each theme meeting the formal presentations, videos, photographs and reports were collected and detailed minutes were prepared. However, there were some grey areas in which it was not clear if the names of the researchers should be mentioned so as to give credit to them for their research work. In the end it was decided to keep the names of those researchers who had made any formal presentations during the meetings. On the other hand, the names of the persons giving any personal testimonies and the names of persons intervening during the discussions were removed from the reports circulated outside the group of researchers. Finally, at the end of the CB-EDR process, the researchers were asked to go through the full report and decide if they were comfortable with it.

As the research had progressed over a period of about 18 months, the researchers had initiated different actions to overcome or at least reduce the impact of the barriers they were studying and identifying. These actions were not always well documented in the research reports as these often took place after the theme meetings. Some of these actions were related to the way the theme meetings were organised, where there was an attempt to engage with different stake-holders for each theme including with the policy makers in the Government, in reducing the barriers. For example, the interactions with the persons from Transport Ministry were documented in the theme report, but other consequent actions (such as the invitation of the transport ministry to invite a few representatives of the researchers in subsequent meetings) were not documented because they occurred outside the research process.

It would have helped to improve this documentation, if each theme meeting had planned time for talking about impacts of previous theme meetings and actions undertaken. This is something that needs to be kept in mind for future development of the CB-EDR approach.

This research was a huge effort, made possible by the generous contributions of the researchers, who did not receive any financial support to go out and collect information. The researchers themselves and their families contributed to this over a period of 18 months. Without their active participation, it would not have been possible to complete this research.

Chapter 4 - Measuring Empowerment

4.1 INTRODUCTION

One of the objectives of the research was to promote empowerment of the persons with disabilities participating in the EDR as researchers. Reflecting on how the research process was impacting the participants' perception of their empowerment, was a recurrent theme throughout the whole period. The impact of the research in reaching this objective was explored both qualitatively and quantitatively.

Qualitative approaches to understand the impact of participation in the CB-EDR process included – 3 group discussions with the researchers on meanings and significance of empowerment and how to measure it, organised in the beginning, during the research (at 12 months) and after the EDR process. In addition, empowerment and barriers to empowerment was one of the research themes selected by them, during which the researchers themselves explored the issue of empowerment.

In addition, there were two quantitative approaches to the empowerment measurement – after 12 months of the research process and after the conclusion of the research.

A summary of the key findings from this process is presented here.

4.2 DISCUSSIONS ABOUT EMPOWERMENT AT THE BEGINNING OF EDR PROCESS

As part of their initial training on EDR, the researchers were asked to discuss their understanding of empowerment and what were the barriers blocking their empowerment. The following points emerged from those discussions:

4.2.1 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. While most of the words they chose to describe empowerment were obvious, some were not, such as - learning to listen to others, respecting others, appreciating different point of views and being honest.

4.2.2 Barriers in persons themselves: 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.

The personal characteristics of the persons with disabilities which denoted or led to disempowerment included – 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.

4.2.3 Barriers to empowerment in the families: Family attitudes are a major factor in disempowerment or empowerment depending upon how much they control, guide and decide for the persons with disabilities. Children with disabilities, as they grow, often need to insist to go out in spite of the family opposition. Family attitudes change only when they see that the persons are managing their lives and surviving on their own. They do not always understand that they are acting as barriers. The family love can also become over-protection. They may be influenced by traditional attitudes, they underestimate the capacities, they doubt that others persons can understand the persons with disabilities.

4.2.4 Barriers to empowerment in the communities: Attitudes of community are also a barrier. They may think that persons with any disability, also has some intellectual disability. The community also includes other persons with disabilities who do not know about the different disabilities and have similar misconceptions. While persons who come in regular contact with persons with disabilities gradually understand the capabilities of that person, other persons do not and this means that disabled persons need to continuously deal with negative community attitudes.

4.2.5 Barriers in the environment: Lack of environmental accessibility is a key contributing factor in promoting disempowerment. Similarly, legal environment and national policies can promote or hamper empowerment. Often, laws are there but these are not applied and thus promote disempowerment.

4.2.6 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.

To overcome disempowering barriers, everyone has to learn to see their own capacities, they have to recognise their own skills, and show them to others. If they change, they can change attitude of the society. Persons with disabilities need to fight, to insist on joining different activities and becoming visible in public, this will help in changing community attitudes. Education is fundamental, it does not mean to learn only reading and writing, it also means meeting others, communicating, expressing and having friends.

4.2.7 Conclusions: These discussions at the beginning of the research were useful in understanding the different meanings of empowerment perceived by the persons with disabilities who were planning to become researchers. These along with the barriers to empowerment identified by them were used as a starting point to reflect on how to measure their perceived change in empowerment at the end of the EDR process.

4.3 PERCEIVED IMPACT OF THE EDR PROCESS ON THE RESEARCHERS

Perceived changes in empowerment were discussed and analysed in different ways. First, a qualitative understanding of the changes was discussed in a review meeting organised in June 2019, one year after the start of the research. A couple of months later, the researchers themselves discussed the barriers to empowerment in a theme meeting in August 2019. Finally, changes in empowerment were discussed at the end of the 18 months period. The key issues emerging from these different discussions are summarised below.

Quantitative measurements of empowerment were carried out through 2 different questionnaires, first in June 2019 and the second in September 2019. The results of these measurements are discussed below under points 4.3.2 and 4.3.3.

4.3.1 Qualitative Analysis of Impact of CB-EDR

According to the researchers, EDR 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.”

One of the researchers worked in the disability department of Ministry of Labour and Social Protection (MoLSP). After every theme meeting, she shared the main findings of the research with her colleagues in the Ministry and this led to some important changes. For example, the meeting on the barriers to sexuality resulted in setting up of a “Sexuality and Reproductive Health Information Service” targeted at the young disabled persons, while the meeting on independent living led to a joint meeting between MoLSP and Ministry of Housing and Construction to see how the laws can be changed to support housing for persons with disabilities.

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. In the school, other girls were talking about things but I could not understand them and I did not know what to say. They looked at me and thought that I was strange. Now I can talk back."

Looking at problems in a systematic way, collecting data and information, and understanding its implications was another skill gained through the EDR process. One researcher who was studying in the university said, "Now I can look at the data and I know how to use it to explain the problems and their importance." He also felt that the research should have included more quantitative methods in the understanding of the issues.

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 EDR. Three (3) researchers also made individual presentations during the congress including one person who spoke about impact of EDR on empowerment of persons with disabilities. This whole process, which included interactions with persons coming from different parts of the world, was also perceived as empowering. One researcher said, "So many persons at the congress told me that they were happy to see so many persons with disabilities playing such an active role in the congress."

The different discussions brought out the different aspects of life in which persons felt more empowered. There was hardly anyone, even among those who had joined only the last phase of the research, who did not feel a change in themselves.

4.3.2 Measuring Perceived Change in Empowerment in 5 Broad Areas of Life

In June 2019, a simple questionnaire was prepared, focusing on 5 life-areas – family relationships, relationship with friends, at the education or work place, use of public transport system and fighting for rights. The questionnaire was anonymous and persons were informed that they could decide to not answer any or all of the questions. For each life-area, the respondents could grade their empowerment level between 0 (no change in empowerment) to 7 (maximum change in empowerment).

For answering the questionnaire, the researchers were asked to think of the time when they had come for the first EDR training and then think of their feelings today and decide if they had become more empowered in the last one year of EDR. Empowerment was defined by the participants through discussions as "*our self-confidence, our ability to make decisions about our life, our ability to go out and express our opinions, our ability to fight for our rights*".

25 persons completed the questionnaire. The maximum perceived gains of empowerment were reported in the areas of relationship with friends and fighting for one's rights with an average score of 5.68 and a median score of 6 (range 1-7). The average scores of perceived gains in empowerment in 5 life areas are presented in table 1 below:

Table 1: Perceived Gains in Empowerment in 5 broad life-areas

Perceived Empowerment Gains in Broad Life Areas	Empowerment Scores		
	Range	Median	Mean
Relationships with friends	1-7	6	5.68
Fighting for one's rights	1-7	6	5.68
Family relationships	0-7	5	4.96
In school/university/work place	1-7	6	5.40
Using Public transport	0-7	5	4.20

Thus, the analysis of the questionnaire showed that EDR had significantly contributed to the self-perceived empowerment process of the researchers, however the changes in different life areas are not uniform – they are more in some areas and less in others. Family relationships was the area in which the persons reported least change.

During the discussions following the completion of questionnaires, some persons explained that they had doubts about filling the scores for some questions, since each broad area covered different aspects of life and they had different perceptions of empowerment in those aspects. For example, one person felt more empowered in talking to some teachers in the university but not to other teachers and classmates. Thus, they were not sure how to give a score to these areas. Their suggestion was that the questions should be more specific.

4.3.3 Measuring Change in Perceived Self-Empowerment in Specific Life Activities

Following the suggestions of the researchers after the first measurement of changes in empowerment, it was decided to have more specific questions for the second measurement. A questionnaire based on 3-dimensional empowerment framework defined by the Commonwealth of Learning was developed in consultation with the researchers. It had questions in 4 domains considered significant by them – family, community, disability and DPOs.

The questionnaire had 12 questions and asked the respondents to share examples of activities/actions which illustrated their empowerment. For each question, persons could give scores between 1 to 5 (1 for little change and 5 for maximum change).

22 persons completed the questionnaire including 1 person who had participated in only 1 EDR meetings and another 3 persons who had participated in only 3 meetings.

Perceived Empowerment in Personal and Family domain: There were 3 questions under this domain - perceived changes in the ability to take decisions and/or take action about their own life, their ability to talk about their situation and disability in front of other persons, and their capacity to participate in the family decisions. Table 2 below presents a summary of the scores to these 3 questions.

Table 2: Perceived Gains in Empowerment in Personal & Family Domain

Specific areas of Personal & Family domain	Empowerment Scores		
	Range	Median	Mean
Ability to decide/or take action about their own life	1-5	5	4.32
Talking about their disability in front of others	3-5	4	4.59
Participate in the family decisions	2-5	4	4.18

Thus, persons felt that they were able to change their own behaviour and take their decisions much more than their capacity to participate in the family decisions. This reconfirmed the results of the first measurement, where the changes in empowerment in terms of family relationships were lowest.

Perceived Empowerment in Community domain: There were 3 questions under this domain as well - perceived changes in the capacity to have a voice and to express their opinions in the community, their capacity to fight when they see that rights of persons with disabilities are violated in the community, and, their ability to do advocacy for changing the attitudes of school teachers, health workers and community leaders. Table 3 presents a summary of scores to these 3 questions.

Table 3: Perceived Gains in Empowerment in Community Domain

Specific areas of Community domain	Empowerment Scores		
	Range	Median	Mean
Express their opinions in the community	3-5	4	4.18
Fighting for violations of rights of other PwDs	2-5	4	3.77
Advocacy for changing the attitudes	2-5	4	4.23

Thus, the researchers felt more confident about speaking to professionals and expressing their opinions in the community, while they were less confident of fighting for the rights of other persons with disabilities.

Perceived Empowerment in Disability domain: There were 4 questions under this domain - perceived changes in the understanding about different kinds of disabilities, understanding of different barriers faced by different groups of persons with disabilities, talking to and sharing of information with other persons with disabilities, and, regarding informing and advising parents of children with disabilities. Table 4 presents a summary of the scores for these 4 questions.

Table 4: Perceived Gains in Empowerment in Disability Domain

Specific areas of Disability domain	Empowerment Scores		
	Range	Median	Mean
Understanding about different disabilities	4-5	4	4.45
Different barriers faced by different groups	4-5	4	4.41
Sharing of information with others	2-5	4	3.64
Advising parents of children with disabilities	2-5	4	3.82

Thus, the researchers felt much more confident about their own understanding of different disabilities and the barriers faced by them, compared to their capacity to talk to and share information with other persons with disabilities or with parents of children with disabilities.

Perceived Empowerment in DPO domain: There were 2 questions under this domain - perceived changes in participation in DPO activities, and, their capacity to intervene and express themselves in the DPO. Table 5 presents a summary of scores to these 2 questions.

Table 5: Perceived Gains in Empowerment in DPO Domain

Specific areas of DPO domain	Empowerment Scores		
	Range	Median	Mean
Participation in DPO activities	2-5	5	4.45
Intervening and expressing themselves in DPO	3-5	4	4.18

Thus, researchers felt that EDR process had a significant impact on their empowerment in terms of DPO participation.

Examples given by the researchers to illustrate their empowerment: Each researcher was asked to share one example some action or activity to explain their sense of empowerment. An analysis of these examples brought out the impact of the research in their empowerment in 4 aspects of their lives:

- *Life styles* changes such as participating in sports, doing regular exercise, pursuing higher education, talking more openly to the families and understanding and accepting their own personal feelings and emotions.
- *Interactions with others* such as communicating with others, expressing themselves, explaining things to others, preparing and making power-point presentations, working in teams, and, understanding the challenges and barriers faced by persons with different kinds of disabilities.
- *Specific skills* related to thinking about issues from different point of views, analysing issues, thinking through the problems before making a decision and, understanding how research works.
- *Learning about laws and rights*, both at national level and international level (CRPD) and the role of advocacy for implementation of those laws.

One of the persons explained that EDR was a special opportunity for her for learning in depth. For example, she said that she already knew about CRPD but during the research, the researchers reviewed specific articles of the Convention and then looked at it from the point of view of different groups of persons with disabilities. This gave her a kind of in-depth understanding which can be very important for their advocacy work in the DPOs.

4.4 CONCLUSIONS

Naila Kabeer (1999) had defined empowerment as an expansion of the persons' capacity to make strategic life choices in a context where they did not have this possibility. In that sense, the researchers are unanimous that the EDR process has contributed to their empowerment. Both the qualitative analysis and quantitative measurement of empowerment among the researchers confirms this.

By using the 3-dimensional framework for empowerment measurement as an example, 4 domains of empowerment measurement were identified for the EDR – family, community, disability and DPO, which were used for measuring perceived changes in empowerment and this exercise showed a significant positive change, though it was variable across specific issues. For example, while persons felt more confident about talking about their disabilities in front of others, they were less confident about fighting for a change.

The 3-dimensional framework for empowerment measurement has 4 levels of each aspect of empowerment (information, resources, desire/wish to make choice and action). In the EDR process in Mongolia, these 4 levels were not examined separately and analysed separately, as the researchers wanted to keep the measurement process simple. However, the practical examples shared by them show that there was a range of changes which touched on all these 4 levels.

As explained in the "Voices of the Stakeholders" later in this report, participation in the EDR process was one of the factors promoting the empowerment of researchers. The EDR process has coincided with other initiatives by the DPOs and federations, such as organisation of a tour of persons using wheel-chairs to some of the provinces to raise awareness. Thus, while participation in EDR process, helped some persons to make the decision of participating in that tour, being away from their families for the duration of the tour itself also contributed to changes in persons' feelings of self-confidence. Thus, in the end, it would be reductive to say that perceived changes in persons' empowerment were only due to EDR. However, we can say that participation in EDR played an important role in researchers' sense of empowerment.

Chapter 5 - Discussion

5.1 INTRODUCTION

Implementing the CB-EDR approach among a group of young persons with moderate to severe disabilities in Ulaanbaatar touched on identification of barriers and facilitating factors which help persons with disabilities to overcome barriers related to 12 broad areas. The whole research process including the choice of those 12 broad areas, was made by the persons with disabilities who were asked to be the researchers.

Research, in the sense of trying to understand problems and their causes, is something which we all engage in during our daily lives. Scientific or academic research on the other hand, has its norms, methods and processes which require specific skills and training. During CB-EDR, a group of persons with disabilities were taken and provided a short training about basics of scientific research approach and then asked to manage the whole research process lasting around 18 months. During this period, they chose the broad areas of the research, as well as the specific issues each of them was going to focus on; they decided if they would collect information individually or in small groups; they decided which information to collect, how and from where; they also shared the information they had gathered and analysed to understand the causes and mechanisms of what barriers stopped them from participating in different life activities and what could or should be done about those barriers.

They received minimum external support and advice from experts and academic researchers, and even for that limited advice, the researchers decided if they wanted to accept it or not. Their plenary discussions during theme meetings and review meetings as well as, some aspects of the research process (such as logistical aspects) were supported by external persons, including a full-time rapporteur for the documentation of their meetings.

The research provided insights about the daily lives of a group of persons with disabilities living in an urban area of Mongolia, their encounters with different kinds of barriers and their perceptions about the causes of those barriers and how they could be removed. At the same time, at a more basic level, CB-EDR approach has raised more fundamental questions about what is research and what is its purpose.

This chapter looks at these and some related issues to discuss the significance of its findings and its usefulness for other contexts, not only in the developing world.

5.2 NEW UNDERSTANDINGS GAINED FROM THE RESEARCH

In spite of the limitations posed by lack of research expertise among the researchers, the research has resulted in collecting new information and understanding about the role of different kinds of barriers on the lives of the persons with disabilities.

The National Report prepared by the Government of Mongolia regarding the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) was lacking in information about environmental barriers faced by persons with disabilities. (OHCHR, 2015, p. 2) There is limited published research in Mongolia regarding persons with disabilities and most of the existing research is related to medical rehabilitation. (Dorjbal D., et al., 2019)

The CB-EDR has brought out rich details of the numerous ways in which persons with moderate-severe disabilities are further disabled by the barriers surrounding them in Ulaanbaatar. Most of the time, individual DPOs look at the barriers facing specific groups of persons with disabilities and there is limited understanding about how different barriers affect the lives of persons with different kinds of disabilities. CB-EDR has brought out a more comprehensive understanding about the different kinds of barriers affecting activities in different life-domains for different groups of persons with disabilities.

For example, the first research theme about the persons with disabilities living in the ger (tents) districts of Ulaanbaatar had brought out the daily struggles of persons and their families in every aspect of their lives, from using the toilet and taking a bath, to going out on uneven roads and accessing health and education services. Even some of the persons with disabilities, among the stakeholders, living in ger districts had expressed surprise at the information put together during the research regarding the barriers.

Having a comprehensive understanding about the barriers provides a roadmap for the service providers for improving the accessibility of their services. It also provides an overview to the DPOs and the federations in terms of deciding the priorities for advocacy. At least some of these barriers can be addressed relatively easily and thus make life easier for a large number of persons, not only persons with disabilities but also for other groups such as elderly persons, pregnant women, and women with small children.

5.2.1 Barriers Faced by Persons with Disabilities

The research showed that different kinds of barriers have different impact in negatively affecting the participation of persons with disabilities in different life domains and contexts.

For the persons living in the ger (tent) districts, the emphasis was on the physical barriers in the environment (both in the natural or unbuilt environment as well as in the built environment) and lack of public services, while negative attitudes were mentioned much less.

On the other hand, during the discussions on sexuality, the key focus was on lack of information and not knowing whom to ask for information, followed by the impact of negative attitudes in the families and among professionals.

Thus, the research shows that there may not be a fixed hierarchy of barriers in terms of their importance in creating disablement. Instead the relative importance of barriers changes according to contexts, the kinds of disabilities and the life-domains.

This means that the barriers encountered by persons with disabilities have different impacts on individuals in terms of their access to rights and the quality of their lives. Therefore, the support for their full participation as mandated by CRPD, should be based on personalised projects which can identify the social and environmental factors which hamper their full participation, as well as their personal characteristics, whose strengthening can reduce the negative impacts of social and environmental factors.

5.2.2 Role of Personal Characteristics in Dealing with Barriers

There were a few examples of the role played by personal characteristics in dealing with the barriers. For example, during the discussions on barriers to empowerment, one researcher who was an entrepreneur and went regularly to China to buy products for sale in Mongolia, shared her experience of negative attitudes and lack of confidence of her family in her capacity to deal with difficulties. Yet those negative attitudes did not stop her, rather they made her strive harder to show it to her family that they were wrong and she was capable.

Thus, persons respond differently to the barriers, depending upon their personal characteristics. When faced with negative attitudes, some close themselves in isolation, others use it as a motivation to fight harder. However, the issue of personal characteristics was not tackled during CB-EDR in a systematic manner and the information collected is not sufficient to start building an understanding about different kinds of personal characteristics and their impacts on persons' lives. From the discussions on different research themes, there was limited information about the different personal characteristics and how these can be sustained or strengthened, to be able to draw any conclusions about them.

5.3 IMPACT OF CB-EDR ON DISMANTLING THE DISABLING BARRIERS

A key objective of any research is to help in understanding the causes of different problems, so that they can be addressed. Numerous studies on evidence-based practice in different fields have highlighted the research-to-practice gap and the difficulties in transferring the understandings gained from research into practical changes in strategies and practices. Most research is published in journals which are not accessible to ordinary public. A book explaining how to write scientific papers states, "*The purpose of a research paper is to present some new result, explain its significance, and place it coherently within the existing body of knowledge. The scientific style, described by its stand on the issues of truth, presentation, scene, cast, and thought and language, creates a unique way of writing that is mostly unfamiliar to the non-scientist.*" (Mack C.A., 2018)

On the other hand, if we consider the transfer of research knowledge into practice, the impact of CB-EDR in Mongolia had an immediate and significant impact. The organisation of the research in 12 broad theme areas sometimes led to specific activities to find solutions and to overcome the barriers identified by the researchers.

5.3.1 Overcoming negative attitudes

The physical barriers can't be wished away just because persons with disabilities are more empowered, they need to be overcome or dismantled. For example, deaf persons, it does not matter how empowered they are, can't overcome the communication barrier if sign language translation or alternate text information is not available. However, empowered persons with disabilities can learn to overcome their own internalised negative attitudes and challenge them in the society and among different service providers. Many researchers mentioned the importance of going out and becoming visible in the public spaces, so that others become aware about them.

Some persons gave testimonies where they explained how they had used negative attitudes to spur them to put additional efforts to reach success, however this seemed to be linked to their personal characteristics.

During different theme discussions, the researchers talked about the need to inform and educate families and communities, starting from school children, about disability related issues. At the same time, a number of stories talked about overcoming the fear of being looked at, the feelings of shame and self-consciousness, and to be visible in the public so that society becomes used to seeing them and understanding their needs. The common assumption in these stories was that by questioning the negative attitudes and by brining these discussions out in the open, societies can be helped to change them.

5.3.2 Examples of Actions Taken by the Researchers to Remove Barriers

As the research progressed, the researchers invited representatives of related policy-makers, service providers and other concerned persons to their meetings. Sometimes this led to promises of change and sometimes, to specific actions to reduce the barriers. On some themes, the researchers took their research findings to the policy makers and service providers to inform them and to ask for an action. A few examples of such actions are provided below, which show how the research discussions prompted changes in practice.

Reducing the barriers related to the Public Transport Services: In August 2018, during the meeting on accessibility of public transport, 2 representatives from the Ministry of Road and Transport development of Mongolia were invited. One year earlier, this ministry had already organised a meeting on the accessibility of the public transport in Ulaanbaatar in collaboration with the National federation of persons with disabilities. During the meeting, the Ministry representative informed that they had created a Disability Committee within the ministry (an advisory committee which includes representatives of various DPOs) and they were working on an amendment of the national transport law. He also said that they were aware of the inaccessibility of the majority of the public buses and their aim was to have 100% accessible public buses. This was an opportunity for the researchers to question them, to learn about the new proposal for the law and to make suggestions about it.

Barriers faced by the persons living in the ger districts: One of the researchers explained, "*I found so much new information about the barriers faced by persons with disabilities from this research, even though I had lived in a ger district for almost 20 years.*" The information from this theme-research was shared with the Department of Disability in the MoLSP, which organised a meeting with the Ministry of Construction and City Planning, and discussed this issue and amendments to the law regarding provision of housing to the residents. They talked about the program for providing housing for needy persons.

Information Services on sexual and reproductive health: From the theme meeting on the barriers to sexuality, it had emerged that many persons with disabilities find it difficult to get any information on this subject. This information was discussed with the Disability department of the MoLSP, which then prepared a project to get funding on the theme of reproductive health and sexuality, so that more could be done about it. In the meantime, the disability department has already set up a centre to provide information and advice on this theme.

Impact on the DPOs: The researchers had been nominated by different DPOs and DPO federations. The researchers took back information from their discussions during the theme meetings to their respective organisations. This led to more discussions in the organisations with influence on their advocacy activities, as well as, on the ideas of preparing new projects to present to the funding organisations.

A representative of one of the DPOs involved in the CB-EDR explained that the researchers have started to understand the issues from different point of views, and they can now understand how something affects different groups of persons with disabilities differently. According to him, these researchers can play an important role in strengthening the cross-disability movement and bringing together different DPOs to fight together.

5.3.3 Role of Impairments in Creating Disablement

The CB-EDR implementation was supposed to be based upon the social model of disability. During the initial training, the researchers were asked to focus on the way different kinds of barriers create disablement and stop persons from participating in different life activities and access different services. They were also asked to not to look at issues through the individual and medical models. However, during different theme discussions, there were many experiences shared by the researchers regarding the limitations placed by the impairment, which were not due to the barriers created by others or external factors. This showed that the boundaries between social and medical model were not always easy to fix in a rigid way and sometimes, it is not easy to separate the impairment related issues from the barriers created by external agents.

For example, during one meeting there was a discussion with two deaf researchers and the sign language interpreter regarding the difficulties of explaining/understanding the meaning of abstract concepts like vulnerability. Their point was that sign language communication is different from verbal communication and communicating abstract concepts to deaf persons with limited education can be difficult.

Another example came from a wheel-chair user during the meeting on personal assistants, when he shared his discomfort in not being able to help his wife to look after the guests. His point was that when guests come to their home, there are limits to what he can do as a wheel chair user and that even with his best efforts, he cannot be a proper host to the guests.

Yet another example, came up during the discussions on livelihood, when some persons talked about finding jobs which do not require sitting in one place for long time or concentrating attention for long time, since they were not able to do it. Their point was that it does not matter which appliances they use and how much efforts are made by the employers in adjusting the work place to their needs, they have needs related to their impairment which do not allow them to do certain jobs.

Thus, while the researchers agreed about the fundamental importance of social model of disability in analysing barriers and fighting to dismantle them, this model does not explain all their challenges caused by their impairments.

5.4 PROMOTING EMPOWERMENT THROUGH THE RESEARCH

The researchers agreed that emancipatory research approach, in the way it was implemented and the way they had participated in it, was empowering. There were also two attempts to measure empowerment quantitatively through an index of questions with Likert scores.

5.4.1 Qualitative Perceptions of Researchers About Their Empowerment

During the review meetings, almost all researchers spoke to share their opinions regarding their empowerment and almost all of them were positive about the impact of participating in the research in different aspects of their lives. One of the researchers who had been operated a few days before the review meeting held in June 2019, had asked for a special permission from the hospital to come to the review meeting. Asked about the impact of her participation, she said that the experience had changed her from someone who was always quiet and shy, she now feels bold and active and therefore, she did not want to miss participating in the meeting.

“Barriers to Empowerment” was also one of the themes chosen by the researchers. During the meeting to share the findings of the research done on this theme, different participants spoke about their personal experiences of empowerment through their participation in EDR.

Different participants also spoke about importance of continuing their experience of the emancipatory research by using this approach in involving other persons with disabilities. One person said that she was planning to organize training courses on emancipatory research in rural areas. Another said that she has spoken about it to Ministry of Labour and Social Protection to see how the Government could support the implementation of emancipatory research approach in different parts of the country.

According to the participants, the part of the research which they found most empowering was in the afternoons of the theme meetings, after they had shared their findings and were discussing what could be done to change the situation. During the research review meeting organised, one of the researchers said: “*It was important that we were not just complaining about problems but that we were looking for solutions. It improved our self-confidence. In every theme research, we discussed and learned about our human rights related to that theme. In this process, we have made many friends. We now understand how to work as a team. We are now able to express our opinions freely. In this same period, some of us have made the shift to living independently. We know our strengths and know that we can work. We are less ashamed of going out in front of the people.*”

According to the researchers, the level of empowerment depended upon their level of participation – persons who participated more actively, were more empowered. Many of them said that in the beginning, they were shy and not very active, feeling that their opinions were not important, but they changed as they observed others and listened to their experiences.

5.4.2 Measuring Empowerment

There were two attempts to measure empowerment – one in broad life areas and the second, in specific life areas. Both these frameworks for measuring empowerment were developed through a participatory approach, based on the different inputs from the researchers regarding the meaning and significance they gave to empowerment.

The first attempt to measure the empowerment in 5 broad areas (family relationships, social relationships, educational or occupational relationships, public transport and rights) had the limitation that most of these areas were composed of different aspects of life and the persons did not feel equally empowered in all of them. Thus, some persons had difficulty in expressing a score for an area in which they felt empowered in one aspect of life and disempowered in another aspect of life.

The second attempt to measure the empowerment had more specific questions. An analysis of scores of this questionnaire confirmed that persons may feel differently empowered in different aspects of an area of life. For example, under the broad area of "empowerment in the family relationships", some persons felt more empowered in "taking personal decisions", but not in "participating and influencing family decisions".

