Barriers Faced by Persons with Disabilities in Liberia

Report of a Community-Based Emancipatory Disability Research (CB-EDR) 2018-2021

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DISABILITY AND STARTUP

NATIONAL UNION OF ORGANIZATIONS OF THE DISABLED (NUOD)

AGENZIA ITALIANA PER LA COOPERAZIONE ALLO SVILUPPO

A Community-Based Emancipatory Disability Research focusing on persons with disabilities was carried out in 3 counties of Liberia during 2018-2021 as a part of the project "*Disability & Start-Up - Civil society as protagonist of inclusive development in Liberia*", funded by the *Italian Agency for Development Cooperation*. It was conducted in collaboration with the Liberian National Union of the Organisations of the Disabled people (NUOD).

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INDEX

Acronyms	04
Foreword	05
Acknowledgements	06
Executive Summary	07
1. Introduction	11
2. Participating in EDR: Voices of the Researchers	13
3. Background and Theoretical Insights	16
4. Methodology & General Information about Researchers	24
5. Research Findings	37
6. Impact of the Research	53
7. Sharing the Results of CB-EDR	60
8. Discussions and Comments	64
9. Conclusions	69
10. References	70
ANNEXES	
Annex 1: Researchers of CB-EDR	74
Annex 2: TAG members	75
Annex 3: Research protocol approved by IRB/Liberia	76
Annex 4: Classification of barriers & Facilitating Factors	83
Annex 5: Measuring empowerment questionnaire	86
Annex 6: Analysis of the 13 theme reports	88

ACRONYMS

AICS	Agenzia Italiana di Cooperazione allo Sviluppo – Italian Agency for Development Cooperation
AIFO	Italian Raoul Follereau Association
CB-EDR	Community-Based Emancipatory Disability Research
CHIEF	Craig Hospital Indicators of Environmental Factors
COVID-19	Corona Virus Infection Disease 2019
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
CwD	Children with Disabilities
DAR	Disability & Rehabilitation team
DASU	Disability & Start-Up project in Liberia
DPO	Disabled People's Association
EDR	Emancipatory Disability Research
ER	Emancipatory Research
ICF	International Classification of Functioning and Disability
IRB/LU	Institutional Review Board of Liberia University in Monrovia
LMIC	Lower and Middle Income Countries
NCD	National Commission of Disabled in Liberia
NGO	Non-Governmental Organisation
NUOD	National Union of Organisations of Disabled in Liberia
PwD	Persons with Disabilities
TAG	Technical Advisory Group
UN	United Nations
WB	World Bank
WHO	World Health Organisation

FOREWORD

Italian Association Amici di Raoul Follereau (AIFO, Italy) has been active in Liberia for more than two decades with programmes focusing on the persons with disabilities including persons with leprosy related disabilities.

During 2018-2021, AIFO together with NUOD, the national umbrella organisation of the persons with disabilities, under the project "*Disability & Start-Up - Civil society as protagonist of inclusive development in Liberia*" (DASU), funded by the Italian Agency for Development Cooperation, organised a Community-Based Emancipatory Disability Research (CB-EDR) in 3 counties – Bong, Nimba and Grand Gedeh.

This research was aimed at understanding the barriers faced by different groups of persons with disabilities in the 3 counties and developing strategies to overcome those barriers. At the same time, by involving a group of persons with disabilities in a long (about 33 months) process, the research also aimed to prepare a group of empowered community leaders who understand the challenges faced by different groups of persons with disabilities, both men and women, and could contribute to the strengthening of Disabled People's Organisations (DPOs) in Liberia.

The CB-EDR process initiated in October 2018 and was supposed to be completed in 2020. It was forced to be prolonged due to the Covid-19 pandemic and was completed in May 2021. Its results are presented in this report.

Our deepest gratitude goes to the researchers of EDR, the persons with disabilities from the 3 counties, 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 Italian Agency for Development Cooperation (AICS) and all the different partners in Liberia for enabling and supporting the EDR process. It saw the participation of individuals from different Liberian institutions and organisations. We express our appreciation for their contributions to this research.

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

National Union of the Organisations of Disabled
Liberia

Italian Association R. Follereau
Italy

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The idea of conducting an Emancipatory Disability Research in Liberia was developed together with NUOD during the feasibility study of DASU (Disability and Start-Up) project, which was approved by the Italian Agency for Development Cooperation (AICS). We thank National Commission on Disability (NCD) and all the DPO partners for their support to this research.

Our special thanks go to the persons with disabilities who became researchers, who collected information from the field on different themes and shared it during the research theme meetings along with their own life-experiences. Many of them had to make personal sacrifices and to overcome numerous barriers, including those created by the Covid-19 pandemic, to continue to be a researcher. **Annex 1** presents the full list of persons with disabilities who participated as researchers in at least one theme research meeting.

We also wish to thank the different Liberian DPOs from the counties of Bong, Nimba and Grand Gedeh which collaborated in the research and identified young persons with disabilities who participated as researchers and made this research possible.

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**). This protocol was approved by the Office of Institution Review Board of Liberia in Monrovia (IRB Protocol n. 18-11-143). (A copy of the approved research protocol is provided in **Annex 3**)

We would also like to acknowledge the key role played by the staff of AIFO-Liberia in Monrovia and Ganta in organising different meetings, providing logistical support and ensuring the preparation of the different meeting reports. At the same time, the support of the AIFO head-office in Bologna is gratefully acknowledged.

Lastly, we would like to thank Italian Agency for Development Cooperation for believing in this project and supporting the implementation of this research.

EXECUTIVE SUMMARY

Introduction: A Community-Based Emancipatory Disability Research (CB-EDR) in Liberia was carried out as part of a project aimed at promoting livelihoods and entrepreneurship among persons with disabilities in 3 counties (Bong, Nimba and Grand Gedeh). The CB-EDR was seen as a way of promoting empowerment and strengthening of the county-DPOs.

Rooted in the ideas of participatory research, the CB-EDR implementation was based on the social model of disability - it focused 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 research protocol was approved by the Institution Review Board of the Liberia University.

Implementing Emancipatory Research: For conducting the CB-EDR, 4 persons with disabilities were identified as researchers in each of the 3 counties, for a total of 12 researchers. Each county-group of 4 persons included the NUOD county coordinator along with 3 other persons with disabilities identified through the county DPOs. These persons participated in a 5 day long residential training to become researchers.

During the research period, some persons decided to discontinue their participation and were replaced by other individuals selected by their DPOs. A second 3-days refresher training of the researchers was carried out in May 2019.

During 2020, due to the Covid-19 pandemic the research activities had to be suspended. In November 2020, when the research activities were restarted, some modifications were made in the field research methodology to provide more guided support to the researchers and there was some repetition of the research themes.

The researchers, individually or in small groups, carried out research on one theme at a time by visiting the field and interviewing individuals and families. After each field research, they all met together during a 'Theme Meeting' 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. As a result of the research, different local initiatives were born to dismantle some of the disabling barriers. For example, some schools have built ramps for the students with mobility difficulties.

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 Liberia and many were also persons with disabilities.

The key assumption underlying the CB-EDR approach was that understanding the barriers, collectively reflecting on them and discussing actions to overcome them, would lead to conscientization and empowerment, and promote concrete actions in that direction in the communities.

Results: The discussions on the selected themes brought out details about how different barriers influence and affect different life-domains. The importance of different kinds of barriers changed for each domain, though poverty, lack of resources, lack of services and community misconceptions about persons with disabilities were common barriers in most of them. Across all the themes, women were the ones who were usually affected more than the men. The research also showed that certain specific kinds of disabilities such as hearing and speech disabilities, mental health conditions, stigmatising conditions such as leprosy and epilepsy were associated with greater barriers, not only in the communities but also in the DPOs themselves.

Initially, the broad themes meant that each researcher was free to choose and focus on specific issues, with the advantage that different researchers could focus on different issues and build information about the key barriers on each theme. However, as the research enquiries mostly remained superficial, during the final phase of the research, there was an attempt to identify specific areas of questions linked with the themes.

At the same time, the EDR process contributed to the empowerment of persons with disabilities who took part as researchers.

At the end of the research process, all the reports of the meeting minutes were coded for different kinds of barriers and analysed for the preparation of this report.

On one hand, this analysis showed 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 some detail, while others are discussed superficially or even ignored. In spite of those limitations, 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 the rural and urban areas of the 3 counties.

Some of the key findings of the research according to the researchers, which they presented in their final meeting with TAG members were:

- Access to education is a big problem for children and young adults with disabilities. Most of the school buildings are not accessible. Children with hearing, speech and vision related disabilities face even greater barriers because there are no trained teachers and schools lack proper teaching aids and materials. Children lack suitable assistive devices.

- Poverty affects a large percentage of persons in the counties. Poverty and lack of economic opportunities are worse for persons with disabilities and it affects all groups of persons with disabilities. Even the Government refuses to employ persons with disabilities. This problem is even worse for women and for persons with stigmatising disabling conditions such as leprosy and epilepsy.

- Gender dimension of disability is important. Both, the disabled men and women face difficulties in finding partners for relationship and marriage and both face abandonment if one of the spouses becomes disabled. However, the problems faced by women with disabilities are greater – often men abandon them when they become pregnant. Communities and services discriminate against women with disabilities.

- Lack of accessibility in the public and private buildings is a big barrier. Reaching offices often requires climbing stairs while elevators and ramps are missing. Persons with hearing and speech problems, communication problems and vision problems, all of them need suitable assistive devices to overcome barriers. There is a lack of sign language teachers and interpreters.

- Accessing the health services is not easy. The distances can be long and public transport is difficult. In the health centres, there is limited attention by health workers, who make them wait or ignore their needs. The medicines are not available and buying them from the market is costly. Many persons take some treatment for the pharmacy or take herbs because they cannot afford going to the health centres.

- Apart from widespread social stigma, persons with mental health conditions and epilepsy lack information about the role of medication and its free availability in the health services. Sometimes, these medicines are lacking in the referral hospitals.

- There are so many persons with disabilities who had faced physical and mental trauma during the wars. Many of them face social stigma and most carry psychological scars of their experiences. Most have not received appropriate counselling and support. They have been forgotten.

- Most persons with disabilities do not have access to any assistive products. There are no mobility devices such as crutches, walking sticks and wheelchairs or wheelchairs. Other assistive products such as eyeglasses and hearing aids are also not available. This creates additional barriers and blocks their participation in community activities.

- The DPOs do not have access to social development funds in the counties – having access to these funds can provide new opportunities to persons who need them most.

- Social attitudes in the communities are negative towards persons with disabilities. People think that a disability is contagious, they think that it will pass to other persons and therefore discriminate. Others think that disability is linked to witchcraft.

Conducting accessibility audit of some community institutions and infra-structures was also a component of the research. Almost all the public buildings and built spaces visited by the researchers had many barriers for persons with physical and mobility disabilities while even the ideas of looking at accessibility for persons with communication, hearing and vision disabilities seemed a novelty to most public institutions.

Testimonies of the researchers showed a positive impact of their participation in the research on their own empowerment, understanding of barriers faced by different groups of persons with disabilities, increase in the DPOs' memberships and inclusion of persons with those disabilities which were earlier not represented. Inspired by the example of Nimba Association of the Disabled, in the Bong county, an organisation to bring together and coordinate the different local DPOs was started.

Lack of a trained accompanying person to facilitate reflections among the researchers and to ensure proper documentation of the discussions, was an issue. It negatively affected the efficacy of the research. These challenges were aggravated by issues linked with the Covid-19 pandemic.

Conclusions: CB-EDR implementation in the three counties of Liberia faced many challenges. Individuals involved as researchers needed more time and accompaniment in learning to go deeper to understand the causes and mechanisms of different barriers. While the researchers were relatively weak and much of their research remained superficial, this problem was aggravated by very uneven reporting and documentation.

However, in spite of these challenges, the CB-EDR experience in Liberia showed that even in isolated rural areas and even when the researchers may be poor and marginalised, sometimes with limited educational qualifications, the research process can stimulate reflections and provide precious insights about their lives and the barriers they face. Even if the changes and actions which this research process promoted in the county and local institutions such as building of ramps in a few schools, may seem to be small and not particularly significant, they had a positive impact in strengthening the DPOs and widening their membership.

Therefore, CB-EDR should be considered as one of the research strategies for poor and marginalised communities for raising awareness, stimulating grassroots participation and empowerment. A CB-EDR process cannot replace academic and conventional qualitative and quantitative research, in understanding different aspect of the disability experience and for finding solutions to the challenges they face, but it can play an important role.

The experience in Liberia underlines the importance of identifying strong supporting systems, especially an accompanying person who can stimulate the researchers in thinking about the kind of questions they can ask and to make sense of the answers they collect. At the same time, it also reiterates the key role of documenting the research process.

1. INTRODUCTION

A Community-based Emancipatory Disability Research (CB-EDR) was carried out by a small group of persons disabilities from Disabled Peoples' Organisations (DPOs) in Liberia. This research was rooted in the social and human rights models of disability and one of its key inspirations was the international Convention on the Rights of Persons with Disabilities (CRPD) approved by the General Assembly of United Nations (UN 2006).

The overarching goal of this research was to look at and to understand the factors which challenge or facilitate the different life-spheres of persons with disabilities living in 3 counties of Liberia – Bong, Nimba and Grand Gedeh.

This research provides a glimpse of the lives of persons with disabilities living in the county towns and rural areas of Liberia. The background of the research included poor communities with limited resources, services and extremely difficult public infrastructures in in one of the poorest countries in Africa, which had been affected by a series of negative circumstances over the past few decades, including a brutal civil war and a devastating epidemic.

This report presents some of learnings from this initiative. There is little published research about persons with disabilities in Liberia. A paper looking at inequalities among disabled and non-disabled persons had noted that "*very little is understood about the lives of disabled people*" in Liberia (Carew MT, Colbourn T., et al., 2019). While imperfect and partial, this report provides some information regarding the lives and specific challenges faced by persons with disabilities living in the county towns and rural and remote areas.

In this report the terms "emancipatory research" (ER), "emancipatory disability research" (EDR) and "community-based emancipatory disability research" (CB-EDR) have been 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").

CB-EDR process in Liberia lasted for more than 30 months. It included a gap-period of many months in 2020, when the research was blocked due to the Covid-19 pandemic. This created additional challenges for conducting this research and had a negative impact on it.

CB-EDR approach is a people's research – a collective research done by a group of persons in the communities to search for answer to questions which matter to them. It does not try to follow the norms of academic research and accepts the limitations this creates about the research-findings.

This report presents some of the information about the research process and its results. It acknowledges the limitations in accompanying and documenting that process. It recognises that its methodology is still developing and needs gentle but qualified support from persons versed in participatory research approaches which was insufficient in some phases of the process.

To ensure that this report is accessible also to the researchers themselves, it has been written in simple language and has tried to avoid jargon, though the author recognises that it may be of limited interest to them because of its complexity, length and details.

2. VOICES OF THE RESEARCHERS

(*Collected at the end of the research process*)

Felix Chelleh/Grand Gedeh County: Participating in the research has given me self-confidence. It has helped me to see the barriers and challenges faced by disabled persons by learning about the social model. It has changed how I take my decisions in my daily life.

Nenlay Doe/Nimba County: I have learned so much. I can now talk to people in a way which I could not do before. For example, now I can go to the court and speak to the magistrates. It has changed the way how I speak to the parents of children with disabilities. I have become a stronger advocate and I am very active in talking to the parents of children with disabilities.

Joanna Kollie/Bong County: I was shy and afraid of talking to people. Now I can go and talk with the county authorities, school authorities and community leaders. I have become more out-going and I have made new friends. I think that it is very important to talk with families, especially with the parents of children with disabilities.

Augustine Padmore/ Grand Gedeh County: Being a part of EDR has given me new skills and at the same time, changed me as a person. I was very shy. The research has given me an opportunity to know persons with different kinds of disabilities and to see the world through their point of views. So, my interactions with them have changed.

Gabriel Sow/Nimba County: I have become bolder, my advocacy has become stronger and when I speak, people trust me. Thus, whenever there is any meeting in the community, they are now inviting me. Many parents who have children with disabilities come to me to ask for advice. I can share with them my learnings and life experiences.

Arthur Bondo/Bong County: Through participation in the research, I have learned new things and it has changed me as a person. During the research, we visited so many places – schools, hospitals, courts and police stations, that I would have never thought of visiting. I have learned that I can talk to all kinds of officials and explain to them about the problems of persons with disabilities. My community has recognised me as an advisor and when they have any disability related questions, they look at me as a reference person and they seek my advice.

Albestine Tozay/Nimba County: When I joined the research, I was the president of the county DPO and thought that I knew everything. Yet, I have also learned new things. For example, the importance of talking to parents of a disabled child. Learning to look at the world in terms of barriers it can create for persons with different kinds of disabilities helps me to deal with people differently.

Winston Varwulu/Bong County: I feel that I am more empowered because of participating in the research. It helped me to go out and talk to people, so today many more persons know me and are aware of my advocacy work for the rights of persons with disabilities. My interactions in my family also changed, I take my own financial decisions now.

