ACCESS TO HEALTH CARE FOR PERSONS WITH INTELLECTUAL DISABILITIES IN GHANA: MAPPING THE ISSUES AND REVIEWING THE EVIDENCE
ACCESS TO HEALTH CARE FOR PERSONS WITH INTELLECTUAL DISABILITIES IN GHANA:
MAPPING THE ISSUES AND REVIEWING THE EVIDENCE

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‘STAR-Ghana is a multi-donor pooled funding mechanism supported by DFID, DANIDA, EU and USAID to increase the influence of civil society organizations and parliament in the governance of public goods and services’

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“It is my aspiration that health will finally be seen not as a blessing to be wished for, but as a human right to be fought for.”

Kofi Annan, Former United Nations Secretary-General

“I don’t think the health workers themselves are even aware of whom persons with ID are... or of the laws protecting them. In my view, it is not the fault of us, the parents, or the health workers. We are all ignorant and our children are the ones suffering from it. Everybody needs general education in ID.”

Parent of a person with ID from Eastern Region, Ghana
Inclusion Ghana (IG), a member of Inclusion International, is a network organization working to reduce stigmatization and ensure full inclusion of all persons with intellectual disabilities (ID) and their families by advocating for their rights and needs. IG envisions equal opportunities and inclusion for all persons with ID in Ghana and has four main intervention areas:

**Training**
- Strengthening the capacity and existing institutional structures of member organizations to support their quality service delivery to persons with ID and their families

**Research**
- Performing research to advocate for the improvement of the lives of persons with ID and their families

**Education**
- Maintaining an authoritative body of information and knowledge about ID
- Supporting proactive community outreach by education of member organizations
- Providing accessible information that supports stakeholder ability to make informed choices

**Advocacy**
- Advocating for inclusion and participation in all aspects of life for persons with ID and their families
- Proactively informing, influencing and developing public policy at the community, regional and national levels in collaboration with the greater disability community
- Supporting court action or other initiatives by persons with ID and their parents/caregivers to demand their rights

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The right to health is one of the most fundamental for all persons and for persons with ID, it is crucial to ensuring they reach their full potential in life. One of the main components for enjoying the right to health is the provision of free or affordable quality health care services. In 2006 the Disability Law (Act 715) was passed in Ghana, which, as discussed in this report, states that general and specialist medical care should be free for persons with disabilities. Yet the National Health Insurance Scheme (NHIS), which was established by an Act of Parliament in 2003, (Act 650) does not currently have a clear mechanism to ensure persons with ID do get access to free health care. Furthermore, knowledge of this entitlement is low.

I have been involved in training relating to promoting health and in supporting inclusion of persons with ID and therefore know their particular challenges in accessing health care. This study sought to explore the challenges faced by persons with ID when utilizing health care and calls for rigorous action to remedy the poor health care experienced by them in Ghana. Alarmingly, this report finds that the lack of training received by health professionals negatively affects their ability to diagnose ID and prescribe appropriate interventions for persons with ID and also leads to negative perceptions of persons with ID. Everybody needs to be healthy and feel good, not just the people who have no disability. I welcome this report and hope that funding and resources will be provided to implement its recommendations. The time has come to ensure that the intentions within Ghana’s health and disability policies – reducing health inequalities, social justice, and ending discrimination – become a reality for persons with intellectual disabilities.

Many individuals and organisations have contributed to this study and the development of this report and its recommendations. This extensive collaboration demonstrates that there is the commitment in Ghana to achieving equality for persons with ID. This is everyone’s responsibility – and everyone’s gain. It is hoped that the content of this report, if utilized well, can serve as relevant and reliable material for advocacy and other development-oriented policy actions on behalf of persons with ID.

Dr. Ebenezer Badoe  
Director, Neurology / Developmental Clinic  
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Director, Department of Child Health  
University of Ghana Medical School
Inclusion Ghana is privileged to have a nation-wide network of committed professionals and community members who continuously offer their time and resources to help make a difference to the lives of persons with intellectual disabilities. Many hearts and minds have contributed in different ways to undertake this important study.

This report was produced with generous funding from Star Ghana, as part of Inclusion Ghana’s larger project, “Obtaining healthcare rights for persons with ID”. Gratitude and thanks go to Inclusion Ghana’s Board of Directors for their practical input and direction throughout this study. We would like to register our recognition and great appreciation for the involvement of our member organizations, Star Ghana access to health implementation committee members and field personnel in the project districts for their help and diverse contributions.

The dedication and untiring efforts put in by Inclusion Ghana staff and volunteers is acknowledged and highly applauded. Inclusion Ghana wishes to express profound gratitude to Voluntary Services Overseas and Australian Youth Ambassadors for Development for their support in allocating two international volunteers, Cindy Laird and Jessica Williamson, respectively, to Inclusion Ghana to help in this study. We also sincerely appreciate the generosity of Dr. Bow Tauro who provided his expertise in scientific report writing on a voluntary basis. To all volunteers involved, we say “ayekoo”!

A special thanks must also be given to all District/Municipal Health Directorates and heads of all the health facilities for their cooperation and contributions.

Last but not least, to individuals with ID and their parents/caregivers, we thank you for your time and courage to talk and share your emotional experiences with us. It is only through your testimonies and accounts that we have begun to understand the current state of healthcare given to persons with ID Ghana. It is to them, persons with ID, that this study is dedicated.

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<td>Center for Disease Control and Prevention</td>
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<td>CHPS</td>
<td>Community-Based Health Planning and Services</td>
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<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<td>FGD</td>
<td>Focus group discussions</td>
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<td>GHS</td>
<td>Ghana Health Service</td>
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<td>GoG</td>
<td>Government of Ghana</td>
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<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>ID</td>
<td>Intellectual Disabilities</td>
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<td>IG</td>
<td>Inclusion Ghana</td>
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<td>LEAP</td>
<td>Livelihoods Empowerment Against Poverty</td>
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<td>MDG</td>
<td>Millennium Development Goals</td>
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<td>MoH</td>
<td>Ministry of Health</td>
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<td>NGO</td>
<td>Non-Governmental Organization</td>
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<td>NHI</td>
<td>National Health Insurance</td>
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<td>NHIA</td>
<td>National Health Insurance Authority</td>
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<td>National Health Insurance Scheme</td>
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EXECUTIVE SUMMARY

Primary barriers to health and health care for the general population are beginning to be well documented, and heightened national awareness of these obstacles has spurred numerous proposals for health care reform. Among the groups that face such barriers are persons with intellectual disabilities (ID). Supporting health needs is an essential contribution towards achieving inclusion and social justice. Persons with ID have often been invisible to mainstream health services and health professionals. They die younger and have poorer health than the general population. These factors are exacerbated for persons living in rural areas. The inequities are to some extent avoidable. The time has come to deploy better Ghana’s resources to improve the health of persons with ID and reduce the disadvantage and inequity that currently exists.

Inclusion Ghana is an organization that works to reduce stigmatization and ensure full inclusion of all persons with ID and their families through participatory research and advocacy. In line with its mission, this study sought to map the issues and review the evidence on experiences of persons with ID accessing health care. The study employed the social model of disability to examine whether persons with ID in the six project districts enjoy their right to health care and if they do not, what the barriers are and identify necessary interventions. A total of 501 population comprising of 79 persons with ID, 138 parents/caregivers and 284 health professionals participated in the study across 6 districts in 3 regions in Ghana.

The study confirmed that persons with ID are excluded from general health care by numerous obstacles, including interplay between cultural and social environments, physical inaccessibility, communication barriers and a lack of training of health professionals. Their exclusion in the mainstream health services is bolstered by a lack of awareness among policy makers and professionals about them being a minority group and their needs. In the absence of equal access to health care, persons with ID are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation. Ghana’s NHIS has provided significant benefits to the Ghanaian population. Even though it is far from attaining its goals of universal coverage, the prospects are encouraging.

Some of the recommendations made by this study, if implemented, would ensure persons with ID in Ghana enjoy their fundamental right to health care include: the Ministry of Health should undertake a public awareness campaign to ensure the public is aware of who persons with ID are so that the myths surrounding them are dispelled; the Minister for Social Welfare should specifically determine persons with ID as a category of differently-abled persons for the purposes of the National Health Insurance Act, so that all persons with ID are exempt from paying the registration and processing fee; the Ghana Health Service should undertake a public education campaign, using easy read materials, to ensure all persons with ID and their parents/caregivers are aware that they are entitled to free NHIS; the Ministry of Health should ensure all training for health professionals includes a component on persons with ID; and the Ghana Health Service should ensure the medications needed by persons with ID are available under the NHIS.
1. INTRODUCTION

It is apparent that the success of any country in the fight to reduce poverty is contingent on the health status of its population. As one of the critical sectors in the growth and development of the Ghanaian economy, the mission of the Health Ministry, Departments and Agencies is to improve the health status of all persons through the development and promotion of proactive policies for good health and longevity; and the provision of universal access to affordable and quality health services. These services must be delivered in a humane, efficient, and effective manner by well trained, friendly, highly motivated and client-oriented personnel.

One of the major obstacles in accessing health care in Ghana is the inability of individuals to pay for health services. In recognition of this fact, the Government of Ghana (GoG) introduced the National Health Insurance Scheme (NHIS) through an Act of Parliament (Act 650) in 2003, to provide affordable and accessible quality health care for all residents of Ghana\(^1\). NHIS is a mechanism of healthcare financing that enables citizens to contribute in advance for health services, in order to access health care when the need arises, without necessarily having to pay out-of-pocket at the health facility. The introduction of the scheme in Ghana followed the passage of its Legislative Instrument, LI 1809 in 2005.

Supporting health needs is an essential contribution towards achieving inclusion and social justice. Compared with other populations, persons with ID often have poorer health and a lower life expectancy.\(^2\) These factors are exacerbated for persons living in rural areas. They also have a higher prevalence of health needs and unmet health needs than the rest of the general population. An earlier baseline study conducted by Inclusion Ghana in 2011 on the level of stigmatisation and discrimination faced by Persons with ID in Ghana showed that they are highly stigmatised and discriminated against within the health care delivery system. The baseline however did not capture opinions of the how, why and when this discrimination occur. In addition to this, there is a lack of awareness of specific health needs more commonly experienced by persons with ID.

This study sought to map the issues and review the evidence on experiences of persons with ID accessing health care. The time has come to better deploy Ghana’s resources to improve the health of persons with ID and reduce the disadvantage and inequity that currently exists.

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1.1 What Does the Term “Intellectual Disability” Mean?

This report adopts the definition of an intellectual disability used by the American Psychiatric Association in its recent Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Importantly, DSM-5, in keeping with international trends, has moved away from using the term ‘mental retardation’ to the now accepted term ‘intellectual disability’ (ID).

From a clinical perspective, an ID involves impairments of general mental abilities (generally recognised as an IQ below 70) that impact adaptive functioning in three areas:

- The conceptual area, which includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social area, which refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical area, which centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.3

Importantly, a person should experience symptoms during their developmental period, which is usually before the age of 18.

Another definition is that an intellectual disability is ‘a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability for an individual to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.’4

Therefore, based on these definitions, persons with ID can experience difficulties in intellectual functioning, communication, self-care, home living, social skills, self-direction, health and safety, leisure, and work. Children with ID may sit, crawl, stand, walk, and run later than other children their age. They may learn to talk much later than others or may have difficulty speaking, for instance they may mumble a lot or stammer. The difficulties experienced differ from person to person. An individual can be mildly affected to profoundly affected and the age at which the person displays symptoms can vary. For example, in the case of some persons with mild ID, it may not be apparent and diagnosed until school age or later.

An ID can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the persons affected, the cause remains unknown. The known causes can be categorized as follows:

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3 American Psychiatric Association (2013), Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

• **Genetic conditions** – These result from abnormalities in genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy.

• **Problems during pregnancy** – For example, the use of alcohol or drugs by the pregnant mother can cause ID. Other risks include malnutrition and illnesses of the mother during pregnancy, such as rubella and syphilis.

• **Problems at birth** – Premature birth, low birth weight and difficulties in the birth process such as temporary oxygen deprivation or birth injuries may cause ID.

• **Health/environmental problems** – Childhood diseases such as whooping cough, chicken pox, measles and meningitis as well as childhood injuries like a blow to the head or near drowning can cause ID. Lead, mercury and other environmental toxins can also cause ID.

• **Poverty and cultural deprivation** – Children growing up in poverty are at a higher risk of malnutrition, childhood diseases, exposure to environmental health hazards and often receive inadequate health care. These factors also increase the risk of ID.  

The severity of the ID can affect the ability of the person to live independently and the level of support needed to do so. It is therefore important that proper diagnosis occurs to ensure the person receives appropriate support and a properly tailored treatment or intervention plan.

The World Health Organisation estimates that between one and three per cent (1-3%) of the world’s population has an ID. Other studies have estimated that up to 8% of populations have some form of ID. It is estimated that the majority of persons, including persons with ID, live in the world’s less developed countries. However, there is often limited information regarding the rates of diagnosis of intellectual disabilities in many less developed countries, including Ghana. As a result it makes it difficult to assess the overall situation for persons with ID and make general statements on the subject of their health status.