5.4.3 Unanswered Questions Regarding Empowerment

Both, the self-perceptions of empowerment and its measurement through questionnaires, point towards an empowering role of CB-EDR on the lives of persons who participated as researchers. However, there is still a lot about individual empowerment that we do not know and needs to be done.

The 2 questionnaires used for measuring empowerment were developed following discussions with the researchers. However, at that time, the barriers identified during different theme meetings had not been analysed. Looking at the different kinds of barriers (**Annex 4**) from the analysis of the theme meeting reports, gaps can be identified and a better framework for measuring empowerment can be developed, tested and standardised.

This same framework can be discussed in consultations with DPOs in other countries to see if they agree with the broad and specific areas that were identified in Mongolia. It can be verified, if these broad and specific change in other countries and different cultural contexts.

The questions used for this measurement were very different from the questions used by other vulnerable groups to measure their empowerment. This group had decided on 50% of the questions being directly linked to the issues of disabilities and DPOs, which reflected the specific focus of the research. The questionnaires had same questions for men and women, implying that areas of disempowerment/empowerment for men and women are same/similar. It is likely that this was just a preliminary approach to understanding of issues about disempowerment and empowerment among persons with disabilities and further research on this area would bring out a better understanding of differences.

There are many questions regarding the empowerment of persons with disabilities compared to other groups of marginalised persons, that are not well understood. If these persons who took part in the EDR and perceived themselves to be empowered, can they go back to feeling disempowered, for example, if they do not get other stimulating opportunities? How long so the feelings of empowerment last? Who feels more empowered, someone of has actively taken part in EDR or someone who was not so active but was listening to others? There are many similar questions that were not touched upon in this research but that can be interesting to look at in future.

The understanding of systems and actions which promote empowerment of persons with disabilities is still in the beginning and would require a lot of more work to clarify and understand better.

5.4.4 Domination by Specific Groups of Persons with disabilities in the research

Each person with disability who became a researcher had a primary identity of his/her disability which he/she used to introduce him/herself. These identities had formed through the life-experiences of these persons. Thus, they introduced themselves as persons with cerebral palsy or persons who used wheel-chairs, etc. Looking at the group through the lens of these identities, there were two big dominating groups among the researchers – wheel-chair users and persons with cerebral palsy. Together these 2 groups constituted 2/3rds of all the researchers. For example, during the first review meeting, one researcher said, "*There are too many persons from the same organisation and they dominate. We should have had more diversified representation of persons with different kinds of disabilities*."

At the beginning of the training of the researchers, they were asked to complete a questionnaire, where they were asked about any difficulties, they faced in different body functions. The analysis of this information shows that majority of researchers have multiple impairments. Thus, looking at this information we can see that many persons, who were wheel chair users or who had difficulties related to cerebral palsy, also had vision and hearing difficulties. Yet, this was not enough for persons whose primary identity was of vision or hearing disabilities, they complained of domination by those 2 groups in the discussions, in the sense that there was greater attention towards the barriers faced by them.

These comments reflect some of the points raised by a few researchers in the review meetings and were discussed and analysed in a systematic manner. These may be linked to discussions regarding hierarchies. For example, a research on the attitudes of persons with disabilities towards other disabled persons had shown that a hierarchy of impairments existed, in which persons with certain impairments such as deaf, arthritis, epilepsy, cerebral palsy, and Down's syndrome were ranked lower. (Deal, M. 2006)

There is a whole area of primary identities and hierarchies related to specific impairments which requires more attention and understanding, which were touched upon superficially in this research and which could have practical implications for the cross-disability DPOs and federations.

5.5 OTHER ISSUES RELATED TO IMPLEMENTATION OF CB-EDR

There were some other issues related to the organisation and implementation of CB-EDR approach which emerged in Mongolia.

5.5.1 Supporting Staff for the Research

In the CB-EDR approach, it is fundamental to have trained supporting staff, preferably with experience in a rights-based disability programme, with good knowledge of CRPD. Since the group of researchers did not have experience and knowledge about different groups of persons with disabilities, and not all the different groups were equally represented among them, having the right supporting staff who organised the meetings, advised about guests to be invited, took notes and sometimes facilitated discussions, made a big difference in this research.

There were 5 main roles among the supporting staff for the research, linked with the organisation of theme meetings – (i) organising and logistical support, (ii) rapporteur for the meetings, (iii) translators for persons with communication difficulties, (iv) personal assistants and (v) persons for Mongolian-to-English translation of the reports. The translators for persons with communication difficulties and the personal assistants were identified through the DPOs and were persons who had been trained specifically and had already worked with other disabled persons.

There was no one among the supporting staff who had specific expertise in conducting sociological research. This was a deliberate choice to avoid “interference” from the expert in the interactions of the researchers.

However, the support staff included a rapporteur, who was provided detailed instructions about preparation of the meeting reports. This person had participated in the initial training of the researchers and was accompanied closely for the preparation of the initial reports. Having the right person for the meeting reports can make a big difference in the way the research is carried out. For example, the meeting on barriers to sexuality meeting was organised separately for men and women. The person engaged for preparing the EDR meeting reports was a woman and thus she participated as rapporteur in the meeting of women researchers. The minutes of male researchers’ meeting were taken by a man from a DPO, who had a university degree and was given detailed explanations about how to take down the minutes. At the end of the two meetings, there were only one and half pages long minutes for the men’s meeting while there were more than 10 pages of minutes for the women’s meeting.

A difficulty for the researchers and the rapporteurs is to understand the importance of documenting their discussions, even when they are talking about their daily lives and issues which do not seem important. Both the researchers and the rapporteur, because they are often talking of things which are common in their daily lives, tend to see these discussions as routine and not very interesting and thus not worthy of documentation. Specific cultural features may not be expressed explicitly, because they are obvious to them. For example, in the Mongolian culture, a wooden bar placed along the ground at entry gates and entrance of the round tent-houses (gers) is an important cultural tradition. During some discussions, this was mentioned as a barrier. However, persons unfamiliar with the importance of that piece of wood in the Mongolian culture, could not understand the difficulties of removing that barrier. Ensuring that the rapporteurs are aware of these blind spots and make an effort to document the apparently "boring details of everyday life" can require constant reminders.

5.5.2 Difficulties in Documenting the EDR research process

In the academic research processes, there is at least one researcher who is aware of the importance of the information gathering and documenting. In CB-EDR approach, there is a big group of researchers, who do not always remember about the importance of documenting the information they are gathering in a systematic manner. The only parts of the CB-EDR research process which could be documented properly were those related to plenary discussions during the meetings and any presentations prepared by the researchers (including photographs and videos), which were the responsibility of the rapporteur.

However, during the EDR meetings, there were also group discussions, which were documented by one of the researchers, who presented a summary to the plenary. The details of those discussions were not documented. A lot of research processes, such as field visits and interviews, which occurred outside the formal plenary meetings were not documented. A lot of information about the impact of the research, such as about the specific activities to reduce or overcome the barriers identified during the research, which were initiated by the researchers were mostly not documented. Collecting information about the research-theme became part of a life-process which included search on internet, discussions in the DPOs, discussions in families and sometimes, interviews. Sometimes, information from all these activities resulted in a formal presentation in which the main findings were presented. More often, there were no formal presentations but interventions to share some of that information in group discussions. Most of this information was lost to the documentation process.

Most of the information about the impact of the research was documented during the review meetings conducted after 12 and 18 months of the research. It is likely that during these review meetings, persons usually mentioned those activities which had taken place recently.

Thus, the research documentation from the CB-EDR process was generated at 3 levels:

(1) The vast amount of information generated when the researchers talked about issues among themselves or when they visited and interviewed other persons. This information was summarised and shared during the meetings. Since meetings have limited time, 2-3 researchers had the opportunity to present their findings in plenary, the remaining experiences were shared only in group discussions. Thus, most of that information remained undocumented.

(2) The formal presentations and plenary discussions including the presentations made by the group representatives during the research theme meetings and review meetings, were documented by the rapporteur for preparing the minutes and formal reports of each meeting.

(3) The present final report prepared by the global research coordinator is based on the English translations of minutes of the different research theme meetings and review meetings. A draft version of this final report was shared with the different stakeholders including TAG members and some researchers who understand English. Their feedback was included in the report for the preparation of the final version. The final version has been translated into Mongolian and shared with all the researchers.

5.5.3 Overlap in the Research Themes

Many researchers complained that there was a lot of overlap between the themes and sometimes when they discussed the barriers, they jumped from one theme to another.

For example, during the meeting on barriers to accessing Social Welfare services, a young man with CP using a wheel chair brought up the issue of education for children with disabilities. When he was asked what was the connection between school education and social welfare said, "*If we think of how many children are in the special schools and for each of them the Government has to pay a variable cost, we should focus on inclusive education. Special kindergartens and special schools make the children underestimate themselves, lose confidence and become shy about themselves, because they only talk to other children like them. Therefore, they cannot show themselves to the society. Social welfare services cover all people in the society and education is connected to that. All these issues are connected.*"

Connecting school education and social welfare services because both use Government funds sounds a little far-fetched. However, for persons sharing experiences about their daily lives, overlaps between themes were probably inevitable, because it is difficult to close life in neat separate boxes. Probably, this could have been avoided, at least partially, by defining the themes in more specific terms but then, that would have raised other problems for the selected research approach.

5.5.4 Quality of Research In CB-EDR

There are some fundamental differences between CB-EDR and emancipatory researches carried out in the Disability Studies courses, which place an overarching value on conducting good research. The way CB-EDR methodology was developed, carrying out good academic quality research was impossible, because it placed value on other things such as knowledge based upon life-experiences among the researchers.

In the initial months, there was regular exchange of ideas regarding the issues to be discussed during individual theme researches between the TAG and the researchers, especially among the core group members. However, as time passed this exchange decreased and researchers became more autonomous. They started feeling that they had understood the goals and methodology of the research. An analysis of the research reports shows that sometimes this led to more superficial discussions and some aspects of the research theme were not discussed by the researchers.

For example, the meeting on meanings and significance of discrimination (May 2019) did not probe deeper into the meanings of discrimination, and thus participants never came around to a common understanding about it and the discussions were confused. On one hand, some researchers talked about the right to be treated like others because being treated differently was considered as discrimination. One of the researchers, while sharing his experience at the work place said that his co-workers are extra helpful to him, which he perceived as being patronising. Another said that employers discriminate against them because they can't work like others, and concluded that they should not be judged in the same way as their non-disabled colleagues. It would have been interesting to probe deeper into those two contradictory positions and reflect on discrimination and its blurry boundaries.

The lack of academic research expertise among the researchers had a direct impact on the quality of the research. For example, they had limited knowledge and personal experiences regarding some of the themes. The planning of research on those themes failed to clarify these challenges and thus, no support was sought from the TAG members or from other sources. This happened for example in the research on the themes 3 (barriers to social welfare), where the researchers did not know the different kinds of social welfare activities.

Even for themes about which the researchers had a better understanding and diverse levels of personal experiences, it is easy to see that the discussions of the issues ignored certain key aspects, while certain other aspects were touched upon superficially. For example, in the meeting on personal assistants, there were significant discussions on privacy and confidentiality. Yet, when a personal assistant was asked to share his experience of being a personal assistant, no one raised any questions to understand how this person looked at the issues of privacy and confidentiality.

Concluding Remarks: CB-EDR approach to disability research is in the beginning stage. Unfortunately, there are no other organisations engaged in this kind of research. Thus, spaces for sharing and comparing ideas and experiences are limited.

CB-EDR approach has clearly many limitations. The most important of which include the difficulties in documenting the process in such a way that more information can be captured.

Not every research has to touch on every aspect of an issue, but in this CB-EDR experience, these decisions happened, rather than being made consciously. Findings other ways to facilitate the research process without taking away the power and control from the persons with disabilities engaged as researchers is another challenge to which solutions must be sought.

Conclusions

CB-EDR places emphasis on knowledge among persons with disabilities based on their personal life experiences. Thus, there were no pre-requisites to select or exclude any persons with disabilities from becoming researchers. 18% of the researchers had limited education, including 6% who could not read or write. 72% of them had multiple disabilities and almost all of them were classified by the Mongolian Disability Certification system as persons with moderate to severe disabilities. This was not a group of persons whom you would assume to be capable of being responsible for conducting a research. Yet they showed that such an approach is feasible.

The research they have carried out does not have the characteristics of a good academic research but they did come up with new information in their Mongolian context regarding the different kinds of barriers they face in their daily lives. In fact, in some contexts, such as persons living in the gers (tents) and persons using public transport, the research has brought out a richness in details about the different ways in which disabling barriers isolate them and block their participation, which were not known to DPOs as well as to different service providers. The CB-EDR methodology allows combining a scientific research approach with the real-life experiences of persons with disabilities, which is usually missing from such academic research.

The CB-EDR has brought out rich details of the numerous ways in which persons with moderate-severe disabilities are further disabled by the different barriers. It showed that different kinds of barriers have different impact in negatively affecting the participation of persons with disabilities in different life domains and contexts. However, it provided limited information about the different personal characteristics of persons with disabilities and how these can be sustained or strengthened, to be able to draw any conclusions about them.

In terms of transfer of research knowledge into practice, the impact of CB-EDR in Mongolia had an immediate and significant impact. In many instances, theme researches led to specific activities to find solutions and to overcome the barriers identified by the researchers. This was its most significant characteristic and it underlined its difference from normal academic research, which finds it difficult to bridge the gap between knowledge and action.

Both, qualitative and quantitative assessments of the researchers involved in it showed this approach promotes individual empowerment. However, there are still different aspects of individual empowerment that are not well understood.

During different theme discussions, there were also sharing of experiences regarding the limitations placed by the impairment, which were not due to the barriers created by others or external factors, showing that disablement cannot be explained exclusively in terms of social model of disability and certain barriers are inextricably linked to specific impairments. At the same time, the research underlines the importance of using social model to look at the issues facing persons with disabilities. It found an immediate resonance among the researchers.

Having competent supporting staff to sustain the research process is a prerequisite for implementing the CB-EDR approach. In this research, the role of the external support provided by the experts and academic researchers through TAG was limited and this requires further explorations to understand how it can be strengthened in ways which do not limit the autonomy of the researchers.

The participation of persons with disabilities in the research was made possible because of personal support of some of their family members and the support of their DPOs, which provided them the personal assistants to carry out the field research and to participate in the theme meetings. At the same time, many of them invested in the research at a personal level, probably because they felt that the participation in the research would help in empowering them and making them stronger to fight for their rights.

CB-EDR approach should be considered as one of the research strategies alongside academic ER and conventional qualitative and quantitative research, in understanding different aspect of the disability experience.

Impact of EDR: Views of the Partners

Different DPOs and academic institutions were partners in this emancipatory research. Some of their representatives were members of the Technical Advisory Group (TAG). Many of them had helped in identifying the researchers and were in regular contact with those persons, and thus, were following it from outside. One of the TAG members was also the mother of one of the researchers. During the review meeting, they shared their views regarding the research and its impact, some of which are presented here.

Mr. Undrakhbayar (Independent Living Movement Mongolia): "It is true that many persons who had attended the initial training did not continue as researchers but it was not because of disinterest. One year is a long time and a lot of things can happen in that period – some of them found jobs, some had personal problems and some had health related problems.

Once those persons became researchers, they received additional stimulations and opportunities for empowerment. For example, after the research started, we were involved in the preparation of the 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. Many of the researchers became active in those initiatives, and these became additional opportunities for their empowerment. So, there were multiple sources of empowerment for the researchers and it was not only from the emancipatory research.

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. Many of them had mostly stayed at home, going out only once or twice in a year for medical check-ups or to get disability certificate. A woman, sister 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 being a researcher, he was completely changed, he has become talkative and his way of life had changed. Now, he wants to go out all the time. They have to keep on telling him to clean his room, because he says that he does not have time.

That guy is not alone in the way he had changed. So many of these researchers come to our office, they have become smiling and talkative persons."

Dr. Batdulam (head of Public Health Program at the School of Medicine of Mongolia National University and mother of one of the researchers): "Participation in the research has helped him to become more self-confident and active. Before EDR, I used to worry about his safety and his education, but I had not thought about his growth as a person. He knew little about other persons with disabilities and was only interested in playing. Researchers have been lucky, it is as if they have been part of a one year long self-learning training course. On every research theme, he carried out a search for information. He wanted to go out and do surveys but for that he needed support and this aspect was weak in EDR – they did not really work as a team. If they had worked as a team, the results would have been even better."

She gave examples of how her son involved the whole family in his research, "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. He had no idea about discrimination, he didn't know the difficulties faced by blind persons and deaf persons. He has learned all that. 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 get a lot of feedback from them. We have tried to involve all the different groups of persons with disabilities in the research. Some of them did not like to be part of wider groups, they preferred to stay with persons who have their similar disabilities. So even after a lot of discussions, they decided not to continue as researchers. Perhaps they needed to gain self-confidence with their own peer groups and only then they can join the dialogue with persons with other disabilities.

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. Even the two illiterate persons among the researchers, they now joke and say that now they know at least how to switch on and off the computers. Depending upon their level of education, their level of empowerment is different, but all of them have improved."

About his role as chair of the TAG he explained, "I receive all the meeting reports from Ms. Battasetseg, the EDR reporter and I send them to all the TAG members. Some of the TAG members are not maintaining their email addresses so sometimes the messages come back, but generally all of them are informed. A lot of information is coming from this research and is a challenge for us to think of how we can respond to this information. There is so much to do and to change. We need to think about how to do it and whom to inform. A final publication on the research will be useful.

The research is not only providing information about the themes but our researchers are going out in the communities and discovering other situations where help is needed. For example, a researcher found a child with cerebral palsy who was having problems in school and so we had to think of how to help that child. Like this, through the research they are also helping so many 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 speak much and she thought that only she had a disability and it was some kind of suffering only for her. After joining the research, she understands that she is not alone, that all of them face difficulties and many others face a lot more difficulties than her. Earlier 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 to communicate with others through sign language and they are not giving importance to reading and understanding. She has learned this in the research and has become more attentive towards reading and understanding. 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."

Mr. Giampiero Griffo (chair of Italian Network on Disability and Development): "After 12 years of CRPD, there has been much progress but still a lot remains to be done. We can't think of disability only in terms of medical model. For example, sometimes they talk of persons with disabilities as a vulnerable group, but we need not always be vulnerable. We become vulnerable when we are excluded, as this research shows. The SDGs say "no one should be left behind", but for centuries, we, the persons with disabilities had been left behind. We have to show to the Governments what excludes and blocks us from participation. We can't be full citizens till those barriers are removed. The first barriers are inside our own heads, till we remove them, we can't fight against other barriers."

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. For me it was difficult to explain to the Government about the CBR evaluation and our findings. We were 5 persons involved as the evaluation team. It was carried out over a short period of time. I think that if like EDR, we had longer period and more support, we could have done it in a much better way. I am a researcher and I will be happy to contribute in the analysis of these research reports."

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LIST OF ANNEXES

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Annex 1

Research Protocol & Consent Form

INTRODUCTION

Persons with Disabilities (PwDs) face numerous physical, attitudinal, social, cultural and economic barriers in exercising their citizenship rights. These barriers affect all the different facets of their lives, starting from their role in families, school education and friendship with their peers to their access to health services, employment, housing, marriage, sports and leisure activities.

This research is an opportunity to gain insights about specific aspects of lives of PwDs. It is an opportunity to learn about the challenges they face and their strategies for overcoming those challenges. It is a part of the project “Closing the gap: a right-based approach towards independent living for people with disabilities”, which is co-funded by EIDHR country schemes of European Union (EIDHR/2017/392-819) for the period 2018-2019 and is managed by Tegsh Niigem (Mongolia) along with AIFO (Italy).

BACKGROUND

The ideas of Emancipatory Research are rooted in the theories of Brazilian pedagogist Paulo Freire and those of the different participatory research approaches: “*Participatory research methods are geared towards planning and conducting the research process with those people whose life-world and meaningful actions are under study. Consequently, this means that the aim of the inquiry and the research questions develop out of the convergence of two perspectives—that of science and of practice.*” (FQS, 2012)

The term Emancipatory Research was coined by Mike Oliver in 1990 when he had proposed that disabled researchers can provide new understandings regarding the challenges faced by persons with disabilities. (Barnes, 2001)

Emancipatory Disability Research (EDR) is rooted in the social and human rights models of disability, which focus on the different kinds of barriers, from attitudinal to physical, social, cultural and economic, that surround persons with impairments and create disablement and promote a fight for the rights. The social model *“defined disability not as an impairment or deficit of body or brain, but as a relationship between people with impairment and a discriminatory society.*” (Shakespeare, 2004)

EDR in the developing countries, specifically in the context of community-based interventions adopts different strategies for promoting empowerment, even while acknowledging the difficulties in “measurement of empowerment”: “*The difficulty of measurement initially stems from the multitude ways in which empowerment is conceptualised. Lack of a universal definition makes measurement problematic and* *it is almost impossible to compare results and outcomes across studies within and between different disciplines.*" (Cross, et al., 2017)

"*Promoting participation and an understanding of socio-political environment*" has been suggested to promote empowerment among the marginalised population groups. (Perkins et al, 1995). Empowerment has three common attributes - multi-dimensional, social, and a process. It is multi-dimensional in that it occurs within sociological, psychological, economic, and other dimensions. Empowerment also occurs at various levels, such as individual, group, and community. Empowerment is a social process, since it occurs in relationship to others, and it is a process along the continuum. (Kasmel, 2017)

RESEARCH OBJECTIVES

The *Objective*s of this research are as follows:

- Learning about the key barriers faced by specific groups of persons with disabilities and building understanding about overcoming of those barriers.
- Promoting grass-root action at community level to overcome the barriers, and fight for human rights.
- Promoting empowerment of persons with disabilities and strengthening their leadership capacities to promote future leaders of the disability movement in Mongolia.

RESEARCHERS

The research will involve around 25-30 young persons of 18 to 35 years age group, both men and women, living in one of the 9 districts of Ulaanbataar.

Selection of PwDs for the role of researchers: The researchers will be identified in collaboration with different federations of persons with disabilities. If possible, they should be persons with different kinds of moderate to severe disabilities. The persons should represent different socio-economic and educational back grounds.

Persons identified as research participants will be provided five days' training on conducting the research and about their roles as researchers. The training of the researchers will include information gathering skills, confidentiality, ethics, interviews, life-stories approach, and the use of narrative, picture and video resources to promote discussions and exchange of ideas around different life issues.

They have to agree to take part in the initial training and then be a part of the research process that will start in June 2018 and finish in October 2019. The selected persons will be asked to sign a consent form and provide general information about themselves.

TECHNICAL ADVISORY GROUP

A group of persons with expertise in the areas of disability, research and human rights will together constitute a Technical Advisory Group (TAG), who will together provide advice and feedback to the researchers on a voluntary basis. The group will include around 12-14 persons from Mongolia including representatives from different DPO federations, academic researchers and professionals with expertise in research areas such as disability studies, sociology or anthropology. Where possible, preference will be given to persons with personal experience of disability as TAG members.

TAG will also include two persons nominated by AIFO/Italy – Giampiero Griffo from Italian Disability & Development Network (RIDS) and Disabled Peoples' International (DPI/Italy); and Sunil Deepak, with experience in emancipatory research and CBR, who will also be the global coordinator of the research and responsible for the preparation of its final report.

TAG will meet three times – at the beginning of the project, in the middle and at the end. Its role will be to discuss the research protocol, follow the progress of the research activities and provide feedback and advice for the field research activities. In addition, TAG members will receive by email all the research reports and their comments and critiques will be shared with the researchers. TAG members can participate in the theme meetings as observers.

RESEARCH COORDINATION & LOGISTICS

A small core group of 5 persons will be constituted, who will provide support to the researchers for the organisation of different research activities and will mediate between the researchers and the TAG. The group will include a representative of a DPO, president of Tegsh Niigem, AIFO representative in Mongolia, rapporteur for EDR, and Sunil Deepak as the global coordinator for EDR.

A rapporteur with experience in participatory research, good inter-personal skills, familiarity with programmes like Word and Excel and proven skill in preparation of reports will be identified. This person will be provided a training on "Reporting for Emancipatory Research" and will participate in the training course for the researchers. The reporter will prepare all the research meetings minutes and reports. The rapporteur will maintain contacts with the AIFO Mongolia, Tegsh Niigem, researchers and the EDR global coordinator; and, will facilitate background research for each meeting and prepare minutes and reports of the monthly research meetings.

RESEARCH METHODOLOGY

During the first TAG meeting in May 2018, suggestions will be asked from TAG members regarding the 12 priority research themes.

The 12 priority themes identified by TAG members will be presented to the researchers during their training course. Through a participatory process, the group of researchers will decide the final list of 12 priority themes for the research to be completed by October 2019.

For each theme, the researchers will interview persons with different disabling conditions, persons representing different age groups, persons representing different socio-economic situations, ensuring equal participation of women. The interviews will be based on generic and neutral questions asking about life-experiences and collect information about both positive and negative experiences related to the theme of the research.

A 2-day meeting of the researchers will be organised periodically focusing on one priority theme. The first day of the meeting will be devoted to sharing of information gathered from the field. On the second day, a specific protocol including background information and key issues to be discussed during the next theme research will be prepared.

Each research meeting will have some invited guests with specific experiences or expertise related to the research theme. The researchers will get around 4 weeks of time to collect information about the next research theme in their communities. They can conduct the field research individually or in small groups.

Day 1 of each research theme meeting will have the following general format, which can be adapted according to the needs of each research theme:

- Presentation of the research theme, key issues and background information
- Sharing of life-stories, personal experiences or specific information related to the research theme by the invited guests and researchers
- Analysis of the issues raised, key challenges, identification of different kinds of barriers faced by persons
- Discussions about what is needed to overcome the challenges and the barriers – by the state institutions, by communities, by DPOs and NGOs.
- Discussion on what can be done by the persons with disabilities themselves to overcome the barriers.

The rapporteur will prepare a report about the key discussions emerging from that meeting. He/she will keep a note of different practical developments taking place during the preparation of and following the theme meetings and record these in the report.

Data Analysis: It will be mainly a qualitative research and will work through sharing of life stories and life-experiences focusing on the role of different barriers faced by persons with disabilities and their strategies for overcoming those barriers. The researchers will also discuss any facilitating factors which enable them to overcome barriers.

During each theme meeting, the researchers will share the information they will collect and together they will collectively analyse that information and identify the most significant barriers and strategies emerging from their stories. Theme-meeting reports prepared by the rapporteur will include both the sharing of information as well as, its analysis by the researchers. The meeting reports will be shared with the TAG members and researchers for their comments.

At the end of the research process, after the completion of the 12 meetings, a summary of issues emerging from all the 12 reports will be presented and discussed with the researchers to identify the key barriers they face.

At the end of the research process with the completion of the 12 meetings, all the different reports will be put together, coded and analysed for their findings in terms of aspirations, vulnerabilities, strengths and challenges faced by disabled persons in different life domains and actions stimulated by the research to overcome the challenges and barriers. The final report presenting the research analysis will be shared with the researchers for their comments and feedback.

The representatives of the researchers will also be asked to participate in the mid-term and final meetings of TAG and share their experiences from the research and the insights they have gained from the research process.

ETHICAL CONSIDERATIONS

The research protocol was discussed with Tegsh Niigem and Independent Living Movement in Mongolia and with AIFO/Italy for the approval.

All the participation of persons with disabilities in the research will be completely voluntary and confidential. All participants (researchers and all the persons they will interview) will be provided information about the research (Annex 1) and asked to give an informed written consent.

The research team will ensure the support of a person with experience in mental health and counselling, in case of any sharing of traumatic personal experiences during the research process that may lead to an emotional crisis.

CONCLUSIONS

The initiative for understanding the challenges and barriers faced by PwDs is a participatory research based on the emancipatory approach in which a group of Persons with Disabilities living in Ulaanbataar, Mongolia will be trained as researchers and then facilitated to explore some key aspects of their lives. The research will focus on understanding the gaps and barriers, and how to bridge those gaps and overcome those barriers, with the promotion of their active citizenship.

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Consent Form for Research Participants

Barriers Faced by Young Persons With Disabilities in Ulaanbaatar, Mongolia

Name, Work Address and Contact Details of the Field manager	**E. Lhagvajav, Tegsh Niigem NGO, Ulaanbaatar, Mongolia** **Tel. xxxxxxxx Email: xxxxxxxxxxxxxxxxxxxxxxx**

We would like to invite you to be a participant and researcher in this study. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Details of Study:

This one and half year study is part of a project on promotion of independent living for persons with disabilities in Mongolia. It is carried by Tegsh Niigem and AIFO with support from European Union. This study aims to understand the aspirations, vulnerabilities, strengths and challenges faced by young persons with disabilities in Ulaanbaatar for promoting their understanding about these issues and for their independent living. If you will accept, you will be invited to participate in monthly meetings for the next 12 months.

The study will require you to meet with other young persons with disabilities and share your ideas and experiences regarding your own life experiences at a voluntary level, so that you can share whatever you will decide and no one can force you to share anything that you do not wish. You can also leave the study at any point if you will wish, without any negative consequences.