Helen Gounleh/Nimba County: I was extremely shy, now people tell me that I have changed. I have travelled to other counties and to Monrovia, I have seen places that so many other persons from my village have not visited. It has given me confidence. I know about different kinds of disabilities.

Emary Jessie/Bong County: I am the founder president of the blind association in my county and I already knew about engaging and responding to disabled and non-disabled persons. Being a part of the research has helped me to become a better leader. I have visited many new places in my county and I have also travelled to other counties. I have met and made friends with a large number of new persons with other kinds of disabilities.

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BACKGROUND, THEORETICAL INSIGHTS & METHODOLOGY

3. BACKGROUND AND THEORETICAL INSIGHTS

3.1 BACKGROUND

Italian Association Amici di R. Follereau (AIFO) has been active in Liberia for more than 25 years, including the period when the country was passing through a brutal civil war. At first it worked through partner organisations while the AIFO-Liberia office was set up in 2003. During these years, AIFO has been active mainly in 2 areas – (1) disability and rehabilitation and (2) leprosy.

AIFO's Approach to Emancipatory Research: AIFO looks at "emancipatory research" as research carried out by marginalised and oppressed groups of people. It has been experimenting with the "community-based emancipatory research" methodology since 2009, when it was attempted for the first time in Karnataka state in India. Since then, this approach has been attempted in different countries including Brazil, India, Italy, Mongolia, Mozambique and Palestine. Not all of these were focused on persons with disabilities – for example, the attempt in Brazil focused on health workers while in Italy it focused on elderly persons. More recently, in 2021, it is being tried with emigrants in Tunisia.

It is a collective approach to research, in which a group of persons is trained and accompanied to collect information about issues which are important for them and reflect on that information to understand the mechanisms of their exclusion and marginalisation. It is an action-oriented research in the sense that taking practical action on the understandings gained from the research is a key part of the process. As it is an experimental approach and it needs to be adapted to specific socio-cultural contexts of different local communities, it has not been always successful in terms of the research outputs, though it has unfailingly provided new insights and learnings.

Origins of Emancipatory Research in Liberia: The idea of carrying out the emancipatory research under the Disability and Start-Up (DASU) project was proposed to NUOD, the national umbrella organisation of the DPOs in Liberia, during its feasibility study. DASU project focused on the promotion of livelihoods and entrepreneurship in Liberia. It was suggested to carry out the research in the rural areas in the counties where little documented information exists about the specific challenges faced by persons with disabilities.

Right in the beginning it was recognised that implementing the emancipatory approach in the rural areas and county towns of Liberia will not be easy. The country still felt the impact of the 20 years of a brutal civil war, which had ended in 2003 but its echoes could still be heard in peoples' life stories. If that was not enough, during 2014-16, the deadly Ebola virus crisis has brought the country's development to a standstill from which it had yet to recover properly. In this situation of chronic poverty and under-development along with limited public services and infra-structures, expecting a small group of persons with disabilities to actively participate and lead a community-research in the county towns and rural areas was risky.

Yet, in spite of all those reservations and challenges, this attempt has concluded successfully. If we compare the kind of information and transformation promoted by the CB-EDR initiatives in other contexts with the results in Liberia, we can see many short-comings and limitations. However, if we consider the kind of challenges the researchers faced in Liberia, the results of this research can be seen as transformative.

Introduction to this report: This report tries to capture and present some of the key results and challenges from a 3 years-long process in a spirit of open sharing and learning. In all the participatory community researches, sharing and communicating the research findings with the communities is a big challenge because the researches are initiated and completed in academic contexts. There is a risk of "*epistemic injustice*" due to "*structural exclusion of marginalised producers and recipients of knowledge*". (Bhakuni H. & Abimbola S., 2021).

In CB-EDR in Liberia, the researchers from the communities conducted the research in complete autonomy without any specific role for persons with academic backgrounds. They were supposed to be accompanied by trained facilitators and this process was supposed to be documented by a dedicated rapporteur – both these roles faced challenges. Thus, the researchers decided which questions to pose, to whom and in which terms. The information they collected contributed to their own understandings. During their periodic meetings, those newly acquired understandings were shared with their peers, collectively analysed and their meanings and significance further elaborated. They are the primary producers and recipients of this knowledge. Due to lack of adequate supporting mechanisms, this process was uneven and patchy.

The reports of their periodic meetings have been used to prepare this final report to share some of those learnings with the wider world.

3.1.1 General Information About Liberia

The Republic of Liberia, located in West Africa, is bordered by Sierra Leone, Guinea Konakry, Ivory Coast and the Atlantic Ocean. It has a population of around 4.5 million and covers an area of little more than 110 thousand sq. kms. English is the official language, and there are about 20 indigenous languages. The country's capital and largest city is Monrovia.

Liberia’s landscape is characterized by mostly flat to rolling coastal plains that contain mangroves and swamps, which rise to a rolling plateau and low mountains in the northeast towards Ivory Coast. The country is divided into 15 counties. The DASU project covered the capital Monrovia and 4 counties while the CB-EDR initiative was located in 3 of those counties, Bong, Nimba and Grand Gedeh (marked with a green star in the map on the previous page).

After the abolition of slavery, Liberia began in the early 19th century as a settlement of freed American slaves of African origin, who together with the different indigenous people already living there, created the American-Liberian identity. It is Africa's first and oldest modern republic. Liberians of American origin formed into a small elite that held disproportionate political power while the indigenous Africans were excluded from citizenship as a birth-right until 1904. American-Liberians promoted religious organizations to set up missions and schools to educate the native populace similar to the work of European colonizers in other parts of Africa.

The turbulent phase of Liberian history began in 1980 with military coups and then a brutal civil war which lasted till 2003. After the end of the civil war, a phase of rapid economic growth was interrupted by Ebola crisis (2014-16) and then more recently by the Covid-19 pandemic (2020-21).

The average life expectancy at birth in Liberia was about 33 years in 1950, had improved to about 60 years in 2015. In the same period, the infant mortality rate per 1000 births came down from 224 to 89. It has one of highest population growth rates in the world.

3.1.2 Demographic information About the 3 Counties

The demographic information about the 3 counties where the research was carried out is summarised in the table 3.1 below (population is based on the 2008 census and thus the present populations are likely to be almost double the figures presented below):

Table 3.1: Demographic information in selected counties

County Name	Capital	No. of Districts	Population
Bong	Gbarnga	12	328,919
Nimba	Sanniquellie	6	468,088
Grand Gedeh	Zwedru	3	126,146

Over the last few years, a newly built road connects Monrovia to Sanniquellie, which also passes through Bong county. This has greatly facilitated the transport and communications in these 2 counties. However, there is no such tarred road going to Grand Gedeh county, which is thus more difficult to visit, even more so during the rainy season. In all the three counties, there are rural areas far away from the main road, which are more difficult to visit, even more so in Grand Gedeh, as it has a comparatively low population density.

There are different cultural issues in Liberia, some of which might have some influence on the lives of persons with disabilities and the barriers they face. For example, one such issue is that of tribal identity. There are many ethnic groups in Liberia such as Mandingo, Kissi and Krahn. Ethnicity had played a role in the civil war. A survey conducted in 2010 had shown that a small percentage of persons (8-10%) in the counties were still having problems with specific ethnic groups. (Vinck P. et al, 2011)

3.1.3 Persons with Disabilities in Liberia

The last National Census conducted in Liberia in 2008 had collected some information regarding persons with disabilities (National Census report, pp. 204-229). A total of 110,260 persons with disabilities were identified in the country, including 56,562 males (51.3%) and 53,698 females (48.7%). A new national census was supposed to take place in 2019, which was postponed to March 2021 and has now been postponed to sometime in 2022.

Among them there were 24,878 persons below 19 years of age (22.56% of all the persons with disabilities). 81.4% of children with disabilities (CwDs) in the 5 to 9 years age group and 52.6% in the 10-14 years age group were not going to school. In the 15 to 19 years age group, 40.9% of young persons were out of school. (p. 249) However, just looking at school-going rates does not provide a full picture of the barriers faced by CwDs. For example, in the 15 to 19 years age group, 78% of them were still in the elementary school, and only 7.4% of them were in high school.

The 2008 census had also collected information about the different kinds of disabilities (p. 251) in Liberia - persons with limited use of legs 17,858 (16%); persons with leg amputations 3,826 (3.5%); persons with limited use of arms 4,193 (3.8%); persons with arm amputations 1,514 (1.4%); persons with hearing difficulty 9,590 (8.7%); deaf persons 2,574 (2.3%); sight difficulty 35,538 (32.2%); blind persons 3,701 (3.3%); persons with speech impairment 1,417 (1.3%); mute persons 1,552 (1.4%); persons with mental retardation 1,797 (1.6%); persons with mental illness 2,924 (2.6%); dumb persons 962 (0.9%); persons with multiple disabilities 6,480 (5.9%); and, persons with other disabilities 18,344 (16.6%).

The categories used for classifying PwDs in the 2008 census, apart from the use of inappropriate terminology (such as ‘mental retardation’ and ‘dumb persons’), were arbitrary and non-comparable to disability data from other countries. National Commission of Disabled (NCD) and NUOD are advocating with the Government to ensure that Washington Group of questions can be used to collect information about persons with disabilities in the next census.

3.1.4 Previous Research on Barriers Faced by Persons with Disabilities in Liberia

There is little published research regarding persons with disabilities in Liberia, even less so those focusing on social model of disability. Only one student thesis was identified which looked at social barriers encountered by persons with disabilities in

Liberia (Kellie K.K., 2019), while no articles on this theme could be identified in a peer-reviewed journal.

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

The idea of "emancipatory research", or research on disability issues conducted by persons with disabilities themselves, was proposed by British disability activist and academic Mike Oliver in 1990. (Oliver M., 2002, p. 4) In the past 30 years, the basic idea of emancipatory research, by asking marginalised groups to conduct research about their marginalisation, has been tried in different domains.

Most of the emancipatory disability research (EDR) seems to be carried out in academic settings, especially in universities running "Disability Studies" courses, during which often university students with disabilities look back and analyse their own life experiences or less often, involve small groups of persons with disabilities. Most such research is based in urban areas where these universities are based, though a few EDR have been conducted in low and middle-income countries (LMIC).

3.2.1 AIFO's Approach to Emancipatory Research: In 2009, an Italian Non-Governmental Organisation called AIFO, took the basic idea of emancipatory research and developed a community-based approach to be implemented collectively through groups of persons with disabilities in low and middle-income countries (LMIC), mostly in rural areas and small towns. It combined ideas of education for poor and landless peasants by the Brazilian pedagogist Paulo Freire and those of participatory research approaches developed by sociologists like Robert Chamber and Don Milani in the poor rural communities.

This experimental approach to emancipatory research among persons with disabilities is still in development, as over the past decade it has been adapted and implemented in different socio-cultural contexts in countries like India, Palestine, Mozambique, Mongolia and Liberia. At different times, different terms have been used for it including - "Emancipatory Disability Research" (EDR), "Frerien approach to EDR" and "Community-Based EDR" (CB-EDR). (Deepak S. 2011 a; Deepak S. et al., 2011 b, 2012, 2014 a, 2014 b, 2016; Biggeri M & Ciani F., 2019 a, 2019 b) A key element of these researches has been their grounding in the social model of disability as well as in the international Convention on the Rights of persons with disabilities. (UN, 2006)

It has been proposed that people can learn in different ways. Greek terms '*techne*' and '*metis*' have been used to differentiate two different modes of learning. Techne refers to formalized knowledge—facts, figures, techniques, plans, and other data that can be conveyed through lectures, field manuals, and other academic training. Metis, by contrast, refers to knowledge that is gained through experience and interaction, learning through failures and successes during day-to-day operations, and spread through networks of practice. (Sagarin R., 2012, p. 53) EDR promotes learning about barriers and exclusion among the participants through the Metis learning mode.

The other key element of the research approach developed by AIFO/Italy is that of promoting collective reflection about the new understandings gained by the researchers throughout the research process, so that they can translate those understandings into practical action and “use” the research to change the barriers.

Similar approach has also been attempted by AIFO among other marginalised groups – elderly persons in a small municipality in north of Italy, community health workers in a small town near Rio de Janeiro in Brazil and emigrants in Tunisia.

3.2.2 Social Model of Disability: The social model of disability argued that it was not the impairment that was the main cause of limitations faced by the disabled people but the way society responded to and created barriers around people with impairments. (Oliver M., 2004)

The World Health Organisation (WHO) focused on health-related aspects of disability and used a medical to understand it as an individual issue of treatment and rehabilitation. The social model of disability influenced it to develop a new classification system (WHO, 2001) called International Classification of Functioning and Disability (ICF), which took account of the influence of both environmental and personal factors on the participation of disabled persons. Thus, the first World Report on Disability suggested a balanced approach, by giving appropriate weight to the both social and medical aspects of disability. (WHO & WB, 2011, p. 4)

3.2.3 CRPD and Emancipatory Research: The approval of the Convention on the Rights of Persons with Disabilities (CRPD) in the United Nations General Assembly 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. 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. Therefore, EDR by focusing on gaining an understanding of different barriers, can be seen as an instrument to collect this information under the guidance of CRPD.

3.2.4 Evolution of Emancipatory Disability Research: When Mike Oliver had proposed the idea of emancipatory research – research on disability issues conducted by disabled persons themselves, at that time social research on disability rarely involved disabled people in the research processes except as a subject. Moreover, the knowledge gained from the research was targeted at academics and was not understood by the majority of persons with disabilities, DPOs and communities. (Barnes C., 2008) In fact, in conventional research, the information collected and the knowledge generated is owned by the researchers.

Different participatory research approaches were developed in the areas of social sciences, which involved the subjects of the research in defining the research methodology. Thus, in the participatory research, the information and knowledge are owned by both, the researchers and the researched. While in emancipatory research, the subjects are also the researchers and thus, the information and knowledge belong to the researched. (Swartz S. & Nyamnjoh A., 2018)

However, the emancipatory research approach developed in academics continued to be cut off from the lived realities of majority of persons with disabilities, even more so in less developed countries. For example, an analysis of research articles about EDR showed that a majority of published articles were about theories, concepts, ethics and challenges of adopting this approach (Traina I., 2015; Chown N., et. al., 2017).

An online search for articles about implementation of EDR, showed 3 broad kinds of studies – (i) personal life experiences of individual persons with disabilities (mostly for student dissertations or Ph.D. thesis), (ii) inclusive research (mainstream academic research which included persons with disabilities as co-researchers), and (iii) few field researches in which a person with disability who is also an academic researcher works with a small group of persons with disabilities or in a DPO (mostly for student dissertations or Ph.D. thesis). (Klara M., 2014, Kincaid K., 2013).

A search for articles about DPOs or groups of persons with disabilities from developing countries joining together to conduct a disability research, as carried out by AIFO in its community projects, did not find any other results. Thus, the adoption of the CB-EDR approach developed by AIFO remains very limited.

3.2.5 Empowerment & Its Measurement: One of the goals of EDR is to promote empowerment of persons with disabilities.

Discussions about the concepts of empowerment go back to at least the last few decades, especially to programmes targeted at women. While all communities have local terms for persons who show autonomy, self-confidence and the capacity for making one's decisions, linking these to the ideas of empowerment has been more recent. More recent are also the efforts to understand the different dimensions of empowerment and to measure them. (Biggeri M., et al., 2019b) Empowerment is broadly seen as increasing poor people's freedom of choice and action to shape their own lives. (Narayan D., 2005)

Zimmerman (2000) proposed three key components of empowerment – control over one's life and decisions, critical awareness about one's situation and participation in events and activities to change the situation. A key pre-requisite for individual empowerment is a state "learned hopefulness" about one's future that things can change and improve. Some other components of empowerment suggested by others include socio-political awareness and understanding, and a feeling of being capable. (Francescato D., et al, 2007)

There have been some attempts to measure empowerment in a systematic manner. Some community-based development programmes have asked the involved persons their ideas about empowering changes which are significant for them and to measure those changes. For example, a community development programme in Bangladesh used participatory methodology to identify different kinds of empowering activities, for which they were asked to give self-scores. (Jupp D. & Ali S.I., 2010, p. 17) However, so far there is no commonly agreed instrument for measurement of empowerment among persons with disabilities.

3.3 CONCLUSIONS

Emancipatory disability research (EDR) is rooted in the social model of disability. It is carried out by persons with disabilities themselves and it focuses at the physical, social, cultural, economic and other barriers faced by them.

The community-based EDR (CB-EDR) approach is an experimental approach developed mainly among groups of persons with disabilities living in small towns and rural areas of developing countries. It is a non-academic approach to research where the main aim is to gain understandings about barriers and to promote local action to remove those barriers.

CRPD asks for collection of disaggregated data about the barriers faced by persons with disabilities. CB-EDR can be seen as an attempt to collect this kind of information. There is limited published research on such barriers from west Africa and especially from Liberia, underlining the importance of this initiative.

