Training Manual for Community Health Promoters on Disability Outreach & Inclusion

Kupenda

KUHENZA fr: children

> A Guide for Equipping Community Health Promoters, Community Health Workers, and Community Health Volunteers to Include and Support Their Patients with Disabilities

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Kuhenza for the Children and Kupenda for the Children would like to thank the following people for all the hours and effort they put into developing this workshop guide. We are grateful for your contributions and believe this guide will be instrumental in creating a more just and loving world for children with disabilities.

Organizations:

Kupenda for the Children is registered in the U.S. and Kuhenza for the Children is registered in Kenya. The organizations' mission is to transform harmful beliefs surrounding disability to those that improve children's lives. Both organizations report to their respective national governments, manage their own operational funds, and are overseen by their own boards of directors. Each year, Kuhenza and Kupenda collaboratively fundraise to support their joint projects. They have been co-designing and co-implementing disability programs since 2003.

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Note on Guide Terminology

Although this guide frequently refers to community health **promoters**, it is also intended for those who serve as community health **workers** and community health **volunteers**. It is also intended for any lay people who live in the communities they serve and who function as a critical link between those communities and the primary healthcare system.

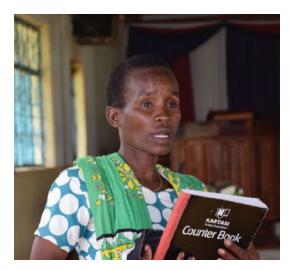
Note on Guide Adaptability

This document exists as a guide for facilitators but can and should be adapted based on the workshop participants' needs, culture, literacy level, and learning styles. The contents of this workshop can also be truncated or elongated, depending on available time and resources.



Introduction





The WHO estimates that 16% of the world's population, over **one billion people, are living with a disability**. Among marginalized groups, children with disabilities remain the most excluded and discriminated against, not only because of their disability, but also because of misunderstandings related to the causes and implications of disability. In numerous countries, the majority of people do not expect children with disabilities to be productive members of society and believe they have been cursed by witchcraft or God. Others see disability resulting from sin, incest, contraception, demons, infidelity, etc. These beliefs often lead families to hide, neglect, abandon, or abuse children with disabilities. Some of these children are even murdered at birth.

In many nations, community health promoters (CHPs) have a strong influence on community beliefs and practices.

Although some support and advocate for children with disabilities, many others share inaccurate information that encourages discrimination, neglect, and abuse of these children. Misinformation is always problematic but is particularly concerning among CHPs because of their breadth of influence, with most serving more than 200 families (comprising 1,400 individuals), who trust them as medical educators and advisors.

Kupenda and Kuhenza for the Children's *Disability Outreach & Inclusion Workshop for CHPs* was developed to **educate and empower CHPs to better support children with disabilities and their families**. By drawing on participants' beliefs and experiences related to disability, the workshop also guides them through the process of developing a compassionate, inclusive response to disability, tailored to their communities' unique context.

At Kupenda and Kuhenza, we have seen hundreds of CHPs complete this workshop with a commitment and concrete plans to improve medical care and referrals for people with disabilities in their communities. The impact of these commitments has been astounding-thousands of people with disabilities have gained access to high-quality medical care and, as a result, experienced improved health, mobility, communication skills, confidence, and independence.

The results from this workshop are lifesaving and long-standing. It changes the landscape for people with disabilities by empowering CHPs to provide effective support and lead a compassionate response to those living with disabilities in their communities.



Arrange All Personnel

• Identify a CHP or nearest health facility to coordinate and host the workshop. This person should have strong and trusted relationships with local CHPs.

Note: If you choose to make arrangements with a CHP, it is still important to invite the PHO (Public Health Officer) to participate in the workshop. The Ministry of Health (MOH) presence will be important for building trust with the CHP participants.

- Work with the CHP and/or MOH to identify 20-25 CHPs to participate in the workshop.
- Invite a rehabilitation professional to present the workshop medical content with you. Ensure this person has a copy of our *Disability Guidebook* and a strong knowledge of the definitions, causes, and interventions for common disabilities in the participants' communities. Remind them to use the simplified *Disability Guidebook* content during the workshop, so their disability explanations do not become too long or technical.
- Invite a person with a disability or a parent of a child with a disability to speak at the workshop. Ideally, this would be someone from the participants' community. Brief this person on what to cover in their speech (see the speech content list on page 49).
- Invite a CHP whose disability-related beliefs and practices have improved as a result of this workshop to share his/her testimony. Ideally, this would be someone from the participants' community. Brief this person on what to cover in their speech (see the speech content list on page 54).
- Gather volunteers or staff who can help with setup, break times, and administering the Media Consent (Appendix A-2) and Survey (Appendix A-3) to illiterate participants.
 - Important: Helping someone complete the Media Consent and Survey usually takes 15 minutes per participant. Prior to the workshop, it is helpful to ask the host how many participants will need assistance with these documents, so you can plan your support staff numbers accordingly.

Arrange Venue and Meals

- When looking for a venue, ensure that it is accessible to all participants. (See full Facility, Communication, and Resource Accessibility Checklist in Appendix A-12.)
- Ensure there are enough chairs and desks for each participant.
- Make tea and lunch arrangements.



Gather Information

- In advance of the workshop, collect as much data as you can regarding disability in the community(ies) of your participants from OPDs (Organizations for Persons with Disabilities), community leaders (churches, traditional healers, local chiefs, etc.), government ministries, nongovernmental organizations (NGOs), schools, medical facilities, etc.
- Determine the 5 most common and/or most life-threatening disabilities in your participants' communities. This will inform the part of the workshop where you present the causes, symptoms, interventions, and risk reductions for 5 different disabilities. You may do this by inquiring at local health facilities or asking local leaders.

Note: If the healthcare staff and leaders are not familiar with the different disabilities, you can show them photos and give explanations using the Disability Guidebook (Appendix A-10).

Note: In Kupenda and Kuhenza's experience, the most asked about disabilities are spina bifida, cerebral palsy, epilepsy, hydrocephalus, and hearing loss or deafness, so we have included those in this guide as examples. If you choose to highlight a different disability, please refer to the Disability Guidebook (Appendix A-10) for more information. You may also refer to the question prompts listed for the sample disabilities on pgs. 28-54 to prompt more discussion from the group.

- Look up the Disability Act of the country that your participants are from.
 - Ensure you've read the Act and are familiar with the local laws regarding people with disabilities.
 - Bring I copy of the Act to leave with the host.
 - If possible, develop a short (ideally I-page) Summary of the National Act or Local Laws Regarding Disabilities and any other supportive legislative summaries (see example in Appendix A-6).
- Prepare your Media Consent Form (see example in Appendix A-2).
- Prepare a Service Referral Guide for Children with Disabilities for the area in which you are presenting (see example in Appendix A-5).
 - Include schools, clinics, assessment offices, child protection centers, Organizations for Persons with Disabilities (OPDs), and nonprofit organizations that can provide services for children with disabilities.
 - Include local facilities, but also look beyond this in case there are more services available at the county and national levels.
- Research and prepare a Sample Access to Healthcare, Insurance, and Birth Certificates Handout for the area in which you are presenting (see example in Appendix A-14).
 - Include any additional notes on how to access disability assessment services.
 - Include instructions on how to access national health insurance.
 - Include instructions on how to access someone's birth certificate.
 - Include instructions on how to register as a person with a disability to access government support.
 - Include any additional notes on how to access healthcare.
- Research laws and penalties related to abuse in the country that your participants are from and add those details to the Abuse Prevention Resources (Appendix A-11).



Prepare Handouts

Before preparing the handouts, speak with the host to decide on the language for the workshop. If you choose a language other than English, translate the workshop handouts and flip chart content accordingly.

Then print each of the following handouts:

- I copy of the Disability Act of the country that your participants are from
- Prepare copies of all handouts for each participant:
 - I notebook
 - I pen
 - I copy of the Participants' Agenda (page 13)
 - I copy of the Disability Guidebook (Appendix A-10)
 - I copy of the Media Consent and 2 copies of the Survey (Appendices A-2 and A-3)
 - I copy of the Sign-In Sheet (Appendix A-I)
 - I copy of the My Disability Outreach Action Plan Worksheet (Appendix A-4)
 - I copy of the Service Referral Guide Handout (see example in Appendix A-5)
 - I copy of the Short Summary of the National Act or Local Laws Regarding Disabilities (Appendix A-6)
 - 4 copies of the Weekly Reporting Form (Appendix A-7)
 - I copy of the Disability Advocate Certificate (Appendix A-8)
 - I copy of the Disability Advocate Commitment (Appendix A-9)
 - I copy of the Disability Guidebook (Appendix A-10)
 - I copy of the Abuse Prevention Resources (Appendix A-II)
 - I copy of the Access to Healthcare, Insurance, and Birth Certificates Handout (Appendix A-14)
 - I copy of the UNICEF Module: Identifying Disability (Appendix A-15)
 - I copy of the Certificate of Participation (Appendix A-16)
- Review the visuals you will be referring to during your presentation (see CHP Guide Presentation Visuals in Appendix A-13).
- Prepare the flip charts with this content:
 - The Participants' Agenda (page 13)
 - The Workshop Objectives (see page 17)
 - The national definition of disability (see page 20)
 - The CHP's roles (see page 19)
 - Action Plan (I flip chart prepared for each small group of 4-5 people) with the following columns:

| Date | Activity | Location | Person Responsible |
|------|----------|----------|--------------------|
| | | | |



Select and Prepare Your Co-Facilitators

Select a group of co-facilitators (ideally 2-5 staff or volunteers) to help you with the following tasks. Ensure these individuals have the disability knowledge and language, organizational, photography, and interpersonal skills needed to provide you strong support.

