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DEPARTMENT OF SOCIAL WELFARE
MINISTRY OF GENDER, CHILDREN AND SOCIAL PROTECTION



**TRAINING MANUAL FOR CAREGIVERS OF
CHILDREN WITH DISABILITIES**



Training Manual for Caregivers of Children with Disabilities

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FOREWORD

Children with disabilities are one of the most marginalized and excluded groups in society. Facing daily discrimination in the form of negative attitudes, lack of adequate policies and legislation, they are sometimes deprived from realizing their rights to healthcare, education, and even survival. Estimates suggest that there are at least 93 million children with disabilities in the world, but these numbers could even be much higher

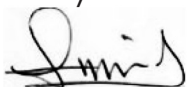
They are often likely to be among the poorest members of the population, less likely to attend school, access medical services, or have their voices heard in society. Their disabilities also place them at a higher risk of physical abuse, and often exclude them from receiving proper care.

Children with disabilities are children first and hence have the same rights as other children. That is why it is stated in the Children's Act 1998 (Act 560) that no person shall treat a disabled child in an undignified manner and also a disabled child has a right to special care, education and training wherever possible to develop his maximum potential and be self-reliant. Additionally, according to the Persons with Disability Act, 2006 (Act 715) a person with disability (including children with disabilities) shall not be deprived of the right to live with that person's family or the right to participate in social, political, economic, creative or recreational activities. One of the ten key strategies for the achievement of the objectives of the national Child and Family Welfare Policy is empowering families in their role as primary caregivers, thus caring for children including children with disabilities has been clearly stated in the laws and policies of the country as part of the rights of every child and is a very important component of the welfare of the child and the family.

The quality of care children receive has a direct impact on the children's ability to learn, to build healthy relationships, and to become the best they can be. However care-givers of children with disabilities sometimes get overwhelmed with taking care of these children mostly due to lack of knowledge of the special features of the various disabilities in children, what to expect during the various developmental stages of children with the various forms of disabilities, the needs of children with disabilities at every stage of their development, what constitutes quality of care and the importance of providing quality care for children with disabilities.

It is therefore important to empower caregivers of children with disabilities with such knowledge in order to provide quality care to these children. This Training Manual for Caregivers of Children with disabilities has therefore been developed by the Department of Social Welfare of the Ministry of Gender, Children and Social Protection (MoGCSP) under the Care Reform Initiative (CRI) to equip caregivers of children with disabilities (which include biological parents, foster parents, adoptive parents, caregivers in institutions, caregivers in day care centers, healthcare providers, teachers of special needs schools, etc.) with the needed knowledge and skill in order for them to be able to provide the required quality of care for the children for them to grow and develop well and become productive in society despite their disabilities. This manual is also to support initiatives under the Inclusive Education Policy by the Ghana Education Service as well as efforts by the Ghana Federation of Disability Organizations. We hope it would also be useful as a reference for other sectors that have contact with caregivers who have or know children with disabilities such as health, nutrition, social protection, etc. in order for all of them to have a common understanding of the importance of providing quality care for children with disabilities.

Hon. Cynthia Mamle Morrison



Minister of Gender, Children and Social Protection

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DEFINITION OF KEY TERMINOLOGIES.

(references are indicated for those definitions with references different from the main reference indicated here)

Alternative Care: Care for children who are not under the custody of their biological parents. Alternative care can be formal and informal. It includes family-based care, residential care and adoption.

ACRWC: African Charter on the Rights and Welfare of the Child Social Welfare Officer is a Social Worker working with the Department of Social Welfare under the Ministry of Gender, Children and Social Protection or a Social Welfare and Community Development Officer working under the Ministry of Local Government and Rural Development (this is an operational definition for the purposes of this manual).

Social Work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. (International Federation of Social Workers - www.ifsw.org)

Social Worker is a person who has acquired the requisite academic qualification in social work and training and is engaged in practise based social work.

Social Welfare is “a nation’s system of programmes, benefits and services that help people meet those social, economic, educational and health needs that are fundamental to the maintenance of society” (Barker,1995, pg. 357).

Child: Child is defined in line with the United Nations Convention on the Rights of the Child (CRC), the 1992 Fourth Republican Constitution of Ghana (Article 28) and section 1 of the Children’s Act 1998, (Act 560), as a person below the age of 18 years. But where a child is in a correctional institution that child may receive continued protection up to 21 years. However, the Child and Family Welfare Policy also considers how a child is defined in the Ghanaian context in relation to the family and the Ghanaian concept of childhood. Thus, a child is a person who is dependent on an adult for care and survival and who is going through the process of socialisation, training and upbringing.

Child Abuse: According to the WHO definition, child abuse (or child maltreatment) constitutes all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child’s health, survival, development or dignity in the context of a relationship of responsibility, trust or power.

Children’s/Child Rights: Children’s rights are the human rights of children as stipulated in the Convention on the Rights of the Child. The Convention is the most comprehensive human rights instrument and outlines the four categories of rights as: the child’s right to survival, development, participation and protection. In the Children’s Act 1998 (Act 560), the rights of children have been broken down into right to name and nationality; right to grow up with parents; right to parental property; right to education and well-being; right to social activity; right of opinion; and right to refuse betrothal and marriage.

Child Protection: Child protection is the term used to describe the philosophies, policies, strategies, standards, guidelines and procedures to protect children from all forms of intentional and un-intentional harm. It is the act of safeguarding the right of all children to a life free from violence,

abuse, exploitation and neglect. The many actors engaged in child protection include children and youth, families, communities, government, civil society and private organizations. It is a process of preventing, responding to and addressing the abuse, neglect, violence and exploitation experienced by children in any setting. It is often manifested as a specialist policy and service sector but of necessity works very closely and is sometimes integrated with other sectors.

Child Protection System: Formal and informal structures, functions, capacities, and other elements organized to achieve safety for children.

Community is a social unit of any size that shares common values including traditional, religious, cultural among others or a social unit whose members reside in a specific locality, and may have a common social/administrative/cultural/traditional and/or religious values

Community Based Inclusive Development: Enhances and strengthens earlier work described as Community-based Rehabilitation (CBR).

Disability: “Persons with a disability include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others,” (UNCRPD).

Family: as defined in the Child and Family Welfare Policy as a group of people related by blood, marriage, law (in the case of adoption), common identity as well as lineage and clan. In the Child and Family Welfare Policy, family is defined as per what the concept commonly means to Ghanaian people; that definition considers the cultural norms of what constitutes family. There is little distinction between nuclear and extended families.

Reintegration: The process of a separated child making what is anticipated to be a permanent transition back to his or her family and community, in order to receive protection and care and a sense of belonging and purpose in all spheres of life.

Residential Care: is care provided in any non-family-based group setting, such as shelters for emergency care, transit centres in emergency situations, and all other short- and long-term residential care facilities, including group homes. Residential care may be considered as a temporary alternative care solution for some children in emergency situations and with no other means of support but only as a last resort if no immediate placement in the community is found. The goal of residential care must be to provide temporary, short-term care and to reunify children with their parents or find a longer-term family-based care alternative within the shortest time possible.

Residential Institution: A residential institution for children is defined as a group living arrangement for more than 10 children, without parents or surrogate parents, in which care is provided by a much smaller number of paid adult caregivers.

UNCRC: The United Nations Convention on the Rights of the Child is a legally-binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.

UNCRPD: The United Nations Convention on the Rights of Persons with Disabilities is a legally binding international agreement and human rights instrument which reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms

Welfare: the welfare of a person is guaranteeing the availability of the basic necessities of life as well as minimizing the levels of violence, exploitation, abuse and neglect. The welfare of a person is safeguarded when certain human and financial resources as well as psychological and material conditions to provide a reasonably comfortable, healthy, safe and secure living are assured.

Well-being is a general term for the condition of an individual or group, for example, their social, economic, psychological, spiritual, mental or physical state. It relates to the state of being happy, healthy or prosperous.

ACRONYMS

CRI	- Care Reform Initiative
CWD	- Children with disabilities
DSWO	- District Social Welfare Officer
DSW	- Department of Social Welfare
GES	- Ghana Education Service
GFD	- Ghana Federation of Disability Organizations
IE	- Inclusive Education
MoGCSP	- Ministry of Gender, Children and Social Protection
NGO	- Non-Governmental Organization
RHC	- Residential Home for Children
SWCDD	- Social Welfare and Community Development Department
SWO	- Social Welfare Officer
PwDs	- Persons with Disabilities
UNCRC	- United Nations Convention on the Rights of the Child
UNCRPD	- United Nations Convention on the Rights of Persons with Disabilities
UNICEF	- United Nations Children's Fund
USAID	- United States Agency for International Development

1.0. INTRODUCTION

1.1. Background

According to the Child and Family Welfare Policy, a Child and Family Welfare System comprise of laws and policies, programmes, services, practices and structures designed to promote the well-being of children by ensuring safety and protection from harm; achieving permanency and strengthening families to care for their children successfully. Thus, caring for children including children with disabilities is a very important component of the welfare of the child and the family.

One of the ten key strategies for the achievement of the objectives of the policy is empowering families in their role as primary caregivers. This is in line with the Children's Act, 1998 (Act 560) which states that parents, care-givers and families shall retain primary responsibility for the welfare of their children (including children with disabilities) and for the provision of their basic needs (food, clothing, shelter, health care and education), support in times of distress or sickness, support for the child's socialisation and identity development. No person shall deny a child the right to live with his parents and family and grow up in a caring and peaceful environment unless it is proved in court that living with his parents would: (a) lead to significant harm to the child; or (b) subject the child to serious abuse; or (c) not be in the best interest of the child (The Children's Act, 1998 (Act 560), Session 3).

Session 10, sub-sessions (1) and (2) of the Children's Act also states respectively that no person shall treat a disabled child in an undignified manner and a disabled child has a right to special care, education and training wherever possible to develop his maximum potential and be self-reliant. The Constitution of Ghana (session 27 sub-session 1a) also states that every child (including children with disabilities) has the right to the same measure of special care, assistance and maintenance as is necessary for its development from its natural parents, except where those parents have effectively surrendered their rights and responsibilities in respect of the child in accordance with law. Thus, the importance of caring for children including children with disabilities has been clearly stated in the laws and policies of the country as part of the rights of every child.

The quality of child care has a direct impact on a child's ability to learn, to build healthy relationships, and to become the best they can be. Millions of children are affected with disabilities worldwide. These children have a wide range of impairments, with greatly varying degrees of severity, and face differing challenges with daily living and attitudes from society (WHO and World Bank 2011). However care-givers of children with disabilities sometimes get overwhelmed with taking care of these children due to several reasons including lack of knowledge of the special features of the various disabilities in children, what to expect during the various developmental stages of children with the various forms of disabilities, lack of knowledge of the needs of children with disabilities at every stage of their development, what constitutes quality of care and the importance of providing quality care for children with disabilities.

1.2. The Rationale and Purpose of this Manual

Around the world, many efforts are being made to reform child welfare systems to promote better care for children ensuring that a consideration of childhood disability is at the heart of these child care reforms. The Care Reform Initiative by the Department of Social Welfare of the Ministry of Gender, Children and Social Protection has the aim of establishing a more consistent and

stable approach to caring for vulnerable children in Ghana so that each child will be assured of a permanent home in a supportive and loving family. As part of this initiative, the Department has developed a Foster Parent Training Manual

. The manual is to build and strengthen the capacities of staff at the national and sub-national levels, foster parents and foster care agencies across the country. It is also extremely useful in upgrading social workers' knowledge needed for post-placement support to foster families and equally of great value for relevant NGOs and others involved in providing rights-based alternative care services and programmes.

However, there is no such manual for caregivers of children with disabilities which would empower these caregivers and strengthen the families to be able to take care of these children who have special needs. It is to address some of these gaps that this manual has been developed to train child protection actors and the various categories of caregivers of children with disabilities. This manual is to equip them with the needed knowledge and skill in order for them to be able to provide the required quality of care for the children for them to grow and develop well and become productive in society despite their disabilities. The manual would also be used by other sectors that have contact with caregivers who have or know children with disabilities e.g. health, nutrition, social protection, education etc. Following the training of all the categories of caregivers with this manual, individual chapters or sessions could be selected for on-going training of caretakers of children with disabilities based in institutions.

This is an introductory but not very specialized training. The manual also does not treat into much details the various topics and hence additional references have been given to help facilitators and participants to refer to for more detailed information on issues around providing care for children with disabilities.

1.3. Learning Objectives and Expected Outcomes

The main aim of this training manual is to train the various categories of caregivers of children with disabilities to be equipped with the needed knowledge and skill in order for them to be able to provide the required quality of care for the children to grow and develop well and become productive in society, despite their disabilities.

The key learning objectives and expected outcomes are that by the end of the training programme the different categories of caregivers of CWD would be able to:

- Define who a caregiver is and describe the different categories of caregivers of children with disabilities as well as list the key responsibilities of these caregivers
- Define who a child is and identify the basic rights of every child in accordance to national and international laws as well as list the key and basic rights of children with disabilities in accordance with provisions made in national and international laws for persons with disabilities including children
- List the various changes that occur during the various stages of a child's growth
- Explain the peculiar behaviours of children during the various stages of their growth
- Identify when there is any form of disability during a child's growth and the associated features that caregivers should know

- Explain the nature of growth and development during adolescence and the support needed from caregivers during these developmental stages
- Define what disability is, list and describe the different types of disabilities as well as explain the causes of disability and what can be done to prevent disability
- Explain the different forms of special needs and types of Disability in children as well as the 'Social Model' of Disability and caring for children with disabilities
- List and explain the basic needs of every child as well as some of the things children with disabilities need to grow and develop properly
- Define and explain what quality of care (for children with disabilities) is made up of as well as the importance of providing quality care for children with disabilities
- understand the concept of healthy and unhealthy attachment and their role as caregivers in supporting healthy attachments.
- Explain why it is important to include children with disabilities in family activities and the need for removing barriers and obstacles as well as challenging stigma and discrimination that may prevent children with disabilities from participating in family and community life to bring about positive social change
- Describe the recommendations for promoting family life for children with disabilities
- Understand the need for taking care of themselves as caregivers of children with disabilities in order to be strong and healthy to be able to provide quality care to the children
- List the various available social services for children with disabilities and how to access them

1.4. Process Involved in The Development of This Manual

In order to ensure that the content of this manual is based on evidence, best practices and current trends and lessons learnt, a comprehensive and extensive review of literature was conducted to kick start the process of its development. These included available national and international documents/manuals on child and family welfare issues including alternative care, children without parental care, etc., research documents on caring for children with disabilities, national policies and strategic documents on child protection, inclusive education, early childhood development and social protection; national and international laws and guidelines; Case Management documents; Standard Operating Procedures available from Ghana and other countries; the Sustainable Development Goals (SDGs); documents on the LEAP Programme and other national social protection interventions as well as other relevant documents (all the documents reviewed and referred to for the development of this manual have been appropriately referenced as footnotes).

Following the comprehensive desk review of documents, extensive consultations with stakeholders and partners including UNICEF, Department of Social Welfare and Department of Children etc. were carried out that resulted in a draft outline of the various chapters describing the main topics to be covered under every one of them. This was followed by consultations with broader groups of stakeholders to review and validate the proposed outline of the various proposed chapters

and to capture inputs from the key stakeholders for the manual to reflect current trends and best practices.

With a revised outline based on comments received from key stakeholders and partners, draft contents of the various chapters of this manual and their sub-sessions including Facilitators' Notes and Exercises were developed. The draft also went through series of discussions, reviews, validations, etc. by key stakeholders and technical working group members and comments and inputs received were used to finalize the manual.

1.5. Guidelines for Facilitators and Users of this Manual

This manual is for training of caregivers of children with disabilities which include biological parents, foster parents, adoptive parents, caregivers in institutions, caregivers in day care centers etc. It is anticipated that this manual would be used by both facilitators who would train the caregivers with the contents as well as the caregivers that are educated and could use the contents as reference material to be referred to while taking care of their children with disabilities. Service providers in other sectors who have constant contact with caregivers of children with disabilities may also use portions of this manual as reference. Elements of the manual could also be used by service providers during home visits to support discussions with caregivers especially those who may not have the chance to participate in the training workshop.

This session provides short descriptions of how the training room environment should be (when the manual is being used for training the caregivers in a workshop setting), setting up a friendly atmosphere, the need to use local examples and exercises, learning materials, ground rules, and rules for the use of the VIPP Cards etc (VIPP Cards are cards cut in different shapes and sizes used to make points during training workshops to make the points very clear. It is normally posted on the walls for the participants to be able to easily refer to).

The Facilitators' Notes included in most of the sessions are supposed to provide more detailed information for the facilitators to use to support discussions by participants during group work as well as help facilitators answer questions and provide clarifications for participants on issues that may arise during the group discussions. Be sure to go through all the notes and practice on a regular basis, as well as do a full run-through of the contents at least one day before delivering a module or sessions of a module of this training. In addition to going through the facilitators notes a day or so before you are scheduled to facilitate, also ensure that you go through as many of the reference materials as possible (the references are listed as footnotes). This would help you as a facilitator to be on top of the issues to be discussed with the participants.

The Training of caregivers is structured as a 3-day training. It is interactive in nature and builds on pre-existing knowledge and experiences of participants. The training is intended to be non-residential and is developed for training in resource constrained settings, without dependence on the use of projectors and related high technology methods. If the Department of Social Welfare has access to a projector and/or Internet, then additional materials could be included in the training such as PowerPoint slides. Depending on the setting, and availability of the caregivers of children with disabilities, the training schedule could be structured differently as required e.g. three consecutive Saturdays or six consecutive afternoons.

Note that since this manual has been developed during the period of Covid-19 pandemic, it is important for the facilitators and participants to strictly adhere to all the precautionary measures (social distancing, wearing of nose masks, frequent use of hand sanitizers or washing of the hands with soap and running water) in order to reduce risks of infection.

a. Teaching and Learning Methods

The delivery of the various chapters of this manual by the facilitator should be carried out using play-based learning and participatory adult learning techniques involving questions and answers, short quizzes, discussions, group work and feedback sessions. In case some of the caregivers that would be trained with this manual are not educated, the facilitators should try as much as possible to use the local language to deliver the training (in this case the choice of the facilitator would be very important since he/she should be able to speak the local language very well).

Facilitators and caregivers should further ensure play in learning is one of the most important ways in which children gain essential knowledge and skills that are relevant to their future. For this reason, play opportunities and environments that promote play, exploration and hands-on learning are critical to support the holistic development of the child.

The manual will direct caregivers to incorporate structured play as a methodological approach and build further on the play/games learning techniques to deliberately and effectively put the child at the centre of stimulation and learning. This is to support cognitive, emotional, physical, and psychological as a positive shift, fully integrated across the continuum of care cycle through play in a progressive manner. It is also to enable the smooth transitioning for a transformational change of all children aged 0-3 to Kindergarten (KG) in preparation for Primary schooling as well as throughout the period of their basic and secondary education.

The manual is based on the following adult learning principles:

- A safe atmosphere and mutually respectful environment between the facilitator and participants enhance the easy transfer of knowledge;
- Learning should be self-directed and highly participatory.
- Learning is experimental (i.e. participants and the facilitator learn from one another – they are co-learners and co-teachers).
- Time is allowed for reflection and feedback.
- Ice breakers, energizers and relaxation exercises are encouraged (in addition to the ones you can give them you can ask some of the participants to come up with some of these ice breakers, energizers and exercises to make the sessions as fun and relaxing as possible).
- Participants are encouraged to use their local language to make contributions and ask ques-

It is recommended that, some of the contents should be presented in:

- Exercises or quizzes to test the level of understanding of the participants before a session is delivered and at the end of every session for the participants to reflect on, relate and summarize the importance of what they had learnt in the session in relation to their responsibilities as caregivers of children with disabilities
- PowerPoint slides for easy understanding and comprehension by the participants
- Group exercises and group work with assignments for participants to research on specific topics and present to the class in plenary sessions
- Role plays by dramatizing some of the issues as seen in their homes and institutions as they take care of children with disabilities.

b. Understanding Participants

Participants at a training workshop may have their own expectations and needs. These expectations need to be bridled and harmonized so that the objectives of the workshop can be achieved without leaving any of the participants feeling disappointed at the end of the training section.

It is absolutely necessary that before any substantive training session gets underway, the facilitator has a good idea about the kind of people who are participating in the workshop. This goes beyond just their names or where they are coming from or the interest groups they represent.

Certain pieces of information about a participant such as the kind of disabilities their children have, visual and hearing impairment, Intellectual and Developmental Disabilities (IDD), likes and dislikes and other personal details would help the facilitator better interact with participants and for participants to mix freely during the training period. This helps a lot in the transfer of knowledge to the participants as well as the easy learning of lessons and experiences among the participants.

Identifying caregivers of children with disability to be participants for the training is very important since they are the key target groups for this training manual. In the identification of caregivers, the Department of Social Welfare (DSW) can explore the possibility of collaborating with the Ghana Federation of Disability Organizations (GFD). GFD has offices across the country and can be very helpful as most of the persons with disabilities (PwDs) are registered with them.

DSW can also engage the Special Education Coordinator of the GES at the district/municipal education directorate for identification of the caregivers. Further, DSW can collaborate with the District or Municipal Health Directorates to get a list of children who were identified with disabilities especially at birth and to engage the caregivers.

During the training at the sub-national levels, the lead implementing partner (IP) in collaboration with the DSW can also explore the engagement of members of GFD, who are PwDs as facilitators and can also serve as role models and agents of change.

c. Training Room Environment and Friendly Atmosphere

As often as possible avoid the rigid classroom type of sitting arranging the chairs into a U or horse-shoe shape to make the seating arrangement as informal as possible. If the room is big enough, the seats could even be arranged into smaller groups which can be named as villages, communities or islands (using names of communities, animals, or trees). In this way, participants will be able to learn and share with each other easily.

d. Setting the Learning Climate and the Stage

It is the responsibility of the facilitator to present the background for each chapter and describe the exercises and activities as clearly as possible. In addition:

- Read each topic in the chapters and review all materials and activities before each training section so that you are fully comfortable with the content and process;
- Start on time and clearly establish yourself as the facilitator by calling the group together
- Organize all the materials you need for every section and place them close at hand and as much as possible stay within the suggested time frames;
- Gain participants' attention and interest by creating comfort between yourself and them;
- Anticipate the unexpected, even embarrassing, questions. In such situations if you feel you don't have the answer to the question, throw it back to the participants for discussion.
- If the question requires that you carry out some research or you refer, give it as an exercise to the participants but be sure to read about it so you can add to the answers the participants will present the next day;
- Prepare responses and examples to help move the discussion forward when training gets underway; Use local resources, materials and examples whenever practicable.



2.0. GETTING STARTED

This chapter sets the stage for the training to begin by introducing the facilitators and participants to each other, explaining the rationale and purpose for the training, listing the key learning/expected outcomes from the training, lists participants' expectations and fears as well as establishes the ground rules for the entire period of the training.

Learning Outcome of this Chapter:

By the end of this chapter participants would

- know who is facilitating the training and who the other participants are
- understand the purpose and learning objectives of the training
- share their expectations and fears
- go through agenda for the entire training
- set the ground rules for the training

Duration: 60minutes

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Attendance register/sheet
- Name tags
- Note pads and pens for participants
- Refreshments for participants
- Facilitators Notes and Handouts (copies of the Agenda)
- COVID-19 Personal Protective Equipment (PPEs)
- Camera for pictures

Remember to apply the flip chart rules presented in the text box below while presenting the ground rules agreed upon by the participants on the flip chart.

VIIP Card Rules and Effective Use of Flip Charts

When using VIIP cards

- Write boldly and clearly so it can be read from a distance.
- Use both small and upper-case letters.
- Write no more than 3 lines per card

When using Flip Charts.....

- Remember to use different color markers for writing your points on Flip Charts to make them clear and stand out (creative presentation of information on a flip chart paper).
- It also helps to use the chisel-tip instead of the round-tip markers to make the points nice and bold
- As much as possible don't put too much information/points on each flip chart page - (there should be at most 5 points on each flip chart page) at most 5 points on each page

Session 2.1: Opening, Introduction and Welcome

Facilitator Action for the Opening Formalities:

- a. Ask for a volunteer from among the participants to pray or lead the group in song to start the training.
- b. Welcome all the participants to the training and ask everyone to complete the attendance register if they have not done that already (circulate round the room).
- c. Introduce yourself and the other facilitators by telling them your name and where you work. Also give a brief background of the workshop and set the participatory tone by asking the participants to introduce themselves in a manner that creates the necessary environment and motivates participants to effectively participate in the training.
- d. Ask participants to pair up and share their names as they would like to be called during the workshop with their partners, where they are coming from, what work they do, how long they have been taking care of a child with disability etc. as well as which tree or animal best describes them or what adjective that starts with the first letter of their names best describes them. (If participants are able to think of an adjective to describe how they are feeling or what represents them, a lot of useful information can be exchanged easily and in a friendly manner). E.g. Evelyn might say “Energetic” Evelyn, Paul might say “Patient” Paul. Participants will be called that for the duration of the training.
- e. First introduce yourself and any other facilitators who are part of the training using the same guidelines as what you’ve given to the participants.
- f. Try to restrict each of the introductions to a maximum of one minute and ensure everyone writes his/her name on the nametag. If participants are willing, ask them to write their names with their corresponding adjective e.g. “Energetic Evelyn”. Make sure that names are written legibly and in large letters (if participants can read each other’s names, this helps them get to know each other and promotes belonging to the group).
- g. After the introduction section you can also let the participants sit in groups of up to 8 (even if the room is not too big). This is very necessary because as stated in the guidelines for the facilitators, this training workshop will involve a lot of group exercises and assignments. Putting participants in groups would also make them feel they belong to their groups (making them feel a sense of belonging to a kind of family in the workshop). This would make them open up easily and participate more freely.
- h. After putting them in the groups inform them that their groups are now little islands and so you need to decide with them what names they would want to give to their groups which are now cities/towns/countries/islands. You can propose or suggest names of some animals like cheetahs, elephants, tigers, rats etc. If they agree, put the names on little pieces of papers and let them ballot by one person from every one of the groups picking from the ballot papers. The name picked by the representative of the group becomes the name of their group/city/town/country/island.

- i. Remember to inform participants that it is not only the facilitators who are bringing important information to the training, but also the participants, who have valuable experience and skills in taking care of children with disabilities to share. Conclude the session by telling participants that you have been looking forward to this workshop to share and to learn from their rich experiences.