4. METHODOLOGY & GENERAL INFORMATION ABOUT RESEARCHERS

Community-Based Emancipatory Disability Research (CB-EDR) implemented in Liberia was a part of DASU project which aimed at promoting livelihood among persons with disabilities in Liberia. It was carried out through a collaboration between the DASU project team of AIFO-Liberia together with the national umbrella organisation of DPOs in Mongolia called NUOD (National Union of the Organisations of the Disabled persons). It involved three counties – Bong, Nimba and Grand Gedeh.

This chapter presents information about the research methodology and about the researchers.

Usually, research reports provide little information about the researchers, limiting themselves to their professional training and roles. However, in CB-EDR, the researchers are also among the primary subjects of their research – they start their gathering of information by looking at their own life experiences and deciding the focus on their enquiries based on those. Their information gathering in the communities involves other persons with disabilities as well as other stake-holders, from families to community leaders and representatives of institutions. Thus, CB-EDR has 2 kinds of subjects – researchers themselves and others. The information about the researchers is given in this chapter focusing on the research methodology, while information about the persons they visited, observed and interviewed are presented in the next chapter along with the results of the research.

4.1 INITIAL PLANNING OF CB-EDR IN LIBERIA

The CB-EDR methodology is experimental and is being developed. The specific ideas about how to implement CB-EDR in Liberia was developed jointly by the DASU project team of AIFO-Liberia and NUOD along with the DPOs in the counties, with the support of an external consultant.

It was decided that even if most persons with disabilities from the three counties would have limited educational qualifications and limited skills and capacities, they will have the full responsibility for conducting the CB-EDR and they will be supported by a trained rapporteur-facilitator.

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

- The first pre-supposition was that persons with disabilities from the local communities and with experience in the county DPOs will have the knowledge and contacts in their local communities and thus, they can talk to persons with disabilities and other stakeholders to gather details about the different kinds of barriers existing in those communities, in ways which other persons from outside cannot do.
- The second pre-supposition was that sharing their personal life experiences and the information they had gathered and facilitating collective reflections on the different barriers they had identified will lead to their understanding about the systematic mechanisms underlying their exclusion.

- The third pre-supposition was that understanding how barriers limit the participation of persons with disabilities in different life-domains will lead to more empowered researchers and stronger county DPOs who will become more inclusive and will promote stronger advocacy activities to remove those barriers.

The research adopted a participatory qualitative approach for sharing of life-experiences by the researchers and collecting information from the field on selected themes, through the following steps:

1. In consultation with the county DPOs, NUOD will identify 4 persons with disabilities from each of the 3 counties for a total of 12 persons, who will be trained to become CB-EDR researchers. Organise a 5-days residential training course for the selected persons.
2. Through participatory discussions, researchers will identify a set of "priority themes" around which developing field researches. As the researchers will gain experience and understand the issues better, they can periodically review and if needed, modify the priority themes.
3. The researchers will meet to share their own life experiences related to each priority theme and develop the questions they want to ask to other persons with disabilities and stakeholders about that theme.
4. The researchers will have 6-8 weeks of time to collect information in their communities.
5. After 6-8 weeks of the first meeting, the researchers will meet again, share the information they had collected and with the help of a facilitator, analyse this information to understand the main barriers linked with that theme and discuss ways for overcoming them. They can invite 2-3 "experts" to each meeting who can provide them with additional information.
6. To document all the meetings through detailed reports, which will be analysed at the end by an external consultant. Three review meetings will also be organised during which the research methodology can be modified, if needed.

The researchers were supported by a group of experts who were members of a Technical Advisory Group (TAG). Globally the research was coordinated by a consultant who conducted the training of the researchers and monitored all the different activities and prepared this final report.

Initially, no financial contributions to the researchers were planned except for covering the costs of their participation in the theme meetings. However, after the first theme research, the researchers explained that they had no resources and had to travel all over the counties to visit people for interviews, which needed funds. Thus, a financial contribution of 100 USD for each researcher for each theme research was given. Considering the local cost of living and salaries, this amount was perceived to be very generous.

4.1.1 Approval of the Research Protocol: As explained above, a draft research protocol was prepared. It was presented to the Technical Advisory Group and finalised. The protocol was then presented to the Institution Review Board of the Liberia

University (IRB/LU) in Monrovia and approved (Protocol n. 18-11-143). Annex 3 presents the final approved version of the research protocol.

4.1.2 Criteria for selection of the researchers: It was decided that from each county a total of 4 persons with disabilities will be selected and trained to conduct the research – 3 of these persons will be members of the county DPOs while the 4th person will be the NUOD coordinator in that county. Thus, a total of 12 persons will be selected.

The following criteria were suggested to the county DPOs for the selection of their representatives:

- Willingness to be a part of the research process and to regularly participate in the meetings over a period of 18 months.
- At least 50% of the researchers should be women.
- The researchers should represent different kinds of disabilities with a special emphasis to include persons with chronic mental health conditions.
- Their willingness to travel in surrounding communities to meet and interview other persons with disabilities.
- Basic reading and writing skills to write down notes regarding the research.

4.1.3 objectives of CB-EDR in Liberia: The *general objective* of CB-EDR in Liberia was to understand the different ways in which the society and the environment create barriers to the participation of persons with different disabilities living in the small towns and rural areas of the 3 counties.

The *specific objectives* of the research were:

- To understand and map the different disabling barriers and enabling facilitating factors affecting the different life-domains of men and women with different kinds of disabilities living in the small towns and rural areas of the county.
- To promote collective reflections on the identified barriers for understanding their underlying causes and mechanisms and then to identify possible strategies for overcoming them.
- To promote advocacy and other suitable strategies identified by the researchers along with their DPOs to dismantle the identified barriers and thus, to promote the empowerment of persons involved in the research.

4.2 TECHNICAL ADVISORY GROUP (TAG)

An international Technical Advisory Group composed of 14 members was formed to support and provide technical guidance to the CB-EDR. It included representatives from the Ministry of Gender, children and Social Protection, Ministry of Health, Liberian DPOs as well as, disability experts and academic researchers. Among them 11 persons were from Liberia and 3 persons from other countries. The members included 4 persons with disabilities. The work of TAG was supposed to be assisted by the person selected for the role of rapporteur-facilitator for the EDR.

The TAG members were supposed to receive the draft protocols for all theme researches to provide their suggestions about the research questions and any experts to be invited. If they had expertise in a theme, they were also invited to participate in that theme meeting. All the theme research reports were to be shared with them for their comments and suggestions.

The TAG members met 3 times during the CB-EDR process – before the start of the research in October 2018 when the research protocol was finalised; after one year of the research in May 2019; and at the end of the research in May 2021.

Annex 2 presents a list of all the TAG members.

4.3 RESEARCH IMPLEMENTATION PLANS

The research protocol was presented to the Institution Review Board of Liberia University while NUOD identified the researchers from each of the three counties. While the research protocol was being approved, a rapporteur-facilitator to accompany the researchers and document all the proceedings of the theme research meetings was also identified. The research protocol was approved on 6 December 2018 (Protocol # 18-11-143).

4.3.1 Training of Researchers: A 5-days long residential training course for the researchers was carried out by the international Research Coordinator in the October 2018 in an accessible location in Gompa (Ganta) town of Nimba county. A total of 12 persons with disabilities took part in the training including 3 NUOD coordinators (2 men and 1 woman) and 9 persons with disabilities identified by the county DPOs.

The training discussed issues related to ethics, privacy and confidentiality and the role of informed consent. It also covered the basics of social model of disability and of conducting qualitative research including conducting interviews and collecting life stories. A full session was dedicated to defining the issues in terms of a research problem and then identifying the potential contributing factors through group discussions. It also touched upon the importance of keeping written notes and sharing information among the researchers for a collective analysis of different kinds of barriers, their causes and strategies for overcoming them. Finally, it also discussed conducting accessibility audits of services and infrastructures. The whole training process was participatory and interactive with ample time devoted to role plays and practicing of practical skills related to conducting interviews and collecting life stories.

The person expected to be the facilitator-rapporteur for the research accompanied this training and followed a parallel training about how to prepare research reports.

4.3.2 Defining Research Themes: During the final part of the training, the researchers were asked to identify the main problems they were facing in their daily lives which affected their participation in different life-domains. Through participatory discussions about those problems, 12 broad thematic-areas were identified for the EDR: (1) health, (2) education, (3) livelihood & income generation, (4) Social participation and family, (5) Empowerment (focus on DPOs and self-help groups), (6) War related disabilities and violence-abuse faced by PwDs, (7) physical and leprosy related disabilities, (8) visual disabilities, (9) hearing and speech disabilities, (10) intellectual disabilities, (11) mental illness and epilepsy, and (12) other disabilities (which are not included under other groups such as - short persons, albino persons, burns and Buruli ulcer disabilities.

Thus, three kinds of broad thematic areas were selected for the research – (1) 5 themes were linked with life-domains: health, education, livelihood, social participation and empowerment; (2) 6 themes were about specific barriers liked with different kinds of disabilities: physical and leprosy related disabilities, visual disabilities, hearing and speech disabilities, intellectual disabilities, mental illness and epilepsy and other disabilities; and, (3) a cross-cutting theme, the impact of the civil war.

4.3.3 Methodology of Conducting Theme Researches: As explained in the methodology, for each of the 12 themes identified by the researchers, the following process was supposed to be followed for conducting the research in each county:

(1) All the researchers meet together to discuss the main problems related to the theme, identify the contributing factors and based on that define the key questions they wish to ask. Depending upon the research theme they also had to identify the kind of target persons to whom they were going to interview in their local communities.

(2) Each county team of 4 researchers would make a list of all the work they had do to collect information on the selected theme including the identification of the institutions and authorities they wanted to interview. This work was to be divided among the 4 researchers.

(3) Each researcher would visit the individuals, institutions or authorities, conduct interviews according to the questions the group had identified and prepare notes about the collected information.

(4) Each county team would meet, put together all the information they had collected and discuss the key barriers related to that theme and how those could be overcome and which strategies were needed. They would prepare a report about their discussions and prepare a presentation to be shared with the researchers from the other two counties.

(5) All the 3 county teams would come together and meet in one place. Depending upon the theme, they could invite one or more external guests, including the TAG members, who had some specific experiences or information to share about those issues. Each team would share its findings and conclusions and then together as one group they would look at the similarities and differences in their findings to come up with common conclusions and recommendations, with support from the facilitator-rapporteur. A formal written report was prepared by the rapporteur for this common meeting.

(6) Initially 12 priority theme researches were planned. In March 2020, when 9 theme researches had been completed, the research was suspended due to the Covid-19 Pandemic. In November 2020, when the situation of the pandemic allowed it, research and meetings were restarted but a few changes were made in the methodology. It was felt that some information was lost during the process of creating a common county presentation on each theme research and thus it was decided to ask each researcher to present his/her findings individually. The second change was that a list of questions related to the theme of the research will be prepared and all researchers will use those questions. An additional 4 theme researches were planned during this phase, which repeated the information gathering around some themes as it was felt that during the

gap period, the researchers had forgotten some of their previous work. Thus, globally a total of 13 theme researches were carried out during the CB-EDR and there were 13 formal reports for the analysis.

4.3.4 Analysis of the Research Findings:

The 13 research reports were analysed for the different kinds of barriers identified by the researchers in their own life stories and in the information they had gathered in the local communities by interviewing persons with disabilities and families of children with disabilities. The results of this analysis are presented in the next chapter.

The analysis of the barriers was based on the classification of environmental barriers and personal characteristics described in the ICF - International Classification of Functioning (WHO, 2001), combined with the barriers identified in the Craig Hospital Inventory of Environmental Factors (CHIEF, 2001). This combined list of potential barriers had also been used during an emancipatory disability research in Mongolia (Deepak, 2020) – this same list of barriers was used for the analysis of the barriers in the theme reports in Liberia and is presented in **Annex 4** of this document.

It was recognised that this list of barriers was not perfect, as it had some duplications and overlapping. For example, the barriers associated with lack of access to different digital apps could be considered as an issue of "Products and Technology", as well as a part of "Assistive Products" under Social Welfare services.

In this list of different barriers, there are 6 broad groups – (1) peoples' attitudes, beliefs and behaviours; (2) environment; (3) policies and systems affecting service provision; (4) information and communication; (5) economic; and, (6) products and technology. Each broad group is further subdivided into specific categories.

The initial 9 theme research reports were coded manually - each time a barrier was mentioned, it was coded according to the 6 categories of barriers and at the end, they were all analysed. This was possible because, the initial reports were combining the information gather by the researchers of each county and thus their reports had fewer details.

In the last 4 theme research reports, each researcher shared the information gathered by her/him and thus there were larger number of interviews and life-stories. For each of these reports, based on the research questions identified in their research protocols, a data entry mask was created with Epi-Info 7, each manually coded information was entered into it and finally converted into an excel table for analysis.

The results of this analysis are presented in the next chapter (chapter 5).

4.4 THE RESEARCH THEMES

As explained above, initially 12 broad research themes were identified for the CB-EDR. Initial 9 researches were conducted according to the initial planning. When the research was resumed after the gap period of many months due to the Covid-19 pandemic, there were a few changes in the research methodology and an additional 4 theme researches.

The themes of last 4 researches were mixed and had some duplications and overlapping with the themes which had been already covered. This was done to refresh the memories of the researchers, to remind them about the kind of discussions they had already had. Another reason for repeating the themes was that during the initial period, the research methodology had resulted in loss of many details from information gathered by individuals, when it was combined in a single county report.

Thus, at the end of the CB-EDR process, a total of 13 theme researches were carried out as shown in the table 4.1 below showing the titles of the theme researches and the period when their research meetings were organised:

Table 4.1: EDR Research Themes Liberia

No.	Thematic areas of research	Period
01	Challenges faced by Persons with vision related disabilities	Dec. 2018
02	Challenges faced by persons with physical, mobility and leprosy related disabilities	Feb. 2019
03	Empowerment of persons with disabilities and role of DPOs in promoting empowerment	Apr. 2019
04	Impact of war and different kinds of violence on the lives of persons with disabilities	May 2019
05	Challenges faced by persons with mental illness and epilepsy related disabilities	Jul. 2019
06	Challenges related to livelihood and economic independence for persons with disabilities	Sep. 2019
07	Challenges related to health, well-being and access to health services for persons with disabilities	Nov. 2019
08	Barriers faced by persons with disabilities in sports participation and leisure activities	Jan. 2020
09	Barriers to education for children and adults with disabilities	Mar. 2020
10	Challenges faced by persons with disabilities in their family relationships and support systems	Nov. 2020
11	Challenges faced by persons with disabilities in relation to law & order and justice system	Jan. 2021
12	Challenges faced by persons with specific disabilities associated with social stigma – leprosy, mental illness, intellectual disabilities, epilepsy	Mar. 2021
13	Barriers to education and to social relationships for persons with disabilities	May 2021

4.5 THE RESEARCHERS

Usually, research reports do not have detailed information about the researchers. At the most, they provide brief information about their professional experiences and institutional roles.

However, in the CB-EDR, the researchers had two distinct roles. They were the first subjects of the research as the information gathering started with the sharing of their own life-experiences and these experiences were used to decide the directions of the enquiries and the information gathering. They also became interviewers of other persons with disabilities but they were not 'neutral' interviewers, because their own disabilities, life stories and their roles in local DPOs were an important part of their interactions. Thus, understanding who they were and their experiences, as well as the impact of research participation on them and their organisations, was an important part of the research analysis.

The exact collocation of this information is debateable. In this case, it has been decided to place them as part of the research methodology.

4.5.1 General Information About the Researchers: Initially, in 2018, a total of 12 persons with disabilities were identified for participating in the residential training course for becoming researchers. They included 3 NUOD country coordinators and 9 representatives of county DPOs.

During the 33 months of the EDR implementation, some of them decided not to continue in the roles of researchers and were replaced by other DPO representatives. A second refresher training was organised for them in 2019. All of them were asked to sign the informed consent for taking part in the research. **Annex 1** provides a list of all the persons who took part in the EDR process.

The initial group of 12 researchers were asked to complete a form providing demographic and disability related information. An analysis of those forms provided the following information:

Gender and age: Among them there were 8 males (67%) and 4 females (33%). Their average age was 40 years. The youngest participant was 18 years, while the oldest participant was 60 years old.

Marital status: Among them 7 persons (58%) were unmarried and 5 were married (42%).

Education: Majority of the participants (9 persons) had completed high school. Among the remaining, 1 person (8%) had primary level education while 2 persons (17%) had university level education.

Participation in the Organizations of Persons with Disabilities (DPOs): All the participants were DPO members. 3 of them, one from each county, were also NUOD coordinators. Finally, one person was also a representative of a national body (NCD coordinator) in his county.

Kinds of disabilities: 2 persons (17%) had visual disabilities, including 1 blind person and 1 person with low vision (who does not use eye glasses).

1 person (8%) had a severe hearing disability, who did not have a hearing aid. The same person also had some speaking difficulties.

9 persons (75%) had mobility difficulties including 3 persons with severe difficulties. One of them used a walking stick, one person used crutches and one person used a wheel-chair.