- Place a pen, notebook, and Media Consent (Appendix A-2) on each participant's desk.
- Tape the prepared flip charts to the walls **face down**. (You will turn these over IxI as the groups discuss them.)
- Place the Sign-In Sheet (Appendix A-I) on a desk at the front of the room.
- As participants arrive, ask them to write their information on the sign-in sheet. Check that they are doing this. If it appears that a participant is illiterate, help him/her complete the sign-in sheet.
- Keep an eye on the time during the workshop and breaks. When it's getting close to the end of each part of the day, prompt the facilitator with a 5-minute and then a 1-minute warning. (You may want to create a sign he/she can hold up that's says "5" and "1.")
- Ensure tea and lunch are served on time and the cooks are paid.
- Take notes on the workshop. Be sure to include:
 - The action plans
 - Any profound notes
 - Any problematic topics, content, or logistics
- During small group activities:
 - Walk around the room listening to different groups
 - Assist groups who are struggling or off track
 - Praise groups that are doing a good job
- Take close-up, engaged photographs during the workshop ONLY after the participants have given their consent.
- Ensure everyone has written their name and contact details on the sign-in sheet and that they've written legibly.
- Distribute and collect handouts as prompted by the facilitator.
- If participants arrive late, ensure they add their information to the sign-in sheet and help them to join a group. Brief them on the workshop content as needed.
- Help illiterate participants complete the survey.
- If applicable, distribute transportation funds and stipends to participants during lunch and tea breaks or at the end of the workshop.

Gather the Materials

- Camera with fully charged battery
- Flip chart and markers
- Post-it notes
- A large roll of tape/push pins/hammer and nails (to put the flip charts on the wall)
- An ink pad for people who are illiterate to use to impress their thumb print on the Media Consent Form (Appendix A-2)
- Appropriate computer/screen/projector/cord(s)/power source (or pre-printed visuals) to show the CHP Guide Presentation Visuals (Appendix A-13)

Important Notes on Workshop Timing

- The following agendas were developed to guide facilitators in conducting the workshop during a single 7-hour day.
 - Facilitators may choose to expand the length of the workshop if they would like or hold it over several days.
 - For those who choose to shorten the workshop, please note that discussions around disability definitions; the causes, symptoms, interventions, and risk reductions for common disabilities; and action planning are the most important parts of the workshop. Facilitators are encouraged to cut down on the other workshop content, as needed, to ensure they have ample time to cover the content in these sections.
- For those who wish to follow the agendas and complete the content in a single day, it is critical to begin the workshop on time. To support this, the facilitator can:
 - Discuss the start time with the host or lead CHP prior to the workshop to ensure he/she encourages and supports participants to arrive on time.
 - Post a piece of flip chart on the venue wall prior to the start of the workshop. When unexpected
 questions emerge from the participants and they may take too much time to address, the facilitator
 can write them on this flip chart. Oftentimes, the questions are addressed in future parts of the
 workshop. If they are not, the facilitator can discuss them individually with the person who asked them
 during the workshop breaks.
- Note: Even with an on-time start, the workshop content may take longer if there are many participants or if the participants have lower levels of education. Shorter discussions and more staff to help low-literacy participants complete pre/post surveys and consents can help facilitators to keep to the schedule.







Disability Advocacy Workshop Agenda

(Add date and location here)

| 9:00 - 9:45 | Media Consent Pre-Survey Song Welcoming Remarks Group Norms Self-Introductions Expectations Workshop Objectives and Agenda Facilitator's Introduction Introduction by a Public Health Officer (PHO) |
|---------------|--|
| 9:45 – 10:00 | CHPs Role and Activities in the Community Disabilities in Our Families and Communities Participants' Disability Stories |
| 10:00 - 10:30 | Disability Definitions |
| 10:30 – 11:30 | Presentation on the Causes, Symptoms, Interventions, and Risk Reductions for Common Disabilities |
| :30 - :45 | BREAK |
| 11:45 - 12:45 | Testimony of an Individual with a Disability (or Parent of a Child with a Disability) Abuse Prevention Discussion Testimony From a CHP Workshop Alumnus |
| 12:45 - 1:45 | LUNCH |
| I:45 - 4:00 | Action Planning Sharing Disability Resources Post-Survey Closing Words and Prayer |

Facilitators' Agenda



| Sample Timing | Activity |
|---|---|
| 8:30 - 9:00 | I. Ask participants to sign in as they arrive |
| Introduction | |
| 9:00 - 9:45 | Administer the Media Consent (Appendix A-2) and Survey (Appendix A-3) Volunteer song Volunteer prayer Velcoming remarks Agree on group norms Self-introductions Review participants' expectations Review workshop objectives Review the participants' agenda Facilitator's introduction Introduction by a Public Health Officer (PHO) |
| CHPs in the Comm | unity |
| 9:45 – 10:00 | 13. The role of CHPs and their activities 14. Ask participants, "What motivates you to do this work?" 15. How CHPs work with local health facilities and organizations 16. Discuss disability in our families and communities |
| Disability Definition | ns |
| 10:00 - 10:30 | Ask participants, "How do you define disability?" Present the national definition of disability Discuss the definitions' similarities and differences and the role of perception Discuss person-first language Discuss the 5 most common disabilities in their communities |
| Presentation on the | e Causes, Symptoms, Interventions, and Risk Reductions for Common Disabilities |
| 10:30 - 11:30 | 22. Large group discussion: Discuss the symptoms and causes of 5 common disabilities 23. Participants share their experiences with effective and ineffective interventions for the 5 common disabilities mentioned above 24. Using content from the <i>Disability Guidebook</i>, present causes, symptoms, and interventions for the 5 common disabilities 25. Ask participants, "Based on all we have discussed, are there ways to reduce the risk of any of these disabilities?" |
| :30 - :45 | BREAK |
| Testimony of an Individual with a Disability or a Parent of a Child with a Disability | |
| 11:45 - 12:30 | 26. Guest speech 27. Participant questions 28. Disability is not inability discussion 29. Participant stories of disability not being inability 30. Conclusion on the influence of attitudes and opportunities on ability 31. Present the Abuse Prevention Resources (Appendix A-11) |

Facilitators' Agenda



| Sample TimingActivityTestimony From a CHP Workshop Alumnus12:30 - 12:4532. CHP introduction 33. CHP testimony12:45 - 1:45LUNCHAction Planning and Discussion of the Role of CHPs1:45 - 2:4534. Write small group action plans 35. Present group action plans and complete individual action plansAction Plan Follow-Up Logistics2:45 - 3:0036. Review the Weekly Reporting Form and submission instructions (Appendix A-7) 37. Discuss challenges that may arise 38. Select a point person for each small group who will report to the host organization 39. Share participant and organization contact information with the selected point personCommitment and Certification Program |
|---|
| 12:30 - 12:4532. CHP introduction 33. CHP testimony12:45 - 1:45LUNCHAction Planning and Discussion of the Role of CHPs1:45 - 2:4534. Write small group action plans 35. Present group action plans and complete individual action plansAction Plan Follow-Up Logistics2:45 - 3:0036. Review the Weekly Reporting Form and submission instructions (Appendix A-7) 37. Discuss challenges that may arise 38. Select a point person for each small group who will report to the host organization 39. Share participant and organization contact information with the selected point person |
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| 1:45 - 2:4534. Write small group action plans 35. Present group action plans and complete individual action plansAction Plan Follow-Up Logistics2:45 - 3:0036. Review the Weekly Reporting Form and submission instructions (Appendix A-7) 37. Discuss challenges that may arise 38. Select a point person for each small group who will report to the host organization 39. Share participant and organization contact information with the selected point person |
| 35. Present group action plans and complete individual action plans Action Plan Follow-Up Logistics 2:45 - 3:00 36. Review the Weekly Reporting Form and submission instructions (Appendix A-7) 37. Discuss challenges that may arise 38. Select a point person for each small group who will report to the host organization 39. Share participant and organization contact information with the selected point person |
| 2:45 - 3:00 36. Review the Weekly Reporting Form and submission instructions (Appendix A-7) 37. Discuss challenges that may arise 38. Select a point person for each small group who will report to the host organization 39. Share participant and organization contact information with the selected point person |
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| Commitment and Certification Program |
| |
| 3:00 – 3:15 40. Distribute 2 copies of the <i>Disability Advocate Commitment</i> to each participant (Appendix A-9) |
| 41. Ask participants to sign 2 copies of the <i>Commitment</i> (Appendix A-9) 42. Distribute a sample <i>Disability Advocate Certificate</i> (Appendix A-8) 43. Explain the certification process |
| Resources Review and Distribution |
| 3:15 – 3:45 44. Present and distribute the Disability Guidebook (Appendix A-10) 45. Present and distribute the UNICEF Module: Identifying Disability (Appendix A-15) 46. Present and distribute the local Disability Law Summary (Appendix A-6) |
| 40. Present and distribute the local Disability Ldw summary (Appendix A-6) 47. Present and distribute the Service Referral Guide for Children with Disabilities (see example in Appendix A-5) |
| 48. Distribute the Abuse Prevention Resources (Appendix A-11) |
| 49. Distribute the Access to Healthcare, Insurance, and Birth Certificates Handout (see sample in Appendix A-14) |
| 50. Present and distribute a copy of the host organization's brochure (if applicable) |
| 51. Administer the Survey again to assess changes (Appendix A-3) 52. Distribute the Certificate of Participation (Appendix A-16) |
| Conclusion |
| 3:45 – 4:00 53. Volunteer reflection |
| 5.45 – 4.00 53. Volunteer relection 54. Closing words |
| 55. Word of thanks |
| 56. Closing prayer |
| 57. Collect sign-in sheet |



Introduction

I. Ask Participants to Sign In as They Arrive

- Place a copy of the Sign-In Sheet (Appendix A-I) at the front of the room.
- As participants arrive, ask them to write their information on the sign-in sheet. Check that they are doing this.
- If it appears that a participant is illiterate, ask one of your co-facilitators to help him/her complete the sign-in sheet.