Session 2.2: Participants' Expectations and Fears and Purpose for the Training

Facilitators' Action:

- a. Introduce the session by asking participants whether they have some expectations for this training workshop. After a few responses ask them whether they also have some fears or uncertainties about the workshop.
- b. Give each of the participants two rectangular VIPP cards (one white and one pink) and ask them to write one expectation from this workshop on the white card and one fear on the pink card.
- c. Collect all the cards (and group them during break sessions); post them on the wall and inform participants that they should use a marker to tick any expectation or fear that is addressed during the course of the training workshop. At the end of each day visit the side of the wall where these expectations and fears are posted with the participants to find out how many have been addressed. This will serve as part of the evaluation for this training workshop.
- d. Ask participants to tell you why they have come to the workshop. This will help you elicit from them whether they know the purpose of the workshop or not. It will also help you set the pace for this session.
- e. After 4 to 6 answers inform participants that this training workshop is as a result of the need to equip caregivers of children with disabilities with knowledge and skills that will enhance the performance of their duties as caregivers.
- f. Ask participants to mention what in their view are the objectives of this training. Write their answers on the flip chat.
- g. After a few answers inform the participants that in order to address their expectations and for the purposes of the rationale mentioned earlier, the key objective of the workshop is to deepen participants' knowledge and develop their skills needed in order to take good care of children with disabilities.
- h. List the learning objectives and ask participants to explain in their own words how they understand them. After a few responses go through the agenda with the participants informing them that the agenda is structured in such a way as to ensure all the topics are treated in order to achieve the objectives of the training workshop. Allow them to ask questions and seek for clarifications. As much as possible allow other participants to answer the questions first before you add onto them if there is the need for more clarifications. This would encourage massive participation by the participants right from this initial stages/beginning of the workshop.
- i. Having gone through the agenda, ask participants to select the ground rules that would guide them in order to be able to cover all the items on the agenda within the stipulated time (Ask: What Basic Rules shall we establish to accomplish the workshop agenda?). Write

the rules they will mention and agree upon on a flipchart and post it on the wall so all participants can refer to during the whole workshop period.

- j. Conclude this session by expressing how excited you and your team of facilitators are about the workshop and your hope that the expectations of everyone would be addressed by the end of the programme.

3.0. THE STAGES OF CHILDREN'S GROWTH AND DEVELOPMENT

Children at certain age brackets display certain behaviour as part of their development and hence knowing and understanding these aged linked behaviours will help parents and caregivers be able to handle the children in a way that will help them feel safe and protected in the house regardless of the children having disabilities or not. However, many caregivers have limited knowledge about child development and therefore they either expect certain behaviours that are unrealistic for a child's age and ability or are unable to identify when there is any form of disability during a child's growth. This chapter is therefore to help caregivers to understand what every child goes through during the developmental process, some of the common features they will depict at every stage and what they need to help them develop properly.

The learning objectives are that by the end of this chapter the participants would be able to:

- List the various changes that occur during the various stages of a child's growth
- Explain the peculiar behaviours of children during the various stages of their growth
- Sensitize caregivers on associated features they should look out for during a child's growth that could be indications of varied forms of disabilities.
- Explain the nature of growth and development during adolescence and the support needed from caregivers during these developmental stages

Duration: 60mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators notes and handouts
- Child Protection Toolkit (the Child's Developmental Ladder)

Session 3.1: Stages of Children's Growth and Development

- a. Introduce this chapter by using these points to inform participants that children, whatever their age, children need care and protection if they are to reach their full potential as adults.
 - Raising children is not an easy task and is often challenging especially when the child has some form of disabilities.
 - Since child development begins in utero taking care of children even begins when the mother is pregnant. Disability can occur in utero hence it is important to ensure that the mothers are healthy and have good nutrition during pregnancy.
 - Many of us learned how to parent from our parents or those who raised us and have continued to use methods of parenting that we have seen practiced in our communities over time.
 - Add that unfortunately, many caregivers have limited knowledge about child development and therefore they either expect certain behaviours that are unrealistic for a child's age and ability or are unable to identify when there is any form of disability during a child's growth.
 - This chapter is therefore to help caregivers to understand what every child goes through during the developmental process, some of the common features they will depict at every stage and what they need to help them develop properly.
- b. Write the key learning objectives of this chapter on a flipchart and ask a volunteer to read them then continue by adding that in this session we will start to explore child development and also look at how we as parents and caregivers respond to common problems and needs. In this session we will start to look at the different stages of child development and their needs.
- c. Inform participants that to look at the stages of children's growth and development you would like to carry out an exercise (the Child Development Ladder) with them.
- d. Add that the purpose of this exercise is to help caregivers understand
 - what every child goes through during the developmental process,
 - some of the common features they will depict at every stage and what these children need to help them develop properly.
- e. Ask all the participants to walk towards the wall where you mount the picture of the ladder with the 8 stages of the child's development as the steps on the ladder (starting from 0-6 months, 6-12 months, 1-2 years, 2-3 years, 3-5 years, 5-9 years, 9-13 years and 14-18 years) on the mat.
- f. Explain to them that you are going to give them 8 pictures of children in the various age brackets and you would want volunteers to pick one each of these pictures and match them with the age brackets on the mat mounted on the wall.
- g. Allow them a few minutes to do the matching correctly among themselves and afterwards ask them whether there are particular practices common in their communities in relation to general behaviour and care of children at these age brackets (circumcision for boys, exclusive breastfeeding, weaning, birthday parties, puberty rights etc.).

- h. After the discussions on the practices give out the other 8 picture cards with the processes, some of the common physical features they depict, the common behaviours at the various stages as well as what they need to develop at each of the stages and ask them to match them with the age brackets on the ladder.
- i. Every participant that picks one of the cards is to read out the inscription on the cards aloud to the hearing of the other participants and mention which age bracket matches with the features described. It is when the entire class agrees that they would be allowed to paste the card to match the age bracket on the mat mounted on the wall.
- j. Use the information in the Facilitators' Notes 3.1 on the Developmental Stages of Children to enhance the discussions after the exercise. Ensure to mention that the ability of the various caregivers to stimulate positive cognitive, emotional and physical growth experiences among children especially CWD depends on their knowledge related to child care and development, child-rearing practices, and the beliefs related to these practices, usually imbibed through socialization. Also include discussion on the definition of adolescence.
- l. To conclude this exercise, remind them of the child's needs already identified on some of the cards and ask them to use their experiences to discuss the needs and possible problems a child may face at the various age brackets.
- n. If a solution mentioned for dealing with the common problems is punishment and harsh treatment, you can have a short discussion on discipline and what it means to teach a child at these various stages in life and then explore what discipline means in the individual families.



Facilitators' Notes 3.1: The Developmental Stages of Children

Numerous studies have demonstrated that the first five years of a child's life are the most important for brain development especially within the first three years (from the time the child is in the womb till it is 3 years) when the brain's architecture is formed. This period constitutes their early years and children learn more quickly at this stage than at any other time of their lives¹. Throughout this initial three (3) year period, a child develops physically, socioemotionally and cognitively. The child also learns to communicate with others and establishes the basis for his or her future life in school and thereafter. It is therefore imperative that during these early years of their lives, children are supported to receive careful nurturing, love and attention as well as good nutrition, all in a stimulating and safe environment.

Clearly the responsibility of achieving these desired results lies mainly with caregivers including parents, siblings, other family members, pre-school teachers and house-helpers (Domestic workers and extended family members who are engaged to support with house chores and provision of care for children in the homes).

Facilitators are encouraged to refer to the Early Childhood Care and Development Standards (0-3 years), by the Ministry of Gender, Children and Social Protection (MoGCSP), March 2018 to add the milestones for each age bracket which is very important during the discussions with the care givers.

o 0 - 6 months old - At this Stage of Development:

- The “0 months” indicates the period of the pregnancy, hence care for pregnant mothers (including good nutrition, constant medical check-ups etc.) is important to prevent disabilities by preventing abnormalities in the development of the foetus.
- Once born, one of the things that babies need most is to be held, cuddled, rocked and carried. This helps the child develop a sense of attachment, trust and connection with the parents which will have an impact on the future development of the child.
- It is very important at this stage that that parents provide the baby with plenty of warmth, breastmilk only and care.
- Babies at this stage don't know any words. They make different kinds of sounds to express feelings. They cry to let others know when they need something, like eating. The most important thing parents can do is to respond to the baby and try their best to figure out what the baby needs.
- Even though babies need to learn that there are times to sleep and times to be active and should be allowed to rest and not encouraged to be active at night babies at this stage don't understand rules or explanations. They only need to know that their needs will be met.

¹ Early Childhood Care and Development Standards (0-3 years), Ministry of Gender, Children and Social Protection (MoGCSP), March 2018,

- Children at this stage don't understand their own feelings or how other people feel. When they cry for long time, they are not trying to make other people mad. Crying is normal at this stage. The most important thing that parents can do at this stage is show the baby that he/she is safe.
 - Babies love to grab things and put them in their mouths. This is not because they are “bad” or “naughty” but because this is the only way they know to learn what the objects around them are.
 - Babies at this stage do not understand danger. The best solution for parents is to ensure that the environment around them is safe.
 - Parents should remove anything from the baby's environment that could harm if touched or chewed (e.g. small objects, sharp cutting utensils, chemicals, etc.)
- **6 - 12months old – At this stage of Development:**
- Babies usually start to crawl, pull to a stand and rock back and forth. They usually cry less and smile more.
 - At this stage the babies need to know that parents are always close-by. When they cry, it may be because they are afraid that parents are gone, for example when they leave the room. They don't understand that parents will come back.
 - Sometimes babies cry also because they feel sick or because they are teething. Babies don't know how to tell parents that they feel feverish, have stomach pain or sore throat; they can only cry. It is important for babies to know that their parents are always near when they get the feelings that cause crying.
 - Babies at this stage begin to speak and make sounds. It is important for parents to respond to the sounds. By doing this, children understand that those sounds are important and that when they speak, their parents will listen and respond to them.
- **1 - 2years Old – At this stage of Development:**
- Children begin to walk independently and start talking. They love to move around and discover the environment around them.
 - They love to touch everything, drop objects from their hands, and taste everything. This is not because they are “naughty or bad”, but because this is how they learn and how their brain develops.
 - The role of parents at this stage is to ensure that the environment around the child is safe from harm so that they can explore it safely.
 - Children at this stage are eager to know the name of all the objects around them and can learn words very fast. Parents can make the most of this opportunity by talking to the child,

reading, telling stories, listening and answering the child's questions.

- Children at this stage become more independent. This sometimes may cause conflict with the parents. For example, if a parent is in a hurry to leave a place and the child says “no” and refuses to move, sometimes it is not because the child wants to be “bad” or “disobedient” and make the parent late. The child might be trying to say “I want to stay”, “I don't want to leave”, “why now?”, but he simply does not know the words. The child does not understand how the parent feels.
- Children at this stage don't understand that when parents forbid them to do something they want to do; this is often in their interest and to protect them. So, they sometimes become frustrated and start screaming and crying, because their language is not developed enough to help them express their feelings. This is important for parents to know, as this can be at times very frustrating and challenging for them.

o 2 – 3years Old – At this Stage of Development:

- Children usually change their behaviour and become more mature. They try to make sense of their own feelings.
- Children start learning about danger and become fearful of being hurt. For example, they might get scared when they are left alone or become very shy when they are with strangers or people that they don't know well. This is not because they are “disrespectful” or “disobedient” but because they are learning the difference between strangers and people that they trust, and they are cautious.
- Children at this stage don't know the difference between reality and fantasy. This is why they can get very scared of monsters and ghosts when reading stories or watching cartoons, because they believe they are real. Self-control and self-confidence begin to develop at this stage. It is important for parents to praise the child for good behaviour to reinforce and build confidence, and at the same time point and explain bad/naughty behaviour.
- At this stage, parents should provide children with reassurance and support so they feel safe and protected and grow up with confidence. As much as possible, parents should avoid shaming and embarrassing them or punishing children for being afraid.

o 3 - 5 years Old – At this Stage of Development:

- Children are very curious and want to learn everything. When they see something new, they want to know what it's called, what it's for, how it works...they ask a lot of questions! And it is normal for parents to feel tired. The important thing is to try and respond respectfully to the child's curiosity and help the child find the answers. Even to say that we do not know the answers sometimes. In this way the child will also learn to be patient.
- At this stage, children also learn to do more on their own and they want to practice their

independence (e.g. feeding, bathing, dressing up, making choices).

- Because children cannot be allowed to do dangerous things, they also have to learn about rules at this stage of their development. Providing structure and explaining the reasons for commonly agreed rules is critical. The more a child understands the reason behind the rule, the more likely he/she is to follow them. And parents/caregivers should be examples of good behaviour.
 - It is important that caregivers are reassuring and encouraging at this stage of the child's development. If a parent or caregiver is over-protective and critical, the child might learn to doubt his/her own abilities and lose confidence.
 - Children need time to play, particularly with other children of the same age. Through play, children solve problems, invent new things and figure out how things around them work.
- o **5 – 9 years Old – At this Stage of Development:**
- Children turn an important point in their development. As they start school, they must quickly learn how to manage on their own without their parents, how to get along with many other children, meet expectations of new adults that are not their family members, and adjust to new schedules and routines.
 - Some children can adjust quickly to all these changes and without problems. Others will face challenges. This is normal, because children have different temperaments. It is important for parents to recognize their children's temperament, not to get angry and to support them in their development.
 - At this stage of development, children observe and learn many things from adults. Children who watch their parents or relatives respect the rules and manage conflicts without violence, are more likely to imitate the positive behaviour and act well. This is why parents have the important responsibility to guide and support their children. They must be the people they want the children to become.
- o **9 – 13 years Old – At this stage of Development: (just the beginning of adolescence)**
- The Child is about to enter puberty. This is a time of psychological, physical and emotional change for both boys and girls. This is also the time for the onset of menstruation for girls. This is a sensitive time for the child, which requires attention, guidance and support from parents and caregivers.
 - Children at this stage spend more time with their friends and peers than with their parents. Sometimes they want to be independent and do what their friends do, even if the parents disapprove. However, they are still young and do not have all the knowledge and skills that they need to make the right decision and protect themselves from harm.
 - It is therefore important for parents and caregivers to provide guidance and advice to children and help them stay safe, while respecting their need for independence and privacy,

and their desire to experience new things. The child's body undergoes a fast transformation. It is important for caregivers to explain these transformations to the child, providing necessary guidance, knowledge and skills for a healthy and balanced transition into adolescence.

- The child might not be always keen to talk when upset or sad. Parents and caregivers should create the space for the child to express him/herself when ready to talk, should listen carefully to his/her concerns and help the child find a solution to problems.

Remember to inform participants of the Definition of Adolescence

Adolescence is the time between the beginning of sexual maturation (puberty) and adulthood. It is often described as the transition between childhood and adulthood. According to United Nations/World Health Organization's definition an adolescent is any person aged between 10 and 19 years.

This definition of an adolescent overlaps with that of a child, which is defined as any person under the age of 18 years, in accordance with the United Nations Convention on the Rights of the Child (CRC).

"Young adolescents" are defined as those aged between 10 and 14 years and "older adolescents" as those aged between 15 and 19 years.

o 13 – 18 years Old – At This Stage of Development:

- Physically, mentally and emotionally the child transitions into adolescent stage. In later adolescence, clear sexual identity – manhood, womanhood is established.
- The most important thing for the child at this stage is to develop his/her own unique identity "who they are", separate from own parents, and establish peer relationships.
- For this reason, often in adolescence the child express himself/herself through a sudden change of choice in terms of clothing, friends, music, hairstyles, beliefs, religion, out of school activities, which often parents don't like. This is because the child is trying to experiment different identities to see which one would fit best, rebelling against the influence from parents.
- Even the best adolescents experience at some stage some identity confusion: some boys and girls might experience self-doubt and peer-pressure to conform to a group and experiment risky behaviours (e.g. minor delinquency, alcohol and drug use, or risky sexual behaviour). Adolescents don't always understand that bad things can happen to them - and they can get hurt, get pregnant or even die. In this phase of transition, it is important for parents and caregivers to listen to the child, provide opportunities for dialogue to address confusion and insecurities, and transfer necessary knowledge and skills to build the adolescents' confidence and sense of responsibility. This will help adolescents to become responsible and mature men and women in later life.

The Importance of good nutrition

Physical growth is one of the primary measures of health and well-being in children. Abnormal growth may be a sign of disruption in a child's nutrition, environment, or health. Decreased body fat and growth have been associated with increased healthcare utilization and decreased participation in society². It seems intuitive to mention how important proper nutrition is to all aspects of a healthy life: Growth, muscle strength, respiratory function, cardiac function, neurologic function, immune function, and wound healing, just to mention a few considerations.

Malnutrition decreases the energy for discretionary activity, which is necessary for social interaction and school participation. Proper nutrition is also important for bone growth and health and mental development. There are many factors causing malnutrition, but the one that impacts parenting the most is actually feeding the child. Although the nutrition of able-bodied children can be difficult, it is nothing compared with the challenges that a parent of a child with disabilities faces. These patients may have prolonged feeding times (sometimes up to 45 minutes per meal), delayed progression of oral feeding skills, and possible respiratory disease from aspiration.

² Effects of Caregiving on the Families of Children and Adults with Disabilities Henry G. Chambers, and Jill A. Chambers, *Phys Med Rehabil Clin N Am* 26 (2015) 1–19, <http://dx.doi.org/10.1016/j.pmr.2014.09.004> pmr.theclinics.com, Elsevier Inc.

4.0. THE DIFFERENT FORMS OF DISABILITIES IN CHILDREN

About 1 billion people in the world today experience some form of disability of whom nearly 200 million experience considerable difficulties in functioning³. Many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life activities. Following the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), disability is increasingly being understood as a human rights issue. Disability is also an important development issue with an increasing body of evidence showing that persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities. This chapter defines what disability is and what different forms of disabilities in children are. The chapter also gives brief descriptions of the different forms of disabilities in children, the peculiar features of the forms of disabilities in children, and how to identify them. Knowledge of the peculiar features of the various forms of disabilities in children would help their caregivers understand and cope with the various challenges associated with caring for these children.

The learning objectives of this chapter are that by the end of this chapter the participants would be able to:

- Define what Disability is
- List and describe the different types of Disability,
- Explain the typology and classification of disabilities in children
- Explain the causes of Disability
- Describe what can be done to prevent Disability
- Explain the different forms of special needs and types of Disability in children
- Describe the Effects of Disability
- Explain the 'Social Model' of Disability and caring for children with disabilities

Duration: 120mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators notes and handouts
- Child Protection Toolkit

³ World Disability Report, 2011, WHO

Session 4.1: Definition, Types, Causes and Prevention of Disability

Facilitators' Action

- a. Introduce the session by summarising the introductory section above informing participants that there are about a billion people in the world living with disability and among these are about 150million children with disabilities.
- b. Also inform them about what the focus of this session would be, i.e. discussions on the definition, types, causes and prevention of disability by reading out the learning objectives.
- c. Divide the participants into 4 groups and let the groups discuss and come up with answers for the following: (give them flip charts on which they would write the answers)
 - o Group 1 - What is Disability?
 - o Group 2 - What are the types of Disabilities,
 - o Group 3 - What are the causes of Disabilities
 - o Group 4 - What can be done to prevent Disabilities
- d. After about 20mins of discussions by the groups, allow every one of the groups to present the answers they came up with during plenary and use the information presented in the Facilitators' Notes 4.1 on Definition, Types, Causes and Prevention of Disability to guide and firm up the discussions after the presentation of every group allowing questions and contributions from members from the other groups.
- e. In a short buzz session ask the participants whether they have an idea about the different typologies of children with disabilities. After they mention a few that you would capture on the flipchart, use the notes on Categories of Disabilities in Appendix, to explain the different typologies/categories of disabilities in children. Inform them that the term children with disabilities (CWD) would be used throughout the period of the training for all the types except when there is the need to specify.

Some categories of disabilities are

1. Physical impairment (e.g. paralysis, neurological disorders)
2. Sensory impairment (e.g. deafness, blindness)
3. Cognitive impairment (e.g. inability to process what is heard or seen, partial learning disability)
4. Intellectual impairment (e.g. mental retardation)
5. Mental-health impairment (e.g. schizophrenia, eating disorders)
6. Psychosocial impairment (e.g. autism, attention deficit hyperactivity disorder)
7. Chronic diseases (e.g. asthma, diabetes mellitus, rheumatism)

All of these categories may be very mild to severe. Classification as a disability requires them to be severe in a way with impedes the child's ability to carry out their day to day activities permanently, or for a longer period of time.

- f. Remember to include the vulnerability of persons with disability in the discussions using the information in the Facilitators' Notes.
 - g. Continue the session by mentioning that the issue of children with special needs is always forgotten when issues about persons with disabilities are being discussed. If not mentioned during the presentations at plenary, ask participants whether they have heard of Special Needs Children.
 - i. Be sure to mention at this point that that Special Needs are commonly defined by what a child can't do – developmental milestones unmet, foods banned, activities avoided, or experiences denied. These hindrances can hit families hard and may make special needs seem like a tragic designation. Some parents will always mourn their child's lost potential, and some conditions become more troubling with time.
 - k. Now ask participants to share what they know or their experiences and understanding about children with special needs. Allow them enough time to share their individual experiences (Note that some may be emotional at this point but as much as possible allow them time to share their experiences as caregivers of children with special needs).
 - m. Facilitate the discussions about special needs children by using the Facilitators' Notes 4.2 on Children with Special Needs (and the notes in the textbox below). Mention that children with special needs often have unique demands at home and at school and hence caregivers must learn to successfully address them to help the child succeed. The good news is that a special needs child can benefit from a variety of therapies, including physical, speech, and behavioural.
 - o. Continue by Asking the participants what in their experience are the Effects of Disability on the entire family as well as on the children.
 - q. Again, allow as many as are willing to contribute by sharing their experiences and also use the portion of the Facilitators' Notes 4.2 on Children with Special Needs that explains the Effects of Disability to guide the discussions.
 - s. If the emotions are very heightened at this point quickly introduce an energizer before you go to the next stage of the discussions.
 - u. After the energizer ask the participants whether they have heard of what the 'Social Model' of Disability is and add that this model changes the focus from the difficulty the child has with for instance walking to the barriers which stop his inclusion.
22. Continue this discussion with the key learning points in the notes and allow participants to contribute to the discussion using their personal experiences as caregivers of children with disabilities, case scenarios and other examples and conclude the session.

Note that there are forms of special needs which are mostly health related which need to be mentioned because meeting the needs of such children sometimes becomes very challenging. Examples are Children with Epilepsy which require very expensive daily and continuous medications; those with Chronic conditions which require regular visits to specialist doctors for reviews and/or special care needs; Children with need for extensive surgery which present financial and care challenge as well as children with ongoing psychological problems who have need for continued therapy. None of these can be placed under any of the “Disability” categories because they do not constitute disabilities; yet they constitute immense challenges for the children and hence they need special care to be provided to them.

Apart from this, there are other forms of special needs that children have for which the term “disability” cannot be used. Examples include child with reduced hearing in one ear who may be medically diagnosed as having a “hearing disability” yet such a child, cannot be called a “disabled child”. A similar example is “mental disability”. What is the cut-off point at which a child qualifies for this category of disability? Is it the child who cannot learn anything at school at all but otherwise can take care of themselves and communicate? Or is it the child who is unable to learn anything at school, can’t take care of themselves, and can’t socially interact adequately? In this case, the school may have a problem, and may not be able to take care of the child within the usual set-up of a usual school, unless the school is designated to care exactly for this target group.

Classifying Physical Disability, can also have the same problem. A child with one leg shorter than another, has a physical impairment but is not disabled. With the issue of Speech – is a child who stammers or with unclear speech a disabled child? Their condition may grossly impact their education and social interactions; it therefore should be mentioned as challenge or special need but does not fall within “disabled”

Facilitators’ Notes 4.1: Definition⁴, Types, Causes and Prevention of Disability

Disability is a complex issue. It can be understood differently and described differently depending on the cultural context. However, there is a general agreement that the definitions provided in global conventions are a good place to start.

The United Nations Convention of the Rights of Persons with Disabilities (CRPD) defines persons with disabilities as: “... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN 2006).

Disability is the complex relationship between the mind, the body and the environment in which a child lives. Disability is a physical or mental condition that limits a person’s movements, senses, or activities. It is an umbrella term, covering impairments, activity limitations, and participation restrictions.

⁴ Enabling reform; Why supporting children with disabilities must be at the heart of successful child care reform, EveryChild and Better Care Network, 2012

This definition acknowledges the move away from a purely medical conception of disability, which focuses on impairments, towards a recognition of the importance of social context. Under this definition it is not only the impairment that is disabling, but also the attitudes and responses towards people with disabilities (see also WHO and World Bank 2011, WHO 2010a, UN 2006).

The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic diseases⁵. Disability is conceptualized as being a multidimensional experience for the person involved. There may be effects on organs or body parts, and there may be effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognized in International Classification of Functioning, Disability and Health (ICF):

- body structure and function (and impairment thereof),
- activity (and activity restrictions)
- and participation (and participation restrictions).

An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden, known as invisible disability.

Understanding Disabilities

Disabilities can be inherited (e.g. Down Syndrome) or acquired (e.g. Cerebral Palsy). They can be permanent or transitory (e.g. fractured bone after an accident, chronic illness). Not every impairment of health constitutes a disability, unless it significantly impacts the functioning of an individual. Some disabilities may, within their category, range from very mild to very severe, whereas a mild form may not require any special treatment and technically may not fall within the category of disability at all. On the other hand, some progressing disabilities require as early as possible special treatment to prevent progression, or at least, slow down the process of deterioration.

Most permanent disabilities can be improved upon by providing adequate measures of care.

Some disabilities, like speech and communication disorders, may have a variety of reasons which can cause them. They may be caused by physical impairment (e.g. malformation of the jaw), or by psychological trauma (e.g. stammering due to fear), or by intellectual or cognitive impairment, or, in this example, simply by means of little guidance and/or habit-formation.

Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some people also have multiple disabilities (e.g. cerebral palsy and Down Syndrome, each affecting a number of functions and organs of the body)

Some disabilities may be invisible (e.g. a deaf child without hearing aids, or an older student who cannot read due to dyslexia).

⁵ <https://www.disabled-world.com/disability/types/> (Assessed on 24th of September 2019)

Some conditions are not disabilities in themselves, like sickle cell disease, but may cause a disability in children who get a stroke due to the disease.

Causes of Disabilities - Disabilities can be caused by many factors and these include:

- **Accidents**

Unfortunate life events such as drowning, automobile accidents, falls and so on can result in people losing their sight, hearing, limbs and other vital parts of their body and cause disability.

- **Diseases**

Lifestyle choices and personal behaviour such as obesity, physical inactivity, tobacco use, alcohol consumption, illicit drugs use etc. that lead to non-communicable diseases are also becoming major contributing factors. The use of drugs, alcohol, tobacco, the exposure to certain toxic chemicals and illnesses, toxoplasmosis, cytomegalovirus, rubella and syphilis by a pregnant mother can cause intellectual disability to the child.