There may be no direct benefit for you for participating in the study, but it can help you to gain understanding about the needs and challenges faced by persons with disabilities in your city and community. Your opinions and discussions expressed during the study will be confidential and will not be shared with any other people. The records of this study will be private. Only the people who are doing the study will be able to look at the answers that you give to the questions.

You are free to ask any additional information regarding the study that is not clear to you.

Participant's Statement

I ___________________________ (name)

- have read/been explained the notes written above and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study.
- agree that reports of research meetings in which I will participate can be used for research analysis. I am assured that the confidentiality of my personal data will be upheld through the removal of identifiers from the reports.
- understand that all personal information will be treated as strictly confidential.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signature of the person with disability	Date:

Annex 2

INTERNATIONAL TECHNICAL ADVISORY GROUP (TAG) – CB-EDR

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	N/A
8.	Erdenetsetseg	Lecturer, Nursing School, National University of Medical Science	F	N/A
9.	T.Batdulam	Executive director of AP CBR Networking	F	Mother of CWD
10.	O.Ganchuluun	Exectuive director, National Center of Mental Health	F	N/A
11.	T.Altantsetseg	Sociology dept, Management Academy	F	N/A
12.	S.Enhsaihan	Management dept, Management Academy	F	N/A
13.	Sunil Deepak	International Research Coordinator	M	N/A
14.	Giampiero Griffo	RIDS & DPI Italy	M	Moving (wheel chair user)
15.	L.Enhbuyant	Tegsh Niigem NGO, Secretary	M	N/A
16.	B.Battsetseg	Rapporteur	F	N/A

Annex 3

CB-EDR RESEARCHERS

The research was initiated with a 5 days long training course in May 2018 for the persons with disabilities selected as researchers. 34 persons took part in this training. Over the next one and half years, around 20-22 researchers took part in conducting field research on individual research themes. However, the participants varied – while some the persons dropped off, new persons joined. At the end, there were a total of 42 persons who had taken part in at least one field research.

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	Car accident, had brain operation, paralysed, hemiplegic
41	Batnairamdal	Munkhbat	M	Spinal cord injury
42	Tugsdelger	Tugsjargal	F	Hard of hearing

Annex 4

Classification of Different Kinds of Barriers and Facilitating Factors

(Used for Analysing Theme Reports)

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	

Annex 5

Measuring Empowerment in 5 Domains

Before answering the questionnaire please read carefully the following explanation:

Empowerment means our self-confidence, our ability to make decisions about our life, our ability to go out and express our opinions, our ability to fight for our rights.
We want to know if participation in emancipatory Research has helped you to become more empowered. For each statement below, think of the first time you had come to the research meeting and then decide if participation in this process has helped you to become more empowered or not. If you think that there is no change in you, you can give it a minimum of "0" points. If you think that it has made a lot of change in you, you can give a maximum of "7" points.
The questionnaire is anonymous. Do not write your name on this questionnaire.

1. Participation in this research has improved my empowerment in my family relationships

0	1	2	3	4	5	6	7

2. Participation in this research has improved my empowerment in my relationship with my friends

0	1	2	3	4	5	6	7

3. Participation in this research has improved my empowerment in my school/university/work place.

0	1	2	3	4	5	6	7

4. Participation in this research has improved my use of public transport system.

0	1	2	3	4	5	6	7

5. I am now more aware of my rights and I can ask others that my rights should be respected.

0	1	2	3	4	5	6	7

6. I feel more empowered in the following activities:

Annex 6

Measuring Empowerment in Specific Activities

Emancipatory Disability Research (EDR) Mongolia

For the following questions, think of the impact of EDR participation on yourself. For each question, think of the time when you first came to an EDR meeting and now, and then decide if today you feel more empowered or less empowered for each of the below questionnaires.

Choose only one answer for each question, in the scale from (0) to (5), where (0) means negative or very little change in your empowerment and (5) means excellent or positive or maximum change in empowerment.

1. How do you judge your participation in the DPO activities?					
0	**1**	**2**	**3**	**4**	**5**

2. In your opinion, how good is your capacity to speak in DPO meetings and to express your ideas?					
0	**1**	**2**	**3**	**4**	**5**

3. In your opinion, how good is your understanding of different kind of disabilities?					
0	**1**	**2**	**3**	**4**	**5**

4. In your opinion, how good is your understanding about barriers faced by different groups of persons with disabilities?					
0	**1**	**2**	**3**	**4**	**5**

5. In your opinion, how good is your ability to take decisions and take action about your own life?					
0	**1**	**2**	**3**	**4**	**5**

6. In your opinion, how good is your capacity to participate in the family decisions?					
0	**1**	**2**	**3**	**4**	**5**

7. In your opinion, how good is your capacity to have a voice and to express your opinions in your community?					
0	**1**	**2**	**3**	**4**	**5**
8. In your opinion, how good is your capacity to fight when you see that rights of persons with disabilities are violated?					
0	**1**	**2**	**3**	**4**	**5**
9. In your opinion, how good is your ability to inform and give advice to other persons with disabilities about their problems and how to access services?					
0	**1**	**2**	**3**	**4**	**5**
10. In your opinion, how good is your ability to give information and advice to parents of children with disabilities in your community?					
0	**1**	**2**	**3**	**4**	**5**
11. In your opinion, how good is your ability to do advocacy for changing the attitudes of school teachers, health workers and community leaders?					
0	**1**	**2**	**3**	**4**	**5**
12. In your opinion, how good is your ability to talk about your own disability and your situation in front of other persons?					
0	**1**	**2**	**3**	**4**	**5**

13. In which ways EDR participation has made you more empowered or less empowered?

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Annex 7

Theme Meeting Reports

There were 12 Priority Research Themes selected by the researchers. For each of these researches, a theme meeting was organised for which detailed minutes were prepared, which have been analysed for the preparation of the research report. The reports presented here are summary versions prepared from the meeting minutes.

In each theme report, only the names of invited guests and of those researchers are mentioned who had made any formal presentations. No real names of persons making personal testimonies or intervening in different discussions are mentioned.

The theme meeting reports were prepared in Mongolian and then translated locally into English. Apart from some minor corrections of obvious mistakes, most of the text has been left unaltered, to give a sense of original voices of the researchers.

LIST of Theme Meetings Held Under EDR

1. Barriers faced by persons living in the ger districts (28 June 2018)
2. Accessibility of Public transport (16 August 2018)
3. Accessing social welfare services for persons with disabilities (1 October 2018)
4. Barriers to Independent living (8 November 2018)
5. Barriers to expression of sexuality (16 March 2019)
6. Right to livelihood and barriers in exercising this right (7 April 2019)
7. Right to education for children and young adults (28 April 2019)
8. Discriminations faced by persons with disabilities (19 May 2019)
9. Personal assistance services in Mongolia (8 June 2019)
10. Barriers to empowerment (25 August 2019)
11. Barriers to health and well-being (13 September 2019)
12. Accessing assistive products (28 September 2019)

Theme Meeting #1 - People with Disabilities, Living in a Ger District

Meeting Report

Persons with disabilities living in the ger districts: This was the first theme meeting. It was held at Holliday Inn hotel, Ulaanbataar on Thursday 28 June 2018. 21 researchers participated in this meeting. Apart from the researchers, Mr. Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Rapporteur) and Ms. Shugarjev, (sign language translator) participated in the meeting. In addition, two external observers were present in the meeting: Mr. Ghulam Nabi Azad (President AP-CBR network) and Ms. Barkha Henry (Representative, Leonard Cheshire Disability).

Meeting coordination: Mr. Otgonbayar as the chairperson and Mr. Duulim as equal-participation observer in the morning session; Mr. Bilegsaikhan as the chairperson and Mr. Munkhbat as equal-participation observer in the afternoon session. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Testimonial: A person with spinal cord injury living in a ger district of UB shared his life story.

“I had spine injury in 2010. Before that I have no idea about persons with wheelchairs, even I didn’t know that these people exist in society. A few days after I was released from the hospital, I met some persons who told me about Mongolia Independent Living Center (MILS), and suggested me to come over there. I went there and learnt about the DPO and other persons with disability.

Right after my injury, I couldn’t do anything by myself and couldn’t go out independently. I have always needed someone’s support. Even for going to toilet, I needed someone’s help. Then I have got married and slowly started to do things independently inside the home. Further, I have started to go outside by myself. However, I still needed other’s help to go up and down the stairs.

Now as a person living in the ger district, there were many struggles. For going to the supermarket or kiosk, there were no ramps or proper streets. At the minimum, the markets and kiosks have a few steps or a doorsill. I was living independently since 2015 in the center of a somon, in countryside. I had removed all steps and doorsills at home so it was accessible for me.

For me, the most challenging thing was bringing water from the community well. I always had to ask someone to bring water from for me. I could split firewood. Another difficulty was the road, it was difficult for wheelchair users and it was challenging to take taxi. There was no accessible bus service. Even though there was an accessible bus to the city but its ramp was broken. Since I have got disabled, lack of opportunity to do what I want is the toughest. For example, when I want to visit some organizations, door would be narrow or no ramp.

Now I am living in Zuragt ger district in the northwest of the UB. I wanted to rent an apartment on second floor but that was not accessible for my wheel chair. So, I am renting a ground floor apartment which has 5-6 steps. For going through those steps, I have to fold my wheelchair. Moreover, all kiosks and supermarkets in our neighborhood have steps, yet no ramps.

Recently I went to the movie theatre. Even though there was a ramp there, it was locked. I asked the staff about why it was locked, they said that they don’t really use it. The ramp is for wheelchair users or for heavy loads, but unfortunately no one knew why it was locked. Luckily 2 men helped me to go into the cinema, but they weren’t there when I needed to go out.

In the countryside, it was difficult for me to go to toilet. Because its door was narrow, it could not be closed. Thus, even it was stormy or windy, I couldn’t close the door of toilet. It was difficult for me to use if there were other persons nearby. In my view, lack of accessibility makes us disabled. For example, I wanted a taxi but couldn’t find it. Taxi drivers think they will have to carry me to sit inside and then deal with my wheelchair, though actually I can do all this by myself. In the ger district, we can make our home accessible but the streets are not proper, the roads are bumpy and pedestrian. These are the reasons that make us difficult to move independently.

PRESENTATIONS BY RESEARCHERS

Presentation #1. Mr, Nyam-Ochir: “I came to UB in 2000, and till recently I was living in a ger district. I had spinal cord injury in 2011. After that, everything in my life was new to me, I felt like a new born. I had to meet the world with my wheelchair.

There are pros and cons in living in a ger district. For example, we don’t have water problem, yet in a ger district sometimes we don’t have money for water from wells. Before my injury, it was my responsibility to bring water from the well and split firewood. However, after my injury, my father had to do it. It hurt me to see that. So in winter time, it was challenging to heat the ger.

My father has a seasonal job. Especially in winter, our family faced financial difficulties, whilst I needed money for my health care. This went on for 2-3 years. As I was staying at home, I was stressed. Then I decided to continue my study. Luckily, my university has an elevator. Moreover, according to the law, we can have up to 70 percent discount on university fee for the first undergraduate degree.”

Nyam-Ochir explained that there is a lack of accessibility of parts of the university building, including its interior. He learned about CRPD, rights of PwD and national legislations at the Independent Living Centre. He concluded, “I have decided to fight against the inaccessible society.” After his presentation he was asked about asking University administration to build ramp. He explained, “When I asked, unfortunately, a professor told me that you don’t have to come here every day, you can study by online. I refused to do that. I needed to gain education and one of my goal was that students and university should see me every day, only then the public will change its negative attitude.”

Presenter # 2. Ms. Selenge: “I have been living in a ger district for one year and 8 months after my back injury. During that time, I couldn’t sit by myself and I stayed at home. My challenges were almost the same as the previous presenter, such as, to heat the ger, to bring water from wells, to go to toilet and to go out. When my husband went to work, I could not heat the ger and was very cold."

"A solution for an accessible toilet, I think, can be by setting the toilet inside the ger by digging the hole underground and set the W.C pan on that and connect it to central sewerage. I know that it requires finance, but family can support to pay it. About the solution for water supply, we can derive from central services, if the ger is nearby the central service. Since splitting firewood is tough for women in wheelchair, we can use electrical heating system since people in a ger district can pay a reduced electric tariff (for example, the night time tariff)."

Presenter #3. Ms Misheel: She brought pictures and video to show the living condition in a ger district. These were also posted in the Facebook page of the research group.

Misheel said, "I have visited the home of a person living in a ger, who has CP like me. At the entrance, there were few steps. He lives with his 2 siblings and parents. He usually doesn't go outside, though he sometimes visits the Mongolia independent living centre (MILS). Before I visited his home, I had no idea about how problematic it is for him to go outside. I used to ask him, why don't you come over often to the MILS? Since I have visited his home, I have decided not to ask this to him."

"The road to his place was steep and bumpy. The toilet was difficult to use not only for him but also for other family members. His younger brother usually helps him but he wasn't there when I visited at his place. He has never studied at school because his parents were not able to pick him up and drop him off. Moreover, he has 2 siblings and his parents had more focus on his siblings rather than on him. He never had chance to go out whenever he wanted. His parents didn't really take care of him and had negative attitude about his disability issues."

She continued, "He always stays alone at home during daytime, therefore he uses diapers. He told me that once his diaper was full and he took it off by himself and then peed in the corridor. For me as a female, it was hard to imagine doing like that." After the presentation, she was asked, "What are your suggestions to resolve his problems?" Misheel said: "Since I cannot change the family, at least we can remove the steps and fix the bumpy road and set the toilet in their home."

Another question was about changing the family members' attitude. Misheel felt that it was difficult as his parents don't support their son to participate in social life. A third question was about how he manages things when he is alone during the day. Misheel explained that his one hand moves better, so he can do by himself some things. There was some discussion about how to help him to come to MILS.

Presenter 4: Ms. Boloroo: "I wanted to do research on 5 people's living condition, but 2 of them refused to be part of the research. I tried to choose people who have difficulties in living in a ger district." She talked to a person with vision difficulties and to a person with moving difficulties.

She also collected the following information about the persons with disabilities living in the ger districts: According to the National Statistic Committee information, the total population of UB is 1,417,000 people out of which, about 56% (797,000 people) live in the ger districts. According to the statistics of 2017, in Mongolia there were 103,630 PwD, around 3.3 percent of total population. Out that about one-third of persons with disabilities (34,636 persons) live in UB and other two-thirds live in the rest of the country. Furthermore, according to statistic of 2015, 40 percent of PwD in UB were living in a ger district. This statistic might have changed in last 3 years. Among the ger districts, maximum number of persons, including most of PwDs, live in Bayanzurkh and Songinokhairkhan districts.

She explained that she wanted to understand the challenges faced by PwDs living in Chingeltei, Songinokhairkhan, Bayanzurh ger districts and in Umnugobi aimag. She had prepared some questions for the persons to understand their situation including those about the disability, education, occupation, housing, etc. She herself has been living in a ger district for 25 years, so they also exchanged life-experiences.

First, she told about a wheelchair user man living in Songinokhairkhan district with his 2 daughters. He had an injury in 2015 and lost his 90 percent of ability to work. For him, the major challenges were – lack of proper roads, missing street lights, and lack of accessible buildings. His relatives had made some adjustments in his home to make it more accessible. (Ms. Boloroo showed the picture of the door, doorsill and a ramp), however the neighbourhood was not accessible for him to move independently.

Then she talked about a woman had a moving difficulty, who lives in Umnugobi province with her husband and 2 daughters. Compared to the man, women's answers were quite different. For her, a major challenge was shopping for food and other things. She started walking only when she was 7 years old. She was adopted and her parents thought that she couldn't study, so she has never been to school. They used to hide her from other schoolchildren. She gets tired easily and has difficulty in walking. She thought that it might be better to live in the UB, so she moved to the capital for a few months. However, she felt that it was tougher to live in UB. For example, people in the ger district use to pour waste water in the street, where it froze during winter so she couldn't walk and the city buses were inaccessible. So she went back to Umnugobi. She says that she needs vocational training and home school so that she can get basic education.

About their full participation in society, both, the man and the woman, felt that personnel assistants are essential and changing the public attitude was important.

The third person interviewed by Ms. Boloroo was a 30 years old woman with CP and epilepsy. She had to talk to her mother. She suggested to mother to talk directly to that person, but the mother said that my child cannot understand what you are talking even if Boloroo thought that the person had the ability to understand. They live in Chingeltei district with the mother and 2 siblings. She was in bed until at the age of 10 years. Though she has finished school, she still cannot read and write.

Challenges in her life are that other people laugh at her and because of road is bumpy and stony, she couldn't go out. Once the mother told her to go out, but other people made her get lost. Her hands can move properly, so she can do many things. There is a care and development center for above 16 years old PwD and living in a ger district. Ms.Boloroo showed a picture of her neighbourhood where this person lives to explain the lack of accessibility.

Boloroo also informed about Mongolian legislation about accessibility and housing. For example, there is a national program on Renting Apartments though it is not targeted only at PwDs. There are also cheaper apartments("Buyant-Ukhaa"), of which 10 percent can be for the PwD. However, to have this apartment they have to pay 30 percent of deposit. Usually most youth with disability marry each other and their monthly income is less than 340,000 Tugrik, so they cannot pay the deposit. She also informed about the ministry of construction, which is working on drafting the PwD housing program. An apartment block for 90 blind people was built in 2017. Finally, she informed about the results of a recent survey which shows that many children with disability living in the ger districts cannot go to the school.

Presenter #5 Mr.Duulim: "Three of us - Ms. Misheel, Mr. Gansukh and I did this research together in the Zuun mod somon of the Tuv province. We thought that it will be important to understand the situation of persons living in the countryside. Luckily this somon was more accessible for PwDs compared with other places. The municipality of this somon has many buildings that are accessibile to PwD.

One the researchers raised the issue of difficulties faced by blind persons as there are no accessible signs. Another researcher, Ms. Enkhjin shared the information she had collected regarding making of accessible toilets. There is a "ger toliet" project which is being implemented. They first dig a hole for the toilet, put cement on it and then set a toilet on the hole. Its price is 250-300,000 Tugrik (while a toilet in an apartment costs around 1.5-2.0 million Tugriks). It can last for 5-6 years. When it is full, there is a service to empty it which costs about 30-50 thousand Tugrik. The W.C pan with the water cover helps to prevent bad smell. People can also put up an exhaust fan to prevent bad smell. A former Parliament member, Ms.Oyungerel has set up a fund to support this initiative, so if we pay 100,000 Tugrik, the fund will pay the rest of the amount.

Afternoon session

The afternoon session was dedicated to discussions in small groups. This session was chaired by Mr. Bilegsaikhan and the Participation and Time Observer was Mr. Munkhbat. The participants were divided into small groups of 5 persons each and asked to discuss the critical conditions related to the living conditions in a ger district focusing on the youth with disability, and to identify the key challenges and the possible solutions to overcome those challenges. After the discussions each group presented the results of their discussions.

Different barriers faced by youth with disabilities living in a ger district:

First the groups discussed the different barriers that create challenges for the young persons with disabilities living in a ger district. The following challenges were highlighted in these discussions:

Attitudinal barriers are a key issue in the families. Families do not think that their children with disabilities can do anything or live independently. Along with the negative thinking about the disabled children in the families, domestic violence against them is an issue in some families, especially in a ger district and this is often hidden. This same negative attitude towards regarding persons with disabilities is one of the biggest challenge among the public authorities such as in education and health services as well as among general public. The negative attitudes of families and general public influence the youth with disabilities. They also lack self-confidence and isolate themselves.

Physical barriers: Physical barriers that block persons with disabilities are everywhere, inside the home, outside in the neighbourhood, in the city and in the public services and institutions. They are even worse in the ger districts. In the traditional tent houses are called ger. These traditional houses are common in the ger districts. In these houses, there are barriers when you enter and when you come out such as the doorsill, steps and double doors. In the ger districts, there are barriers linked to some activities of daily living such as getting water from the well, to stoke and clean the furnace used for heating the house, to split firewood, to carry coal, access to the toilet, access to shower for taking a bath, and gravel and stones in the courtyard. There are barriers outside the homes in the ger district areas including dogs in the streets, uneven and unpaved roads, throwing of domestic waste and waste water on the road and air pollution; Outside the ger district, in the city there is a complete lack of accessible public services such as transport, schools, markets, health centres and hospitals.

Support Services: There is a lack of personal assistants for disabled youth who cannot carry out their daily living activities and need support. There is a lack of options for independent living. The safety of the personnel assistants is another problem in a ger district.

Getting information: Difficulties in getting information about the different services and options available to persons with disabilities living in a ger district.

Work and income: There are no possibilities for work. There is a lack of accessible work places. This adds to the financial difficulties of the families who do not have enough resources to cover the needs of their children. For example, schools can be very far.

Possible solutions: The groups then discussed possible solutions to some of the key challenges. There were three main areas where the groups focused their discussions – improving the home environments to make them more accessible, changing the attitudes in families and in public and asking for an improvement in the public services.

More accessible home environment: How to make the home environment more accessible was the most common area of discussions in the groups. Improving the accessibility of toilets was discussed in all the groups. As shown in one of the presentations in the morning session, there were some suggestions about constructing a toilet inside the ger without the need to go out in the courtyard. Another solution was to build small ramp for the toilet in the courtyard. There were suggestions about bio-toilets. There were a few similar discussions on the accessibility of shower for taking bath for the young persons with disabilities living in the ger districts. Regarding the difficulties in splitting wood, bringing wood, stoking and cleaning the furnace, there were alternative systems such as floor heating system or the use of a low-pressure stove.

For the difficulties created by the doorsills for the wheel chairs, different solutions such as the use of temporary ramps or building a proper ramp or full reconstruction of the house, were discussed. Though the technical solutions against all these different barriers in the home environment already exist, the critical issue is how to get access to those solutions, because their cost is high and families in the ger districts do not have the money to make all the changes.

Changing attitudes: How to change the attitudes in the families was another big area of discussions in all the groups. Groups agreed that changing the family attitudes is crucial to independent living. They had to build awareness of the families. Once the PwD can live independently, the care-givers can also have an opportunity to work and earn money. There were a few suggestions about how to change the family attitudes. One suggestion was to bring persons with similar disability who are already living independently to meet the families and talking to these persons can change the family attitudes.

Improving the access to the services: This was the third most common area of discussions in the groups. One suggestion was to create awareness among the persons responsible for providing that service. For example, it was suggested that for improving the accessibility of the public transport, awareness needs to be created among the public transports staff. They need to understand that bus stop time is too short for persons with disabilities to enter, so the stop duration has to be longer. Another similar suggestion was for providing more information to the construction companies about the standards for building the ramps.

For improving the access to education, inclusive education is needed, which means that in every class there should be one or two PwD. Another suggestion was to teach sign language to all the school children. There were different discussions on asking for better services and better infrastructure from the Government. For example, one group said that there is a need for more accessible buses for the wheelchair users. Another group suggested that at least 10 percent of new apartments should accessible to the PwD. One group pointed out that laws are already there but they are not implemented properly and there is a need to implement the domestic legislation effectively.

Solutions in the neighbourhood: This issue was discussed by two groups. Regarding the problems on the roads in the ger including uneven roads, lack of lighting on the road and lack of signage and addresses, the groups agreed that they had to talk to the people who are responsible for city planning, management and services. One group was more ambitious and suggested that there should be central heating system and water supply in the ger district.

Domestic violence: This issue was raised by only group. They felt that the relevant legislation needs to be amended or renewed. However, they did not specify what was missing from the existing legislation and how it has to be modified.

COMMENTS & CONCLUSIONS

The first theme meeting on the challenges faced by young persons with disabilities living in the ger districts had active participation by the researchers.

There was one testimonial and presentations by another 5 researchers, some of whom had created small groups to go out and visit ger districts, to talk to persons with disabilities living there and to collect information about their lives. One person collected some general and demographic information about the ger districts. These presentations were examples and inspiration for the other researchers, who could plan more active participation in the future theme discussions. Many of the challenges faced by persons living in the ger districts, identified during the discussions require interventions at infrastructure policy and management issues by the city municipal and national governments. To make such changes requires understanding the government decision making processes and having long term advocacy and lobbying strategies.

Some other challenges identified during the discussions affect all the inhabitants of the ger districts. Making roads that are safe for pedestrians, having street lights, having signage for addresses so that persons do not get lost, are some examples of the proposals that affect all the people living in the ger districts and asking for such changes cannot be done just by persons with disabilities. It requires building of transversal and broad partnerships with other concerned citizen groups. The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme of public transport accessibility.

Theme Meeting #2 – Accessibility of public transport

Meeting Report

Accessibility of public transport This was the second theme meeting. It was held at Ibis hotel, Ulaanbataar on Thursday and Friday, 16-17 Aug 2018. 20 researchers participated, including 1 one new person (Ms.Uyangasaikhan who has CP and is a member of Independent Living Movement Mongolia) in this meeting. Apart from the researchers, Mr. Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Reporter) and Ms.Sarantuya, (sign language translator) participated in the meeting. In addition, two external observers were present in the meeting – both were representatives from the Ministry of Road and Transport development of Mongolia

Meeting Programme: Introduction by Mr. Enkhbuyant; sharing of brief introduction on public transport accessibility policy of Mongolia by invited guest Ms. Munkhnasan, a senior officer at the Ministry of Road and Transport Development of Mongolia followed by a questions & answers session; 5 presentations about public transport accessibility by 6 researchers (Mr. Bilegsaikhan, Ms. Bayartsetseg, Ms. Sumiyakhuu, Ms. Boloroo and Mr. Byambadorj and Ms. Enkhjin); group discussions and their presentations; conclusions.

Meeting coordination: Mr. Tsenguun was the chairperson and Ms. Sumiyakhuu was the equal-participation observer on the first day; Mr. Sandag was the chairperson and Mr. Bilegsaikhan was the equal-participation observer in the second day. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Testimonial: Ms. Munkhnasan shared brief information about the legal and policy reforms on public transport accessibility in Mongolia.

The Ministry, in collaboration with the National federation of Persons with Disabilities (PwDs), had organised a meeting on public transport accessibility in 2017. As a result of this meeting and the discussions with the PwDs, a Disability Advisory Board has been created within the ministry (it includes representatives of various DPOs). This board has an annual plan along with an action plan. This year, there have been a lot of discussions about needs of legal reform in the transport sector. Therefore, they are producing documents about Transport law amendments, amendments of the regulation on passenger transport and shipment, and a new national policy on auto transport. A working group has been created to discuss the different amendments.

According to the new national policy on auto transport, public transport should be accessible for all people who have special needs. At present, there are 20 new buses which are accessible for PwDs.

Ms. Munkhnasan said, "*Many drivers don't know how to use this equipment, so PwDs cannot access those buses. According to the law, at least 1 out of 10 buses should be accessible for PwDs. However, the service providers are not keen to import those buses, so they prefer to pay penalty instead of import them. Therefore, we are* *proposing an amendment of the law so that all the 100 percent of buses in public transport should be accessible for PwDs.*"

The discussions in the Government cabinet about the new national policy on auto transport are scheduled in 3rd quarter of this year (which means between July to September). Ms. Munkhnasan said, "As an expert of your life, you can send us your suggestions and opinions regarding the new law. You can send us your written suggestions and via internet or you can come to our office and meet a person who is in charge of receiving suggestions. Recently we have received suggestions from the National federation of PwDs."

The Ministry is making arrangements so that there will be announcements of names of the Bus stops in the buses and there will be smart boards at each bus stop for finding information. Same information will also be available through a smart phone application. On the other hand, the discussions have not yet begun on the amendments of passenger transport regulation.

After her testimony, she was asked questions by the participants such as time needed for having accessible buses, new bus routes, locations of the bus stops and duration of the stops.

Ms. Munkhnasan explained that in 2019, 400 buses will be replaced by new accessible buses. She also talked about smart cards for payments that can be used for different public transport services. She reminded the participants to send their suggestions, though since modifications have cost implications, not all suggestions can be accepted.

The participants informed that they had also invited a bus driver to the meeting but the invitation was not accepted.

PRESENTATIONS BY RESEARCHERS

Presentation #1. Mr. Bilegsaikhan: He had assessed the accessibility of buses and different services and showed pictures to explain the different points.

The pavement around the bus stop was bumpy and there were many obstacles around such as a maypole and a kiosk, which create difficulties for blind persons and wheelchair users.

Buses had broken door-handles and the space near the bus exit was not enough. He said, "When I got off from the bus, I was close to falling down."

There was an information board, but it was not easy to read for people with vision disabilities, it was put outside the window. The LED board inside the bus was broken, so people with hearing difficulties had problem. At first, he thought that there were no signs for special seats. Later he saw that signs were there but were written in very small letters and difficult to see.
He concluded, "Government has accessible busses in Mongolia, but they were not in service."

Presentation #2. Ms. Boloroo: She had done research by collecting data and by interviewing 5 people from Sukhbataar, Songinokhairkhan, Bayanzurh, Baganuur and

Khan-Uul districts of UB. She explained that she had also prepared some videos but they were accidently deleted. She showed some pictures with her presentation.