3 persons (25%) had impairments related to the upper limb, including one person with an arm amputation.

1 person (8%) reported difficulties related to memory and concentration.

Finally, 3 persons (58%) reported difficulties in activities of daily living such as washing and dressing. Globally 4 persons (34%) reported more than one kind of disabilities.

<u>Age at becoming disabled</u>: 3 persons had disabilities since birth (25%), another 7 persons (58%) became disabled in early childhood (less than 10 years old) while the remaining 2 persons (17%) became disabled later.

<u>Personal experiences of stigma and discrimination</u>: 10 persons (83%) reported occasional personal experiences of stigma and discrimination. For none of them, it was a serious problem.

<u>Replacement of researchers during the research process</u>: 2 researchers from Bong and 2 from Grand Gedeh counties stopped participation in the research due to different reasons and were substituted by new persons. Finally, one researcher from Grand Gedeh did not participate in any meeting in 2021 and was not replaced.

Replacement of a deaf person from Bong by a person with physical disabilities meant that 10 out of 12 researchers were persons with physical and mobility related disabilities.

4.5.3 Barriers Faced by the Researchers in their Daily Lives

During the theme meeting on family and community relationships, 11 researchers shared information about their own lives, which provides information about their successes and their challenges and the barriers they face in their daily lives. The key findings from these interviews and discussions are presented below.

<u>Family attitudes</u>: Negative family attitudes is/was a problem for some of the researchers, though in most cases it was compensated to some degree by the support and encouragement of other family members. In many cases, the success achieved by the researchers in their lives had helped in changing the negative perceptions of the family members.

For example, one of the women researchers said, "*My eldest brother, who used to work as a big person at a mining company, never had time for me. He only cared for his children and didn't consider me due to my disability. Another older brother, he looked after me. He used to take me to school in a wheel-barrow. He stood-up for me and helped me to cope with the negative comments in the school. Given my* *improvement in life, now even my eldest brother respects me and considers me as his sister*."

Another example was from one of the male researchers, who shared, "*In my family the person that was most helpful was my mother. My father did not have confidence in me due to my disability and he was harmful for my development*."

Marriage: In Liberia, marriage ceremonies are very costly due to social customs and due to bride-price to be paid as dowry to the women's families. It is common to see couples living together and having children together and then getting married when they have sufficient money.

All the male researchers were married or co-habiting with their fiancees and planning to get married, mostly with non-disabled women. For example, a male researcher said, "*I had proper marriage and I paid the dowry for my wife. We have six children*". Another man said, "*I am not married but living together with a woman. We have been together for 9 years. She helps me and does very well in cleaning my clothes, cooking and taking other care for the home. We together decided to first complete our house and then later we will get married. In the beginning, her family members discouraged her from loving me but she loved me so dearly and didn't listen to them*."

On the other hand, among the women researchers, only one was married, while the others said that finding dependable husbands was a problem for women with disabilities. The married woman researcher said, "*I am legally married to a man who really loves me. We got married in the church and my dowry was paid. He is not ashamed about my disability, and has been understanding and very helpful*."

However, the other 3 women researchers felt that men do not want stable relationships with them. One of them said, "*I am not thinking about getting married, most men are not responsible. They feel that I will be a liability. If I find a good person, I might get married. I am still a virgin*."

Looking after Children: Almost all the researchers were involved in child-care, either of their own children or of other relatives. The most common difficulties they mentioned regarding those children were economic, in terms of costs for sending them to school, buying uniforms and school-books. Many of the researchers were members of Parents-Teachers Associations (PTAs) in their children's schools. None of them reported any negative attitudes of the school authorities or about physical barriers in the schools. This might be more a reflection of their roles and visibility in their communities as leaders and different from the experiences of other disabled parents.

For example, one woman researcher said, "*I am looking after more than 10 children, including those of my brother and sisters. I go to their schools for the PTA meetings and talk to their teachers about their discipline*." A male researcher shared similar experience, "*I have 2 kids and other 2 children of relatives who live with me, so there are 4 children. As a disabled person without employment, I find it difficult to pay the kids fees and provide for their needs. I attend their PTA meetings*."

Looking after elderly persons in the family: Around 40% of the researchers were involved in taking care of some elderly person in the families. For example, one of the men said, "*I go to my mother or father when they are sick or need food. I don't have* *money to look after all their needs*." Another man said, "*I was never been very close to my parents but I always visit them when I have some money*."

Regarding looking after the elderly persons, once again the main challenges were economic and no one mentioned any other barriers.

Both marriage and looking after elderly family members and children seemed to have specific Liberian customs linked to their clans or ethnic groups, which were not very clear and were not discussed explicitly. They all seemed to understand these implicitly and these were not clarified for non-Liberians.

Community Attitudes & Participation: None of the researchers reported facing significant negative barriers in their local communities.

There were a few small complaints like a male researcher complaining that "*when he does not get sufficient time to present his point of view during a community meeting, he feels excluded*" and another said that "*sometimes the community meetings are held in places which are not easily accessible for me*".

On the other hand, most of them felt that they were respected in their communities, invited to meetings and present their opinions. One of the researchers said that this was not always so but the change had happened because of active advocacy by the persons with disabilities. Probably, it also reflected their involvement in the DPOs and their recognition as leaders by their communities.

Only a couple of researchers spoke about friends. One person said that sometimes his friends make jokes about his disability but he does not take them seriously and also makes jokes about them. A woman said, "*I don't feel excluded. I like playing games on my phone for leisure, but sometimes I visit friends to talk and joke together*."

On the other hand, many of them spoke about going to church and playing an active role in its functions. For example, one researcher said that disabled persons were part of the church choir group. Another said that he serves as organist, plays jazz drum, and holds the leadership position in his church as head of the youth department. One of the researchers agreed that some persons with disabilities in his community do feel excluded in the church but he had been very active and does not feel so.

Violence and Abuse: A couple of persons spoke about facing pejorative words linked to their disability in their families or in the community but for most of them these were past experiences which they had managed to overcome with their education and active advocacy. A couple of them said that abuse can be in the form of jokes and profanity, but they don't take these seriously and give back 'as good as they get'.

One of the male researchers confessed that he himself had problems of being violent, "*I am an ex-combatant and the war made me violent. When the war was over, I never had any trauma counselling and I often reacted violently. I was beating my partner, who then left me. However, being a part of the EDR research has helped me to understand the world in a different way, it has eased my stress and helped me to cope with people, especially when I see my fellow disabled person actively contributing to society*."

Leisure-Free time: A couple of the researchers spoke about their leisure time activities. One researcher said that he goes regularly to visit entertainment centres to listen to music. Another plays music. One of them said that he goes to the stadium to watch football and to the video club. None of them reported any specific barriers in terms of these places.

Alcoholism and drug addiction: Four researchers talked about issues of drug addiction. One said that he had participated in training courses about how to help persons with drug addiction and is involved in community advocacy and information on this theme. Another person said that in his extended family, there were some problems with drug addiction.

A third person informed that between 2014-2016, he was drinking a lot of alcohol but since then he has given it up and now only drinks sometimes for leisure. Finally, the fourth confessed that he used to be very addicted to drugs and alcohol, but now he only smokes cigarette. He said, "*I gave up drinking alcohol at the 9th EDR meeting due to advise from fellow researchers. I am also trying to quit smoking cigarettes*."

Remarks about the researchers: Two of the criteria for identification of researchers – gender and different kinds of disabilities – were both not possible to implement. The DPOs had difficulties in identifying women researchers and most of them had physical/mobility related disabilities. Both these factors point towards greater barriers faced by women and by persons with other kinds of disabilities, not only in the communities but also in the DPOs.

Though there were some researchers with severe disabilities, most common barriers emerging from their stories were economic barriers and some attitudinal barriers. Only one person spoke about "physical inaccessibility".

4.6 CONCLUSIONS

The CB-EDR implementation methodology in the 3 counties of Liberia was developed based upon the approach used successfully in other countries like India and Mongolia, though it needed more detailed guidance and instructions to the researchers on the questions to be used and their individual roles in conducting the research.

The overall methodology of CB-EDR implementation – training persons with disabilities from local communities and facilitating them to collect and analyse information on broad thematic areas perceived as a priority by them, to understand the different barriers which block their full participation and inclusion – was applied successfully in Liberia.

There were some challenges in implementing CB-EDR in Liberia due to the turn-over of the researchers which had an impact on the group dynamics as the total number of researchers was small. It also had limited participation of women and a dominance of persons with physical and mobility related disabilities among the researchers.

RESEARCH FINDINGS & THEIR SIGNIFICANCE

5. RESEARCH FINDINGS

5.1 INTRODUCTION

This chapter focuses on the understandings gained during the research about the different kinds of barriers faced by persons with different disabilities living in small county towns and rural areas of Bong, Nimba and Grand Gedeh counties of Liberia.

5.1.1 Report Analysis and Understanding the Barriers

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

- The first level of analysis was done by the researchers themselves. It was initiated when the individual researchers went out in the field and spoke to individuals, families, DPO members and other stakeholders to gather information. It continued as the 4 researchers in each county met together to discuss their findings and what they wished to take to the theme meetings. It also continued during the theme meetings, while they listened to researchers from other counties, while they shared their own findings and while they interacted with guests and other persons participating in the meetings. This first level of analysis led to practical action in relation to specific themes including advocacy activities in the communities, sharing of information with individuals and their families and with stakeholders including their own DPOs. A little bit of this information comes out this report while most of it remains with them. From the point of view of outsiders this information is 'lost'.

- The second level of analysis was based on the 13 theme-research meeting reports prepared by the rapporteur. These reports could capture only the parts that were shared formally during the plenary sessions of the meetings. Though the rapporteurs were repeatedly reminded to 'transcribe' the words of the speakers, the actual reports are mostly summaries of what was said. One of the researchers and the rapporteur were also supposed to raise issues, stimulate discussions and ask for clarifications but a cursory reading of the meeting reports shows that this happened only rarely. Some of the latter reports were prepared many months after holding the meetings and thus, it is likely that even more information was lost in those periods. All these issues underline the weakness of the research process as well as, those of its documentation process. A set of categories along with different sub-categories was used for this analysis. **Annex 4** provides details of this classification.

5.2 RESEARCH FINDINGS - BARRIERS FACED BY PERSONS WITH DISABILITIES

During the CB-EDR in Liberia, research was conducted in 13 broad thematic areas. There was some overlapping between the themes, partly due many months of block of the field researches in 2020 due to Covid-19 epidemic. In the last part of the research, there were some changes in the way the researchers conducted the interviews and thus, the last 4 theme research reports were supposed to be more detailed and provide more vivid accounts of interviewed people's lives. However, it did not happen in a uniform manner. For example, in the 13th theme research, researchers from one county (Nimba) used the protocol questions in a more systematic manner compared to those from the other 2 counties.

A summary of the key findings on each thematic area is presented below, which has been prepared by analysis and re-grouping of relevant information from different reports. More detailed analysis of each theme research report is presented in **Annex 6**.

5.2.1 Persons with Disabilities and Other Stakeholders Among the Interviewees: For each theme research, a research protocol was prepared and discussed with the researchers. It gave indications about the main issues related to the theme about which they had to collect information. It also gave indications about the kind of persons with disabilities they had to interview in terms of age, sex, kind of disabilities and other characteristics. However, these indications were not always followed.

For example, for the research on the theme of education, the researchers were asked to interview persons from 12 to 25 years of age, ensuring that 50% of them were females and a family member was present during the interviews of minors. They were also supposed to ensure that persons with different disabilities were represented among them. However, when the theme research meeting was held, it seemed that only around one-third of the respondents were in the 12-35 years age group, while the average age of the respondents was around 35 years. In terms of representation of different disabilities among the interviewees, around 42% were persons with physical and/or mobility disabilities, 38% had vision disabilities and all the other groups of persons with disabilities together formed 20%.

The information about the interviewees for each theme was not always recorded in the reports. In the 10 reports, where this information was recorded, the number of interviewees for each field research varied from 31 to 99 persons, with an average of about 55 interviews for each theme. Thus, for the total 13 theme researches, the researchers probably interviewed around 700 persons with disabilities or their families.

The researchers also collected some demographic and disability related information from the interviewees. This information was recorded unevenly in the meeting reports. Thus, we do not have the global information about education levels or livelihood or kind of disabilities about all the 700+ persons who were interviewed. However, we have some of this information in relation to specific themes. This allows us to see some broad trends and guess possible situations but does not allow us to draw any conclusions which can be generalised.

They also interviewed other stakeholders. For example, researchers from one of the counties interviewed 17 stakeholders for the research on the theme of justice and police systems. However, this information was also not recorded systematically in the reports and thus, it is not possible to analyse it systematically. However, where suitable in the following analysis, this information is presented together with the relevant thematic area.

Most of the persons who were interviewed, were identified through purposive sampling, especially with the help of specific DPOs or other institutions such as health system. This is another reason why the information about persons with disabilities and other stakeholders cannot be generalised.

5.2.2 Access to Education

Barriers to educational opportunities for children and young adults with disabilities came up during the discussions of different theme researches, in addition to the two theme researches which had a specific focus on education.

Extent of the problem: According to the research, very few children with disabilities have access to education, as seen from the examples presented below:

> Tchien district in Grand Gedeh county has a total population of about 35 thousand and if persons with disabilities are 5% of the population, we would expect more than 1500 disabled persons in the district. Since around 41% of the Liberian population is below 15 years of age, Tchien district can have more than 600 children with disabilities. However, according to the education officer of Tchien district, in 2020 there were only 10 students with disabilities in the regular schools.
>
> In Nimba county, out of the 22 persons with vision disabilities who were interviewed, only 2 had been to high school, while the remaining 20 persons (91%) had no education or a few years of elementary education.
>
> 45 persons with disabilities were interviewed in the 3 counties. Among them, 16 (35.5%) had never been to school and only one of them had informally learnt some reading and writing skills, while the remaining 15 were illiterate. 9 persons (20%) had less than 5 years of elementary education; 8 persons (18%) had been to middle or high school but did not complete high school; 7 (15.5%) had completed high school and 5 (11%) had been to university.
>
> The above 45 persons included 19 persons with mobility/physical disabilities, 17 with vision disabilities, 4 with epilepsy, 2 deaf persons and 2 persons with multiple disabilities. Among the 25 persons who had either no education or only some elementary school education, there were 11 (65%) were persons with vision disabilities, 7 (37%) were persons with physical/mobility disability, 3 (75%) were persons with epilepsy, 2 (100%) persons with multiple disabilities and 2 (100%) deaf persons.

Special schools: There were few special schools in the counties. They also lacked trained teachers, specific equipment and learning materials for disabled children. A teacher from a special school in Grand Gedeh county complained that he had no specific training, school lacked proper facilities and his monthly salary was about 13 US dollars only.

The special schools lack teachers who know sign language or the Braille. Bong county has a teachers' training college but the training course does not include any information about teaching to children with disabilities. With support from an international NGO, 2 school teachers from Grand Gedeh county were sent to Ghana for a 2 years of sign language training. However, without support for further Training of Trainers in the county, their impact will be limited.

For example, during the theme research on barriers faced by persons with vision disabilities, the researchers noted that the focus of education for children with vision disabilities was through special schools and there was the need for inclusive education in public schools, because the special schools were few and not sufficient. They reported that none of the special schools in the counties was able to teach orientation and mobility training to the blind children.

Inclusive education: While the research showed the need for inclusive education, it also highlighted some barriers in the ordinary schools. The teachers in ordinary schools lacked training, specific skills and equipment needed to include children with disabilities. An article of the new education law (4.4.1) was considered as problematic - "*A school may exempt a child entirely, partially or conditionally from free and compulsory school attendance if it is in the best interest of the child, especially those with disabilities*. (4.4.1.c.iv)". This meant that the school head-masters could decide if they wished to accept the children with disabilities and often, they refused admission to children with moderate to severe disabilities.

School buildings are not accessible to children with physical disabilities as schools with ramps are rare. Lack of persons who know sign language or Braille also has a negative impact on accessibility of the schools. Schools lack specific equipment for the inclusion of disabled children such as Braille writers or printers or head-phones or audio-books.

According to the parents of children with physical and mobility disabilities., their reasons for not sending children to schools included long distances, poverty, lack of accessible transport and high costs of private transport. Other contributing factors were negative attitudes in the communities, among the school authorities and among other students.

Widespread poverty in the counties, even more so for families with disabled persons, is another big barrier to education. There are private schools and faith-based schools in the counties but they are not accessible to disabled children due to their fees. In the Government schools, education is free but children still need uniforms and books, and even this affects the accessibility of children with disabilities as their families are poor. Most of the persons interviewed for this research did not have smart-phones and were unaware of different Apps which can help communication and notes-taking for disabled children.

Lack of accessible transport is a huge problem in rural areas where students may need to travel longer distances to reach the schools. The cost of the transport and the unwillingness of vehicle drivers and other passengers to accommodate them all contribute to the transport difficulties.