Childhood diseases such as a whooping cough, measles, and chicken pox may lead to meningitis and encephalitis. This can cause damage to the brain of the child. Toxic material such as lead and mercury can damage the brain too. Communicable diseases (Infectious diseases) such as lymphatic filariasis, tuberculosis, HIV/AIDS, and other sexually transmitted diseases; neurological consequences of some diseases such as encephalitis, meningitis, and childhood cluster diseases (such as measles, mumps, and poliomyelitis) can also contribute to disability.

- **Complications during pregnancy, childbirth and postnatal period**

Diseases or medical complications during pregnancy and child birth can cause distress in the foetus, prolonged labour leading to lack of oxygen, prematurity, low birth weight and infections. Other risk factors include babies born with jaundice especially in the first week of life, birth abnormalities and birth injuries. All these can lead to all forms of disabilities and developmental delays. Birth asphyxia, which means, lack of oxygen during a prolonged period of delivering a baby, causes cerebral palsy.

- **Nutritional deficiencies (during pregnancy and early childhood)**

Malnutrition leads to developmental delays and physical, sensory and intellectual disabilities. On average, preschoolers between the ages of 2 and 5 grow and gain weight as well as significant brain development. Healthy eating and providing good nutritional choices for children are extremely important to ensure normal development in a number of areas, including: Cognitive development, or the development of the brain i.e. the ability of children to develop language skills and short and long-term memory, and make connections; Physical development, which refers to the actual physical growth of a child, including his/her height and weight as well as Emotional and social development, or the ability of children to form relationships with others and mature.

There is increasing awareness of the interrelationships between malnutrition and disability; malnutrition can lead to disability and disability can also lead to malnutrition⁶. Many types of disability

⁶ Stronger Together: Nutrition-Disability Links and Synergies - UNICEF Briefing Note, by Nora Groce, Eleanor Challenger, Marko Kerac, Leonard Cheshire Disability and Inclusive Development Centre, University College London, UK; https://www.unicef.org/disabilities/files/Stronger_together_Nutrition_Disability_Groce_Challenger_Kerac.pdf

ity can be caused by malnutrition: through lack of essential nutrients or exposure to high concentrations of toxin.

Mothers who are malnourished are more likely to give birth to low birth weight babies, a risk factor for mild intellectual disability. Iodine deficiency during pregnancy has been reported to increase incidence of poor foetal growth and low birth weight babies. Anaemia – a deficiency of iron is considered one of the leading causes of disability worldwide. Anaemia in the pregnant mother is associated with low birth weight and traumatic delivery and can affect a child's cognitive development. Aneamic children may tend to be inexplicably tired most of the times.

Infants whose mothers were severely malnourished when they were in-utero are reported to have a higher incidence of mental illness and can be up to twice as likely to develop schizophrenia in later life. This may be due in part to slow neurodevelopment and altered brain shape and size of the foetus in utero.

- **Environmental factors and poverty**

Environmental factors that impact child development usually fit into categories like: the Social environment, which is the child's relationship with others at school and in the community; the Emotional environment, which is how well families meet the child's relational needs at home as well as the Economic environment, which is the family's ability to provide financially for the child.

Physical environmental factors, may also impact development through exposure to drugs, alcohol, tobacco, or environmental toxins like lead before or after birth, can impact a child's physical development. Problems associated with this kind of exposure might be low birth weight, premature birth, or major long-term medical problems. The child's home, neighborhood, state, and even land may be part of the physical environment. Children may have been exposed in utero to some of these environmental factors, but the symptoms may manifest as difficulties in preschool age development.

Poverty in pregnant mothers can also cause a deficiency in vital minerals and result in deformation issues in the unborn child (as described above in nutritional deficiencies). After birth, poverty may lead to malnutrition in the child which in turn can also cause poor development of vital organs in the child, which can eventually lead to disability.

- **Genetic factors**

Abnormalities in genes and genetic inheritance can cause intellectual disability in children. Down Syndrome is the most common genetic condition, and a lot of babies with Down Syndrome are born each year. Sometimes, diseases, illnesses, and over-exposure to x-rays can cause a genetic disorder.

- **Unknown Causes**

The human body is a phenomenal thing. Scientists have still not figured out exactly what and how some things in the body, cells, brain, and genes come about. Humans have still not found all the answers to all the defects in the human body.

- **ii. Prevention of Disability**

Prevention can be carried out using social and public education, immunization as well as treatment of symptoms. Prevention of health conditions associated with disability is a development issue. Attention to environmental factors – including nutrition, preventable diseases, safe water and sanitation, safety on roads and in workplaces – can greatly reduce the incidence of health conditions leading to disability. Preventing disability should be regarded as a multidimensional strategy that includes prevention of disabling barriers as well as prevention and treatment of underlying health conditions. A public health approach distinguishes:

- **Primary prevention**

Actions to avoid or remove the cause of a health problem in an individual or a population before it arises; thus, this level deals with action taken prior to the onset of the disease/disability, which will remove the possibility that a disease/disability will occur. It includes health promotion and specific protection (for example, HIV education).

- **Secondary prevention**

Actions to detect a health problem at an early stage in an individual or a population, facilitating cure, or reducing or preventing spread, or reducing or preventing its long-term effects; thus, this level deals with action, which halts the progress of the disease/disability at its incipient stage and prevents complications. The specific interventions are early diagnosis and adequate treatment (for example, supporting children with intellectual disability to access teaching models and toys that can easily help to explain words and sentences).

- **Tertiary prevention**

Actions to reduce the impact of an already established disease by restoring function and reducing disease-related complications, thus this level deals with all measures available to reduce or limit impairments and disabilities, and minimize suffering caused by existing disability. This phase is also called rehabilitation, which includes physical, psychosocial and vocational measures taken to restore the patient back to normal or near normal condition (for example, rehabilitation for children with musculoskeletal impairment).

It is extremely important that women undertake adequate and effective preventive measures during their pregnancy and immediate postnatal period and also for their children especially during the early childhood period, in order to significantly reduce the incidence of impairment and disabilities in them.

- **General Preventive Measures**

- o Marriage between very close blood relations like uncle, niece, first cousin should be avoided for prevention of hereditary disorders.
- o Avoid pregnancies before the age of 18 years and after the age of 35 years (because these age brackets predispose women to pregnancy complications that may result in disabilities in the babies).
- o Consult a doctor before planning the pregnancy;

- If there is incidence of birth defects in your family.
- If you have had difficulty in conceiving or have had a series of miscarriages, still births, twins, delivery by operation (Caesarean), obstructed labour/prolonged labour (more than 12 hours) and/or severe bleeding in previous pregnancy.
- If you have diabetes, hypertension or any other medical condition.

- **iii. Vulnerability of Persons with Disability**

Half of people with disability cannot afford health care. They are also more likely to experience barriers when accessing health facilities, information and equipment. The core environmental barriers to daily life for people with mental disorders and other non-communicable diseases (NCDs) are:

- the lack of assistive products for mobility,
- and the availability of personal assistance.

People with disabilities have the same basic health needs as non-disabled people – for immunization, general health checks or screening, referrals for more specialised care plus additional health needs etc.

They also may experience a narrower margin of health, both because of poverty and social exclusion, and also because they may be vulnerable to secondary conditions, such as pressure sores or urinary tract infections.

Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings⁷.

7_ <https://www.who.int/topics/disabilities/en/> (Assessed on 24th of September 2019)

Facilitators' Notes 4.2: Children with Special Needs

Persons with Disabilities include Children with Special Needs⁸. “Special needs” is an umbrella term for a wide array of diagnoses, from those that resolve quickly to those that will be a challenge for life and those that are relatively mild to those that are profound. It covers developmental delays, medical conditions, psychiatric conditions, and congenital conditions that require accommodations so children can reach their potentials.

Special needs are commonly defined by what a child can't do – developmental milestones unmet, foods banned, activities avoided, or experiences denied. These hindrances can hit families hard and may make special needs seem like a tragic designation. Some parents will always mourn their child's lost potential, and some conditions become more troubling with time. Other families may find that their child's challenges make triumphs sweeter and that weaknesses are often accompanied by amazing strengths. “Special needs” is a very broad term and every situation is unique. Families should focus on seeking the help and guidance needed for their particular concerns. Children with special needs often have unique demands at home and at school. Caregivers must learn to successfully address them to help the child succeed. A special needs child can benefit from a variety of therapies, including physical, speech, and behavioural. It is important not to forget shifting the focus on what children disabilities CAN do, during the course of the training! Almost all children with disabilities can do something.

How many children have disabilities?

It is problematic to provide a universally agreed figure on the numbers of individuals with disabilities. Accurate diagnosis is often hard to achieve, especially in resource constrained settings, and where stigma is high, parents may be reluctant to admit they have children with disabilities (UN 2011). The cut-off points used in relation to the severity of impairments, reasons for data collection and method used to collect data also contribute to the difficulty of measurement and comparison (WHO and World Bank 2011, UN 2011).

A World Health Organization (WHO) and World Bank report (2011) indicates that 15 per cent of the population have disabilities and cites studies that suggest that between 13 and 150 million children have disabilities, depending on classification of severity. Other research places this figure at closer to 200 million children (UNESCO 2010). A UN report on children with disabilities suggests that in countries where data are available, 14 to 35 per cent of children have disabilities, but that the reliance on household surveys means that many children with disabilities living on the streets or in residential care go uncounted (UN 2011).

According to the results from the current Multiple Indicator Cluster Survey (MICS) in Ghana⁹ about one in every five children 2-17 years have a functioning difficulty and these functioning difficulties include seeing, hearing, walking, communication, learning, remembering, playing, self-care, anxiety, depressions etc. The functional difficulties are more prevalent in the 5-17 years age group when compared to children 2-4 years.

Different forms of special needs in children may include: (refer to Appendix for detailed descriptions of these conditions)

⁸ <https://www.verywellfamily.com/what-are-special-needs-3106002>. (Assessed on 24th of September 2019)

⁹ Ghana Multiple Indicator Cluster Surveys (MICS), 2017/2018; Snapshots of key findings, updated in January 2019, Ghana Statistical Service (GSS) and UNICEF

- Learning disability or educational issue
- Attention deficit disorder or ADHD
- Autism
- Mental illness, depression
- Mental retardation,
- Developmental delay
- Emotional problems
- Behavioural issues
- Short-term physical conditions
- Long-term physical conditions

Medical Issues for children include serious conditions like cancer, heart defects, muscular dystrophy, and cystic fibrosis. It also includes chronic conditions like asthma and diabetes, congenital conditions like cerebral palsy and dwarfism, and health threats like food allergies and obesity. A child may need frequent medical testing, hospital stays, equipment, and accommodations for disabilities. Establishing a good support system is very important when dealing with uncertainty and any medical crises.

Children with Behaviour Issues may not respond to traditional discipline. Diagnoses like Attention Deficit Hyperactivity Disorder (ADHD), Foetal Alcohol Spectrum Disorder (FASD), dysfunction of sensory integration, and Tourette's syndrome require specialized strategies that are tailored to their specific needs. Behaviour issues can increase the risk of problems at school. As a parent, you will need to be flexible, creative, and patient.

Developmental disabilities can change one's visions of the future and provide immediate difficulties in caring for and educating one's child. Diagnoses like autism, Down syndrome, and intellectual disabilities often cause children to be removed from the mainstream. Quite often, parents become fierce advocates to make sure their children receive the services, therapy, schooling, and inclusion they need and deserve.

Children with learning disabilities like dyslexia and Auditory Processing Disorder (APD) struggle with schoolwork regardless of their intellectual abilities. They require specialized learning strategies to meet their potential and avoid self-esteem problems and behavioural difficulties. Parents of learning-challenged kids need to be persistent. This includes working with one's child at home as well as teachers and schools to ensure they get all the help they need.

Mental Health Issues - Realizing that your child suffers from anxiety or depression or has attachment difficulties can be unexpected. Again, every child will be different, yet these can leave one's family dealing with a roller coaster of mood swings, crises, and defiance.

Types of Disabilities in Children

There are many types of disabilities, such as those that can limit a child's participation in an unaccommodating environment. A child may have difficulties with:

- Vision/Seeing;

- Hearing;
- Comprehension (understanding);
- Movement (mobility);
- Communicating;
- Managing their emotions;
- Social relationships;
- Mental health, Thinking, Remembering
- Learning

These difficulties can affect a child's ability to:

- Use words to communicate;
- Speak clearly and be understood;
- Understand simple directions;
- Sit, crawl or walk;
- Hold or manipulate objects; or
- Use the toilet, dress or feed themselves appropriately.

A child may also be extremely sensitive (hypersensitive) or not responsive (hyposensitive) to the environment. This means they may have an acute reaction to a minor environmental stimulus such as being distracted by common sounds like the humming of a refrigerator; or they can be unresponsive to the world around them and need additional sensory stimulation to feel content, such as touching things excessively, always turning the volume very loud, or constantly putting objects in their mouth. They may also show unusual or uncontrollable behaviour. Sometimes this behaviour can be caused because the child is sick or in pain and cannot communicate this. It can also be related to emotional issues if the child is sad or unhappy, or to being hypersensitive or hyposensitive to their environment. There can be many causes and it is important to ask a doctor or other specialist in case the behaviour is linked to an illness, injury or other physical cause.

Because each child is unique, disability can affect individual children in different ways, even among children with the same type of disability. Children can also be affected by more than one type of disability; for example, their movement and sight can both be affected.

Following the social model of disability, and because individual children develop at different rates, disability is assessed and described in terms of what a child can do and how a child 'functions,' rather than a description of a condition. For example, each child with Down Syndrome will have capacities and difficulties in different areas.

A child's disability can be present at birth, sometimes described as a congenital disability. These can be as a result of a genetic inheritance or mutation, such as Down Syndrome. They can also be the result of environmental factors in the time before conception and during pregnancy or during birth, such as anaemia, foetal exposure to alcohol, or being deprived of oxygen during the birth

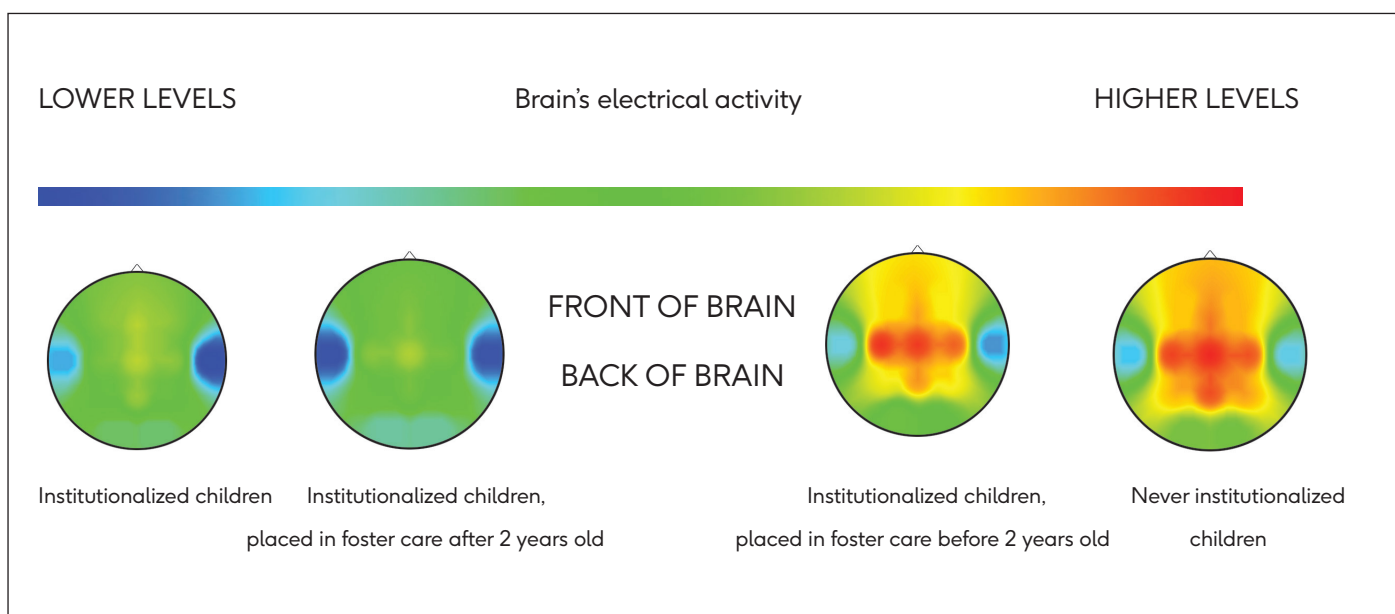
(cerebral palsy).

Children can also acquire a disability later in life, for example because of an injury or an illness, or because they are exposed to violence, abuse or neglect. This is sometimes referred to as adventitious disability

Children living in a residential institution can acquire a disability because of the severe neglect they often experience. This can include physical under-development and motor skills delays as well as psychological harm.

The Bucharest Early Intervention Project¹⁰, a randomized controlled trial measured profound impacts of institutionalization on the brain function of children institutionalized at a young age, and the potential for recovery when removed and placed in good-quality family care. The study included 136 children in Romanian institutions, half of whom were placed in high-quality foster care, some before they reached age two and others after that age. A cohort of children who had never been institutionalized served as a comparison group. The figure in the text box below illustrates at eight years of age their respective levels of brain activity, with red, orange, and yellow indicating higher levels of activity. By age eight, those who went into foster care before they turned two or who were never institutionalized showed markedly higher levels of brain activity. “The Deprived Human Brain: Developmental deficits among institutionalized Romanian children—and later improvements, strengthen the case for individualized care,” Nelson, Charles A., III, et al, *American Scientist* (97). 2009.

When children, particularly young children, live outside of family care they are at increased risk of developmental impairments and lasting psychological harm. Children in residential care settings, particularly those who enter at an early age or who stay for an extended period of time, can experience social, emotional, and cognitive delays, and negative effects on their physical growth, neurological development, and mental health. A meta-analysis of 23 studies found poorer behavioral and psychosocial outcomes for children placed in residential care settings as compared to those in family foster care.



¹⁰ Nelson, Charles, et al. “The Deprived Human Brain: Developmental deficits among institutionalized Romanian children—and later improvements—strengthen the case for individualized care,” *American Scientist* (97): 222. 2009., as referenced in *Advancing Protection and Care for Children in Adversity, A U.S. Government Strategy for International Assistance, 2019–2023*

Children with a disability can also experience a mental health disorder. For example, they can be bullied, can have difficulty engaging with their peers, and particularly in adolescence can find it hard to be involved in social activities - all of which can lead to depression and anxiety or other mental health disorders. Some disabilities may not be visible. This means that the disability is not immediately obvious. For example, you may not immediately know that a child is deaf if you cannot see a hearing aid. A child's learning disability may not become obvious until they begin school. As a worker who comes into contact with children and families regularly, it is very important that you consider if a child has a hidden disability which is a barrier to their full participation.

Effects of Disability

Disability affects the child, and can affect family, friends and the local community as well. It can have physical, emotional and psychological impacts. If you are working directly with children and families, you can support them to adjust to these profound changes. Having a disability can cause a child to be thought of as different. This perception can also spread to the rest of the family. Being different can create suspicion. If someone looks different and acts differently, it can take an extra effort for you and for other people to feel comfortable with them. Thinking about the child first, and believing in what they CAN DO, is the first step in making sure that everyone believes being different is OK.

Disability can also result in abuse of the child. The child may be physically punished because of their disability; they may be shunned or neglected as well as bullied in school. As the child becomes older, they can sometimes be locked in the house or be physically restrained. This is sometimes justified by families who will say that they are trying to keep their child safe. You can help to discuss with families more appropriate ways to maintain safety.

Being different can result in stigma and discrimination. Sometimes cultural or religious beliefs can encourage families and communities to believe that the birth of a child with a disability is a punishment or brings 'bad luck.' This can be related to a belief that one or both parents have acted badly in the past, or that the child has been born with a disability because of a curse or bad spirits. In these cases, you can discuss the rights of the child and work with the child's family and caregivers to make sure they have the same opportunities as other children in the community.

Such factors can stop children with disabilities from participating fully in the life of their community and prevent them from fulfilling their true potential. It can mean that children with disabilities are bullied by other children in their community and by adults. Their families, including their siblings, may also experience the same stigma and discrimination. This can mean that the whole family becomes isolated. It is important to talk about this with the child and the whole family, and then to work together to find solutions to help them to maintain their community presence and social status. This can include families of children with disabilities helping each other, individually and in family peer support groups.

What is the 'Social Model' of Disability?

In the past, disability was treated as a medical issue. The child was believed to be sick and, although sometimes treated with medicine or other passive methods of therapy, was often considered incurable. The child was a patient and, in many communities today, may still be seen like

that. This medical model looks at what it considers is 'wrong' with the child and focuses on curing or managing the disability. During the 1980s, the Community-based Rehabilitation (CBR) movement started to question the medical focus and suggested that it was society that was putting the barriers in place for children with disabilities, and that it was these barriers which prevented them from being involved in their communities like other children.

This social model looks at how society is organized and focuses on making changes which increase opportunities and choices for children with disabilities. For example, not everyone can grasp a door with a round handle, but, if a lever-type handle is attached, it is much easier for everyone to open the door. This is an example of inclusive thinking to remove a barrier which stops everyone from being involved. Like all children, a child with a disability may also require medical treatment for specific medical conditions and should have equal access to medical care. Equally, consider a child with a disability who has difficulties with walking, who uses a wheelchair and is being educated at home. In the medical model, the child learns at home because he has a disability and cannot walk. In the social model, the child learns at home because the school is not accessible for children with mobility difficulties or who use a wheelchair.

The social model is linked to the rights-based model which focuses on the humanity of children with disabilities and their rights. Rights are indivisible and universal and therefore children with disabilities should be included in mainstream systems of development to prevent discrimination and exclusion. Inclusive education is an example of the social model of disability which ensures access and learning for all children especially children with special needs including those with disabilities. The IE policy of Ghana locates inclusion as a part of the wider reform of the education system, that aims to create learning environments that are responsive to all learners' needs and conducive to successful educational outcomes, and ultimately to a more equitable society. It goes beyond the education system to the communities in which learners live to ensure that they are welcomed, nurtured and given the opportunity to thrive to their optimum capacities.

5.0. THE BASIC RIGHTS OF CHILDREN

Children with disabilities are children first and hence all of the provisions of the Constitutions of Ghana, the Children's Act as well as the United Nations Convention on the Rights of the Child (UNCRC) apply to them. These national and international instruments also make specific provisions for children with disabilities in order to protect them from harm, negligence and all forms of violence and abuse. It is important for parents and other caregivers of children with disabilities to know about these rights of the children they are caring for in order to protect them from all forms of harm and abuse. This chapter therefore introduces biological parents, foster parents, adopted parents, caregivers in institutions, caregivers in day care centres, teachers etc. to what the laws in Ghana and the international instruments say about the basic rights of children with disabilities as well as their responsibilities as caregivers in ensuring that those rights are upheld.

The expected outcomes for this chapter are that by the end of this chapter the participants would be able to:

- Define who a child is and identify at the basic rights of every child in accordance to national and international laws
- List and explain the guiding principles on which the national and international laws on the rights of children are based
- List the key and basic rights of children with disabilities in accordance with provisions made in national and international laws for persons with disabilities including children

Duration: 120mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators Notes and handouts

Facilitators' Action

1. Begin this session by introducing the entire chapter to the participants using the introductory paragraph above. Inform the participants that children with disabilities are children first and hence all of the provisions of the national and international also apply to them. In fact, specific provisions have also been made for children with disabilities in order to protect them from harm, negligence and all forms of violence and abuse.
2. Continue by mentioning that it is important for parents and other caregivers of children with disabilities to know these rights of the children they are caring for in order to protect them from all forms of harm and abuse.
3. Add that the aim of this chapter is to introduce caregivers of children with disabilities to what the laws in Ghana and the international instruments say about the basic rights of children with disabilities as well as their responsibilities as caregivers in ensuring that those rights are upheld.
4. Continue by letting some participants read out the learning objectives (write them on a flip chart so they can easily see and read too) of the entire chapter as listed above to the participants and ask volunteers from among them to explain the various learning objectives one by one.
5. Now ask the participants in a buzz section to define who a child is and what is childhood. Use definition in the text box below to contribute to the discussion stressing that for the purposes of the Ghanaian context the Child and Family Welfare Policy also takes into account how a child is defined in relation to the family and concept of childhood such that a child is also one who is still largely dependent on an adult for the necessities of life.

Who is a Child?

The Child and Family Welfare Policy recognizes a child as a person below the age of 18, in line with the UN Convention on the Rights of the Child, the 1992 Fourth Republic Constitution of Ghana (article 28) and the Children's Act 1998, (Act 560) (section 1).

What is Childhood?

It is a period when a person is under the authority, control and care of some persons considered as adults in society. Childhood for a child under care can even be extended to 21 years.

Childhood may include one or several of the following characteristics:

- the period before puberty rites or rites of passage;
- when a person is not married; a period in school, particularly if fees are being paid by an adult; - - a period of learning a trade;
- a period when decisions are made for a young person;

- a period when a young person is living under the same roof as their parents.

Note that the characteristics cited are not exhaustive; they present some considerations related to the concept of childhood. These are not stand-alone characteristics but should be considered as a combination of two or more.

6. Continue the discussion with the participants by adding that because of their dependency on adults in society for their care, children especially children with disabilities are vulnerable and hence sometimes their rights are infringed upon. Most often due to lack of knowledge of the rights of the children by their parents and other adult caretakers.
8. Ask participants to define children's rights in their own simple words and after a few definitions include that children's rights are the human rights of children. Human rights are rights inherent to all human beings, whatever their nationality, place of residence, sex, national or ethnic origin, colour, religion, language or any other status. Every human being is equally entitled to all human rights without discrimination and all these rights are interrelated, interdependent and indivisible.
9. Mention that all the rights of children have been grouped into four main/broad categories of and ask if the participants could mention them.
10. Allow a few contributions in this regard and use the information in the text box below in the Four Categories of Children's Rights to explain these 4 categories such as survival rights, development rights, protection rights and participation rights.

The FOUR Categories of Children's rights

Survival Rights – this includes rights to resources, skills and contributions necessary to survival of the child and requires the existence of the means to fulfill the rights as well as access to them

Development Rights – this includes rights to resources, skills and contributions necessary for the development of the child

Protection Rights – this includes rights to protection from all forms of child abuse neglect, exploitation and violence as well as the right to special protection in times of war

Participation Rights (child inclusive practices) - this is the freedom to express opinions and be heard

11. Continue by asking the participants whether they have heard of the United Nations Convention on the Rights of the Child (CRC) and continue by mentioning that the CRC, which was unanimously adopted on the 20 November 1989, at the UN General Assembly is the first legally binding international treaty governing children's rights. It defines the fundamental rights of the child and covers all aspects of child protection. Ghana was the first country/state to ratify the CRC.