According to data on public transport in UB that she had collected, there 579 taxis which cost 100 Tugruk for the first km, and then 800 Tugruk per km. There are 388,448 cars and 18,550 buses registered in UB, while on the roads the number of carts is much higher – 815,000 cars in 2017. The highest number of cars is in Bayanzruh district, which has 109,400 cars. Every day, there are 650,000 travellers on the roads (2015) but there is no data on how many of these were PwDs. Only 1 out 20 transport companies was state-owned in 2015, the remaining were all private.

Then she explained about the transport related difficulties faced by the 5 persons she had interviewed. First, she told about a person who lives in Bayanzurh district and has a spinal cord injury. He was injured 13 years ago. He explained that he cannot use buses because they have introduced a new card system, which means that the entrance has become narrower and he cannot enter. Therefore, he is forced to use taxi, but its cost is higher and he has financial problems. He also needs someone's support to get a taxi, because when he tries, the drivers do not stop. He feels that other passengers' attitude to him is positive because they held him to enter (Note: the taxis are used by multiple passengers, each pays an amount). He had never used a train or an airplane.

The second person was from Khan- Uul district and had a vision difficulty. She needs help from others to use public transport as there is no announcing service in the bus. Other passengers tell her about the bus stops. She would like the bus stop information in braille, to increase number of accessible busses and have announcements about the next bus stop in the buses. More importantly, she felt that changing the drivers' attitude can create disability friendly public transport.

The third person lived in Baganuur district and was a wheelchair user. Lack of accessible public transport has affected her life. She had to change her school and she could not accept a job offer because of it.

The fourth person was from Songinokhairkhan district and had a hearing disability. Using public transport is a challenge for her. Sometimes the bus signboards don't write the direction, so she takes the wrong bus. Since her disability is not visible, therefore when she taps her disability card, other passenger assume that she is using someone else's card.

The fifth and last person was a 16 years old with CP, who stays at home because it was difficult for her to take buses. She had never studied at school and learnt how to read and write at home. Once she got into the bus with her parents, but she felt uncomfortable by the way other persons were looking at her. She feels that seats at the bus stops are too short. However, for her, the most important change would be to change the attitudes of other people including drivers so that they do not stare at her.

Ms. Boloroo informed that she herself had not used the public transport for last many years, ever since she was 20 years old. However, earlier when she had tried it, the attitudes of the drivers discouraged her. Sometimes, the bus moved before she had sat down which was difficult. She said, "Other passengers tried to help but they don't know how to help us appropriately."

She also informed about the Mongolian laws about accessible public transport. For example, law on public transport and the Government resolution on exempting PwDs from public transport payment. Moreover, she informed that even train-passages were too narrow for the wheelchair users and it was not possible to use the toilets of the trains. (She showed pictures of trains and buses in Mongolia and compared them with those in Japan)

She also informed about some Government actions regarding accessible public transport. Apart from the information already shared by Ms. Munkhnasan, she told about the ramp built outside the auto transport centre and the "queue free" services for PwDs; set up of a led board and speaker for announcements for people who have hearing and vision difficulties at the main transport centre and at some centres in districts; built ramps at the railway station; introduced SOS service for passengers who need someone's help at the international airport; made "reserved seat for PwDs" signs for the first 2 rows of the local buses; the online ticket services so that PwDs can choose appropriate seats; and, installing pedestrian signals for crossing the streets in some points.

She concluded that public transport should be accessible for all, there should be appropriate training for the drivers, the kerb height at bus stops should be changed so that wheel chair users can get in the buses and if PwDs cannot use the public service then they should get a cash subsidy.

Presentation #3. Ms. Sumiyakhuu and Ms. Bayartsetseg: Ms. Sumiyakhuu explained that as she is a wheelchair user, it is difficult for her to enter into the bus. If she uses a walking cane, she is too slow to catch the bus, so drivers leave her at the bus stop. There are private microbuses but they ask her to pay double. The buses in the downtown area are better than the buses in the peripheral Ger areas. She lives in Bayankhushuu ger district and works in 19th khoroolol, thus she needs to change 2 buses to reach her work place. Even if she is more comfortable in a wheel chair, for the buses, she is forced to use a cane. Like for Ms. Bolroo, she also has problems when the bus moves before she has found a seat and if she complains the drivers get angry. The seats reserved for PwDs are often occupied by elderly persons and they don't want to give their seats.

Ms, Bayartsetseg talked about their assessment of the long buses. It showed that the direction information on the bus is too small and unclear to see; drivers don't stop parallel to kerb, so the space between the kerb and the bus-door is a problem for the wheelchairs; the bus doors are too narrow to move freely or have no door handle; the LED board announcement about the bus stop station is made just before it stops so, people with moving difficulties have no time to prepare to get off.

They suggested to organise campaign a tv or video campaign.

Presentation #4. Ms. Enkhjin: She had interviewed 2 PwDs and 1 bus driver to understand the issues related to accessibility of public transport service.

The first person she interviewed told her that he tried to take the bus, the driver left him at the bus stop station. He has a car and if needs to go somewhere, he has to pay to get a driver who can take him.

The second person she interviewed, uses wheelchair and lives in Uvurkhangai province. He rarely uses public transport and uses own car usually. He said, “I took bus once but it was difficult because there was no way to lift WC to the bus, and the doors and space in the bus were narrow. Taxis are expensive. On the road, drivers sometimes yell at me with bad words and tell me get out from the road.”

She also explained her experiences of using the public transport, “I can walk so entering and getting off from bus wasn’t too problematic though I had difficulties with the steps. The most problematic thing was at bus stop station. When the buses come, they often stop way too far and they just leave me before I get to them. In some buses, windows have stickers so you can’t look out and see the stop. The seats for PwDs are too few.”

Her suggestion was to have an automatic lift instead of steps, which will make it easier for the drivers and will save time, because it takes 3-5 minutes to setup a ramp and at the end, fold it back. She also suggested the possibility of a contract with taxi service providers so that taxi service can be offered to PwDs at discounted price.

Presentation #5. Mr. Byambadorj: He talked about asking for help from others for getting in the bus and how this can lead to falling down and getting injured. The buses are crowded and other passengers get mad at him for making their clothes dirty.

He suggested that learning about disabilities must be compulsory for all drivers. Even taking a train is difficult.

Discussions

After all presentations, participants discussed about challenges to use public transport and how to make it more accessible. One person raised the point of attitudes of the persons by explaining that a person selling the transport cards refused to sell a card for him because of his disability. His other point was regarding the missing Government transport services from somons and aimags to UB, which means that the transport is only through private services which have no insurance.

Another person raised the issue of lack of announcements in the trains regarding the train stations.

On the other hand, another researcher, a wheel-chair user who travels regularly by public transport explained, “I use public transport every day and I face all challenges people have mentioned. However, in my opinion, things are better today compared to past. Even though sometimes we cannot use them, Mongolia have several accessible buses. Even if it may not always work, signals for blind people have been installed at traffic lights. So, some progress is there.”

He advocated for a more proactive role of PwDs in creating public awareness, “I should be visible to the society every day to change public attitudes. Thus, even if I feel more comfortable to take taxi, I take public buses. I have a personnel assistant, so that helps me to use public transport. If didn’t have a personnel assistant, it would also be challenging for me. Drivers and conductors must be trained about disability issues and they should know that assisting to PwD passengers is compulsory not optional. There is enough legislation to ensure PwD’s rights, yet effective implementation, and its assessment is needed. Accessibility is not only about our special needs. It is about children, older people as well."

His other point was that some trains are accessible for PwD, they have more space and easier to move. But PwD don't have the right to use all trains, which should be accessible.

One researcher told an episode regarding her interaction with a bus driver, "I can move slowly and the bus driver was impatient, so I explained to him about my condition and PwD's special needs. Today morning, it was the same driver. He asked other passengers to give me a seat, so I sat in the special seat. He allowed me to use front door for getting down. Therefore, I want to say that we can explain our needs to drivers and for building public awareness."

Second day

The second day was dedicated to discussions in small groups. The participants were divided into small groups of 5 persons each and asked to discuss the policy that needs to apply, action including management and regulation that needs to implement, service that needs to provide regard to accessible public transport, and your wish to make public transport accessible. After the discussions, each group presented the results of their discussions.

1. Policy: First the groups discussed the policy on accessible. The following polices were highlighted in these discussions:

Effective implementation of legislation is key issue to make public transport accessible. Even though all rights are protected by both internationally and nationally, its effective implementation is missing.

*Public servant's salary***:** the state should focus on to increase public servant's salary who are providing services to PwD and create comfortable working condition for them. Then their labour productivity will increase and it will influence positively to PwD's inclusion to society.

Building strong accountability system is vital to ensure PwD's right to get accessible service. Service providers get more responsible for ensuring the rights of PwD, once strong accountability system works. There is no regulation if there is accident while PwD is entering or getting off the busses. Someone or organisation should responsible for cover all damages.

In addition, people should respect all legislation including traffic rules properly and it should be binding. For example: taxis or cars should not stop at bus stop station.

*Correspondence between state organisations and DPO***:** State organisations including police, public transport, inspection agencies and DPO's must work closely together. Therefore, legislation regards to accessible public transport can be implemented effectively and it can be assessed properly.

Capacity-building of service providers: Drivers and conductors of bus and train should be trained before they get job. Another significant thing is increasing number of human resource. So that, services during night time will be available for ger district. All staff including pilots, flight attendants, drivers, and conductors should learn about special needs of PwD and special services they should provide. The training should be organised regularly.

Information board and call centre: Information board should be installed at all bus stop stations which is accessible for PwD. Public transport except busses should provide call centre service. So that customer can call and make reservation. Lack of addressing makes difficult for transporting passengers especially in ger district area. Therefore, installing GPS and LED board which shows the address in the taxi is vital for accessible public service.

Buses should be accommodated reasonably: The government should allocate budget for accommodating reasonably busses which are providing service. In addition, renovating kerb with ramp is helpful to make public transport accessible.

Stable and fair rate for taxi services: The reason why taxi rate is not unified, drivers ask to pay more. For people with difficulties, they usually don't understand what drivers say, therefore if rate is stable, they can calculate how much to pay.

Public awareness campaign: One group mentioned that the government should implement "Let's get cultured" public campaign for improving transport service control.

2. Action: The groups then discussed about possible actions to implement for accessible public transport. There were two main areas where the groups focused their discussions – amending legislation and regulation regard to public transport service, changing the attitudes in public and improving access to the public transport.

Improving access to the public service was the most common area of discussions in the groups. Free wi-fi services, LED Boards, public announcements, stop buttons in the buses, etc. were mentioned.

Changing attitudes in public: This issue discussed by all groups. They agreed that staff should be trained about disability and learn their special needs regard to providing public service. Two groups discussed about importance of collaboration of public transport providers and DPOs. By collaborating, they can improve public awareness on disability together and share their experience.

COMMENTS & CONCLUSIONS

The second theme meeting on the accessibility of public transport for persons with disabilities had active participation by the researchers.

There was one testimonial and presentations by another 5 researchers, some of whom had created small groups to assess public buses and took pictures, to talk to persons with disabilities and to collect information about public transport. One person collected some general and interesting facts about public transport.

These presentations were examples and inspiration for the other researchers, who could plan more active participation in the future theme discussions. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

Many of the inaccessibility issues faced by PwD, identified during the discussions require interventions at infrastructure policy and management issues by the city municipal and national governments. To make such changes requires sending their suggestions on amendments to the government and having long term advocacy and lobbying strategies.

The meeting showed improvements in the capacities of the researchers, who are more open to each other. Some persons are conducting small surveys.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme of Social Welfare. The dates for the next meeting will be communicated.

Theme Meeting #3 – Social welfare

Meeting Report

Social welfare: This was the third theme meeting. It was held at Ibis hotel, Ulaanbataar on Monday and Tuesday, 01-02 Oct 2018. 21 researchers participated in this meeting. There was no invited testimonial at 3rd meeting. Apart from the researchers, Mr. Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Reporter) participated in the meeting.

Meeting Programme: 1. Researchers discussed issues regarding ~~to~~ past themes related activities and news. 2 presentations about social welfare services by 2 researchers (Mr. Bilegsaikhan, Ms. Erdenezul); 3. group discussions and their presentations; 4. conclusions.

Meeting coordination: Ms. Selenge was the chairperson and Ms. Urantugs was the equal-participation observer of the meeting. As agreed by the participants, the chairperson and observer were not changed on the second day. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Discussion about past theme:
Mr. Enkhbuyant asked about any news and comments regard to the past themes. During these discussions, researchers mentioned the negative things that were already mentioned during the theme discussions, such as the drivers are very aggressive when PwDs ask to get off, bus stops are far from the bus station, and usually drivers don't announce the stops which makes it difficult for the persons with vision difficulties to get off and, taxi rates are not stable, drivers usually require PwDs to pay more.

Conversely, Ms. Saranchimeg told that some drivers are supportive, however there are many people in the bus. During the discussion Mr. Myagmarsuren suggested that conductors can be trained to become supervisors, so that they could support PwDs in the bus, instead of just yelling to the passengers to tap the card on the device.

After their discussion, Mr. Enhbuyant suggested to discuss what can the PwDs (researchers) do to solve the problem. Researchers told that talking to managers at the bus company is vital. Because when we request to stop longer at the bus stop, drivers reply bus stop duration is stipulated by the regulation and renovating accessible bus stop station would make it easy to get in or get off for PwDs. They continued that, private taxi service providers (drivers earn money for providing taxi service by themselves) have less respect for ensuring PwD's rights.. Ms.Selenge also mentioned about prepaid card system in taxi service.

PRESENTATIONS BY RESEARCHERS

Presentation #1. Mr. Bilegsaikhan: He presented about the law on social welfare allowance clauses and provided the following information:

- for females who are older than 55 and males who are older than 60 - 126500 tugrik per month;

- for persons with short stature, older than 16 years old - 126500 tugrik per month;
- for PwD who is older than 16 years old and has lost 50 percent or more of his or her ability to work - 126500 tugrik per month;
- for children and persons under 28 years old and who have lost their guardian - 126500 tugrik per month;
- for single mother who is 45 years old or older; for single father who is 50 years old or older and who have up to 4 children under the age of 18 - 126500 tugrik per month;

Nursing allowances from the Government are as follows:

- for person who is looking after or supporting child at risk; or person who adopted orphan child - 70000 tugrik per month;
- for single older person who has no children and relatives to take care of him or her - 70000 tugrik per month;
- for persons who are nursing older people in need of regular medical care and its control; and taking care of child or person with disability - 70000 tugrik per month;

Allowances for particular cases and livelihood aid from the Government are as follows:

- persons who have lost their home during sudden danger or accident - 1200.000 tugrik for once;
- 18-24 years old person who got orphan when he or she was under 18 years old - 1200.000 tugrik for one time aid;
- for homeless person who just got released from prison - 1200.000 tugrik for one time aid;
- for homeless single mother or single father- 1200.000 tugrik for one time aid;
- for mother who gave birth twins and raising them as well - 1000.000 tugrik for one time aid;
- for child under the age of 16 who needs regular nursing - 60.000 per quarter of the year;
- for single mother of single father who has 3 or more children-
    - for mother who has 4 or more children- 100.00 tugrik for one time aid;
    - for mother who has 6 or more children-200.000 tugrik for one time aid;
    - for mother who has a baby up to 5 months old- 40.000 tugrik per month.

Presentation #2. Ms, Edenezul: She presented about the system of Social welfare in Mongolia. In her presentation, she explained that social welfare system includes social insurance and social care services. She also explained about the social welfare beneficiaries in accordance with legislation.

According to her explanation, all residential, ~~and~~ foreigners and stateless persons who have fulfilled the requirements in Law can get allowance.

- Insurance of losing trustee:

To get this benefit, insurer must have paid insurance premium for not less than 20 years or person who paid last 3 years of insurance premium within 5 years before he or she died. Then the family members who have no work ability can get allowance. The term “family members who have no work ability” refers to the following situations:

- Adopted or born child who is under 19 years old; and a child who was born within 280 days after the death of his or her father;
- Grandchildren or younger siblings who has no other guardians; or children and older or younger siblings or grandchildren who got disabled when he or she was younger than 16 years old;
- Parents who are older than 55-60; or disabled parents or husband or wife; or grandparents or siblings who has no other guardians.

In her presentation, she also showed the pension rates and required materials to apply for the allowance.

Second day

The second day was dedicated to discussions in small groups. The participants were divided into small groups of 7 persons each and asked to discuss about types of social welfare and social care services and how researchers can make a difference on social welfare service effectiveness. After the discussions, each group presented the results of their discussions.

All groups mainly agreed that the social welfare is favourable services which state is providing its vulnerable groups of people. As they basically agreed social welfare services are compensation for children under 18 years old, allowance for old people, employment of PwD. However, one group mentioned that allowances regarding nursing, university fees, public transport, and inclusive education should also be a part of the social welfare.

The groups discussed that, social care services include health care service, domestic and international scholarships and all types of social insurance. One group mentioned about the statistics regarding social welfare.

After the group exercise, they continued to discuss about whether they are happy about social welfare services. They concluded that even though social welfare service is for ensuring human rights of vulnerable groups, services that the Government is providing are not effective enough.

Social services can be the issue to discriminate PwD: One group took example of bus card. When PwD tap the card on the board, it says loudly “passenger with preference” which make them feel ashamed. Further, one group said that when decision makers talk about inclusive education, they just open a special school for PwD to fulfil their obligation, which is actually exclusion from the society.

State spends inefficient cost to ensure vulnerable group’s right: They took an example of overall expenditure for PwD in 2017. It was 122.1 billion tugrik, whilst they don’t exactly know how these were spent or don’t feel their rights has been fulfilled. The Government spends approximately 2 billion for bus allowance. Also, the government is paying 3 times more amount of allowance for children with disability than other children. Therefore, special schools get more to compare with ordinary secondary school. As they all agreed it is better to focus on improving accessibility rather to spend money on allowance.

Determining the ability loss is inappropriate: During the discussion, one of the researchers raised the issue of determining ability loss. She took example of her own situation. As it was determined by the commission, she had lost 90 percent of her ability to work whilst her hands can move freely. By determining 90-100 percent loss of work ability, excludes them from society. This system of determining disability can be wrong while the social welfare services cannot reach to persons who really need. If there is accessible work place, she can work with other people. One person also agreed with the issue. He said I lost 100 percent of my vision ability, but it doesn't mean that I have lost 100 percent of work ability.

Social welfare services don't fully ensure their rights: All groups agreed that PwD are not happy with social welfare service from the Government. Even though there are legislation with regards to giving preference to PwDs such as quota at workplace and 50 percent discount on electricity and heating payment. Unfortunately, employers prefer to employee person with not too serious disability. The Government can produce better policy such as discounting tax of employee if they hire person with serious disability.

Another point they mentioned was, special secondary schools. As per their opinion, special schools induce them to underestimate themselves rather to fulfil their right to educate. Even though the Government encourages teachers, it doesn't really think of children with disability.

To compare with other people, PwDs have less income and it difficult for them to buy apartment. Therefore, payment discount on heating and electricity can be inefficient.

At the end of the discussion, researchers generally agreed that at least people should respect the legislation and public should change their attitude by showing themselves to the society.

How social welfare can be changed?

After Mr. Enkhbuyant has explained about ICF classification, groups discussed about their opinion on how social welfare can be effective.

Inclusive Education: All the groups mentioned that inclusive education is crucial. Based on their opinion, inclusive education should start from kindergarden rather school. Reform is needed in education system. Therefore we need to learn about foreign countries best practices.

Further second most- mentioned issue was labour. Nursing, personnel assistance, and accessible health care service were also discussed during the last session of the second day.

COMMENTS & CONCLUSIONS

The third theme meeting on the social welfare services for persons with disabilities had active participation by the researchers.

Even though there wasn’t testimonial, participants actively studied about legal clauses and prepared presentations by 2 researchers.

These presentations were mainly focused on national legislation on social welfare, social care and its allowances. All presenters signed for confirmation form for using their presentation and pictures that they have prepared. The meeting showed improvements in the capacities of the researchers, who are more open to each other. Some persons are conducting small surveys.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme of independent living. The dates for the next meeting will be communicated.

Theme Meeting #4 – Independent living

Meeting Report

Independent living: This was the third theme meeting. It was held at Ibis hotel, Ulaanbataar on 08th-09th Nov 2018. 23 researchers participated in this meeting. There was 3 invited testimonial at 4th meeting. Namely Mr.Undrakhbayar, represented MILC, Mr.Enkhbaatar, represented parents who have children with disability, and Ms.Sukh-Erdene, represented personal assistants. Apart from the researchers, Mr. Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Reporter) participated in the meeting.

Meeting Programme: 1. Testimonials gave a speech about their life story and experience regarding chosen themes. 2. Researchers shared own obstacles and life story among them. 3. There were 4 presentations about independent living and 2 presentations about PwD employment by 9 researchers (Ms. Urantugs, Ms. Erdenezul, Ms.Bayartsetseg, Ms. Sumiyakhuu, Mr. Bilegsaikhan, Mr. Byambadorj, Ms.Gantsetseg, Mr.Elbegdorj and Ms. Boloroo); 3. conclusions. There was also group discussion between testimonials and presentations.

Meeting coordination: Mr. Byambadorj was the chairperson and Mr. Elbegdorj was the equal-participation observer on the first day. Ms. Gantsetseg was the chairperson and Mr. Sandag was the equal-participation observer on the second day. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Testimonial 1: Undrakhbayar (Director of MILC and TAG member)
Mr. Undrakhbayar shared a life story of a girl at MILC who has inspired to live independently by personal assistants. Even thogh she already at her late 20s, she barely leaves home yet she has not sever disability. She goes out once a year for extending her disability certificate. She has started to come to MILC sometimes. One day when she went to MILC, one of her relatives visited her ffamily and keep asked whether the family has changed furniture decoration. When he saw te girl arrives, he said that oh you weren't at home, I thought something has changed. When we heard this story, we laughed loudly at first then it was hurtful for me. Because she lived like a furniture at home for her whole life.

He added PwD got excluded just because of the terminology and took examples of other countries' experience namely Japan and the USA. His point was implementing mechanism or process is different in countries. For instance, in the USA and in Japan, independent living is fundamental of inclusion. Just because their lifestyle is different from each other, fulfilment of independent living is different. Usually people think that independent living is all about personal assistant, yet this is one of the approaches to fulfil PwD's independent living. For fulfilling independent living, we need to define our priority first. I hope your surveys or presentations will help us to define Mongolia's priority to fulfil independent living.

Another point was personal assistant service can be a priority in Mongola. Because we already have the fundamental of it. Then we can support to increase PwD's life capacity and education issues through personal assistant. Since everything reltated to the PwD has stated in the legislation. The government must do something to ensure the right. Unfortunately, the government has no idea how to implement. PwD who are living independently will show how to do. For example, Nyam-Ochir, he is on mission in Japan. He is the one of ideal example of how personal assistant service has influenced his life. In this year he traveled overseas for 3 times which are all assisted by the personal assistant. Thanks to personal assistant service he received many benefits not only for him, for his family and for the MILC as well. By monetary value he did work for approximately 10.000.000 tugrik. He is influenced by youth at MILC. The process was like that, circled.

Testimonial 2: Ms.Sukh-Erdene (personal assistant): I work for MILC. I understood how to assist PwD since I participated in public awareness campaign. I feel wonderful that PwD can participate fully in the society by having our assistance.

Testimonial 3: Mr.Enkhbaatar (journalist. He writes about PwD and has own "Oyunii darkhlaa" NGO. He also has child with disability): Concept of disability was quite different 20 years before. Journalists had negative approach towards disability issues. Their understanding was very bad. People usually take information from what journalists wrote. Therefore, public awareness activities that AIFO has organized for journalists were influential. Now we don't need to talk about what is disability, we talk about how we improve the situation. My daughter has CP and she got so many medical treatments. Once she got surgery and surgeons came from the USA. Because it was too late, she didn't get healed. I don't see my daughter as a disabled. Her brother is 1 year older than her. Therefore, we decided to send her to school with her brother. She graduated from Mongolian National University. Usually PwD prefer to stay at home. Therefore, I think they creates discrimination by themselves.

After his testimony researchers interested about how his reaction in case of his daughter will wants to live independently and how's father and daughter relationship. He replied that his daughter is living with sibling and preparing to live independently step by step. Further, he said that he has no fight with daughter because of the disability and even she helps to review his writing. As a parent, he wishes his daughter had a family one day.

Personal Life stories of the researchers:

Researcher 01: During Mr.Undrakhbayar speech I also recalled how I started to get out from home. I have been at home until I was 17. One day I suddenly decided to get out from home and just took a bus. My family was extremely worried about me and tried to find me. One thing I couldn't overcome was studying. I was born with disability and because of that I have never studied at school. District authorities organized a training and I learnt a program. I have tried to find job and couldn't find. Now the problem is accessibility of pedestrian.

Researcher 02: I have injured for 4 years. Because I was living in a countryside I have been staying at home. People and even I didn't know about disability issues in countryside. One day I hang out with my friends and people pitied me and I felt hurtful. Once I came to Ulaanbaatar and found out that there are so many PwD like me.

Researcher 03: I have got injured for 3 years. I face troubles from getting up, washing face and getting dress. For doing mentioned things I need my family members' support. Thanks to personal assistant I overcome all those troubles in my life. Since last year I started to participate the project and got out from home. Before that I have be closed to other people. Now I am becoming more socialized.

Researcher 04: I had spinal cord cancer surgery and got disabled. Part of my body which is below collar is disabled. I need other's assistance from morning to the night. I have been seeing doctor for lasr three years. I hoped I could stand on my feet. Unfortunately, it didn't happen. I stayed at home for 1 year and faced many troubles. I got depressed at that time. I even tried to suicide. I would like to say participaing a canada funded project at MILC helped me to overcome this. A the first staff told me that I have to be well planned. I usually plan my day very well since that time. Before I have met people at MILC, I have been a bit scared of others' eyes and I have been feeling a bit of guilty. Thanks to personal assistan service, I started to get out of my home freely and understood that wheelchair users can work like others. Since february I became supervisor at the MILC and I got income for my self. Most importantly, I could go out freely and started to feel confident about my self. Further a road nearby my home wasn't accessibleand it got accessible since this summer. Therefore, I think I influenced my neighborhood.

Researcher 05: I got epilepcy since I am 9 yers old. Since that I stayed at home. I couldn't go to school, go out home, work. When I came to the MILC I found out that there are many people who have severer disability and learnt that I need to be includedin the society.

Researcher 06: This summer I have made very brve decision which is living independently. I have been living with my mom before. The best thing was feeling freedom. In contrary, carrying water, cleaning home and financial issues. Because the only income I am getting is social welfere allowence. Hte lesson I have learnt was youth needs to have independent finance, work and have personal assistant.

Researcher 07: I have physical disability. Therefore, I move slow and slow at remembering. However, I like to study. Because I have disability, teachers usually don't understand my special needs. I borrow my classmate's notes because I couldn't understand what teacher taught us in the class. I think I didn't fully get my studies at school. Further I like to learn new languages. I took English classes. Recently when I check my English language level via online, it hasn't changed since I have been taking the English class. Therefore, I understood that I need to be more diligent. I wish that teachers improve their teaching capability to teach something to the PwD.

Researcher 08: I have hearing disability. When my friends hang out at somewhere, I usually don't know where the place is. Then I ask my family members about where the place is, they cannot explain me because they don't know sign language. I don't have enough source to get the information and I just stay at home. Therefore, I wish family members need to learn sign language.

Researcher 09: I am a chef. Because I work with "normal" people, sometimes I don't catch what they are talking. In that case, it will be my fault. Further I cannot fully express myself. In contrary, others just talk to each other. I have experience that I got fired because I didn't hear what others said.

Researcher 10: I have got spinal injury in 2014. Since then I used to stay at home only and thought myself as a plant and scared to get out home. I didn't even like to go to the hospital, because I knew that my health couldn't be better. Last year, I participated in the project and it has changed my life. I became more open and got confident myself to live independently. Since then I started to hang out with people and attended trainings and projects. Now I can go out independently.

Researcher 11: I have studied at ordinary secondary school and university. After the graduation I have stayed at home for 1 year. Even though I have applied for many jobs, they didn't choose me because of my outlook and the way I am talking. Then I started to work from home. Last week I got interview and got new job supported by my friend.

Researcher 12: I will talk about my life at secondary school. I was the best schoolboy. until 6th grade and my foot and hands started to ache at that time. Since that time, I didn't really work hard on my studies and my scores decreased. At my 7th grade, I have met with a guy who also has disability and he gave me priceless advice. Further a TV content influenced my life as well.

Researcher 13: I am a student at Mandakh university. I have decided to study at vocational training center at my 9th grade. But 3 days before school starts, I have changed my decision and decide to study continuously at secondary school. My parents surprised about my decision. At secondary school I had no trouble. So, I decided to study at university. My mom wanted me to be an engineer, yet I wanted to be an accountant. I was the first PwD student at my university and they had no experience with PwD. I learnt that talking to lecturers at fist is vital. I had almost 30minutes of sleep at my 1st year in university. Because I need to rewrite the lecture and to do my homework for whole night. Then my lecturers confirmed to send me lectures at least one day prior the lecture date and I have plenty time to learn. Now I am at my last year.