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1.2 The Right to Health

The right to health is a universal human right, meaning that it is a right everyone is entitled to. In broad terms, this right can be understood to encompass a right to health care and a right to ‘healthy’ social conditions such as adequate sanitation, nutrition, housing and safe drinking water. These two components must be available, accessible, accepting and quality for all persons (Figure 1). It is important to note that the right to health is not a limitless right to medical treatment or social care, nor should it be understood as the right to be healthy. Instead, it should be understood as the right to enjoy a variety of facilities and conditions which the State is responsible for providing, and which are necessary for the attainment and maintenance of good health.

![Diagram of the Right to Health](Figure 1: The Right to Health based on General Comment No. 14 of the Committee on Economic, Social and Cultural Rights)

The right to health has been enshrined in international and regional human rights treaties, as well as national legislation all over the world, including Ghana. For example, the right can be found in the Universal Declaration of Human Rights; the African Charter on Human and Persons’ Rights; the International Covenant on Economic, Social and Cultural Rights (ICESCR); Convention on the Elimination of All Forms of Discrimination Against Women; and the Convention on the Rights of the Child.

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10 Universal Declaration of Human Rights 1948, Article 25.
Of all international conventions, the ICESCR provides the most comprehensive outline of the right to health. The ICESCR states that everyone has the right to enjoy “the highest attainable standard of physical and mental health”. It also states that in order for the right to health to be realized, Governments must take steps that:

- reduce infant mortality and ensure the healthy development of the child;
- improve environmental and industrial hygiene;
- prevent, treat and control epidemic, endemic, occupational and other diseases; and
- create conditions to ensure access to health care for all.\(^{15}\)

The UN Committee on Economic, Social and Cultural Rights, which monitors compliance with the ICESCR, adopted a General Comment on the Right to Health in 2000. According to the General Comment, the right to health contains four elements:

- **Availability**: A sufficient quantity of functioning public health and health care facilities, goods and services, as well as programmes.
- **Accessibility**: Health facilities, goods and services accessible to everyone. Accessibility has four overlapping dimensions:
  - non-discrimination
  - physical accessibility
  - economical accessibility (affordability)
  - information accessibility.
- **Acceptability**: All health facilities, goods and services must be respectful of medical ethics and culturally appropriate as well as sensitive to gender and life-cycle requirements.
- **Quality**: Health facilities, goods and services must be scientifically and medically appropriate and of good quality.

This right to health will next be explored in the context of persons with ID.

### 1.3 Health Care and Persons with Intellectual Disabilities

Whilst the right to health applies to all individuals equally, the right to health has been considered further in relation to persons with disabilities in the Convention on the Rights of Persons with Disabilities (CRPD). This is in part due to the particular health needs and challenges faced by persons with disabilities.

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\(^{15}\) International Covenant on Economic, Social and Cultural Rights 1966, Article 12.
While it is clear that persons with ID can be healthy,\(^{16}\) it is understood that persons with ID experience a different level of health than their non-disabled peers.\(^{17}\) They have very high rates of health problems that are often not diagnosed or appropriately treated. Studies have indicated that the most common causes of mortality for persons with an ID are respiratory, cardiovascular, and gastrointestinal diseases, neoplasms, and external causes such as accidents and poisonings.\(^ {18}\)

Diagnosis and treatment of persons with ID are often hampered by a lack of training of health professionals, communication barriers, a lack of co-ordinated care, insufficient health outreach programs and a lack of appropriate policies. In the absence of equal access to health care or an inclusive health care system, persons with ID are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation.\(^ {19}\) The Center for Disease Control and Prevention and the National Center on Birth Defects and Developmental Disabilities assert that persons with ID experience worse health outcomes than persons without ID.\(^ {20}\) As a result of these inequalities, it is believed that persons with ID usually live with complex health conditions and have poorly managed chronic conditions such as epilepsy, obesity, undetected poor vision, and mental health problems.

In recognition of the fact that persons with disabilities are vulnerable members of the community that need additional protection, the UN Convention on the Rights of Persons with Disabilities (CRPD) entered into force on 3 May 2008. The CRPD obligates states to provide equal access to health care and related services for persons with disabilities, and represents the first legally binding international instrument that specifically protects the rights of some 650 million such persons worldwide. It is also the first treaty in which non-governmental organisations were present during negotiations and could make interventions. Persons with disabilities participated as members of organisations of persons with disabilities, state delegations, and UN organisations. Partly due to this inclusive process, the CRPD has received wide support, with Ghana having signed and ratified the instrument.

The core principles of the CRPD include respect for human dignity, non-discrimination, full participation, social inclusion, equality of opportunity, and accessibility. Rights relating to equal access to health care are set out in separate articles on health, habilitation and rehabilitation, personal mobility, accessibility, women with disabilities, children with disabilities, and general obligations, amongst others. Article 25,\(^ {20}\)

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\(^{19}\) Stein, Michael Ashley; Stein, Penelope J S; Weiss, Dorothy; and Lang, Raymond (2009), *Health Care and the UN Disability Rights Convention*, Popular Media. Paper 34.

which focuses on health, not only ensures the right of persons with disabilities to equally enjoy “the highest attainable standard of health without discrimination on the basis of disability”, but also requires states to provide free or affordable general and specialist health services. Moreover, Article 25 mandates that health-care professionals must always obtain “free and informed consent”. States must also work towards “raising awareness of the human rights of persons with ID”. Article 26 (Rehabilitation and habilitation) requires States to “organize, strengthen and extend comprehensive habilitation and re habilitation services and programmes” while ensuring that programming supports community participation, is voluntary, and is located as close as possible to persons with disabilities in their own communities, including rural areas. Article 4 (General obligations) mandates governments to take specific action, include promoting the availability of assistive devices, providing accessible information, promoting research on assistive technologies, advancing universal design (ie, accessible for all persons), and training professionals working with persons with disabilities.

This study will focus on Article 25 as this is the overarching health provision in the CRPD. Article 25 states:

*State Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:*

a. *Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*

b. *Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*

c. *Provide these health services as close as possible to Persons ’s own communities, including in rural areas;*

d. *Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*

e. *Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*

f. *Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*
State compliance with the CRPD has precipitated worldwide domestic law reform, as well as consideration of how these laws will be effectively implemented. In Ghana, the Disability Law (Act 715) was created in 2006, prior to the CRPD entering into force in 2008. The Disability Law contains several sections regarding health care for persons with disabilities, being the following:

Medical treatment
31. The Ministry of Health in formulating health policies shall provide for free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons with total disability.

Training of health professionals
32. The Ministry of Health shall include the study of disability and disability related issues in the curricula of training institutions for health professionals to develop appropriate human resources to provide general and specialized rehabilitation services.

Health programmes
33. The Ministry of Health shall include education on disability and disability issues in health care programmes.

Periodic screening of children
34. The Ministry of Health in collaboration with the Ministries responsible for Education and Social Welfare shall provide for the periodic screening of children in order to detect, prevent and manage disability.

Establishment of assessment centres
35. The Ministry of Health in collaboration with District Assemblies and the Ministry responsible for Social Welfare shall establish and operate health assessment and resource centres in each district and provide early diagnostic medical attention to mothers and infants to determine the existence or onset of disability.

As at 15th November 2013 the legislative instrument, which is needed to implement the Disability Law, has not yet been finalized by the GoG. In fact, a review of the Disability Law to ensure it is compliant with the CRPD is currently underway, suggesting this law may be reformed in the near future. For this reason, Inclusion Ghana is using the ICESCR and the CRPD as the basis for its analysis of the right to health care, as any future Disability Law in Ghana must, at minimum, be in compliance with these Conventions.

A health care system that ensures persons with ID enjoy this right to health care has been referred to as ‘inclusive healthcare.’ In other words, it is ‘an effective response to the needs of patients, not just in terms
of treatment of health predicament, but also by addressing the overall well-being through understanding, informing, involving, counseling and respecting the individual.\textsuperscript{21} Inclusion Ghana advocates for such a system, which would hold at its core the principles of patients’ empowerment, self-determination, and community inclusion. This is the right to healthcare as envisioned by Inclusion Ghana.

1.4 The Ghanaian National Health Insurance Scheme (NHIS)

The overall objective of Ghana’s health policy is to improve the health status of all its citizens. This involves promoting access to health, primary health care services, community health services and specialist health services as required.\textsuperscript{22} The Ghana health care delivery system has been structured around four main levels of health service delivery points. These include teaching hospitals, regional hospitals, district health centers and clinics, and village or community health posts to ensure access by all manner of persons irrespective of their location. The GoG is the major source of health care delivery service through the activities of its MoH and GHS.

The National Health Insurance Scheme (NHIS) was initiated in 2003 by an Act of Parliament (Act 650) to replace the ‘cash-and-carry’ system to promote quality healthcare access for all citizens in Ghana. The NHIS “is a social intervention program introduced by government to provide quality and affordable health care for residents in Ghana.”\textsuperscript{23}

In accordance with Act 650, in order to have access to the scheme, all Ghanaians must pay a scaled premium to access NHIS unless they fall into one of the following categories:

- Formal sector employees who contribute to the Social Security and National Insurance trust (SSNIT)
- Self employed who contribute to SSNIT
- Under 18 years of age
- Persons who are over 70 years of age
- SSNIT pensioners
- Indigents
- Pregnant women

In 2012 the new National Health Insurance Act of Parliament, Act 852 was introduced. Act 852 sets out new criteria for fee exemption, however the legislative instrument for this new Act of Parliament has not yet been finalised so some of the exempt criteria which was not in the previous law (Act 650) are not yet being followed. The new exempt criteria are as follows:


\textsuperscript{23} National Health Insurance Scheme, \textit{Register and access NHIS NOW!: A guide to registering and accessing the NHIS}, 3.
A child
A person in need of ante-natal, delivery and post-natal healthcare services
A person with mental disorder
A person classified by the Minister responsible for Social Welfare as an indigent
Categories of differently-abled persons determined by the Minister responsible for Social Welfare
Pensioners of the Social Security and National Insurance Trust
Contributors to the Social Security and National Insurance Trust
A person above seventy years of age
Other categories prescribed by the Minister

At present, persons with ID are not a specific category of differently-abled persons and hence do not yet have a clear system for registration to access the NHIS for free and enjoy its benefits, thus compounding their plight. Discrimination, stigmatisation and stereotypical beliefs regarding person with an ID in less developed countries like Ghana serves as causative factors to a high unmet health care needs for persons with ID.24

1.5 Health facilities in Ghana

The regional and the teaching hospitals are providers of the highest quality curative and preventative health care services in Ghana. They provide care for major cases that have been sent from smaller district hospitals. At the district level, the district management team provides supervision management support to the smaller sub-districts. District hospitals and polyclinics are the main providers of curative secondary health care services. The polyclinics serve as a ‘first point of contact for primary health care in urban centres and hence offer a combination of both preventive and curative care and use the regional hospitals for referrals.’

Further, within the sub-districts are health centres, health posts and the Community-Based Health Planning Service (CHPS) compounds. The health centres have at least a physician assistant and a laboratory technician where minor cases can be treated. The village or community health posts often provide preventive and primary health care services as well. They are often managed by nurses and midwives who provide first aid services and refer extreme cases to the district hospitals and polyclinics. CHPS compounds provide fast basic health services to remote communities. However, community health officers cannot give prescriptions or injections and can only deliver first-aid. Generally the staff will refer patients to a larger clinic.

1.6 Discrimination Towards Persons with ID Whilst Accessing Health Care

A baseline survey conducted by Inclusion Ghana in 2011 indicated that persons with ID experienced difficulty and were discriminated against while accessing health care. In addition to this, Inclusion Ghana’s ongoing work indicated that there was a lack of awareness generally in the community about persons with ID and Inclusion Ghana was concerned that this may extend to a lack of knowledge amongst health professionals.

The 2011 baseline study, however, did not capture opinions of the how, why and when this discrimination occurred when accessing health care for persons with ID. Inclusion Ghana deduced that this discrimination was occurring because health professionals did not receive a sufficient amount of training on persons with ID, both in terms of their particular health needs and also in terms of how to facilitate communication. Furthermore, Inclusion Ghana suspected that the stigma and the belief that persons with ID are the result of juju or wickedness may also be affecting the willingness of health professionals to work with and treat persons with ID. Thus it was believed that barriers to health care access for persons with ID in Ghana can be attributed to two core sources: the inequalities in accessing the health system and the knowledge, attitudes and beliefs of health workers towards persons with ID.

This study was therefore developed to investigate the barriers faced by persons with ID when they try to enjoy their right to health care. The study seeks to explore the current state of healthcare given to persons with ID in Ghana and also identify the challenges they face during health care utilization. It is hoped that the findings of this study will inform policy makers about some of these challenges persons with ID face in the current health care system in Ghana and call for proper and better policies to address these challenges. In addition, it is anticipated that this study will serve as a source of reference for future researchers.