Liberia does not have production of different assistive products, from walking canes, crutches and wheel-chairs to hearing aids, nothing is produced locally. All the products are imported and sold in private market or are occasionally distributed through humanitarian organisations and thus, difficult to access in the counties. Even getting a decent pair of eye-glasses may be difficult. This is an additional barrier for children with disabilities.

A young man from Bong county who had polio as a child told that "*I had no other way except to walk on both hands and knees for going to school. Moving like that, all my clothes used to get dirty and it was even worse during rainy season. It was very tough for me to continue going to school. When I reached eight standard then a missionary helped me to get a wheel chair, so that finally I could move with dignity.*"

Parents of children with disabilities do not know that their children can be educated. Even when they know, they not know if there are any employment opportunities for them and thus feel that education is not useful. Lack of resources for school expenses and transport coupled with physical barriers and lack of assistive products are additional negative influencing factors.

Negative attitudes: Negative attitudes in the peers, teachers, professionals and general communities prevent children with disabilities to come out of isolation. In the rural areas and small towns, many believe that disabled children are witches or bring misfortune and are thus actively avoided. The negative attitudes in the communities and in parents of the other children put pressure on the schools to refuse admission to disabled children.

An education officer from Grand Gedeh county felt that unless the communities understand and start to support the education for disabled children, it will be very difficult to change this situation.

Growing up isolated and surrounded by negative attitudes in the families and communities, children with disabilities often lack self-confidence and self-esteem. Even when they start going to school, mocking and bullying by the other children and lack of support from schools often lead to abandonment of studies.

The interviews showed that some groups of children and young persons with disabilities including those with hearing and speech problems and those with intellectual disabilities face even more barriers compared to other groups.

During the theme research on education, in Nimba county the researchers collected information from 30 interviewees regarding negative attitudes. Among them, 9 persons (30%) shared positive experiences, where they found respect and understanding, while the remaining 21 persons (70%) spoke of different difficulties they faced in the schools.

In terms of peer relationships, most of those who spoke about it, had mixed experiences – some helpful classmates, others who did not support them and some who made fun of them or called them names. Only a few researchers spoke of teachers and most of them said that though the school did not have any facilities for disabled students, the teachers were supportive.

There were a few positive stories. For example, a disabled boy in the Bong county, who had a computer and whose classmates shared notes with him and his teachers sent him learning materials by email.

Teachers' opinions: The meeting report provided information about 7 interviews with school teachers. Their age-range was 25 to 62 years. Among them, there were 4 men and 3 women. 2 females who were teaching in elementary school had only high school diploma while the remaining 5 persons had university education. None of them had any specific training about dealing with and teaching to disabled children. They had 5 to 33 years of teaching experience. Two teachers had 1-4 children with mild disabilities in their classes. All of them felt that their schools were not accessible, they had no specific equipment or materials or training to deal with children with disabilities.

Action against the barriers: The new Inclusive Education policy finalised by the Government in December 2018 foresees acceptance of all children with disabilities in ordinary schools – county DPOs need to become familiar with the new policy and use it to strengthen advocacy activities in the counties so that more children can go to schools. The new policy also plans for training of all the school teachers.

5.2.3 Access to Health: Compared to the discussions about education, the issues related to health and health services raised during the CB-EDR were limited.

Attitudes, knowledge and skills of the Health Professionals: The researchers agreed that health services in the counties face different challenges but many health professionals are helpful. A total of 39 persons with disabilities in the three counties, shared information about their experiences about the attitudes of health professionals during their visits to the health services – 23 persons (59%) felt that health workers and nurses were helpful and supportive, while the remaining 16 persons (41%) had negative experiences.

However, many women with disabilities shared that their experiences with the health services in relation to pregnancy and child-birth were negative because of the negative attitudes of the staff. Many health professionals feel that disabled women should not have children and can be very negative. Many women said that they preferred to have child-birth at home and not at the hospital or clinic.

However, the researchers felt that health workers do not know much about disabilities and even less about intellectual disabilities and mental illness. In the hospitals and clinics, persons with disabilities were often kept waiting and attended only after all the other persons needing health care. In the counties there were few or no specialists and no one knew how to take care for serious conditions such as strokes.

Most persons with disabilities could not afford to pay for services at private clinics. At the government hospital the services were supposed to be free, but usually persons needed to buy their medicines and other things required for medical care. Therefore, financial barriers were perceived as the most significant barriers

Other Barriers in Accessing Health Services: The major difficulties in accessing health services were physical barriers in the buildings, long waiting times and high costs of the medicines.

Often disabled persons have little or no knowledge regarding their health conditions, their disabilities and the different treatment options.

Barriers perceived by specific groups of persons with disabilities: Persons with vision disabilities said that the health services do not think of the needs of blind and low-vision persons and unless they are accompanied by a family member, no one communicates with them. Similar problems were reported by deaf persons, who faced communication difficulties.

Elderly persons with cataracts said that it was impossible to have cataract operations in counties, as the costs are very high and there are no specialists.

Persons with epilepsy convulsions also complained of widespread lack of awareness about medications for treating convulsions among the people and at the same time, facing difficulties in receiving regular anti-convulsion medicines from the health services.

For persons with physical and mobility disabilities, long distances and bad conditions of roads was a big barrier. Another difficulty in accessing the health services was physical barriers, as hospitals and clinics have many stairs and there are no ramps. For example, at the main hospital of Grand Gedeh (Martha Tubman Hospital), there were stairs even for entering the emergency room.

Other examples of difficulties faced by persons with physical disabilities included -the beds were very high, the x-ray machine was not be suitable for a person with physical disability, and the child delivery room is not suitable for women with disabilities. One of the researchers from Bong county who used a wheel-chair shared his difficulties: "*Whenever I visit the hospital, I have to crawl on my kneels to visit the various departments for check-ups, registration, treatment etc. as there are no ramps*."

5.2.4 Barriers to Assistive Products: Receiving assistive products for different disabilities was a huge problem for all the different groups of persons with disabilities, as Liberia does not have local production of any kind of assistive products. After the end of the civil war, some international organisations have started services for producing some orthotics and prosthesis but these were all interrupted due to the Ebola crisis in 2014. Some technicians trained by INGOs were still active in the counties and could repair old assistive devices. Social Welfare department had provided some financial contributions to buy appliances to residential institutions for persons with disabilities but not to individuals in the counties.

Extent of the problem: Most persons said that they had old products, which they repaired and kept on using. During a theme research, 40 persons from the 3 counties answered the question regarding use of an assistive product. Among them, 19 persons had physical/mobility disabilities and 6 of them (32%) needed assistive products, while 13 of them had a product (1 artificial leg, 9 crutches, 1 wheelchair, 2 walking sticks). Among them 17 persons had vision disabilities, and 7 (41%) had no assistive product while 10 persons had them (7 white canes, 3 eye-glasses). Among the remaining 4 persons with different disabilities, no one had any assistive products.

During the whole research process, about 20 persons with hearing problems were interviewed, none of them had a hearing aid.

During another theme research, 24 interviewees from the 3 counties answered the question regarding mobile phones – 9 (37.5%) had no mobile phones, 10 of them (42%) had old style phones and 5 (20.5%) had some kind of smart phone.

Comments from persons with specific disabilities: From eye-glasses and Braille writers to white canes, none of the assistive products commonly used by persons with vision disabilities are easily available in Liberia. There is no orientation and mobility training in the counties, not even in the special schools.

There was no production of orthopaedic appliances in the country. Even the inner tubes for certain tyres of a wheelchairs had to be bought in neighbouring countries. At the Rehab department of the national hospital JFK in Monrovia, there were no appliances like wheelchairs and crutches. A researcher from Bong county said: "*The persons with physical and mobility disabilities whom we interviewed, even those with amputations or paralysis, didn't have wheel chairs or crutches. Only two persons had old wheel chairs. Those who need crutches, they usually try to make something on their own but those who need a wheel chair, they have to crawl.*"

There was a market in Monrovia where they sell some appliances brought from Ghana and Nigeria, but the costs are high.

The persons with disabilities due to leprosy also faced difficulties even if an international organisation provides some support to the leprosy rehabilitation centre located in Gompa/Ganta. An orthopaedic technician from Nimba county, who was trained by an INGO said: "*My father had leprosy, he had lost all of his fingers due to the disease. Proper appliances can help in ensuring mobility and inclusion however, in our country no one can get all the products that they need. Very often people make wrong choices about products which can create problems and complications.*

Persons with albinism often have very low vision and they require specially made eyeglasses. Most of the persons with albinism complained that they were unable to get satisfactory eyeglasses in Liberia because the country lacks trained opticians who can make the lens for persons with both vertical and spherical errors.

5.2.5 Access to Livelihood and Economic barriers: Issues related to lack of livelihood opportunities and widespread poverty were raised repeatedly during the research and affected a lot of persons though families with a disabled person were among those worst affected. While persons with disabilities complained about lack of skills and vocational training opportunities, they also felt that even with such skills, finding paid jobs in the counties was very difficult.

Extent of the problem: During a theme meeting, information regarding livelihood and occupation was asked from 30 persons with disabilities in the age group of 18 to 62 years. Among them, only 2 persons (about 7%) had paid jobs (a dispenser and a school teacher), while there was another person, who was a teacher but she had lost her job after becoming disabled. The remaining 93% had some income from informal jobs or begging. The most frequent occupation for 16 persons (57%) was a self-run business, which was usually a small sales-point (setting up something to sell on a table in an open area known as table market) or informal selling on the roads. Another 11 (37%) described their work as farming/agriculture, while 2 were beggars. Many of them were doing more than one income-generation activity but most of them also needed some family or charity support for their daily needs. They included one homeless person and two, who were living with their families in an abandoned building.

Barriers to Livelihood: The most common barriers was "lack of job opportunities" in the counties.

Lack of self-confidence was also seen as an important barrier to livelihood, identified and discussed by all the three groups. It was expressed in different ways – not having the confidence to get a bank loan, lack of self-trust and fear of success.

Lack of finance was another common barrier, discussed in two groups. Banks did not see them as reliable persons for receiving loans. They also lacked management skills.

One interviewee said: "*Often persons think that disabled persons are into witchcraft and so they don't want to give us a job. Limited public trust in capacities of persons with disabilities is a barrier.*"

Barriers to Livelihood perceived by specific groups of persons with disabilities: Persons with vision disabilities said that there were no jobs, their only options were informal selling or begging. Many persons said that lack of any technical working skills and assistive devices were both big barriers. At the same time, they also felt that even for persons with skills, the employment opportunities for them are limited or even non-existent. Their only option was to start something on their own.

In Nimba county, a group of persons with physical and mobility disabilities said that some of them were engaged in informal work – for example, working on farms or gardens, selling different types of goods, weaving fishing baskets and making nets. Some of them were part of local savings and financial clubs in the communities. Among them 4 persons said that they had vocational skills but still had found no paid work.

5.2.6 Barriers related to Police and Justice Systems: During initial discussions while planning the priorities in the research themes, some researchers felt that this was an important area. For example, one researcher had said that persons with vision disabilities were not taken seriously by the police and the justice system and when they want to lodge a complaint, police did not listen to them and sometimes, they may be put in jail without a proper enquiry.

However, the research on this theme brought out a different situation. This did not mean that there were no barriers, but rather that the barriers were mostly of inaccessibility of buildings and lack of support for Braille and sign language.

For example, in one of the counties, all the interviewees talked about physical inaccessibility of most buildings of police, courts and jails; however, no one of them reported being subjected to negative attitudes due to their disabilities – instead, a couple of persons accepted that they were given additional benefits and preferential treatment by the justice system.

Extent of the problem: During the theme research on this theme 43 persons were interviewed, including about 44% women. 16 persons (37%) had some experience of dealing with the police – among them, 13 (81%) felt that the police had treated them fairly and was supportive of their disability, while 3 persons (19%) felt that police did not understand their disability and was not helpful. For example, a person with epilepsy described his experience of having a convulsion in the police station and the police had been afraid of him and had accused him of witchcraft.

13 persons (30%) had experiences in the court – among them, 10 persons (77%) said that judges and magistrates were understanding of their condition and were helpful, while 3 persons (23%) felt that courts did not treat them properly. For example, one person said that a magistrate called him a cripple.

Only 3 persons (7%) among the interviewees had been in a jail and all of them felt that in the jail they were treated fairly and the jail officers had been supportive of their disability.

Thus, the research did not bring out any big barriers related to negative treatment of persons with disabilities in the police and justice system. The biggest challenges were linked to physical inaccessibility of buildings, high cost of the court fees and lawyers and lack of equipment and facilities for persons with disabilities such as Braille printers and sign language translators.

A researcher from Bong county explained that there is a regional disability hub in their county with a public outreach office where persons with disabilities can present complaints regarding any violation of human rights. The researchers also noted that Government of Liberia wants to include disability related questions in the next national census (planned for 2022) and that NUOD is working with National Institute of Geo-Information Services (LIGIS) to ensure this.

5.2.7 Gender-related barriers: Researches across different themes brought out much bigger barriers faced by women and girls with disabilities compared to those faced by men and boys.

Extent of the problem: In one theme research, a total of 54 persons with disabilities (32 male and 22 females) were interviewed. Among them, around one third of the men had never been to school while among the women, almost 60% had never been to school. In this same group, information regarding marriage/living with a partner showed that more than 70% of men were married or had a cohabiting partner, while among women the percentage was 50%.

In another theme research, out of the 15 female interviewees, 11 had had at least one experience of having a child. They shared information about their experiences with the health services during their pregnancy and child-birth. 8 of them (73%) had some negative experience in the health system including negative attitudes, lack of care, abuse by the staff, lack of proper beds and equipment for women with disabilities, and lack of communication. Almost all of them felt that it was better for them to deliver at home.

Experiences of women with specific disabilities: Researchers from Bong county said that the participation of girls and young women with vision impairments in schools was a problem, they faced greater barriers. Grand Gedeh county researchers reported that in their area, some people think that blind women are witches and mistreat them.

Researchers from Nimba and Grand Gedeh counties said that women with disabilities more difficulties in finding men willing for stable relationships with them. Very often, men leave them when they get pregnant and do not provide any support for their children. Complaining about them to the village councils did not show much results.

Speaking of high costs of education, Nimba county researchers reported that some female students with disabilities were forced into prostitution or into accepting sexual favours to earn money for paying their living and school expenses.

5.2.8 Barriers in the Families and Communities: Many testimonies during the research underlined the fundamental role of families in ensuring food, shelter and living support for persons with disabilities, as there were no other institutions in the counties which can provide systematic help. For example, a woman who had polio as a child said: "*My elder sister took care of me and taught me to use crutches. When I was 12, she accompanied to the mission school and talked to the school principal for my admission.*"

With a few exceptions, most persons who had become disabled in the childhood, spoke of receiving love in the families, especially from their mothers and some siblings. Some persons said that their fathers had abandoned the family due to their disabilities. However, about 50% of the adults complained of strained relationships with their siblings and parents, some for their part of the family property. Many of them felt excluded in the family gatherings and discussions.

Community participation: In one theme research, interviewees were asked if they had ever been to a village council meeting and to describe their experience. 17 (40%) out of 43 interviewees responded that they had experiences with the village councils. Among those 17, 10 persons (59%) felt that the council was fair and helpful to them and listened to them. The remaining 7 persons (41%) had negative experiences in the council. For example, 2 persons complained that the council accused them of witchcraft due to their disability; 2 persons felt that their opinion were ignored by the council while some persons complained of inaccessible meeting places.

In terms of community institutions, many interviewees spoke of going regularly to church and playing an active role in the church activities. Some of them received charitable help from the church.

Another community institution mentioned by many participants was the parents-teacher associations (PTAs) of their children. Even here, most of the testimonies were positive and many parents with disabilities played an active role in the PTAs of their children.

Negative attitudes and lack of knowledge in families and communities: Theme research on barriers faced by persons with visual impairments concluded that most parents have no understanding about the importance of schools education for their children, and must do not try to make their children independent through the orientation and mobility training.

Public transport is another difficult area as private vehicles do not wish to take in blind persons, and often they have to wait for 3-4 hours before getting someone who accepts them. Inside the vehicles, no one wants to sit near them. This is because many persons in the community believe that blind persons can do witchcraft. For this reason, even the families regard their children with very low or no vision as carriers of bad luck and abandon them.

Persons with leprosy disabilities spoke of strong social stigma and therefore, they are often abandoned by their families. Persons with epilepsy and albinism also spoke of difficulties due to social stigma.

5.2.9 Continuing impact of the Civil War on Persons with Disabilities: Though the civil war finished 17 years ago, some of its impact still continues to be felt by the persons with disabilities. All the researchers of CB-EDR had their own war related experiences and for some of them, the brutality of the violence had left a sign on their minds and hearts.

Many former soldiers witnessed the gruesome murders of their family members and relatives. They are mostly perceived by the people as perpetrators of the war and not seen as victims. Many of them became physically disabled during the war, while many more carry psychological wounds of their experiences. Some of them live on the streets in a poor condition and are called Zogoes. Many of them had no life skills and no means of livelihood at the end of the war. Many of them have substance abuse problems.