Researcher 14: I met with MILC since 2009 and I was the first CP member. Mr. Undrakhbayar explained me many things at first and I didn't really understand those things. Then I have started to participate actively in activities organized by the MILC. Once I went to Japan and learnt their experience on personal assistant and got personal assistant for myself. Further I have been stayed at families which are living independently in Japan. These were 3 different families with 3 different disabilities. One of them was CP person who has severer CP than mine. It has surprised me. He asked my age and he advised me to use personal assistant and live independently because I am young and energetic. This spring members at MILC chased me to live interpedently. Because I was a bit timid, I still didn't decide to live independently. But I know I have capability to live independently near in the future.

Researcher 15: I am learning how to cook alone. I think I need to work on me. I didn't cook by myself yet.

Researcher 16: I have CP. I cannot live independently and go out. Further I cannot work, and I always need someone to help me. I have never studied at university.

Researcher 17: I live independently. I usually don't go out. Sometimes I even wanted to suicide. One day I decided to push myself and took wheelchair. At the first people look at me a bit curiously. I thought myself as shame. Then I decided to go out regularly and got confident about myself. I can feel people started to understand PwD's special needs. I made many friends since I am here in UB and participated in trainings. I believe person should believe in own self.

Researcher 18: I spent 4 years to learn how to use ball pen. By learning that, I enrolled to the secondary school. Even though I was one of the best students I couldn't attend Olympiads because of my writing skill. My teachers supported me to participate in Olympiads and I got opportunity to study at university. Next obstacle was delivering baby. Even though doctors prohibit me to get pregnant, I decided to have baby and I am super happy now.

Researcher 19: I had a dream when I was little boy. My dream came true recently. This was learning intellectual sport. I had a chance to meet Mr. Hatanbaatar, director at Intellectual academy and invited him at MILC for the speech. I have never thought that I could meet him in person. I learnt one thing that there is always opportunity.

Researcher 20: I also stay at home usually. It is difficult to come here. Accessible road is much needed.

Researcher 21: I started to use public transport since I am here at MILC. Soon I will live independently.

Researcher 22: By hearing your stories, I have understood that I can do anything that you have mentioned. I have one hand since I am 5 years old. One thing I couldn't do is wigging my hair by myself. This is my dream which cannot come true forever. I can do it by one hand, unfortunately it doesn't look good.

Researcher 23: I became MILC member in 2011. One year after, I enrolled 1 secondary school, 1 university at the same time. I got tired so much. I graduated from both in 2017.

Day 2:
Researchers presented their group presentation to others.

Presentation Group 1
Everyone has inherent dignity and of the equal and inalienable rights.
Violation of dignity:

- Traditional approach
- Medical approach- Rehabilitation
- Nursing center
- Inaccessible infrastructure
- Family is responsible for caring
- Other.

Traditional approach – After getting sick parents prefer to go to lama or monk. Lama or monk says becoming disability is karma. For instance, when my nephew came and sat on my wheelchair, his parents takes it as a bad sign. Even some people think that being a disability is a sick and they act like they might be affected by touching me. This is traditional approach.

Medical approach- Rehabilitation: I need someone 's favor when I go out from home. So, people who helped me always ask if I am going to the hospital or they say that this is very unfortunate because such beautiful girl got disabled. I have been seeing a doctor for more than 3 years. Before I got disabled, I bought an apartment by income which I earnt from Korea. I used to have a rehabilitation service which cost 35000 tugrik for each and I need to spend 11000 tugrik more for transport and 5000 for lunch. So, I have been spending approximately 50000 tugrik for a day. After 3 years of rehabilitation service I gave up and accepted myself. At that time, I wish to clench at least and to cook for my daughter.

Nursing center- Usually family members send their siblings or children to nursing centers if they are disabled or they tend to send their children to special schools. If they exclude PwD, PwD won't be socialized, and other people won't understand properly what a disability is.

Family is responsible for caring: It is general to all PwD. Siblings or parents take care of a member who is disabled. People who care about us are usually stressful. Because they worry about it the case of, they pass away what shall we (PwD) do.

Inaccessible infrastructure: This is key point. Even if we use personal assistant and her or she help us to move, it gets troubles when there is doorsill. Buses are inaccessible. Even though there is accessible bus, driver doesn't assist us to get in.

Right to live independently: first ILC was established on 1972 at California, USA. PwD all over the world started to fight against discrimination and to include in society.

- Decision making;
- Choose freely- it is important. Person will be responsible for own choice. By participating in society PwD can feel they are alive.
- Being responsible

Right to live independently covers:

- independent finance
- housing
- education
- accessibility
- employment
- campaign for independent living
- personal assistance
- services which fits PwD's special needs

Right to live independently stated at the CRPD article 19 and Incheon strategy which Mongolia has already adopted and law on PwD rights of Mongolia article 32. Therefore, the government of Mongolia must fulfil PwD's right to live independently. Article 32.2.2 stipulates that PwD must be fulfilled personal assistance and peering counseling service.

MILC is organizing one day training personal assistants.

During her presentation, she took one case: Ms.N who has CP and bad at clenching hands. She started to live independently supported by personal assistant from February 2018. She takes 100-160 hours of personal assistant service per month.

Presentation by Group 2

As it was stated in the section 32, article 32.1-32.6 of Law on human Rights of Persons with Disabilities:

Section 32. Right to live independently

32.1. Persons with disabilities have a right to live independently.

32.2. Right to Independent lives of persons with disabilities shall be ensured through personal assistance, mutual exchange of experiences, counseling services.

32.3. Procedure, types and forms, requirements for service providers of support of independent living of persons with disabilities shall be approved by government member in charge of persons with disabilities. 32.4. Individuals and legal entities shall be allowed to deliver services in support of independent lives of persons with disabilities;

32.5. Public organizations in charge of welfare services at the province and capital city levels shall arrange selection of service providers that are expected to deliver service in support of independent living of persons with disabilities;

32.6. When enforcing sections 32.2, 32.3, 32.4, 32.5 of the present law, participation of nongovernment organizations that work for protection of human rights of persons with disabilities, shall be secured.

Approaches to ensure right to live independently:

- Personal assistant- person who has capability to support PwD’s independent living. He or she should attend in course.
- Peer counseling- experience sharing activities between persons who are living in a same condition for improving their self-confidence.
- Temporary housing- a service provides temporary house for training and building capacity to live independently.

How it implements:

Even though the ministry is about to adopt the resolution on personal assistance service, public attitude and PwD knowledge are still limited. Effective collaboration of DPO and the public organization will be vital to ensuring right to live independently.

In their presentation, Ms. Bayartsetseg mentioned that I thought I have enough experience on disability related issues, but when we started to do our survey, I found that I have lack of knowledge about independent living. Now I know that personal assistance is not only for PwD, everyone can use Personal assistance. Effects of implementing personal assistant service are as follows:

- PwD can be an employer
- PwD can manage own life
- PwD can be empowered
- It will help to eliminate Public organization’s workloads
- Finance of NGO or DPO can be stabled.

One researcher asked: Do you think the legislation can be implemented?

Answer: Even though there is legislation, it cannot meet our special needs. For instance, if I lost 69 or 79 percent of my ability, I couldn’t have personal assistant. Because law says person who lost 80 percent of own ability can have a personal assistant. But I still need to have one. It also needs for older people.

Another researcher: I lost 50 percent of my work ability. But I need personal assistant in the case of breastfeeding my child.

Presentation Group 3 Self-assessment to live independently.
At first, he listed things that he can do by himself:

- Get up and wash my mouth and use toilet;
- Have a breakfast but someone needs to prepare it for him;
- Clean home

My unique character:

- I am active for social media- has 1500 followers at Instagram
- I have positive thinking

Obstacles:

- I need someone's help when I go out
- I cannot cook
- I cannot write by hand

University's accessibility:

- Elevator doesn't work
- Toilet is not accessible

Conclusion: I have 70 percent capability to live independently.

Presentation Group 4: Employment
I thought meeting theme was employment. Disabled or dwarf persons shall be employed at a level of not less than 3 percent of its total staff by a business entity or organization having more than 50 employees, unless it is contrary to the job or production feature.
Main reasons employer doesn't want to hire PwDs:

1. Ramp and accessible toilet are rare in Mongolia. Almost all companies no accessibility, even though employer wants to hire PwD. Moreover, they usually rent an office, so that they cannot renovate the office without is owner's consent.
2. Employers have lack of knowledge about disability. Therefore, they usually prefer to pay penalty rather hire PwD.
3. In accordance with labour law, PwD should work up to 4 hours a day. However, we have way more ability to work effectively.
4. Negative attitude from coworkers. For instance, in the case of PwD go up and down the stairs or to go to toilet, we need some others favor. People usually consider it complicated.
5. Employer refuse to train PwD at workplace. However, we need more detailed or repetitive explanation, we work more honestly.
6. Employers a bit aware of responsibility towards PwD. They usually think we are sick because we have disability. They don't know about our special ability.

Presentation Group 5:
First, mother language for deaf people is sign language. Because family members don't know, we cannot live independently. They don't get anything I told them.
Second, at the school, I can have any information from other deaf students. But I cannot get information from teachers or staff. We just rewrite what teachers wrote.
Third, all services providing by the state are inaccessible. Policeman or doctor cannot understand what I am saying. For instance, in case that police came, they just talk to other people. Because they don't know sign language. It could make us convict rather victim.
Forth, foreign movies have subtitle, yet Mongolians haven't. Basically, entertainment activities including libraries must have sign language interpreter.

Fifth, family planning. Because of lack of information about legislation, we don't know regulation for getting married or benefits from the state. At workplace, others always kame decision upon us. Even though, I know my professional capacity they just say I cannot work appropriately. I cannot hear but I can do everything.

Presentation Group 6: I am practicing at Ministry of Labour and social welfare. My first survey covers implementation of Law on Human rights of PwD /at least one PwD employee per 25 employees. /
He showed he whole survey. He collected data from 878 public organization including ministries, agency, local municipalities, secondary school and kindergarten and 62 private sector legal entities.
About the penalty, in case of not hiring PwD at workplace, employer should penalize for 50 percent of minimum wage in UB, Darkhan and Erdenet, 30 percent of minimum wage in other aimag. As per my survey, employers prefer to be finalized rather to hire PwD. Further employers are slow at paying penalty.
According to his survey Ministry of Labour and social welfare was the best among the other ministries. Implementation of obligation to hire PwD was 75 percent.

A blind researcher said: For blind people, lack of accessibility affects independent living. Even though all people talk that it is going wrong way, new roads or buildings still are not accessible. Even IP TVs are not accessible for blind people.

Another researcher said: Before we talk about independent living, I think we need to talk about development of the country. Ibelieve everyone should live happily including PwD, Moreover, we as PwD need to prefer live independently.

Another researcher said: I have studied Chinese from 2016-2017 in China. It was my first time that I was living alone by myself. It was also a bit complicated that seeing new people and live with them. Studying Chinese was hard too. But I learnt that if person really want and work hard, everything will be fine. I was a bit slower than other students. However, if school or teachers support, everyone can learn anything.

Presentation Group 7:
First protest for ensuring PwD rights was held in the UK 1960-1970. During that time Union of the Physically Impaired Against Segregation: UPIAS has established /1976/. At the beginning Poll Hunt who was at the Le Court nursing center protested the service via social press and campaign all over the world has begun. He said that PwD who are living under the pressure of society.
Living independently refers to decide own life and to be responsible for own choice on daily life.
As per PwD want to live independently, financial issue has arisen. Because public think that PwD cannot manage money by themselves. Thankfully, Independent living centers are established in developing countries.
Although it has rejected for 14 times, law on anti-discrimination has adopted in 1995. Meanwhile DET has been created. More clearly DET is inseparable from anti-discrimination law.
International human rights treaties:
1. ensures specific human rights
2. creates obligation for the state to ensure human rights

3. creates monitoring and complaint handling mechanism
The main objective of the Convention is to define rights and obligation and participation of the government, state organizations and individuals for ensuring, fulfilling and protecting PwD's equal participation in society; and to build opportunities for improving PwD's self-esteem, working based on own ability, having social welfare service which fits their special needs and health care services.

Convention appeals that the government will adopt legislation or policy regards to protecting human rights of PwD.
In accordance with the law on human rights of Persons with disability, discrimination means any distinction, exclusion on the basis of disability which restricts persons with disabilities to exercise basic human rights and fundamental freedoms in political, economic, social, cultural field on an equal basis with others and to access distribution of social wealth, contribute to the development and to be supplied with appropriate devices.
However, the Government's action which is not building accessibility with universal design and reasonable accommodation; and public transport and public services or refusing to do so induce to ineffective implementation of legislation
DET is one of the effective approaches to implement human rights.

Obstalces:
1. DPOs don't usually collaborates with each other.
2. Even DPOs who are working in the sector for many years are still seeing PwD based on medical or traditional approach.
3. Some DPOs just using PwD as an approach for making money.
4. Public officials have lack of knowledge.
5. Services which offers for PwD are usually special services only for them.

<u>Summary</u>:
- Accessibility in countries which PwD have protested for their rights are better than the others.
-PwD should be the most responsible human being for ensuring their rights
-We should build public awareness on social approach. Because we not problem, contrary society is the problem.
-Even though there is a legislation, it cannot implement effectively because of lack of public awareness.

COMMENTS & CONCLUSIONS

The forth theme meeting on the independent living of persons with disabilities had active participation by the researchers. Even though there wasn't testimonial, participants actively studied about legal clauses and prepared presentations by 2 researchers. These presentations were mainly focused on national legislation on social welfare, social care and its allowances. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

The meeting showed improvements in the capacities of the researchers, who are more open to each other. Some persons are conducting small surveys and some others did survey on their daily life. It seems quality of research is improving, and researchers are getting more active to do research and discuss the issue.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme of sexual life. The dates for the next meeting will be communicated.

Theme Meeting #5 – Sexuality

Meeting Report

This was the fifth theme meeting. It was held at Holiday Inn hotel, Ulaanbataar on 16th March, 2019. 24 (of which 11 males and 13 females) researchers participated in this meeting. There was no invited testimonial at the meeting. Apart from the researchers, Mr. Enkhbuyant, President, Tegsh Niigem and Mr. Undrakhbayar, Director of MILC and member of TAG, attended at the males' session. Conversely Ms. Battsetseg, Reporter and Ms. Myadag sign language translator attended at the females' session.

Meeting Programme: This meeting was a bit different than usual. Since sexuality is a part of privacy, organisers decided to split researchers by gender. The meeting was more like a round table discussion at the males' session. Women's meeting had some presentations. Ms. Enkhmaa and Ms. Boloroo did a micro research and introduced those researches at the females' session, and females discussed about the theme. Ms.Battsetseg gave brief speech on national legislation regards to sexual abuse and prostitution after each session.

Meeting coordination: On a request of male participants, Mr Undrakhbayar was a chaiperson at men's session. Ms. Boloroo was the chairperson and Ms. Erdenezul was chairperson's assistant; and Ms.Uynagaa was the equal-participation observer at the female session. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

MEN'S MEETING

Discussion was more focused on how they ensure their sexual needs and what is needed to ensure their sexual needs. At the beginning of the discussion Mr. Undrakhbayar shared 2 life story of PwDs .

A life story case 1:

The story is about a guy who has hypodomia.

One day he came to MILC. He said that I am 24 and my brother must take care of me for every 30 minutes and I decided to surf the internet to relax my brother while we were drinking. Honestly, I watch porn videos or movies while everyone is sleeping. Because my physical development is same as the others. But I have never touched females. To tell you the truth, it is even harder to die.

Soon after this discussion, we tried to help him to have sex and we tried to find prostitute to have sex with him. We met few prostitutes and explained het that he cannot even move his fingers, so he needs some one's assistance. At first, the prostitute couldn't understand.

He died after 2 years since then. He said that I am happy before I had sex in my life before I die.

A life story case 2:

A guy who is 19 and has intellectual disability. For him woman is woman, he cannot recognize his closed ones. So, he gets more like animal when he wants sex and mother has to protect his younger sister from him at that time. She was telling it while crying that she helps to masturbate him.

One participant who is deaf sent his opinion in written. (He hadn't attended this meeting). In his letter he mentioned that every information related to this theme is completely closed to us. Sometimes we share own experience to each other. Even if there is information in written, we cannot understand completely.

Researcher01: I have messaging with a girl who knows about my disability. She said that if your family confirms, I will marry you in the case of you love my 2 sons. So, I asked from Lama (Monk) whether she can be a good wife for me. Unfortunately, Lama said that she doesn't suit me, and he said you such a poor guy, how dare you interest in woman. Further my mom said that there is no one like me who cares about you. I relied her that you cannot take care of me forever.

After the cases and storytelling, Mr.Undrakhbayar also mentioned that there is subsidy system for PwD who has severe disability in Europe. Conversely in Mongolia, this kind of information is closed to everyone.

Males session continued to discuss about how they can get information. Even though they invited sexologist, she couldn't attend because of workloads.

Basically, they mentioned that they get information from their friends rather specialist whereas one of them got such kind of information from the internet. Main obstacle is they cannot get out independently which means they always need someone's assistance. In one hand, family members are too protective, and they cannot talk this topic with their family. So, family members usually think that PwD has no idea and no need of sex. In other hand, PwD avoid making this issue open to the public.

One of the participants also mentioned that he tries not to think about sex when he feels to have it whereas others say that they cannot see girls because of embracing their disability. Sometimes people believe in myths which is false. For example, usually people say that CP people cannot have child.

In the result of discussion, they concluded that information resources are as follows:

- Friends
- Colleagues
- Family members
- Religion
- Internet.

As per their discussion, colleagues give them more proper information. In the reality they want information or advise from specialist. At the end of the session, male participants concluded that followings are key things to ensure their sexual needs:

- Accessibility
- Personal assistance
- Consult with close people

WOMEN’S MEETING

This session has more focused on how participants have met with their husbands and boyfriend at first, what was family’s reaction at that time, and syptoms of sexual imbalance. Most of participants shared own life story

There were 2 presentations done by 2 researchers.

Presentation 1: My target group of people was people with intellectual disability and spinal cord injury. The reason why I was choosing those kinds of people as a target group was, I have met a local authority when I was organizing a training in the countryside. She told me that sexuality issue for PwD is hidden, no one wants to talk about this, yet this is crucial to solve. People were not too open about their sexuality. Because I offered 5 people to interview with me yet 2 of them accepted. 3 wheelchair user which I offered to discuss this issue, rejected to discuss. I have met with 2-3 parents who have a child with intellectual disability and asked about troubles they are facing. One of them was a person who is living in the countryside and another one a person who is in UB. However, I prefer not to tell where he is living in the UB for his privacy.

Person A is 32 years old who has severe intellectual disability. She usually takes off all clothes and run away in the street when she feels sexual excitement. She has been like this for 3-4 years. The family doesn’t know how to deal with this issue.

Person B and C: They live in the UB. One is 25 and other is 31 years old. One of them has told me that he is being in a serious condition when he feels sexual excitement. Another person is living with his 2 younger sisters. He gets out of control when he feels sexual excitement. Thus, his mother helps him to cum. As she said, she has done it for his son for nearly 10 years.

There are 105691 PwD in 2018. 19.2 percent of them are Person with intellectual disability. Nearly 60 percent of Persons with Intellectual disability are 35-64 years old. /she showed pie chart and tables with detailed information. /
In accordance with Researchers’ view, they describe sexuality as a set of biological and psychological impacts on sexual behavior and its impact. Sexual behavior is based on a combination of three processes: sexual intimacy, sexual desire, and sexual orientation. Sexual desire is motivated by the desire to engage in sexual intercourse. It is a form of mental activity that is manifest as a love. Sexual intercourse is a process that is based on multiple stages. Some researchers divide into the phases, namely prelude, pseudo, and polarity.

The interest in sexuality begins with the age of 12 to 13 and body physique begins to change.The sex life of married couples has general picture, and the number of intercourses since the marriage has decreased gradually, and as the age progresses, it decreases fast. Female and male are different by few things namely, the way they are having sex, cumming and masturbation.

9 symptoms of the hormonal imbalance: Overweight, Fatigue, Sweating, Dark circles under the eyes, Depression, Acne, Changes in breast size, Hair loss and Growth of excess hair.

Legislation: There no specific clause on sexuality at the CRPD yet article 16 and 25 mentioned about sexual abuse and health. In accordance with the Law on PWD rights, article 6.3.5 (discrimination)and article 29 have clauses about sexuality.

Conclusions: Sexuality of PwD is hidden; Public takes PwD's sexuality as sexual abuse, reproductivity and health side; In the legislation there is no specific clause. Clauses only mention about health, mental health and reproductivity. No one never tried to solve their problems in sexual life.

Recommendations: To promote public awareness for amending the legislation. Specifically, to article 25.1 of the law on PwD's right: 25.1.X Persons with disabilities are entitled for income, sufficient to meet their own (biological and social needs) and families' living and health needs including food, clothing, accommodation, treatment, care, social services and government shall take the following measures to secure this entitlement. So Materials for ensuring biological needs should be included in article 25.1.1 of the law on PwD rights and Sexuality needs should be included in article 26 of the Law on PwD rights /26. Benefits and subsidies from Social welfare fund/

In her presentation, she also introduced about Viagra to others.

She also presented a small research on protection center for prostitutes: In countries the government subsidizes money for prostitutes whereas some others' government collaborates with this kind of institution for ensuring PwD sexuality. In the case of Mongolia, prostitutes who are in street are 40000-80000 tugrik for an hour, 150000 tugrik for a night and they pay 20000 from each customer to their agent as a fee. In sauna girls are up to 60000 tugrik for a once, whereas up to 200.000 tugrik for a night and the pay 50 percent of their income to the "boss". In the striptease bar girls are 30.000 tugrik for a sitting with customers and 70.000 tugrik for striptease dance and they pay 10.000 tugrik to the "Boss". In the end of her presentation she also showed sex toys photos' which sex shop in Mongolia is selling.

Presentation 2. Her research focused on three main areas namely obstacles, suggestions to solve the issues, and needs of the PWD.

Obstacles:

Symptoms of Hormonal imbalance of women PwD: Stress, Acne, Menstrual imbalance, Appetite increase, Overweight and Fatigue

Lack of public and family members' knowledge and understanding - They usually take PwD as a child. They presume that PwD has no feeling to love and don't know about love. Girls or women PwD are at risk of sexual abuse. For instance, taxi drivers,

Doctors do incorrect diagnosis in some cases. For instance, a lady who is CP have had hormonal medicine for 10 years because doctors were saying that her diagnosis is hormonal imbalance. But in the reality her menstrual period was imbalance because of she had back pain.

2. Suggestion to solve the issues: Hormonal medicine. But people need to take the medicine with doctor's prescription. Public awareness campaigns. Inclusive education system from kinder garden

3. Needs of the PwD: People usually obey with each other such as when girls as same age as I has a boyfriend, I also want to have boyfriend. BUT SHOULD I OBEY PEOPLE AND LIVE EXACTLY LIKE HOW THEY ARE LIVING.??? Some people think that because I am PwD, that is why I am living like this. They should think about "ordinary people have such kind of problems in their lives as well. Even couple with severe disability is living happy and full without sexual intercourse.

Life story cases: Some researchers shared their personal experiences regarding sexuality:
Researcher01: When I was at high school, I was feeling stressed to see my friends are in relationship. Even I sometimes used to think that I have no purpose to be alive. Then I met someone whom I have a feeling and into him. But still my mom calls me constantly when I go out. One day I decided to talk to my mom, and we understood each other well. Usually family which has PwD is very protective. Members always worry that if the guy was just killing the time with us. At the beginning of my relationship, I didn't tell my mom that I am seeing a guy. I also created false contact name for him (Such as Bayarmaa). I faced such issues for many times. After I got job, I could change my families' understandings and got approval to meet with a guy.

Researcher 02: At the beginning she shared a story how she met her husband for the first time in detail. She said that sometimes people ask me how I deal with my sexuality because he is in prison. But I am sorry, honestly, I have crush at the university. We have no sex, but I feel so loved even I see him. Sometimes I watch porn site and have masturbation until I meet my husband for 3 days a month. I don't know when my husband will release from the prison.

Researcher03: I am representing people who got injured accidently. People like me cannot protect us from others attach or abuse. She shared that how men tried to abuse her verbally and physically yet at first they told that they want to assist me to get into home. She also pointed out that taxi drivers usually try to do same thing when PwD are taking a taxi because they are not able to protect themselves.

Further, she continued about her relationship. In her point of view, family is too protective and members usually extremely worry about men will hurt her after all. She said that since I have a boyfriend, I have other issues to solve like how to have sex because I use catheter, how to prevent getting pregnant and what should I do in the case of I am pregnant. I don't know how to deal all of these issues and don't know whom to ask. We just share our information rather ask from specialist.

Researcher 04: At the beginning of her life story, she shared her story how chiropractor and driver's action made her uncomfortable. As she said, she got injured 5 years ago. At beginning she used to see a chiropractor. He requires to take off all her clothes to massage and ask to leave them alone in the room, yet she felt uncomfortable. After 7 days, she told her mom that she doesn't want to go to see him again. She continued, as mentioned in the earlier testimony, taxi drivers usually touch me and ask me whether I want to have sex or if I have husband.

I have thought that I cannot do everything for 2 years after the accident. Since I started to come the MILC I understood that we can do everything including sex. I often tell my family that I wish to marry and have child. My family say that oh that will be difficult to take care both of you albeit my colleagues support me.

Since I am alive and human being, I fall in love with someone. So, it is difficult to ask family member's assistance to see him. My mom always checks who is he, where are we going and when we will come back. Now I am having personal assistant. So, the condition is getting better. I can just say I will be late. Further my family say that I should stay at home and marry "ordinary" guy in the case of marrying someone. For Mongolians, it is odd to see when wheelchair user female and "ordinary" male couple. Even though my family will be happy if I see "ordinary" guy, public will be negative. So, I can say family members usually have negative attitude when we talk about or have partner.

I am seeing a guy for 1 year and he is also wheelchair user. I believe my family assume that I am having relationship. The thing we focus on, is family members' reaction. When we are arguing, the reason is family's attitude rather our issue. He already told about me to his mom and his mom asked about if I can use my hands to do something. Because he cannot. For males who has spinal injury, it is difficult to have sex and have child. Therefore, my boyfriend frustrates about that and says I have problem not you. There are few cases the wheelchair users got a child. I have researched a lot about this issue and discussed with my colleagues. I couldn't find anything form the internet. Someone told me that he could do masturbation. But since he hadn't sex for many years, this couldn't help. Lately I found out that we could use his G spot for pleasure, yet it is a bit unsafe. I usually talk about this issue at my office, some of my colleagues say that I am such an addicted person.

I know a case about a boy who is 16 and CP. He was at MILC and he had with his mom a brazen manner. She said loudly that when I am without out clothes he comes and hug me from behind. Maybe it is because of his sexuality, I wish him to have vasectomy. He cried when heard what his mom just said. We made him to calm down and explained his mom that he feels everything same as the others. However, she said that he cannot live like this for his entire life.

So, all want to say is we just talk to each other when we have needs to discuss or get information.

Researcher 05: she started her story about first love. Then shared about her hormonal imbalance and how she dealt with this issue. She said that I started to feel hormonal imbalance. Gynecologist suggested to me take medicine or have sex with someone. So, I told this issue to 2 of my female friends. One of them suggested me to tell about it to one of the male friends and ask his favor. So, I decided to tell about this to my one of the closest male friends. He took it so weird. Then I felt embarrassed and told him that it was a joke.

After 2-3 months later than that, 3 of my friends including the guy I have told about my issue came at my place and we had drinks. After few drinks he told that me and he have things to discuss with me and ask my friends to leave us few minutes. They left and he touched me. I felt being loved when he was touching me, and we had sex. It was first time for me. But right now, I am thinking that girls should have sex with her loved ones, especially for the first time. Since that our relationship goes normal as usual. Now I am a bit I have never told about this to anyone. What do you guys think about that.

Researcher 06: Myth is people think CP people will deliver CP child. One of my friends got pregnant albeit her parents forced to abort her child and she did it. Now no one knows whether she can get pregnant again. I also had sexual intercourse at late. I tried not to tell someone about it at first. But I decided to tell my mom. My mom is gynecologist. So, she gave me advise related to sexuality. I don't have boyfriend at that moment, so it becomes tough to ensure my sexual needs. My mom offered me to use vaginal tablet for balancing hormone. I used it for a while. Now I am in a relationship.

Researcher 07: She said that I believe obstacles are same as the others. In my case, I never had sexual intercourse, so I cannot say anything specific. Taxi drivers attitude is also mentioned in her speech. Add to that she mentioned that deaf guys usually don't ask whether I want it, they just tell that let's have sex. Her main point regard to sexuality is lack information by their mother language.