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2. RESEARCH QUESTIONS AND OBJECTIVE

2.1 Research Questions

As noted above, the Ghana Disability Law (Act 715) still lacks a legislative instrument and further, it is under review to ensure compliance with the CRPD. As such, this report focuses on the ‘right to health’ as contained in the ICESCR and CRPD, as the future Disability Law of Ghana must meet these international standards. Further, Inclusion Ghana has narrowed its investigation of the right to health to examine the ‘right to health care’ for persons with ID in Ghana. In future Inclusion Ghana hopes to investigate the second limb of the right to health, being the right to healthy social conditions. The right to health care has been summarised to contain five (5) elements which has been turned into research questions. The questions and sub questions used in this study are below.

In the six project districts,

1. Do persons with ID enjoy the right to health care?
   a. Are persons with ID provided with free or affordable quality health care?
   b. Are health professionals trained on the needs of persons with ID?
   c. Are persons with ID provided with health services that are specific to their disability (such as early identification services)?
   d. Are these health services (general and specialist) located as close as possible to communities?
   e. Do persons with ID experience discrimination in the provision of health care?

2. What barriers do persons with ID face when accessing health care?

3. What interventions are necessary to overcome these barriers?

2.2 Research Objective

The objective of this study is to examine whether persons with ID in the six project districts enjoy the right to health care and if they do not, what the barriers are and identify necessary interventions.
This research is based on the social model of disability, which places the emphasis not on individual impairments as the source of disability but on the way in which physical, cultural and social environments exclude or disadvantage persons who are labelled disabled.\(^{27}\) The social model does not deny the problem of disability but rather locates the problem firmly within society. A basic tenet of this model is that it is society’s failure to provide appropriate services and to fully take into account the needs of all persons, which is the cause of the problem of disability.\(^{28}\) The social model separates out disabling barriers and impairments. The action required to vindicate a person’s right will differ according to situations (Figure 2).

![The Social Model of Disability](image)

**Figure 2:** The Social Model of Disability

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\(^{27}\) Barnes, C (2001) *Emancipatory Disability Research: project or process?*, Public Lecture at City Chambers, Glasgow.

3.1 Research Design

This research involved both quantitative and qualitative data collection methods in order to obtain reliable and robust data to answer the research questions and achieve the research objective. Additionally, given the short time frame to conduct this study, this design enabled the researchers to cover a large number of respondents in an efficient manner.

3.2 Study locations

The study was carried out in 6 districts across three regions in Ghana. These included the La-Nkwantanang-Madina and the Accra Metropolitan districts in the Greater Accra Region, the Kwaebibirem and Upper Manya Krobo districts in the Eastern Region and the Ho Municipal and Adaklu districts in the Volta Region (Figure 3).

![Map of the 6 surveyed districts in Greater Accra, Eastern and Volta Regions of Ghana.](image)

Figure 3: Map of the 6 surveyed districts in Greater Accra, Eastern and Volta Regions of Ghana.

**Accra Metropolitan**

The Accra Metropolitan has a total land size of 200 km² and is made up of six sub metros namely Okaikoi, Ashiedu Keteke, Ayawaso, Kpeshie, Osu Klotey and Ablekuma. The metropolitan area has a population of about 1,848,614 persons making it one of the most populated and fastest growing metropolis of Africa,
with an annual growth rate of 3.36%. The sectors of the metropolitan area economy consist of primary sector (farming, fishing, mining and quarrying), secondary sector (manufacturing, electricity, gas, water, construction, etc) and tertiary sector (wholesale trade, retail trade, hotel, and other services).

The metropolitan area has 28 hospitals, 130 health centers/posts and 60 other health facilities out of which 20 are government facilities, 7 quasi-government, 4 mission facilities and 187 are non-government and private facilities. Concentration of the health facilities in the six sub-metro are as follows: Okaikoi (2 hospitals, 19 health centers, 6 other health facilities) making 12.4%, Osu Clottey (3 hospitals, 27 health center/posts, 7 other health facilities) making up of 17%, Kpeshie (7 hospitals, 19 health center/posts, 11 other health facilities) forming 37%, Ayawaso (9 hospitals, 33 health centers/posts, 15 other health facilities) making 26.1%, Ashiedu Keteke (1 hospital, 19 health centers/posts, 7 other health facilities) forming 12.4%, Ablekuma (6 hospitals, 13 health centers/posts, 14 other health facilities) forming 33% of the total health facilities in the metropolis.

La-Nkwantanang-Madina District

La-Nkwantanang-Madina, with its administrative capital, Madina, was carved from the Ga East Municipal and forms part of the new districts created in 2012. The municipality shares boundaries with Ga West Municipal to the west, Adentan Municipal to the east, to the North with Ga East Municipal to the North and to the south with Accra Metropolitan. There are four main economic activities in the district which are commerce, agriculture, service and industry. Farming is the major economic activity for about 55% of the economically active population. About 70% of the rural population depends on agriculture as their main source of livelihood with about 95% of them being small scale farming.

The La-Nkwantanang-Madina district has 2 government polyclinics and 1 health centre. The polyclinics are Madina Polyclinic at Kekele and Madina Polyclinic at Rawlings circle, whiles there is a health centre at Danfa.

Ho Municipal

The Ho Municipality covers an area of 2.66 km$^2$. It shares boundaries with the Adaklu District to the South, Hohoe Municipal to the north, South-Dayi District to the west and the Republic of Togo to the east. By location, the Ho Municipality is a home to the regional capital of Volta Region and this makes it the largest urban centre in the region. The major economic activities are in the rural areas of the Municipality where about 63% of the persons live and is made up of subsistence farming and animal rearing. The formal sector of the economy is made up mainly of employment in the public service, private construction companies, and a few large trading companies. Other activities of any significance are stone and sand winning at Akrofu, Sokode, Klefe and Bame.
The municipality has 2 government hospitals, being Volta Regional Hospital and the Ho Municipal Hospital and a polyclinic. The municipality can also boast of 26 health centres out of which 2 are not properly functioning. Furthermore, there are 4 reproductive and child health clinics.

**Adaklu District**

Adaklu District, with its capital Adaklu Waya, is one of the newly created districts in Ghana in 2012. The Adaklu Anyigbe from which the Adaklu district was carved from is bordered to the east by the Republic of Togo, Akatsi and North Tongu districts to the south and the Ho Municipal to the west and north. The district covers a total land area of 1,060 km\(^2\). The district has a population of 52,850 and a relative rural–urban distribution of 75% for rural and 25% urban. The most dominant economic sector in the district is agriculture which employs about 70% of the total labour force. The district is well known in the region for the production of tomatoes and maize. Adaklu as a new district has 4 health posts and two CHPS zones.

**Kwaebibirem District**

The Kwaebibirem district is one of the 21 districts in the Eastern Region, with Kade as its capital. The district has a land area of about 12.3 km\(^2\). The district is located in the south-western corner of the Eastern Region of Ghana. On the west, it is bounded by the Birim North District, on the east by East Akim Municipal, and to the south by West Akim Municipal. The current population is projected at 213,259. Over two thirds of these persons live in the rural areas. Crop farming is a predominate economic activity and thus serves as the source of livelihood for over 72% of the population and contributes about 80% of the generated found of the district.

The district has 1 hospital, 3 health centers, 22 CHPS zones. The district can boast of 29 general nurses, 37 community health nurses, 9 disease control units, 5 medical assistants, 9 medical doctors and 76 other paramedical staff.

**Upper Manya Krobo District**

Upper Manya Krobo district was carved out of the Old Manya Krobo District in 2007 with its capital at Asesewa. The district is located at the north-eastern corner of the Eastern Region of Ghana and covers an area of 885 km\(^2\) constituting 4.8% of the total land area of the Eastern Region. The district is bounded to the north by the Kwahu North District, to the south by the Lower Manya Krobo and Yilo Krobo Districts, to the east by the Asuogyaman District and to the west by the Fanteakwa District. The population of the district was 100,046 in 2010. Agriculture accounts for about 80% of the labour force in the district, commerce 12%, and manufacturing and other sectors account for about 8%. The district can boast of 1 government hospital, 4 health centers and 28 CHPS compounds.
3.3 Recruitment of Participants and Ethical Considerations

Letters of introduction were taken from the Regional and District Health Directorates to all the heads of health facilities in the study areas where data was collected to seek their approval for interviews to be conducted with the health workers. An explanation of the rationale of the study was given to all respondents for their consent. They were informed of their right to withdraw at any point of the study. Respondents remained anonymous and were not required to write their names on the questionnaires.

Also, letters of introduction were sent to all ID institutions such as non-governmental organizations (NGOs) and special schools within the study areas to seek approval for parents/caregivers and persons with ID who have registered with them to be interviewed. Consent was obtained from all the eligible identified parents/caregivers and the persons with ID to be interviewed. In few instances where the parents/caregivers were a couple, each parent/caregiver was interviewed separately. The data was analyzed in aggregate to ensure that the identities of the respondents were not disclosed.

The participants for the focus group discussion (FGD) consisted of parents/caregivers of persons with ID who have registered with Inclusion Ghana member organizations within the study locations and were also members of the parents/caregivers self help groups (PSHGs). The lead researchers attended each discussion group together with other members of the research team. The focus groups were heterogeneous, comprising of both males and females. During the discussion each participant was given the opportunity to contribute to any question raised before proceeding to another question. All the FGDs were moderated by one of the principal investigators.

3.4 Population and Sample Size

The population of the study comprised four groups. These included persons with ID who could communicate (sometimes using a parent/caregiver as an interpreter), parents/caregivers of persons with ID, an official from the National Health Insurance Authority (NHIA) and government health workers who are directly in contact with persons with ID when they visit facilities for care and treatment. These health professionals included medical officers (e.g., doctors, physician assistants), nurses, pharmacists, and lab technicians. Overall, the study population was comprised of 79 persons with ID, 138 parents/caregivers and 284 health professionals. The study population is also distributed across 6 districts in 3 regions (see Table 1). This sample size was determined using Yamane’s formula for computing sample size. The formula is as follows:

\[ n = \frac{N}{1 + Ne^2} \]

where \( n \) = sample size, \( N \) = total number of target population in the district and \( e \) = desired level of precision = 0.05.
The study population is distributed across 6 districts in 3 regions as follows:

**Table 1. Distribution of study population surveyed**

<table>
<thead>
<tr>
<th>Region</th>
<th>District</th>
<th>Health Professionals</th>
<th>Parents/Caregivers</th>
<th>Persons with ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater Accra</td>
<td>Accra Metropolitan</td>
<td>97</td>
<td>23</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>La-Nkwantanang-Madina</td>
<td>32</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Eastern</td>
<td>Kwaebibirem</td>
<td>19</td>
<td>22</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Upper Manya Krobo</td>
<td>44</td>
<td>29</td>
<td>15</td>
</tr>
<tr>
<td>Volta</td>
<td>Ho Municipal</td>
<td>51</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Adaklu</td>
<td>41</td>
<td>33</td>
<td>25</td>
</tr>
</tbody>
</table>

**Persons with ID selection**

In each of the six districts, all ID institutions were used to identify participants for this study, with persons with ID then randomly selected to be surveyed. A total of 79 persons with ID were interviewed; this comprised 39 male and 40 female respondents. Almost half (49%) were aged between 11 and 20 years of age *(Figure 4)*. This age distribution was also reflected in their reported level of education, in which the majority were enrolled in primary and junior high school. Those who had some formal education were generally more able to understand and answer the questionnaire. Interestingly, 1 in 4 persons with ID are/were not enrolled in school. When considering marital status, 90% of persons with ID were single/never been married and 85% did not have children of their own.

**Figure 4:** Age distribution of persons with ID
Parents/Caregivers Selection
As with the persons with ID, all ID institutions were used to identify parents/caregivers for this study. A total of 138 parents/caregivers were then randomly selected to be surveyed. The majority of parents/caregivers were women (62% women compared with 38% men) with 64% of the respondents married (Figure 5). Two thirds of the parents/caregivers had just one person with an ID in their care.

![Sex of parents/caregivers of persons with ID](image)

**Figure 5:** Percentage of male and female parents / caregivers interviewed.

Health facility and health professional selection
The health facilities were selected using the following steps. First, a complete list of all the health facilities including hospitals, polyclinics, health centers, clinics, health posts, CHPS zones were obtained from the district health management team for all 6 districts covered for this study. The sampling was done in proportion to the size of the district with all health facilities in that community considered for the study. Overall, a broad selection of government health facilities including hospitals, polyclinics, health centers, and CHPS compounds were selected in each district to obtain a varied population pool. The type and distribution of health facilities that were visited are outlined in Table 2. The majority of health facilities visited were polyclinics, health centres and hospitals. Most facilities (96%) were government run, while only 4% were managed by religious organisations.
Table 2. Distribution of health facilities surveyed in Greater Accra, Eastern and Volta Region

<table>
<thead>
<tr>
<th>Region</th>
<th>District</th>
<th>Types of health facilities used</th>
<th>Hospitals</th>
<th>Polyclinics</th>
<th>Health Centers</th>
<th>CHPS Compound</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater Accra</td>
<td>Accra Metropolitan</td>
<td></td>
<td>5</td>
<td>7</td>
<td>4</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>La-Nkwantanang-Madina</td>
<td></td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Eastern</td>
<td>Kwaebibirem</td>
<td></td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Upper Manya Krobo</td>
<td></td>
<td>1</td>
<td>0</td>
<td>6</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Volta</td>
<td>Ho Municipal</td>
<td></td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Adaklu</td>
<td></td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
</tbody>
</table>

Subsequently, health professionals who were willing to take part in the study were considered. This randomised approach also allowed for a varied population of health professionals to complete the survey (Figure 6). The majority of those interviewed were nurses (63%) with other (18%) consisting of health extension officers, midwives, health promotion officers, ward assistants and administrators. Overall, 69% of health professionals interviewed were female.

