# **Barriers Faced by Persons with Disabilities in** Liberia

A Community-Based **Emancipatory Disability Research** 

SUMMARY REPORT









AGENZIA ITALIANA PER LA COOPERAZIONE ALLO SVILUPPO

An Emancipatory Disability Research focusing on persons with disabilities from 3 counties (Bong, Nimba and Grand Gedeh) of Liberia, was carried out in 2018-21. It was a part of the project "*Disability and Start-Up - Civil society as protagonist of inclusive development in Liberia - AID 11516*" (DASU Project), co-funded by the Italian Agency for Development Cooperation (AICS) and implemented by Italian Association Amici di R. Follereau (AIFO) in collaboration with the Liberian National Union of the Organisations of the Disabled people (NUOD).

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#### FOREWORD

During 2018-21, an Emancipatory Disability Research (EDR) was conducted by persons with disabilities in 3 counties of Liberia – Bong, Nimba and Grand Gedeh. This research was a part of the project "Disability and Start-Up - Civil society as protagonist of inclusive development in Liberia - AID 11516" (DASU Project), co-funded by the Italian Agency for Development Cooperation (AICS).

Different organisations of persons with disabilities (DPOs) based in the 3 counties collaborated for the implementation of this research.

This research focused on identifying the barriers faced by different groups of persons with disabilities and strategies to overcome those barriers. It presents a summary of the main findings from this research in a simple language, as asked by the researchers in their final meeting.

Our thanks go to all the persons with disabilities and their organisations, who were involved in this research and also to all the experts of the Technical Advisory Group who guided it. We also wish to thank the Italian Agency for Development Cooperation for co-funding this project and all the communities in Liberia for enabling and supporting the research process.

National Union of the Organisations of Disabled (NUOD) Italian association R. Follereau (AIFO)





## **1. INTRODUCTION**

An Emancipatory Disability Research (EDR) was organised in 3 counties of Liberia, during 2018-21. The research period included a gap of some months in the research activities in 2020 due to the Covid-Pandemic.

This research was conducted entirely by persons with disabilities belonging to county DPOs. It was a Community-Based EDR (CB-EDR) as it was managed completely by persons from local communities the counties. This report presents the key findings from this research.

#### **1.1 RESEARCHERS**

12 persons with disabilities were identified with the help of DPOs in Bong, Nimba and Grand Gedeh counties to be the researchers. They participated in a 5-days long training on conducting qualitative research. The research protocol was approved by the Institutional Review Board of the University of Liberia on 6 December 2018 (Protocol *#* 18-11-143).

The researchers included 3 NUOD county coordinators and 9 representatives of county DPOs. 33% of them were females and 67% males. The youngest researcher was 18 years and the eldest was 60 years old. Their education levels varied from primary school (8%) to university education (18%). 42% of them were married or had a stable partner. Majority of them (75%) had mobility and/or physical disabilities while one-third of them had more than one disability.

Of the 12 persons trained initially, one-third dropped out during the research process, and were substituted. A second, 3-days long researchers' refresher training was conducted in May 2019.

Annex 1 provides a list of all the researchers.

#### **1.2 TECHNICAL ADVISORY GROUP**

A Technical Advisory Group (TAG) composed of disability activists, academics, specialists and research experts was created to support the research. It had 12 members, including 9 persons from Liberia and 3 international members. Among them 30% were persons with disabilities.

The TAG met three times during the research – in the beginning to finalise the research protocol, in mid-2019 and at the end of the research process in 2021 to review the research progress and results. Some TAG members also participated in specific theme meetings of the research as invited guests. The research and TAG meetings, were documented by a rapporteur. Annex 2 presents a list of the Technical Advisory Group members.

### **1.3 RESEARCH OBJECTIVES**

The main objective of the research was to identify and understand the different barriers faced by persons with different disabilities living in the county towns and rural areas in Liberia.

Secondary objectives of the research were:

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

## **1.4 RESEARCH METHODOLOGY**

Through a participatory approach, the researchers identified 12 broad thematic areas for collecting information about the barriers. The thematic research areas included the following: (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 disabled persons, (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 (persons who are not included under other groups such as - short persons, albino persons, burns and Buruli ulcer disabilities.

There were a few changes in the research themes towards the final stage, when the activities were restarted after the gap caused by the Covid-19 situation. Thus, an additional, 13th theme research was added, which relooked at some of the issues discussed in earlier researches.