13. Again ask them whether they have heard of the Children's Act 1998 (Act 560) before and add that The Children's Act (560) of 1998 is an Act to reform and consolidate the law relating to children, to provide for the rights of the child, maintenance and adoption, regulate child labour and apprenticeship, for ancillary matters concerning children generally and to provide for related matters.
14. At this point inform the participants that you are going to have a fun exercise with them in which they are going to mention the rights of children that they have heard of (either from the CRC or from the Children's Act 1998).
15. Tell them that you are going to mention one of the rights of children that you know and have heard of after which you would throw the colourful small ball in your hand (show it to them) to one of the groups that you would randomly pick. Whichever group the ball gets thrown to is supposed to mention one of the rights of children. When the group gets it right, they then pass on the ball to another group to also mention another one of the rights of children. This can continue till all the groups have had their turns.
16. After the exercise read out the rights summarized from the CRC and the Children's Act one by one with the explanations as in the Facilitators' Notes 5.1 on Key Provisions in the CRC and the Children's Act 1998 (Act 560).
17. Also remind the participants that all the rights that have been mentioned both from the CRC and the Children's Act are based on the 4 guiding principles of: Non-discrimination; Priority given to the best interests of the child; Right to life, survival and development and Respect for the views of the child
18. Before concluding the session allow participants to ask questions and after clarifications conclude by mentioning that as penalty for contravening is that any person who contravenes a provision commits an offence and is liable on summary conviction to a fine not exceeding ₺5 million (or penalty points) or to a term of imprisonment not exceeding one year or to both.

Facilitators' Notes 5.1: Key Provisions in the CRC¹¹ and the Children's Act 1998¹²

The CRC has 54 articles for the protection of the rights of the child

The first article of the CRC stipulates that anyone below the age of 18 is to be considered as a child. The text holds that the best interests of the child should be a primary concern to each State. It encompasses all human rights: civil, political, economic, social and cultural, and recognizes that the enjoyment of a right should not be separated from the enjoyment of other rights.

The four guiding principles of the Convention on the Rights of the Child are:

- Non-discrimination
- Priority given to the best interests of the child
- Right to life, survival and development

¹¹ The United Nations Convention on The Rights of The Child (CRC), 1989

¹² The Children's Act 1998 (Act 560)

- Respect for the views of the child

Beyond these principles, the essential rights of the child are:

- **The right to an identity (articles 7 and 8)**
All children have the right to a name and nationality from birth, ensuring his protection and support by his own country. If the birth is not registered, the child will not be recognized by the state and will neither receive care nor education.
- **The right to health (articles 23 and 24)**
All children should be cared for if sick, be well-fed, protected from drugs, and enjoy living conditions which are not dangerous to their health.
- **The right to education, (article 28)**
All children have the right to an education and access to skills which will help them prepare for their future.
- **The right to a family life (articles 8, 9, 10, 16, 20, 22 and 40)**
All children have the right to live with people who love and care for them, preferably their families, or by carers if their own families cannot look after them.
- **Right to be protected from violence (article 19 and 34)**
Each child must be protected from violence, from his own family or any person who wishes to harm him. He should never be obliged to suffer or inflict ill-treatment or any act of sexual or physical violence.
- **The right to an opinion (article 12 and 13)**
All children have the right to express their views. They also have the right to be informed and give their opinion about the world around them.
- **The right to be protected from armed conflict (articles 38 and 39)**
All children must be protected from war and its consequences, such as being a refugee, injured, prisoner, or forced into armed conflict.
- **The right to be protected from exploitation (articles 19, 32, 34, 36 and 39)**
A child should not be obliged to work in difficult or dangerous conditions, in order to survive or support his family.

The right to equality and respect for differences - Each child has the same rights, regardless of his race, colour, religion, language or culture, gender, or abilities.

Key Provisions of the Children's Act - Sub-Part I – Rights of the child and parental duty

Definition of Child - For purposes of this Act, a child is a person below the age of eighteen years.

The Welfare principle

1. The best interest of the child shall be paramount in any matter concerning a child.
2. The best interest of the child shall be the primary consideration by any court, person, institution or other body in any matter concerned with a child

Non-discrimination - No person shall discriminate against a child on the grounds of gender, race, age, religion, disability, health status, custom, ethnic origin, rural or urban background, birth or other status, socio-economic status or because the child is a refugee.

Right to name and nationality - No person shall deprive a child of the right from birth to a name, the right to acquire a nationality or the right as far as possible to know his natural parents and extended family subject to the provisions of Part IV, Sub-Part II of this Act.

Right to grow up with parents - No person shall deny a child the right to live with his parents and family and grow up in a caring and peaceful environment unless it is proved in court that living with his parents would –

- (a) lead to significant harm to the child; or
- (b) subject the child to serious abuse; or
- (c) not be in the best interest of the child.

Right to parental property - No person shall deprive a child of reasonable provision out of the estate of a parent whether or not born in wedlock.

Right to education and well-being – (1) No person shall deprive a child access to education, immunization, adequate diet, clothing, shelter, medical attention or any other thing required for his development. (2) No person shall deny a child medical treatment by reason of religious or other beliefs.

Right to social activity - No person shall deprive a child the right to participate in sports, or in positive cultural and artistic activities or other leisure activities.

Treatment of the disabled child (the child with disability)–

1. No person shall treat a disabled child in an undignified manner.
2. A disabled child has a right to special care, education and training wherever possible to develop his maximum potential and be self-reliant.

Right of opinion - No person shall deprive a child capable of forming views the right to express an opinion, to be listened to and to participate in decisions which affect his wellbeing, the opinion of the child being given due weight in accordance with the age and maturity of the child.

Protection from exploitative labour - No person shall subject a child to exploitative labour as provided under section 87 of this Act.

Protection from torture and degrading treatment

1. No person shall subject a child to torture or other cruel, inhuman or degrading treatment or punishment including any cultural practice which dehumanises or is injurious to the physical and mental well-being of a child.
2. (2) No correction of a child is justifiable which is unreasonable in kind or in degree according to the age, physical and mental condition of the child and no correction is justifiable if the child by reason of tender age or otherwise is incapable of understanding the purpose of the correction.

Session 5.2: Rights of Children with Disabilities

Facilitators' Action

- a. To begin with this session, inform participants that once they have learnt about the basic rights of every child which includes children with disabilities you are going to discuss with them the additional provisions that have been made in the national and international laws for the children with disabilities.

Children with disabilities are children first and hence they have the same rights as other children

- b. Continue by mentioning that knowledge about these provisions is very important for them as caregivers in order for them to be able to protect the children they are caring for from all forms of harm, violence and abuse.
- c. Remind them that as part of the rights of children that you just learnt from the Children's Act it was stated that no person shall treat a disabled child in an undignified manner and also a disabled child has a right to special care, education and training wherever possible to develop his maximum potential and be self-reliant. This shows the importance the government plays on the right of children with disability.
- d. Ask them whether they have heard of the Persons with Disability Act of Ghana and mention the key provisions in the Act that mentions the rights of persons with disability (and this includes children with disabilities) in Ghana (using the information in the text box below) and be sure to mention the provision of user-friendly facilities and equipment for different categories of disability as provided in the Persons with Disability Act 2006 (Act 715).

Rights of Persons with Disability in Ghana - Persons with Disability Act, 2006 (Act 715)

- Right to family life and social activities - A person with disability shall not be deprived of the right to live with that person's family or the right to participate in social, political, economic, creative or recreational activities.
- Differential treatment in respect of residence - Except as otherwise required by the condition or the need for improvement of a person with disability, a person shall not subject a

person with disability to different treatment in respect of residence.

- Living conditions in specialized establishments - Where a person with disability has to be put in a specialised establishment, the environment and living conditions of the establishment shall, except as otherwise required by the condition of the person with disability, be as close as possible to those of a person without disability of the same age as the person with disability.
- Access to public places - The owner or occupier of a place to which the public has access shall provide appropriate facilities that make the place accessible to and available for use by a person with disability.
- Access to public services - A person who provides service to the public shall put in place the necessary facilities that make the service available and accessible to a person with disability.
- Penalty for contravention - A person who contravenes Section 1, 2, 4, 6, or 7 commits an offence and is liable on summary conviction to a fine not exceeding fifty penalty units or to a term of imprisonment not exceeding three months or to both.

- e. Also ask participants whether they are familiar with the Inclusive Education Policy in Ghana. Add that the policy guarantees the right of children with disabilities to education where there is a learning environment which is barrier free and enables all learners including those with disabilities to move about safely and freely, use facilities and participate in learning and all aspects of school life. Inclusive education (when practiced well) is very important because: it helps other children to learn to accept their class mates with disabilities, mingle and play with them easily without stigmatizing or discriminating against them. It also helps children with disabilities not to feel any different from their other class mates, improves their self-esteem and helps them get integrated into society easily.
- f. Before concluding the session mention that a range of international documents have highlighted that disability is a human rights issue. Many nations have adopted disability discrimination legislation with the Convention on the Rights of Persons with Disabilities (CRPD) being the most recent, and the most extensive recognition of the human rights of persons with disabilities.
- g. Summarise the key points in the Facilitators Notes 5.2 on International Documents on Rights of PWD and conclude the discussions for this session allowing participants to ask questions.

Facilitators' Notes 5.2: National and International Documents on Rights of PWD (including CWD)

There are several national and international documents that protect the rights of children with disabilities. These include the Constitution of the Republic of Ghana, the Children's Act, the Inclusive Education Policy among others. For example, as stated already according to the Children's Act no person is to treat a child with disability in an undignified manner and a child with disability has a right to special care, education and training wherever possible to develop his/her maximum potential and be self-reliant.

The Inclusive Education Policy (IEP)¹³

This policy draws on a number of national and international commitments to the provision of education for all. At the national level, it confirms government pronouncements in the 1992 Constitution to ensure that every Ghanaian is afforded equitable opportunity in terms of access to

quality education. It draws on other national legal documents including the Ghana Shared Growth and Development Agenda (GSGDA), the Education Strategic Plan (2010-2020), the Disability Act, and the Education Act. It is also based on the international commitments to education to which Ghana is a signatory,

The overarching goal of the Inclusive Education (IE) policy is to redefine and recast the delivery and management of educational services to respond to the diverse needs of all learners within the framework of Universal Design for Learning and Child Friendly School Concept. According to the policy inclusion is defined in its broadest sense as ensuring access and learning for all children: especially those disadvantaged from linguistic, ethnic, gender, geographic or religious minority, from an economically impoverished background as well as children with special needs including those with disabilities. The IE policy locates inclusion as a part of the wider reform of the education system, that aims to create learning environments that are responsive to all learners' needs and conducive to successful educational outcomes, and ultimately to a more equitable society. It goes beyond the education system to the communities in which learners live to ensure that they are welcomed, nurtured and given the opportunity to thrive to their optimum capacities.

The policy recognizes different groups of learners with varied educational needs. These persons include but are not limited to: Persons with Intellectual Disability, Street Children, Gifted and Talented Persons, Nomadic children (shepherd boys, fisher-folks' children and domestic child workers), Persons with Physical Disability, Children exploited for financial purposes, Persons with Specific Learning Disability, Persons with Autism, Children living with HIV/AIDS, Persons with Attention Deficit, Hyperactivity Disorder, Persons with Hearing Impairment, Persons with Visual Impairment, Persons with Deaf-Blindness, Persons with Speech and Communication Disorders, Persons with other health impairment, and chronic diseases such as Rheumatism, Epilepsy, Asthma, Spina Bifida, Cerebral Palsy and Sickle Cell Anaemia, Children displaced by Natural, Catastrophes and Social Conflicts, Persons with Multiple Disabilities, Persons with Emotional and Behaviour Disorder etc.

¹³ Government of Ghana Inclusive Education Policy, Special Education Division (SpED) of the Ghana Education Service (GES). Ministry of Education, 2013, supported by UNICEF, STAR Ghana and Ghana Blind Union.

International Documents on Rights of PWD (including CWD)

A range of international documents have highlighted that disability is a human rights issue, including the World Programme of Action Concerning Disabled People (1982), the Convention on the Rights of the Child (1989), and the Standard Rules on the Equalisation of Opportunities for People with Disabilities (1993).

More than 40 nations adopted disability discrimination legislation during the 1990s. The Convention on the Rights of Persons with Disabilities (CRPD) – the most recent, and the most extensive recognition of the human rights of persons with disabilities – outlines the civil, cultural, political, social, and economic rights of persons with disabilities. Its purpose is to “promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity”.

The UNCRC also makes a specific provision for children with disabilities: Article 23 says that children with disabilities have the right to live full and decent lives with dignity and, as far as possible, independence and to play an active part in the community, and that the State must do all it can to support children with disabilities and their families. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) also supports the rights of children and is designed to expand on and support Article 23 of the UNCRC.

International Conventions and Guidance Relating to Disability and Children’s Care

- **Convention on the Rights of the Child (1989)**

Preamble: all children should grow up in a family environment in an atmosphere of happiness, love and understanding, the family should receive necessary assistance to fulfil its responsibilities;

Article 2: the right to protection against all forms of discrimination;

Article 3 & 9: children should not be separated from their parents unless it is in their best interest;

Article 18: parents have the prime responsibility to care for children and states should offer support in helping parents fulfil child-rearing responsibilities;

Article 20: the right of any child deprived of a family environment is entitled to special protection;

Article 23: specifically relates to children with disabilities and recognizes their right to “...enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community”; and “..... the right of the disabled child to special caresubject to available resources.” There are also relevant rights in relation to freedom from exploitation and abuse, education and development, and health and survival.

- **The Standard Rules on the Equalization of Opportunities for People with Disabilities (adopted by the UN General Assembly 1993)**

Rule 9: Persons with disabilities should be enabled to live with their families. States should encourage the inclusion in family counseling of appropriate modules regarding disability and its effects

on family life. Respite-care and attendant-care services should be made available to families which include a person with disabilities. States should remove all unnecessary obstacles to persons who want to foster or adopt a child or adult with disabilities.

- **Convention on the Rights of Persons with Disabilities (2006)**

This convention emphasizes the need to focus on the child's abilities not disabilities, and on the right to social inclusion, and in particular recognizes the obligations of the state to:

Article 19: "States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right."

Article 23: make provision of support to families in order to ensure against the abandonment or concealment of child with disabilities; "... where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting."

See also relevant articles on non-discrimination, social protection, education, health and the importance of disaggregated data collection.

- **Guidelines for the Alternative Care of Children (UN 2010)**

The Guidelines recognize the family as the 'natural environment' for children and call for a range of high quality, protective care environments for all children who cannot live with their parents. The Guidelines make repeated references to children with disabilities, including:

Article 9: "As part of efforts to prevent the separation of children from their parents, States should seek to ensure appropriate and culturally sensitive measures... [t]o support family caregiving environments whose capacities are limited by factors such as disability..."

Article 10: "Special efforts should be made to tackle discrimination on the basis of any status of the child or parents, including ... mental and physical disability."

Article 34 (b): "Supportive social services ... and services for parents and children with disabilities. Such services, preferably of an integrated and non-intrusive nature, should be directly accessible at the community level and should actively involve the participation of families as partners, combining their resources with those of the community and the carer."

Article 38: "States should ensure opportunities for day care, including all-day schooling, and respite are which would enable parents better to cope with their overall responsibilities towards the family, including additional responsibilities inherent in caring for children with special needs."

Article 58: "Assessment should be carried out expeditiously, thoroughly and carefully. It should take into account the child's immediate safety and well-being, as well as his/her longer-term care and development, and should cover the child's personal and developmental characteristics, ethnic, cultural, linguistic and religious background, family and social environment, medical history and any special need."

Article 86: “Carers should ensure that the right of every child, including children with disabilities, living with or affected by HIV/AIDS or having any other special needs, to develop through play and leisure activities is respected and that opportunities for such activities are created within and outside the care setting. Contact with the children and others in the local community should be encouraged and facilitated.”

Article 87: “The specific safety, health, nutritional, developmental and other needs of babies and young children, including those with special needs, should be catered for in all care settings, including ensuring their ongoing attachment to a specific carer.”

Article 117: “Agencies and facilities [responsible for formal care] should ensure that, wherever appropriate, carers are prepared to respond to children with special needs, notably those living with HIV/AIDS or other chronic physical or mental illnesses, and children with physical or mental disabilities.”

Article 132: “Children with special needs, such as disabilities, should benefit from an appropriate support system [in relation to process of transition from care], ensuring, inter alia, avoidance of unnecessary institutionalization.”



6.0. CATEGORIES OF CAREGIVERS OF CHILDREN WITH DISABILITIES

This chapter gives a definition and explains who a caregiver is and lists the different categories of caregivers of children with disabilities in the various settings/environments within which children with disabilities grow. These settings and environments include home with the biological parents, foster parents or adopted parents, or with a family member, and institutions e.g. day care centres and other schools dedicated for children with disabilities (like school for the blind, school for the deaf or school for the intellectual and developmental disabilities etc. under the Special Education Division of the Ghana Education Service). Additionally, there are children with mild and moderate disabilities in regular schools – as indicated in the Inclusive Education policy. The chapter also lists and describes the key responsibilities of the various categories of caregivers of children with disabilities.

The expected outcomes for this chapter are that by the end of this chapter the participants would be able to:

- Define who a caregiver is
- Describe the different categories of caregivers of children with disabilities
- List the key responsibilities of caregivers of children with disabilities

Duration: 90mins

Materials:

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators Notes

Facilitators' Action

- a. Begin this session by summarizing the introductory portion of this chapter in addition to the expected outcomes.
- b. In a buzz session ask the participants to explain or define who a caregiver is (write the responses on a flipchart) and after a few responses (say 4 or 5 responses/or one response from each of the groups), use the key information on the different definitions of a caregiver in the text box below to explain to them who a caregiver is.

Who is a Caregiver?

A caregiver is a family member or paid helper or professional who regularly looks after a child or a sick, elderly, or disabled person.

A caregiver is someone, typically over age 18, who provides care for another.

A caregiver or informal caregiver is an unpaid and without formal training member of a person's social network who helps them with activities of daily living.

Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder¹⁴.

It may be a person who is responsible for the direct care, protection, and supervision of children in a child care home, or someone who tends to the needs of the elderly or disabled or someone who provides for the needs of children or of people who are ill or cannot provide for their own needs¹⁵.

Caregiver or Carer¹⁶ is a person who takes primary responsibility for people who cannot fully care for

themselves (in this context, children). This may be a parent, another family member, a trained professional or another individual. A caregiver may be paid or unpaid for caring for the child.

- c. Discuss the different definitions of who a caregiver is with the participants and let them as a group decide on what they would use as the definition of a caregiver throughout the period of the training (their operational definition).
- e. Ensure that this definition they choose captures all the key words that describe who a caregiver is.
- f. Write it on a flipchart and post it on the wall where every one of them can see and refer to at any point during the workshop.

¹⁴ <https://en.wikipedia.org/wiki/Caregiver>

¹⁵ <https://dictionary.cambridge.org/dictionary/english/caregiver>

¹⁶ Early Childhood Care and Development Standards (0-3 years), Ministry of Gender, Children and Social Protection (MoGCSP), March 2018,

- g. Conclude this session by congratulating the participants for the good work done in coming up with their operational definition of a caregiver that would be referred to during the entire period of the workshop.

Session 6.2: Different Categories of Caregivers of Children with Disabilities and their Key Responsibilities

Facilitators' Action

- a. Begin this session by informing participants that now that they have an operational definition of who a caregiver is (refer again to the definition posted on the wall, if possible, ask one volunteer to read it again), it is important to know the different categories of these caregivers.
- b. Continue by informing the participants that there are many categories of caregivers (which you are going to learn about in this session). Some caregivers render 24-hour care, others live with care receivers that is the children, some care from a distance, and this has led to diverse classification of caregivers. There are mainly two types of Caregivers. These are:
 1. The Primary Caregivers who routinely provide daily care for children or a loved one who is ill. Primary caregivers assist with daily activities such as bathing, dressing and medications.
 2. The Secondary Caregivers who provide back-up typically to primary caregivers.
- c. Ask two volunteers to explain the difference between primary and secondary caregivers using typical examples or case scenarios (for instance primary and secondary caregivers of a sick person).
- d. Clarify if the need arises by saying that a primary caregiver for a sick person could be a spouse, sister, brother or a relative, and the secondary caregiver could be other family members.
- e. Another example you can give is that the Primary Caregiver of a child is mostly the parent and the Secondary Caregiver could be siblings or other family members who take care of the child in the absence of the parents.
- f. Also add that Primary Caregivers are mostly non formal (from the family), not professionals and are also mostly not paid but Secondary Caregivers could be formal caregivers who are trained individuals and professionals, including healthcare providers, who render care and are paid for their services. Secondary Caregivers could also be non-professionals who are paid for what they do.
- g. To explain further the types of caregivers you have mentioned give an example of the parent of a child as a Primary Caregiver (informal) and a domestic help or a nanny employed and paid to help the parent take care of the child as a Secondary Caregiver. If the house help or nanny are trained professionals, then they are formal caregivers.
- h. Inform the participants that having now learned about the two types of caregivers they are going to do a group exercise in which they are going to list the different categories of caregivers of children (having in mind, children with disabilities). Alert them that the different

categories of caregivers depend on the environment within which the children grow up.

- i. Allow them 10mins for this exercise and provide each of the groups a flip chart paper on which to list the categories they would come up with. As part of the instructions ask them to list the categories of caregivers together with the environment within which each category provides care for children.
- j. After the 10mins ask the groups to present the outcomes of their discussions to the bigger group of participants. As much as possible allow each group to present and let the other groups clap after a group completes its presentation (to boost the morale of the groups and those who would present of behalf of the groups).
- k. After all the groups have presented support the discussion with the participants using the categories of caregivers listed in the text box below.
- l. Allow for questions and further discussions. Use this opportunity to explain to the participants what Alternative Care (especially who a foster parent is and who an adopted parent is) as well as why institutional care of children is being reduced to the barest minimum by using the key points in the Facilitators' Notes 6.2a on Alternative Care for Children below.

Categories of Caregivers

The different categories of caregivers of children with disabilities in the various settings/environments within which children with disabilities grow include:

- the parents which include biological parents (father and mother), foster parents or adoptive parents in the home setting.
- a family member which include an older sibling, an older cousin, an uncle, an auntie or a grand or great grandparent also in the home setting
- domestic workers, usually called “house helps” in Ghana some of whom are paid but others are extended family members who are engaged to provide support to relatives living in the cities at no fee
- Teachers and care takers in institutions e.g. day care centres and other schools dedicated for children with disabilities (like school for the blind, and school for children with hearing impairment etc.).

- m. Continue the discussions by stating that quality caregiving that comes from the heart has the ability to promote the physical, emotional, mental, spiritual and social well-being of the care receiver¹⁷ and in this case the children with disabilities.
- n. Also mention that as has been explained earlier there are different kinds of caregivers and these caregivers also have diverse responsibilities and then next group exercise is going

¹⁷ Role of Caregivers of Children with Intellectual Disabilities and Support Systems Available to them in Ghana, by Acheampong Enoch, Wisdom Kwadwo Mprah, Owusu Isaac and Bediako Joseph, Centre for Disability and Rehabilitation Studies, Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana, DOI: 10.5463/dcid.v28i4.645, March 2018,

to be about the responsibilities of the diverse categories of caregivers that have been discussed above.

- o. As a group exercise ask the participants to discuss and list the key responsibilities of the various categories of caregivers that have been discussed and listed above. They are to list the responsibilities of parents, family members, domestic workers/helps, teachers and caretakers of day care centers as well as teachers and caretakers of institutions/schools dedicated for children with disabilities.
- p. Give every one of the groups flip chart papers to write the outcomes of their discussions on and allow them about 20mins to complete the exercise.
- q. After the 20mins ask representatives of the groups to present their answers during plenary and as was done previously let the other groups clap after a group completes its presentation (to boost the morale of the groups and those who would present of behalf of the groups).
- r. After all the groups have presented support the discussion with the participants using the key information listed in the Facilitators' Notes 6.2b on Key Responsibilities of the Different Caregivers of Children with Disabilities (first present the information in the table).
- s. Allow the participants to ask questions and encourage them to contribute further to the discussions using their personal experiences and other case scenarios they know or have heard of. Use the opportunity to dispel myths and misconceptions about taking care of children with disabilities.
- t. Before you conclude the discussions, ask participants whether they know of other groups of people or organizations that provide direct or indirect support for the care of children with disabilities and allow them to mention these groups and the kind of support they provide. Encourage them to use their experiences and other case scenarios.
- u. Use the information in the Facilitators' Notes 6.2b on Key Responsibilities of the Different Caregivers of Children with Disabilities (below) that lists Other groups that may indirectly help in taking care of children with disabilities to contribute to the discussions.
- v. Conclude the discussions by mentioning that most of the times the roles the Community within which the child is being brought up, Civil Society Organizations (CSO) and Religious Groups play in the care of children with disabilities are overlooked but are very important.

The Constitution of Ghana (session 27 sub-session 1a) states that every child (including children with disabilities) has the right to be taken care of by the natural/biological parents except where those parents have effectively surrendered their rights and responsibilities in respect of the child in accordance with law. Session 3 of the Children's Act, 1998 (Act 560) also states that parents, care-givers and families have the primary responsibilities of taking care of the child (the welfare and for the provision of their basic needs). No person is to deny a child the right to live with his/her parents and family and grow up in a caring and peaceful environment unless it is proven in court that living with his/her parents would lead to significant harm to the child; would subject the child to serious abuse; or would not be in the best interest of the child. It is only under such conditions that an alternative home or care is arranged for the child.

- Alternative care: Care for children who are not under the custody of their biological parents. Alternative care can be formal and informal. It includes family-based care (kinship care, foster care and adoption) and residential care.
- Family-based care: Family-based care is the alternative care of children in a family environment. Family-based care includes: Kinship care (living with relatives); and short term or long-term foster care (living in a home with a foster parent, who provides round-the-clock care – in the same capacity as a biological parent – but is not paid a salary)
- Formal care: All alternative care in which placement has been ordered by a competent administrative body or competent court of jurisdiction. Residential care is always considered formal care even if the necessary orders have not been obtained. Placements in residential care without the necessary authority are illegal.
- Informal care: Any private arrangement provided in a family environment, whereby the child is looked after on an ongoing or indefinite basis by relatives (kinship care) or by others in their individual capacity, at the initiative of the child, his/her parents or other person without this arrangement having been ordered by a competent administrative body or judicial authority.
- Foster care: Foster care is a way of providing a family life for children who cannot live with their biological parents. Foster care is often used to provide temporary care while parents get help sorting out problems, or to help children or young people through a difficult period in their lives. Often children will return home once the problems that caused them to come into foster care have been resolved and it is clear that their parents are able to look after them safely. Others may stay in long-term foster care, some may be adopted, and others will move on to live independently. There are times when the child needs or is referred to a formal foster care which is a statutory placement requiring the involvement of the Department of Welfare.
- Kinship care: is Family-based care within the child's extended family or with close friends of the family known to the child. Kinship care arrangements are also sometimes referred to as informal foster care.