![Health professionals interviewed](image)

**Figure 6:** Positions of health professionals.

**Focus group discussion participant selection**

In keeping with the participatory ethos of all research conducted by Inclusion Ghana, the researchers held two FGD in each of the 6 selected districts, making a total 12 FGDs. The FGD members consisted of persons with ID and their parents/caregivers and were purposively sampled. In each of the FGDs, the total number of participants was between 8-10. The purpose of the FGD was to obtain further qualitative data of healthcare experiences.
3.5 **Data Collection, Quality Assurance and Analysis**

To ensure high data quality, the data for the study was collected by an implementation committee formed for all the 6 districts with support from Inclusion Ghana staff. The implementation committee was made up of Special Needs teachers, representatives of member organisations of Inclusion Ghana, parents of children with ID and field officers at the Municipal District Assemblies. The study was preceded by two levels of training: the first training was for the implementation committee members and Inclusion Ghana staff where the objective of the study and research instruments were thoroughly discussed. Role-play was conducted and appropriate revision and reshaping of the research instruments done. A primary pilot study was then carried out using a small representative sample to test the reliability of the questionnaire and the feasibility of the study in each of the 6 districts. In general, the questionnaires and the discussion guide were found to be adequate, reliable and easy to carry out.

The second training was for the implementation committee members and IG field officers to have a common understanding of certain concepts in order to avoid variations in questioning which could generate varied responses. On the average it took about 25 minutes to complete each questionnaire. Completed questionnaires were edited for errors.

The following methods of data gathering were used:

- semi-structured interviews with persons with ID;
- semi-structured interviews with parents/caregivers of persons with ID;
- semi-structured interviews with health workers;
- focus group discussion with parents/caregivers of persons with ID; and
- an in-depth interview with a top official of the National Health Insurance Authority.

A coding scheme was developed for the open-ended questions prior to data entry in Microsoft Excel. To further enhance data quality, the data gathered from the health professionals, parents/caregivers, and persons with ID was validated at a separate stakeholder meeting in Accra. The Microsoft Excel Office suite was used for data entry, tabulations, frequencies, graphs, charts and bars to attain good visual impression regarding the presentation of results and findings.

3.6 **Limitations of the study**

A good number of stakeholders co-operated and gave information on which this report is based, however, the findings of this report are subjected to some limitations due to the following:

- The research sample was taken from 6 districts across three regions in Ghana and is therefore not representative for the whole population of Ghana, although it does give a good indication of healthcare in those regions.
Due to the locations of the interviewees, especially the persons with ID and their parents/caregivers, the study involved only those who have registered with ID institutions such as NGOs and special schools. Persons who are registered with these organizations are self-selected and may therefore not represent all parents/caregivers and persons with ID in the communities.

The researchers found that due to a social desirability bias, the reliability of the answers from the respondents (the parents/caregivers as well as the persons with ID) were sometimes influenced by their interactions with ID institutions.

The researchers found many parents/caregivers and their families have suffered discrimination for so long they have become used to it and often had difficulty identifying the negative treatment that they experienced as discrimination.

The use of proxies with parents or carers responding for the person with ID. The extent to which proxy responses may converge with that of the person with ID is uncertain

These limitations notwithstanding, the quality of data in this report is not compromised due to the adoption of mix methodology and validation for data collection.
To investigate the status of access to health care for persons with ID in Ghana, the data gathered from the surveys has been analysed against the five elements of the right to health care, to assess whether persons with ID do in fact enjoy the right to health care.

4.1 Free or affordable quality health care

The first element of the right to health care is that all persons are provided with free or affordable quality health care, including access to both services and medication.

In Ghana the situation for persons with ID is extremely challenging, due to the stigmatisation and discrimination that persons with ID and their families face. As was found in Inclusion Ghana’s 2011 baseline report, the financial situation of many persons with ID and their families is dire, with education and employment opportunities for persons with ID being extremely low.\(^{29}\) Due to the lack of opportunities for persons with ID to earn a living and the limited government safety, the financial and care-giving responsibilities of persons with ID generally fall on their families. For families with a person with a severe ID, care-giving can become a full time responsibility, meaning that often at least one parent is unable to work. For families with a single parent, the financial burden can be so great that families are unable to meet even their most basic needs of food and shelter. Due to the severity of this situation in Ghana, Inclusion Ghana therefore believes that in the case of persons with ID, the correct assessment should be whether persons with ID are provided with free health care, as opposed to free or affordable, as most persons with ID are unable to meet even their most basic needs.

As noted above, the Ghana NHIS is the mechanism the GoG introduced as a means of ensuring the Ghanaian population enjoys free or affordable health care. Currently some persons with ID are registered via the Livelihoods Empowerment Against Poverty (LEAP) programme which is a social protection intervention established by the GoG to reduce extreme poverty, hunger and starvation among the most severely disabled and incapacitated persons. Under the LEAP programme each beneficiary is to be registered under the NHIS to then enjoy free health care. Also a few NGOs and special schools have managed to get some of the District Offices of the NHIA via the Department of Social Welfare office in the district to register persons with ID in their organisation.

\(^{29}\)Research by Inclusion Ghana indicated 85% of people believe it is very difficult or difficult persons with ID to obtain employment in Ghana and 93% believe it is difficult for persons with ID to obtain a good education. See: Inclusion Ghana, *Baseline report on level of stigmatisation, discrimination and exclusion of persons with intellectual disability and their families in Ghana*, 2011, p 14, available at: http://www.inclusion-ghana.org/resources/reports/Final%20Version%20on%20Baseline%20Report.pdf.
With this background, the first section of this analysis was to evaluate the current NHIS process as it relates to persons with ID. To do this, our researchers investigated the level of knowledge that NHIS registration is free for persons with ID, the rate of uptake of NHIS registration amongst the surveyed group, and further, of those who are registered, the number who registered for free. The reasons behind a failure to enrol or renew NHIS registration were also explored.

It is important to note that, as set out in our limitations, persons interviewed are connected to ID institutions and some of these institutions have arranged for mass free NHIS registration of persons with ID that they work with.

For example, one parent/caregiver reported:

“At first we were not aware that persons with ID are not supposed to pay any money for their premium or registration for NHIS but through the intervention of Inclusion Ghana, Kekeli Foundation and the social welfare, now we are fully aware and we are not paying because we have collectively submitted our children names to the NHI office.”

For this reason, the data below may be affected by this limitation and the wider situation for persons with ID in Ghana is likely to even be more dire than is reported in this study.

With this limitation in mind, as a starting point, the research indicated that amongst communities and health professionals, knowledge that NHIS is free for persons with ID was incredibly low, with 2 out of 5 parents/caregivers and less than half of health professionals being aware of this fact (Figure 7). In fact, many parents/caregivers informed our researchers that they were the first to inform that persons with ID are entitled to free NHIS registration.

![Are you aware that Persons with ID are entitled to free health cover by NHIS?](image)

**Figure 7: Awareness that persons with ID are entitled to free health cover by NHIS**
In addition, qualitative data gathered during the FGD indicated that staff at some NHIS posts were unaware that persons with ID are entitled to free NHIS or did not recognise who persons with ID were and so refused to give free registration. A parent/caregiver commented:

“I think something should be done about this free registration because I once heard of it and when I sent my child to get her registered for free, the insurance workers didn’t agree. They told me my child does not have any physical disability to use as evidence.”

A top official at the NHIS also reported on the lack of knowledge about this arrangement amongst NHIS staff during Inclusion Ghana’s 2011 report on stigma and discrimination of persons with ID.30

Our researchers then tested the responses in (Figure 7) against the actual NHIS registration status amongst the surveyed persons with ID. Our research revealed that less than half of the surveyed persons with ID reported being currently enrolled in NHIS (Figure 8). Furthermore, of the 49% that reported being enrolled in NHIS, a staggering 3 out of 4 persons with ID reported that they paid a premium for their NHIS registration (Figure 9). This means that overall, just 13% of the surveyed population of persons with ID were enrolled in the NHIS for free.

The evidence gathered showed that while 48% of parents/caregivers reported being aware that NHIS is free for persons with ID, this response is likely to have been affected by a social desirability bias and that the true rate of knowledge is actually closer to only 13%. This conclusion in part relies on the assumption that most persons with ID would be enrolled in NHIS if it was known that registration was free.

Figure 8: NHIS enrolment status of persons with ID

The researchers then probed the 28% of parents/caregivers who reported that they had never enrolled their child with ID in NHIS to explain this situation. The majority of parents/caregivers (54%) responded that they cannot afford the premium (Figure 10). The other two main reasons given were that parents/caregivers had no confidence in the scheme (23%) or that the registration point was too far away (12%).

A single father noted the challenges of caregiving, earning an income and registering his child for NHIS:

“I don’t take my child to the hospital or clinic because I have not registered him for the NHIS. Paying for his medical bills is a big challenge to me because I am a single parent. My wife left the marriage when she was fed up with the child’s continuous sickness. The boy has never attended school before and I find it difficult to leave him to go to work. None of my family members is willing to help with his up keeping so I do everything for him by myself.”
The researchers then investigated the reasons why the 23% of respondents failed to renew their NHIS registration. Half of such people reported that they did not renew because they could not afford the renewal payment. A further 11% stated that they had difficulties accessing services, while 8% of parents/caregivers reported that they were not satisfied with the provider. An additional 8% also reported they didn’t renew because they had to buy drugs outside of the facility.

Reporting on the financial challenges of renewing her child’s NHIS registrations, one parent/caregiver stated:

“I was a seamstress. Now am stuck to one place without even going to work or travel to make some income, so I cannot afford to take him to health center. I have registered him on the health insurance but I have not renewed it since there is no money. Sometimes what to eat in a day is a problem.”

Another parent/caregiver commented on the financial challenges in her family:

“I have not been able to renew my child’s NHIS since it expired. I don’t have the resources to do so since these days I can hardly leave him to go to work on my farm. I cannot take him to the farm and I have no body to look after him when I leave him behind.”

On the basis of the above discussion, a major finding in this report is that financial reasons are reported to be the major barrier to persons with ID accessing health care services. Furthermore, knowledge that NHIS registration is in fact free is extremely low amongst persons with ID, their parents/caregivers, health professionals and NHIS workers. This means that despite the GoG developing the NHIS as a mechanism for providing free or affordable health care, this mechanism is failing persons with ID. It is clear that the minimum annual premium of GH¢7.20 (equivalent to US$3.50) is too high for persons with ID, baring them from registering or renewing their NHIS. Linked to this barrier, is the fact that the knowledge that NHIS is free for persons with ID is very low and the systems in place to obtain free registration are not clearly set out.

In addition to the challenges of registering with NHIS for free, many parents/caregivers reported that once they attended the health facilities, they were unable to afford the drugs they were prescribed or unable to access ‘quality’ drugs. An interviewed parent made the following comments:

“Sometimes the medicine given at the health facilities when we present the NHIS is not very good but when we complain, we are told we have to pay to get the quality drugs.”
Another parent similarly stated:

“Because we use the health insurance to assess health care, we are always given first aid drugs and pain killers and we are asked to buy the rest of the prescribed drugs which we usually are not able to afford.”

The NHIS reports that the scheme covers over 95% of disease conditions that afflict Ghanaians. However, a representative from the NHIA informed Inclusion Ghana that the frequently reported issue in relation to medication is that many health professionals prescribe the branded version of the medication, rather than the generic medication/drug name. This causes problems because not every brand of medication is covered by the scheme and further, some health facilities only stock one brand, so if a different brand is prescribed the health facilities cannot provide it. The NHIA representative stressed the importance of health professionals always prescribing the generic name of the drug to avoid this issue.

It is clear that an understanding of the role of generic drugs in the NHIS scheme amongst health professionals is creating an additional financial burden on persons with ID and their parents/caregivers, as they frequently reported having to pay for the prescribed drugs. This has a disproportionate effect on persons with ID due to their increased need for medications.

As noted above, many parents/caregivers did not enrol their child under NHIS because of a lack of confidence in the scheme. When probed further, on the whole parents reported that problems in the scheme related to long wait times, ineffective drugs and the fact that in private health facilities, their children experienced less discrimination. One parent commented:

“I prefer to go to the private health facilities to seek health care for my child because I see that the health workers there show much concern and give quality drugs which help my child to get well fast when she is sick.”