Further she shared that lately she is having acne on her forehead. After hearing previous presentations, she understood that it might be because of hormonal imbalance. At the end of her speech, she said that I have heard that as getting older than 24 years old, maidenhead gets thicker and I was worried about that. But now I found out that it was just trash.

Researcher 08: She shared that she never had sex and she worries about her prosthesis will fall in case of she meets a guy and has sex with. Therefore, meeting with a guy or seeing a guy and having sex is very tough for her. She also mentioned about family members don't respect her opinion and privacy and recommend her to have child for caring about me in the future; and taxi drivers' case. Even I had experienced that someone tried to abuse her. Therefore, she cannot trust guys.

Researcher 09: She shared a case while she was doing research on women with disabilities' reproductivity from 5 aimag including more than 300 people. A wheelchair user girl who has sexual intercourse with her father, even her mother knows about it and parents explained that since she has physiological needs, who else will do it for her. She said that it is a case of abuse under the name of loving.

About her case, I have stayed at home for 4 years since I got injured and believed that this is how PwD live. But after attending in a training at MILC, she understood that she still needs sexual affairs and love life. She continued, now I am seeing a guy and happy right now. But public look us as vulnerable group of people and don't want to understand our needs as an adult.

After the presentation and life stories, participants concluded suggestions to solve the problem regard sexuality. Their suggestions are as follows:

- To subsidize payment for prostitute service for PwD
- To be open about PwD's sexuality in the society including public, family members, PwD
- To train sexologist. There is lack of human resource.
- To adopt law against discrimination
- To provide special curriculum for students

In the end of discussion, female participants briefly discussed about usage of sex toys (instrument). Some of them said that friends or family members are very supportive and gave them vibrator. But because of it makes noise, they cannot use it regularly whereas some of participants mentioned that CP people cannot use it and some of them don’t know from where to buy it.

COMMENTS & CONCLUSIONS

The fifth theme meeting on the sexuality had active participation by the researchers.

Even though there wasn’t testimonial, 2 participants prepared presentations. These presentations were mainly focused on life story of PwD. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

Lack of accessible information and specialist who are trained to give advice for PwD are the mainly mentioned needs in both sessions. Further, they mentioned that family members are too protective, yet it can be violence against PwD. Most importantly, it can be clearly seen from their life story, women with disability are at risk of sexual abuse.

The meeting showed improvements in the capacities of the researchers, who are more open to each other. It seems quality of research is improving, and researchers are getting more active to do research and discuss the issue.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme of labour. The dates for the next meeting will be communicated.

Theme Meeting #6 – Labour

Meeting Report

This was the Sixth theme meeting. It was held at Ochir timem center, Ulaanbataar on 7th April, 2019. 20 researchers participated in this meeting. There was no invited testimonial at the meeting. Apart from the researchers, Mr. Enkhbuyant, President, Tegsh Niigem Ms.Tulgamaa, representative of AIFO, Ms. Battsetseg, Reporter and Ms. Myadag sign language translator attended this meeting.

Meeting Programme: At the first part of the meeting Mr.Enkhbuyant gave short and detailed speech about concepts and needs of working, and international and national legislation regard to labour. Further 4 participants (Mr. Bilegsaikhan, Ms.Enkhmaa, Ms.Sumiyakhuu, and Mr. Elbegdorj) prepared presentation, and Mr. Nyam-Ochir shared about what he learnt from Japan's experience and Ms. Gantsetseg shared about obstacles which deaf people are facing to work. At the afternoon session, participants divided into small groups and discussed about obstacles regard to labour, how things can be changed in the future and solutions.

Meeting coordination: Mr. Bilegsaihan was the chairperson and Ms. Misheel.E was the equal-participation observer. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Researchers' Presentations:
Mr. Bilegsaikhan: He did small research on obstacles that PwDs face to work and problems in the Government policy.
The following are difficulties for young people to work in.

- Lack of information
- Lack of skills for submitting application to the job.
- Lack of assistance
- Lack of accessibility /Bus, road/
- Lack of public's understanding regards to the disability issues
- Lack of experience to work
- There is no one to assist how to work at workplace
- Lack of accommodated workplace

We need followings to get the job:

- To be educated
- To study at vocational trainings
- To learn from others' best practices.

Other countries' experience:

- Provide assistant service to define persons' skills and submit job application.
- Accommodate workplace which is suitable for PwD.
- Workplace training
- Colleagues support PwD at workplace
- Accessible transport for PwD to get to the work

Presentation 2. Ms. Enkhmaa: She took obstacles for PwD depending on disability issues and shared Japan's practice.

1. People with hearing disability

For them lack communication is main obstacle. Most people don't know sign language. Thus, those group of PwD got in trouble to fully communicate with colleagues and managers. In the event of communicating via writing, often they cannot have fully understanding. This can be one of the main causes for overworking without salary.

2. People with vision disability

- Inaccessibility
- Unqualified and uncompetitive primary education. Because of that people with vision disability cannot study at universities and work.

Since 2017, Mongolian national federation of blind, collaborating with Korean federation, did survey to define appropriate workplace for blind people. In accordance with this survey barista can be most suitable job for them. So, 6 blind people trained as a barista.

3. People with movement disability

- Personal assistant is much needed
- Inaccessibility

4. People with CP

- Negative attitude of family members. They prefer PwD to stay at home.
- Lack of public awareness
- Limited access to education

Japan's practice

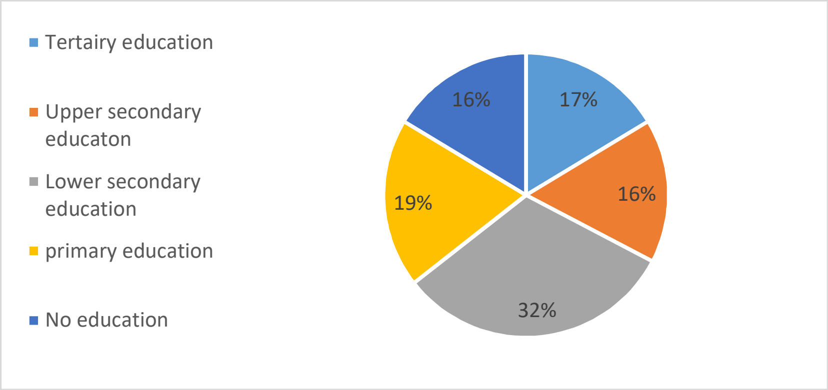
There is special service to assist PwD to work and to find job, and trainings at workplace to get experienced. Usually people with intellectual disability use this kind of services. I personally think that this service is also suitable for CP people. Moreover 2 PwD can work at one workplace and split working hours.

Presentation 3: Ms. Sumiyakhuu

At the beginning of her presentation she showed the legal terms of national legislation and CRPD regards to the labour, and shared classification of labour.

Moreover, she did small survey on 30 PwD of which 10 males and 20 females. 5 of them are 18-25 years old, 15 of them are are 26-35 years old, 8 of them are 36-45 years old, 2 of them are older than 45.

By their education level:



About employment: 6 of them are unemployed and 8 of them has small family business whereas 6 of them are working in informal sector and 8 of them are working for NGOs

In accordance with the Labour law, legal entities obliged to pay following payment for not hiring PwD.

- Legal entity which has up to 50 employees- 40 percent of minimum wage at UB, Orkhon and Darkhan-Uul aimag
- Legal entity which has more than 51 employees- 50 percent of minimum wage at UB, Orkhon and Darkhan-Uul aimag whereas 30 percent of minimum wage at other aimags.

Presentation 3. Mr.Elbegdorj: Even though he didn't show presentation, he showed abstract of his research on labour. His speech was mainly focused on PwD's statistics from 2015 to 2017 and employment rate.

There were 91465 PwD labour force registered, of which 19715 of them were employed in 2015. This rate has increased in 2016, 2017. He explained it because of the Government pushed legal entities either to hire PwD or pay penalty.
Further he mentioned about a survey which is done by the Ministry of Labour and social welfare in 2017. In accordance with the result, 8.8 percent of them said that they can to work, 35.5 percent of them said that they cannot work, 7.7 percent of them said that they are able to work, 46 percent of them said that they are able to work in the case of workplace is accommodated.

Graphic: employment rate by disability classification

	2015		2016		2017	
	Non-congenital	Congenital	Congenital	Non-congenital	Non congenital	Congenital
Western area	2560	1847	1961	2435	2051	1553
Khangai area	2389	1850	1249	3066	2213	1406
Eastern area	1023	679	643	1265	989	613
Central area	2456	1511	1278	2536	4301	1511

UB	2954	2446	1267	3863	3947	1390

Following those presentations Mr. Nyam-Ochir shared his opinion on labour issues and what he learnt from Japan while he was attending capacity building training at there. He said that he had a chance to visit at social welfare center which provides trainings, labour exchange service. The service was complex which offers PwD to live together for 6 days a week and work at there. He also shared that Japan public organisations strictly follow the legislation and it encourages for requiring effective implementation from other organizations.

At last, he states that employers in Mongolia have high requirements which PwD cannot achieve.

Ms Gantsetseg also shared her opinion and deaf people's problems to find job. As per her point, employers either usually don't hire us because of communication or offer us inappropriate workplace which doesn't exist our ability. People usually think that we can communicate via writing since we cannot hear them whereas we don't even know meanings of words. Therefore, deaf people cannot understand and express themselves properly. She concluded that deaf people are more stable at workplace to compare with others.

Group work:
Afternoon session was dedicated to discussions in small groups. The participants were divided into 4 small groups and asked to discuss obstacles regard to labour, how things can be changed in the future and solutions. After the discussions, each group presented the results of their discussions.

1.Current employment situation: First the groups discussed the policy on accessible. The following polices were highlighted in these discussions:

lack of education is the key issues to get hired. As per discussion, PwD either go to special secondary schools or don't go to the schools. Thus PwD cannot compete with others at workplace.

Ineffective legislation induces to discriminate PwD to get hired. Moreover, groups also stated that mechanisms of defining ability loss to perform labour is completely inappropriate.

Lack of family's support was the situation that mentioned twice during the discussion. As per their opinion, family members usually think that PwD cannot work and live independently because of doctors' recommendation. Doctors have common negative attitude to see disability as a medical model.

Inaccessibility is one of the common situations which creating obstacles to work. It includes public places' accessibility and workplace's accessibility. Groups also mentioned that there is no accommodated workplace and flexible working hour which is based on PwD 's ability.

Further actions to improve the situation: After defining current situation on labour issues for PwD, they worked on the issues of how they can improve the situation. Basically, group's recommendations were almost same.

Building public awareness: All groups agreed that building public awareness to change public attitude is crucial to ensure PwD's right to work. As per their discussion, changing family members' attitude should be covered.

Amending legislation: Two groups mentioned that one of the reasons that PwD cannot find decent work for them is inappropriate definition of loss ability to perform labour. Thus, PwD themselves need to push decision makers to amend relevant legislation.

They have also mentioned that effective personal assistance services, inclusive education and accessible information are vital to improve current situation for PwD employment.

Solution: In this part of the discussion groups focused on how they can solve the problems they face to find job. All groups agreed that building public awareness is one of the crucial activities that they can do by themselves whereas one group mentioned that hiring teachers who have hearing disability for school #29, developing application to convert from written materials to sign language, promoting successful PwD to the public, and introducing Dual profession system.

Further, they also agreed to monitor legislation whether its meets PwD's special needs, and Labour exchange should be accessible for PwD.

Conclusion and comments:

The sixth theme meeting on the labour of persons with disabilities had active participation by the researchers.

Even though there wasn't testimonial, participants actively studied about legal clauses and prepared presentations by 3 researchers and 1 researcher shared Japan's practice on labour of PwD.

These presentations were mainly focused on national legislation on labour and statistics whereas one presentation looked obstacles from both PwD and public side. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

The meeting showed improvements in the capacities of the researchers, who are more open to each other. One person was conducting surveys on statistics. It seems quality of research and researchers' presenting skills are improving, and researchers are getting more active to do research and discuss the issue.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme education. The dates for the next meeting will be on 27th of April.

Theme Meeting #7 – Education

Meeting Report

This was the third theme meeting. It was held at Ulaanbaatar hotel, Ulaanbaatar on 28th of April 2018. 21 researchers participated in this meeting. There was 1 invited testimonial at 7th meeting. Namely Ms. Baigalmaa, represented teachers. Apart from the researchers, Mr. Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Reporter) and sign language interpreter Ms. Myadag participated in the meeting.

Meeting Programme: 1. Testimonial gave a speech about her story and experience regarding chosen themes. 2. Researchers shared own obstacles and life story among them. 3. There were 4 presentations about education by 4 researchers (Mr.Bilegsikhan, Ms. Erdenezul, Ms.Enkhmaa, Ms.Enkhjin,); 3. conclusions. There was also group discussion on how researchers can affect to accessible and inclusive education.

Meeting coordination: Mr. Byambadorj was the chairperson and Mr. Elbegdorj was the equal-participation observer on the first day. Ms. Gantsetseg was the chairperson and Mr. Sandag was the equal-participation observer on the second day. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Testimonial: S.Baigalmaa (She has been teacher at special school and has 7 years of teaching experience.) I have been working for special school in UB. During that time, I had a chance to learn the USA and Japan's experience. After that I started to work in Umnugobi aimag. I opened special class for PwD and it slowly transferred into inclusive education.

In special schools, schoolchildren are 5 times fewer than ordinary schools and have 1-2 teachers. When it comes to inclusive education, teachers couldn't work closely with children with disability because of workload. I personally think that there is no need to open special classes for PwD when there are accessibility and accommodated areas. Even though Mongolia started to discuss about inclusive education since 1990, human resources are not trained for the inclusive education. Thus, human resource in Mongolia is still not enough.

In USA, there are contingent classes at school, and these have 2-3 children with disability. So, teachers assist to learn lessons on a request of those children. There is no special education system in the USA whereas there are special health centers such as therapy and physical training centers. Moreover, Best buddy program in the USA offers possibilities for PwD and their friends to develop together through assisting and supporting each other. So, I tried to adopt this program to my work.

In 2017, I had a chance to visit in Japan. During my visit, I found out PwD who needs others' assistance are working at Sushi place. The place was established and financed by parents who have children with severe disability. Parents and teachers assisted them for doing their job.

I had a 16 PwD schoolchildren, who are from 6 to 16 years old at Umnugobi aimag. My bosses convinced me to teach them exactly same program and evaluate them as ordinary schoolchildren at first whereas I preferred to evaluate them based on their ability improvement. Since then they started to understand, and it took 1.30 hour to get exam for only one lesson.

Since end of 2018, I am sick and living in UB. So, other teachers must teach in my class. They told me that finally they have understood how hard it is to teach PwD with other school children even though they have enough experience.

Following her speech, researchers asked about reason of choosing to work in rural area disadvantage of special education, curriculum of special education and negative effects for qualified and competitive education. As per she said, because curriculum for special schools is drafted by the teachers at there, curriculum is not sufficient for PwD and PwD cannot get lifetime education, usually they need to stop studying after the secondary school because of incompetence of education. Therefore, credits should be increased at universities and legislation should be amended. She continued, she was organized trainings and visits at school children's home for changing parents' and other colleagues' attitude and such events influenced to change their attitude positively; and work with children with disabilities to improve their self-confidence. After working hard with all stakeholder, local authorities started to understand her activities and encouraged her trainings. In her speech she also mentioned that accessibility and human resource are the key issues for inclusive education. So she accommodated the classroom and organized trainings for teachers. At the end of question and answer session, she added, salary system is different between teachers at special schools and teachers at ordinary schools. Therefore, teachers are not keen to improve their skills.

After the testimonial some researchers shared their story of studying at school. Some of them told that they decided to leave school because of teachers' attitude and education is uncompetitive whereas some one of them had never studied at school because parents' decision.

Presentation1. Mr. Bilegsaikhan: His presentation was based on analysis of university environment which he and other 4 students with disabilities study Mongolian national university. He did survey on 2 students who have hearing disability, and 3 students who have spinal cord injury including him. He evaluated obstacles first and suggested what university should do for ensuring their right to study.

Obstacles for students with spinal injury: Stairs are higher, many and without handrail; WC room has door sills, and no toilet potter; Need to reduce drinking and avoid you to use toilet; Elevators rarely works; No handrails for going up and down through stairs.

Obstacles for students with hearing disability: They cannot sufficiently hear lecture, and classroom is too noisy, and it is difficult to hear; They cannot fully understand some lecture; They are embarrassed to clarify what lecturer said; Lecturers talk fast; Lecturers cannot use sign language.

What we want: Ramp at university; to use WC whenever we want; elevators to be worked properly and should be accessible. (audio and braille); Handrails at stairs; Supportive lecturers; Essential tools such as computer, sign language interpreter, and lens for studying would be provided by the university.

Presentation 2. Ms.Enkhmaa: She focused on factors that influences negatively to study and shared Japan best practice which she learned during her visit in Japan.

Unqualified education and teachers' negative attitude on disability: Education that we had from special school is uncompetitive. Teachers' professional capability is not enough to teach PwD and there are no assistants at class.

Lack of family members' support: There is no counseling center for parents and parents don't know how to develop their children's skills. Usually parents get divorced or they don't want to send their children to the school.

Inclusive education: Assistant teachers should give extra remediation after the classes. Teachers need to be qualified to teach PwD. If not there should be accountability system.

Recommendation to resolve: I had a chance to visit Japan by JICA DPUF project. I intend to know about infrastructure accessibility and how parents get information. There was a animation for parents who have children with disability and they can share their best practices. there are parents counseling centers. Further, cooperation between health, education and social welfare organization is strong. So they can discuss about children with disabilities.

In addition, counseling parents and caregivers with children with disabilities and prioritizing the challenges in health, and consulting the educational institution to educate them about how they can benefit from social welfare pensions and referral to other organizations. There are also many psychological counseling centers at districts and public organisations which provide free psychological counseling services.

Presentation 3: Ms.Erdenezul: Purpose of the research was to provide obstacles for PwD to study. In her presentation she showed international and national legislation clauses regards to PwD's right to study. She included PwD statistics regard to education of PwD also included in the presentation, and shared some real life cases.

Purpose of the Survey: Assessing obstacles of studying at school and needs to ensure right to education.
Legislation: Constitutional law of Mongolia, National policy on education, Law on education, Law on primary education, Law on Secondary education, Law on Tertiary education, Law on tertiary education finance and social guarantee of schoolchildren, Law on rights of PwD.

According to the survey from United Nations Children's Fund, there are approximately 32,000 children with disabilities in Mongolia. When this information is integrated into the official statistics of the Ministry of Education, 8878 of these children attended pre-primary and secondary education services and the remaining 23,122 children were out of school. (Sustainable development - General education conference report 2018)

Three out of ten persons with disabilities living in urban areas have completed secondary education. One in 2 persons with congenital disability has acquired an education, while 87.8 percent of the people with acquired disabilities are educated One in every two persons with speech and mental disabilities is uneducated 11.7 percent of people with hearing disability and spinal injury have access to education.

As of November 2010, there are 1986 children with disabilities who enrolled primary school. These are 1.8 percent of all children with Disability. In accordance with consensus in 2010, Of all 13.4 thousand children with disabilities aged 6-19 years old, 55.6 percent are enrolled at an appropriate level, and 44.4 percent are out of school. 9.3 thousand or 30.7 percent of 30.1 thousand people with disabilities in 6-29 years are enrolled in formal schools. As it can be seen from the statistics, we can tell that right to education of PwD is not ensuring effectively.

At the national level, 1.7 percent of the population aged 10 or older are illiterate or simply unable to read, write and understand. This figure is 14.6 percent of the population with disabilities. (2010)

According to statistics from the 2017-2018 academic year nationwide, 1599 children with disabilities are enrolled in kindergartens and 7279 children are enrolled in general secondary schools. 1637 of children with disabilities attending secondary schools are studying in a special school.

Case 1. Mother of A whose child has intellectual disability: My son studies at school #67 and he is 6th grade. He is still illiterate and cannot count 1 to 10. However, I prefer him to be included in the society. He does something which he likes to do during his classes, and he likes to study at school. Therefore, I am sending him to the school.

Case 2. E who has spinal injury and 31 years old: I have got injured when I was at my university's first year and needed to take 1 year leave from the university. My classroom was at 3rd floor, so that my mom or my brother needed to carry me on the shoulder. It was hurtful when people seeing me curiously and whispering about me. Even though there was accessible toilet at my university, it locked all the time. Therefore, I couldn't drink anything at my school, and I have never used toilet for 3 years during my study. The class was also tiny, and it was difficult for me to make notes during the lecture. I needed to copy my friends' note after the class.

Even though children with disability have passion to study at school, inaccessible school environment, public transport buildings induce to exclude them from the school. Another main obstacle to study at school is lack of appropriate handbook and inappropriate curriculum. For instance, 24 children with disability in one class at Uvurkhangai province have 2 alphabet books and the books were published in 1975.

Reasons of PwD cannot study at school: Children with disabilities usually enroll to the schools in their late ages to compare with others or they drop out from school at first year of school. Unable to go to school from home. This is one of the main problems in rural areas. Dorms are also inaccessible. Children with several disabilities and intellectual disability are unable to go to school. Lack of public attitude. Inaccessibility. Lack of information. Teachers' negative attitude.

Recommendation to implement: To provide braille techniques (PC, printer, program etc). To provide graduation certificate in braille. To provide handbook for preparing graduation exam which is accessible for all PwD. To provide audio and sign language version of regulation on graduation examination. To provide exam database for special schools. To evaluate negative impacts for PwD study and provide report. To accommodate accessible environment at school. To build awareness among teachers. To improve teachers' professional capability. To make handbooks accessible. To provide personal assistance to people who have severe disability for studying at school. To provide more systematic education for PwD from their early age and build coherence between educational organizations and employers.

Presentation 4: Ms.Enkhjin: In her presentation she also mentioned about national and international legislation; and statistics. Add to that, she evaluated internal and external factors to study at school for PwD.

Rationale: Concept of the education is aimed at ensuring equal access to education, in the context of universal education, access, continuity, flexibility, humanitarian, open and inclusive education regardless of difference of children. Therefore, I tried to evaluate the obstacles to study and suggest recommendation.

Purpose: to study and define some issues that need to be addressed in the education and training of children with disabilities.

Law on human rights of PwD: 4.1.1."Persons with disabilities" means those who have physical, intellectual, mental and sensory impairments, which in interaction with various barriers; hinder them from fully and effectively participating in social lives.

CRPD article 24. The Government actions and initiatives regard to Children with disability. Mongolia ratified Convention on the Children's rights on 1990 and CRPD in 2009. In accordance with concepts of these treaties, The Parliament of Mongolia adopted Law on Human rights of PwD in 2016.

Article 28 wholly covers human rights of children with disability and article 37.2.1 states that Disability of children 0-16 ages shall be determined by health, education and social protection commission of children with disabilities and the commission should be established by the Ministry of Labour and social welfare. Determination of disability specified in 37.2.1 of the present law and methods of formulating comprehensive child development program shall be approved by government members in charge of health, education and persons with disabilities.

Conditions of children with disability in Mongolia: According to the official report of the National Statistical Office in 2017, 3.2 percent of the population of Mongolia (103,630) has disabilities, and of which 11 percent are (11,453) children aged 0-17. 11.1 percent of these children have visual, 7.4 percent are speeches, 7.4 percent are hearing, 17.4 percent are mentally, 22.4 percent have spinal injury, and 23.6 percent are children with complex disability.

Mongolia started to establish a special school for children with disabilities from 1964 and trained human resources in abroad. there are 6 special schools at the moment and 4 of them are for children with intellectual disability, others are for children with hearing and vision disability. Even though school providing classes in accordance with the curriculum for PwD, persons with severe disability are still excluded from the schools.

Factors affecting inclusive education: External factors: infrastructure around and inside my university were inaccessible at first time. Now it moved to new building which has elevators, accessible toilet and spacy library. Family. Friends and colleagues. Public attitude- Public attitude wasn't problematic for me yet inaccessible infrastructure was the problem. I am slow writer so I asked from my lecturer that send me lecture before the class. University also offered me longer exam period than usual. Legislation and its monitoring. Education

Internal factors: Honest, diligent, and consistent personality. Purpose and dreams. Tranquility and despair. Self confidence.

Afternoon session: Participants divided into 4 small groups to discuss about priority to do and What they can do to fulfill those priorities. Each groups presented own discussion to others.
Priorities to do: *Family members' and public attitude including teachers' attitude* were common topic for groups. as per they were saying too spoiling child with disability or being too protective is can be factor to violate human rights' of PwD.

Accessibility of infrastructure at school environment and public places such as way to school and vehicles are key point to ensure right to study. Moreover some of groups mentioned about PwD also need to have self-confidence, teachers need to be educated to teach PwD more specifically people with intellectual disability and teachers need to know sign language in every school; and counselling centers for parents .

What we can do to achieve those priorities: *Building public awareness campaign:* researchers basically agreed that they can use social media for more effectiveness. Add to that they also mentioned about their active participation is crucial.

Amend and monitor legislation: Some groups said that even though there are legislation exiting, implementation is not effective enough. So they told that meeting with decision makers for amending or monitoring existing legislation is substantial to do.

Furthermore they discussed that statistics should be based on the PwD's ability, so that others can tell that who can go to the ordinary schools and policy or legislation can meet PwD's special needs. one group raised the issue regards to building self-confidence for PwD and there should be committee which is in charge of handling complaints whereas another group said parents should know sign language.

Conclusion and comments:

The seventh theme meeting on the education of persons with disabilities had active participation by the researchers.

Participants interested in testimonial speech and asked variety of questions regard to education system and her point of view to improve.

These presentations were mainly focused on national legislation on education and statistics whereas one presentation looked obstacles from both PwD and public side. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

The meeting showed improvements in the capacities of the researchers, who are more open to each other. As it can be seen from their presentation and group discussion, their analysing skill is much improved and they learnt how to source the information. One person was conducting surveys on statistics. It seems researchers are getting more active to do research and discuss the issue.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme discrimination. The date for the next meeting will be on 17th of May.

Theme Meeting #8– Discrimination

Meeting Report

This was the eighth theme meeting. It was held at American corner, Ulaanbaatar on 19th of May 2019. 22 researchers participated in this meeting. There are 5 new researchers in the meeting whereas 7 researchers are formally eliminated because of their constant absence and inactivity. There was 1 invited testimonial at 8th meeting. Mr.Bolorsaikhan, who represented human rights defenders.

Apart from the researchers, Mr.Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Reporter), Mr.Undrakhbayar (MILC) and sign language interpreter Ms. Myadag participated in the meeting.

Meeting Programme: 1. Testimonial gave a speech about his story and experience regarding chosen themes. 2. Mr.Undrakhbayar gave brief speech about Japan's anti-discrimination practice. 3. There were 2 presentations about discrimination by Ms.Enkhmaa and Ms.Boloroo; and Mr.Myagmarsuren gave brief speech on discrimination 4. Conclusions.

Meeting coordination: Ms. Khulan was the chairperson and Ms.Gantsetseg was the equal-participation observer on the day. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Testimonial: Mr.Bolorsaikhan: At the beginning of his testimony he gave a brief information on Emancipatus and Sui Juris concepts. He gave an example for how discrimination starts:

- Fear: discrimination starts from fear. Fear's source is unclearness which means people scares from things they don't know;
- Prejudice: This is kind of thoughts. But it is acceptable because people don't know everything.
- Stigma: this is action by people who do actions on behalf of others without consent.
- Stereotype: then this action can be stereotype. This slowly makes human's life typical
- Inter-sectionality: There are many factors which can define person in the society. People usually accept others who are similar to them.
- Dependency: then people become dependent from someone or something.

As can be seen from above mentioned factors, discrimination is not only one word. This has many factors behind this word. Further, he showed international human rights treaties which prohibited discrimination. As per he said, even though people know what is exactly in the legislation, they don't know how to ask effective implementation and push authorities to ensure rights.

Then he explained the terms - inclusion, integration, exclusion and segregation. He took examples of segregation about school 29 in Mongolia, school children asked qualified and competitive education and lockout classes. Albeit teachers explained that because of sign language has limited variety of words, deaf children cannot study properly. But in reality deaf children express themselves properly if they start to study sign language from 6 months. Further when people start to complain about segregation, education system is transferring into integration. Authorities established one class at district and include all children with disabilities in one class without sorting them based on disability. But in Mongolia, general picture is segregation and exclusion. But we should tend to establish inclusion in the society.

For fighting against discrimination, PwD should participate actively in the society and show them society has not only a one color. To do so PwD need to live independently. So people should fight against exclusion. If society don't pay attention, you need to be mixed in the society. He added, for researchers in the EDR are producing social capital together; and society should be mobilized. In the end of his speech he showed some photos for motivation and justice (liberation).

Followed by his presentation, researchers told him about a story how employers, co-workers and lecturers discriminate them at workplace and university area; and ask about how to fight against them. Mr.Bolorsaikhan recommended them to discuss the people who discriminate them directly. If they really care, PwD can get support from others who understand their different ability. Further he mentioned that PwD should try to explain accessibility is not only for them and systematic reform is needed.

Presentations: Ms.Enkhmaa: she tried to show how discrimination starts and how we can overcome.