18 Care Reform Initiative (CRI) Ghana, #FamilyBestPlaceForChildren, Foster Parent Training Manual, "Empowering Caregivers, Strengthening Families", UNICEF Ghana and Department of Social Welfare of the Ministry of Gender, Children and Social Protection, August 2018

- Residential Care: Residential Care is care provided for children in any non-family-based group setting, such as shelters for emergency care, transit centres in emergency situations, and all other short- and long-term residential care facilities, including group homes. Residential care may be considered as a temporary alternative care solution for some children in emergency situations and with no other means of support but only as a last resort if no immediate placement in the community is found. The goal of residential care must be to provide temporary, short-term care and to reunify children with their parents or find a longer-term family-based care alternative within the shortest time possible.

Facilitators' Notes 6.2b: Key Responsibilities of the Different Caregivers of Children with Disabilities

Children with disabilities mostly have affected adaptive functioning in communication, social judgment, memory, personal care, self-management, home care, learning, self-direction and difficulty in undertaking daily living activities. Therefore, parents and other caregivers have to constantly care for them to help promote their holistic well-being.

Caregiver	Key Responsibilities
Parents (including biological parents, foster parents and adopted parents)	<ul style="list-style-type: none"> • Responsible for the child's total development and well-being • Provide food and nutrition, starting with breast feeding (preparation of special diets) • Provide safety and comfort for the child • Everyday tasks such as mobility, feeding, grooming, dressing, bathing, toileting and bedtime routines (called activities of daily living ADLs) • Demonstrate love, companionship and emotional support to the child • Provide social, moral and ethical training • Advocating on the child's behalf for other people including the peers of the child to understand the child's condition and the need to handle them with care and support • Provide the child's health and nutrition needs (medications/treatments, physical exercises/therapies), • Mental exercises and games • Ensuring the child's safety and security • Responsible for ensuring that the child is educated

¹⁹ Early Childhood Care and Development Standards (0-3 years), Ministry of Gender, Children and Social Protection (MoGCSP), March 2018,

²⁰ Role of Caregivers of Children with Intellectual Disabilities and Support Systems Available to them in Ghana, by Acheampong Enoch, Wisdom Kwadwo Mprah, Owusu Isaac and Bediako Joseph, Centre for Disability and Rehabilitation Studies, Department of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana, DOI: 10.5463/dcid.v28i4.645, March 2018,

<p>Family members (and sometimes very close friends of the parents)</p>	<ul style="list-style-type: none"> • Assist the parents in caring for the children • Provide guidance to parents, particularly first-time mothers and fathers to care for their children • Demonstrate love towards the child • Help the children in their development • Provide guidance for the children to play as they also play with them • Provide social, moral and ethical training for the child • Support the child to learn and practice family and community norms and culture • Support parents with funds for children's upkeep, where necessary
<p>Domestic helps and nannies</p>	<ul style="list-style-type: none"> • Assist the parents in caring for the children (assist in almost all the roles of the parents, including the everyday tasks such as feeding, grooming, dressing, bathing, toileting, playing and bedtime routines also called activities of daily living ADLs) and also ensure that the children are safe and secured • Expected to demonstrate love towards the child • Provide social, moral and ethical training for the child • Support the child to learn and practice the family and community norms and culture
<p>Teachers and caretakers of Day-care Centres, crèches and nurseries</p>	<ul style="list-style-type: none"> • Assist the parents in caring for the children, including some of the everyday tasks such as feeding, grooming, dressing, bathing, toileting etc. (during working hours) • Promote the child's social and relationship development by providing platforms for the growing child to interact with other children • Help the children in their speech development • Provide social, moral and ethical training for the child • Support the child to learn and practice family and community norms and culture • Track the progress of the child for the purpose of remediation • Document observations on children with possible delayed or impaired development
<p>Teachers and caretakers of institutions for children with disabilities</p>	<ul style="list-style-type: none"> • The house mothers/fathers are responsible for ensuring that all the pupils are healthy; ensuring the safety of the children; providing assistance; and training the children to perform activities of daily living. • The Teachers are responsible for imparting functional skills and knowledge to the children; providing companionship and emotional support; assisting the children with activities of daily living; mobility, mental exercises and games and occasionally providing financial support (to cater for the fees and some learning materials the children may need if the parents are unable to afford)

Other children with disabilities (older children and adolescents)	<ul style="list-style-type: none"> • Support their peers in playing • Share their experiences whilst growing to help the younger children cope with challenges that may occur through their developmental stages
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Other groups that may indirectly help in taking care of children with disabilities

- **The Community within which the child is being brought up**

- Provide moral values and security and help the parents in the moral upbringing of the child
- See to it that the parents care for their children
- Ensure that the child grows up in a clean environment
- They help clean the environment and support existing child care and health facilities
- Provide the appropriate cultural environment for the child's social development

- **Civil Society Organizations (CSO)**

- Care for neglected children with disabilities
- Provide parents and childcare facilities with health and educational materials
- Develop and implement child development projects
- Undertake public education on effective ways of caring for children with disabilities
- Undertake advocacy interventions to promote the rights and development of children with disabilities
- Supply of health materials like mosquito nets, vaccines and others
- Support child development projects with funding

- **Religious Groups**

- Provide effective moral education of children
- Set up and provide funds to help the development and care of children
- Teach moral values and cater for the spiritual needs of the child
- Support parents to provide adequate care with educational programmes on parenting

70. BASIC NEEDS OF CHILDREN

Children, especially those with special needs and disabilities, are precious and vulnerable; therefore, they need a lot of love, attention and quality time with caregivers. Parents have known this instinctively for centuries and research continues to confirm that a human child cannot survive without someone providing food, protection and affection. Because of this, human babies are born with a very strong instinct and need to bond with a caregiver.

The basic needs of every child including those with disabilities are: Physical/survival needs - (including food, water, shelter), Intellectual needs - (Education), Emotional needs - (Love), Social needs - (Sense of belonging to a family or community), Spiritual needs - (Belief in a higher being), Need for Protection - sense of security in the environment etc.

Knowledge of these basic needs by caregivers is crucial since it would help them understand what they have to provide for the children under their care in order for them to grow and develop properly. This chapter therefore concentrates on the basic needs of children including those with disabilities for their proper growth and development.

The learning objectives are that by the end of this chapter, the participants who are caregivers of children with disabilities would be able to:

- List and explain the basic needs of every child
- Explain some of the things children with disabilities need to grow and develop properly

Duration: 60mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators Notes
- Child Protection Toolkit (the Maize Plant Exercise and the Family-Based Care Flash Card #2)

Facilitators' Action

- a. Begin this session by mentioning that children with special needs and disabilities especially are precious and vulnerable like other children; therefore, they need a lot of love, attention and quality time with caregivers. Parents have always known this instinctively for centuries and research continues to confirm that a human child cannot survive or develop properly without someone providing their basic needs. However sometimes some of these basic needs are not understood by caregivers and hence it affects the development of the children.
- b. The purpose of this session therefore is to help caregivers appreciate what children need for their proper development and to understand that these needs are the responsibility of the parents, primary caregiver and other members of the family to help provide a safe and protective environment for the children.
- c. Continue by saying that children are like maize plants, they need to be cared for and if you take good care of your maize, you will have strong plants and a good harvest. It is the same with children, if you look after them, they will grow strong. Our harvest is the next generation of children who will grow up to respond to any challenge as well as help the society.
- d. After these introductory statements inform the participants that you are going to carry out an interesting exercise with them named "The Maize Plant"
- e. Show the pictures of the maize plant with a baby in it as the maize fruit and pictures of a mother, father, brother, sister, extended family to the participants and ask them to describe what they see in the pictures.
- f. With the picture of the child in the maize plant placed in the middle, ask the participants what they think a maize plant needs to grow and as they mention the things needed one by one, ask them to look through the pile of pictures for this exercise to identify the items mentioned and place them around the picture of the maize plant.
- g. Continue the discussion by drawing the attention of the participants to the fact that the child is the maize plant with the family members attending to the maize plant differently by pouring water, putting manure or fertilizer around the plant, weeding around the plant etc.
- h. One major need is to protect the plant from the weeds by weeding around it so ask one member to identify that picture and place it around the maize plant.
- i. Another critical need is sunshine without which the plant will die and will not be able to bear fruits. Ask one of the participants to look for the picture for sunshine and ask him/her to describe why the sunshine has a smiling heart in it - this is the love from all the family members for the child to grow. This is to help you enter the next stage of the discussion.
- j. Inform them that "now we are going to look at what a child needs to grow into a strong adult" and ask them to mention these needs and remind them that the needs are linked to their rights.

- k. As they mention the needs write them on a flipchart and let them look through the rest of the picture cards and identify which picture corresponds to the need mentioned/identified.
 - a house representing -Physical/survival needs - (including food, nutrition, water, shelter)
 - a school representing - Intellectual needs - (Education)
 - a heart that is smiling representing - Emotional needs - (Love and care)
 - smiling people embracing the child representing - Social needs (Sense of belonging to a family or community)
 - church/mosque with pastor/imam representing - Spiritual needs - (Belief in a higher being)
 - a parent crossing street with the child representing - need for protection - sense of security in the environment
 - a child being listened to in a family discussion representing - the need for child participation - being allowed to contribute to decisions that concerns them (right to participation)
- l. Show them the pictures of the family/people and the picture of money (to be used to group the needs of children into either needing money or people). In determining the cost of meeting the needs of children identified, ask the participants to indicate which of these needs can be met with or without money by letting them group the pictures representing the needs under the pictures of money or people.
- m. Count with them the number of needs that can be met by people, and those that can be met by money. Usually, this exercise will show that PEOPLE are more important than MONEY in meeting the needs of children.
- n. Conclude this exercise by pointing out that some needs of children including children with disabilities require both people and money, but the most important needs (like love, play, trust, protection and a sense of belonging) can be given by families and communities without needing any additional resources. These are called protection needs – to help protect the children from all forms of harm and abuse.
- o. At this point ask the groups to list some of the things (which may not necessarily cost money) the family members and community members can do in order to provide these protection needs of love, play, trust, protection and a sense of belonging etc. especially for children with disabilities.
- p. After about 10mins allow the groups to present their responses and contribute to the discussions using the information on Examples of Community Activities That Meet the Protection Needs of Children in the text box below. Mention the various categories of needs and the activities that go with those needs as listed in the text box and ask the participants to explain or describe how children with disabilities can benefit from such activities (using examples of disabilities in children).
- q. As much as possible allow the participants to ask questions for clarifications and share their experiences as well.
- r. Continue the exercise by showing the participants the Family-Based Care Flash Card #2 and ask them the following questions, probing further to stimulate the discussion.

- What do you see in the picture?
 - What kinds of difficulties do parents face in caring for children with disabilities at home, especially severe or multiple disabilities?
 - Why do some parents of children with disabilities abandon them or place them in residential homes for children (orphanages, children's homes)?
 - What do you think are some of the negative things about living in an orphanage for a child?
 - Why is it so important for a child to grow up with his or her family?
 - How can families and communities support parents to care for their children with disabilities at home?
 - What kinds of services for children with disabilities are available in your community?
 - How can parents be supported to access these services?
- s. During the discussion you can add some of the points in the text box below that may not have been mentioned by participants.
- t. Continue the discussions by mentioning that as the child with disabilities ages and is in the primary school years, the family is faced with the same concerns as other typical developing families (who have children that are also growing), as well as their own unique problems. Mention also that some of the challenges raise a lot of questions which you are going to discuss with them shortly.

Needs and rights of children including Children with Disabilities

Children with disabilities have the same social and emotional needs and rights as other children. They need to be loved and respected. They need to play and explore their world with other children and adults. They need opportunities to develop and use their bodies and minds to their fullest ability, whatever that may be. They need to feel welcome and appreciated by their family and in their community.

As with all other children, the best place for children with disabilities to grow is in a loving, nurturing family environment. Caring for a child with a disability can be very challenging for families.

Most families need a lot of support to help them to care for children with disabilities at home so they don't end up in residential care. This support can include medical care, physiotherapy, assistive devices e.g. wheelchair, and counselling.

Communities can also support the family by including them and their child in community activities and by not stigmatizing or discriminating against them or their child.

Some children with severe or multiple disabilities may need special services not available in their community and may need to be placed in residential care/institutions to receive these services. But even in these cases, the family still needs to keep in contact with their child.

If a child with severe or multiple disabilities has to be placed in residential care/institution this must be a home that is registered with the Department of Social Welfare (DSW) and must provide quality care in line with the National Standards for Residential Homes for Children.

- u. Ask the following questions in a buzz session and allow participants to provide answers using their experiences or case scenarios.
- What will their child do for leisure and recreation?
 - How will they access technology?
 - What are the mobility options available to their children? How will physical therapy affect their mobility and their quality of life?
 - Is more physical, occupational, and speech therapy better?
 - Does their child need braces?
 - What about a power wheelchair? How will they transport the wheelchair and is their home accessible?
 - How would they craft their child's Individualized Educational Plan (IEP) to ensure that their child gets all that they need to succeed in school?
 - Are the typical social relationships between children usually affected by a child's disability (for example getting together for play groups, birthday parties, soccer etc.).
 - Do the families of children with disabilities often have to make choices between having more therapy or actually letting the child and the family rest from all of the other extra demands from school and therapy?
 - How is the self-esteem of a child with a disability affected? And how is it managed? (check the information in the text box below for some tips to assist in discussing this)
- v. Allow for extensive discussions with the participants and conclude by mentioning that caring for children with disabilities surely come with a lot of challenges. Housing amenities for example have a lot to do with the opportunity to satisfy the special needs of disabled children, but housing amenities alone do not create adequate environment to satisfy the special needs of children that need full care. These children need the lodging to be adapted to the specifics of their needs that requires reconstruction of housing and special equipping to provide a way for the children to move around in wheelchairs, take showers or baths, have a room for exercise units and a special type of bed.

Examples of Community Activities That Meet the Protection Needs of Children Including Children with Disabilities

Intellectual Needs

- Setting up homework clubs (parents and community volunteers helping with homework)
- Helping children remain in school

Social needs

- Encouraging and supporting activities outside of school (for example, sports, art, music)
- Spending time with orphans and children with difficult lives - or helping them to cope with various daily chores
- Forming support and play groups for children (children' clubs, youth clubs, drop-in centres)
- Training community aunties and uncles on educating children on how to socialize and prevent HIV infection.

Physical needs

- Establishing communal gardens
- Income generation activities for community guardians, caregivers or older children
- Collecting or making clothing for children
- Teaching orphans how to look after themselves, and their brothers and sisters (cooking, cleaning and child care)

Emotional needs

- Raising community awareness to support the emotional needs of children
- Forming support groups for caregivers (especially of children with disabilities)
- Memory Books

Spiritual needs

- Praying with children
- Inviting children to participate in religious activities (youth groups, meditation, etc.).
- Religious teachings with messages of hope for the future
- Encouraging religious groups to participate in activities that support children

Protection needs

- Awareness-raising campaigns and activities
- Training on children's rights
- Identifying and taking action against places that exploit children

How is the self-esteem of a child with a disability affected?

Depending on the cognitive awareness of the child that suffers from a disability, self-esteem may or may not be affected. For a child who was once healthy and free of any disabling conditions who experienced a change that left them disabled, the child's self-esteem may suffer dramatically. To become disabled leaves the person in a state of grief, grieving for the loss of abilities or functions that one previously had. For the child who is not aware of their disability or does not understand that they are different from others, there may not be any issues with self-esteem. On the other hand, the child with a mild disability, such as a learning disability, may have many issues with self-esteem due to the awareness of their difficulties and the lower or too high expectations placed on their performance. Every individual case is different, but it is important to bear in mind that all disabled children can suffer from issues with self-esteem, so it is important to be aware of this and promote the child's positive attributes and praise their accomplishments to promote a healthy attitude.

8.0. THE BASIC ELEMENTS OF QUALITY CARE FOR CHILDREN

The quality of the care of every child has a direct impact on the child's ability to learn, to build healthy relationships, and to become the best they can be²¹. The importance of quality of child care is the most consistent finding among the many studies linking child care to children's development.

A child's needs depend upon the age, of course, but all high-quality care will include certain key ingredients. Among these are sensitive and responsive emotional and consistent caregiving, cognitive and language stimulation, and a safe and healthy environment. Warm and responsive caregiving is the key to quality child care, just as it is the key to effective parenting. When a caregiver has a positive attitude, gives praise and encouragement, and promotes language and social and emotional development, the children being taken care of will thrive.

It is important to ensure that quality care is delivered in a suitable environment and that the development and safety of the children being taken care of are paramount. This chapter discusses what quality of care is made of (the basics of quality of care) and the importance of quality care for the development of children with disabilities.

The learning objectives are that by the end of this chapter, the participants who are caregivers of children with disabilities would be able to:

- Define and explain what quality of care (for children with disabilities) is made of
- Explain the importance of providing quality care for children with disabilities

Duration: 60mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators Notes
- Child Protection Toolkit (The Family Gift Box and the Balloon Game)

Quality of Care is

- The right type of care for one's health condition
- Care that results in the best possible outcome
- Care delivered with attention to one's concerns, needs, and life goals
- Care that keeps one safe from hazards and harm

21 <http://www.urbanchildinstitute.org/why-0-3/child-care>

Session 8.1: Quality of Care for Children with Disabilities

- a. Introduce this session by informing participants that having learnt about the basic needs of children and for that matter children with disabilities as caregivers, it is very important to also understand what the basic components of the quality of care for children is.
- b. Add that just as children with disabilities have the same rights as other children, they also have rights to quality of care.
- c. Continue by summarizing the information in the introductory session of this chapter above and states that the quality of the care received by every child has a direct impact on the child's ability to learn, to build healthy relationships and to become the best they can be. Even though every child's needs depend upon the age and whether the child has any form of special needs/ disabilities or not, but all high-quality care will include certain key ingredients which would be discussed in this session.
- d. List the learning objectives on a flipchart and discuss what they mean with the participants.
- e. In a buzz session, ask the participants what they understand by the term "Care" in the context of caring for children with disabilities (use the small colourful balls to select participants randomly from each of the groups – throw the ball to the first volunteer to answer the question who in turn throws it to the next volunteer in that sequence).
- f. After a few responses from the participants inform them that Care²² in the context of Early Childhood Care and Development (ECCD), refers to the total support provided for a child, such as children's health and nutrition, their evolving emotional and social abilities, and also their mental development. Care is what children, especially infants between the ages 0 to 3 years receive to promote cognitive development, body development, language and relationship development.
- g. Add that it is not enough for parents and caregivers to just provide children with their needs but warm and responsive caregiving is the key to quality child care, just as it is the key to effective parenting. When a caregiver has a positive attitude, gives praise and encouragement, and promotes language and social development, the children being taken care of will thrive.
- h. Introduce the "The Family Gift Box" from the Child Protection Toolkit by informing participants that the purpose of the exercise is to help parents and other caregivers of children (especially children with disabilities) think about what they can do for their children in the house (the gifts they can give to the children) to make them feel secure and protected in order for them to grow and develop to become responsible members of society.
- i. This exercise is to remind participants that there are gifts besides money, food and clothing that parents and communities can give children to make them feel secure and protected. These gifts are also their rights. Examples of these gifts are love, acceptance, trust, respect, protection, feelings of a sense of belonging, encouragement, appreciation, attention, guidance, approval, and parent/caregiver-to-child communication.

²² Early Childhood Care and Development Standards (0-3 years), Ministry of Gender, Children and Social Protection (MoGCSP), March 2018

- j. This exercise should be carried out in a fun mode to ensure that parents and caregivers who participate in the exercise happily and willingly agree on their responsibility in providing a safe and protective environment as part of a quality of care to the child in the home. Provision of quality care should also be seen as part of the child's right.
 - k. Ask participants to think of a 'gift' that their parents or guardians gave them when they were children – something that made them feel safe and protected and helped them to grow strong (qualities such as courage, or trust, or determination, or self-esteem etc.).
 - l. After a few of the participants mention the gifts their parents or guardians gave them, put the small (foldable/collapsible) colourful paper box on a table or the floor in front of participants and ask them to mention what they can do to make the children they take care of feel safe and protected (their gifts to the children)
 - m. As they mention these "gifts" ask them to pick the colourful pads (which are in different shapes with smiling faces of children on them) and drop them in the box.
14. Use some of the examples of gifts that parents and caregivers can give to children (listed in the text box below) to support the discussions.

Some of the 'Gifts' that parents and other family members can give to children include:

- Providing a caring and healthy home environment: giving children love, acceptance, guidance, protection and a sense of security, healthy living and well being
- Creating a child-friendly space for play and recreation in the house
- Allowing the children to go to school and providing the needs for the school
- Assisting more vulnerable children in the family
- Story-telling time in the evenings as part of entertainment for the children
- Participation - giving children a voice in their families and communities
- Religious and moral teachings
- Training children in skills – cooking, traditional crafts etc.
- Making sure that children with disabilities are included in all activities in an approach that "lets children be children", which means allowing them to learn through play and experiencing a wide range of artistic, cultural, cognitive, social and physical activities.
- Giving equal value to the development of boys and girls.
- Not sending children into hiding because you are shy to let other people see them
- Not sending children away from home for servitude/as house-helpers or house-boys, porters, or to foster parents when the parents are alive

- Speaking to children as a form of discipline instead of beating them up or caning them.
- Registering children at birth to give them an identity (this is a very important right of a child)

- o. As much as possible allow the participants to ask questions for clarifications and also provide contributions. Use the key points provided in the Facilitators Notes 8.1 on The Basics of Quality of Care for every Child to list the key elements of quality of care for children
- p. As much as possible provide responses to the questions that participants would ask and correct myths and misconceptions that would come up during the discussions.
- q. Be sure to mention that though personal ideas about what constitutes the quality of care for children can vary depending on values, beliefs and cultural or social context and also on who is making the judgment, research shows that high-quality child care can have long-term benefits for children, including:
 - increased cognitive abilities
 - improved language development
 - better relationships with peers
 - less conflict with caregivers and self confidence
- r. As part of the conclusion for the discussions, mention that children have been created with the inner strength to solve many problems on their own however the “gifts” that parents and other caregivers give to children help to build and sharpen this inner strength further and sometimes it takes committed and passionate individuals to bring about the desirable changes during the growth and development in the lives of children who even face difficulties as they grow. No matter how strong or weak children are or may appear to be, parents, caregivers and family members need to remember that they are still children and need all the love and support for them to grow to become responsible future leaders.
- s. You can also carry out the “Balloon Game” (instructions in Handout below) with the participants and conclude that one element of quality care is protection which is about safe guarding children from every form of harm and helping those who have been harmed.

Facilitators Notes 8.1: The Basic Elements of Quality Care for every Child

The importance of quality of child care is the most consistent finding among the many studies linking child care to children's development. A child's needs depend upon the age, of course, but all high-quality care will include certain key ingredients. Among these are sensitive and responsive caregiving, cognitive and language stimulation, and a safe and healthy environment.

Though personal ideas about quality child care can vary depending on values, beliefs and cultural or social context and also on who is making the judgment, research shows that high-quality child care can have long-term benefits for children, including:

- increased cognitive abilities
- improved language development
- better relationships with peers
- less conflict with caregivers

However, these benefits may not be realized if the quality of care is low

Through the eyes of children - a high-quality care may mean feeling accepted for who they are no matter what their ability or culture. It means having friends and responsive adults, being emotionally and physically comfortable and the possibility of having a variety of fun, interesting and engaging activities despite the presence of any form of disabilities.

Overall elements of quality through the eyes of parents

The quality of life describes the level of satisfaction of human needs that is determined in accordance with the existing norms, habits and traditions of particular society, as well as in comparison with the level of personal ambition. The quality of life is characterized by the individual's satisfaction with the current living conditions that provide satisfactions of the needs in all areas that affect his or her everyday life.

While there is no single definition of quality in child care, there are some overall elements of child care that are identified as critical to the well-being of children. These include:

- Health, safety and good hygiene
- Good nutrition
- A well-maintained environment set up for children (in this case children with disabilities)
- Opportunities for active play - especially outdoors
- Opportunities for quiet play and rest
- Opportunities for developing motor, social, language and cognitive skills through play
- Positive interactions with adults (apart from their primary and secondary caregivers)
- Practices that support positive interaction amongst children (with both children with disabilities and children without disabilities)

- Facilitation of emotional growth
- Participation of, support for and communication with parents and other caregivers
- Respect for diversity and difference, gender equality and inclusion of children with disabilities

A high quality child care is generally understood to have broad learning and development goals for children, going beyond narrow academic aims like early literacy and numeracy to social, emotional, cultural, artistic and physical goals

Physical wellbeing is mostly associated with an environment where the family quality of life is formed and that affects other areas of quality of life; environment is reflected by the conditions that form it. Physical wellbeing of the families is largely affected by material provision. Physical wellbeing is a prerequisite of the provision of quality of life for children with disability, since physical wellbeing includes such areas as suitability of housing and environment to the family needs, also mobility and accessibility of health care.

Depending on the needs of the disabled child, there are many available adaptive devices that are designed to make activities and quality of care easier. Many children that suffer from a disability may require wheelchairs, helmets, floor mats, braces, hospital beds, adaptive rails, shower chairs and so much more depending on the needs of the child.

As the caregiver for a child with a disability, you will know best how much assistance the child requires, sometimes the care can be complex in the sense that it entails a lot of different things to be done at the same time. Also, as the child gets older or the needs change according to the progression of a disease or disability, the care requirements may become greater and may seem possibly less manageable for the home setting. However, it is very helpful to speak with the child's physician if you have any concerns regarding the safety of home care for your child e.g. in the case of epileptic children or the quality of care necessary for the child. The nutritionist/dietician or physiotherapist may also have an advisory role to play.

Hand out on the balloon game

The Purpose of this exercise is to help community members understand that children are like balloons (very vulnerable) tied to our legs that need to be protected from every form of danger.

How to facilitate discussions with this tool: Two groups of people, the first tie balloons on their legs and try to protect the balloons from being destroyed, the second group tries to burst/destroy the balloons.