Another parent/caregiver reported:

“I have not registered my child because I have no confidence in the health insurance. I hear comments from those who have registered that they are given poor drugs at the facility when they present the health insurance card so I have decided not to join. So I prefer paying for every treatment and drug I get for my child at the health facility.”

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32 Interview with representative from National Health Insurance Authority.
Also a parent commented on the differences between public and private health facilities:

“The nurses are very rude at the government hospitals so I don’t send my child there. At the private hospital, even though my child has difficulties in communicating, they still have time to listen to whatever he says. I only help him with some of the things that he finds it difficult to mention or say.”

“Because he falls sick a lot and I have to endure the nurses’ attitude all the time, some friends have advised that I should be sending him to the private clinics but I don’t have that money to pay at the private hospital. I am a single parent and the private clinic does not accept the health insurance.”

It is clear that many of the issues with the scheme are cross cutting issues faced by all Ghanaians when accessing health care. Inclusion Ghana did note that many of the health facilities that were visited lacked the equipment, medication and staff and that urgent funding is needed generally to improve the quality of the health care system for all Ghanaians. While this is of critical importance, general improvements to the health care system in Ghana is not the focus of this report and so were not explored further. The matter of discrimination faced by persons with ID when accessing health facilities covered under the NHIS is explored below in section 4.5.

Another trend was recognised in this research, being that the alternatives to attending health facilities exist, in the form of spiritual or tradition healing. Some parents reported turning to spiritual healing or prayer camps. For example, one parent noted taking her child with ID to prayer camps:

“I send my child to the healthcare center in this community when he has a health problem but I have been visiting so many prayer camps since I don’t always have money to go to the health facility.”

Another parent turns to the church for healing:

“Once a while I take him to the government clinic in our community here but most at times I send him to church for prayers especially when I cannot afford the bills at the clinic.”

However, the underling reason as to why the above parents turned to spiritual or traditional healing was financial, as it was recognised that such healing was a cheaper alternative to attending a health facility.

On the whole, Inclusion Ghana has found that while there is a National Health Insurance Scheme that allows persons with ID to access free health care services and medications, the details of this scheme remain unclear and largely unknown by persons with ID, their parents/caregivers, health professionals and NHIS staff. Thus, persons with ID are not enjoying free quality health care.
4.2 Training for Health Professionals

The second element of the right to health care is that health professionals must receive training on the needs of persons with ID. In accordance with the Disability Law (Act 715) (2006), the MoH is required to include the study of disability and disability related issues in the curricula of training institutions for health professionals and to develop appropriate human resources. However, according to earlier research conducted by Inclusion Ghana in 2011, most health professionals in Ghana, especially those in rural areas, seem to have only very basic knowledge about intellectual disabilities.33

Researchers then asked health professionals in depth questions about their knowledge of ID and the training they have received. As a starting point, researchers asked health professionals what they understood the term ‘intellectual disability’ to mean. The majority of health professionals had a very basic understanding of who persons with ID are with most responses referring either to difficulties in mental capacity, such as in communication, intellectual ability and self-care. There were, however, some health professionals who gave incorrect and worrying responses during the interviews, including that an ID is a spiritual condition, a physical condition or they are persons who lack proper parental control.

When probed further, few health professionals interviewed were able to explain what causes an ID. Some wrong responses included – ‘It is a spiritual disease which affects the whole body’, ‘juju’ and ‘lack of parent education’. A common answer also given by health professionals was that ID is by caused mothers who have unsuccessfully tried to abort their babies. Those that gave this response generally did not know of any other cause of ID. These responses reveal an underlying belief that mothers are often responsible for causing ID in their child and a lack of knowledge around the causes of ID. Such attitudes will be explored further in section 4.5 below.

When health professionals were questioned if their training was adequate to treat persons with ID, approximately 2 out of 3 believed it was not (Figure 11). When asked how their training was inadequate, many health professionals stated that while they had received some general training on disabilities, they had not received specific training on intellectual disabilities and so many reported knowing little or nothing about ID. Health professionals at the smaller health facilities reported that they generally referred such patients to hospitals, as they did not know how to treat persons with ID. They also noted that due to their lack of knowledge parents often did not bring their children with ID to these smaller health facilities. One health professional commented:

“The majority of the nurses here know nothing about ID and so those persons with ID who come are not able to be looked after very well.”

Another health professional commented:

“We have not heard about ID during our training, we heard about it through Inclusion Ghana.”

**Figure 11: Health Professional Training levels in ID**

When asked if this lack of training presented a major problem to the care that health professionals can give to persons with ID, an astounding 8 out of 10 health professionals agreed (*Figure 12*). Such an overwhelming response clearly demonstrates that there is a severe lack of training and knowledge about persons with ID amongst health professionals and that this lack of knowledge is likely to have severe health implications for persons with ID.

**Figure 12: Responses of Health Professionals on Lack of Training**
Furthermore, 4 out of 5 health professionals also believed that their facility did not have the necessary resources to treat persons with ID (Figure 13). When asked what resources were needed, health professionals provided an extensive list, including needing wheel chairs, reading and communication materials appropriate for persons with ID, additional treatment beds to allow extra time with patients with ID, as well as an increase in general medical supplies. The most frequently given answer was that health professionals need specialist training and specialists at health centres.

![Facility does not have the necessary resources to treat persons with ID](image)

**Figure 13:** Health Professionals Response on Health Facility Support for ID

Parents of persons with ID also frequently noted that training was needed amongst health professionals. Some parents/caregivers commented on the importance of improved general knowledge of ID, for example:

“I don’t think the health workers themselves are even aware of who persons with ID... or of the laws protecting them. In my view, it is not the fault of we, the parents, nor the health workers. We are all ignorant and our children are the ones suffering from it. Everybody needs general education in ID.”

Another parent commented that the impact that this lack of training increase incidents of ID:

“Training must be provided to doctors and nurses to handle children of such nature because I believe sometimes the ID occurs at the health facilities during child delivery.”

Some parents/caregivers also noted that the lack of knowledge of ID leads to discriminatory treatment. For example, one parent notes:

“Sometimes the nurses in this community clinic are confused about the behaviour of our children with ID when we send them there. The nurses seem not to know anything about ID and they turn to
ask us what is wrong with the children. Some even make fun of the way the children behave so I think yes, we should have nurses who are trained in ID here in the community clinic!”

Other parents made the following comments:

“Heath workers should be educated and advised that they should always treat persons with ID well because they are the children that we have. We cannot throw them away because they have disease and they are always sick.”

“I think some of the nurses look down on our children with ID because the nurses themselves don’t know what ID is about.”

Inclusion Ghana’s research has made it overwhelmingly clear that health professionals are not receiving the appropriate level of training needed to treat persons with ID, leading to poor health care and discriminatory treatment of such patients.

4.3 Specialist Health Services

The third element of the right to health care for persons with ID is that they must be provided with health services that are specific to their disability. These specialist health services include services such as early identification services and early intervention services, like speech therapy and physiotherapy. The Disability Law (Act 715) also sets out that the MoH must provide general and specialized rehabilitation services for persons with ID.

Inclusion Ghana’s 2011 report revealed that there are only a few specialists in Ghana who have experience in supporting persons with ID and their families. Ghana, has for example, 6 speech and language therapists most of whom are based in the capital cities Accra and Kumasi. Even the Accra Psychiatric Hospital that treats persons with ID is severely under resourced, with just one psychiatrist who is responsible for diagnosis and treatment. Furthermore, many persons with ID who are brought to this facility are left by their families and have little in the way of stimulation or activities. Persons with ID need support and assistance to ensure they reach their full potential and such an emphasis on rehabilitation was not witnessed by the researchers who visited the hospital.

Of the remaining health facilities visited, 4 out of 5 health professionals also noted that there was no specialist for persons with ID at the health facility they worked at. Nearly one quarter of interviewees responded that there has been a time when the health professional could not treat the person with ID,

which indicates that there is likely to be a need for specialists in these cases. Certainly, based on WHO’s worldwide rate that approximately 750,000 people in Ghana have an ID, the extremely low rates of diagnosis and intervention in Ghana and the lack of available statistics, a significantly larger number of specialists are needed across Ghana to ensure persons with ID have their disability diagnosed and they receive proper health care.

Figure 14: Inadequate Specialist Treatment of Persons with ID

Inclusion Ghana is alarmed at the significant lack of specialist health services for persons with ID. It is clear that persons with ID do not have access to much needed specialist services. The next section further considers the fact that the limited services available are concentrated in Accra, which is concerning for persons with ID living in the rest of Ghana.

4.4 Well-located Health Facilities

The fourth element of the right to health care for persons with ID is whether they receive general and specialist health services close as possible to their communities.

The majority of persons with ID either listed hospitals (61%) or community health centres (20%) as their primary health care source. 13% of respondents answered ‘other’ and elaborated that this included prophetesses, prayer (church), local drugstore/self medication, health clinic and herbalist (Figure 15). This reflects the comments of many parents and health professionals, that community health centres and CHPS compounds are unable to provide appropriate health care, meaning that most persons with ID rely on treatment from hospitals.
When asked how long persons with ID travel to reach their healthcare provider, the majority reported travelling less than 1 hour (Figure 16). 33% took between 1-2 hours and 1 in 10 took more than 2 hours to reach their local health facility. Interestingly, travel times for each region varied. It was found that on average it took persons with ID from Eastern Region (Kwaebibirem and Upper Manya Krobo) the longest time to reach their local health facility with over 60% taking between 1-2 hours. Not surprisingly, Greater Accra Region (Accra metropolitan and La-Nkwantanang-Madina) residents had the shortest travel, with over 80% taking less than one hour. Volta Region (Ho Municipal and Adaklu) residents took a similar time with 76% taking less than 1 hour to reach their local health facility.
Parents/caregivers commented on the effect that the travel has on the health care received by persons with ID, noting that it can prevent person with ID from receiving health care and can lead to a worsening in their health condition:

“The distance between here and the hospital is almost 2 hours so this would prevent me from taking my child to hospital sometimes.”

“The hospital is very far. The persons with ID need the doctor the most but sometimes before we even reach it, the condition of the person ID is much worse. Persons with ID have extra health needs and need more care so they suffer disproportionately more.”

As the second parent/caregiver rightly points out, the distance of health facilities from communities has a disproportionate effect on persons with ID, as they need health facilities more frequently. This means that they generally suffer more than when general members of the communities when it comes to the lack of access to health facilities.

The challenges faced by those in more remote areas to access health care are also reflected in the lack of available transportation to take the person with ID to hospital. Most parents/caregivers (56%) of persons with ID use public transport to reach health care. Significantly, 1 out of 3 is forced to walk on foot to seek medical treatment, while just in 1 out of 10 drives themselves (Figure 17).

![Figure 17: Mode of Transportation to Health Facilities](image-url)
Furthermore, as is noted above, the majority of the hospitals that persons with ID are taken to lack any specialist services in the treatment of persons with ID. For those that Inclusion Ghana spoke to, the treatment sought related to general ailments and almost never related to identification or intervention services to assist the person with ID reach their full potential.

During the FGD many parents/caregivers commented on the lack of specialist services available for persons with ID and the fact that the health professionals at their local health facility often refer persons with ID to larger facilities that are very far from their communities. One parent notes:

“Most times the nurses at the community clinic here tell me I should take my child to a mental home for better treatment and diagnoses but there is no mental homes in this community or even near to this community.”

Parents/caregivers commented on the need for specialists, saying:

“We need lots of assessments centres in Ghana and not only in Accra. Sometimes you will never imagine what the children go through before finally they are detected to have an ID. They receive a lot of bad comments, treatments and names tags to them because of their behaviour. When we send them to the health facilities, their experience there is no different. I remember a nurse once passed a comment that “so persons like these too are here, he should be in the mental home” but I knew my child was not mad! He has autism! So what I told myself was that “I know better than some of the nurses over there.”

One parent/caregiver reported deciding to move to Accra to ensure her child received appropriate health care:

“When I was told my child has cerebral palsy there was no health worker who could assist me as to what to do. My child was becoming stiffer and stiffer every day until I was told to send him to Korle-Bu in Accra by a friend. I wanted him to get better so I moved to stay in Accra with a relative and I was sending him for the physiotherapy every week. Things became difficult for me because I had stopped working and am a single parent with 4 other children to care for. With time, I had to quit the physiotherapy and come back to my village and my child is not getting any better since there is no physiotherapist in this community clinic so I think the right of persons with ID to health have be neglected for a long time. We need specialists and special units for them or at least some of the nurses we have here should be given training in some of these areas of ID so that they can help reduce the burden on us.”
Another parent commented:

“We used to beat [my sister] a lot because she was not listening to instructions and would repeat same attitude over and over. I think special doctors must be provided at every community clinic to assess them early so that they don’t go through the ordeal my sister went through because we didn’t understand her.”