Family: We know they love us. But because of loving too much, they limit our ability. So this induce to discriminate us. For example, my family members told me that since you are human being you have to have child. So it makes me hurt. I know it is not discrimination. However, it means since you cannot marry with someone at least you can have child or adopt child.

Classmates (friends at school): When I was in the school at early 2000. Because I was studying at ordinary school, pupils discriminate me every time. Even though it can be seen that teachers or pupils are helping me, they discriminate me indirectly. They usually ask me how you got to live. Pupils bullied me and made fun at me. My classmate who sits next to me pinched me all the time. I was afraid of complaining about it because I thought they will discriminate me more. But now I believe things has changed and got better.

Co-workers or colleagues: They discriminate PwD based on professional background and ability. Obviously, people work as a group at workplace. But other people don't usually want to include PwD in the group. They have stereotype that PwD cannot work properly. They also pity.

In the society: People usually who are providing services to us discriminate us.

Negative impacts: Spoon-feed/ laziness; Under estimation: Because we think we cannot do something independently, we lose our self confidence; Exclusion from the society: We tend to stay alone.

Recommendations to Solve: Inclusive education: from kindergarten to workplace, we don’t need to be segregated, We need to be included; Proper information regards to disabilities, Authorities need to provide information regards to disability in the curriculum of secondary school.

Presentation 2: Mr.Myagmarsuren: He shared his life story which he discriminated.

In my point of view, discrimination begins from early age of child. I wanted to share my story. I have been to study at kindergarten in the countryside. My mom used to piggy backing me from home to school. So children teased me when they see me. Teacher’s usually segregated me at class. I had a friend. When I want to have photo with him, his parents say that do not to have photo with me.

When we had ceremony after we have finished to learn all alphabet, then teacher required us to split by who are fluent to read and who cannot read. This is the absolute discrimination.

Then I had a girlfriend when I was at university, unfortunately her parents refused to date her. Because they said that how am I got to be responsible for our lives. But honestly, they should know that I won’ live with her parents.

Lately, I was going out with my friends, we saw a place with ramp and had dinner at there. We asked beer. Unfortunately, waiter told us they don’t provide service. Even we saw children under age were sitting and drinking next to us. We called police, but police didn’t talk to us. He came to the place and talked to waiter rather us. Police said that you’d better to have drinks at home.

Presentation 3: Ms. Boloroo: Her presentation more focused on legislation regards to anti-discrimination and implementation of legislation. At the beginning of her presentation, she gave statistics on PwD. There are 105691 PwD in 2018, Of which 10.9% are people with vision disability; 4% are people with speaking disability; 7.9% are people with hearing disability; 20.4 % are people with physical disability; 19.2% are people with intellectual disability; 6.8% are people with multiple disability; 30.4% are people with other disability.

Then she showed international treaty clauses (article 12, 24 or UDHR, preamble (h) (i) (j), article 2, 3, 4 (e), 5 of the CRPD) and national legislation clauses (Article 14 of Constitutional law of Mongolia, Article 6.20.8 of the Law on Breach, Article 4.1.2, 5, 6.3, 6.4, 6.5 of the Law on Human rights of PWD) regard to discrimination.

She shared that nothing mentioned about disability in the article 14 of Constitutional law of Mongolia and inaccessibility is one of the main discrimination. So we need to ask and push to ensure right to accessibility. She added, when someone violates our rights we just talk about it within our zone rather to push to ensure our rights. Moreover, many families tend to hide their children. It is prohibited by the legislation. But there is nothing about how to control it and investigate it. Further there is many clauses regard to ensure PwD rights, albeit there is no implementing mechanism in the legislation or too general. It may because of our voice is not strong.

Positive impacts to ensure PwD's rights in 10 years: Ratification of CRPD- 2009; Focal point- 2012; Incheon strategy- 2014; Law on human rights of PwD- 2016; Committee on ensuring Human rights of PwD.

Conclusions: Lack of understanding and attitude: Basically no one knows about legislation; Lack of understanding regards to different ability; Social model; People usually think that discrimination is insulting someone; Unclear and too general legislation; Lack of accountability mechanism; PwD are wittol. We are too weak to push authorities for ensuring our rights.

Afternoon session: This session was a bit different from usual meeting. Oriented by Mr. Undrakhbayar, researchers did following things:

Participants divided by two and discussed with each other about discrimination in their lives and each person need to talk within 2 minutes. Then 3-4 pairs will present their life story which wasn't mentioned in the morning session. After the pairs' presentation, researchers discussed about their influence to fight against discrimination.

In accordance with their discussion, family members basically discriminate them indirectly and directly by not respecting their privacy and dignity.

People's lack understanding and stereotype about PwD 's different ability is one the main factors to discriminate them.

More over researchers pointed out that sometimes PwD themselves discriminate PwD as well whereas some of them said that even if people don't discriminate them, accessibility can be a factor to be discriminated.

At the end of the discussion some researchers told that sometimes discrimination gives us motivation to fight against it and helps to be a stronger person.

Conclusion and comments:

The eighth theme meeting on the discrimination had active participation by the researchers. Participants interested in testimonial speech and asked variety of questions regard to discrimination and his advice. There were 3 presentations, done by researchers. These presentations were mainly focused on discrimination in the society. Presenters brought their life story in their presentation whereas one presentation was focused on national and international legislation on anti-discrimination and statistics. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

At the end of the meeting researchers have concluded that discrimination is done by people's action, policy, and inaccessibility. For fighting against discrimination, active participation in all level is crucial. Another mentioned point by the researchers was discrimination between PwD themselves.

The meeting showed improvements in the capacities of the researchers, who are more open to each other. As it can be seen from their presentation and group discussion, their analysing skill is much improved and they learnt how to source the information.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme personal assistant. The date for the next meeting will be on 8th of June.

Theme Meeting #9– Personal assistance

Meeting Report

This was the eighth theme meeting. It was held at American corner, Ulaanbaatar on 8th June 2019. 28 researchers participated in this meeting. There are 1 new researcher in the meeting whereas 1 researcher voluntarily gone out from the group. There was 1 invited testimonial at ninth meeting. Ms.Sukh-Erdene, represented personal assistants. Apart from the researchers, Mr.Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgamma (AIFO representative), Ms. Battsetseg (Reporter), Mr.Undrakhbayar (MILC) and sign language interpreter Ms. Myadag participated in the meeting.

Meeting Programme: At the beginning of the meeting new participant Mr.Byarsaihan (deaf) has introduced himself to others. 1. Testimonial gave a speech about personal assistance. 2. There were 2 presentations about personal assistance. 3. Ms.Enkhmaa and Ms.Misheel.B presented their presentation. 4. Group work.

Meeting coordination: Mr.Otgondelger was the chairperson and Mr.Sandag was the equal-participation observer on the day. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

Testimonial speech. Ms.Sukh-Erdene: She introduced about peculiarity and accountability about personal assistance service.

Who is personal assistant: Personal assistants assists to support PwD’s daily life and encourage to live independently. They assist to do things what PwD cannot do independently. For example: they help to organise meetings. Personal assistance service is neither nursing, guardian nor slavery. It is a service based on Social approach to ensuring PwD’s human rights.

3 main rules to follow: Any actions should be based on PwD’s request; Any actions should be based on PwD’s choice; Any actions should be based on PwD’s decision

Things to be noted for personal assistance: To respect and protect human rights; To follow strictly rules for their action; Not to decide things upon PwD; To respect PwD’s privacy; Don’t lend money or borrow things from PwD; Don’t disclose confidentiality.

Personal assistants’ job description except assisting PwD : To do daily management actions at MILC. To organize trainings for new personal assistants and share their experience. Training should be theoretical and practical.

Question and answer session: After the testimonial Mr.Undrakhbayar, who is a person with disability and associated with Independent Living Centres Mongolia, invited 3 researchers (Ms.Gantsetseg, Mr.Nyam-Ochir, Ms.Sumiyakhuu) to share their opinion and experience of having personal assistants.

Researcher 01: When I ask assistance from my family, some of them gets upset or says to me that I am not your servant.

Researcher 02: Just after I got injured, I was depressed and got more silent. Once I started to study, my mom helped me to go to the university. When we ask my father’s assistance to get in or get out car, he seldom gets annoyed to get up early. I was hurtful for his reaction.

Coordinator: I would like to ask from a deaf researcher about her difficulties to participate in society without sign language interpreter.

Researcher 03: I need to write when I am without sign language interpreter. We can do whatever we want by ourselves. So, I think that sign language interpreter is different from personal assistant.

Coordinator: As per Sukh-Erdene's presentation, personal assistant should not make decision upon PwD. But in Mongolia, family has full responsibility to care of their PwD member. What is the difference between a personal assistant and a family member.

A personal assistant: We assist PwD to do something which they want to do. We just help them what they want to do.

Coordinator: For one of the researchers, he is living independently for 2 years. Is there any differences and advantages?

Researcher 04: the best thing is I can make decisions independently. When I Was living with my family, they were too protective. They always advise and convince to do right. By living independently, I can learn from my mistake. Personal assistants assist to live like others (person without disability)

Coordinator: As per researcher 03 explanation, she only needs a communication support. Sign language interpreters are assisting her to do something that she cannot do by herself. Isn't it personal assistance?

Researcher 03: Sign language interpreters are not personal assistants. Not everyone has to hear, it is all about communication and we are using our body language to communicate with each other. So I don't think this is personal assistance.

Coordinator: Even though there are clauses regard to personal assistance, we have no clear understanding about personal assistance. This affects negatively to implement legislation. For example, In Japan, everyone who are assisting to PwD are personal assistant. In Mongolia, Blind federation said guide dogs are not personal assistant and deaf people say that sign language interpreters are not personal assistant. So today we need to unify our views and offer proper solution to implement personal assistance service effectively. Moreover, personal assistants should be responsible and keep confidentiality of PwD's private life. Because they know everything about PwD including intimate things which other people don't know. Personal assistants encourage to change negative attitude in society about disability issues. Sometimes they work like secretary. So, there should be fair value of this service In Mongolia it is 35000 tugrik whereas 50000 tugrik in Japan.

Presentation 1. Ms. Enkhma: she introduced about personal assistant service's development and its peculiarity. She also added responsibility of PWD and personal assistant; and own life story case.

Introduction: Independent living has started in the 1980s in the USA. Ed Roberts, the key person to develop personal assistance service and was human rights activist of PwD. He had polio and severe disability.

Who is personal assistant and responsibility of personal assistant? Personal assistants assist to PwD for doing things that they cannot do independently; be responsible; be careful.

Who can work as a personal assistant: workplace is open to everyone who is looking for a job; students can work during their part time.

Significance of personal assistance and independent living system: Workplace will increase; Ensure full participation in Society; Ensure right to choose; Ensure right to decide; PwD will live more responsible.

Rules for PwD and personal assistant: Respect each other, respect each others' time, understand clearly each others' accountability.

Brief introduction of Mongolian Federation of Independent Living Centres: Established in March, 2010. MILC has more than 140 members, 18 employees (of which 11 are PwD) and 5 personal assistants. Add to that it has more than 20 part time employees. MILC is ASIA Kokorozashi IL network member

Purpose of the organisation: Any person with a disability should choose by her or himself , make decisions independently, take full responsibility. MILC will create an inclusive society for everyone.

In accordance with the Law on human rights of PwD: Section 32. Right to live independently; Art. 32.1. Persons with disabilities have a right to live independently. Art. 32.2. Right to Independent lives of persons with disabilities shall be ensured through personal assistance, mutual exchange of experiences, counseling services. Art. 32.3. Procedure, types and forms, requirements for service providers of support of independent living of persons with disabilities shall be approved by government member in charge of persons with disabilities. Art. 32.4. Individuals and legal entities shall be allowed to deliver services in support of independent lives of persons with disabilities; Art. 32.5. Public organizations in charge of welfare services at the province and capital city levels shall arrange selection of service providers that are expected to deliver service in support of independent living of persons with disabilities; Art. 32.6. When enforcing sections 32.2, 32.3, 32.4, 32.5 of the present law, participation of non government organizations that work for the protection of human rights of persons with disabilities, shall be secured. Art. 32.7. State shall train guide dogs to assist blind persons to navigate around obstacles without danger and price of locally trained dogs shall be reimbursed once in nine years. Central government body in charge of persons with disabilities shall approve procedures for training and use of guide dogs, in partnership with central government body in charge of agriculture. Art. 32.8. Persons with disabilities shall be entitled for free travel access in public transports (other than taxis) in the capital city and province centers regardless of residential areas. Finance required for this benefit shall be set aside in the state budget on an annual basis

Presentation 2. Misheel B.: I came to MILC in 2009 for the first time. I had no idea at that time about personal assistance. I was the first person who has a severe disability. In 2010, I had a chance to visit Japan and see what is personal assistance service. I tried to go there without my mom, et she didn't want to. So I traveled with her. Just after we arrived there, we went to Independent living center. They asked me whether I can live without my mom. I told them yes. Then I started to have personal assistant for 24 hours. Before that My family always took care of me. At the beginning, me and my personal assistant had a bit of trouble with communication. I had 6 personal assistants for 14 days in Japan. Now I take personal assistant for 2 hours a day. Thus I need to do things within 2 hours. Things got changed to compare with my life before I take personal assistant. Because before that family used to influence my decision.

But sometimes, my personal assistants feel a bit embarrassed about me when we are out. At home, we cannot do everything I need within tight time. From now, my family are getting to understand that I can live independently if I take personal assistance service.

Coordinator: One of the mothers told me that she spent more than 20 years and she has no friends and colleagues. Further, she got sick and didn't pay any social insurance. So based on that story, personal assistance service can be an approach to what the Government cannot deal with.

One researcher: People see me as a person who has a slight disability yet I cannot do many things independently. I spent 4 years to study how to write. If there was a personal assistance service at that time, I could save time. Personal assistance is substantial approach in countries like Mongolia which just left PwD with the family.

Coordinator: We hired a translator to translate project proposal. Unfortunately she mixed the terminology caring and assisting. Because of that the purpose of the proposal has changed. Terminology is different for caring and assisting. For example, Person who provided caring service should submit a report monthly. Report should show like how many times a person peed, how many times a person poop, or how many times a person got his or her nails done whereas personal assistance service just provide an assistance that PwD cannot do by themselves. There concepts of caring and assisting are quite different.

The sign language interpreter: I am working as a sign language interpreter, not because my husband has hearing disability. I prefer to interpret exactly what a person said. So, I like to assist people.

A Deaf researcher: I think sign language interpreter is substantial for us. The only thing is that they must interpret 100 percent what we exactly said and they must not make decision upon us. The government has no proper policy to prepare sign language interpreter. Thus, there is a lack of human resources. Further, sign language interpreters learn from deaf people which means there is no standard on sign language.

Coordinator: I would like to ask about one of the researcher's life story after the injury. He is a chemist. It seems to me that his working capability decreased since the injury. How was it in reality?

Researcher 05: I have got injured for 4 years. I was 100 percent at other's hand. About my job, I cannot do it independently yet I can advise when I see someone is doing the same as mine. I am having personal assistance for half a year. I had thought many times about why it is important for having personal assistant. One day I had a chance to participate in the conference at Government palace. in that conference presenter said there are 1.3 million adults in Mongolia, 10 percent of them are PwD. Those PwD got approximately 200,000 thousand tugrik per month. If those people have jobs, they will get 400,000-500,000 tugrik per month. In that case, PwD will be value producer rather caretaker and can influence to reduce the Government's economic pressure. We also can develop our skills and public will see us from positive point of view.

Coordinator: I guess everyone knows Mr Researcher08. He can do whatever he wants. One day we were talking about personal assistance service. He told us he needs personal assistance. Everyone told him that you don't need personal assistants. Then he said that you don't understand all situation. When my wife's relatives visit us, they see me as a disrespectful person. Because my wife does household. Therefore, needs of personal assistance is not depending on severity of disability.

Researcher 07: I just understood that personal assistance is quite different from caring service while I was watching the video. I learnt that even I am PwD, I didn't fully understand about personal assistance. For me, I need a person who assists to carry water from a well.

Afternoon session: Afternoon session participants divided into 4 small groups and discussed about the issue they have chosen.

First group: Discussed the Advantage and disadvantage of Personal assistance service from the economic point of view.

Advantages: PwD got approximately 200,000 thousand tugrik per month. if these people were employed, they would get at least 500,000 tugrik as a salary. Add to that family member who is in charge to take care of PwD can work as well. In the case of Personal assistance service is financed by the Government, PwD can work and produce value in society.

Disadvantages: Accommodating accessible workplace will require cost at the beginning.

Group 2: Discussed Is there any positive and negative influence to accessiblity by developing personal assistance? if yes how?

Positive influence: PwD can participate fully in Society. It will influence to build positive public awareness. Sign interpreter will influence to develop accessible information. Public attitude will be changed.

Negative influence: To prefer ready made things. Authorities will care less about making things accessible. Active participation may decrease in the case of PwD want personal assistants to do something on behalf of them. Society will focus more on PwD's different ability. That could influence negatively to change public attitudes.

Group 3: Discussed How we can use Personal assistance service other than ordinary ways?

At first we need to have a clear understanding what is personal assistance. To share proper information about personal assistant to the society. To share benefits about having personal assistant from individuals to the Government. To do so, we need to organise, public awareness campaign. To improve sustainable finance for everyone. To develop services rather than caring. Personal assistance can be developed when people see as a business and it will be fair competition between service providers. So PwD will get all benefits.

Group 4: Discussed What kind of approach will influence to develop personal assistance? what is your role to do so?

Needs: to revise a draft of regulation on the personal assistance service which needs to adopt by the Minister of labour and social welfare. To effect decreasing unemployment. To build public awareness about disability among personal assistants. To increase the number of Independent living centres. To build effective approach for motivating personal assistants to work sustainably.

Our role: active participation, to organise campaign among the schoolchildren, to take personal assistant as a workplace.

Our responsibility: to have the right approach and understanding about disability, to push effective implementation of the regulation, to unify our voice about PwD's rights, to learn about etiquette to communicate with personal assistants. More specifically PwD should know what are not allowed to ask or request from them.

Comments and conclusions:

The ninth theme meeting on the personal assistance had active participation by the researchers.

After testimonial, researchers discussed about positive impact of personal assistance service and needs. Then 2 researchers prepared presentation. They have shared their own life story and national legislation regards to personal assistant. All presenters signed for confirmation form for using their presentation and pictures that they have prepared.

The meeting showed improvements in the expressing themselves to others. They became more open to each-others. As per their discussion, they mutually agreed that it is important to increase labour value of personal assistance service and personal assistants are substantial to change public attitudes on disability issues. they also stated that personal assistants influence to reduce family's pressure of caring PwD.

The final part of the meeting was devoted to planning for the next theme meeting. By consensus the group decided to hold the next meeting on the theme of empowerment. The dates for the next meeting will be communicated.

Theme Meeting #10 - Empowerment

Minutes of the meeting

This was the tenth theme meeting. It was held at American education center of City library, Ulaanbataar, on Sunday, 25 August 2019. 21 researchers participated in this meeting.

Apart from the researchers and Mr.L.Enkhbuyant (President, Tegsh Niigem NGO), who coordinate the meeting, Ms. D.Tulgamaa (AIFO representative) worked as reporter in English in the meeting since Ms. Battsetseg delivered her baby. Mongolian report keeping was made by B.Galya and Yu.Tsolmon, Tegsh Niigem NGO staff. Ms. Myadag (sign language translator) participated in the meeting. Personal assistants (Munkhbold, Sukh-Erdene, Byambaa and Erdenekhuu) supported to the researchers.

Guests from Japan (Mainstream ILC) attended in the meeting as observer. Mr.Ch.Undrakhbayar, President of National Federation of Independent Living Centers of Mongolia translated to the Japanese guests.

Meeting coordination: Mr. Byambadorj as the chairperson in the morning session; Mr.Bilegsaikhan as the time keeper in the morning session. The group also agreed **the Rule**: respect each other, not to talk at same time, no use of mobile phone and participate actively.

Testimonials: Ms. Takahashi Eriko, Mainstream Independent Living Center (ILC), Japan: I started to use wheel chair 8 years ago. In the beginning I was thinking the independent service is only for persons with disabilities. But after coming to the ILC, I understood that the barrier created by the society, not from the PWDs. When I wanted to work in the ILC, my president asked me that if you have any medicine that heals your disability will you take such a medicine? I answered No, I will not take this medicine. Then the President decided to employ me. I started to work in the ILC one year ago. Sometimes I want to ask from other people that how do answer to that question? I wish all the society will be open for persons with disabilities. Everywhere people with disabilities are same to combat for their rights in order to have accessible society.

Mr. Kawakami Taisuke, Mainstream Independent Living Center (ILC), Japan: When I was 17 year-old I became disabled. I had an accident. I was staying home for a while. To go out it was very difficult. I was depressed. I was very aggressive to my family. I didn’t want to continue studying. Everything seems negative to me. Even I tried to go out, it was not pleasant to me. Then one of my friends offered me to visit to a Center. Then I visited to ILC. After I had possibility to be part of the Empowerment program of young people of the ILC and came first time to Mongolia. I am very impressed to be here and to learn from other people. I want learn the challenges that you are addressing in Mongolia. It will be helpful to me to understand you. Thank you for giving us opportunity to participate in your meeting.

PRESENTATIONS BY RESEARCHERS

Presentation #1. Boloroo

Good morning to everybody. This is my presentation that I had presented during the APCBID Congress in July 3, 2019. I am going to talk about basic understanding of Empowerment. Before to speak Empowerment, we need to know about what does this mean "to have no power". It is negative attitude from the family members. They see you as someone who cannot do anything. They have very less choice and less opportunity.

In my childhood, she never chooses her clothes. I was living under pressure. This is one of the examples. My family loves me a lot and too much. They overprotect me. They never allowed me to do anything. Once I tried to make a tea for myself without any support from the parents. It took so big activity for me. So, I think that I never had power. I was inactive recipient. How to transform me so that I become empowered? The only thing is mind change. Then empowered process will start. Understanding process is very important.

Information- the most poorest person has no information. For PWDs, they can't receive information with accessible format. So they need to receive information with accessible format.

Capacity building- we must do what I can. When I was child, I had quite important role to count the Buuz (bone pieces with specific shapes, traditionally used in Mongolia for counting). Of course I can't make Buuz. I was very good in counting. It is same to other people. For example we all know that Nyamka is good in drawing and able to monitor the accessibility.

Help to each other – when I was meeting with other people, majority of them said that I was at home, I thought I am alone. When they go out home they see that there are many people like me.

Participation- must participate in an event and activity when it is correct place and correct time.

Partnership, Coalition – Then we need to unite our power to establish own organization

When I was going to prepare my presentation for the Congress, I was wondering to pick a word "empowerment" from the Convention. Indeed at the end I understood that the Convention itself is empowerment process.

Empowerment components: Advocacy and communication, Community mobilization, Self-help group, Political participation, DPOs

Emancipatory research- this is the research first time organized in Mongolia with the support and collaboration from MIL, AIFO and EU. Total of 34 young researchers started to work for over 1 year. The researcher didn't mean to gain academic knowledge. It is about to collect information from PWDs. When researchers study certain themes by reading and studying, they benefit a lot. Our researchers worked very hard to identify the facing challenges to the persons with disabilities. For example, Misheel visited to a Ger district and she made video. Bilegsaihan experienced travelling with bus when he was preparing his presentation in public transport. The research has helped us to come out of our homes.

I remember that very few people were talking in the beginning. But now I see that among us there are many people start to share own experiences. We join our effort to understand the situation. This is very big improvement. Empowered person can influence to your family and friends. If you are able to decide and choose for yourself, that means you are empowered person.

Presentation #2. Enkhmaa: Good morning to everyone. I tried to focus on more How to empower PWDs. I prepared with following concept on Education, Job, occupation, society and persons with disabilities.

Education: We need start from the very basis. PWDs are very rare to participate in the society. So parents need to get more information at first. There can be a advising center for parents. Parents don't know many things that they face problem everyday. It is needed to train advisor for children with disabilities and persons with disabilities. Many of the time persons with disabilities don't accept yourself that they hare disabled person. So they need advices. Psychologist is very important for the persons with disabilities.

Inclusive education is very important concept. Children with disabilities and people with disabilities must stay with other people. If they are separated they can't develop themselves. Active participation will come out only they are included in the society. Children with disabilities must study in regular school. But they face many difficulties. One of the issues is assistant teacher. Assistant teacher must be quite knowledgeable. To have one assistant teacher is not appropriate for the disabled students. I think different assistant teachers can assist to the disabled student according to their skills. For example, physics teacher can assist him/her only in physics lesson. Mongolian language teacher can assist only in Mongolian language lesson.

Job and occupation: Organizations must receive the knowledge of disability. Then PWDs can have more opportunity to work. It is not only accessibility. It is about humanity. There is another concept called Job coach in other countries. It is needed to establish Job coach service.

Society: It is needed to organize DET. I think this training is very important to give better understating to the public. Advocacy events are very important to change social attitude. Training courses at the organizations contribute much effort to change the society.

How we, persons with disabilities, should be? Participation is very important. We need to participate in the activities by ourselves. Communication skills are important. Sometimes persons with disabilities themselves think that other people must respect. Personal management is important. Time-keeping is sometimes difficult for persons with disabilities. They are dependent from other people who can bring them to the activity. Even though persons with disabilities must prepare themselves in advance. Sometime 2-3 hours before we need to start going. Persons with disabilities need hard working. They must be initiator. Otherwise no one will bring you out of home. We need to try by ourselves. We must read a lot.

Persons with disabilities must be responsible. Sometimes they can't be responsible person. But it mustn't be the respected reason. We have many difficulties. But if we try ourselves there are possibilities.

I take an example of Hellen Keller, who had lost hearing ability during her childhood. I would like to take the note of Hellen Keller. Happiness is not something you do in the future. Happiness- is what you are doing now.

Another example is Steven Hawkings. He has many difficulties. But he contributed a lot to physics science. He said that "Anyone can get out from black hole if you are only trust and live. But don't forget that only if you try you can go out"

Nick Wuiwich, has no four joints. He said that "Everything is possible". Fear is the most biggest disabilities. It will suffer you more than wheelchair. The biggest difficulties will bring you to biggest success. I don't see me as persons with disability. I just had no legs and no arms. Maybe my outside looking is different. But it doesn't influence to what I do.

These are the words of well-known people. But I didn't mean to become well-known person. We just need to be needed person to anyone. Our life must be worth.

Afternoon session

The afternoon session was dedicated to discussions in small groups. This session was chaired by Mr. Bilegsaikhan and the Time keeper was Mr. Otgonbayar.

The participants were divided into three groups of 7 persons and asked to discuss about Empowerment. After the discussions each group presented the results of their discussions. Every group will nominate presenter, note taker and leader. Each group members try to talk as active as possible.

Three groups were asked to discuss the following questions: What does the Empowerment mean for you? Since May 2018, what you have understood? How you have changed in this period? Based on your experience?

Group presentations

Group 1 (Nyam-Ochir, Urantugs, Uyangasaihan, Gantsetseg, Bilegsaihan, Misheel): Empowerment means: Regardless nationality, language, culture,

Researcher 01 - Before to be member of Researchers, I was communicating with only people with hearing difficulties. I was also communicating with only family members. After becoming researcher, I started to study to the selected theme. Now I am able to express myself freely.

Researcher 02 – I couldn't speak on behalf of other people. Now I can speak with others. I learnt other disabled people. I never knew about other people, how they live. I never ask any permission to speak raising my hand. Now I can raise my hand and speak.

Researcher 03 – I couldn't express my self before.

Researcher 04 – I didn't understand who is researcher. When I am trying to study, I understood that anyone can do research. I tend to speak without listening others. But now I can listen others and respect others.

Group 2 (Sumiyahuu, Boloroo, Enhmaa, Erdenezul, Altangerel, Otgonbayar, Bolor, Nomin-Erdene):

Researcher 01 – one year ago I couldn't go on the street. Family members tend to buy his clothes, regardless he likes or not, big or small. After one year he can go on the street go to market and buy his clothes. He is able to use public transport (he learnt quarrelling with the driver). He is able to express himself.

Researcher 02 – He was unable to communicate with other people. He was communicating only with his family members. After coming to "Universal Progress" ILC he is able to communicate. Altangerel had girlfriend.

Researcher 03 – First 4-5 theme she was unable to prepare her presentation. During the last 4-5 meeting she started to attend actively. She started to present her presentation. She learnt to present her presentation. They started to influence to others. They were able to make a choice. They unite with others.

Nyam-Ochir asked there were changes in the individuals. Do you have any plan to contribute to the social attitude?

One researcher answered – The EDR supported us very much. We also wish that such kind of program can continue. About herself, she expressed her wish to her director. She is planning to organize training course about EDR in rural area.

Another person said that Empowerment doesn't mean that I went out of home. But it means that I am influencing positively to others.