Important: Ensure that your co-facilitators do not take any photographs until the *Media Consent* has been signed by all participants.

2. Administer the Media Consent and Survey (Appendices A-2 and A-3)

• Explain the following before you pass out the document:

Timing: You have 15 minutes to complete this worksheet.

Part A: Media Consent

- No one is required to give media consent.
- However, providing this consent will allow us to share your photographs for the purpose of:
 - 1. Telling other CHPs about these workshops
 - 2. Reporting to donors and funders
 - 3. Sharing information to educate the general public about disabilities
- Explain that the photographs could appear on:
 - I. Organization reports
 - 2. Our website
 - 3. Marketing materials
 - 4. Social media sites

Part B: Survey

- They should not speak to one another as they complete the survey.
- They should not look up the answers on their phones.
- They should be honest. They will not be judged.
- This is not an exam.
- We will give you another survey at the end of the workshop.
- The results will be used to assess the workshop, but their specific names and answers will be kept confidential.
- If some participants are illiterate or have a low level of literacy, assign volunteers or staff members to administer the surveys verbally to them and then write down their answers.

Note: Remind volunteers or staff members that they should not provide the survey answers to the participants while assisting them.

- Walk around the room helping people who are stuck or confused.
- Ensure they answer every question.
- Give them time warnings when there are 5, 3, and 1 minute(s) remaining.
- Ask people to submit their worksheets. Read them and ask those who wish not to be filmed or photographed to move to a seat on the periphery. This way you can easily keep them out of photographs.





Introduction (continued)

3. Volunteer Song

Invite a volunteer to initiate a song to be sung together.

4. Volunteer Prayer

Invite the lead CHP to open the workshop in prayer.

5. Welcome Remarks

• Invite the host to welcome the participants and introduce the facilitator.

6. Agree on Group Norms

- Ask the participants to come up with "group norms" guiding the workshop.
- Explain that these "norms" are ways we'd like everyone in the room to conduct themselves in order for a productive, collaborative workshop.
- As participants give answers, write them on a flip chart.
- Ensure participants say things like:
 - Do not interrupt one another.
 - Put your cell phones in silent mode or turn them off.
 - Contribute to all discussions.
- Once you've developed the list, tape the flip chart to a wall in the workshop room.

7. Self-Introductions

- · Ask each member to briefly share the following:
 - 1. Name
 - 2. Where they come from
 - 3. Profession

8. Review Participants' Expectations

- Ask participants what they expect to happen during the workshop and what they expect to learn.
- · As participants give answers, write them on a flip chart.
- At the end of the exercise, tape the flip chart to a wall in the workshop room.

Note: Since every audience is different, this exercise helps the facilitator to understand the group. He/she can tailor the content and direct the conversation around their needs and interests.

9. Review Workshop Objectives

- Explain to participants that you will now review workshop objectives that will help build the capacity of CHPs to handle disability issues in their community.
- Call on participants randomly to read the workshop objectives from the prepared flip chart. (Random selection helps participants to pay attention.)
 - I. To share information about the services that the facilitators' organization provides
 - 2. To learn how the participants support families impacted by disability in their communities
 - 3. To learn about the disabilities participants see in their communities and the causes, risk reductions, and interventions for those disabilities
 - 4. To brainstorm together how we can improve support for children with disabilities and their families
 - 5. To make action plans that outline how we can better support families impacted by disabilities in our communities
 - 6. To answer participants' questions and concerns regarding disability





Introduction (continued)

9. Review Workshop Objectives (continued)

- Explain any items that need more detail.
- Answer any questions the participants may have.

10. Review the Participants' Agenda

- Hand out copies of the Participants' Agenda.
- Hang the prepared flip chart with the agenda written on it.
- Call one participant randomly to read the agenda items. (Random selection helps participants to pay attention.) Explain any agenda items that need more detail.
- Answer any questions the participants may have.

II. Facilitator's Introduction

- Introduce yourself and your group or organization. Remember to cover these topics:
 - Your information:
 - Name
 - Job
 - Why you care about children with disabilities
 - Your organization's:
 - Mission
 - · Strategies for helping people with disabilities

Sample Organization Introduction That Engages Participants and Reiterates the Workshop Objectives:

Kupenda and Kuhenza work to transform harmful beliefs surrounding disability to those that improve children's lives. We also provide some direct medical and education services to children with disabilities to show people in the community what is possible when these children are valued, supported, and included.

We believe strongly in supporting community-led solutions to disability support and inclusion. For example, after one of our disability trainings, the trainees identified dozens of children with disabilities in their community and realized there were no schools available to educate them. In response, they petitioned the local government for support. This motivated leaders to provide land and teaching staff for a school. This facility is now serving 24 children with cerebral palsy in Timboni, Kilifi, Kenya, who previously had no access to education or therapy.

These are not Kupenda and Kuhenza's communities. They are your communities, and you can serve them more effectively and sustainably than we can. These locally led solutions are a central focus of our organizations and the purpose of this workshop.

12. Introduction by a Public Health Officer (PHO)

• If possible, invite a public health officer (PHO) to give an introduction.



CHPs in the Community

13. The Role of CHPs and Their Activities

- Ask participants to share their views on the role of CHPs in their communities.
 - Prompt them with questions like, "How do you help communities?" and "Why are CHPs important?"
 - Write their answers on the board or flip chart.
- Tell participants that you will now call on them randomly to read the following roles of CHPs, according to the Ministry of Health.¹
- Then explain that, particularly for #5, this training will help them to build capacity on issues of disability in order to help them execute their role.

CHP Roles

- I. Sensitize the community on the importance of healthy lifestyles and of quality health services
- 2. Provide community disease surveillance by reporting early signs of imminent health disasters or emergencies
- 3. Enroll and monitor the health status of members of the households assigned to the community health promoter
- 4. Keep and maintain a record of members in all households assigned to the community health promoter
- 5. Monitor the rehabilitation and integration of persons who require such services in the community
- 6. Provide appropriate health advice to an assigned household in a language that members of the household understand, including advice on functions of community health promoters
- 7. Submit reports, at such intervals as shall be determined by the county director of health, on the health of each member of an assigned household and the barriers to health and healthcare in the household to the community health officer
- 8. Collect information on the health status of the assigned households

14. Ask Participants, "What Motivates You to Do This Work?"

- Write their answers on a flip chart.
- Ask, "Why are you motivated to help families impacted by disability in your communities?"

15. How CHPs Work with Local Health Facilities and Organizations

- Ask "How do you liaise with health facilities and other local organizations?"
- Ask, "How were you trained? What training opportunities are still available to you?"
- Then ask, "How would you describe your reporting system and related paperwork?"

16. Discuss Disability in Our Families and Communities

- Ask participants to raise their hands if they or someone in their family has a disability.
- Ask participants to raise their hands if they know anyone in their community with a disability.
- Elicit responses and stories. Ask a few participants to share their experiences with disability.
- Write the disabilities they mention on the board or flip chart.
- Keep these on the board or flip chart as you will refer to them during the later discussion regarding disability symptoms, causes, and interventions.
- When helpful, you can use the laminated photos of different disabilities to support this discussion.
- Share the data you have gathered from the participants' region and the global data in Box 1.

[&]quot;"Community Health Promoters Basic Modules," Community Health Services, accessed January 29, 2025, https://drive.google.com/file/d/IP6-03Ltv4JCaHvXoA7r8Hgd-6VML-LZm/view.



CHPs in the Community (continued)

Box I: Global Disability Data

Prevalence

- I.3 billion people (16% of the population) have disabilities.² (For example, since the population of Kilifi County, Kenya, is 1,566,335 people, approximately 252,374 people have disabilities.)³
- 80% of these people live in low-income nations.⁴

Children

- I in 10 children worldwide have disabilities.⁵
- Children with disabilities are 3-4x more likely to be victims of violence.⁶
- Children with disabilities earn 3x more than other children in forced begging situations.⁷

Health

- 76-85% of people with disabilities lack access to healthcare.⁸
- 83% of women with disabilities experience violence.⁹
- 90% of people with disabilities are excluded from the Church.¹⁰
- I0,000 people with disabilities die each day due to extreme poverty.

Education

- Only 10% of people with disabilities ever attend school.¹²
- Only 5% of people with disabilities complete primary school.¹³
- 97% of men and 99% of women with disabilities are illiterate.¹⁴
- Emphasize the following:
 - There is a high prevalence of disability in their families, communities, and country.
 - They may not see so many people with disabilities in their communities because they are:
 - I. hidden out of shame or fear,
 - 2. locked up for their own safety, or
 - 3. murdered at birth.

Disability Definitions

Note: To stay on track with your agenda timing, remember to keep this Disability Definitions Section brief-ideally just 5-20 minutes so there is ample time for action planning. If participants have lots of questions or comments, you can discuss at another time.

17. Ask Participants, "How Do You Define Disability?"

Invite volunteers to share their definitions and write them on the board.

18. Present the National Definition of Disability

• This is an example of the definition in Kenya's 2010 Constitution. Ask a volunteer to read the national definition off the flip chart that you prepared in advance.