The following process was used to conduct this research:

- For each thematic research, the researchers met to collectively discuss the key issues associated with that theme and the potential directions of their enquiries.
- The researchers went out in the field individually or in small groups to gather information regarding the theme and its related barriers by interviewing individuals, families, service providers and authorities. The researchers also conducted accessibility audits in the community buildings and institutions.
- After a period of 6-8 weeks, the researchers met again to share their findings, to analyse and identify the key issues, to reflect on the mechanisms causing those barriers and to discuss possible strategies for overcoming them. Local authorities and representatives of institutions were sometimes invited to these meetings.
- A rapporteur prepared a draft report of the theme meeting, which was circulated to the researchers and Technical Advisory Group members before being finalised.

#### **1.5 DATA AND INFORMATION ANALYSIS**

11-12 individual researchers took part in each of the 13 theme-researches. For every theme research, each researcher spoke to or interviewed an average of 5 individuals. Thus, globally the research involved more than 700 persons with disabilities and/or families for the information collection. Additional persons involved in the research were school teachers, health workers, community representatives and local authorities.

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

- While collecting information in the field, the researchers reflected on that information individually or in small groups. Sometimes, they also discussed the related issues with other members of their DPOs.
- During the theme meetings, the researchers came together for a collective analysis and reflection on the collected information and for discussing potential strategies for overcoming the identified barriers.
- At the end of the research process, all the 13 theme reports, were coded manually according to 6 categories of barriers described in Annex 3 and analysed for the preparation of a formal research report.

6 possible categories of barriers were defined for the analysis of the barriers identified by the researchers. These categories were based upon those identified in ICF - the International Classification of Functioning and Disability (WHO, 2001) and in the Craig Hospital Inventory of Environmental Factors (CHIEF, 2001). **Annex 3** presents this classification of barriers.

This report summarises the main findings which emerged from the 13 theme-researches.



# 2. RESEARCH RESULTS

#### 2.1 INTRODUCTION

The Community-Based Emancipatory Disability Research (CB-EDR) in Liberia was conducted through 13 theme-researches. For each theme research, the presentations by the researchers were analysed to identify the key barriers related to that theme and a theme meeting report was prepared. The main findings from those 13 theme-research reports were combined and summarised for this global analysis.

## 2.2 KEY BARRIERS PERCEIVED BY PERSONS WITH DISABILITIES IN LIBERIA



In the following analysis, issues from different theme meetings have been grouped together according to the thematic areas.

#### 5.2.2 Access to Education

Barriers to educational opportunities for children and young adults with disabilities came up repeatedly during the discussions of different theme researches, in addition to the two theme researches which had a specific focus on education. This shows the importance given to this area by the researchers.

*Extent of the problem*: According to the research, very few children with disabilities had access to education in Liberia. For example, Tchien district in the Grand Gedeh county had a total population of about 35 thousand and if persons with disabilities were 5% of the population, we would have expected more than 1500 disabled persons in the district. Since around 41% of the Liberian population was below 15 years of age, Tchien district would have had more than 600 children with disabilities of school-going age. However, according to the education officer of Tchien district, in 2020 there were only 10 students with disabilities in the regular schools.

*Special schools*: There were few special schools in the counties. Research showed that they also lacked trained teachers, specific equipment and learning materials for disabled children. For example, a teacher from a special school in Grand Gedeh county complained that he had no specific training to teach disabled children while their school lacked proper facilities.

Bong county had a teachers' training college but the training course did not include any information about teaching to children with disabilities. None of the special schools in the counties for children with visual



disabilities, was providing orientation and mobility training to the blind children.

*Inclusive education*: The teachers in ordinary schools lacked training, specific skills and the equipment needed to include children with disabilities in the classrooms. An article (4.4.1) of the new education law (2018) was considered as problematic because it mandated that the school head-masters could decide if they wished to accept the children with disabilities. It was found that they often refused admission to children with moderate to severe disabilities.

School buildings were not accessible to children with physical disabilities as schools with ramps were rare.

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.

There were some private schools and faith-based schools in the counties but they had high fees. In the Government schools, education was free but the costs for uniforms and books were a barrier.

Lack of assistive products, from walking canes, crutches and wheel-chairs to eyeglasses and hearing aids, was another contributing factor among the barriers to education.

Lack of transport was a huge problem in rural areas where students needed to travel longer distances to reach the schools. The cost of the private transport and the unwillingness of vehicle drivers and other passengers to accommodate them, all contributed to the transport difficulties.