Group 3 (Khulan, Gansukh, Enhsanaa, Byambadorj, Batdelger, Otgondeleger, Namuuntsetseg):

Researcher 01 – if someone cannot express yourself (soft skills) there will not be any empowerment. Empowerment means to reduce negative attitude and improve his/her soft skills; to participate equally in the social life. We, researchers, have gained legal knowledge on disability. Had friends and started to see the issues from different angles.

I use walker. In the beginning I thought I am the only one who is severe. But I learnt that there are other people who are severe. I learnt to provide primary health care. One day I went to one of our researchers' home. Suddenly he had a fit. I didn't know what to do. Then I searched a tip from the internet. And I was able to provide primary health care.

I was nervous when I speak in the school. But I am able to speak better.

Researcher 02– I was nervous when I start to speak.

Researcher 03 – I had no financial knowledge. My mother was solving my problems on behalf of me. One day I spoke with my mother. And tried once to solve my financial problem. I felt that I could manage it.

Comments and conclusion: The tenth theme meeting on the Empowerment had active participation by the researchers. After testimonial, 2 researchers prepared presentation. Then researchers discussed about empowerment processes happened to themselves. They have shared their own experiences on improvements. The Researchers attended actively. They shared openly about themselves.

Enhbuyant: Today we remembered back how we were in the beginning. After the one-year period you also started to compare about yourself. We are sure that your best-gained knowledge will contribute in your future. Everybody had changed. It is very important that you try to solve your facing challenges based on your knowledge and information. Thank you for expressing your thoughts freely. Our success and achievement is everybody can analyse the incoming information and identify the reality and find a way to solve it. Through the research and empowerment process you are going to contribute to the change of main definition of persons with disabilities, that community see you. All your contribution will change the social attitude positively.

We have two more theme left. The next meeting will be about Health. We wish you participate actively to identify the health issues. The next meeting will be organized before September 15. We will let you know when we fix the date. The last meeting will be about Assistive Technology.

Theme Meeting #11– Health

Meeting Report

This was the eleventh theme meeting. It was held at Grand Hill hotel training hall, Ulaanbaatar on 13 September 2019. 23 researchers participated in this meeting.

Apart from the researchers, Mr.Enkhbuyant (President, Tegsh Niigem), Ms. D. Tulgaama (AIFO representative and reporter), Mrs. B.Galya (Tegsh Niigem Board member and keeping minutes in Mongolian) and Mrs. Yu. Tsolmon (Executive director of Tegsh Niigem and and keeping minutes in Mongolian), Mr.Undrakhbayar (MILC) and sign language interpreter Ms. Myadag participated in the meeting. Personal assistants (Otgonsuvd, Tumen-Ulzii, Sukh-Erdene, Munkhbold) supported to the researchers.

Meeting Programme: 1. Presentations by the researchers; 2. Personal experiences (barriers and future suggestions)

Meeting coordination: Ms. Uyangasaikhan was the chairperson and Mr.Gansukh was time-keeper on the day of the Morning session. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

The group all agreed **the Rule**: respect each other, love each other, not to talk at same time, keep time, no use of mobile phone and participate actively. Undrakhbayar also added some warning regarding to the Rule of the Day. Some researchers are communicating rudely to the personal assistants and logisticians. Sometimes they are demanding. Personal assistants are not your servants. So, try to change your communication behaviour.

Enkhbuyant highlighted about the Article 25 and Article 26 of CRPD. Mongolia also ratified Optional Protocol. That means individuals can apply their complaints to CRPD Committee. DPOs can send their shadow report to CRPD Committee about the implementation of CRPD. DPOs did send their shadow report twice in 2014 and 2018. As a result List of Issues prior to Reporting is sent to the Government of Mongolia in September 2018 and the Government of Mongolia is answering to the questions, which will be considered as Second and Third report of the Country. He also informed about the National Disability Action Plan, which was approved by the Government of Mongolia in 2017.

PRESENTATIONS BY RESEARCHERS

Presentation #1. Enkhsanaa: Enkhsanaa showed short youtube video (https://www.youtube.com/watch?v=h6fcK_fRYaI) . He also signed to the Consent form for pictures and videos. The video is about a person who died because of sudden car accident met with God or something vague. And person is reincarnated. Don't know how many the human is reincarnated. If you victimizing someone, it means you are victimizing yourself. If you are doing something kind, it is also for you. If you are sad, this is also only experience by you.

Enkhsanaa wanted to tell you that everyone's life is depend on you. You are not living on this time. Comment: It is quite philosophic video, which wanted to warn to the people that everyone's life will not end on this time.

Presentation #2. Erdenezul: I wanted to share with you about my experiences on health. There are 103.6 PWDs. 42.8% congenital; and 57.2% - acquired disabled.

Barriers: Lack of awareness of Doctors, No specialized doctor on disability, No hospital to provide advice to PWDs, Doctors see us as patients, No accessible health facilities, No personal assistants, Financial difficulty

Legislations: Health Law: Article 20.1 – Article 20.3: Health service delivery to PWDs Article 21.1: Artificial limbs and assistive device, The law described already what to do. But when we enter to the hospital the law doesn't apply to the practice.

Dentistry: everybody have dental problem. Ordinary people go to any dentistry. For us we need to go State Stomatology Center to get the order to see the dentist. I am still couldn't get the order yet since March.

Disabled people can't get medical service from State health facilities. First reason is it is also very expensive. Secondly it is not accessible. So I needed to go to private dentistry.
But there is no facility for CP people. Dentists are afraid of us. Either we need to get whole body anaesthesia. Doctors don't want to provide medical service to us because of their understanding and attitude. People with hearing difficulties can't go to pharmacy, because they couldn't communicate.

Hospitalization: Too much queue in the state hospital. No accessible building, no toilet. They also said that other patients rose complaints that they don't want to stay with disabled person in one ward.
I never received medical service whenever I want. I only went to my family doctor's health center twice, but someone carried me to reach to there. Because it is in second floor. There is no accessible bed and toilet. Especially for the disabled girls for gynaecology purpose, they don't have accessible bed for medical check-up.

Afternoon session

The afternoon session was chaired by Mr. Nyam-Ochir and Time keeper was Ms.Erdenezul.

The participants are asked to share their opinion on following questions: Difficulties encountered to you on health? Current health service delivery to you (how do you solve your health issues?) In the future how the health service should be? (your suggestions)

Researcher 01: Accessibility is the biggest issue. We are physically limited. Service: because of lack of understanding and knowledge, health workers show the negative attitude. Doctors don't know how to carry the person who falls down from high building.

In the morning I attended in the evaluation closing event, that I was working for over one year. It was the project funded by GIZ. We made website and accessibility application in the smart phone (IOS and Android system). Then we piloted it in the Construction school. After the testing, the accessibility of the Construction school was evaluated using the application. We made evaluation together and planned together like “Nothing about us without us”. The students drew the construction design by themselves and the Construction College students and teachers made accessible ramps according to the standard. I think it is good example. Like this other organizations can work better.

Researcher 02: Accessibility is the issue. Lack of awareness of doctors: I need to go neurologist. I explained to my doctor that I don’t feel anything from armpit until down. But doctor still advised me that go to rehabilitation doctor, crawl on your knee. Gradually your health will be better. Neurologist is telling me like this, so it is more obvious what family doctors will say. Doctors need training courses. For example DET is helpful for the people who don’t know anything.

Researcher 03: I had a tumour in the spine. Then I had a surgery, and became disabled. I went to Court and doctors won. Hospital bed: it is given for only 10 days. But 10 days will it enough for the persons with spinal cord injury? At least 3 days out of 10 days they don’t provide any service, 2 days can be weekend.

We already agreed that my future life will be on wheel chair. But doctor said that you are lazy, do your exercise, you will stand on your feet. But everybody is different. Undergraduate student need to visit to the specialized DPOs to see the reality.

Researcher 04: I was born blind. Anyway it will not be revised. Disability description system is wrong. Person who has lost his/her sight 100% doesn’t mean he/she has lost the working ability. Person who has lost his/her sight 70%, but receives monthly provision with amount of 100% lost. The term between the loss of seeing ability and loss of working ability is completely different, in my opinion. I think this is the most challenging thing. I don’t know what way it will be solved.

Researcher 05: I went to dental hospital. The doctor didn’t talk to me. Just talked to my parents. I tried to speak. The doctor ignored me. I wanted to say that doctor has no understanding about us. They need to get knowledge about persons with disabilities

Researcher 06: I have a difficulty to call Emergency doctor. I dialled 103. They understood what I am talking about. But operator said to me that you don’t need to talk, give your phone to someone else. I heard that 2 million tugriks are planned per person on health service. But the services are fixed, like….If I wanted some other service I can’t get any service. Because it is not in the list of the service provided. All the student who graduate Health schools must know well about the disability. Then they will come to the health centers to provide services to the persons with disabilities

Researcher 07: I went to family doctor’s health center together with my son, who is 4 year-old to prepare for medical analysis (urine and …) for the kindergarten. There was long queue. We needed to wait long and stayed outside. Doctor didn’t say the sorrow, but the doctor was not allowing me to do by myself. I was like discriminated somehow.

Researcher 08: I was in hospital together with my mother (caregiver). But my mother had no health insurance. So she needed to pay her hospital bed. So, the State should think about the health insurance of the caregivers. Sign language translator must work in the hospital. Health education must be taught in the school.

Researcher 09: Responsibility of the doctors must be increased. I became disabled because of the lack of responsibility of health workers. Midwife dropped me on the floor when I was just born. They didn't tell my mother for three days. There was no punishment at all to that health worker. I am sure this is repeated to other children to become disabled. New technologies need to be introduced to Mongolia. For example, chip to the brain to control body function.

Researcher 10: Every year for me to go to Disability Describing Committee is the problem. It is obvious that my spine is damaged. But I need to go MRI and pay more than 400 thousand tugriks. So financially and psychologically it is quite big pressure to the persons with disabilities. Women with disabilities can't go gynaecologist, because of no bed for medical check-up. No toilet. Women with hearing difficulties can't communicate with doctors directly. Sometimes they don't want to tell to their parents and relatives. But there is no chance to talk to the doctors directly. There is no specialized doctor.

Bayanzurh district Health center No 10 opened Gynaecology cabinet for women with disabilities, with accessible bed and toilet inside the cabinet. The Cabinet is for all women with disabilities regardless the district and aimag coverage. The Cabinet is equipped with the support of FLOM under the project of Wheel Chair Users Association.

Researcher 01: I Forgot to say some things. Young people who acquired disabled have no information on their body function. After the accident there is no good advise. Then we turn to complicated situation, for example pressure sore and correct wheel chair etc. I heard that in abroad they teach to PWDs during the hospitalization how to use wheel chair, how to care yourself etc. Such kind of training run in the hospital almost for 6 months. This training is very helpful for the PWDs. It was possible that my disability level became lighter. Because they didn't carry me correctly. The emergency doctors don't know how to carry me. So my disability level became worse. There are lot of people whose disability level became worse.

Researcher 11: I had difficulty to see the dentist. I can't open my mouth properly. Doctor diagnosed wrongly. Because doctors don't understand what we are speaking. Some disabled people can't express themselves, where is the pain. They can't tell to doctors. Doctors don't know well about the pressure of the person who has spinal cord injury. And the situation became worse. The doctors can't provide proper advice to the person who has pressure sore. Doctors need to send to abroad to upgrade their knowledge.

One person asked researcher 11: The dentist used an equipment to let my mouth open when I was child. Have you ever used it? Researcher 11 answered that the risk is to dislocate jaw.

Researcher 12: 10 years ago I had dental problem. I needed to go dentistry. The dentist said that there is no technology. They refused to see my teeth. After all I had anaesthesia, like I was going to have a surgery and took my teeth out. After that I got acquaintance with the doctor, who graduated in Japan. He was very well dealing with persons with disabilities. After 2-3 years, I lost the communication with the doctor. Recently I went to hospital. There were cancer doctors. One was little bit older. Another was little bit younger. The communication behaviour was completely different. I didn't mean to say badly. But I was so much wondered. The older one was angry to Misheel that why you have breast cancer. The younger one was better and communicated better, who is quite knowledgeable. The younger one said that "Don't worry, it is not cancer. It is just inflammation".

These two doctors are completely different. I was saying to my parents that why your generation is so badly communicating with the person. You are getting older and experiencing so many things except dying. Young generation was better, they gain better knowledge. I wish young people can provide better knowledge to others. Even the doctors are growing. But still the understanding is lacking. So disabled people need to teach to doctors by themselves.

Researcher 13 (deaf, new researcher): Majority of the deaf people can't express their pain. At all level we can't communicate. Health workers try not to communicate with us. They prescribe some medicine, but without good diagnose. So we can't use the medicine properly. If there is application it will be very helpful. We can't call to emergency service. I can't always ask sign language translator. They will ne be available every time. Blind people are listening and they are doing application. But deaf people can't do it, maybe because of economically difficulty, sometimes just don't do it because of loss of heart.

Researcher 14: I agree with one of other researchers. Every year we need to go to hospital to prolong the Disability pension. Sometimes we see the people, who prolonged it no limitation. This year I investigated and asked about it. In the beginning it was possible to prolong it. But at the end the Disability describing committee said that it is not possible to prolong my disability pension.

For more than 10 years my parents needed to accompany with me to see the doctors. Just few years I was able to go alone to the hospital to see my doctor. I also agree with the other person. I was healthy during the fetus. But I became disabled when I was born. I was lucky that my parents realized me earlier. I had lot of massage and medication. Because I had two hip dislocation. The doctors were saying that your daughter cannot walk, she can only use wheel chair. But now I walk. So the responsibility of the doctors is very crucial issue.

Researcher 15: In my opinion psychology is very important. Many young teenagers have psychological problems. It is very easy that young teenagers turn to psychological problem. This topic is never discussed in Mongolia. In the future the psychologists need to be trained more. If psychology is good and health status will be become better. It is very important issue. There is no one who is doing in reality. People are just talking and talking. There is no trained human resource where young disabled people go and meet them.

Researcher 16: I want to add. Our wheel chairs are called medical equipment. The wheel chair is provided by the Social Welfare office. But if the medical equipment, it must fit to the person. But the Social Welfare office provide us just available wheel chairs. They are not fitting to my body. And it became more disability.

I heard that in Korea the insurance of parents or sisters and brothers can be used to the person with disability. Such kind of system is needed in Mongolia.

Researcher 17: I also want to add that when people with epilepsy go to hospital for 10 days they have some difficulty. Sometimes there is no caregiver who accompany with him/her in the hospital. I was wondering that is there personal assistant who can stay with him/her to stay in the hospital together.

Comments and conclusion:

The eleventh theme meeting on the health had active participation by the researchers. The researchers attended actively. Enhbuyant appreciated to the researchers for their active participation and respecting each other.

Enhbuyant: Today we have discussed possible change in health sector. We wish that all our talkings will not be forgotten. We do hope that the issue will be discussed in the future. The next meeting will be about assistive device and accessible technology. The meeting will be held in Ulaanbaatar hotel on September 28, 2019.

First of all, we wish all the researchers come and attend to the meeting. The topic is very important for all people. We need the assistive devices and accessible technology to live independent. Assistive devices are important and everybody need to know about it. So, try to bring all the researchers to the meeting.

Theme Meeting #12– Assistive devices

Meeting minutes

This was the last theme meeting of EDR in Mongolia. It was held at Ulaanbaatar hotel, Ulaanbaatar on 28th September 2019. 28 researchers participated in this meeting.

Apart from the researchers, Dr. Sunil Deapak (international coordinator for this research), Mr.Enkhbuyant (President, Tegsh Niigem), Ms.D. Tulgamma (AIFO representative), Ms.Battsetseg (Reporter), Mr.Undrakhbayar (MILC), Ms.Lkhagvasuren (Tegsh Niigem) and sign language interpreter Ms. Myadag participated in the meeting.

Meeting Programme: All participants presented and gave a speech to each other about the theme for 12 minutes in the morning session and had group discussion regard to given questions from organizers. There were 7 presentations by 10 participants and 2 participants gave speech based on their special needs

Meeting coordination: Ms. Misheel.B was the chairperson and Ms. Nomintsetseg was the equal-participation observer on the morning session, Mr. Temuulen was the chairperson and Mr. Sandag was the equal-participation observer on the afternoon session. They ensured that discussions were focused, respectful, timely and all participants had opportunities to share their views.

At the beginning of the meeting Mr.Enkhbuyant briefly introduced the plans about activities after the conclusion of emancipatory research and gave some information about the new project.

The presentations for the last meeting were different from all other theme meetings. This time, some of the presenters did not talk about challenges facing persons with disabilities, they spoke about innovations, new ways to support lives of persons with disabilities and their dreams about AT services in Mongolia.

Presentation1. Ms. Enkhmaa: she introduced about accessible technology and showed picture of assistive devices for kids, kitchen utensils, taking on or taking off clothes which can be used for 4 different types. She also showed picture of renewed office interior of Ministry of labour and social protection (car parking, ramp, tactile paving, board for PwD to climb up and down, accessible sign for people with vision disability and restrooms

Mr. Sandag: He didn’t prepare presentation and shared information about innovative assistive device for person who is lying in the bed in foreign countries. He shared about robot wheelchair which assist to get up and it has a special board for shifting from wheelchair to shower.

He also mentioned about accommodated car for wheelchair users. He said that the car has special board from back and help to move out from car. Just pressing the button, person can get into the car. Special car has automatic board to move wheelchair.

Mr. Batdelger: He didn't prepare presentation but gave a speech about assistive devices and accessible technology for blind people.

I think assistive devices and accessible technology are different. For example, canes for blind people is assistive device yet screen reader of mobile phone is accessible technology.

Since 2013, the Government of Mongolia decided to provide assistive devices once in 3 years. Unfortunately, those assistive devices are useless. Because, devices for read a book are too old and it has no Mongolian. So, we cannot read Mongolian book and we use it as a mp3 player rather to read a book.

Accessible technology has problems to use as well. It has no Mongolian language. Once text to speech software will have Mongolian language, we can use it. Text to speech is a program that reads text for us (screen reader). If there is Mongolian speech, we can access to everything. For example, to use atm, read a book. This is substantial for blind people.

Presentation 2. Mr.Enkhsanaa: He prepared presentation on latest innovations of assistive devices for PwD.

- Computer usage: PwD can use own cellphone to use tablet or computer by installing application. (showed video)
- EMOTIV LLC is developing an eye control program. Persons thoughts/eye can control the objects on the computer. (Showed video). This software can be used for person who has communicative disabilities.
- He also showed a video of innovative device for feed and alternatives for human relationship.

Presentation 3: Mr.Nyam-Ochir: he chose to introduce about demand and needs of toilet in a public places. UB has 1.3 million populations and its soil and environment dirt-80 percent. It induces many diseases. There are also limited number of accessible buildings.

In accordance with resolution adopted by the Governor of UB, 22 city toilets have been built in the most populated places in UB in 2009. Per toilet costs 63 million tugrik. All toilets have almost same design. As per researchers and other people say, city toilets are accessible yet they are not. (He showed picture). For example, there is not enough space to move in the toilet for wheelchair users and persons who have severe disability cannot use City toilet. They can use assistive devices (bed in the toilet, holding devices) to urine in the toilet rather than waiting to go back home just for ensuring their physiological needs (urine). Therefore, city toilet is not accessible for every PwD.

Presentation 4. Ms.Gantsetseg and Mr.Bayarsaikhan: They worked together on the presentation and introduced about needs of assistive devices for persons who have hearing difficulties.

1. In emergency case, we need talking or touching or vibrating watch to notify us. Light which can turn on when someone knocks the door.
2. Sign language converter application from Mongolian to sign language. So that we can save our privacy rather to use sign language interpreter.
3.Further we want to establish sign language sub-committee behind the National Mongolian language committee by the President of Mongolia. Committee members can support to develop new application. Some people say that sign language should be standardized albeit it cannot. For example, there are 2 types of sign for “teacher”. So, the subcommittee should do survey and make sign language formal in close collaboration with the ministries.

Presentation 5. Mr.Bilegsaihan: he introduced a survey report on PwD’s needs of assistive devices done in 2017 on a request from WHO. AT devices availability for different groups.

For People with vision disability: Eyeglass – 52.85%, Magnifying glass/ Screen magnifier – 52.3%, Talking or touching watch- 47.2%

For people with hearing disability: Audio devices- 52. 3%, Hearing devices- 43%, Alarm signaler with light -39.7%

Assistive devices for moving: Walker – 52.8%, Chair with table – 52.3%, Wheelchair – 50.5%,.

Presentation 6. Ms. Uyangasaikhan, Ms. Bolor, Mr.Otgonbayar, Mr.Altangerel: They presented about accessibility in the public places, assistive devices. In the presentation they did comparison between Mongolia and Japan.

Accessible bus – they showed picture of bus in Mongolia and Japan. Ramp- they said that even though there are many ramps in the city, they are not standardised. (showed standard ramp and not standardised ramp)

Ms.Uyangsaikhan said that because I cannot walk by myself, my family built a pavement for me and made handle at step, outside of our house. This is the example of assistive devices. (Showed picture). Compared electric wheelchair and ordinary wheelchair (Showed picture). They also mentioned that toilet should be accessible for all PwD and it should have assistive devices inside.

Ms.Bolor showed an assistive devise for fasten button and said that it saves time and easy to fasten a button by herself (Showed a picture). They also mentioned that some people need voice recorder depending on their disability (they cannot write by hands) and they use their feet to write.

In the end of the presentation they said that personnel assistants are also an assistive device. Because they help to explain and deliver speach on behalf of PwD who is working as a facilitator ad cannot speak properly.

Presentation 7. Ms.Boloroo: she presented about PwD statistics, legislation regards to Human rights of PwD, lists of assistive devices which the Government provides, summary of accessibility assessment report, actions which the Government did.

Accessible technology: Statistics: There are 105,691 PwD in 2018. 10.9 % of them are persons with vision disabilities, 4% of them are persons with communicative disabilities, 7.9% of them are persons with hearing disabilities, 20.4 % of persons with moving disabilities, 19.2% of them are people with intellectual disabilities, 6.8% percent of them are people with multiple disabilities, 30.4 % of them are others.

Legislation: CRPD, Incheon strategy, Law on human rights of PwD

1. Law on human rights of PwD - *Section 26. Benefits and subsidies from Social welfare fund* **:** 26.1. Persons specified in 3.1 of the present law shall be entitled for the following benefits and subsidies from the Social welfare fund; 26.1.6. Communications subsided shall be made available for adult, fully vision and hearing impaired and persons with language impediments; 26.1.14. Letters printed in braille letter, publications and up to 10 kg parcels of blind persons shall be dispatched locally free of charge and equipment and materials for blind persons shall be delivered locally for free;

2. The Governmnet resolution #316 "List of orthopedics, prostheisis assistive devices' quota"

Braille stationaries (paper, typer, notebook, ruler)	100,000	PwD (1005 blind)
DZ player (talking book)	520,000	
Braille watch	30,000	
Magnifying glass	30,000	
Talking software and additional devices	200,000	
Thermometer (talks)	50,000	Elders and PwD (100% blind)
Watch (talks)	25,000	
Blood pressure apparat (talks)	150,000	
Radio player	50,000	

I.Accessibility assessment for persons with vision disabilities: In accordance with State secretary resoluotion A/183, 2016. 10.21, of Ministry of Labour and Social protection, collaborating with National Blind federation of Mongolia and National deaf federation of Mongolia, the ministry organised information accessibility assesment on more than100 websites.

Result: Websites cannot be read by the screen reader. Assistive devices that Government provides are too old, not innovative. Accessibility of assistive devices was 20 percent. ATMs were inaccessible. It can have ear pod, so that blind people can use it. IPTV is also inaccessible. Overall result was 25 percent.

Recommendations: To develop Convertor application Mongolian writing to speaking; To codify ITU H.702 IPTV into Mongolian; To encourage assistive device production and software development by state budget. To establish committee which is responsible for assessing information accessibility and provide recommendations

II. Accessibility assessment for persons with hearing disability: Working group did assessment on 101, 102, 103; and handbooks for schoolchildren; and IPTV and other TV channels. It also took questionaire from National center for rehabilitation and specila school #29.

Accessibility of TV channels: No subtitles instead of HBO, CINEMAX. Therefore, working group recommended that other TV channels are discriminating Persons with hearing disabilities. Even though National TV and TV9 channel provide sign language interpreter, size is too small and people cannot see it. Therefore, size should get bigger and standard should be renewed.

Accessibility of addresses and information board for blind people: Ministry did this assessment with blind people and splited into 2 working groups to do this. Working group choose to assess Khan –Uul district's administration building, hospital, airport, and train station's accessibility.

Result: Police department and hospital has no accessibility for people with hearing disability. Therefore, public servants might have lack of information about new legislation regards to PwD's human right.

Even though Sign language interpreter's association got 7,2 million tugrik for providing service for PwD, none of person with hearing disability knows about it. Therefore, it was ineffective action. The association might get budget for providing service for people who committed a crime.

Even though Chingis khan airport is the place that we can advertise our country, it has limited accessibility for PwD. It should add information board with subtitle and guide by using innovative technology.

Recommendations on Information accessibility: Books and DVD with sign language and subtitle. Teachers and public servants need to know sign language. Websites need to provide information with sign language interpreter. Light at rest rooms, especially at airplane. Movies and TV serials should have subtitle. TV broadcast or Government news should have subtitle and this should be compulsory by the resolution. Codify innovative technology of voice and video. To adopt sign language service's regulation. Doorbell with lighter or vibrator, talking or touching or vibrating watch, and smart phone. To develop a software which can provide video sign language interpreter.

Actions implemented by the Ministry:

- Subcommittee which is responsible for ensuring human righs of PwD, is established inaccordance with Government resolution 116 and its members are newly selected in 2019.
- Developed "My helper 104" hotline, collaborating with Unitel LLC and Communication committee. It recieves phone calls by video and voice. However, only 400 people out 1000 used this hotline and of which more than 300 people didn't pay the payment and 238 people terminated the service.
- New standards have been adopted.

- Model TV channel and website. Subcommittees are working on deeloping these.

6. Additional information: Rehabilitation Act of the USA has adopted in 1973 and most of congress members mutually agreed to adopt article 504 of this act. For example, organization should buy and use accessible devices for PwD.

At the end of the morning session, Tegsh niigem NGO has introduced about state policy and legislation on assistive devices and procedure to apply to get assistive devices.

Afternoon session: Participants divided into 3 groups and discussed following topics: What are the obstacles to get assistive devices from the state, what kind of devices you get? What would be done to come over the obstacles.

Each group presented what they have discussed to other groups.

Group 1: (Mr.Bilegsaikhan, Ms. Gantsetseg, Ms.Boloroo, Ms.Enhkhmaa, Ms.Gunjidmaa, Ms.Khulan, Mr.Byambadorj)

What are the obstacles to get assistive devices from the state, what kind of devices you get? Difficult to get proper Wheelchair, toilet Pot, Canes and False teeth. Other obstacles - Documentation procedure, Officers at social welfare has limited knowledge about special needs and assistive devices and poor Quality of assistive devices.

What would be done to come over the obstacles: Periodic training for officers. Because public servants' work place is unstable. Service guarantee for assistive devices. Revise the list of assistive devices which are offering from the state. To support public private partnership to provide assistive devices. So that people can have more choice.

Group 2: (Mr. Temuulen, Mr.Batdelger, Mr.Otgonbayar, Ms.Misheel, Ms.Namuuntsetseg, Ms.Uyangasaikhan, Mr.Altangerel, Ms.Bolor, Ms. Urantugs)

What are the obstacles to get assistive devices from the state: Difficult to get Thermometer, Blood pressure monitor, Book sense, Watch, Braille paper, Braille board and Magnifying glass (for blind and low vision persons).

Products should be useful to ensure PwD's special needs. For example, I don't need magnifying glass (Mr.Batdelger) Documentation procedure should be simpler. Accountability to importers/tenderer. Because the products which they offer are unqualified. It is risky for PwD 's health because of having inappropriate assistive devices. Usually assistive devices which other companies offer are expensive to compare assistive products which the state provide to us.

What would be done to come over the obstacles: Because each person's needs are different from other, we need specific assistive devices which can meet person's special needs instead of list. Public private partnership. For example, state should transfer money to the companies and companies can offer discounted price to us.

Group 3: (Mr.Nyam-Ochir, Ms.Nomintsetseg, Mr.Enkhsanaa, Mr.Bataa, Mr.Tsedendamba, Mr.Sandag, Mr.Otgondelger, Ms.Erdenezul)

what kind of devices you get: Wheelchair, Walker, Canes, Belt, Hearing aids, Prosthesis, Bed bank/ night stool, Bracket for teeth, Boots.

They provide needless products, Documentation procedure difficult and there is Budget delay.

What would be done to come over the obstacles: Need to provide assistive products which can meet special needs of PwD, Assistive devices can be qualified and standardized. Period of providing assistive devices should be flexible in order to fulfill PwD's specific needs rather than every 3 years. Effective monitoring system- state should monitor or assess quality of the products. No systematic approach to define PwD and their specific needs. Defining by the work ability percentage is inappropriate.

At the end of the afternoon session, participants filled a questionnaire about empowerment through their participation in EDR and the meeting was closed.