"Disability includes any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities."¹⁵

¹⁴ "Factsheet on Persons with Disabilities," United Nations.

² "Disability," World Health Organization, last modified March 7, 2023, https://www.who.int/news-room/fact-sheets/detail/disability~ and-health.

^{*} Disability. World Health Organization, last induined reaction, 2022, https://www.citypopulation.de/en/kenya/admin/coast/03_kilifi?. * "Kilifin," City Population, last modified December 20, 2023, https://www.citypopulation.de/en/kenya/admin/coast/03_kilifi?. * "Challenges Facing Persons with Disabilities in Sub-Saharan Africa," The World Bank, accessed September 27, 2023, https://www.world with-disabilities-in-sub-saharan-africa-in-5-charts#:-:text=About%20one%20billion%20people%20globally.or%20them%20in%20develop orldbank.org/en/topic/poverty/brief/challenges-facing-people-

⁵ "One in 10 children worldwide live with disabilities," United Nations, last modified November 10, 2021, https://news.un.org/en/story/2021/11/1105412.

⁶ "Children with Disabilities More Likely to Experience Violence," Pan American Health Organization, accessed September 25, 2023, https://www3.paho.org/hq/index.php?option=com_content &view=article8/d=6998:2012-children-disabilities-more-likely-experience-violence<emid=0&lang=en#gsc.tab=0.

⁷"Children forced into beggary and coerced to produce earnings," Global March Against Child Labour, last modified April 9, 2012, https://globalmarch.org/children-forced-into-beggary-and-coerced-to-produce-earnings/.

^{*&}quot;The Global Mental Health Crisis: 10 Numbers to Note." ProjectHOPE.accessed October 3, 2023, https://www.projecthope.org/the-global-mental-health-crisis-10-numbers-to-note/ #~text=Obstacles%20include%20lack%200%20resources,disorders%20lack%20access%20to%20care.

^{*} "Sexual Abuse." Disability Justice, accessed September 25, 2023, https://disabilityjustice.org/sexual-abuse/#:~:text=ln%20general%2C%20people%20with%20disabilities,sexually%20assaulted %20in%20their%20lives.

¹⁰ "Rochelle Scheuermann, "Christian Evangelicalism: How a Renewed Vision of Church as an Alternative Community of Reconciliation Necessitates the Inclusion of People with Disabilities," Christian Scholars Review, last modified May 8, 2023, https://christianscholars.com/enabling-evangelicalism-how-a-renewed-vision-of-church-as-an-alternative-community-of-reconciliation-necessitates-the-inclusion-of-people-with-disabilities!,""retext=lm220globally%2C%20globally%2C%20ninety%20to,are%20unreached%20by%20the%20gospel.&text=What%20i s%20more%2%20when%20people,to%20know%20how%20to%20respond.

¹¹ Rebecca Yeo, "Executive Summary: Disability, poverty, and the new development agenda," last modified September 2005, https://assets.publishing.service.gov.uk/media/57a08c5340f0b652dd00 125c/RedPov___agenda_ex.pdf. 12 "Factsheet on Persons with Disabilities," United Nations, accessed September 25, 2023, https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html

^{13 &}quot;Education for All Global Monitoring Report 2007," UNESCO, last modified 2006, https://unesdoc.unesco.org/ark:/48223/pf0000147794.

^{15 &}quot;Kenya, Parliament, The Constitution of Kenya, adopted August 4, 2010, sec. 260, http://kenyalaw.org/kl/index.php?id=398.





Disability Definitions (continued)

19. Discuss the Definitions' Similarities and Differences and the Role of Perception

- Ask participants, "What are the similarities and differences between the definitions you provided and the national definition?"
 - Elicit their answers and write them on the flip chart.
 - Guide the discussion to include the following point:
 <u>Difference</u>: "Barriers" in the national definition might include things like the perception of others.
- Explain that disability is not just physical but also social and shaped by the way people view or respond to a person with a disability.
 - Ask if they know of any situations where someone with a disability was perceived to be less capable than he/she actually was and listen to their stories.
 - If needed, prompt them by asking if they know anyone with a disability who got married, obtained a job, completed a course, or had a child when people in their community thought he/she was not able to do those things.
- Emphasize language that shows how perception of one's ability or inability has a role in these defini-

20. Discuss Person-First Language

- Show a photo of a person with a visible disability and ask, "What do you see?"
 - Elicit responses until someone says:"A person."
 - Then write "A Person" on the board.



• Show a photo of a person with hydrocephalus and ask, "What do you see?"



- Elicit responses until someone says: "It's a person with a large head."
- Then write: "A Person with Hydrocephalus" on the board.



Disability Definitions (continued)

• Show a photo of a person with microcephaly and ask, "What do you see?"



- Elicit responses until someone says:"It's a person with a small head."
 - Then write: "A Person with Microcephaly" on the board.
- Then share the following points:
 - These people are like any other people.
 - Ask them why it is more appropriate to say "a person with a disability" rather than a "disabled person"?
 - Write these two phrases on the board or a flip chart to show the difference.
 - Guide them to the conclusion that "a person with a disability" emphasizes that someone is a person first and not defined by his/her disability.
- Prompt the group to use the right language for other disabilities by sharing some of the negative phrases below and asking them to rephrase them more positively.

| Negative Phrases | Affirmative Phrases |
|--|---|
| Retarded, mentally defective | Person with an intellectual, cognitive, or developmental disability |
| The blind | Person who is blind Person who is visually impaired |
| The disabled, handicapped | Person with a disability |
| The deaf, deaf and dumb | Person who is deaf |
| Suffers a hearing loss | Person who is hard of hearing |
| CP victim | Person with cerebral palsy |
| Epileptic | Person with epilepsy Person with a seizure disorder |
| Wheelchair bound, confined to a wheelchair | Person who uses a wheelchair |
| Stricken by MD | Person who has muscular dystrophy |
| Crippled, lame, deformed | Person with a physical disability |
| Dumb, mute | Person who is unable to speak |
| Crazy, nuts, mad | Person with a psychiatric disability |



Disability Definitions (continued)

21. Discuss the 5 Most Common Disabilities in Their Communities

- Refer participants to the earlier list of disabilities they came up with and which you wrote on the board.
- Ask participants which of these disabilities are the most common in their communities and circle the 5 most common ones they agree upon.
- Tell the group that we are going to discuss the symptoms, causes, interventions, and risk reductions for 5 common disabilities.

Presentation on the Symptoms, Causes, Interventions, and Risk Reductions for Common Disabilities

Note: Remember to facilitate this section alongside the medical professional you have invited.

22. Large Group Discussion: Discuss the Symptoms and Causes of 5 Common Disabilities

- Show photos of 5 common disabilities at the same time.
- Ask the participants, "Have you seen people who look like this?"
- Ask the participants, "What do you or people in your community believe are the causes of these types of disability?"
- Write each answer and separate them into Medical and Non-Medical columns like this:

| Medical Causes | Non-Medical Causes |
|----------------------------------|-----------------------|
| • Accidents | • Demons |
| • Disease | • Infidelity |
| • Genetics | • Curses |
| • Birth Defects | • Punishment from God |
| Malnutrition | • Witchcraft |

- Ask participants, "In your community, which cause do people believe in more?" Point to the two sides and elicit answers from a few people.
- Ask participants, "What about most CHPs? Which causes do they believe in more?" Point to the two sides and elicit answers from a few people.
- Then ask, "What about you as a CHP? What do you believe to be the causes of disability? Which of those columns do you associate with?" Elicit answers from a few people.
- Then ask, "How do these beliefs affect how children with disabilities view themselves?" Elicit answers from a few people.
- Then make a large question mark on the board or flip chart and explain that sometimes we don't know the causes of certain disabilities, and it's ok not to have all the answers. We don't need to make up explanations.



Presentation on the Symptoms, Causes, Interventions, and Risk Reductions for Common Disabilities (continued)

23. Participants Share Their Experiences with Effective and Ineffective Interventions for the 5 Common Disabilities Mentioned Above

- To elicit a discussion, ask some of these questions.
 - Show photos of each disability and ask the participants, "How does the community treat people who look like this?"
 - Elicit their responses.
 - Ask, "Is there a cure for this condition?"
 - Then ask,"What are the interventions for this disability?"
- Ask participants to share some of the practices they have used or seen being used in their communities that have **helped** children with such disabilities.

Examples:

- Soaking jelly leaves to lower a high fever
- Wearing leg jingles to encourage walking
- Massaging muscles to help them relax
- Steaming herbs to clear congestion
- Ask participants to share some of the practices they have used or seen being used in their communities that have **not helped** children with such disabilities.

Examples:

- Cutting the skin to help medicine get into the bloodstream
- Putting the mother and child in a grave to remove evil spirits
- Eating dog meat to remove evil spirits
- Burning the skin to drain fluid when someone has hydrocephalus
- Ask, "What happens if children like these do not get an intervention?"
- Ask, "What is the responsibility of the family and community when it comes to children with these disabilities?"
- Ask, "What challenges do children with these disabilities face?"
- Ask, "Can children with disabilities like these go to school?"
- Ask, "What do you do if you encounter children with these disabilities who have not yet been diagnosed or had proper intervention?"
- Then ask, "What are ways to reduce the risk of some of these disabilities?"
- Explain that you will now present information that has helped many CHPs serve their communities because it includes medical best practices that have been proven to help people with disabilities.
- Also explain that, when people improve, it builds trust with the CHP who has helped them, and they will tell others in the community.