A young man from the Bong county who had polio as a child explained: "*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. It was even worse during rainy season. It was very tough for me to continue going to school. When I reached eighth standard, a missionary helped me to get a wheel chair, so that finally I could move with dignity."

*Negative attitudes*: Negative attitudes in the peers, teachers, professionals and general communities prevented children with disabilities to come out of their isolation. In the rural areas and small towns, many believed that disabled children were witches or brought misfortune. The negative attitudes in the communities and among parents of the other children frequently put pressure on the schools to refuse admission to disabled children.

Parents of children with disabilities themselves did not know that their children could be educated. Even when they knew, they thought that there were no employment opportunities for these children and thus felt that education was not useful.

Some groups including those with hearing and speech problems and those with intellectual disabilities faced even more barriers compared to other groups.

*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 of the women, who were teaching in elementary school, had only a high school diploma while the remaining 5 persons had university education. None of them had received

any specific training about dealing with and teaching to disabled children. They had 5 to 33 years of teaching experience. Among the 7, only 2 teachers had a few children with mild disabilities in their classes. All the teachers 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 that all children with disabilities will receive education 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 wide discussions about education, the discussions on issues related to health and health services were much more limited.

Attitudes, knowledge and skills of the Health Professionals: The researchers agreed that health services in the counties faced different challenges. Many of them felt that generally the health professionals were helpful towards persons with disabilities. However, the experiences of women with disabilities related to pregnancy and child-birth, were usually negative. They felt that the health professionals in the maternity services viewed them negatively, therefore they preferred to have delivery at home.

Researchers also felt that health workers did not know much about disabilities and even less about intellectual disabilities and mental illness.

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 in accessing the health services.

*Other Barriers in Accessing Health Services*: The other major difficulties in accessing health services were physical barriers in the buildings, and lack of specific policies for facilitating the services for disabled persons who thus had long waiting times.

Barriers perceived by specific groups of persons with disabilities: Persons with vision disabilities said that the health services did not understand the needs of blind and low-vision persons and unless they were accompanied by a family member, no one communicated 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. Persons with epilepsy also complained of widespread lack of awareness about medications for treating convulsions and difficulties in receiving the free medicines from the health services.

For persons with physical and mobility disabilities, long distances and bad conditions of roads was a big barrier, along with the physical barriers in the buildings.

**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 in the 3 counties. Some technicians trained by INGOs in the past, were still active in the counties and could repair old assistive devices. However, there was no local production of new assistive products in Liberia. Government support for facilitating access to assistive products was extremely limited - Social Welfare department had provided some financial contributions in the past to some residential institutions for this purpose but not to individuals in the counties.

*Extent of the problem*: Most persons said that they only had old products, which they got repaired and kept on using. Access to some products such as hearing aid was even more difficult. For example, none of 20 persons with hearing problems who were interviewed in a theme-research, had a hearing aid.

From eye-glasses and Braille writers to white canes, none of the assistive products commonly used by persons with vision disabilities were easily available in Liberia. There were no opportunities for 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 the Bong county said: "Majority of the persons with physical and mobility disabilities who were interviewed, even those with severe disabilities like amputations or paralysis, didn't have wheel chairs or crutches. Only two persons had old wheel chairs. Those who needed crutches, they usually made something on their own."

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 lacked trained opticians who could make complex lenses needed for persons with both vertical and spherical vision errors.

**5.2.5 Livelihood and Economic barriers**: Issues related to the lack of livelihood opportunities and widespread poverty were raised repeatedly during the research. These affected a lot of families in the counties, though those with a disabled person were among the 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 was very difficult, because there was "lack of job opportunities" in the counties.

Lack of self-confidence was also seen as an important barrier to livelihood, as it was 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, which affected incomegeneration activities. Banks usually did not see them as reliable persons for receiving loans. They also lacked management skills.

Barriers to Livelihood perceived by specific groups of persons with disabilities: 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 were limited or even non-existent. Their only option was to start something on their own.

**5.2.6 Barriers related to Police and Justice Systems**: During the research planning, this was perceived as an important area of exclusion for persons with disabilities. The research on this theme brought out that the barriers were mainly related to accessibility. For example, most interviewees talked about physical inaccessibility of police-stations, courts and jails. However, examples of negative attitudes or mistreatment by the police or justice personnel were few. At the same time, a few persons reported that they were given additional benefits and preferential treatment by the justice system.



Some of the challenges faced by disabled persons in the justice system included the 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. On the other hand, the testimonies showed that the courts asked for opinions of the DPOs in dealing with accusations against persons with disabilities.