Many parent/caregivers suggest that to overcome these problems, the government should fund outreach health services for persons with ID living in rural areas. These services should be provided regardless of the road conditions:

“Health professionals should reach out to those in rural communities because the roads are very bad. Maybe a team that travels around. Sometimes the government sees such a bad road and won’t send a car to the kids so they get worse.”

This parent has again pointed out when persons with ID live in areas with poor road access they experienced an even greater lack of access to health services. Thus while, Inclusion Ghana recognises that a lack of health facilities and poor road access are factors experienced by many persons around Ghana, those with ID suffer disproportionately as they have increased health needs as a result of their disability. It is therefore clear that much needed general and specialist services are not located near communities where persons with ID live; and that this is not currently occurring.

4.5 **Equality in the Provision of Health Care**

The fifth element of the right to health care is that persons enjoy this right equally, without discrimination. A large focus on this study was on any areas of potential discrimination faced by persons with ID in the provision of health care.

Our researchers asked parents/caregivers about discrimination occurring at health centres and whether they were satisfied with the level of medical care received by persons with ID. Interestingly, half of parents/caregivers believed that persons with ID are currently discriminated against at health centres in Ghana, while a surprising 44% of parents/caregivers did not believe this was the case *(Figure 18).*
The remaining data gathered from parents/caregivers discussed below, however, does not support the statistic that nearly half of surveyed parents do not believe persons with ID face discrimination when accessing health care. One limitation of this study and possible reason for this is that that many parents/caregivers had difficulty identifying situations of discrimination. They regularly discussed problems that their children faced when accessing health care, such as the fact that they are treated badly, they are sent away from the facility untreated and so on, however many parents/caregivers did not identify these instances as discrimination. Those that answered that their child did face discrimination recalled some very disturbing stories.

“As for the nurses especially, they need to be advised about their attitude towards persons with ID, since they have some preconceived and funny ideas about we the parents and our children. Some of them pass comments that we wanted to abort our children when we were pregnant and that this has resulted in them having IDs, which is not true.”

“I once had a very hot argument with some nurses at a hospital sometime back. They just insulted me because I told them for 3 days my child had not defecated and I was worried and so I was trying to find out from them if they could help me and my child out. The boy was on admission by then but the nurses started insulting me that my boy is not “correct”, “he is mad” and that if he does not want to visit the toilet he should just lie there and suffer.”
When asked who was responsible for discriminating at the health facility, the overwhelming majority of parents/caregivers responded that nurses were responsible for the discrimination. As some parents commented:

“Not all the health workers discriminate against us when we go to the health facility. When I take my child to the hospitals, the doctors are very nice to us. It is the nurses who look down on us through their comments. I remember I sent my child to a health center and a nurse who came to attend to us asked me why I am wasting my time on such a child and asked me if I will not be happy if the child dies. I felt bad and just ignored her comment but when we finally managed to see the doctor, he really showed much concern.”

“I hardly send my child to the government health facility because of the way the nurses behave.”

“Sometimes the nurses say we have not been giving good training to our children at home. My child has autism but he has no physical deformity. He is very difficult to control since he hardly understands instructions. At the government hospitals, the nurse will straight away rain insults on me that am over pampering my child. I used to cry a lot any time I heard these comment from health workers, whom I expected to know better and even advise me as to what to do.”

The second most common answer provided was that other patients were responsible for the discrimination at health facilities. Parents/caregivers discussed the discrimination that they and their child with ID faced when accessing health care as being a significant reason to want to avoid health facilities. A statement from one parent echoes the feeling of many our researchers spoke to:

“The other patients we go to meet at the health centres make us feel that our children are not human beings.”

Other parents similarly commented:

“The patients at the facility look at our children strangely and when our children try to go near them, they quietly move away. It makes me feel bad and wonder why God has decided to punish and disgrace me with a child with an ID.”

“We need a specialist who will come to the clinic regularly or on particular days so that we can meet them on specific days for them to treat our children with ID. This will help us not to mingle with the other patients who refer to our children as “water children” more often.”

“It is the other patients who would not even want me nor my child to get closer to them. Some have
very offensive names they call our children to show that our children have mental problem and they must be avoided.”

Interestingly, although nearly half of parents did not agree their child experienced discrimination, a staggering 82% of all parents/caregivers surveyed believed that something should be done to stop discriminating against persons with ID at health facilities (Figure 19).

![Figure 19: Parents/ Caregivers views on Discrimination by Health Professionals](image)

The matter of discrimination was probed further, with the researchers asking all the respondents a series of questions relating to whether persons with ID are treated fairly, with respect and with the same level of care as other patients. This was designed to investigate further occurrences of discrimination at health facilities that individuals themselves may not recognise as ‘discrimination’. Respondents were also asked about the general attitude that persons with ID face at health facilities.

Persons with ID were asked whether there were times that they feel uncomfortable with the health professionals. Some of the persons with ID elaborated on the times that they have felt uncomfortable, saying:

“They don’t put a good facial expression, I thought they were angry with me.”

“I don’t know why some of the nurses dislike me but others like me.”

“They get angry and shout at me.”
“I feel uncomfortable when they pass a bad comment that I am not normal.”

“I feel uncomfortable when they shout at me but I don’t know why they like doing that.”

Persons with ID were also asked if health professionals treated them with respect, with 85% agreeing that health professionals have a genuine interest in them and treat them with respect. Persons with ID were asked whether there are times that health professionals have made them feel foolish. 36% of persons with ID agreed with this statement. Of those that said they had felt foolish, some of the answers given include the following:

“They give me the same treatment but they make me feel foolish because they think I am useless and cannot be part of society.”

“Sometimes they tell me I am foolish, they shout at me or ignore me.”

“They shout at me a lot to sit down and they pass bad comments about me.”

“They laugh at me when I say something.”

“They call me a mad person and my sister also as a caregiver of a mad person. Sometimes my sister cries.”

“They laugh when they see me or my sister approaching the health centre.”

“They act as if I am not one of those who deserve access to treatment. They do not think about me.”

When asked whether persons with ID were treated with the same level of respect as other patients in health facilities (Figure 20), many parents/caregivers did agree that their child is treated with respect, making statements such as “they play with my child and give proper healthcare delivery”, and “the health professionals are always good and caring for persons with ID.” However, 44% of parents/caregivers did not agree, saying that “persons with ID are not seen like other persons and some persons think they should not be brought to the clinic – instead left to die at home.”

Interestingly, when health professionals were asked the same question, 4 out 5 believed persons with ID were given the same level of respect. Approximately 1 out 6 health professionals believed that persons with ID are not given the same respect (Figure 20). Some health professionals are quoted as saying, “Sometimes because the nurses are not happy about IDs behaviour they turn to ignore them and at times the mothers
will not even bring them for treatment”, “the staff do not want to help them at the facility but rather think the burden is on the support who brings them”, “the persons with ID have stopped using this facility because they are always looked down by the other patients and some health workers” and “the persons with ID who come here are hardly given attention because they are difficult to control”. In a contrary belief, one health professional said, “everybody who comes here receives the same attention. Even sometimes because of the nature of persons with ID we treat them first”.

Persons with ID were asked to describe the differences between the care they receive and that of other patients. Generally persons with ID responded that they are given the same level of care. Some commented, however, that they don’t get the same medication that other get or that they are not given a bed at the facility, despite being sicker than other patients who are given beds.

One parent commented on the level of care received by his child:

“We don’t receive the same level of care for our ID children as persons without intellectual disability at all. I usually sense that my child is being discriminated against because of her disability. There are no wheel chairs and the nurses don’t show any concern at all. In fact something should be done about it because it makes me always sad that persons with ID are treated as less human at the health centres.”

Persons with ID were then asked to describe the general attitude of health professionals towards them. Most responded that they feel liked and treated well by the health professionals. Some responses were revealing a poor attitude towards persons with ID, such as:

“Some are good but the rest don’t want to come near me.”
"The nurses are not friendly towards me at all."

"Sometimes they frown when I am in their office."

"Some of them have a bad attitude but some of them are friendly."

"Sometimes they ask me questions and if I can’t answer it, they get angry."

The researchers then considered communication issues when accessing health care and in particular, whether the opinions of persons with ID are valued when accessing health care. Good patient-health professional communication is crucial to ensuring correct diagnosis. Furthermore, the CRPD confirms that the views and opinions of persons with ID must be listened.

When persons with ID were asked if health professionals sometimes ignored what they said, approximately 43% of persons with ID either agreed (or strongly agreed) with this statement (Figure 21). This response is significant as it represents nearly half of the sample population of persons with ID feeling like their opinions and views were not valued by health professionals. Some comments from the interviewed persons with ID include the following:

"Sometimes I have a headache and they will start to deprive me from eating certain foods like sugar. I get confused and don’t understand why they do this. They don’t explain it to me."

"Sometimes they don’t mind me and they tell me I am foolish."

![Health professionals sometimes ignore what I say](image)

**Figure 21:** Beliefs of Persons with ID regarding treatment from Health Professionals


36 CRPD Articles 7(3) and 21.
Health professionals were similarly asked about their communication with persons with ID. 1 out 3 health professionals were not satisfied with the communication they had with persons with ID. Health professionals were also asked whether they believed persons with ID were always allowed to say what they thought was important during treatment. It was unsettling to find that approximately 1 out 5 health professionals believed that persons with ID are not always allowed to say what they think is important (Figure 22).

![Figure 22: Communication Level between Health Professionals and Persons with ID](image)

While the majority did allow persons with ID to say what they wanted, those that did not provided some very disturbing reasons as to why they did not listen to persons with ID, including:

“I think since their brain is not functioning or since they have a low IQ they cannot be allowed to make any decisions.”

“Since they are regarded as fools, anything they say will not be taken into consideration.”

“Because they lack a lot of knowledge about everyday life.”

“No mental patient can tell you what is wrong with them.”

“Those who have spiritual ideas that can influence we, the health professionals.”

“I think they have nothing important to tell us.”
Even some of the health professionals that said they always allowed persons with ID to say what they wanted, explained that they did so not because they thought the person with ID would have something meaningful to say, but because it is nice or important to allow someone to say what they want. For example, one health professional explained:

“We should allow them to talk even if it does not make sense so that the persons with ID do not feel left out.”

Finally, parents/caregivers and health professionals were then asked about their overall satisfaction with the level of health care given to persons with ID. The majority of parents/caregivers in each district were ‘satisfied’ with the level of health care given to persons ID. Only in La-Nkwantanang-Madina were more parents/caregivers dissatisfied with the level of care. Overall, approximately only half of the parents/caregivers were satisfied with the current medical care their child receives (Figure 23).

![Satisfaction of healthcare given to persons with ID](image)

**Figure 23:** Responses of Parents/Caregivers on Healthcare Satisfaction of Persons with ID

In contrast approximately 2 out of 3 health professionals were satisfied with the care given to persons with ID (Figure 24). Approximately 1 in 4 were dissatisfied and about 1 in 10 were neutral.
One additional finding that has come out of this study is the desire for separate access points or health facilities for persons with ID. Many parents commented that they would feel more comfortable receiving health care for their child if they had a separate facility. A surveyed parent explains:

“I always have problems with my child when she has to be in a long queue at the health facility. She cannot stay at one particular place for long without causing problems. When I explained at the hospital, they ignore me and still ask me to join the queue. She turns to disturb the other patients and they all shout and insult her. It is always a problem for me to send her for medical care. If we can get a special unit or card that shows that they have ID and should be treated first without delays, I will be grateful.”

Underpinning this response is the belief that having a separate facility for persons with ID would mean they would avoid discrimination from other patients and ensure wait times are lessened. The issue of long wait times was a recurrent theme throughout the study, with parents explaining that during the wait, persons with ID faced discrimination and that also it was difficult for parents to manage their children during long waits. Parents also explained that when they finally had a chance to see the doctor, the doctor rushed through the appointment. Echoing the feelings of the parents, our research has revealed that 2 out of 3 surveyed health professionals also believed that persons with ID should have different health service access points at health facilities to assist with their care. Health patients explained the need for separate access points as ensuring persons with ID were not disturbed by other patients, and so that health professionals can have additional time to work with persons with ID.
Inclusion Ghana has been interested to receive these responses and recognises the significant challenges that persons with ID, parents/caregivers and health professionals face in these situations. However, Inclusion Ghana advocates for an inclusive society and is concerned that should separate access points be given this would increase the segregation of persons with ID from persons without ID. Inclusion Ghana therefore advocates for inclusive healthcare. At present it is clear that persons with ID face deeply entrenched stigma and discrimination when accessing health care.

4.6 Available Health Information

Emerging from this research was the fact that many parents/caregivers knew little about the health condition of their family member with ID and knew little about the rights and entitlements of persons with ID. For example, many parents discussed the spiritual causes of their child’s disability:

“I have to consult the gods at the shrine to find out the cause of my child’s illness. I was told he is born to serve the gods so we must send him back to the fetish priest when he is 15 so he can start serving the gods and the community.”

“My relatives claim I am a witch and my witchcraft is the cause of daughter’s disability.”