The researchers themselves included different persons who had taken part in the violence and had seen violence against their family members. One of the researchers said that he was forced to become a child soldier after seeing the killing of some of his family members. Another person sharing his experiences as a child soldier, talked of violence among the soldiers including the cutting of his ear as a punishment, and how today his cut ear is seen as the sign of being a thief by some community members, who make jokes about it. Yet another person who was a child soldier talked of the rape of his sister. Thus, war experiences had closed links with mental health conditions.

Researchers from Grand Gedeh talked of the social stigma of being disabled ex-soldiers and how the communities see their disability as a just punishment for their war crimes and they are considered unworthy of receiving any assistance.

Researchers from Nimba spoke about a disabled woman who was forced to have sex with soldiers in exchange for food for her children and the social stigma she still carries within herself because of those experiences. Another researcher talked of his abandonment by his family, who had left him with missionaries because he was disabled and could not walk with the rest of the family to escape from the war area. Another researcher shared the story of an ex-soldier in his village whose both ears were cut by his commandant as a punishment and how it creates strong social stigma for him.

The researchers felt that most persons with psychological trauma, of seeing violence, of experiencing violence and of inflicting violence on others, need counselling and support but such support has not been provided in a systematic way. They avoid talking about it but deep inside those psychological scars continue to hurt them.

5.2.10 Barriers faced by Persons with Specific Disabilities Associated with social stigma: Many of the challenges faced by persons with stigmatizing disabling conditions have been mentioned under other headings. However, there are a few aspects of this issue which need more attention and are presented here.

On cross-cutting themes such as livelihood or education or social relationships, around 50-60% of interviewees were persons with physical or mobility disabilities, another 20-30% were with vision disabilities while the remaining 10-20% interviews included persons with other disabilities.

To understand the specific barriers faced by persons with other disabilities, a specific theme research was organised. This meeting report was incomplete - out of 50 interviews, it provided details about 22 interviewees. Among those 22 interviewees, there were 2 short persons, 9 persons with hearing and/or speech disabilities, 1 person with leprosy, 1 person with burns and Buruli ulcer, 4 persons with epilepsy, 2 with albinism, 1 person with intellectual disability and 1 with multiple disabilities. An analysis of the information collected from them showed that about one third of the respondents had negative experiences in the family ranging from neglect and negative attitudes to abuse. Around 40% of the respondents perceived negative behaviour in the community ranging from mocking, name calling to accusations of witchcraft, while almost 75% did not know about DPOs.

Specific groups of persons with disabilities, especially those with epilepsy and those with speech and communication difficulties faced greater barriers compared to the other groups. Persons with albinism reported difficulties in getting appropriate eyeglasses and thus faced difficulties in educational institutions and workplaces. Persons with epilepsy faced difficulties in receiving medication.

Challenges of talking about barriers faced by persons with mental health conditions: There were repeated attempts to involve persons with mental health conditions in the research. One theme meeting was organised focusing on this specific issue, yet it was almost impossible to discuss the specific barriers they face during the research. There is a national DPO in Liberia which brings together persons with mental health conditions and persons with epilepsy. However, almost all discussions in the research were limited to persons with epilepsy.

For example, in the theme research on mental health conditions, the researchers from the 3 counties had interviewed a total of 54 persons including 34 persons (63%) with epilepsy and 20 persons (37%) with mental illness. However, all of the researchers spoke almost exclusively about the barriers faced by persons with epilepsy, while the information about the persons with mental health conditions was limited to some details about their strange behaviours. Though a representative from the DPO (Care for Users' Hope or CFUH) participated in a couple of theme meetings, this did not help in bring out any discussions on the specific barriers faced by persons with mental health conditions.

There was only one testimony regarding the lack of understanding among families regarding mental health conditions. A 33 years old woman with mental illness shared her story: "*Since my parents were farmers, they did not understand about my mental illness. They used to tie a chain on my legs, lock me in the house and went to the farm without giving me any food and water. People started to call me a witch. When my sister from the city came to visit us, she saw my condition. She told my mother that I* *was not a witch and I needed to go for medical treatment. I was later taken to the hospital and got treated. The main challenges I faced at the time was lack of financial support and lack of information about health care*."

5.2.11 Barriers to Sports & Leisure activities: While the owners and administrators of entertainment centres, film halls and stadiums said that they would be happy to make an effort to allow persons with disabilities to join their activities, a few interviewees said that they did not like going out because of the mocking reactions of the non-disabled people. A much bigger barrier was economic.

Many persons with disabilities said that they liked to watch football while a few said that they liked kick-boxing or basket-ball or other sports. However, hardly anyone had experience of actually going out to try to play anything.

There were a few positive stories about participation in sports and leisure activities. Some of these were linked with the Liberia Amputee and Sports Federation which was created in 2017. Through this federation, disabled sports-persons from Liberia have won some international competitions in amputee football. They are now trying to start wheel-chair basketball and set-up county branches and a team from Liberia took part in the Tokyo Paralympics held in 2021 even if they did not win any medals.

5.2.12 Barriers in the DPOs themselves

Some groups of persons with disabilities (such as persons affected with leprosy, person with mental illness, person with epilepsy, albino persons, deaf person, person with speech difficulties and persons with intellectual disabilities) faced barriers even in the DPOs and SHGs, and were little represented in the DPO-membership. Some other groups such as persons with visual impairments were better represented in Bong county as that DPO was started by a blind person while their percentage in the other 2 counties was lesser.

In the Bong county, they found that 77% of the interviewees had no knowledge about the DPOs and their roles. In another theme research in Nimba county they found that 65% of the interviewees did not know about the DPOs and their roles.

Even when persons were part of a county DPO, issues of physical accessibility of the DPO offices and difficulties of the transport services were a barrier to their participation. Most members came to DPO offices only when they knew that there was going to be distribution of some benefits.

At the same time, the DPOs had limited membership and little understanding of the challenges faced by persons with other disabilities including hearing and speech disabilities, intellectual disabilities, persons with albinism or leprosy, and short persons. Thus, there advocacy activities did not raise these issues.

5.2.13 Accessibility Audits in the Counties

The researchers were asked to visit the government and private institutions related to the research themes and provide accessibility audit reports. The reporting of these accessibility audits was very uneven in the meeting reports but its results were overwhelming negative. In all the three counties, it was rare to find a public building or infrastructure, including schools, clinics, hospitals, government offices, banks, and market places, which were completely free of physical barriers. They lacked signboards. Even if the buildings were inaccessible, some of the administrators had some idea about physical barriers and many of them promised to build ramps and to find some solutions. However, there was no understanding and attention towards reaching out to persons with hearing, speech and vision difficulties.

The situation was particularly serious in Grand Gedeh county, which is not connected to Monrovia by a proper road and traveling in the county during the rainy season is impossible. Thus, in Grand Gedeh, both buildings as well as unbuilt environment presented accessibility challenges. However, the situation was serious also in the other 2 counties.

For example, for one theme research, the researchers in the Bong county visited different buildings and conducted accessibility audits. The buildings included a bank, the offices of local authorities, education officer's office, churches, university and school buildings. They found wide-spread physical barriers which did not allow easy access to persons with crutches and wheel-chairs in all those buildings. They estimated that more than 90% of the public buildings in the county were not accessible to them.

One wheel-chair user from Nimba county said, "*Even the main city streets of our town, which is the county capital, does not have any sidewalks, so with my wheel-chair, I must pass on the roads in the middle of the traffic, risking my life every time I go out. So, you can imagine the situation in the rest of the county*."

5.3 CONCLUSIONS

The implementation of the research on different themes perceived as important by persons with disabilities representing the DPOs from the three counties faced a large number of challenges, including challenges with preparation of the meeting reports. However, as the above analysis shows, for the first time, it is also providing some details about what does it mean to be live as a person with disability in a small town or a rural area in a county in Liberia. No such information about barriers faced by persons with disabilities in Liberia exists.

While there were challenges in documenting the research findings, first by the researchers themselves and then by the meeting rapporteurs, there were almost 700 interviews and there were numerous discussions among persons with disabilities, in the self-help groups and in the DPOs about the issues those researchers were identifying and asking. It would be useful to interview these researchers and other persons from the DPOs in a few years to see the real impact of this research process on them.

Among the challenges faced by the researchers were low literacy levels among the researchers and among the persons they interviewed in their local communities. Widespread and high levels of poverty was another big challenge, in front of which often it was difficult to speak of other barriers. Lack of institutions providing different services, from schools to clinics to other public institutions, was another big challenge because it forced people to look for self-help and independent solutions to their problems. All these factors influenced the quality of discussions during the research.

The researchers themselves and most of the persons who came in contact with them, had many experiences linked with the long decades of the civil war and the brutal violence associated with it – it was an unexpected insight from the research.

The research showed that in a society marked by widespread poverty and where basic human rights such as access to education and health are inadequate, there all the poor persons in the communities face barriers and challenges. In this situation, disability became an additional marker of exclusion, worsening other deprivations. Gender and disability, and specific stigmatizing disability conditions, are additional markers which worsen the access to basic human rights.

Compared to EDR experiences in other countries, in the three counties of Liberia, often the interviews remained superficial in terms of personal challenges faced by individuals in their daily lives while the episodes of abuse and exclusion were mentioned briefly and without much emphasis. This became even more critical in the last period of the research as the international research coordinator could not travel to Liberia due to Covid-19 restrictions and there were no specific persons to accompany the researchers and to remind them about the use of the protocols. The staff who accompanied the researchers over late 2021 and first half of 2021, had other responsibilities and limited understanding about the research process.

However, in spite of all these challenges and limitations, this research has managed to bring out some the key barriers faced by different groups of persons with disabilities living in the three counties (Bong, Nimba and Grand Gedeh) in Liberia.

6. IMPACT OF THE RESEARCH

One of the objectives of CB-EDR was to promote the empowerment of the persons participating in it. 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.

The testimonies of the researchers during the last EDR meeting held in May 2021 provide an insight into its impact on their empowerment and how it helped them to bring about some changes in the DPOs, local institutions and communities.

This chapter focuses on these two aspects of the impact of the research. It also presents the results of the measurement of the empowerment though an experimental questionnaire during two separate moments of this research process, which provide an indirect testimony to the impact of CB-EDR. Finally, this chapter briefly examines the impact of the research on the partner organisation, NUOD.

6.1 VOICES OF THE RESEARCHERS REGARDING THE IMPACT OF CB-EDR

During the last theme research meeting held in May 2021, all the researchers discussed the impact of being a part of the CB-EDR process on themselves, on the county DPOs and on other local institutions and communities. Here is a summary of the main findings which emerged in this discussion:

Arthur Bondo/Bong County: I am the NUOD coordinator for Bong county, so I can tell about the impact of EDR in different places in our county. During the research I visited and interacted many times with different county authorities, to ask questions and to inform. I have been hired as an advisor to the County administration on disability issues, which means that now I am also seen as a reference person in my community. My interactions with the key stakeholders in the county have improved.

Now, our county DPOs have become more inclusive and are open to different disabilities. Before EDR, they were only looking at 3 categories of disabilities – vision, physical and hearing. Now they include all persons, such as those with albinism, epilepsy and leprosy.

Before EDR, the educational sector had never worried about accessibility but as a result of our interactions, the Bong county education-officer along with his team is now conducting an assessment of the schools and the goal is to ensure accessibility at all the major public and private schools. During one of the theme research meeting of EDR, representatives from Ministry of Education had participated in our meeting and that helped them to gain some understanding about the importance of accessibility issues.

We had also invited a court official in one of our theme meetings on justice and police. Now in the court, whenever a disabled person is accused or arrested, they inform the DPO and ask for our participation in the discussions.

Nenlay Doe/Nimba County: I am the NUOD coordinator for Nimba so I know the situation and I can talk about our county. During EDR, I have visited schools, clinics, courthouse, police station, county administration, communities, everywhere. Due to this, I am now recognised in all the communities and in institutions – from the schools to the government offices, everyone knows me now. I have been talking to high level government officials on the issues of accessibility and this has promoted some action. For example, the mayor of the county city Sanniquellie has promised us to ensure full accessibility to the city hall.

Another change due to the EDR, is that now persons with different disabilities are joining the county DPOs. Therefore, the membership of the county DPOs has increased and new persons are bringing new ideas to the organisations. The DPOs have seen advocacy in action, so they are more active.

One area on which the research has had significant impact is that of schools. Many schools were not accessible for children with disabilities but during the research we conducted accessibility audits and gave those reports to the school authorities, so some schools have constructed ramps.

Augustine Padmore/Grand Gedeh County: Due to our participation in the EDR, our DPO has become stronger in advocacy and engagement with the local authorities. It also engages more with parents of children with disabilities to make sure that they send their children to school and also to make sure that those children become part of a DPO and understand the roles and importance of DPOs.

For example, during the research once I visited a faraway village. There was a 5 years old child with mobility disability who was kept closed at home. After I spoke with his parents, he began attending a pre-school centre.

Joanna Kollie/Bong County: By participating in the research, I have changed personally and this had an impact on our DPO. Before becoming a researcher, during our DPO meetings, only the president and vice-president used to speak and anything they said was taken as the final word. Slowly, I started talking and now the process is more open and more persons have the opportunity to contribute to the discussions.

There were many barriers in our communities. Many community services and meeting places, we were not joining them because most of those places were not accessible. During the research, we went around to different community places and we did the accessibility audit and informed them that those places were a barrier to participation. This helped to raise awareness about accessibility so that community can make a change.

Gabriel Sow/Nimba County: The EDR has impacted our communities. For example, during the research, we found that most persons with mental illness and epilepsy were not going for treatment because they thought that they had no money to buy medicines. We found that the health centres were providing free medication for them and so we informed them. Many of them are now taking treatment.

We have become more aware of the needs of the different groups of persons with disabilities. For example, I understand better the needs of persons with speech and hearing disabilities, so I can explain to the parents the importance of sending their children to the deaf school in our community. Our interaction with teachers also had a positive impact - some teachers said they were going to be more inclusive and will ensure accessibility in the classroom. One disabled person from our community has been hired to teach at a teachers' college in Ganta.

Felix Chellah/Grand Gedeh County: Due to my participation in the research, our DPO has changed. We have more members and many groups of persons who were not a part of our DPO have now joined it. For example, before the research, people who are living with epilepsy thought that they can't be a member of a DPO but now many of them have joined us.

Research also had some impact on the institutions in our communities. For example, I went for conducting an accessibility audit at a local school and after the findings were submitted to them, the school administration got built ramps in 2 strategic places.

Emary Jessie/Bong County: I am the founder-president of our DPO. Participation in the research has helped to make our DPO stronger. Our meetings and our dialogue have improved within the organisation and we have improved our rules. We have also expanded our membership with additional new groups in isolated areas of our county.

The questionnaires which we developed for theme researches of EDR, they have been useful for us to document the DPO membership. They have helped to create a lot of awareness in the communities. They have also helped us to uncover some major issues faced by disabled persons in our communities about which we were not aware and now we can take action.

Albestine Tozay/Nimba County: I am the president of the county level DPO federation in Nimba. As a result of the research, our member DPOs have been encouraged to work in teams and not depend on a single person because that is the only way we can impact the communities. Our members have reacted positively and are more active.

Our meetings and discussions with the district education office were initially difficult because they did not understand the issue about disability in education. After repeated dialogue and researchers engaging them and their participation in a research meeting, they invited me to become a part of district education team and through this role I want to champion the inclusion of children with disabilities in the education sector.

Besides, our county has decided to build a disability centre and it should be ready soon. The mayor invited me as a representative of persons with disabilities to be a part of the county advocacy taskforce. So, through the research, we have been able to make some important changes in our county.

Winston Warwulu/Bong County: As a result of participation in the EDR, I learned about the importance of uniting our forces and making joint action. Therefore, along with other persons in our community we have setup the Bong County Disabled Network, which brings together all the DPOs in the county. It is being legally registered.

We were afraid of taking part in the political system in the county, but participation in EDR and visiting authorities, institutions and community leaders has helped to build our confidence. Some persons who play an active role in the DPOs, they are now thinking of contesting elections and raising the issues of persons with disabilities in the national assembly.

Conclusion: The researchers had presented a picture of different directions in which their participation in the CB-EDR process had led to different changes in their organisations as well as in local institutions and communities. It might be useful to talk with these same individuals, as well as with others not involved in the research, after a couple of years to see the medium-term durability and impact of those changes.

Experience from other CB-EDR interventions shows that changes rarely happen only due to one specific activity. DASU project itself had many other activities in those same counties, so some of the changes presented by the researchers could also have been influenced by other activities. In any case, it may not be possible and it may not be really important to be able to show how many of these changes were exclusively due to the CB-EDR initiative.

6.2 IMPACT OF CB-EDR ON THE EMPOWERMENT OF THE RESEARCHERS

As the report shows, this research process was far from perfect – often specific theme researches were superficial, the researchers did not ask many important questions and sometimes they did not go deeper to understand the hows and whys of the barriers encountered by persons with disabilities in their daily lives. Economic deprivation plays such a big role in the lives of persons with disabilities living in the 3 counties covered under the research that often it dominated the research discussions, to the exclusion of all other dimensions of barriers. Yet, in spite of all these limitations, the words of the researchers above and in chapter 2 of this report express the different ways in which CB-EDR empowered them.