1. Divide participants into 2 groups and explain their roles:
 - Group 1 ties fully blown balloons (several colourful balloons with pictures of smiling children on them) around their own ankles with string and then tries to protect these balloons from any attacks;
 - Group 2 are the attackers and must try to burst the balloons;
2. Start the game by asking the participants to carry out their different roles. Let the two groups interact for approximately 10 minutes. Call an end to the game and ask the participants for their thoughts:

3. Ask group 1, 'How did you feel when you were trying to protect the balloons? What made protecting your balloons easier? What made it harder?'
4. Ask group 2, 'What made it easy for you to attack the balloons? What made it difficult?'
5. Conclude the exercise by explaining that the balloons are like children (including children with disabilities) and the carriers of the balloons are like parents/families/caregivers, who are trying to protect their children from danger. The attackers represent all the dangers that children with disabilities face in their schools and communities. Protection is about safe guarding these children from all forms of harm and helping those who have been harmed.

9.0. KEY THINGS TO KNOW ABOUT THE ATTACHMENT THEORY^{23, 24}

Over the past several decades, clear evidence has emerged that the quality of the relationship between caregiver and a child in the first few years of life is central to a child's later functioning and there is converging evidence that attachment quality has an important influence on the success of a child's developmental pathway toward self-reliant adulthood. This applies to children with disabilities as well. This chapter simplifies and explains the key concepts within the Attachment Theory that caregivers of children with disabilities need to know.

Learning Outcome:

Participants will understand the concept of healthy and unhealthy attachment and their role as caregivers in supporting healthy attachments.

Materials: Flip-Chart paper and pens

Facilitator Action:

- a. Begin this chapter by summarizing the introductory part above and inform participants that you are going to discuss with them what attachment is and why it is very important for them as caregivers to understand the key concepts of attachment theory.
- b. Ask participants if they can share some ideas on what they think "Attachment" means in the context of childcare.
- c. Validate their inputs and complement with points from the facilitators' notes on attachment below.
- d. To explain the classification of attachment styles to the participants mention that the quality of relationships that children and adults have with other people, particularly those with whom there is an attachment relationship, will depend on the physical and emotional availability, sensitivity, responsiveness, reliability, and predictability of the other person:
 - Attachment figures who are warm and attentive, create secure attachment relationships.
 - Relationships that are inconsistent, cold or confusing increase levels of anxiety, producing attachments that feel less secure.
- e. Continue the discussion by mentioning that each adult attachment type leaves children needing to develop an internal working model of and psychological adjustment to the relationships in which they find themselves. Children develop different attachment styles/strategies, dependent upon their care giving experience. These can be classified as:
 - Type A – Secure
 - Type B – Anxious avoidant
 - Type C – Anxious ambivalent
 - Type D – Disorganized

23 Kent T. Hoffman, Robert S. Marvin, Glen Cooper and Bert Powell, Changing Toddlers' and Pre-schoolers' Attachment Classifications: The Circle of Security Intervention, *Journal of Consulting and Clinical Psychology* 2006, Vol. 74, No. 6, 1017–1026

24 Care Reform Initiative (CRI) Ghana, #FamilyBestPlaceForChildren, Foster Parent Training Manual, "Empowering Caregivers, Strengthening Families", UNICEF Ghana and Department of Social Welfare of the Ministry of Gender, Children and Social Protection, August 2018

- f. Ask the participants if they understand these types of attachment styles/strategies and ask volunteers who said they understood the types to explain them one by one. Complement their explanations with the key points in the facilitators notes below on Types of Attachment Styles and Strategies. The environment in which a child grows can also affect the attachment process. Considerations should be made in this regard not to derail or affect the process.
- g. Continue the discussions by mentioning that in supporting secure attachments in children with disabilities it is encouraging to note that potentially problematic attachment experiences are often successfully overcome by children and their families and secure attachments can develop.
- h. Ask participants to reflect on the following questions and discuss in plenary using the information in the text box below.
- What does a baby or young child do that elicits a caregiving response from an adult?
 - What if the baby or child is with disabilities or has special needs?
 - What is required from the caregiver or environment to enable secure attachment?
 - • What factors might impede the development of secure attachments?
- i. Continue the discussion by mentioning that children (especially those with disabilities/special needs) who are displaying problematic behaviours such as having difficulty managing their emotions, having aggressive behaviours, or who often act whiny or needy may benefit from attachment-based activities. These are activities that enhance the attachment between the child and the parent or caregiver.
- If you are a caregiver and your relationship with your child has been strained for any reason, if you and your child don't seem to be getting along very well, or if you simply want to strengthen the relationship between you and your child, attachment-based activities (examples are in the facilitators notes below) can help to do that. This is particularly true if the child has experienced challenges during the first few years of life.
 - Attachment-based activities can also be helpful for children who may have experienced some trauma or even less severe stressful situations. These activities are even useful for well-behaving, happy children.
- j. Divide participants into pairs and ask them to do as many different attachment-based activities in the facilitators' notes below as availability of equipment and space can permit. Where it is not possible to do the activity, ask partners to discuss how they would feel about doing these activities with a child in their care.
- k. Following the activities, ask participants to share how they felt doing these activities and whether they can identify any other similar (culturally relevant) attachment-based activities. Conclude the discussions on this session after allowing participants to ask questions for clarifications as well as sharing their experiences.

What does a baby or young child do that elicits a caregiving response from an adult?

- In a baby: crying, clinging, sucking/feeding, smiling, babbling
- In a toddler: calling, greeting, following, playing, exploring and returning

What is required from the caregiver or environment to enable secure attachment?

- A loving warm relationship with a caregiver who is predictable and attuned to the individual child

Stimulating interactions and environment

- Physical contact and soothing
- Attentiveness (looking, touching, playing, etc.)
- Recognizing and giving meaning to the baby's communication and finding the right pitch, tone and moment to respond whether with words, sounds or movement
- Verbal stimulation

What factors might impede the development of secure attachments?

- Within the child: being premature, chronic illness, disability, irritability, difficult birth, difficult relationship with parent
- Within the parent or family: mental health problems, physical health problems, disability, history of poor parenting, family structure, family dynamics, loss, separations, abuse, neglect, stress, difficult relationship with child
- Within the environment: poverty and deprivation, social exclusion, persecution, disaster

Facilitators Notes 9.1: What is Attachment?²⁵

Attachment is the bond that children develop with their primary caregivers in the first few years of life. This attachment is extremely influential on how the child relates to others, the nature of their relationships, and how they view themselves and, other people, and the world for the rest of their life. This is not to say that what happens in the first few years of life is totally deterministic of the child's outcome. There is the possibility that later experiences and the child's internal processes and personality can alter the effects that early attachment may have (in a positive or negative way). Attachment theory is broadly seen as a theory of personality development arising out of John Bowlby's work on children's development.

Attachment theory is a way of understanding what happens between children, babies, particularly,

and their parents. When a baby mammal is born, whether a baby cow, or a baby cat, or a baby human, they have to find a way to survive. And the only people, the only creatures that can help them to survive are the adults of that species. A baby needs to have control over its adult carers and make them come when they need something. So whether they're tired, whether they're hungry, whether they got a dirty nappy, they need to be able to get the adults in their world to come and look after them. In the human world, something else happens in that relationship.

²⁵ Care Reform Initiative (CRI) Ghana, #FamilyBestPlaceForChildren, Foster Parent Training Manual, "Empowering Caregivers, Strengthening Families", UNICEF Ghana and Department of Social Welfare of the Ministry of Gender, Children and Social Protection, August 2018

Usually children will go through a protest phase when separated or not responded to: they cry, they are uncomfortable and difficult to soothe, they may reject the efforts of intimacy from their new foster parents. This is in fact a normal and healthy reaction: the child's attachment system is activated by the separation as it should in order to prevent further separation.

You can see a demonstration of this reaction in Dr. Ed Tronick's "Still Face Experiment". First, the mother is responsive and cooperative – then she is asked to make her face still. The infant immediately starts trying to get her attention, becomes desperate and finally cries. You can imagine how an infant with a mother who is not able to respond can experience states of excessive anxiety. Note: If there is access to a projector and internet show the "Still Face Experiment": <https://www.youtube.com/watch?v=apzXGEbZht0>

Types of Attachment Styles and Strategies

- o Type A - Secure

Distress/crying from the child leads to prompt and reliable soothing. The infant is able to predict parental availability and sensitivity and they become secure and trusting - able to explore. Older children are able to express genuine feelings and learn easily. In addition, they are able to form close relationships, develop empathy and good self-esteem.

- o Type B - Anxious avoidant

Distress/crying from the child leads to parental anger or rejection. The infant learns to inhibit distress and this keeps the infant safe and parent available. Older children may become compulsively compliant or caretaking. Children may become self-sufficient and avoid emotional closeness.

For infants aged 0 – 24 months, if another attachment figure is not offered after separation, or if caregivers don't respond to the child's crying, the child may give up crying and apparently become calm, indifferent and withdrawn. This is in fact a signal of danger: the activity of the attachment system may have stopped, but the child may be in a permanent state of grief and may respond less or not at all to care and efforts to offer intimacy and comfort.

This can develop into a state of depression and withdrawal, where the child does not thrive or grow sufficiently. This reaction is common in children who have experienced many early changes in caregivers or attachment figures, and children who have received too little interaction in for example, orphanages or hospitals.

- o Type C - Anxious ambivalent

Distress/crying from the child lead to an insensitive or unpredictable response. Infant learns to escalate arousal to ensure a response. Parent remains available but infant's distress is not soothed. The older child splits the affect – alternating between positive and negative effects in order to control the parent.

- o Type D - Disorganized

Distress/crying from the child leads to a frightening parental response. The infant experiences unmanageable anxiety and confusion and is unable to develop a coherent strategy; they appear disorganized. This creates a dilemma for the infant in that the attachment figure who is needed to protect against danger is the source of the danger. Older children often become vulnerable and may require formal supports as a consequence of serious behavioural, emotional and cognitive difficulties.

Or, if the separation has been sudden and very shocking – perhaps the infant may have been taken

away by authorities and police while the parents were crying and fighting – the infant may develop a general state of stress and separation anxiety. Perhaps the infant's attachment system has become

much too sensible and “hyperactive” due to one or more early shocks. So, every time you leave the room or just turn away, the child may be extremely afraid and panic, and need constant confirmation that you will stay where you are. e.g., say, “Sweetheart, I’ll be back in a moment”, and do as you have said. This creates trust.

Children who have become hypersensitive to separation may cling to you all the time, have major problems falling asleep and need reassurance and comforting for a long time even after a short and normal separation. This is a frequent problem in the first phase for children placed in foster care.

Examples of attachment-based activities²⁶

1. Playful Copycat (or Mirroring the Child)

This activity does not necessarily require any physical items or toys. All it takes is having the parent and child both present and ready to interact with each other. The basic idea for this activity is to have the parent playfully copy what the child is doing, such as having the child begin by clapping his hands together and having the parent clap their hands in the same volume and speed as the child.

When the child changes his style of clapping (such as louder or softer), the parent should imitate the child. Eye contact, smiles, and laughs are also helpful to promote a healthy relationship and repair or enhance attachment. Mirroring can also be done with other activities, such as jumping, playing with toys, or facial expressions.

2. Bean Bag Game

Have the child place a bean bag or another soft toy (or object) that is fairly easy to balance on top of his head. Have the parent sit in front of the child and place her hands in front of her. The child is then directed to tip his head forward to try to get the bean bag in the parent's hands. The child should tip his head when the parent blinks her eyes. (This will promote eye contact.) Have the parent use as much eye contact as possible. Again, it is important for the parent and child to have

²⁶ Care Reform Initiative (CRI) Ghana, #FamilyBestPlaceForChildren, Foster Parent Training Manual, “Empowering Caregivers, Strengthening Families”, UNICEF Ghana and Department of Social Welfare of the Ministry of Gender, Children and Social Protection, August 2018

fun with this activity. Laughter has been found to be healing and can help to repair and enhance a relationship. (activity adapted from Walton)

3. Piggy-Back Rides

Piggy-back rides can help to strengthen parent-child relationships and repair or enhance attachment because they involve fun and physical closeness. When children are babies, they need plenty of physical contact with their parents. Babies thrive not only from being fed and kept physically safe, but also from feeling the comfort and security of having their parent close to them.

4. Lotion Massage

Using lotion to massage a child's hands or feet can enhance attachment and strengthen a parent-child relationship. The massage can relax a person's physical body by reducing tension and bringing the brain into a less defensive state.

5. Brushing Hair

Sometimes girls can be fussy about getting their hair brushed, especially if they have experienced pain from well-meaning parents brushing their hair too hard. However, allowing a daughter to gently brush her mother's hair and having a mother gently brush her daughter's hair can be an activity that can promote connection. This can be a calming activity that includes a sense of nurturing which connects to a person's internal experience of attachment and bonding.



10.0. PROMOTING FAMILY-BASED CARE FOR CHILDREN WITH DISABILITIES^{27, 28, 29}

Millions of children with disabilities remain in harmful institutional care³⁰ mostly in such large-scale facilities that provide limited opportunities for rehabilitation and are often associated with abuse, neglect and an absence of individualized attention. Such poor care can cause or exacerbate disability. However, being actively included in the social life of one's family and community is important for personal development. The opportunity to participate in family and social activities has a strong impact on a person's identity, self-esteem, quality of life, and ultimately his/her social status.

Those working in support of disability rights have long understood that it is as much the barriers imposed by society that define disability, as it is the physical impairment of the person. The main thrust of the disability movement has been towards establishing a society that includes children and adults with disabilities on equal terms with those without disabilities, whether in rich or low-income countries. The UN Convention on the Rights of the Child (CRC), the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Guidelines for the Alternative Care of Children together highlight the need to end the use of institutional care for children with disabilities, and instead support care in families and communities³¹.

This component highlights the importance of these issues in the lives of children with disabilities and therefore the need to ensure the full inclusion and involvement of children with disabilities in the social life of their families and communities and the need to support and assist them to enable them access social opportunities.

The learning objectives and outcomes are that by the end of this chapter, the participants who are caregivers of children with disabilities would be able to:

- Explain why it is important to include children with disabilities in family activities
- Explain the need for removing barriers and obstacles as well as challenging stigma and discrimination that may prevent children with disabilities from participating in family and community life to bring about positive social change
- Describe the recommendations for bringing up children with disabilities in a family setting

Duration: 120mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)

27 A better future is possible, Promoting Family Life for Children with Disabilities in Residential Care, Manual for Professionals, International Social Service (ISS) General Secretariat, 2016

28 Community Based Rehabilitation (CBR) Guidelines, Social Component, WHO, 210

29 Enabling reform; Why supporting children with disabilities must be at the heart of successful child care reform, EveryChild and Better Care Network, 2012

30 Enabling reform; Why supporting children with disabilities must be at the heart of successful child care reform, EveryChild and Better Care Network, 2012

31 Ibid

- Colourful small balls (about 4 of them)
- Facilitators Notes
- Child Protection Toolkit (the Circle of Support Exercise)

Session 10.1: Importance of Inclusion of Children with Disabilities in Family Activities

Facilitators' Action

1. Begin this session by mentioning that safe and loving environments are essential for learning and development of all children, including those with disabilities, who need to receive love and affection, stimulation and opportunities that enhance development. Continue by summarizing the introductory paragraphs of the beginning of this chapter above. Be sure to mention that being actively included in the social life of one's family and community is important for one's personal development because the opportunity to participate in family and social activities has a strong impact on a person's identity, self-esteem, quality of life, and ultimately his/her social status. This is why it is very important for children with disabilities to be brought up in a loving family setting and also be included in family activities.
2. List the learning objectives on a flip chart and ask volunteers to read them one by one (make it fun by using the small colourful balls). Ask the participants to explain in their own words how they understand those objectives, add to their explanations and be sure to address any misconception about the objectives. Also allow participants to ask questions for further clarifications before continue with the next steps/actions.
3. Continue by saying that a wide range of barriers may restrict the participation of children with disabilities in activities of the family. Because people with disabilities (including children with disabilities) face many barriers in society they often have fewer opportunities to participate in social activities. In the past, many rehabilitation programmes for children with disabilities have focused on health issues and rehabilitation activities, often ignoring their social needs. Even till date, access to cultural, sporting and recreation activities, and to justice, is seen as unnecessary.
4. Ask the participants what they think and (in their experience) these barriers may include. Use the examples provided in the text box below to contribute to the discussions and the points they would raise. As much as possible allow participants to ask questions about these points that you would include and let others also contribute by sharing their experiences.

Some examples of barriers that may restrict the participation of children with disabilities in activities of the family:

- children with disabilities may have poor self-esteem and think that they do not deserve or have the ability to take part in activities and events;
- family members may feel that having a member with a disability brings shame, and so they do not encourage or allow this person's social participation;
- there may be the irrational thoughts, myths and beliefs about disabilities, that make families excludes children e.g. of such myths are that children with disabilities are cursed and need cleansing, that children with disabilities are gods and have supernatural evil powers etc.
- sometimes family members genuinely feel it's a bother to involve children with disabilities in activities because they consider them to be "too sick" to be involved or need more "protection" and hence prevent the children from playing
- physical barriers to social participation include inaccessible transport and buildings, e.g. community centres, sporting venues and cinemas.
- Denial of justice because sometimes parents and caregivers feel it is not necessary

5. Conclude this session by mentioning that children with disabilities are to be valued as members of their families and allowed to play a variety of social roles and responsibilities in accordance with their level of ability;
 - they are to be encouraged and supported to contribute their skills to the development of their communities and society as a whole;
 - families are to recognize that children with disabilities are valued members, and can make positive contributions to the family;
 - barriers that exclude children with disabilities and their families from participating in social roles and activities are to be challenged and addressed; There is also the need to challenge and overcome stigma and discrimination that may prevent children with disabilities from participating in family and community life to bring about positive social change etc. (use the notes on Overcoming Stigma and Discrimination below to expand the discussions on this).

The UNICEF easy-to-read explanation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), “It’s About Ability”, says: “Have you ever felt left out? Children and adults who find it difficult to see, learn, walk or hear often feel excluded. There are many barriers that can prevent them from participating in the same way as others, and most of these barriers are imposed by society. A child in a wheelchair, for example, wants to go to school, too. But he or she may not be able to do so because the school has no ramp and the principal or teachers are not supportive. For everyone to be included, we need to change existing rules, attitudes and even buildings.”

“Society is composed of individuals and groups with diverse ways of functioning. Disability is part of everyone’s life cycle and it can appear in different moments of life”. Each family and individual communities within may have a different context and history that may also affect how people think about disability. Sometimes the child and their family can experience stigma and discrimination.

- Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different.
- Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma. This lack of understanding can have serious consequences for people with a disability and their families.

Attitudes and beliefs can be shaped by context, culture and religion. For example, in some countries and communities sometimes people can think that the family of a child with a disability is being punished for some earlier ‘bad behaviour,’ or that having a disability is a person’s bad curse. Sometimes the caregivers feel that the good luck they earn from caring for a child with disability has great value for their own future.

In other countries there can be a belief that people with a disability live permanently in a state of childhood, and so they are not given the opportunities to learn and grow up like their peers and be considered as adults. They are not thought of as people who can live independent lives. Such attitudes and beliefs can interfere with the rights of children with disabilities. What one needs to think about is whether the beliefs in one’s country and community support the rights of children with disabilities or not. Talk about this with your friends and family and with the people you work with. They may have a personal experience which you can discuss.

The words we use are also important. They can reinforce stereotypes, stigma and discrimination. For example, some people with a disability do not like it when someone says they are ‘vulnerable’ and need ‘care.’ They prefer to think of themselves, and to be thought of by others, as capable, and want the focus to be on the barriers to their inclusion that have been created by society (than on their disabilities or incapability). Sometimes the words used to describe people with a disability can also be used as terms of abuse. In some countries for example the laws use words such as “with limited health opportunities” to describe disability in order to avoid persons with disabilities to feel stigmatized.

Spend some time thinking about and discussing this with the participants

- What words do people in your community use to describe disability?
- Are these words positive or negative?
- As caregivers of children with disabilities what words would you prefer are used to describe your children? (use encouraging words to describe your children)
- How do you think these stereotypes about disabilities can be changed in the society?

Session 10.2: Promoting Family-Based Care for Children with Disabilities

Facilitators' Action

- Introduce this session by stating that millions of children with disabilities remain in harmful institutional care³² mostly in such large-scale facilities that provide limited opportunities for rehabilitation and are often associated with abuse, neglect and an absence of individualized attention and such poor care can cause or exacerbate disability.
- Ask the participants to discuss in their groups what they think normally results to children with disabilities being sent to institutions or residential facilities?
- Allow them about 10minutes for this group exercise and allow each group to present in plenary section. You can support the discussion with the list of some of the reasons below:
 - the child being abandoned by the parents for no apparent reasons
 - parents being divorced and both wanting to move on and so not willing to keep the child,
 - parents and families of the child thinking such children are a curse or carry evil spirits,
 - parents or families of the child thinking taking care of the child would be too difficult and prevent them from living their normal lives;
 - parents thinking the child would get a better care when in such an institution
 - parents not very aware of the advantages of inclusion education and wanting their disabled children have a specialized form of education
 - one or both parents not being in the position to take care of the child (e.g. one or both parents being mentally challenged, not employed and so not having what it takes to be able to take care of the child etc.)
 - fear of stigmatization and discrimination
 - parents feeling, they do not have the capacity to care for the child due to the nature and type of disability, especially children with severe multiple disabilities that may require specialized care
- Allow the participants to ask questions as well as contribute to the discussions asking them to share their experiences or other examples they may have witnessed.

³² Enabling reform: Why supporting children with disabilities must be at the heart of successful child care reform, EveryChild and Better Care Network, 2012

- e. After a lot of discussions about why children with disabilities are sent to institutions mention that because such large-scale facilities provide limited opportunities for rehabilitation and are often associated with abuse, neglect and an absence of individualized attention the UN Convention on the Rights of the Child (CRC), the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Guidelines for the Alternative Care of Children together highlight the need to end the use of institutional care for children with disabilities, and instead support their care in the family settings³³. Thus even if the child has been sent to an institution or a residential facility every effort should be made to reintegrate the child into his/family or be provided with an alternative care that provides family settings (foster care or adoption).
- f. Again, ask the participants to go back to their groups and brainstorm on why it is important not to leave a child with disabilities in an institution or residential care. Allow them 10mins to discuss and use the colourful small balls to ask each of the groups to mention one of the reasons they came up with as a group. Write them on a flip chart
- g. Give copies of the Handout on Promoting the Upbringing of Children with Disabilities in Family Setting to the groups and ask them to read, study and discuss as follows:
 - **Group 1** - General Principles that are recommended for the reintegration of children with disabilities into their families.
 - **Group 2** - Practical Elements - supporting the family to enable them care for their child
 - **Group 3:** General Principles for Foster family placement
 - **Group 4:** Selection of Foster families
 - **Group 5:** Preparing and training the foster family and following the child
 - **Group 6:** The process of identifying an adoptive family for children with disabilities
- h. After 20mins of group discussion ask the groups to present what they learnt in plenary (as per the topics assigned to them). After the presentation from every group allow members from the other groups to ask questions as well as contribute to the group's presentation using examples from personal experiences (especially from the foster parents among the participants).
- i. After the presentations by the groups support the discussions by adding the bit on Reintegration into the extended family using the key points in the text box below. When a child cannot be reintegrated into his/her family of origin and therefore brought up by his/her own parents, members of the extended family may be willing and able to care for the child.
- j. Also state very emphatically that if mediation is unsuccessful and the child is clearly abandoned by his/her family the competent services should duly inform the family that the child can be fostered or adopted by a substitute family and advise them, when required, about the consequences of simple and full adoption on their parental rights.
- k. Add that as part of the process promotion and recruitment of foster families an awareness of the specific needs of children with disabilities should be conducted together with a discussion on the possibility of caring for one of these children in order to promote fostering

³³ ibid

and recruit foster families. This is very important in order to prepare the minds of the prospective foster parents on what caring for children with disabilities entails.

- l. Before concluding this session carry out the Circle of Support Exercise from the Child Protection Toolkit using the instructions listed the Handout for the exercise below.
- m. Ask participants –
 - What lessons did you learn from this activity?
 - How can we become a more caring community to support children facing problems?
 - How can we support ourselves in the work we do?
 - How do communities work collectively to solve children’s problems?
 - What lessons from this exercise can be learned to enhance the quality of care we provide to the children with disabilities in our care as well as the support we can give to other caregivers of children with disabilities in our communities.
- n. Allow as many contributions as possible and as much as possible encourage the participants to use their experiences as examples while giving contributions.
- o. Note that one practical option that can also be explored and discussed during this session is the possibility of some of the community members volunteering to care for a child with disability for specified period e.g. a day, over the week-end or some hours to give the parents/caregivers some respite or time off to attend to other things. This is one kind of support that can be promoted among the participants. Inform participants that this type of care is sometimes called Respite Care. Respite Care is a form of short-term substitute care provided by someone other than the parents or usual carers for a child. Use the information on Respite Care in the textbox below to give further information to participants on what respite care is, why it is necessary and the different forms in which one can access respite care.
- p. Ask the participants if there is anything like that in the community or whether any of them has had access to such a service. Let them describe and allow for questions from other participants for clarifications.
- q. Also do your best to address myths and misconceptions that may arise in the course of the discussions and conclude the session by stating that children with disabilities like every child, need the care and love from family members in order to thrive and develop properly and the best quality of care can be given within a family setting not in institutions.

Respite Care

As a parent or caregiver raising a child with a disability, you might find that “me time” is more of a fantasy or a wish than a reality. You may love to have some time to yourself, or one-on-one time with a spouse, partner, friend, another child or other children. But the difficult question is how you can find that perfect person to care for your child, whether you can trust someone else to provide just what your child needs.

However, finding respite care - a well-deserved break from caregiving with a caring person that you can trust might be easier than you think. When your child has special needs, handing

over responsibility can be a real challenge. You might feel as if you are the only person who can do the job, and doubt that anyone else could meet all of your child's needs. But remember, caregivers are not superhumans and there's only so much a caregiver can give before he/she will feel mentally, emotionally, and physically drained. That's why it's a necessity, not a luxury, to take breaks from time to time by having a respite care for the CWD you are caring for. When you take time off to recharge and be renewed, you'll be able to provide more quality care and enjoy doing it, and your child will also benefit. Remember that as children grow, they need to learn that they can count on others for help (though not just anybody/strangers or other people, who could even be a family member, who may harm them). They can form new friendships, experience new environments or people, and have fun.

The many types of respite care include: a caregiver who comes to your home for a few hours daily, weekly, or as needed, drop-off day programmes (at a school, health care facility, or faith-based or volunteer agency) that provide activities daily or weekly. Or respite programmes offered by community-based agencies, host family, residential facility, etc. Another option that families may enjoy is respite care offered through parent "groups/co-ops." This is when families of children with special needs take turns watching each other's children. For example, you can take someone else's child for one day or evening a month, and that person can do the same for you. Support groups for families with your child's condition are a good place to meet other families.