24. Present the Symptoms, Causes, and Interventions for the 5 Most Common Disabilities From the Disability Guidebook



Presentation on the Symptoms, Causes, Interventions, and Risk Reductions for Common Disabilities (continued)

Hydrocephalus

Description

- Tell participants, "Now we are going to discuss a disability called 'hydrocephalus." (Print a large photo of a child with hydrocephalus or use the presentation visuals in Appendix A-13.)
- Ask, "How does the community act towards people who look like this?"
- Ask, "How would you describe hydrocephalus?"
- Get a few participants to answer.
- After they provide answers, share this description:



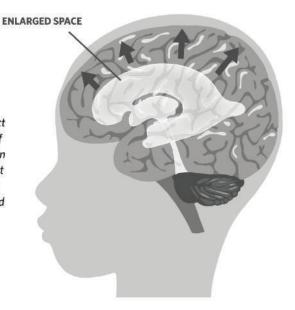
"Hydrocephalus is the buildup of extra fluid on the brain, typically in an infant, resulting in a larger-than-average head size."

• Share the following diagram to show what hydrocephalus looks like inside the head and then describe it. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

NORMAL SPACE



These two graphics depict the increasing buildup of fluid in spaces of the brain as well as the subsequent head size of a child with hydrocephalus, compared to a child without hydrocephalus.





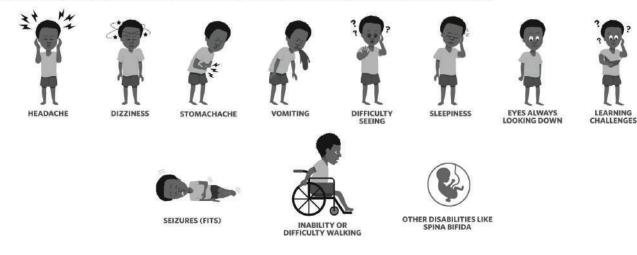


Hydrocephalus (continued)

• In addition to a larger head size, ask participants if they have observed any signs or symptoms connected to hydrocephalus. Then share the remaining signs and symptoms using the diagram below. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

SIGNS AND SYMPTOMS 6, 7, 8, 9, 10

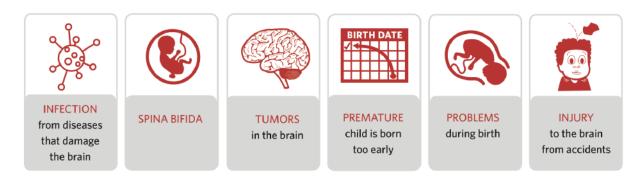
People with hydrocephalus have several symptoms that differ in severity from one person to another.



Causes

- Ask,"What are the medical causes of this disability?"
 - Get a few participants to answer the question. (Refer to the chart on the wall with medical and non-medical causes as they answer). If they respond with non-medical causes, ask them to share medical causes.
- Share the diagram below to explain the causes. (Print a large photo of the following diagram or use the
 presentation visuals in Appendix A-13.)

POSSIBLE CAUSES AND RISK FACTORS 11, 12, 13







Hydrocephalus (continued)

Interventions

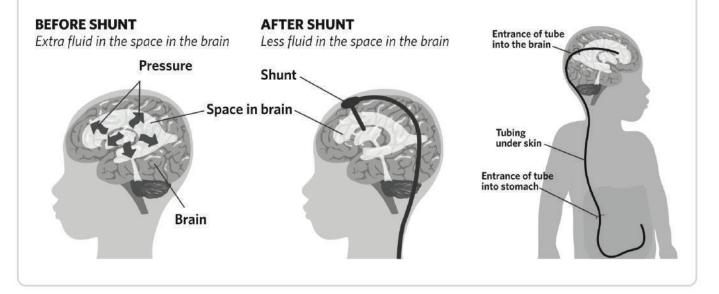
- Ask participants the following questions:
 - What can be done to help a child with this disability?
 - What can happen if a child with this disability does not receive an intervention?
 - What interventions are available?
- After they answer the questions, refer to the diagrams to fill in gaps in their answers. (Print a large photo of the following diagrams or use the presentation visuals in Appendix A-13.)
- Emphasize that, if the CHP is the first point of contact, he/she may help offer relief to a child but should not delay referring the child to the hospital for proper diagnosis or intervention. Medical and educational professionals can provide other services in the images below.

INTERVENTIONS 14, 15, 16

Professional Interventions: Inserting a shunt

A doctor trained in hydrocephalus may decide it is best to insert a tube (shunt) in the brain. This tube will drain the fluid from the brain to the stomach, heart, or lining of the lungs and be absorbed by the body.

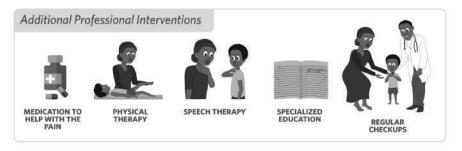
*This intervention may be necessary to prevent death or increased damage to the brain.



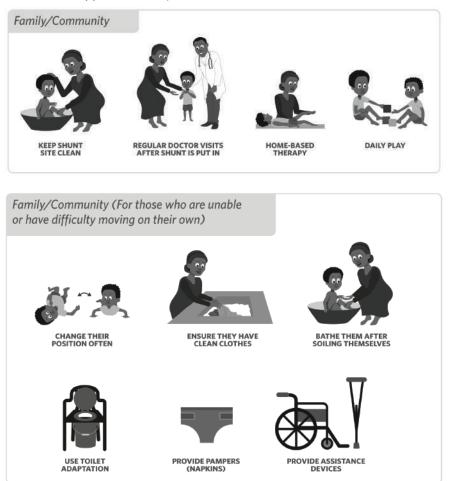


Hydrocephalus (continued)

- Ask, "What kinds of community support can be given to a child with hydrocephalus?"
 - Have a few people provide answers. Write them on the board if they are in line with the diagram below (or if they are helpful to the child or family).



• Show the chart below for community interventions. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)





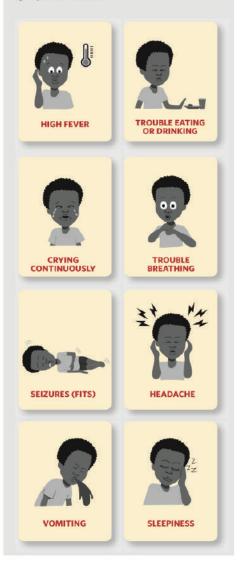


Hydrocephalus (continued)

- Ask, "What are the signs of an infection to watch for after a shunt is inserted?"
- After a few participants answer, refer to the diagram below to fill in answers they didn't give and/or reinforce correct answers. (Print a large photo of the following diagrams or use the presentation visuals in Appendix A-13.)
- Ask, "Is there a cure for this condition?"
- Ask, "What should be done if you observe signs of an infection?" (Correct answers are in *italics*.)
 - Bring them to the closest medical facility for intervention.
- Ask, "What do you do if you encounter a child with hydrocephalus who has not yet been diagnosed or had proper intervention?"
 - Explain the causes and interventions for this condition to the family.
 - Refer them to the closest medical facility for intervention

SIGNS OF INFECTION

Watch for signs of infection and visit a doctor if any of these symptoms arise.





Presentation on the Symptoms, Causes, Interventions, and Risk Reductions for Common Disabilities (continued)

Spina Bifida

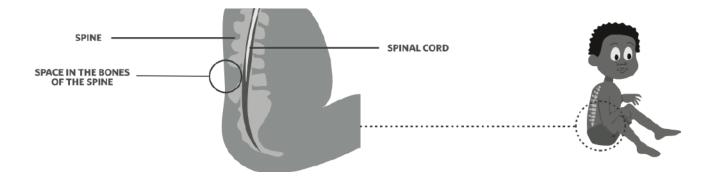
Description

- Tell participants, "Now we are going to discuss a disability called 'spina bifida.'" (Print a large photo of a child with spina bifida or use the presentation visuals in Appendix A-13.)
- Ask, "How does the community act towards people who look like this?"
- Ask, "How would you describe spina bifida?"
- Get a few participants to answer.
- After they provide answers, share this description:



"Spina bifida (SB) is a condition where there is a hole in the backbone that often causes damage to the spine and nerves in the back."

• Share this diagram to illustrate the description. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13).

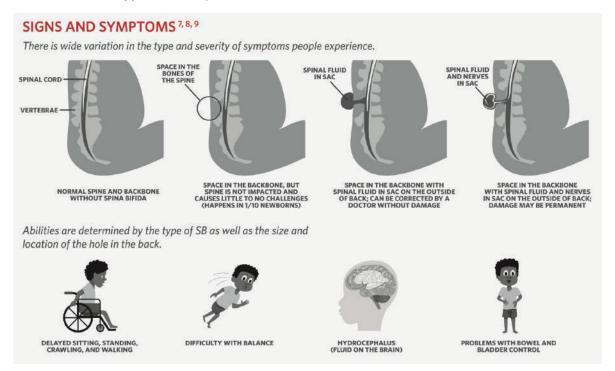






Spina Bifida

• Share this diagram to show the signs and symptoms. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)



Causes

- Ask, "What are the medical causes of this disability?"
 - Get a few participants to answer the question. (Refer to the chart on the wall with medical and non-medical causes as they answer.) If they respond with non-medical causes, ask them to share medical causes.
- Share the image below to explain the causes. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

POSSIBLE CAUSES AND RISK FACTORS 10, 11, 12

The reason for spina bifida is unknown.