During a discussion with the researchers in May 2019 about their experiences of empowerment, one of the researchers had said: "*Becoming a researcher means learning to ask questions and not accepting the things as they are. We grow up in the middle of the barriers, so we think that that is the way things are and we just accept them. Learning to question is the first step of empowerment. Sometimes, this is enough to change your life because we learn to become proactive.*"

A questionnaire for measuring empowerment was developed through participatory methodology in the CB-EDR process in India in 2010. This questionnaire was inspired by the 3-dimensional framework for empowerment measurement and through discussions, 4 domains of empowerment measurement were identified for the EDR process involving persons with disabilities – family, community, disability and DPO. On each domain, individuals were asked to express perceived changes in a sliding scale (Likert scale), where 0 or 1 meant minimum change and 4 or 5 expressed maximum change.

This questionnaire was further refined in another CB-EDR initiative in Mongolia in 2019, where additional questions were added to it, though the 4 domains remained unchanged.

The same questionnaire was used among the researchers in Liberia in October 2019 and March 2021. Though this questionnaire has not been verified for internal coherence and has not been standardised, it has been discussed and approved by persons with disabilities trained as researchers in CB-EDR initiatives, who feel that it does catch most of the areas which they feel are part of their empowerment. Thus, it can provide an additional input on the impact of participation in the CB-EDR process among the researchers in Liberia.

Indirectly, the questionnaire also looks at the areas suggested by Zimmerman and discussed in chapter 3 of this report – control over one's life and decisions, critical awareness about one's situation and participation in events and activities to change the situation, along with hopefulness, socio-political awareness and a feeling of being capable.

The questionnaire used for the measurement of empowerment in Liberia is presented in **Annex 5** of this report.

Unfortunately, it was not used at the beginning of the EDR process in Liberia in October 2018, thus the comparison presented in it does not refer to the baseline situation at the beginning of the process. The questions along with average scores of the researchers for each question in October 2019 and March 2021 are presented in the table 1 below:

Table 1: Average Empowerment Scores of Researchers

Area of Empowerment	Average score 2019	Average score 2021
Participation in DPO	4.5	4.2
Speaking out in DPO meetings	4.8	4.3
Understanding different disabilities	4.2	3.9
Understanding different barriers	3.9	3.9
Decision-making about your life	3.9	4.5
Participation in family decisions	4.3	5.0
Expressing opinions in community	4.0	4.5
Fighting for the rights	3.8	4.5
Inform & advise other disabled persons	4.0	4.8
Inform & advise parents of CwDs	3.8	4.6
Advocacy with different professionals	3.6	4.4
Sharing personal experiences	4.8	5.0
Total Average Score	49.5	53.5

Thus, the scores above do not represent a perceived change among the researchers from "before" to "after" joining the EDR process. Instead, they measure empowerment along the process – one after joining the process and at the end of the process.

While the total scores show an increase after longer participation in EDR, the scores for individual questions show variability – some were higher in the first measurement, and some were higher in the second measurement. This variability might represent the influence of recent experiences linked with the question-domains or subjective feelings of individuals.

Since the questionnaire has not been standardised and controlled for coherence and internal validity, its importance by itself is limited but seen along with qualitative discussions about the impact of the research participation, it does provide additional evidence.

6.3 IMPACT OF CB-EDR ON NUOD AND OTHER STAKEHOLDERS

The research in the counties was organised in partnership with the national umbrella organisation of Disabled Peoples' Organisations (National Union of Organisations of Disabled – NUOD) in Liberia.

NUOD took an active role in the research process. It helped in the identification of researchers through its network of county organisations. It was represented in the Technical Advisory Group (TAG) created for the research. The county-coordinators appointed by NUOD in each of the three counties were part of the researchers. During the different theme meetings during the EDR process, some its Board members participated in the meetings or suggested specific guests to be invited to those meetings.

Thus, even if persons from central office of NUOD in Monrovia did not take part in the field activities of the research, they had different ways of being involved in the process, especially at the county level. Therefore, the impact of CB-EDR process on the central structure of NUOD in Monrovia might have been limited, it had a strong impact on the NUOD county coordinators in the three counties. The feedback from the three counties was positive regarding the impact of the research on DPO membership, inclusion of persons with different disabilities in the research, on their advocacy activities and on the level of discussions and participation in the DPO meetings.

National Commission on Disability (NCD), the statutory body of Liberia to deal with different issues related to persons with disabilities had also been involved in CB-EDR initiative since the beginning. Representatives from NCD had participated in some theme meetings and were also part of the Technical Advisory Group (TAG) for the research. NCD appreciated the basic idea of CB-EDR and asking persons with disabilities to become researchers about their own challenges.

Cultivators for Users' Hope (CFUH), the DPO representing persons with mental health conditions and epilepsy was also represented in the TAG and CFUH representatives had taken part in a couple of theme meetings.

6.4 CONCLUSIONS

The biggest achievement of the research is that of providing a picture of lives of persons with disabilities in the three counties of Liberia and the challenges they must face in their everyday lives. It can be seen as a starting point or a baseline information, which can be strengthened and detailed in future. It is the first time in Liberia that persons with disabilities have themselves contributed to collecting information about issues and areas which they feel as significant.

The information collection process followed by collective reflections, discussions and analysis seems to have some positive impact on the researchers themselves and their DPOs, as well as on some county institutions and services. Some of these changes have been confirmed by the independent evaluation of the DASU project conducted in 2021. It might also be useful to look at them by interviewing these same researchers, their DPOs as well as, some of the county institutions in a couple of years to look at the actual medium term impact on the ground.

7. SHARING THE RESULTS OF THE CB-EDR

A key part of the CB-EDR process is related to the sharing of the research results with the key stakeholders. While the present report provides an overview of the analysis of the research findings on different themes, the researchers also had an opportunity to exchange their views with the main stakeholders and to share their own impressions about what they had learned and understood.

Thus, at the end of the research process, in May 2021, the major stakeholders represented in the Technical Advisory Group (TAG) of the EDR met with the researchers. During this meeting the researchers from each county presented their main findings to the TAG members and discussed with them the positive and negative aspects of the research process. This chapter provides a brief summary of this exchange of views.

Compared to the formal analysis of the discussions and findings made during the 13 theme research meetings and presented in chapter 5 of this report, the presentations by the researchers from the 3 counties to the TAG members can be seen as their own summary of their key findings.

7.1 The Most Important Challenges Faced by Persons with Disabilities in the Three Counties of Liberia

The researchers from each county made a presentation about their insights gained from the research to the TAG members and the main stakeholders. The following were the points raised during these presentations:

Grand Gedeh County: Both, the disabled men and women face difficulties in finding partners in relationship and marriage and both face abandonment if one of the spouses becomes disabled. The problems faced by women with disabilities are greater – often men abandon them when they become pregnant.

Access to education is a big problem for children and young adults with disabilities. Most of the school buildings are not accessible. Persons with hearing, speech and vision related disabilities face even greater barriers because there are no trained teachers, lack of appropriate assistive products and lack of teaching aids.

Poverty and lack of economic opportunities for persons with disabilities affects all groups of persons with disabilities. This problem is worse for persons with stigmatising conditions such as those with leprosy and those with epilepsy.

Persons with hearing loss and hard of hearing face big challenges in the county due to lack of sign language teachers and interpreters. For example, there are no sign language interpreters to assist in the justice system

Apart from widespread social stigma, persons with mental health conditions and epilepsy lack information about medication. Sometimes, their medicines are lacking in the referral hospital

Most persons with disabilities do not have access to any mobility devices such as crutches, walking sticks and wheelchairs or other assistive products such as eyeglasses, hearing aids. This creates additional barriers and blocks their participation in community activities.

The DPOs do not have access to social development funds in the county – having access to these funds can provide new opportunities to persons who need them most.

Bong County: Lack of accessibility in the public and private buildings is a big barrier. Reaching offices often requires climbing stairs while elevators and ramps are missing. Persons with hearing and speech problems, communication problems and vision problems, all of them need suitable assistive devices to overcome barriers.

There are so many persons who faced physical and mental trauma during the wars, who have not received appropriate counselling and support. They have been forgotten.

Social attitudes in the communities are negative towards persons with disabilities. People think that a disability is contagious, they think that it will pass to other persons and therefore discriminate. Others think that disability is linked to witchcraft. Women with disabilities face greater problem. Social awareness needs to be created.

Persons with mental health conditions face social stigma. They need medicines but often these medicines are not available and they do not have money to buy them.

There are very few economic opportunities for persons with disabilities. Even the Government refuses to employ persons with disabilities.

Nimba County: It is very difficult for persons with disabilities to move in the community. Public transport is costly and does not accept them. There are no mobility aids such as crutches or wheelchairs, only some persons can get them through the charitable organisations.

There is lack of employment and economic empowerment opportunities for persons with disabilities. In the communities, persons with disabilities are among the poorest persons.

Accessing the health services is not easy. The distances can be long and public transport is difficult. In the health centres, there is limited attention by health workers, who make us wait or even ignore our needs. The medicines are not available and buying them from the market is costly. So many persons take some treatment for the pharmacy or take herbs because they cannot afford going to the health centres.

In the communities, there is lack of knowledge and understanding along with ignorance and misconceptions about persons with disabilities. Some people think of disabled persons as witchcraft. Others don't want to sit near or eat with us.

The inaccessibility of the public and private buildings, from the market places to the community meeting places, means that our participation is difficult.

7.2 What Can be Done by NUOD and DPOs

After sharing their main learnings from the research process, the researchers also talked about the action needed by DPOs and by other stakeholders, to answer the main challenges. They suggested the following actions:

- DPOs and national organisations must promote continued awareness to schools, families, homes, and through radio stations to ensure the rights of persons with disabilities;

- Advocacy actions need to be strengthened and should be directed towards local authorities and duty bearers asking them to ensure the rights of persons with disabilities;

- The national bodies should have periodic engagements in a systematic way with the county authorities to ensure the inclusion of needs of persons with disabilities in the county plans and programmes;

- The DPOs themselves must become more inclusive and must include all the different groups of persons with disabilities to reflect their broad-based representation in all activities.

7.3 Continuing the EDR Experience in Liberia

The researchers also made a statement regarding the EDR process to the TAG members, which is presented below.

"*The EDR process is very admirable and effective in building and strengthening the DPOs in the counties. We suggest that initiatives like EDR should continue in future. For example, during EDR we found that even the Government officials were not aware of UNCRPD and that Government of Liberia has signed this international convention.*

EDR has helped us to uncover issues about which we had limited awareness. For example, there is little participation of persons with disabilities and our DPOs in the political processes in the counties. Another issue was that of frequent abandonment of women with disabilities and their children by men, who father the children but do not provide any support. We need to uncover such issues, raise them in our communities and find solutions to them.

Our DPOs are active in the county towns and neighbouring areas. Research has helped us to meet persons with disabilities living in faraway areas and they are very interested in joining the DPOs. So many of them do not know anything about the Disability Act of the Government of Liberia and this information should reach to all the persons with disabilities. Future research should look at more depth on some issues like why Braille and sign language are not taught in the Liberian School system?

EDR has helped us to interact with the local officials and inform them about our needs. This is an important skill for the DPOs. It helps us to build confidence in ourselves and to assume active leadership. Therefore, such a research approach should be extended to other counties in the country. Inviting Government officials *responsible for development to our meetings is a good strategy. Government should be asked to support EDR process, it should not be only a work for the NGOs.*”

At the end of the discussions and exchange of opinions with the TAG members, the researchers made the following 3 recommendations:

- Researchers trained in EDR have gained new skills and they should be motivated to pursue courses related to social development to help contribute to socio-economic development of Liberia.
- The EDR report should be widely disseminated to key stakeholders and should also be prepared in a simple and easy-to-understand version for DPOs and persons with disabilities.
- Researchers should become champions of disability issues in their respective communities and continue the process started with EDR.

8. DISCUSSION & COMMENTS

There were some other issues related to the organisation and implementation of CB-EDR approach in Liberia, which are briefly presented in this chapter. It also looks at the key challenges and limitations related to the implementation of CB-EDR.

8.1 CB-EDR IMPLEMENTATION CHALLENGES

There were different challenges in implementing the CB-EDR plans in Liberia. These affected the organisation of the research activities and its documentation. The main challenges are briefly explained below:

8.1.1 Challenges regarding the Rapporteur: Rapporteur is one of the most important roles in organising a CB-EDR because s/he is the link between the researchers and the experts. S/he has to facilitate and support the researchers without taking over any of their roles in the research-related decision making. S/he can make sure that researchers form a group based on mutual respect and solidarity and can help in defusing tensions and conflicts. Thus, identifying the right person for this role is crucial for the success of CB-EDR.

In the CB-EDR initiative in Liberia there was a turn-over of persons in the role of rapporteur. The first person selected for this role was young and inexperienced, and though enthusiastic, he needed support and follow-up. He was changed after 4 meetings. The second replacement had more experience but there were other issues and he was also replaced after 1 meeting. Finally, a person from AIFO Liberia office was asked to take on this role. He had many other work responsibilities, therefore the quality of the reports was uneven and sometimes there were delays in the preparation of research reports. These issues related to the rapporteur also affected his role as the facilitator and had a negative effect on the quality of the work of the researchers.

8.1.2 Challenges related to the Researchers: There were 3 kinds of challenges in relation to the researchers – in terms of representation of different kinds of disabilities, gender representation and frequent turn-over.

In terms of representation of different kind of disabilities among the researcher, except for one person with vision disability, all the other researchers had physical or mobility related disabilities. A deaf person came for the initial training but finding a sign language interpreter was a difficulty and he decided to discontinue.

In terms of gender representation, ensuring that 50% of the researchers were women was not possible in all the 3 counties – it was possible only in one county (Nimba).

Finally, frequent turn-over of the researchers was an issue, especially in Bong and Grand Gedeh counties. 2 researchers from each of these counties, who had attended the initial training in 2018, were replaced during the first 8 months. Thus, a second training course for the researchers was organised in 2019. Still one of the researchers from Grand Gedeh county did not continue during some of the final meetings and was not replaced. These changes created difficulties for the group dynamics and functioning.

4.4.3 Challenges related to the research themes and methodology: The biggest challenge was in relation to the sub-division of research roles and the quality of information collection among the county teams of the researchers.

For each theme research, there was a research protocol explaining the key issues related to it. However, very often the researchers did not touch on all the issues during their interviews. Thus, the information they collected was incomplete. For example, the theme meeting on "War and Violence" was supposed to talk about the impact of the civil war, but it was also supposed to talk about impact of abuse and violence faced by people in their daily lives. However, the information collection and the discussions of the researchers did not touch on issues of abuse and violence and were limited to the impact of the civil war.

In May 2019, during the second round of the researchers' training, this issue was discussed. The researchers said that when they interviewed persons in the community, those persons saw them as some kind of official and expected some kind of practical solutions and help from them.

During the last 4 theme researches, instead of generic indications to ask questions regarding different issues linked to the themes, the researchers were given a set of questions which they were supposed to ask. However, even this gave uneven results. The uneven quality of meeting reports also made their analysis difficult. Probably, a lack of supervising and facilitating role from AIFO-Liberia staff also contributed to this difficulty.

8.1.4 Difficulties related to Covid-19 epidemic: EDR related activities were blocked between February and November 2020. The impact of this gap was not clear. The Covid-19 related travel restrictions meant that the international members of TAG, including the global research coordinator, did not participate in the final meeting.

8.1.5 Challenges related to involvement of persons with mental health conditions and other specific groups: A key goal of the CB-EDR was to involve persons with mental health conditions in the research. At one level, the researchers agreed that they had little knowledge about persons with mental health conditions while there was a lot of social stigma attached to these conditions. At another level, most researchers agreed that mental health was also an issue for many other persons with disabilities, though in most cases, it was not a dominating condition in their lives. For example, during the theme meeting on "Civil war and persons with disabilities", many testimonies by persons with different disabilities also touched on their mental health conditions, and how they are seen as persons with physical disabilities.

There were 2 theme meetings during the CB-EDR process, when the researchers focused on persons with mental health conditions. The national association of persons with mental health condition (Cultivators of Users' Hope) was involved in these meetings. However, these theme researches contributed little to an understanding of different issues related to mental health conditions as discussions were mostly focused on issues of persons with epilepsy. The discussions about persons with mental illness, focused on behavioural problems and need for medication, they did not have any discussions on barriers faced by the individuals.

Similar concerns were also raised for persons with leprosy related disabilities and those with intellectual disabilities, whose participation in the research was marginal. On the other hand, limited involvement of persons with hearing and speech disabilities in CB-EDR was related to lack of knowledge of sign language in rural communities and difficulties in finding sign language translators for the research.