“My family claimed my child has a spiritual connection with a river in our village. I was therefore sent to the river called Abanza. We paid for all the items requested for but it did not solve my child’s problem. So I later sent him to the prayer camp since I also felt it was spiritual but to no avail.”

“My husband left the marriage when my child was born and she was said to be a curse on me as a result of my behaviour when I was pregnant. Persons tell me I ate food that was a taboo for pregnant women and others tell me I consulted a spirit for the baby. I get confused most at times because I am innocent about all these accusations I always tell myself that it is only God who is my witness that I have no idea why this child was born this way.”

This research also revealed that the lack of knowledge regarding ID and the treatment options available for parents/caregivers themselves is a significant barrier to persons with ID accessing health care. This is because this lack of knowledge can affect the decision making of parents/caregivers regarding what type of health care should be accessed, making them in effect the ‘gatekeepers’ of health facilities for persons with ID. Many surveyed parents, particularly those out of the Greater Accra region, reported seeking out traditional or spiritual healing for persons with ID, to the exclusion of modern therapies and treatments. Parents made the following comments:

“It worries me a lot that my child is not normal and I can’t continue paying monies at hospitals and
clinics when I am not seeing any improvement. Now I send him to the prayer camp and the spiritual leaders keep encouraging me that one day he will be normal like my other children so I hope God will one day listen to my prayers because as at now he is 15 years but cannot even tell me when he wants to use the wash room. It is a big challenge to me and the rest of the family and we are hoping that one day all his problems will be solved.”

“Why will I waste my time to send him to a clinic or hospital when is his condition is a spiritual condition? Until I came for this discussion, I never knew other persons have similar children like mine.”

“I go to prayer camp because of the nature of my child’s sickness for God to intervene and I have seen great improvement because at first he was not able to talk but now he can talk even though I have not sent him to any health facility.”

“My child was initially not able to do anything on his own. A friend advised me to seek spiritual help and now I am seeing great improvement. So to me the prayer camps help a lot because I strongly believe that sickness of this nature does not just happen, there is always a spiritual aspect.”

“I send her to the prayer camps often and sometimes I go to the drug store for medication. At the prayer camps, I see lot of improvement and for me I know her sickness is very spiritual because at times she is well and even tries to talk to me and at times her behavior would just change and she will refuse to talk. Nobody in my family or my husband’s family has such sickness so I really think there is a spiritual solution and that is what persons tell me most. I will continue with the prayers, this sickness has nothing to do with hospital or clinics!”

Some interviewed parents/caregivers explained that gaining health care knowledge was very important to ensuring they took their child to a health facility:

“I think teaching the pregnant women about ID is good because sometimes when we know that there is something called ID, we will be careful in what we eat and do during pregnancy and also we will be able to resist persons who call us names after they see that we have given birth to IDs.”

“I think ID should be part of the education that pregnant women get at antenatal because sometimes when our children start to show the symptoms of ID, we get a lot of information from the community. Some tell us it is spiritual, some tell us we have been bewitched by someone. For instance when my child stopped communicating and started behaving funny, I was told I should seek spiritual care to know the cause. It was my husband who stays abroad who prevented me from doing so. He seems to know about ID so he encouraged me to see medical care from the mental home.”
One parent explains that her child’s health deteriorated significantly as a result of attending a prayer camp:

“My child ended up in a spiritual camp and was given different types of concussions which led to more complicated issues and finally he was declared as a mad person. I gave up hopes on him and everybody in the family also did the same all because we were confused about what was actually wrong with him. Where we were located, there was no assessment centre and I was even ignorant of the existence of such things. It was when I moved to settled in Accra that I heard about ID and assessment centres and decided to bring him from the village for the assessment and he was declared to be a persons with ID. I strongly believe a lot of parents out there go through the same situation as mine and there is no help for them.”

Another parents points out that not only will having information ensure that more persons with ID will be taken to health facilities, having this information will ensure parents are able to respond to any discrimination they face:

“Parents must get proper education so that even if the health workers want to tag their ID children with madness, we the parents can correct them because as I see it, most health workers don’t have any idea about ID.”

In order to address the needs of parents/caregivers to access information, Inclusion Ghana and its member organisations use the model of a Parent Self Help Group (PSHG), which is a small support group for parents of persons with ID where parents/caregivers can share stories, experiences and information, as a means of ensuring parents receive proper information. This intervention has proven successful and some interviewed parents that were members of a PSHG commented on this:

“What I used to believe before I started attending parent self help group meetings was that, someone somewhere bewitched me and my family and have given me such a child but I still used to love her. So I would withdraw her from the school and when I started attending a parent self help group, I got to know that she is not mad but she has ID.”

“I thank God I belong to the parents self help group, I get to know a lot of things about ID that I didn’t know previously.”

While Inclusion Ghana has noted the PSHG is successful, a larger effort needs to be made by government to ensure parents/caregivers are educated on the health needs of their child with ID. It is clear that parents need health information on ID.
Persons with intellectual disabilities have often been invisible to mainstream health services and health professionals. They die younger and have poorer health than the general population. These differences are to some extent avoidable. The study confirmed that persons with ID are excluded from general health care by numerous obstacles, including interplay between cultural and social environments, physical inaccessibility, communication barriers and a lack of training of health professionals. Their exclusion in the mainstream health services is bolstered by a lack of awareness among policy makers and professionals about them being a minority group and their needs. In the absence of equal access to health care, persons with intellectual disabilities are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation. Ghana’s NHIS has provided significant benefits to the Ghanaian population. Even though it is far from attaining its goals of universal coverage, the prospects are encouraging.

The following recommendations, if implemented, would ensure persons with ID in Ghana enjoy their fundamental right to health care.

**Ensuring persons with ID are provided with free and affordable quality health care**

**Recommendation 1:**
Access to quality healthcare for persons with ID in Ghana must be free until such a time that the living and social conditions for persons with ID have drastically improved.

**Recommendation 2:**
The Ghana Health Service should undertake a public education campaign, using easy read materials, to ensure all persons with ID and their parents/caregivers are aware that they are entitled to free NHIS.

**Recommendation 3:**
The NHIA should organise a mass registration of persons with ID.

**Recommendation 4:**
The Minister for Social Welfare should specifically determine persons with ID as a category of differently-abled persons for the purposes of the National Health Insurance Act, so that all persons with ID are exempt from paying the registration and processing fee.

**Recommendation 5:**
NHIA should carry out internal training for its staff on the new categorisation and/or registration process for persons with ID to access free registration.
**Recommendation 6:**
The Ghana Health Service should ensure the medications needed by persons with ID are covered under the NHIS.

**Recommendation 7:**
The Ministry of Health should ensure all health professionals are aware of the requirement to prescribe medication in the generic name, to ensure they are covered by the scheme.

**Ensuring health professionals are adequately trained**

**Recommendation 8:**
The Ministry of Health should ensure all training for health professionals includes a component on persons with ID.

**Recommendation 9:**
The Ministry of Health should train currently working health professionals about persons with ID.

**Ensuring persons with ID have specialist health services**

**Recommendation 10:**
The Ministry of Health should undertake targeted recruitment and training of specialists for persons with ID. These specialists should be available throughout Ghana.

**Recommendation 11:**
The Ministry of Health should ensure that at every district, regional and training hospital there are health professionals that have received detailed training on working with persons with ID.

**Ensuring health services are accessible to persons with ID**

**Recommendation 12:**
The Ministry of Health should ensure permanent general and specialist health services for persons with ID are located outside of major cities.

**Recommendation 13:**
The Ghana Health Service should provide a system of mobile health vans to ensure those in rural areas access health care.
Ensuring health care service provision is free from discrimination

Recommendation 14:
The NHIS should adopt an easy read application form.

Recommendation 15:
The NHIS should ensure its staff are trained on who persons with ID are and their eligibility for free health care.

Recommendation 16:
The Ministry of Health should undertake a public awareness campaign to ensure the public is aware of who persons with ID are, so that the myths surrounding them are dispelled. Importantly, this campaign should inform the public of what an ID is, what causes an ID and the rights of persons with ID.

Recommendation 17:
Factsheets on who persons with ID are should be available at health service delivery points to ensure the public is aware of who persons with ID are and the myths are dispelled.

Health information for persons with ID and their parents

Recommendation 18:
Persons with ID and their parents/caregivers should receive health information about ID and interventions that parents/caregivers can make to ensure their children reach their full potential.
REFERENCES


Stein, Michael Ashley; Stein, Penelope J S; Weiss, Dorothy; and Lang, Raymond (2009), Health Care and the UN Disability Rights Convention, *Popular Media*. Paper 34.


*Universal Declaration of Human Rights* (1948).


INTERVIEW GUIDE

Health Care Professionals

Name of Interviewer: _________________________  Date of Interview: ____________________

Place/ District: _________________________  Name of Health Facility:______________________

Please tick as [✓] in the box as it corresponds to your answer or write your answer in the space provided. There are no right or wrong answers so please feel free to express your opinion.

SECTION A: DEMOGRAPHIC DATA

1  Sex          [ ] Male          [ ] Female

2  Type of facility:
   [ ] Hospital   [ ] Poly clinic   [ ] Health centre  [ ] Health post
   [ ] Pharmacy   [ ] Mobile clinic/ outreach health program [ ] CHPS Compound
   [ ] Other: _________________________________________________

3  Facility operated by
   [ ] Government                   [ ] Private, for-profit entity     [ ] Charitable organisation
   [ ] Religious organisation    [ ] Nongovernment organization (NGO)

4  Profession
   [ ] Medical Officer     [ ] Nurse    [ ] Pharmacist     [ ] Lab Technician
   [ ] Other: _______________

5  Position:_______________________________________________________

6  Employment status with this facility
   [ ] Full Time     [ ] Part Time     [ ] National Service personnel

7  Years of work
   [ ] Less or equal to five years  [ ] More than five years

SECTION B: HEALTHCARE RESOURCES/ TECHNICAL QUALITY

SA = Strongly Agree, A = Agree, D = Disagree, SD = Strongly Disagree, U = Undecided

8  What do you understand intellectual disability to mean?
   …………………………………………………………………………………………………………………
9. This facility has specialist(s) who regularly cares for persons with intellectual disability.

[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

10. The doctors and the health staff at this facility are well-trained and have the capacity to treat patients with intellectual disability.

[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

a) If the Doctors and health care professionals here are not well-trained and do not have the capacity to treat patients with intellectual disabilities, please describe how.

........................................................................................................................................................................

b) Do you think a lack of training presents a major problem to the care that health staff give to persons with intellectual disabilities?

[ ] YES  [ ] NO

11. This facility has the necessary resources to effectively treat patients with intellectual disabilities

[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

If not, what resources are needed?

........................................................................................................................................................................

12. This health facility accepts National Health Insurances (NHIS)

[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

13. Are you aware that persons with intellectual disability are entitled to free NHIS?

[ ] Yes  [ ] No

14. How do you think the facility could improve the capacity of its health professionals to handle patients with intellectual disabilities

........................................................................................................................................................................

SECTION C: CULTURAL COMPETENCE

15. Persons with intellectual disabilities are treated fairly at this health facility

[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

If not, please cite examples of unfair treatment

........................................................................................................................................................................
16 Persons with intellectual disabilities are accorded the same respect as other patients in this facility  
[ ] SA [ ] A [ ] D [ ] SD [ ] U  

a) If not, please describe the difference in respect given to patients with intellectual disabilities and those patients without intellectual disabilities  
........................................................................................................................................................................

b) What do you think causes the difference in respect?  
........................................................................................................................................................................

17 Patients with intellectual disabilities see the same level of care as patients without disability  
[ ] SA [ ] A [ ] D [ ] SD [ ] U  

a) If you agree or strongly agree, please describe the difference in the level of care given to a person with intellectual disabilities and a person without.  
........................................................................................................................................................................

18 What is your attitude towards patients with ID? How do you perceive them?  
........................................................................................................................................................................

19 What do you see as the cause of intellectual disability? How does the perceived cause affect the way you treat a patient with intellectual disability?  
........................................................................................................................................................................

SECTION D: COMMUNICATION

20 During treatment, persons with ID are always allowed to say anything they think is important  
[ ] SA [ ] A [ ] D [ ] SD [ ] U  

a) If they are not allowed, please explain why  
........................................................................................................................................................................

b) Do you think patients with intellectual disabilities should be allowed to say everything they think is important?  
[ ] YES [ ] NO  

c) Please explain why  
........................................................................................................................................................................

21 Patients with intellectual disabilities should have different health service access points at a health facility than patients without intellectual disabilities  
[ ] SA [ ] A [ ] D [ ] SD [ ] U
22 Overall, how satisfied are you with the communication you have with persons with ID / their parents with regards to their treatment
[ ] Very satisfied [ ] Satisfied [ ] Neither satisfied nor dissatisfied [ ] Dissatisfied
[ ] Very dissatisfied
If not satisfied, please explain
........................................................................................................................................................................