Spina Bifida

Interventions

- Ask participants the following questions:
 - What can be done to help a child with this disability?
 - What can happen if a child with this disability does not receive an intervention?
 - What interventions are available?
- After they answer the questions, refer to the diagrams below to fill in gaps in their answers. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)
- Emphasize that, if the CHP is the first point of contact, he/she may help offer relief to a child but should not delay referring the child to the hospital for proper diagnosis or intervention. Medical and educational professionals can provide other services in the images below.

INTERVENTIONS 13, 14, 15

The type of intervention depends on the severity and location of the hole in the spine. They may or may not benefit from...



- Ask, "What kinds of community support can be given to a child with spina bifida?"
 - Have a few people provide answers. Write them on the board if they are in line with the diagram below (or if they are helpful to the child or family).
- Show the chart below for community interventions. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)





Spina Bifida





Cerebral Palsy

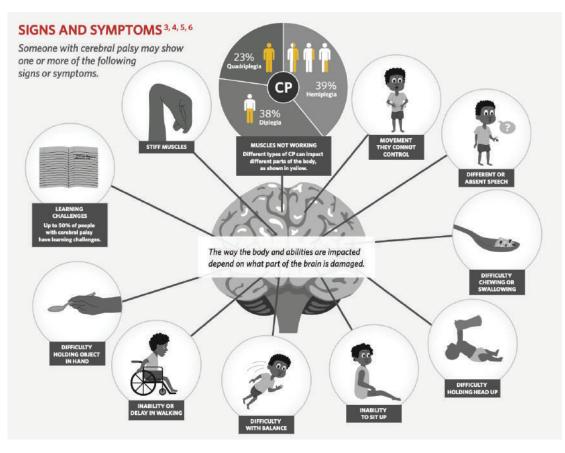
Description

- Tell participants, "Now we are going to discuss a disability called 'cerebral palsy." (Print a large photo of a child with cerebral palsy or use the presentation visuals in Appendix A-13.)
- Ask, "How does the community act towards people who look like this?"
- Ask, "How would you **describe** cerebral palsy?"
- Get a few participants to answer.
- After they provide answers, share this description:

"Cerebral palsy (CP) is caused by brain damage to children below the age of 5 that impacts their muscles and ability to move and balance. The damage to the brain does not get worse over time, but new challenges may occur as they age."



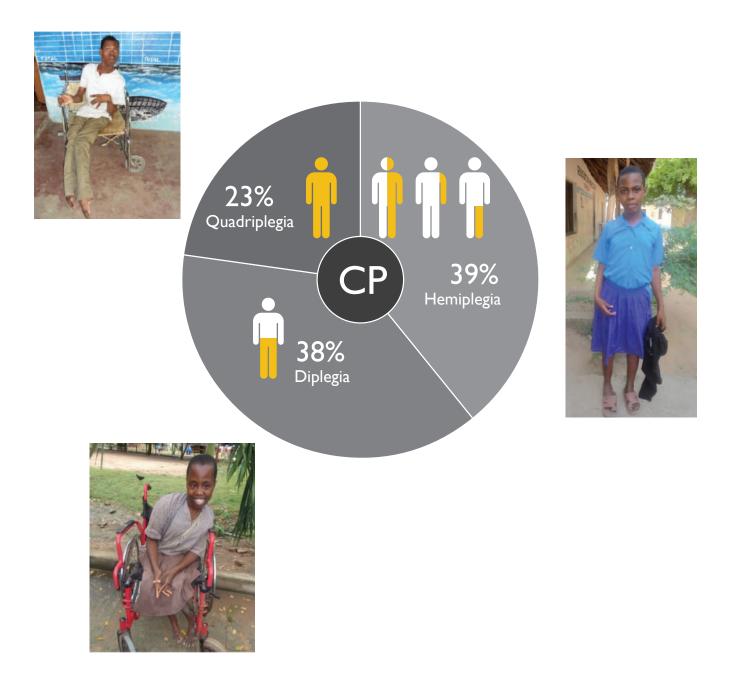
 Share this diagram to show the signs and symptoms. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)





Cerebral Palsy (continued)

• Tell participants, "Notice that cerebral palsy looks different depending on what part of the brain is damaged. Also note that 50% or more of children with cerebral palsy do not have learning challenges."





Cerebral Palsy (continued)

Causes

- Ask,"What are the medical causes of this disability?"
- Get a few participants to answer the question. (Refer to the chart on the wall with medical and non-medical causes as they answer). If they respond with non-medical causes, ask them to share medical causes.
- Share the image below to explain the causes. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

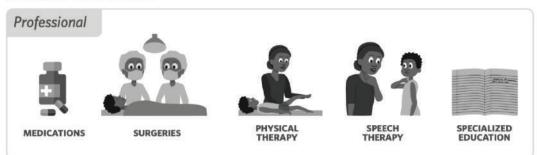
POSSIBLE CAUSES AND RISK FACTORS 7, 8, 9



Interventions

- Ask participants the following questions:
 - What can be done to help a child with this disability?
 - What can happen if a child with this disability does not receive an intervention?
 - What interventions are available?
- After they answer the questions, refer to the diagram below to fill in gaps in their answers. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)
- Emphasize that, if the CHP is the first point of contact, he/she may help offer relief to a child but should not delay referring the child to the hospital for proper diagnosis or intervention. Medical and educational professionals can provide other services in the images below.

INTERVENTIONS 10, 11, 12, 13



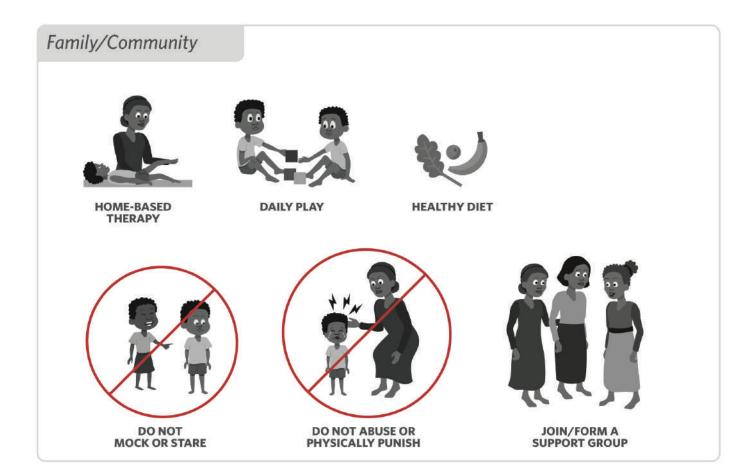
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Cerebral Palsy (continued)

- Ask, "What kinds of community support can be given to a child with cerebral palsy?"
 - Have a few people provide answers and write them on the board if they are in line with the diagram below (or if they are helpful to the child or family).
- Show the chart below for community interventions. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

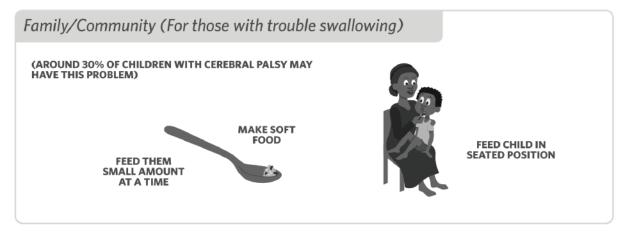




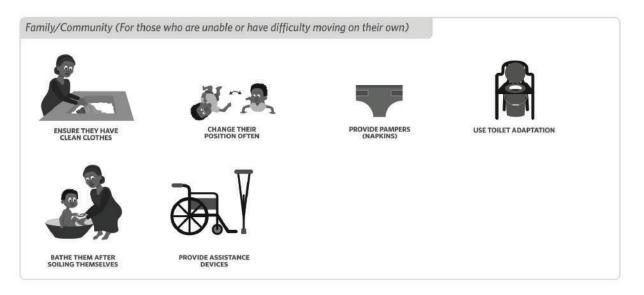


Cerebral Palsy (continued)

- Ask, "How do you help a child who has trouble swallowing?" (This can be a challenge for some children with cerebral palsy.)
- Have a few people provide answers and write them on the board if they are in line with the diagram below.
- Show the diagram below to guide them. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)



- Ask, "How can the community and family support a child who has challenges walking?
 - Have a few people provide answers and write them on the board if they are in line with the diagram below.
- Show the diagram below to guide them. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)





Presentation on the Symptoms, Causes, Interventions, and Risk Reductions for Common Disabilities (continued)

Epilepsy

Description

- Tell participants, "Now we are going to discuss a disability called 'epilepsy." (Print a large photo of a child with epilepsy or use the presentation visuals in Appendix A-13.)
- Ask, "Have you seen someone have repeated seizures (fits)? If yes, describe what you observed."
- Ask, "How does the community treat people who have seizures (fits)?"
- Then ask, "How would you describe epilepsy?"
- After they provide answers, share this description:

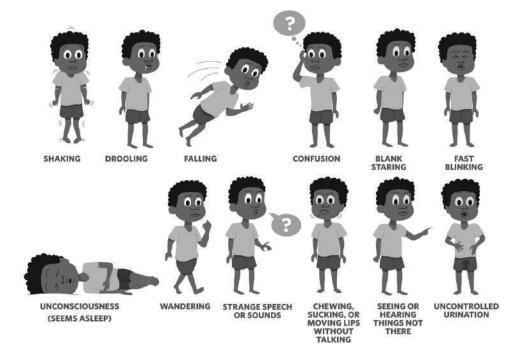
"Epilepsy is a disorder where there is a sudden change in normal brain activity which causes the person to have several seizures or 'fits' over a long period of time."