8.2 DIFFICULTIES FACED BY THE RESEARCHERS

Researchers were asked to share their views about limitations and difficulties of the CB-EDR process. The following points emerged from their discussions:

- Accessibility of meeting places was a challenge. During the research, we went around and conducted several accessibility audits and raised awareness about it, but then we had to accept that even for our own meetings, it was difficult to identify a fully accessible meeting place. Even we lacked sign language translators and Braille documents.
- When we went around the communities to meet persons with disabilities and to interview them, they often thought that we were there to bring some help to them. It was difficult to explain to them that we were there only to understand the barriers they were facing and that we did not have any resources to help them.
- Reaching the faraway rural areas was a challenge in all the three counties. However, the barriers to travel and visit communities were worst in Grand Gedeh county which lacks roads and bridges. Travel in the rainy season was difficult and dangerous.
- During the theme meetings, often there were heated discussions between the researchers because we had different point of views. However, at the end we recognised that even such confrontational discussions were useful as they helped us to understand the issues better.
- During the initial phase of the research, each county was asked to prepare a county report, that was a big challenge as we were unable to express our different point of views and bring them together in one report. The methodology during the last few meetings, when each researcher was asked to present our own interviews was easier.

8.3 RELECTIONS FROM THE GLOBAL RESEARCH COORDINATOR

Based on the experience of dealing with the research organisation from a distance, the global research coordinator, who is also the author of this report, shared a few reflections.

8.3.1 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 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 can organise the meetings, provide advice about guests to be invited, takes detailed notes for the reports and when needed, facilitates discussions, can have made a big difference in this research.

To improve the quality of discussions, one of the researchers was given an additional responsibility to identify issues and raise them up for the group's attention. However, this had limited impact.

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, the researchers do not always remember about the importance of documenting the information they are gathering in a systematic manner. Thus, ensuring high quality of meeting reports when the researchers present their work is fundamental to the process.

8.3.2 The researchers' group: The researchers in Liberia had limited educational background and most of them came from extremely resource-deprived backgrounds. Most of them had never heard of the social model of disability before the research and were used to looking at disabilities as problems of the individuals and thus through a medical-model approach. Thus, the researchers faced some difficulties in the initial phases in understanding the importance of looking at issues through a rights-based approach.

These initial problems were exacerbated by the decision of a significant proportion of researchers to not continue in EDR after the initial training. Thus, new persons were inducted and a second EDR training course was held one year later. Having only 4 persons from a county and replacing 50% of them, had a big impact on the group dynamics and thus on the research itself. It would be better to start CB-EDR process with a larger group, so that even if a few persons decide to not continue with it, the remaining group can continue the research.

8.3.3 Quality of information in CB-EDR: During CB-EDR, a key aspect of the research is to make the participants aware about specific aspects of their sociocultural system. The local researchers take for granted certain aspects of the local culture because it is familiar to them and they do not explain it. This can have a negative impact on the research. Two examples of sociocultural practices in the 3 counties, which were not properly explained in any research report, are mentioned below.

For example, in a number of testimonies during CB-EDR in Liberia, there was mention of community beliefs regarding links between persons with disabilities and witchcraft, however it was never really explored during the research. Thus, it was not clear if the ideas of witchcraft were associated only with certain kinds of disabilities or they were linked to all the different kinds of disabilities. It was not clear if there is a gender dimension to these ideas of witchcraft or if it is associated with certain age groups such as elderly persons. Similarly, the impact of such associations with witchcraft on the concerned individuals and their families and how can they counteract and fight against such ideas, were also left unexplored.

Another issue which was raised in many testimonies of women with disabilities was that of men having sex with them and when they become pregnant, abandoning them. Since formal marriages are supposed to be costly affairs, both for the dowry to be paid by men for the brides and due to the high costs of the ceremonies, even if the church frowns on co-habitation without marriage, in practice such live-in relationships seem to be common in Liberia. Couples who live together for long time and have children, can decide to get formally married when they have sufficient financial resources. Thus, communities have norms and expected behaviour from the live-in relationships and community leaders can punish men for abandoning the women and their children. However, all these issues and their implications for the women with disabilities were never clearly spelled out in the research reports.

8.4 CONCLUSIONS

There were different limitations in the CB-EDR process in Liberia. Two key limitations were – small number of researchers along with a high turn-over; and difficulties related to the role of rapporteur-facilitator. Both of these affected the quality of the research and its reports.

In spite of these limitations, the CB-EDR research in the 3 counties of Liberia has provided information about barriers faced by persons with disabilities living in the small county towns and rural areas for the first time. This information gathering has been accompanied by a strengthening of the DPOs and their federations in the three counties. At the same time, there are some signs of small changes in the local communities which are trying to overcome some of the barriers.

9. CONCLUSIONS

CB-EDR places emphasis on generation and sharing of knowledge among persons with disabilities starting from their personal life experiences. Thus, there were no pre-requisites to select or exclude any persons with disabilities from becoming researchers in the CB-EDR conducted in 3 counties of Liberia.

10 out of 11 researchers who stayed till the end of the research process had school level education and many of them had difficulties in writing descriptive reports in English. 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 and important information about the different kinds of barriers they faced in their daily lives in small county towns and rural areas of Liberia, where resources, services and infrastructures were limited and poverty and negative ideas about disabilities and persons with disabilities were prevalent. It was the first time that such research was being conducted in Liberia. With all its limitations, the research did provide a glimpse of real-life situation of persons with disabilities in the three counties.

The CB-EDR has brought out rich details of the numerous ways in which persons with 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.

In terms of transfer of research knowledge into practice, the impact of CB-EDR in Liberia had an immediate impact at least on some areas such as building of ramps and creating awareness among county authorities. This was one of its most significant characteristics 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.

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.

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LIST OF ANNEXES

Annex 1: List of researchers

Annex 2: TAG members

Annex 3: Research protocol and Consent form

Annex 4: Different kinds of barriers for analysing the theme reports

Annex 5: Questionnaire for the measurement of empowerment

Annex 1

List of Researchers (Initial group and their replacements)

No.	Name	County	Disability
1	Diamond Moore (M)	Bong	Hearing
1	Winston Waruwulu (M) (replacement of Diamond Moore)	Bong	Physical
2	Emery A. Jesse (M)	Bong	Vision
3	Amelia Sumo (F)	Bong	Physical
3	Joanna Kellie (F) (replacement of Amelia Sumo)	Bong	Physical
4	Arthur Bondo (M)	Bong	Physical
5	Augustine Padmore (M)	Grand Gedeh	Physical
6	Alice Doe (F)	Grand Gedeh	Physical
6	Debora Sohn (M) (replacement of Alice Doe)	Grand Gedeh	Physical
7	Aloysius Blaye (M)	Grand Gedeh	Physical
7	Felix T.S. Chelleh (M) (replacement of Alosius Blaye)	Grand Gedeh	Physical
8	Patrick Jarwleh (M) (Not in 2021 and not replaced)	Grand Gedeh	Physical
9	D. AbestineTozay (M)	Nimba	Physical
10	Hellen Gounleh (F)	Nimba	Physical
11	Gabriel Soh (M)	Nimba	Short person
12	Nenlay G. Doe (F)	Nimba	Physical

Annex 2

LIST OF TAG MEMBERS

No.	Name	Position	Institution
1.	Min. Lydia Sherman	Deputy Minister	Ministry of Gender, Children & Social Protection
2.	Mrs. Angie Tarr	Director Division of Mental Health	Ministry of Health (MoH/DMH)
3.	Ms. Caroline Saye Willie	Division of Mental Health	Ministry of Health (MoH/DMH)
4.	Mrs. Tonieh Wiles	Commissioner	Independent National Commission on Disabilities (INCHR)
5.	Mr. G. Alphonso Woiwor	Intern INCHR	Independent National Commission on Human Rights (INCHR)
6.	Mr. Barkon Dwah	Medical Consultant	World Health Organization (WHO)
7.	Mrs. Ricardia B. Dennis	Executive Director	National Commission on Disabilities (NCD)
8.	Mr. Wilfred S. Gwaikolo	Acting Head & Deputy Programme Lead	The Carter Center (TCC)
9.	Mr. Felipe Neis Araujo	Anthropologist, Lecturer	University of Liberia (UL)
10.	Ms. Naomi Harris	President	National Union of Organizations of Disabled (NUOD)
11.	Mr. Giampiero Griffo	Representative	Italian Network on Disability & Development (RIDS) & Disabled Peoples' International (DPI/Italy)
12.	Dr. Sunil Deepak	Consultant & Global coordinator CB-EDR	AIFO-Italy

Annex 3

Persons with Disabilities in Bong, Grand Gedeh and Nimba Counties of Liberia: People's Lives and Their Challenges

RESEARCH PROTOCOL

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 school education and friendship with their peers to access to health services, employment, housing, marriage, sports and leisure activities.

In Liberia, the situation of the persons with disabilities has been further complicated by the long civil war and then the more recent, Ebola Virus Crisis, increasing the barriers they need to overcome for their participation in different life-activities. Limited information exists in Liberia regarding the different groups of PwDs and regarding specific barriers they face in their lives.

For example, at the end of a 14-years long civil war in 2003, the country faced numerous challenges including the issues of reintegration of war veterans, former women fighters, former child soldiers and persons injured and disabled due to the war injuries. Many persons had faced violence, abuse and sexual abuse. Others had faced traumatic stress. Many of them were persons with disabilities, including both physical and psychosocial disabilities. Today, in 2018, 15 years after the end of the war, how are their lives and what issues do they face?

Another example is about the inclusion of different groups of PwDs in the Disabled Peoples' Organisations (DPOs) in the counties. For example, persons with disabilities related to chronic mental health conditions are a small part of DPOs. On the other hand, there is little understanding about the psychological problems among different groups of PwDs. What are the different barriers they face in their daily lives?

There can be many more such examples about the barriers faced by persons with different disabilities living in Bong, Grand Gedeh and Nimba counties of Liberia, linked to their age, gender, and sexuality, as well as, regarding their access to health, education, livelihood and social services.

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 "*Disability & Start-Up - Civil society as protagonist of inclusive development in Liberia*", a three-year initiative funded by the Italian Agency for Development Cooperation. The research will focus on PwDs from three counties (Bong, Grand Gedeh and Nimba) and will be carried out in collaboration with the National Union of the Organisations of Disabled (NUOD) in Liberia.

BACKGROUND

The ideas of ER 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 Disability Research (EDR) was coined by Mike Oliver in 1991 when he had proposed that disabled researchers can provide new understandings regarding the challenges faced by persons with disabilities. (Barnes, 2001)

Emancipatory disability research 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 PwDs and strengthening their leadership capacities to promote future leaders of the disability movement in Liberia.

- Building documentation about key issues facing PwDs in Liberia that can be used by NUOD and DPOs for planning their future activities, and for strengthening their advocacy and fund-raising activities.

Ideally the research should have involved all the counties of Liberia. However due to budget limitations, the project approved by AICS for co-funding did not have national coverage and has activities only in three counties – Bong, Nimba and Grand Gedeh. This research is part of a wider project limited to those 3 counties.

RESEARCHERS

The research will involve around 12 persons with disabilities from the three counties who will be trained as researchers. The researchers will come from the different DPOs active in the three counties such as SAPRO, Group of 77, NDC, CAB and GGDA.

Selection of PwDs for the role of researchers: 3 PwDs should be identified from each county to be trained as researchers. In addition, the 3 NUOD coordinators from the 3 counties will also be part of the researchers' team. If possible, they should be persons with different disabilities. If there are different ethnic groups in a county, all efforts should be made to involve persons from all the different ethnic groups. The persons should represent different age groups (minimum 18 years) and different educational back grounds.

Among the researchers identified by the county DPOs there are 8 men and 4 women. Thus, one-third of the researchers are women.

PwDs identified as research participants will be provided four-and-half days' training on conducting the research and about their roles as researchers. The training of the researchers will include life-stories approach, and the use of narrative, picture and video resources to promote discussions and exchange of ideas around different life issues.

Among the researchers in each county, one contact person will be identified, who will maintain contacts with the research persons in Monrovia. Among all the researchers, a chair-person of the group will also be identified.

The most important criteria for identifying the persons is that they should be active, have capacity of taking initiatives, able to go around their communities and have good inter-personal skills and empathy to talk to persons. They have to agree to take part in the initial training and then be a part of the research process that will start in October 2018 and finish in April 2020 (one meeting every 6 weeks for total 12 meetings and 2-3 days of research work for every meeting). 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 10-12 persons from Liberia such as representatives from National Commission on Disability (NCD), National Union of Organisations of Disabled (NUOD), national level DPOs, and university academics and persons 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, DASU project "Technical Expert in inclusive and emancipatory processes for PwDs", with experience in emancipatory research and CBR.

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.

RESEARCH COORDINATION & LOGISTICS

A small group of 3 persons will be identified by DASU project, 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 person from DASU project, the reporter for the EDR and Sunil Deepak as the global coordinator for EDR.

A reporter 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 by DASU project. 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 reporter will maintain contacts with the DASU-office, researchers and the EDR global coordinator; and, will conduct background research for each meeting and prepare minutes and reports of the monthly research meetings.

RESEARCH METHODOLOGY

During the first TAG meeting in October 2018, through a participatory exercise, 12 priority research themes will be identified.

The 12 priority themes identified by TAG 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 April 2020. The 12 themes finalized for this research are as follows:

(a) 6 themes related to different kinds of disabilities: (1) persons with vision disabilities (2) persons with physical disabilities & leprosy related disabilities (3) persons with mental illness and epilepsy (4) persons with intellectual disabilities (5) persons with other disabilities such as albinism, short persons, burns and scars, etc. (6) persons with hearing and speech disabilities
(b) 6 cross-cutting themes affecting different groups of persons with disabilities: (7) health (8) education (9) livelihood (10) social relationships and family (11) empowerment, DPOs and SHGs (12) war, violence and abuse

A 2-day meeting of the researchers will be organised every six weeks focusing on one priority theme. A specific protocol including background information and key issues to be discussed during the meeting will be prepared for each meeting.

Each research meeting will have some invited guests with specific experiences or expertise related to the research theme. 3 guests will be identified with advice from TAG, and they can be persons from national level or from any county. The other 3 guests will be identified by the researchers from the 3 counties. The researchers will have around 6 weeks of time to collect information about the next research theme in their communities. From their knowledge of the communities and their information collection for the research theme, they can also suggest guests to be invited for the meetings. The invited guests can be persons with disabilities with specific experiences or personal stories that add new points of view or provide specific contribution to the theme of the meeting. The guests can also be representatives of specific institutions linked to the meeting-theme. The group of researchers from each county will decide the guest they wish to invite to a specific theme meeting.

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.

On each theme, in each county, the researchers will conduct at least one accessibility audit of a public building/space including both Government and private buildings/spaces such as schools, clinics, markets, cinema and playing grounds.

Each research 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 with Question-Answer sessions
- 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 institutions, by communities, by DPOs and what can be done by the PwDs in the counties.

Before closing the meeting, the researchers will decide the date and the theme for the next meeting, as well as the main areas of enquiry and how to organise that meeting including any suggestions for inviting the guest speakers.

The reporter will prepare a report about the key discussions emerging from that meeting. The reporter 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 is 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.

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 reporter will include both the sharing of information as well as, its analysis by the researchers. The meeting reports will be shared with the TAG 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 and analysed for their findings in terms of aspirations, vulnerabilities, strengths and challenges faced by PwDs in different life domains and actions stimulated by the research to overcome the challenges and barriers. The analysis with SPSS will serve for the identification of key issues and findings emerging from the research, and for the preparation of a scientific publication.

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 presented to the Institutional Review Board of Liberia, NUOD/Liberia and AIFO/Italy for the approval (Approval n. FWA00004982/18-11-143).

All the participation of persons with disabilities in the research will be completely voluntary and confidential. There will be no report linking the research discussions and conclusions with any specific persons. 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.

Ideally EDR should involve much larger number of PwDs, who participate in the theme meetings and share their experiences, giving opportunity to all the researchers to listen to all the testimonies. This also ensures that all the different sub-groups are represented and can share their voices. However, due to limitations of project budget, this is not possible. This research will cover only 3 counties of Liberia and can have only a limited number of invited guests. To overcome this limitation, researchers have to visit their communities and to interview persons, with the limitation that they may not be able to visit far away communities and the persons living in more isolated areas.

EDR is a subjective approach to research since the researchers themselves are persons with disabilities and their own life experiences would influence the persons they will interview and the testimonies they will collect. To counter this, while planning each theme a guiding paper will be prepared including information about any previous research on that theme, findings from significant international documents, different categories of persons/groups who should be interviewed and other key issues related to that theme.

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 three counties of Liberia (Bong, Grand Gedeh and Nimba) will be trained as researchers and then facilitated to explore some key aspects of their lives in the counties. 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. The research is expected provide insights about areas and issues about which little information exists.

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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

Questionnaire Used for Measurement of Empowerment

For the following questions, choose one answer in the scale from (0) to (5), where (0) means negative or bad or very little and (5) means excellent or positive or maximum.

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**

Annex 6

Analysis of the Research Theme Reports