Reintegration into the extended family

When a child is at a residential home and cannot be reintegrated into his/her family of origin and be brought up by his/her own parents, members of the extended family may be willing and able to care for the child.

Care by the extended family enables the child to grow up in an environment s/he knows, to maintain close ties with his/her family and to more easily overcome the trauma of separation.

Professionals should therefore examine this option very carefully particularly when the child has been removed from parental care due to abuse. In this context it may not always in the best interest of the child to be cared for by the extended family.

If reintegration into the extended family is possible and decided, the family should benefit from the same social protection services as those cited in the Practical Elements for supporting the family and enabling them to care for their child.

Handout on Guidelines and Recommendations for Promoting the Upbringing of Children with Disabilities in Family Settings³⁴

These guidelines and recommendations were adapted from Part C - p.83-96 of the International Social Service (ISS) General Secretariat's 2016 Manual for Professionals, "A better future is possible, Promoting Family Life for Children with Disabilities in Residential Care".

³⁴ A better future is possible, Promoting Family Life for Children with Disabilities in Residential Care, Manual for Professionals, International Social Service (ISS) General Secretariat, 2016

i. The reintegration of children with disabilities into their families of origin

The reintegration of children with disabilities into their families often costs much less than residential care. It should however be noted that residential care by NGOs doesn't cost the family and is therefore rather a financial, social, and emotional relief. On the other hand, residential care in private institutions is too expensive for low-income earners. More so, in Ghana, only day-care is available in a private setting, at most boarders but then, the family needs to take their ward back home during vacations. Note that even though this session of the manual is focused on the search for alternative solutions for children with disabilities who are already in residential care, and no part is specifically dedicated to the prevention of family separation, the recommendations below, concerning the reintegration of the child into his/her family, can be applied equally for the prevention of separation of the child from the family.

o General Principles

- This section is based in particular on the preamble and article 20 of the CRC, article 23 of the CRPD and paragraphs 14, 15, 32-52, 76-79 of the Guidelines.
- Poverty and the difficult living conditions of the family of origin should never be the sole reason for placing a child in residential care, (as specified in paragraph 15 of the UN Guidelines). When this is the case, the competent authorities should put in place a support mechanism to help families provide for their child again.
- The disability of the child and its perception within society should not be at the origin of abandonment. Widespread campaigns should be carried out in order to raise awareness of the population on the issue of disabilities so families would not abandon any child with disabilities.
- Whenever possible, and when it is in the best interest of the child, the prospect of reintegration of the child with his/her parents or extended family should be considered and assessed as a priority.
- A social assessment of the family (e.g. interviews, home visits, etc.) should be conducted in order to determine if the child will be secure in his/her family environment and if the family can provide appropriate and quality care. Therefore, a social assistance service (social protection services) should be put in place, which includes a sufficient number of trained personnel to cover the task of the assessment, contact and social work with the family of the child placed in care.
- Once a decision is made the return of the child should be carefully planned and the child and family should be prepared for this.
- If necessary, a system of family support should be implemented to allow the family to assume the therapeutic, medical and educational care of their child. Indeed, it is important that the child benefits from the same opportunities for the treatment or rehabilitation of his/her illness/disability within the family as within a residential care institution
- Services dedicated to children with disabilities (e.g. specialized schools, professions related to disability, etc.) should be decentralized as much as possible (to make it easily accessible) in order for every child to be able benefit from appropriate care

- If the child is old enough s/he should be involved in decisions taken and have the opportunity to be heard.
- If the family is identified and/or found again the social worker can:
 - » Make contact with the family and study with them, through interviews with the parents, the possibility of the return of the child. If possible, the interviews should take place together and then separately;
 - » Encourage contacts whenever possible, between the family and the child (e.g. visits from the family, telephone calls, letters and /or photos etc.) if this is in the child's best interests;
 - » Carry out mediation with the family, when appropriate, especially in situations where children born out of wedlock are a major cause of abandonment and where disability is highly stigmatized and also considered as a cause of abandonment. In such situations, mediation between the family of origin and the mother (or future mother) could be very useful to allow her to be accepted in the social fabric and supported by members of her family. This work with families can greatly increase the chances of a family reunification if the child is already placed and it is an effective method of prevention of child abandonment for young girls at risk;
 - » Make the parents and family aware of the importance for the child to grow up with his/her parents and of the negative impact of residential care on the child's development;
 - » Assess the needs of the family for the care of the child, in terms of equipment adapted to the child's disability and of resources for example, and anticipate the support needed to help the family;
 - » Prepare the child and his/her family for reintegration. For example, this process could be conducted through progressive visits by the child to the family till the child is finally reintegrated.

Practical Elements for supporting the family and to enable them care for their child, - specific help can be put into place which include:

- Specific work on the subject of disabilities can be conducted within the community in order to promote the acceptance and inclusion of children with disabilities, for example through discussion groups, awareness campaigns and movies.
- The family can be integrated into programmes of income generating activities and micro-credit by national or international NGOs specialized in this field, in order to develop autonomy and financial stability and so be able to keep or regain their child placed in an RCI.
- A free crèche and day care system for children of pre-school age can be offered by the government to enable the mother to work, especially when she lives alone and has to support her family.
- Respite Care should be established to help families who may be overwhelmed with looking after a child living with disabilities or a specific medical condition and help them to cope with the care of their child. This temporary support can be given in the form of occasional day care or short stays in an establishment. In addition to facilitating the reintegration of the

child into his/her family, this system can also help avoid the need beforehand of alternative care.

- Children with disabilities should be able to benefit from free sessions of care tailored to their disability or from rehabilitation equipment when their family cannot finance these services.
- Professional support and/or a psycho-social follow-up of the family should be proposed once the child is reintegrating in order to anticipate any new risks with the placement and to help and encourage the family to cope with the difficulties and stress linked to the care of a child with disabilities.
- The creation of support groups for parents of children with disabilities allows parents to feel less isolated and to share their experiences.

ii. **Foster family placement - General Principles**

- This section is based in particular on the preamble and article 20 of the CRC, article 23 of the CRPD and paragraphs 118 to 122 of the Guidelines.
- The placement within a foster family, whom the child has no family link with, is generally considered as temporary. For children who are temporarily separated from their family this option is preferable to residential care because they benefit from a personalized care and a protective and beneficial living environment for their development whilst waiting until they can be reintegrated into their family of origin. For children who cannot be reintegrated into their families of origin, foster care should lead to permanence through adoption or a long-term solution as permanent fostering.
- In certain specific situations placement in a foster family may be the most appropriate solution for the child, in particular when the family of origin maintain regular and positive contact with the child without being able to reintegrate him/her or when an adoptive family cannot be found for the child. Permanent fostering must be a commitment to care for the child to adulthood; in many cases this becomes a lifelong relationship. Sometimes a temporary placement becomes permanent – through a formal process (not by default). In these circumstances, the foster carers would be re-assessed for permanence, and the child's situation within the family would also be assessed to ensure that staying permanently with this family is in his/her best interests.
- Foster care should never be sought as a means to circumvent an adoption process, the latter being permanent in nature and clearly distinct. Nevertheless, it may be that a family wishes to adopt a child they are caring for. In this case, given the differences between the two projects, the conversion process should include an appropriate assessment of the motivations and abilities of the family and preparation and support for both the foster family and the child with a view to adoption. This should also be discussed with the child if s/he is old enough and the relationship with his/her family of origin should be reassessed.
- As with all care options, child placement in a foster family should be considered in the best interest of the child. Such a placement does not constitute a response to the needs of all children who are temporarily or permanently separated from their parents.

o Selection of Foster families

- As for all other children, families willing to care for a child with disabilities should be selected and assessed according to a precise procedure, in an objective manner, on the basis of clear, established criteria which takes into account the specificities of this type of care.
- Guarantees and basic checks on the prospective foster families (e.g. no criminal record, good reputation in the community, care conditions in accordance with national standards, commitment, income, etc.) should be scrupulously respected.
- While it is true that all families cannot be foster families and that all the selected families cannot care for all children, it is also true that people who have never cared for a child with disabilities could nevertheless be a very good foster family. It is important to be able to detect an engagement on the part of the candidates for this plan. The motivations behind their plan should be assessed and their ability for caring should be studied (e.g. suitable environment, access to specialized care for the management of the disability or specific medical condition, efforts towards integration in the outside community). The resources and limitations of the foster family must be part of the criteria evaluated in order to better identify the profile of the child they could care for.
- The matching process of a child and a prospective foster family should be adapted to the needs of the child.

o Preparing and training the foster family –

There are 3 levels/Phases of training the foster family and the information below should be considered for the preparation of the foster family for children with disabilities:

PHASE 1 - At an initial stage for all future foster carers (practical Elements)

Example of topics that can be addressed during generic preparation and information about the issues of looking after someone else's child:

- The impact on the new family's life-style;
- the impact on and involvement of the foster family's own children (current and future impact); the need for strong family and community supports;
- the financial implications
- the fight for services, benefits, appropriate education;
- post-placement agency support.

PHASE 2 - Adapted preparation for selected families who will foster children with disabilities:

Once foster families for children with disabilities are selected an adapted training on disabilities should be provided in order to address the main issues related to the care of a child with disabilities. Professionals specializing in the field of disabilities could be invited to participate during the meetings (for example and according to the existing specialties in the country: physiotherapists, paediatricians, psychomotor therapists, psychologists, etc.). It can also be useful to invite families who have already cared for a child with disabilities to participate in order to talk about their experiences.

PHASE 3 - Specific and individualized preparation once the child is matched with a foster family: Once a child is assigned to a foster family, a specific and individualized preparation should be implemented. Families caring for a child with disabilities should be put in contact with one or more health professionals related to the medical condition or disability of the child. A progressive connection between the family and the child is advised and both parties should be listened to if they have specific questions.

Following the child

- The foster family should be considered as a partner in the child protection system and should be included as far as possible in the decision-making process about the child, as mentioned in paragraph 121 of the UN Guidelines.
- Once the child is in foster care, a regular and continuous follow-up and support should be implemented by social workers that know the foster family and the child to ensure the child is cared for in an adequate way. Nevertheless, social work visits can be seen by the child as a reminder of non-permanence. It has to be handled with great sensitivity.
- In case of contacts with the child's family of origin it is important that supervision is ensured.
- It may be useful to bring together host families regularly to enable them to share their personal experiences, both the difficulties and the happy times, in compliance with paragraph 122 of the UN Guidelines.
- Organizing continued training or reflection workshops for families could be a beneficial option.

iii. The process of identifying an adoptive family for children with disabilities

General Principles

- If adoption is the life plan envisaged for the child, this should be carried out as a matter of priority at national level. Intercountry adoption should only occur as a subsidiary option, if no family can be found within the country. This principle is valid for all children, including children with disabilities.
- Initiatives should be taken to promote and value domestic adoption for children with disabilities and raise awareness of this issue at State level and within the RCI. These initiatives should be tailored to the cultural background of the country, as well as respect acknowledged principles, protected by international conventions. It is for example essential that in every circumstance, the matching between the child and his/her adoptive family is made by a professional.
- Example of initiatives that can be taken to promote national adoption for CWD:
 - » Organization of information campaigns in the various media (e.g. newspapers, television, radio, Internet and social networks, etc.) to raise awareness and inform the population that children, including children with disabilities, are waiting for a family;
 - » Organization of poster campaigns, conferences, televised debates, painting and/or photographic exhibitions and diffusion of documentary films for example, in order to

fight against the prejudices and taboos about disability (of the child) and to value these children in the eyes of the general public. These events should be part of a national action plan carried out annually and with the participation of the authorities involved in the care of children with disabilities, so that all questions relative to health, education and social protection can be addressed;

- » Organization of general information sessions on adoption and raising the awareness of prospective adoptive parents to the needs of children with disabilities and to the possibilities of adopting these children. In particular families who have already adopted a child with disabilities could be invited to these sessions to share their experience and generate interest from the prospective adoptive parents. However, when a prospective adoptive family orientate their adoption plan towards a child with disabilities or with a specific medical condition, this should be discussed with professionals. The limits of the Prospective Adoptive Parents (PAPs) relating to the child's profile they wish to adopt should be assessed and precise information given to them in order to avoid any failure of the adoption;
- » Setting up a national information point (and if possible, in each regional child protection service) to inform the PAPs about the specifications of adoption procedures in general and to raise their awareness about the needs of children with disabilities in need of a family, the implications, realities and the support put in place for the families;
- » Creation of programmes specifically dedicated to the search, at national and/or regional level, for adoptive families for children with disabilities;
- » Creation of an exchange platform, a place of dialogue for adoptive parents in order to work on parenting;
- » Encouragement and support in the establishment of associations of parents (including adoptive parents) of children with disabilities, who could be the spokespeople for children and share the experiences of parents and adoptive parents;
- » Inclusion of the Ghana Federation of Disability Organizations (GFD) in the sensitization activities as well as engaging their members (who have disabilities) as change agents or role models to advocate and promote the national initiatives for CWD.
- » Implementation of state financial aid for the healthcare costs of the adopted child with disabilities, according to the medical and/or paramedical benefits available in the country (e.g. physical rehabilitation, physiotherapy, psychotherapy, psychomotricity, occupational therapy, etc.). Such aid could then be extended to other areas such as education for example.

Hand out on the circle of support exercise

The Purpose of this exercise is to show how Circles of Support can help protect children in the community.

How to facilitate discussions with this tool: This activity helps the community to realize how they can become a more caring community to support children facing problems by working together to solve children's problems.

1. Begin the exercise by asking the participants which types of people provide support to the child's life as he/she develops. Then ask eight (8) or ten (10) participants to stand in a circle around a child to represent the different people in the child's life who support children as mentioned by the participants. For example, 'the school teacher, a family relative, the religious leader (imam or pastor, a neighbour or co-tenant, the nurse, the chief, assemblyman etc.' Note that one or two children can also become part of the Circle of Support for each other (as peers providing encouragement or playmates).
2. Inform the participants in the circle that they are the Circle of Support around the child. The child has a problem – her mother, her last surviving parent has died, and this problem is leading her to try to break through the Circles of Support, and get lost on a wrong path. The participants in the circle are to allow the child some room to run about inside the circle but should prevent him/her from breaking out by holding hands to keep the child safely supported.
3. After a few minutes of holding hands to prevent the child from breaking free from the circle, ask the participants what challenges can a child face that may make the people in the circles of support want to stop supporting the child.
4. Stop the game after a few minutes. Explain that things have changed now that the girl has become pregnant. The religious leader is refusing to support the child, so ask the religious leader to move out of the circle. The teacher does not want a pregnant child in her class in case the other children get ideas, so he/she is also refusing to help. Ask the teacher to leave the circle. One of the girl's relatives thinks the girl is irresponsible and must have encouraged the man to sleep with her, so he also refuses to help and leaves the circle. Leave the gaps open. Tell participants that they cannot make the circle any smaller. They may not hold hands or touch each other, but they must still try to prevent the child from breaking out.
5. Now ask the participants left to continue the game. The girl tries to break out of the circle, with participants attempting to block her. Because of the gaps in the circle, the girl will usually succeed in breaking out of the Circles of Support.
6. After a few minutes, stop the game and explain that when a support system is weak, absent or harmful, the child may do destructive things with his/her life.

11.0. SELF-CARE FOR THE CAREGIVERS OF CHILDREN WITH DISABILITIES

Four fifths of the estimated 150 million children with disabilities in the world live in resource poor settings where the role of the family is crucial in ensuring that these children survive and thrive³⁵. Research in low to medium income countries (LMICs) highlight that caregivers of children with disabilities frequently experience a range of difficulties: high levels of stress, anxiety, depression, and physical exhaustion, stigma, and discrimination often shaped by traditional beliefs and poverty³⁶. These can result in poorer caregiver quality of life, compared to caregivers of non disabled children as well as having a negative impact on parenting.

Benefits of training the caregivers of children with disabilities include improved understanding of the children's situation, that helps to build their self-confidence and self-esteem, and a reduction in self-blame resulting in their wellbeing and hence improved care for the child. This chapter therefore focuses on giving the caregivers of children with disabilities key tips on how to take time to relax and to get refreshed so they don't get burned out in order to be able to give off their best in providing quality care for the children.

The learning objective and expected outcomes are that by the end of this chapter, the participants would be able to:

- List and explain some of the challenges of caring for children with disabilities and the effects these challenges have on their health and wellbeing
- Understand the importance of taking care of themselves as caregivers of children with disabilities in order to be able to provide quality care to the children under their care
- Carry out some self-care exercises including self-assessment and relaxation exercises

Duration: 120mins

Training Materials

- Projector and laptop computer
- Flip chart paper and stands (you may need more stands especially during group exercises)
- Pens and markers (different colours)
- Masking tapes, cello tape or blue tack
- VIIP Cards (in different shapes, sizes and colors)
- Colourful small balls (about 4 of them)
- Facilitators Notes
- Copies of the Handouts on Self-Assessment for every participant
- Copies of the Handout on Effective Time Management for every participant
- One copy of the Handout on the Relaxation Exercises (for the facilitator)

³⁵ Enabling reform; Why supporting children with disabilities must be at the heart of successful child care reform, EveryChild and Better Care Network, 2012

³⁶ Maria Zuurmond, Gifty Nyante, Marjolein Baltussen, Janet Seeley, Jedidia Abanga, Tom Shakespeare, Martine Collumbien, Sarah Bernays - A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers, Child: care, health and development, 12 Aug 2018

- You would also need a cool and motivational song and something to be used play the song – most probably a Laptop Computer – this would be needed during the relaxation exercise (it is very important)

Session 11.1: Challenges Associated with Raising a Child with a Disability³⁷

- Introduce this chapter by mentioning that research has shown that caregivers of children with disabilities frequently experience a range of difficulties and challenges and these can result in poorer caregiver quality of life, compared to caregivers of non disabled children as well as having a negative impact on parenting. This is why training caregivers to understand some of these challenges and how to manage them helps build their self-confidence and self-esteem, and a reduction in self-blame resulting in their wellbeing and hence improved care for the child.
- Continue by adding that this chapter therefore focuses on giving the participants who are also caregivers of children with disabilities key tips on how to take time to relax and to get refreshed so they don't get burned out in order to be able to give off their best in providing quality care for the children
- With the learning objectives written on a flipchart and using the colourful small balls, ask volunteers from among the participants to read (one participant reads one objective and passes the ball to the next volunteer who reads the next).
- Ask participants to explain the objectives that have been read by the volunteers in their own words based on how they understand them.
- Allow them to ask questions for clarification and inform them that there are going to be very interesting and exciting exercises that are they are going to carry out as part of the sessions that would help make them to understand the points that would be discussed better.
- In a group exercise ask the participants to brainstorm, list (on a flip chart) and discuss
 - some of the challenges they face as caregivers of children with disabilities
 - some of the challenges other members of their families are confronted with
 - how do they manage these challenges as caregivers and as families with children with disabilities?
- After about 20mins of group discussions allow the groups to present the outcomes of their group exercise at plenary.
- After the presentations by all the groups allow the participants to ask questions as well as share contributions using their experiences, examples from what they have seen others experience and case scenarios.
- Use the key points in the Facilitators' Notes on Challenges Caregivers of Children with Disabilities Face to add to the discussions. Remember to mention that apart from being faced with the shock of the diagnosis of the disability in their children itself, caregivers encounter a host of new challenges which include learning new medical terms, such as cerebral palsy etc.; stress of caregiving, negative impact on caregiver health, sharing the burden, worry about the future, and caregiver coping strategies.

³⁷ Effects of Caregiving on the Families of Children and Adults with Disabilities Henry G. Chambers, and Jill A. Chambers, Phys Med Rehabil Clin N Am 26 (2015) 1–19, <http://dx.doi.org/10.1016/j.pmr.2014.09.004> pmr.theclinics.com, Elsevier Inc.

- j. Continue by adding that there are also a host of physical and mental health problems in caregivers' lower back pain, incidence of migraine headaches, gastrointestinal ulcers, and greater overall distress, anxiety, anger, guilt, frustration, sorrow, social isolation, self-deprivation, and depression.
- k. Before concluding mention that the stages in coping with the challenges have been shown to be early reactions of shock, anxiety, and denial; intermediate reactions of depression, internalized anger, and externalized hostility and later reactions with knowledge and adjustment. Ask volunteers from among the participants (using the colourful balls) to share their experiences through the 3 stages by taking the stages one by one.
- l. Conclude by stating that it is because knowledge helps in adjustment and coping with the challenges confronted them as caregivers that is why this training is being carried out to equip them with the knowledge they need in order to provide quality care to the children.

Raising a typically developing child is difficult enough for most families. However, the parents of a child with a disability, in addition to being faced with the shock of the diagnosis of the disability itself, encounter a host of new challenges.

The families are learning new medical terms, such as cerebral palsy, muscular dystrophy, and a myriad of concepts that are probably foreign to them. The diagnosis of a disability for their child alone is usually one of the most unexpected and life-altering revelations in a family's life.

There are also a host of physical and mental health problems in caregivers of children and adults with chronic disabilities. The consequences of impaired caregiver health include recurrent hospitalizations and the decision to place their child outside of the home.

- Seventy percent of mothers of children with physical disabilities have lower back pain.
- There is a higher incidence of migraine headaches, gastrointestinal ulcers, and greater overall distress.
- Parents report more anxiety, anger, guilt, frustration, sorrow, social isolation, self-deprivation, and depression.

The quality of life of the families with the children with disability is often affected by conditions that are connected to the meeting of the needs of the disabled children which in turn restricts ability of these families to meet their needs.

Parents of these children quite often are limited in their employment and education opportunities that interdicts the necessary resources for these families to meet their needs.

They are also faced with limited opportunities to get involved in cultural life of the community, create social contacts, and ensure life condition adequate to the family needs.

Such a situation has developed not just because of the socio-economic situation in the country, but also due to the disinterested disposition of the society towards the phenomenon of special needs and the limited capacity of the state to provide the necessary support³⁹.

The sequential stages of a family's response to the diagnosis of a disability include:

- Early reactions of shock, anxiety, and denial;
- Intermediate reactions of depression, internalized anger, and externalized hostility;
- And Later reactions with knowledge and adjustment.

Within each of these processes, there are additional classes of variables:

- Those associated with the disability itself,
- variables associated with sociodemographic characteristics,
- and variables associated with physical and social environmental factors.

³⁸ Effects of Caregiving on the Families of Children and Adults with Disabilities Henry G. Chambers, and Jill A. Chambers, *Phys Med Rehabil Clin N Am* 26 (2015) 1–19, <http://dx.doi.org/10.1016/j.pmr.2014.09.004> pmr.theclinics.com, Elsevier Inc.

³⁹ Quality of life of families with children with disability in the area of physical wellbeing in Latvia, by J. Millere and S. Senkane, by EDP Sciences, 2014, Article available at <http://www.shs-conferences.org>

Facilitators' Action

- a. Begin this session by mentioning that because the health and well-being of every caregiver impacts on the quality of care they are able to give to children under their care, it is very important for caregivers of children with disabilities to take care of themselves so they would be healthy and provide high quality care to their children.
- b. In a buzz session (using the colourful balls thrown to volunteers) as the participants to mention some of the things that affect their health and well-being as caregivers of children with disabilities. Capture their responses on the flipchart and again ask them what they think they can do in order for them to be healthy and well. Also capture their responses on a flipchart.
- c. Continue the session by informing them that one key aspect of self-care is self-assessment which is defined as finding out the important roles your skills, interests, personality or motivational factors and values play in whatever you are involved in. It is also the process of gathering information about yourself in order to make an informed decision about whatever you are involved in. Add that the components of self-assessment are Values, Interests, Personality or motivation and Assessment of one's Skills.
- d. Back into their groups ask them to discuss and with examples come up with explanation for Values, Interests, Personality or motivation and Skills Assessment are made of and after 10mins allow the groups to present in plenary. Contribute to the discussions by using the key points listed in the Facilitators' Notes 11.2 on Self-Assessment.
- e. Continue by mentioning that the importance of self-assessment can be described best after they carry out the Self-Assessment Exercise.
- f. Give each of them the Handout for the Self-Assessment Exercise and ask them to answer the questions on the handout. After about 10mins ask about 6 volunteers (maybe one from each group) to share the responses they gave for the self-assessment questions and ask the entire group of participants in a buzz section how they felt when carrying out the self-assessment exercise and what they think the importance of self-assessment is using examples and personal experiences. Capture their responses on the flipchart.
- g. Continue the session by mentioning that another component of self-care as a caregiver is effective time management. Ask them these rhetorical questions: whether they often feel stressed out with too much of workload? Whether they feel like they have more tasks on hand than they have time to do as time passes by or they feel they could have effectively used your time to complete all the given tasks?
- h. Add that the trick is to organize your tasks and use your time effectively to get more things done each day. This can help you to reduce stress and do better in taking care of your child in addition to the other chores you may have (workload, household chores etc.). Time management is a skill that takes time to develop and is different for each person and so you just need to find what works best for you.
- i. Share copies of the Handout on Time Management with the various groups to study and discuss the time management strategies. Allow them about 10 minutes for the group discussion and in a "buzz" session ask the groups one after the other to explain the strategies

(Delegate Tasks, Prioritize Work, Avoid Procrastination, Schedule Tasks, Avoid Stress, Set up Deadlines, Start Early, Take Some Breaks, Learn to say No). Allow for questions and further contributions from the participants.

- j. Finally, before concluding the session inform the participants that one key component of self-care is relaxation. With a background of the cool music and the lights in the room switched off or dimmed read the instructions on the Handout for the Relaxation Exercise aloud to take the participants through the exercise (read them one by one by pausing in between them).
- k. After the exercise ask them how they feel and conclude by saying that apart from going for medical check-ups the exercises have shown that the other important components self-care don't have to cost money and hence they have to do them often to improve their wellbeing.