 Share this diagram below to show the signs and symptoms of a seizure. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)



SIGNS AND SYMPTOMS 4, 5, 6, 7, 8, 9

Someone who is having a seizure may show one or more of the following symptoms before or during a seizure:







Epilepsy (continued)

Causes

- Ask,"What are the medical causes of this disability?"
 - Get a few participants to answer the question. (Refer to the chart on the wall with medical and non-medical causes as they answer). If they respond with non-medical causes, ask them to share medical causes.
- Share the image below to explain the causes. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

POSSIBLE CAUSES AND RISK FACTORS 10, 11, 12, 13



NOTE: Epilepsy has biological causes that can be treated with medicine and is not the result of witchcraft or demons.

Interventions

- Ask participants the following questions:
 - What can be done to help a child with this disability?
 - What can happen if a child with this disability does not receive an intervention?
 - What interventions are available?
- After they answer the questions, refer to the diagrams below to fill in gaps in their answers. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)
- Emphasize that, if the CHP is the first point of contact, he/she may help offer relief to a child but should not delay referring the child to the hospital for proper diagnosis or intervention. Medical professionals can provide other services in the images below.



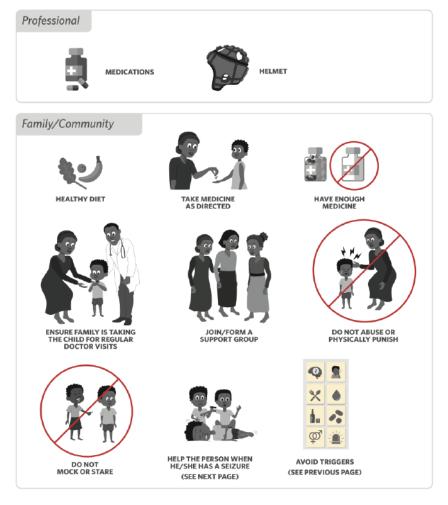


Epilepsy (continued)

Interventions (continued)

INTERVENTIONS 14, 15, 16

Anti-seizure medication is the most effective treatment for people with epilepsy. If taken as directed by the doctor, medications may completely stop seizures for some people or reduce the frequency and severity of the seizures for others. There are also different kinds of medication. If one doesn't work, the individual should go back to the doctor to see if a different kind of medication may work better. Some people will need medicine their whole lives, while others may not need it as long.





Epilepsy (continued)







Epilepsy (continued)

- Ask participants, "What do you do when a person has a seizure or shows signs that he/she might have one?"
 - After a few participants answer, share the diagram below and add anything they may have missed. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

Family/Community (During a seizure)

WARNING SIGNS: Some seizures have warning signs, like the person saying he or she is seeing strange lights or smelling something. The person may also make a strange noise or start to have confused speech. Others may not show any signs before their seizure.

As soon as a person becomes aware that someone is going to have a seizure or is having a seizure, he or she should follow these steps.





MOVE ANY

OBJECTS AWAY FROM THE PERSON



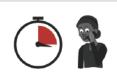
LAY THE PERSON ON HIS OR HER SIDE TO PREVENT CHOKING



RECORD HOW LONG THE SEIZURE LASTS AND HOW LONG THE PERSON IS UNABLE TO RESPOND



GIVE THE PERSON TIME to relax after the seizure is over, as the person will likely be tired and confused.



CALL A MEDICAL PROFESSIONAL if the person is unable to respond after 15 minutes. Tell him or her how long the seizure or unresponsiveness lasted.



Presentation on the Symptoms, Causes, Interventions, and Risk Reductions for Common Disabilities (continued)

Hearing Loss or Deafness

Description

- Tell participants, "Now we are going to discuss a disability called 'hearing loss or deafness."
- Ask, "Have you seen someone who has difficulty hearing or has no hearing at all?"
- Ask, "How does the community treat people who have difficulty hearing or no hearing at all?"
- Then ask, "How would you describe hearing loss or deafness?"
- Get a few participants to answer.
- After they provide answers, share this description:

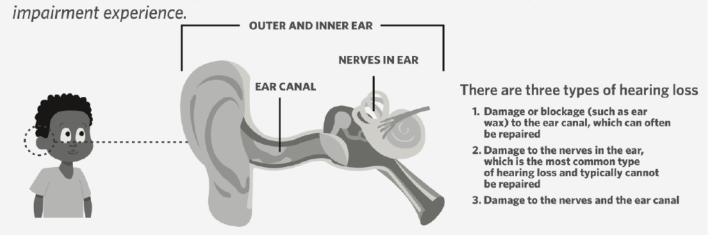


"Inability to hear the same level or type of sound as people without hearing loss, typically impacting the ability to verbally communicate"

• Share the diagrams below to show the signs and symptoms. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

SIGNS AND SYMPTOMS 4, 5, 6, 7, 8

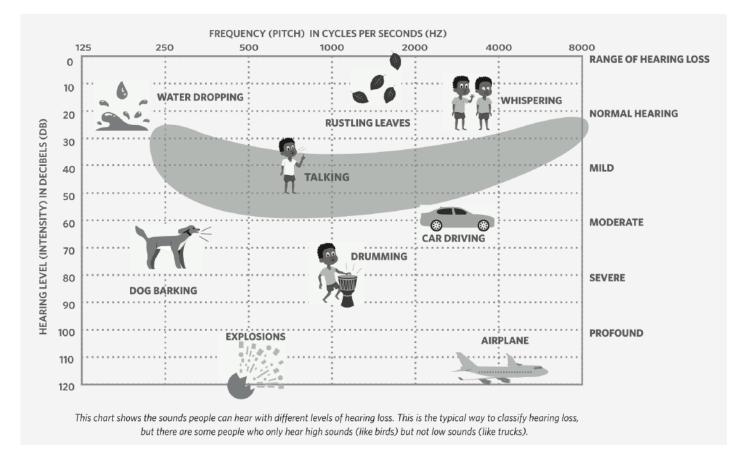
There is variation in the types and levels of sounds people with hearing







Hearing Loss or Deafness (continued)

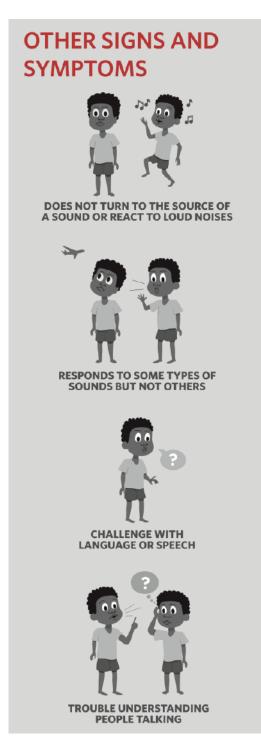


- Ask participants, "What are some of the other signs of someone who has difficulty hearing or no hearing at all that you've noticed?"
 - Then share the following diagram with them. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)





Hearing Loss or Deafness (continued)





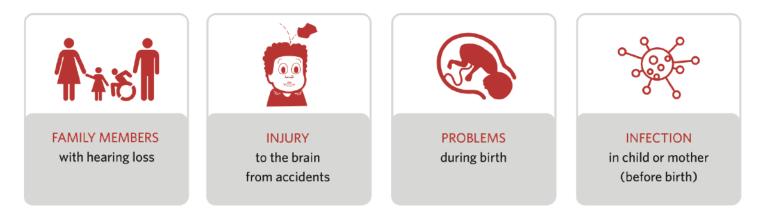


Hearing Loss or Deafness (continued)

Causes

- Ask, "What are the medical causes of this disability?"
 - Get a few participants to answer the question. (Refer to the chart on the wall with medical and non-medical causes as they answer). If they respond with non-medical causes, ask them to share medical causes.
- Share the image below to explain the causes. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)

POSSIBLE CAUSES AND RISK FACTORS 9, 10, 11



Interventions

- Ask participants the following questions:
 - What can be done to help a child with this disability?
 - What can happen if a child with this disability does not receive an intervention?
 - What interventions are available?
- After they answer the questions, refer to the diagrams below to fill in gaps in their answers. (Print a large photo of the following diagram or use the presentation visuals in Appendix A-13.)
- Emphasize that, if the CHP is the first point of contact, he/she may help offer relief to a child but should not delay referring the child to the hospital for proper diagnosis or intervention. Medical and educational professionals can provide other services in the images below.





Hearing Loss or Deafness (continued)







25. Ask Participants, "Based on All We Have Discussed, Are There Ways to Reduce the Risk of Any of These Disabilities?"

• Elicit answers from participants, such as the following:

Examples:

- Sleeping under treated nets
- Delivering in health facilities
- Eating a balanced diet
- Taking medications as instructed by the doctor
- Mention that these strategies may help to reduce the risk of disability but do not guarantee that disability will not occur.

Testimony of an Individual with a Disability or Parent of a Child with a Disability

26. Guest Speech

- Invite the guest with a disability (or the parent of a child with a disability) to come speak to the group.
- Introduce him/her to the participants.
- Ensure he/she covers the following points in his/her speech. If he/she does not, prompt him/her with questions:
 - What were his/her initial feelings when he/she discovered he/she (or his/her child) had a disability?
 - What was the community's response to him/her and the child?
 - How did he/she cope with stigma and discrimination related to disability?
 - What is his/her experience(s) with intervention through traditional medicine and facility-based medical care?
 - What are the successes and achievements he/she has experienced in relation to his/her child's disability (socially, academically, emotionally, physically, spiritually, or professionally)?
 - How would he/she advise CHPs to support people with disabilities?
 - How would he/she advise community members to support people with disabilities?

27. Participant Questions

• If there is time, allow the participants to ask the guest questions about his/her experience.