**5.2.7 Gender-related barriers**: Different theme-researches brought out the gender dimension of barriers faced by women and girls with disabilities compared to those faced by men and boys. In almost every area, girls were worse placed – they had less education, they faced more problems in the health care system, they had less livelihood opportunities and they faced more discrimination in families and communities.

For example, the Grand Gedeh county researchers reported that in their area, some people think that blind women are witches and mistreated them. Researchers from Nimba and Grand Gedeh counties said that women with disabilities had more difficulties in finding men willing for stable relationships with them.

Speaking of high costs of education, in one place, the 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 Role of 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 with disabilities complained of strained relationships with their siblings and parents, especially for getting their part of the family property. Many of them also felt excluded in the family gatherings and discussions.

In terms of participation in the community institutions, many interviewees spoke of going regularly to church and playing an active role in the church activities. Some of them also 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 said that they played an active role in the PTAs of their children.

One negative area related to community attitudes was that of considering them unlucky and calling them witch-craft people. However, the researchers did not provide much details about the impact of such community-beliefs on the lives of disabled persons.

**5.2.9 Continuing impact of the Civil War on Persons with Disabilities**: Though the civil war in Liberia finished 17 years ago, some of its impact still continued 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 had witnessed gruesome murders of their family members and relatives. They were 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 carried psychological wounds of their experiences. The researchers themselves included different persons who had taken part in the violence and those who had seen violence against their family members.

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

The researchers felt that most persons with psychological trauma of violence - of seeing violence, of experiencing violence and of inflicting violence on others, they needed counselling and support but such support had not been provided to them in a systematic way. They avoided talking about it but deep inside those psychological scars continued to hurt them and affected their lives and their behaviours.

**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 such as leprosy, mental illness and epilepsy, have been mentioned above under other headings.

To understand the specific barriers faced by these persons, a specific theme research was organised. An analysis of the information collected from them showed that about one third of them 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. They were usually not part of any DPO.

Thus, specific groups of persons with disabilities, especially those with epilepsy, mental illness 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.

**5.2.11 Barriers to Sports & Leisure activities**: Sports and leisure activities were not perceived as very important by the researchers and only limited information was collected on this theme.

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 difficulties, which meant difficulties in paying for the costs of the leisure activities.

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.

#### 5.2.12 Barriers in the DPOs themselves

A key part of the research was to focus on the barriers existing in the DPOs themselves in relation to the different themes. It showed that certain groups of persons with disabilities (such as persons affected with leprosy, person with mental illness, person with epilepsy, albino persons, deaf persons, persons with speech difficulties and persons with intellectual disabilities) faced more barriers in joining and participating in the DPOs and SHGs, and were little represented in the DPO-membership.

In rural areas outside the county towns, few persons knew about DPOs and their roles. For example, in the Bong County, the researchers found that 77% of the interviewees had no knowledge about the DPOs and their roles, while in Nimba county, 65% of the interviewees did not know about it.

Even when persons were aware of and became a 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.

#### 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 to prepare accessibility audit reports.

The reporting of these accessibility audits was very uneven in the meeting reports but generally they highlighted a difficult situation in terms of accessibility of buildings and services. In all the three counties, it was rare to find a public building, institution or infrastructure, including schools, clinics, hospitals, government offices, banks, and market places, which did not have physical barriers. They lacked signboards and directions about the different services.

Some of the administrators had some idea about the physical barriers and many of them promised to build ramps and to find some solutions. However, there was little understanding and attention towards the barriers faced by persons with hearing, speech and vision difficulties and how these could be addressed.

#### 2.2.7 Additional Comments Regarding the Barriers

Most discussions on barriers during the research were about lack of accessible services and programmes from the Government, especially in relation to education, health care, assistive products, transport services and livelihood opportunities. Sometimes, the discussions touched on inappropriate laws and policies, such as the education law which allowed headmasters to decide if disabled child could attend their school.

A second area of barrier, which came up repeatedly in different thematic discussions was related to poverty and economic barriers. The third most common area of barriers encountered by people was about environmental and physical barriers, especially due to inaccessible buildings.

The fourth area of barriers was those of negative family and community attitudes, which had a strong gender dimension – these barriers affected women and girls with disabilities much more than the men and boys.

In comparison, discussions related to other categories of barriers – communication difficulties and barriers related to technology were not so frequent during this research.