Facilitators' Notes 11.2: Self-Assessment

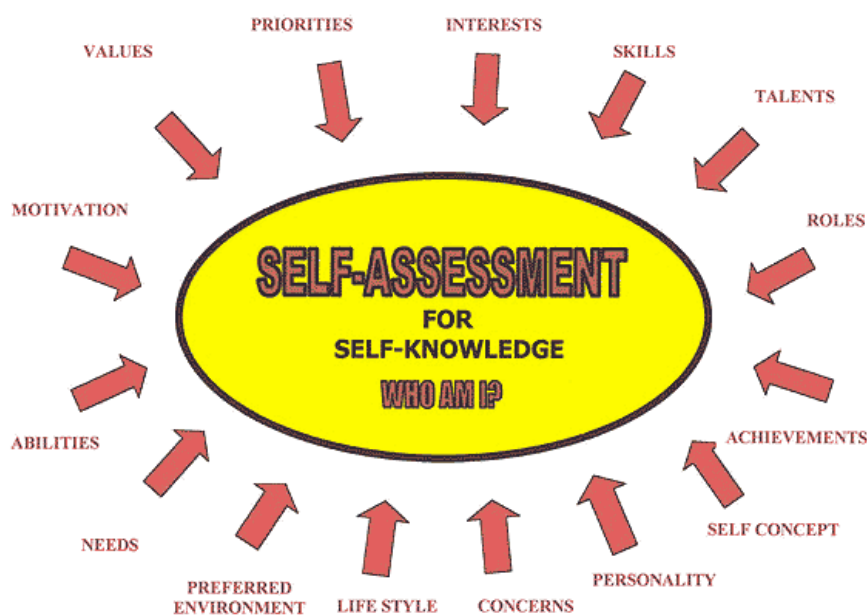
In social psychology, self-assessment is the process of looking at oneself in order to assess aspects that are important to one's identity. It is one of the motives that drives self-evaluation, along with self-verification and self-enhancement.

It is also finding out the important roles your skills, interests, personality or motivational factors and values play in whatever you are involved in.

It is also the process of gathering information about yourself in order to make an informed decision about whatever you are involved in

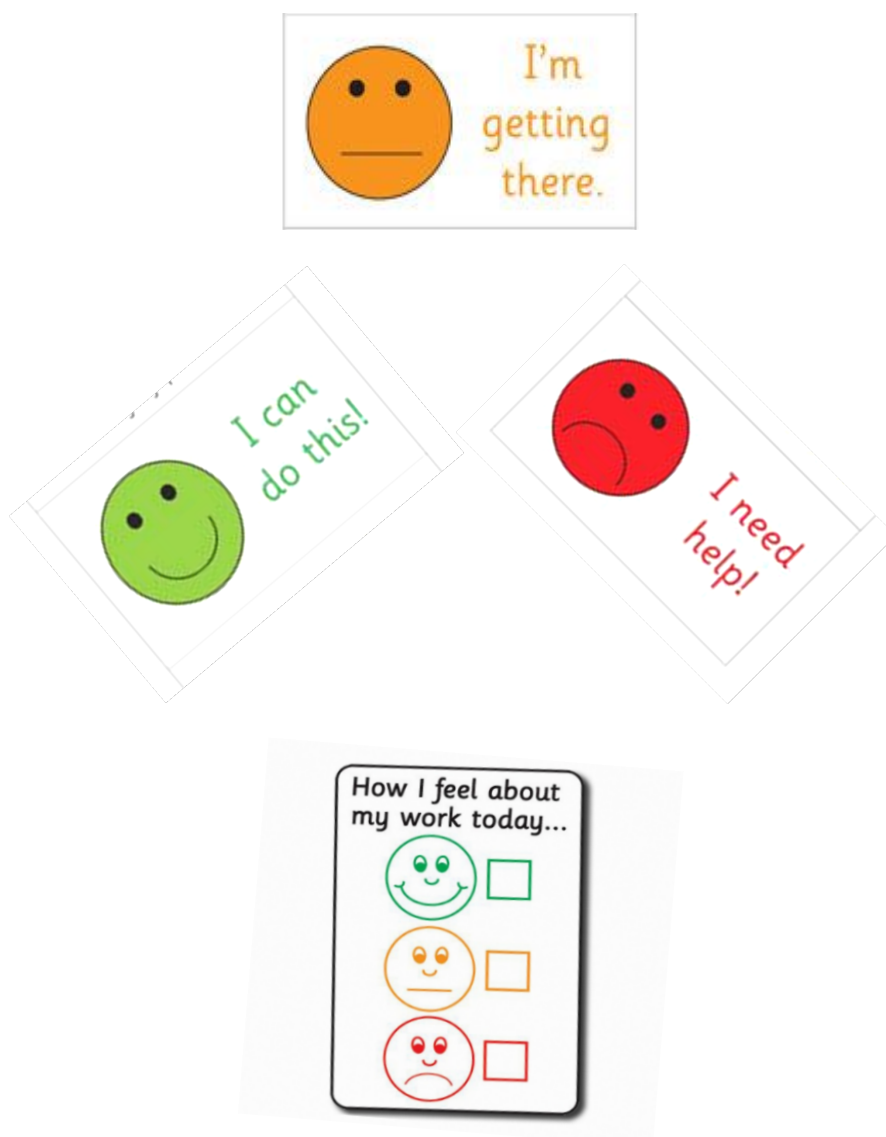
Aspects of self-assessment

- Values - the regard of something as important, beneficial or worthy. Value inventory is how important different values are to you. Examples of values, which play an important role in whatever one is involved in include status/prestige, achievements, security, interpersonal relations, helping others, flexible work schedule, outdoor work, freedom of action, high salary etc.
- Interests - your likes and dislikes regarding various activities. People who share similar interests mostly enjoy the same type of activities. Examples of interests include Reading, running, playing or watching football, listening to music, dancing, taking long walks, jogging etc.
- Personality or motivation - What motivates you as a person, is it the need for achievements, the need for affiliation – eager to interact, seek the company of others, the need for power – tend to be firm, try to be persuasive in dealings, act as representatives and spokesperson?
- Assessment of your skills - Helps you to determine what you are good at, helps you to figure out what you enjoy doing. Skills you use in whatever you do should combine these 2 characteristics (what you are good at and what you enjoy doing). Results from your skills assessment can be used to make some changes by acquiring the skills you need for carrying out the activities as a caregiver of a child with disability



Handout for the Self-Assessment Exercise

- What were you very proud of doing whilst taking care of your disabled child in the last 3 - 6 months
- What would you like to do differently?
- How would you do it
- Write a letter to your future self which you would want to read at the end of the year to see whether you were able to achieve the one goal you set for yourself (the facilitators could help participants who cannot read or write by asking them to describe what they would have loved to write and writing it for them or asking them to represent what they want to write with a drawing to express themselves)



Handout on Time Management

Strategies for Improving your time management skills

- **Delegate Tasks:** Delegation is not running away from your responsibilities but is an important function of management
 - **Prioritize Work:** Before the start of the day, make a list of tasks that need your immediate attention, prioritize your tasks to focus on those that are more important.
 - **Avoid Procrastination:** Procrastination badly affects productivity and can result in wasting essential time and energy.
 - **Schedule Tasks:** Carry a planner or notebook with you and list all the tasks that come to your mind. Make a simple 'To Do' list before the start of the day, prioritize the tasks, and make sure that they are attainable. (participants who cannot write can present the tasks with drawings)
 - **Avoid Stress:** Stress often occurs when we accept more work than our ability. The result is that our body starts feeling tired which can affect our productivity. Instead, delegate tasks to your juniors and make sure to leave some time for relaxation
-
- **Set up Deadlines:**
 - » When you have a task at hand, set a realistic deadline and stick to it.
 - » Try to set a deadline few days before the task so that you can complete all those tasks that may get in the way.
 - » Challenge yourself and meet the deadline.
 - » Reward yourself for meeting a difficult challenge.
-
- **Start Early:**
 - » Most of the successful people have one thing in common.
 - » They start their day early as it gives them time to sit, think, and plan their day.
 - » When you get up early, you are more calm, creative, and clear-headed.
 - » As the day progresses, your energy levels start going down which affects your productivity and you don't perform as well.
 - **Take Some Breaks:** Too much stress can take toll on your body and affect your productivity. Take a walk, listen to some music or do some quick stretches. The best idea is to take off from work and spend time with your friends and family.
 - **Learn to say No:** Politely refuse to accept additional tasks if you think that you're already overloaded with work. Take a look at your 'To Do' list before agreeing to take on extra work

Handout on the Relaxation Exercise

This exercise will help participants to relax their muscles and release immediate stress. Before conducting the exercise, make sure that the room is quiet and that there are no distractions.

The following exercise is an example of “Progressive Relaxation.” Progressive relaxation involves first tensing your muscles and then letting the tension go. You might wonder why we first tense the muscles. Imagine a pendulum. In order for you to get the pendulum to swing furthest to one side, you have to pull it far along the other. Similarly, to relax your muscles, it can help to tense them first. As well, you become more aware of what each muscle feels like, where it is located in your body, and what to look for in the future when you are trying to determine whether muscles are relaxed or tense.

1. Find a comfortable position in a chair with good back support. You may also do this lying down.
2. Loosen any restrictive clothing or jewellery that you are wearing.
3. Close your eyes. Begin to focus on the feelings inside your body - mentally scan your entire body, from head to toe, and note any signs of tension that there may be.
4. For each muscle group outlined below, first tense that area, hold the tension for 5 seconds, and all at once let go of the tension and say to yourself “relax.” Notice the feelings of tension when you are tensing, and notice the feelings of warmth and relaxation as you let the muscle relax. Be sure to relax by letting the tension go all at once, releasing the muscle tension quickly.

The first muscle groups to tense and relax are the hands and forearms. Starting with your right hand, make a fist and hold that fist for 5 seconds. Then, all at once, let go of your fist. Let your hand drop loosely into your lap or on to the support of your arm chair. Notice the feelings of relaxation. Repeat this one more time - tense the hand, hold for 5 seconds...and relax. Proceed in this manner for each of the muscle groups outlined below:

- o Right hand and forearm
- o Right bicep
- o Left hand and forearm
- o Left bicep
- o Forehead (tense by making a frown, scrunching up the muscles above your eyebrows)
- o Cheeks and nose (tense by pretending you are smelling something awful) -Mouth (tense by pulling the corners of your mouth outwards)
- o Neck and shoulders (tense by shrugging)
- o Chest and stomach (pretend you are about to be hit in the stomach)
- o Right thigh
- o Right foot and calf

- o Right toes (press your toes down to the bottom of your shoes. Be careful not to make them too tense or else they may cramp)
 - o Left thigh
 - o Left foot and calf
 - o Left toes
5. Once you've relaxed your entire body, alternating tension and relaxation in each of the 15 muscle groups, allow yourself to enjoy the feelings of relaxation. Allow your mind to wander throughout your body, scanning for any tense areas. If you find one, repeat the exercise of tension and relaxation for that area. You may find that you cannot attain a relaxed state by doing this exercise the first few times.

The more you practice, the better and more proficient you will become.

APPENDIX

What is a Disability? - A disability is defined as a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic disease. Disability is conceptualized as being a multidimensional experience for the person involved.

There may be effects on organs or body parts, and there may be effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognized in International Classification of Functioning, Disability and Health (ICF):

- Body structure and function (and impairment thereof)
- Activity (and activity restrictions)
- Participation (and participation restrictions)

The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes.

Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden, known as invisible disability. There are many types of disabilities, such as those that affect a person's: Vision, Hearing, Thinking, Learning, Movement, Mental health, Remembering, Communicating and Social relationships

Categories of Disabilities

Categories of disability types include various physical and mental impairments that can hamper or reduce a person's ability to carry out their day to day activities. Disability can be broken down into a number of broad sub-categories, which include the following:

1 - Mobility and Physical Impairments

This category of disability can be caused by various factors, from fractures of bones to neurological, often inherited diseases, which may either cause weakness or paralysis of muscles. Some children are also born with missing limbs or contorted limbs, body, or face. Poliomyelitis, an infectious disease, may cause one or both legs to remain shorter as the child grows.

Brain and spinal injuries may also cause impairment of mobility.

Spinal Cord Injuries may lead to lifelong disabilities. This kind of injury mostly occurs due to severe accidents. The injury can be either complete or incomplete. In an incomplete injury, the messages conveyed by the spinal cord are not completely lost, therefore the function to move the affected limbs may be reduced but not gone. Whereas a complete injury results in 1. the inability to move the affected limbs (paralysis), and 2. a total dis-functioning of sensory organs (e.g. inability to control urine and stool). In some cases, spinal cord disability can result from a birth defect (Spina bifida).

40 - <https://www.disabled-world.com/disability/types/> Revised and Updated: Saturday, 14th December 2019

Brain Damage may occur due to a brain injury (trauma due to external forces applied to the head), or it can be acquired (e.g. by means of an infection, stroke, or during a prolonged birth process which causes lack of oxygen in the brain of the baby, leading to cerebral palsy) or, in rare cases, it can be genetic. Brain damage can impact the ability to move limbs, feed, speak, memorize, as well as impact the intellect, behavior and appropriate emotional responses, among others.

2 – Sensory Impairment

Vision Disability - There are hundreds of thousands of people that have minor to severe vision impairments. Some of the common causes include injuries of the eye, diabetes-related eye conditions, river blindness, glaucoma, or blindness from birth. Children with undetected poor vision may suffer headaches. They may lose interest in school and fall behind academically.

Hearing Disability - Hearing disabilities include people that are completely or partially deaf. People who are partially deaf can often use hearing aids to assist their hearing. Deafness can be caused during pregnancy if the mother contracts a rubella infection. Later in life, infections such as mumps, measles, and meningitis can cause deafness.

Deaf people use sign language as a means of communication. Hundreds of sign languages are in use around the world. In linguistic terms, sign languages are as rich and complex as any oral language, despite the common misconception that they are not “real languages”.

Deafness can be detected shortly after birth by means of special testing (OAE). If not picked up early, that is, at the time children normally begin to speak, deaf children cannot develop speech.

3 - Cognitive and Learning Disabilities

Cognitive Disabilities come in various forms, usually limited to one or two specific learning disabilities (therefore also called “partial learning disability”), such as dyslexia or dyscalculia, despite normal intelligence. Children with dyslexia have a problem reading and spelling. They often write mirror images of letters, e.g. “q” instead of “p”, or swap letters within a word. They may read and not understand what they have read, despite normal desire to learn. Dyslexia often comes with attention deficit hyperactivity disorder (ADHD), developmental language disorders, and difficulties with numbers (dyscalculia).

Not being able to process what a child hears or sees is also part of cognitive disabilities. They may be able to name an object but cannot envision what a simple task relating to that object means.

4 – Intellectual Impairment

Each person is born with a level of intellectual aptitude which can be enhanced or decreased by environmental, health, and psychosocial factors. Some children are born with very little intellectual capacity, often for unknown reasons. In some cases, the cause may be ascribed to infections or alcohol abuse during pregnancy. The intellectual capacity may also be damaged by brain trauma, or in cases of prolonged labor during child birth with resulting lack of oxygen to the child’s brain.

Often, intellectual impairment goes hand in hand with delayed development but not all delayed development is due to intellectual impairment.

5 – Mental-Health Disorders

Mental Health Impairment is the term used to describe people who experience psychiatric problems or illness such as:

- Affective Disorders - disorders of mood or feeling states (e.g. depression, bipolar disorder)
- Personality Disorders - defined as deeply inadequate patterns of behavior with significantly negative impact on day-to-day activities and social interactions
- Schizophrenia - a mental disorder characterized by disturbances of thinking, mood, and behavior, which are completely outside of realistic expectations
- Anxiety disorders
- Eating disorders (e.g. anorexia, bulimia)

6 – Psychosocial Impairment – e.g. autism, attention deficit hyperactivity disorder (ADHD)

Children born with autistic disorder may not be able to communicate well with other persons. They may refuse to be touched, to keep eye contact, and to speak. They may prefer sitting away from others, and could engage in repetitive actions for a long time, like rocking back and forth. Children with ADHD on the other hand may appear wild and uncontrollable, not fearing or respecting boundaries, and like taking risks. They find it difficult to stay focused on necessary tasks like school work.

Psychosocial impairment or disorders can have a serious effect on the formation and sustainability of relationships, and ability to function within expected social norms.

7 – Chronic Diseases – e.g. asthma, diabetes mellitus, rheumatism, etc.

Chronic diseases do not constitute disability in itself but in some cases may have debilitating effect. A child with severe asthma for instance may not be able to participate in sporting activities. A diabetic may develop complications with vision or renal function among others, and a child with severe rheumatism may be crippled by pain and restricted mobility.

Symptoms of Common Developmental Disabilities in Children⁴¹

Developmental disabilities include a complex group of disorders that cause physical impairments, intellectual disabilities, speech disorders, and medical conditions. Developmental disabilities are sometimes diagnosed at birth, but more often, are not easily identified until ages three to six. Developmental disabilities may range from mild to severe. Some of the more common developmental disabilities include:

⁴¹ <https://www.verywellfamily.com/what-are-developmental-disabilities-2162827> by Ann Logsdon and Medically reviewed by Sarah Rahal, MD on November 07, 2019

- Tourette syndrome⁴²: Tourette syndrome is a condition characterized by repetitive, uncontrolled movements and vocalizations known as “tics.” This childhood-onset movement disorder is often associated with obsessive-compulsive disorder (OCD), attention-deficit disorder (ADHD), and other disorders. Tourette’s is usually noticed in children between the ages of 7 and 10, although tics may begin anywhere from 5 to 18 years of age. Tics are considered involuntary movements. There are a wide variety of tics, ranging in type and severity of expression: Rapid eye blinking, Shoulder shrugging or a jerk of the head or shoulders, Facial grimacing, Grunting or clearing throat, clicking, Shouting, making snort sounds, blurting obscenities.
- Cerebral palsy⁴³ - Cerebral palsy (CP) is a group of disorders that affect a person’s ability to move and maintain balance and posture. CP is the most common motor disability in childhood. Cerebral means having to do with the brain. Palsy means weakness or problems with using the muscles. CP is caused by abnormal brain development or damage to the developing brain that affects a person’s ability to control his or her muscles.

The symptoms of CP vary from person to person. A person with severe CP might need to use special equipment to be able to walk, or might not be able to walk at all and might need lifelong care. A person with mild CP, on the other hand, might walk a little awkwardly, but might not need any special help. CP does not get worse over time, though the exact symptoms can change over a person’s lifetime.

- Signs of Attention Deficit Hyperactivity Disorder (ADHD) in children can include a wide range of academic, social, and behaviour problems. Trouble staying on task, taking a long time to complete assignments, or having difficulty sitting still, may become bored easily, and may appear to have trouble listening during conversations are a few common symptoms children exhibit.
- Symptoms of dyslexia in children aged 5 to 12 include: problems learning the names and sounds of letters. spelling that’s unpredictable and inconsistent. putting letters and figures the wrong way around (such as writing “6” instead of “9”, or “b” instead of “d”)
- Fetal alcohol spectrum disorders (FASDs)⁴⁴ are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. They are physical and mental damage in a child due to alcohol exposure while in the womb. These effects can include physical problems and problems with behavior and learning. Distinctive facial features, learning disabilities, bone and joint deformities, heart defects and hyperactivity are some symptoms. This condition can be prevented by abstaining from alcohol during pregnancy. The syndrome is irreversible. Treatment, especially if early, can help reduce some symptoms. A person with an FASD might have: Low body weight, Poor coordination, Hyperactive behaviour, Difficulty with attention, Poor memory, Difficulty in school (especially with math), Learning disabilities, Speech and language delays, Intellectual disability or low IQ, Poor reasoning and judgment skills, Sleep and sucking problems as a baby, Vision or hearing problems, Problems with the heart, kidneys, or bones, Shorter-than-average height, Small head size as well as abnormal facial features, such as a smooth ridge between the nose and upper lip.

42 <https://www.verywellfamily.com/what-are-developmental-disabilities-2162827>

43 <https://www.cdc.gov/ncbddd/cp/facts.html>

44 Basics about Foetal alcohol spectrum disorders (FASDs), Center for Disease Control and Prevention (CDC) <https://www.cdc.gov/ncbddd/fasd/facts.html>

- Autism is a serious developmental disorder that impairs the ability to communicate and interact. The range and severity of symptoms can vary widely. Common symptoms include difficulty with communication, difficulty with social interactions, obsessive interests and repetitive behaviours. Early recognition, as well as behavioural, educational and family therapies may reduce symptoms and support development and learning.

Autism spectrum disorder (ASD)⁴⁵ is a developmental disability that can cause significant social, communication and behavioral challenges. There is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

Children or adults with ASD might: not point at objects to show interest (for example, not point at an airplane flying over), not look at objects when another person points at them, have trouble relating to others or not have an interest in other people at all, avoid eye contact and want to be alone, have trouble understanding other people's feelings or talking about their own feelings, prefer not to be held or cuddled, or might cuddle only when they want to, appear to be unaware when people talk to them, but respond to other sounds, be very interested in people, but not know how to talk, play, or relate to them, repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language, have trouble expressing their needs using typical words or motions, not play "pretend" games (for example, not pretend to "feed" a doll), repeat actions over and over again, have trouble adapting when a routine changes, have unusual reactions to the way things smell, taste, look, feel, or sound as well as lose skills they once had (for example, stop saying words they were using). In severe cases, child seems to anxiously avoid interaction with others, sits in a corner with back turned to others, rocks back and forth, screams when touched, may not respond when spoken to or called.

- Down syndrome⁴⁶ is a condition in which a person has an extra chromosome. Chromosomes are small "packages" of genes in the body. They determine how a baby's body forms during pregnancy and how the baby's body functions as it grows in the womb and after birth. Typically, a baby is born with 46 chromosomes. Babies with Down syndrome have an extra copy of one of these chromosomes, chromosome 21. A medical term for having an extra copy of a chromosome is 'trisomy.'

Down syndrome is also referred to as Trisomy 21. This extra copy changes how the baby's body and brain develop, which can cause both mental and physical challenges for the baby.

Even though people with Down syndrome might act and look similar, each person has different abilities. People with Down syndrome usually have an IQ (a measure of intelligence) in the mildly-to-moderately low range and are slower to speak than other children. Some common physical features of Down syndrome include: A flattened face, especially the bridge of the nose, Almond-shaped eyes that slant up, A short neck, Small ears, A tongue that tends to stick out of the mouth, Tiny white spots on the iris (colored part) of the eye,

45 <https://www.cdc.gov/ncbddd/autism/facts.html>

46 <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>

Small hands and feet, A single line across the palm of the hand (palmar crease), Small pinky fingers that sometimes curve toward the thumb, Poor muscle tone or loose joints, Shorter in height as children and adults

- Symptoms of Auditory Processing Disorder (APD) include difficulty localizing sound, difficulty understanding spoken language in competing messages, in noisy backgrounds, in reverberant environments, or when presented rapidly, taking longer to respond in oral communication situations as well as frequent requests for repetitions, saying “what” and “huh” frequently.
- Spina bifida - Spina bifida is a condition that affects the spine and is usually apparent at birth. It is a type of neural tube defect (NTD). Spina bifida can happen anywhere along the spine if the neural tube does not close all the way. When the neural tube doesn't close all the way, the backbone that protects the spinal cord doesn't form and close around it as it should. This often results in damage to the spinal cord and nerves.

Spina bifida might cause physical and intellectual disabilities that range from mild to severe. The severity depends on: The size and location of the opening in the spine and whether part of the spinal cord and nerves are affected.

Do Children “Grow Out Of” Developmental Disabilities?

Very often, doctors will refer to a child's developmental disabilities as “developmental delays.” This euphemistic term can be very misleading. After all, a train that's delayed does finally arrive at the station - and delayed gratification isn't the same thing as NO gratification!

The vast majority of developmental disabilities are genetic in origin. It is not possible to “grow out of” your genetics. Thus, children don't “grow out of” developmental disabilities. If you have heard stories of children with a particular developmental disability suddenly being “cured,” be very skeptical. Chances are, that child had a mild version of the disability and a great deal of therapy. As a result, that particular child may be able to show an improvement in function, at least for a period of time.

When Children with Developmental Disabilities Grow Up

Children with developmental disabilities become adults with developmental disabilities. Their level of functioning (and social, economic, and career success) will depend upon a number of factors:

- Type of disability. Some developmental disabilities (such as spina bifida) may make it possible for an adult to function well socially or at a job while requiring significant physical supports. Others, such as Down syndrome, may make it possible to function well socially - but require some level of support in a work setting.
- The severity of the disability. An adult with a mild disability may be able to work around and/or build skills to the point where they can function independently or with relatively little support.
- Amount and quality of therapy they received as children. A child who receives intensive, appropriate therapies as a youngster is more likely to build skills and self-confidence - thus boosting the likelihood that he will do well as an adult.

- Personality. Every person with a developmental disability is different. Some adults with such disabilities feel “disabled,” while others are determined to be as independent or successful as possible. These personal differences have a great deal to do with outcomes.
- Social network. An adult with a developmental disability may be quite isolated - or may be included in a warm and loving family and/or community. Not surprisingly, it is easier to be relatively independent in a community of people who know you and are willing and able to help you to succeed.

Where caregivers and families of children with disabilities can get support

1. Caregivers and families of children with disabilities can get support by calling the integrated complaints-handling service center of the Ministry of Gender, Children and Social Protection, (MoGCSP) “Helpline of Hope” where grievances, questions and complaints from clients are received via phone through toll-free lines. The Contacts to this MoGCSP Helpline of Hope Call Centre are: 0 800 800 800 OR 0 800 900 900
2. The caregivers and families can also contact the Social Welfare Service Directory at <http://directory.mogcsp.gov.gh/> for several listings of services in the various districts and regions in service areas such as Child and family support, counselling and psychosocial support, economic empowerment, education, legal and justice support, medical and healthcare as well as social protection
3. Special Education Division (SPED) of Ghana Education Service (GES), whose vision is to increase access to quality education and training of learners and young people with disabilities and special educational needs in an Inclusive School Environment leading to employable skills for economic and independent living. Their mission is to work towards the creation for equal educational opportunities for learners and young people with disabilities and special educational needs through the promotion of suitable and sustainable support structures in an inclusive school environment. Contact and Email for general enquiries are: (233) 302 673-957 and infor@ges.gov.gh, <https://ges.gov.gh/2019/07/31/special-education-division-sped/>
4. National Directory of Inclusive Education Service Providers, Compiled by Ghana Federation of Disability Organizations (GFD), Inclusion Ghana and Ghana Education Service, with support from UNICEF and USAID, November, 2019. The directory is aimed at complementing the efforts of the State to make primary and secondary education truly accessible to all children, including those with Special Educational Needs and Disability (SEND). It has been produced to assist parents, caregivers, local authorities, schools and work-based learning providers in ensuring that children with SEND receive appropriate, quality education on equal basis as other children without SEND. Caregivers and families of CWD may call, email or visit the website of providers to learn more about their services, and whether they are able to provide services to the child or children involved.
5. They can also contact the directory of support organizations in girls’ education in Ghana in case the child they are taking care of is a girl and needs support. This directory is managed by the Ghana Education Service.
6. They can also contact the Ghana Federation of Disability Organizations (GFD) previously known as the Ghana Federation of the Disabled (GFD) which represents over 3 million persons with disabilities in Ghana. It is a civil society organization which brings together the key organizations of persons with disabilities in Ghana. GFD champions engagements towards assuring the rights of persons with disabilities to access education, employment, health, economic welfare, recreation, the built environment, justice, information and governance. <https://www.gfdgh.org/>. Tel: +233302240530 and Email: info@gfdgh.org

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