23 Over all, how satisfied are you with the medical care you give at your health facilities to persons with ID
[ ] Very satisfied [ ] Satisfied [ ] Neither satisfied nor dissatisfied [ ] Dissatisfied
[ ] Very dissatisfied
Please describe any dissatisfaction that you have and describe ways you think the medical care for persons with intellectual disabilities can be improved.
........................................................................................................................................................................
Name of Interviewer: _______________________________________________________________

Date of Interview: ________________________ Place/ District: __________________________

Please tick as [✓] in the box as it corresponds to your answer or write your answer in the space provided. There are no right or wrong answers so please feel free to express your opinion.

SECTION A: DEMOGRAPHIC DATA

1. Sex [ ] Male [ ] Female

2. Marital status
   [ ] Married [ ] Single/Never been married [ ] Separated/Divorced [ ] Widowed

3. Number of children/ persons with intellectual disability in your care
   [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 and above

4. Level of Education
   [ ] None [ ] Primary [ ] J.H.S [ ] S.H.S [ ] Tertiary and above

5. Main Occupation: .................................................................

SECTION B: HEALTH CARE RESOURCES/ TECHNICAL QUALITY

6. What is your regular source of medical care for your child with ID? (Please check only one response)
   [ ] Personal doctor [ ] Intellectual disability specialist [ ] Community Health Centre
   [ ] Hospital [ ] Other: __________________________________________________________

7. Do you have a personal doctor who regularly cares for your child?
   [ ] Yes [ ] No

8. What is the NHI status of your Child?
   [ ] Currently enrolled [ ] Previously enrolled [ ] Never enrolled
9 From which of the following do you obtain the health insurance?
[ ] From employer  [ ] From spouse’s employer  [ ] From National Health Insurance Scheme

10 Does your child pay premium for the health insurance?
[ ] Yes  [ ] No

11 Are you aware that your child is entitled to free NHIS because they have a ‘disability’?
[ ] Yes  [ ] No

12 How were you able to pay for the registration and premium for your child?
[ ] Sold agricultural produce  [ ] Salary  [ ] Sold assets  [ ] Money from savings
[ ] Employer registered  [ ] Borrowed money from relative/friend

(Please go to question 15)

13 Why has your child not renewed his/her NHI membership?
[ ] Employer registered  [ ] Difficulties accessing services  [ ] Not satisfied with provider
[ ] Facility too far  [ ] Had to buy drug outside facility  [ ] Received poor quality care
[ ] No transport  [ ] Could not afford renewal payment
[ ] Others (Specify)………………………………………………………………………………

(Please move to question 15)

14 What is the main reason why your child has never been enrolled on NHIS?
[ ] Cannot afford premium  [ ] Never Heard of NHIS  [ ] No scheme in the area
[ ] Registration point too far  [ ] Not close facility in the area
[ ] No confidence in the scheme  [ ] Mostly healthy, do not need to be insured

15 Are there things about the medical facility where you receive care from for your child that need to be improved?
[ ] Yes  [ ] No
If yes, list them ………………………………………………………………………………………………………

16 Can you give examples of instances when the medical facility could not appropriately care for your child?
……………………………………………………………………………………………………………………………………

17 In what ways do you think the medical facility and the staff can improve to better care for your child?
……………………………………………………………………………………………………………………………………
SECTION C: ACCESSIBILITY AND CONVENIENCE

18 During the past year, have you had difficulty getting medical treatment for your child?
[  ] Yes  [  ] No

a. If yes, please explain the difficulties.

b. Can you identify the source of the difficulties?

19 How do you normally travel to see your child’s healthcare provider?
[  ] Drive myself  [  ] Have a friend/family member drive me
[  ] Take public transportation  [  ] Walk on foot

20 How long does it take you to travel to the healthcare provider?
[  ] Under one hour  [  ] 1 – 2 hours  [  ] Over two hours

21 Are you usually kept waiting for a long time when you are at health facility with your child because he/she has an ID?
[  ] Yes  [  ] No  [  ] Sometimes

If yes or sometimes, please describe a time when this happened to you and your child. How were you and your child treated?

SECTION D: CULTURAL COMPETENCE
Please tick the appropriate box for your answer. There are no right or wrong answers. (SA = Strongly Agree, A = Agree, D = Disagree, SD = Strongly Disagree, U = Undecided)

22 Persons with intellectual disabilities are treated fairly at health facility where your child receives care from
[  ] SA  [  ] A  [  ] D  [  ] SD  [  ] U

23 The doctors and other health professionals who treat persons with ID have a genuine interest in them as persons and treat them with respect
[  ] SA  [  ] A  [  ] D  [  ] SD  [  ] U

24 Please describe the general attitude of the health professionals towards your child.

............................................................................................................................................................
25 Patients with intellectual disability receive the same level of care as patients without disability

[ ] SA [ ] A [ ] D [ ] SD [ ] U

Explain:

…………………………………………………………………………………………………………………………...

26 Persons with intellectual disabilities are discriminated against at health centers in Ghana

[ ] SA [ ] A [ ] D [ ] SD [ ] U

a) If you agree or strongly agree with this statement, Can you give specific examples?

…………………………………………………………………………………………………………………………...

b) Who is it that discriminates? Doctors, Nurses, Pharmacist, Lab Technicians, other patients etc?

…………………………………………………………………………………………………………………………...

c) Do they give any indication of why they discriminate?

…………………………………………………………………………………………………………………………...

27 Something should be done to stop the discrimination towards persons with persons with ID at health facilities

[ ] SA [ ] A [ ] D [ ] SD [ ] U

28 What do you think can be done to stop the discrimination?

…………………………………………………………………………………………………………………………...

SECTION E: COMMUNICATION

29 Have there been times when your child has tried to tell a health professional something and was ignored?

[ ] Yes [ ] No

30 If Yes, please describe a time when this happened. What was your child trying to say?

…………………………………………………………………………………………………………………………...

31 What did the health professional do in response?

…………………………………………………………………………………………………………………………...
32 Doctors and other health professionals listen carefully to what I have to say about my child’s condition
[ ] SA [ ] A [ ] D [ ] SD [ ] U

If you marked ‘disagree’ or ‘strongly disagree’ please give an example. Did the health professional ignore you? Did they give a reason for doing so?

…………………………………………………………………………………………………………………………

33 Overall, how satisfied are you with the medical care your child receives at health facilities?
[ ] Very satisfied [ ] Satisfied [ ] Neither satisfied nor dissatisfied [ ] Dissatisfied
[ ] Very dissatisfied

34 Please describe any other concerns you have with the medical care your child receives and any improvements that you think would be appropriate

…………………………………………………………………………………………………………………………
INTERVIEW GUIDE

Persons with ID

Name of Interviewer: _______________________________________________________________

Date of Interview: ________________________ Place/ District: __________________________

Please tick as [✓] in the box as it corresponds to your answer or write your answer in the space provided. There are no right or wrong answers so please feel free to express your opinion.

SECTION A: DEMOGRAPHIC DATA

1. Age
   [ ] < 10 years [ ] 11-20 years [ ] 21-30 years [ ] 31-40 years [ ] 41 years and above

2. Sex
   [ ] Male [ ] Female

3. Marital status
   [ ] Married [ ] Single/Never been married [ ] Separated/Divorced [ ] Widowed

4. Number of Children
   [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 and above

5. Level of Education
   [ ] None [ ] Primary [ ] J.H.S [ ] S.H.S [ ] Vocational training

6. Main Occupation: .................................................................

SECTION B: HEALTH CARE RESOURCES/ TECHNICAL QUALITY

Please tick the appropriate box for your answer. There are no right or wrong answers. (SA = Strongly Agree, A = Agree, D = Disagree, SD = Strongly Disagree, U = Undecided)

7. When you feel sick, who do you tell?
   [ ] Parent [ ] Teacher [ ] Siblings [ ] Friend [ ] Other .............................

   Please explain why you tell that person?
   ..................................................................................................................
8 When you feel sick, where do you go for treatment?
[ ] Personal doctor [ ] Intellectual disability specialist [ ] Community Health Centre
[ ] Hospital [ ] Other: ________________________________________________

9 Do you feel better after you visit the doctor?
[ ] Yes [ ] No

Please explain your answer

..............................................................................................................................

10 Have you ever needed some treatment and the health professional could not give it to you?
[ ] Yes [ ] No

If yes, please give an example

..............................................................................................................................

11 Do you think there is anything that health professionals could do to help you more?

..............................................................................................................................

SECTION C: ACCESSIBILITY AND CONVENIENCE

12 Can you remember a time when you needed medical care and you could not get it? If yes, what happened??

..............................................................................................................................

13 Do you or your parents/caregivers have difficulty paying for your medical care.
[ ] Always [ ] Sometimes [ ] Never

Please explain your answer

..............................................................................................................................

14 Sometimes I go without the medical care I need because it is too expensive
[ ] SA [ ] A [ ] D [ ] SD [ ] U

15 I have National Health Insurance coverage
[ ] Yes [ ] No [ ] Unsure

16 The health facility I receive care from accepts National Health Insurance
[ ] Yes [ ] No [ ] Unsure
SECTION D: CULTURAL COMPETENCE

17  Do you like the health professionals that treat you?
[ ] Yes  [ ] No  [ ] Sometimes

Please explain your answer

18  Do you think that your health professionals like you?
[ ] Yes  [ ] No  [ ] Sometimes

Please explain your answer

19  Have there been times when you don’t feel comfortable with the health professionals that treat you?
[ ] Yes  [ ] No  [ ] Sometimes

Please explain your answer

20  Health professionals who treat me have a genuine interest in me and treat me with respect
[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

21  Please describe the general attitude of the health professionals towards you

22  I receive the same level of care as other patients without intellectual disability
[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

If not, please describe the difference between the care you receive and the care other patients receive

23  Sometimes health professionals make me feel foolish
[ ] SA  [ ] A  [ ] D  [ ] SD  [ ] U

If you agree, what do they do that makes you feel foolish?
SECTION E: COMMUNICATION

24 Health professionals sometimes ignore what I tell them
[ ] SA [ ] A [ ] D [ ] SD [ ] U

Can you remember a time when you tried to say something and were ignored?
..............................................................................................................................................

25 During my medical visits, I am always allowed to say everything I think is important
[ ] SA [ ] A [ ] D [ ] SD [ ] U

26 Are there any other difficulties you face in accessing health care?
..............................................................................................................................................
GUIDE FOR FOCUS GROUP DISCUSSION

Parents Self Help Group

Name of Facilitator: _______________________________________________________________

Date of Discussion: ________________________ Place/ District: __________________________

Please tick as [✓] in the box as it corresponds to your answer or write your answer in the space provided. There are no right or wrong answers so please feel free to express your opinion.

SECTION A: DEMOGRAPHIC DATA

1. Self Help Group Name: ...............................................................
   Number of Males ..........
   Number of Females ..........

2. Levels of Education
   ..............................................................................................................

SECTION B: HEALTH CARE AND DISCRIMINATION

3. When your child has a health problem, what step(s) do you take to find out the cause and seek care?
   Probe further on the following:
   a. Do you take your child to see a doctor or nurse at a hospital or community health facility?
      [ ] YES  [ ] NO
   b. If no, where do you take him/her?
   c. If yes, is the facility managed by private / individual / or government
4 If your child has a health problem, what would prevent you from taking him/her to a health facility/to see a health professional?

**Probe further on the following:**

a. Are your children on a health insurance?
   [ ] YES [ ] NO

b. Which type of Insurance? NHIS or others?

c. Does the parent pay premium for the insurance?
   [ ] YES [ ] NO

d. Does the health facility you seek medical care accept NHIS
   [ ] YES [ ] NO

5 Please provide a copy or read to them the article 25 of UNCRPD.

a. Were you aware of these RIGHTS to health for PWIDs?

b. Do you find that your child has access to these rights and services?

c. In what ways do you think your child lack these rights to health?

d. What do you propose should be done for your child to access these rights?

6 How would you generally describe your child’s experience at a health facility/with medical professionals?

**Probe further on the following:**

a. How do the health professionals allow you or your child to say anything she/he thinks is important in the treatment?

b. How is your child treated with respect at the health facility?

c. How does your child receive the same level of care as persons without intellectual disability?

d. How do you sense that your child is being discriminated against because of his/her disability?

e. What do you propose for improvements in the health facilities so discrimination will stop?
INTERVIEW GUIDE

National Health Insurance Authority

1. Do you know what a person with an intellectual disability is?

2. What NHIS cover is available for persons with ID?

3. We have read on your website about ‘indigents’. Do persons with ID fall in to this category? What criteria must they meet to be ‘indigent’?

4. The NHIA website states that there is cover from GH₵7.2 (minimum) to GH₵48.00 (maximum). What level of cover do PWIDs get when they are registered for free?

5. What is covered by the different levels (minimum vs. maximum) in terms of treatment, drugs etc?

6. What is the current process for a persons with ID to become registered in the NHIS and receive a card?

7. What is the process of going to the doctors and using the NHIS/the card?

8. Does the patient have to pay anything (e.g., for treatment or drugs etc)?

9. What is the renewal process and how long does it take? What do persons with ID do about health cover while they are waiting for renewal?