On the other hand, the impact of the different barriers also depended upon the kind of disabilities the individuals had. Persons with stigmatising conditions such as leprosy, mental illness, epilepsy and communication difficulties faced greater barriers.

Finally, there was another cross-cutting area of discussion – the continuing after-effects of the long period of the civil war, which continues to affect the lives of persons with disabilities, in terms of continuing

stigma and marginalisation, issues of substance abuse and issues of psychological problems.





# **3. IMPACT OF EDR**

#### **3.1 INTRODUCTION**

Three kinds of changes were perceived by the researchers during the EDR process:

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

Use of the research findings for initiating practical action in the counties occurred in 3 ways:

- During the theme researches, the researchers visited different stakeholders and posed questions focusing on barriers posed by their families, communities, institutions, services and programmes. This created critical awareness among the interviewees about their own roles in exclusion of persons with disabilities and sometimes stimulated a change.
- During the meetings organised at the end of each theme research, the researchers reflected together on what could be done to overcome the barriers. This sometimes stimulated a change or development of a plan of action.
- During and after the end of each theme research process, the researchers also took the discussions back to their own DPOs. This led to some advocacy campaigns and other DPO activities in asking for the change.

The following testimonies by the researchers touch on some of these changes brought about the research process in their own DPOs as well as in their local communities and institutions.

# 3.2 VOICES OF THE RESEARCHERS: IMPACT OF THE RESEARCH ON DPOS AND COMMUNITIES

**Arthur Bondo/Bong County**: I am the NUOD coordinator for Bong County, so I can tell you 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 them.

As a result of those interactions, I have been hired as an advisor to the County administration on disability issues, which means that now I am officially seen as a reference person in the County. My interactions with the key stakeholders in the county have improved. Our county DPOs have become more inclusive and are open to different disabilities due to the research. 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 meetings 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 DPOs and ask for our participation in the discussions.

**Nenlay Doe/Nimba County**: I am the NUOD coordinator for Nimba so I know the situation of DPOs and I can talk about our county.

During EDR, I visited schools, clinics, courthouse, police station, county administration, communities, everywhere. Due to this, I am now recognised in all the communities and in the 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 capital 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 the new persons are bringing new ideas to the organisations. The DPOs have seen advocacy in action during the research, 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 in its 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 vicepresident 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 communities 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 that 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 city.

**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 our 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 so that 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 have an impact on 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 through our participation in EDR and visiting the authorities, institutions and community leaders has helped us 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.

#### **3.3 EMPOWERMENT OF THE RESEARCHERS**

During EDR, "empowerment of persons with disabilities and what role can be played by DPOs in promoting empowerment" was one of the research-themes. During the discussions related to this theme-research, most of the researchers had talked mostly about economic dimension of empowerment. Their views had seemed to imply that without economic self-sufficiency, there cannot be any empowerment. In fact, there were a few testimonies collected during this theme research, which seemed to suggest that people whose financial situation was good, were also more empowered.

At the end of the research process, the researchers were asked to reflect on the changes they had perceived in themselves as a result of their participation in EDR. The following testimonies from the researchers were related to those reflections:

**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 also 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 County administration 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.

The above reflections of the researchers about the changes they had perceived in themselves, with one exception, do not use the word "empowerment" but they do touch on many themes which are related to "becoming empowered", such as – having more self-confidence, becoming more articulate, talking and explaining to authorities and families, being seen as a reference person, becoming less shy and more outgoing, having more friends, and visiting new places.

#### **3.4 CONCLUSIONS**

The emancipatory disability research implemented in the 3 counties of Liberia has created a detailed map of the challenges faced by persons with disabilities living in these counties. Those challenges are huge and there are no easy solutions to them. While EDR can show what is missing and where are the most urgent barriers, it cannot create the missing infrastructures, institutions, professionals and services.

In spite of all those challenges, this research gives an idea of what does it mean to be a person with disability in the county towns and rural areas of Liberia and to fight for their rights. The impact of the research on the local institutions has been limited but at the very least, it has probably resulted in greater awareness among some of the authorities and professionals about the different barriers faced by persons with different disabilities.

Perhaps, its biggest impact has been on the county DPOs about the different barriers faced by persons with different disabilities even in their own organisations and to promote more inclusive organisations. It has also given them a tool to experiment with advocacy to bring changes in the local institutions and services.

It would be interesting to look at the medium and long-term impact of having more active DPOs on the county institutions and services, as well as on the national DPOs. That would require going back to these counties and DPOs after a few years and look for the changes. May be NUOD can do that.

The EDR process lasted a few years and it needed significant human and financial resources. Compared to the academic researches, it certainly had an almost immediate impact, at least in the transfer of knowledge and some skills to DPO leaders. An evaluation of its medium-term impact would give a better idea of its usefulness.



## 4. SHARING THE RESULTS OF EDR

A key part of the CB-EDR process was related to the sharing of the research results with the key stakeholders. Thus, at the end of the research process, in May 2021, the members of the Technical Advisory Group (TAG) of the EDR met with the researchers.

# 4.1 CONCLUSIONS OF THE COUNTY TEAMS OF RESEARCHERS

The researchers from the 3 counties summarised their learnings from the emancipatory research for the TAG members and the main stakeholders. The following were the points raised during those presentations:

**4.1.1 Grand Gedeh County**: Both, the disabled men and women faced difficulties in finding partners in relationship and marriages, and both



faced abandonment if one of the spouses became disabled. However, the problems faced by women with disabilities were greater. For example, often men abandoned them when they became pregnant.

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

Poverty and lack of economic opportunities for persons with disabilities affected all the groups of persons with disabilities. This problem was worse for persons with stigmatising conditions such as those with leprosy or epilepsy or mental illness.

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

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

Most persons with disabilities did not have access to any mobility devices such as crutches, walking sticks and wheelchairs. Other groups of persons with disabilities lacked other assistive products such as eyeglasses and hearing aids. This created additional barriers and blocked their participation in community activities.

The DPOs did not have access to social development funds in the county – having access to these funds could provide new opportunities to persons who needed them most.



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

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

Social attitudes in the communities were negative towards persons with disabilities. People thought that disability was contagious, they believed that it can pass to other persons and therefore they discriminated. Others thought that disability was associated with witchcraft. Women with disabilities faced greater problem. Social awareness needed to be created.

Persons with mental health conditions faced social stigma. They needed medicines but often these medicines were not available and they did not have enough money to buy them privately.

There were very few economic opportunities for persons with disabilities in the county. Even the Government itself refused to employ persons with disabilities.

**4.1.3 Nimba County**: It was very difficult for persons with disabilities to move in the communities. Public transport was costly and often refused to accept them as passengers. There were no mobility aids such as crutches or wheelchairs, only some persons could get them through the charitable organisations.

There was a lack of employment and economic empowerment opportunities for persons with disabilities. In the communities, persons with disabilities were among the poorest persons.

Accessing the health services was not easy for disabled persons. The distances could be long and public transport was difficult. In the health centres, there was limited attention by health workers, who made us wait or even ignored our needs. The medicines were not available and buying them from the market was costly. So many persons took some treatment from the pharmacy or took herbs because they could not afford going to the health centres.

In the communities, there was a lack of knowledge and understanding along with ignorance and misconceptions about persons with disabilities. Some people thought of disabled persons as those who do witchcraft. Others did not 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, meant that our participation in community and family became very difficult.

#### 4.2 FURUTRE ACTION 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 that were identified.

The researchers 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 broadbased representation in all activities.

#### **4.3 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.



#### **REFERENCES**

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CHIEF (2001), Craig Hospital Inventory of Environmental Factors, version 3, Research Department, Craig Hospital, Engelwood, Colorado, USA – available online at <u>https://craighospital.org/uploads/CraigHospital.ChiefManual.pdf</u>

#### **LIST OF ANNEXES**

Annex 1: List of researchers

Annex 2: Technical Advisory Group members

Annex 3: Different kinds of barriers for classification

#### **CB-EDR RESEARCHERS**

### 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. Abestine Tozay (M)	Nimba	Physical
10	Hellen Gounleh (F)	Nimba	Physical
11	Gabriel Soh (M)	Nimba	Short person
12	Nenlay G. Doe (F)	Nimba	Physical

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

## **TECHNICAL ADVISORY GROUP (TAG)**

	Family	Close family
		Extended family
	Community	Friends
People's Attitudes, Beliefs & Behaviour (including		Neighbours
cultural & social factors)		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
	Natural	Terrain
Environment		Water bodies (wells, ponds, rivers, lakes)
Environment		Climate (heat, cold, snow)
	Built for	Roads, sidewalks, crossings
	Collectivity (Buildings)	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

## **Classification of Different Kinds of Barriers**

		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
	Written	Font size, colour, contrast
Information & Communication		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	
rounces and recimology	Car modifications	



Adapted cupboards, kitchen, etc.	
Sexuality Others	