Sample Testimony: George

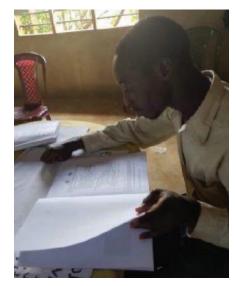


I was born with a disability. After I was born, I didn't cry for three hours. As I was growing, I did see myself as normal, but those who were my same age or older-they did not see me as a normal person. Some did not allow me to play with them. As any child would-I felt bad. I loved to play with other kids, but they didn't want to play with me. I wasn't happy when people were running away from me because that is the only thing that made me discover I had a disability.

The community generally did not accept me. Some people ran away when I came near them. Others would imitate how I walk. This really hurt me.

The community gave me two names: the first was simply "drunkard" and the other was a name that means someone used me in a traditional ritual to make money for themselves while leaving me with a disability. Because of my walking style, they thought I was always drunk.

But one thing that helped me overcome was that I come from a place called "Mashasheni." The school in my community did not have a special school or unit where children like me could receive an education, so I had to learn in a mainstream school. Kids would laugh at me and beat me, because they knew I would do nothing in return. That is when my parent thought it best to take me to Gede



Special School. At this school, I met a group of pastors who used to come to the school to take the students to a neighboring church.

Going to church encouraged me a lot and made me think, "I am a person like anyone else." Reverend Mangi really encouraged me too. He used to sing with me in church and show me love. We used to sing together. Pastor Mangi, he loved me. My teacher, Leonard Mbonani, and most of the teachers at Gede also showed me a lot of love. Leonard was the one who called pastors-by doing their different activities the pastors surrounded me with their teachings. Leonard said, "When we educate this boy, he will become a very important person." So he encouraged me and made me believe I was also a person.

I was able to complete my primary and secondary education and join a computer college through Kuhenza's support. Now I can do anything like any other person.



Sample Testimony: George (continued)

Sample Facilitator Questions to Prompt More Details

Facilitator Question to George:

What did your parents do after you didn't cry for three hours?

George's Answer:

I went three years without walking. My mother used to carry me, taking me to the hospital for therapy. Even after I was able to walk, my mother didn't stop taking me to the hospital. If she did not take me to hospital for therapy, I would be in a wheelchair and unable to do any activities of daily living.

Facilitator Question to George:

What advice do you have about children with disabilities in your community?

George's Answer:

When you see a child with a disability, a child is a child. They have a right to education. When the child achieves the age of enrolling in school, you should give them a chance to go to school. When you see a child with a disability, please take them to the hospital. If I did not go to the hospital like I said, I would currently be in a wheelchair. It took three years before I could walk, and if I didn't go to the hospital, could I have walked?

Facilitator Question to Participants:

When you look at him what do you think he can do?

<u>Participant Answer:</u> Because he has an education, he can do anything ... even marry.

Sample Facilitator Closing Remarks

Facilitator Comments to Participants:

They took him to the hospital early enough to help him achieve what he has achieved in his life. I want you to learn from his testimony that when you see these children, you should advise these parents and see that they are taken to the hospital early enough. Before we can take them to school or the hospital, we need to love and accept them. As CHPs, do you agree you have a responsibly to help these children?

Participant Answer:

We have a responsibility to work with other stakeholders to cooperate and to achieve the dream that, at some point, children with disabilities will be valued, loved, and accepted.





Testimony of an Individual with a Disability or Parent of a Child with a Disability (continued)

28. Disability is Not Inability Discussion

- Ask participants to share ideas of what they think the person with a disability who just shared his/her testimony cannot do.
 - Elicit a long list and write it on the board.
 - Then allow the person with a disability or his/her parent to explain that he/she can, in fact, do many (or all) of those things.
 - If possible, demonstrate some of the abilities in question and have others present who can also testify to his/her abilities.
- If there is time, allow participants to ask the guest any additional questions.

29. Participant Stories of Disability Not Being Inability

• Invite participants to share other stories of people they know with disabilities who are exceeding expectations (i.e., they are in school, working, helping their families, etc.).

30. Conclusion on the Influence of Attitudes and Opportunities on Ability

- Ask participants, "What were some of the reasons our guest excelled?"
 - Have a few participants share their answers.
- Ask participants, "What happens when we give people with disabilities opportunities?
 - Have a few participants share their answers.
- Pick someone with glasses in the audience or one of the staff that has glasses and ask if he/she can see without his/her glasses. He/she will likely say "no" or "not very well."
 - Ask if he/she is considered disabled and, if not, why he/she is accepted while other disabilities are seen more negatively?
- Ask participants, "Are there any diagnoses, interventions, or beliefs about disabilities that exist in your community that could be harming or limiting to children with disabilities?
 - Have a few participants share examples.
- Conclude this section by making the following points:
 - Our guest was given an opportunity and that's why he/she excelled.
 - If we give people with disabilities opportunities, they will realize their potential. If we don't, they never will.
 - Some of us cannot see without glasses-it's like we all have a disability (i.e., impaired vision), but the cultural norms around glasses are accepted, while the norms around other disabilities are negative.
 - Some of you were mistaken about what our guest could and could not do.
 - Some of our diagnoses, interventions, and beliefs about disability could be mistaken and could be harming or limiting children with disabilities.



Testimony of an Individual with a Disability or Parent of a Child with a Disability (continued)

31. Present the Abuse Prevention Resources (Appendix A-II)

- Ask participants, "What is abuse?"
- Elicit responses from the participants.
- Read the definition of abuse from Appendix A-11:
 - Example: National Definition of Abuse from Kenya's Children's Act of 2001: "Child abuse includes physical, sexual, psychological and mental injury"¹⁶
 - World Health Organization (WHO): "All types of physical and/or emotional ill-treatment, sexual abuse, neglect, negligence, and commercial or other exploitation, which results 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."¹⁷
- Then ask participants, "What types of abuse did the speaker experience?"
 - List their answers on the board.
- Ask participants what other types of abuse exist in addition to the ones they listed from the speaker testimony.
 Elicit examples of types of abuse like physical, emotional, verbal, sexual, child labor, neglect, etc.
- Tell them they will receive a document about abuse at the end of the workshop that they can refer to. (Note: Handing this out before the workshop is over is usually a distraction.)
- Ask, "What are some of the penalties for abuse in your country?"
 Answer: In Kenya, the penalty for abuse is jail time and fines. Refer to local laws and Appendix A-11 for specific penalties.
- Then lead participants in a discussion about the "Steps for Reporting Sexual and Physical Abuse." Ask these questions:
 - What is the first thing a person should do if he/she is sexually abused? Answer: Leave the scene immediately and go to a safe place.
 - Why do you think he/she should not remove his/her clothes or take a bath? Answer: Because his/her body and clothes may have evidence that would help the police convict the perpetrator.
 - How can someone preserve the evidence if he/she must remove his/her clothes? Answer:Wrap them in a newspaper, not a plastic bag.
 - What are 3 services the person will receive at the hospital? Answer: Medical treatment for physical injuries; prevention for pregnancy, HIV, and other sexually transmitted infections; counseling support
 - Who are some people the person should tell about the incident? Answer: A trusted friend or family member, the police, the Child Protection Center, the hospital staff
 - What should be brought to the Child Protection Center in addition to the person who was assaulted? Answer: The police report
 - What other services should the person receive? Answer: Legal counsel
 - What can be done to prevent future abuse?
 Answer: Establish a safety plan for the person and his/her caretaker to follow

¹⁷ "Child maltreatment," World Health Organization, last modified September 19, 2022, https://www.who.int/news-room/fact-sheets/detail/child-maltreatment.

¹⁶ Kenya, Parliament, Children Act, Children CAP 141, adopted March 1, 2002, Revised Edition 2012 [2010], art. I, sec. 2, https://www.ohchr.org/sites/default/files/Documents/Issues/Migration/ CallEndingImmigrationDetentionChildren/CSOs/RefugeeConsortium_of_Kenya_Annex3.pdf.



Testimony From a CHP Workshop Alumnus

32. CHP Introduction

- Invite the CHP to come speak to the group.
- Introduce him/her to the participants.

33. CHP Testimony

- Invite a CHP whose disability-related beliefs and practices have improved as a result of this workshop to share his/her testimony. This person should prepare to share the following:
 - A successful intervention that he/she has done for a disability
 - An intervention for a disability that he/she used that was ineffective
 - Problems he/she encountered with an intervention
 - Ways he/she is helping others to learn successful interventions
 - Ways he/she is helping to refer people with disabilities to clinics and special schools for intervention and how they are supporting them
 - Examples of children who have been helped because of interventions and support they've received at clinics and/or special schools
- Ensure the CHP covers the points above in his/her speech. If not, prompt him/her with questions.
- If there is time, allow the participants to ask the CHP questions after his/her presentation.



Action Planning

34. Small Group Action Plan Writing

- Ask participants, "Based on our discussions today, what do you think the role of CHPs should be when it comes to identifying and supporting people with disabilities?"
- Ask for the workshop participants to get into groups of 4-5 people who live relatively close to one another.
- Explain that each group will have 15 minutes to develop a Disability Advocacy Outreach Action Plan.
 - The secretary will write the groups' action plan on the flip chart. (Hold up the flip chart.)
- Pass out the prepared flip charts with this chart (one flip chart per group).

| C | Date | Activity | Location | Person Responsible |
|---|------|----------|----------|--------------------|
| | | | | |
| | | | | |

- Mention that while we think others will support children with disabilities in our communities, it's all our responsibilities to support them, just like any other child.
- As they are doing the exercise, walk around the room and provide positive feedback to those who are doing it well, and help those who are struggling.
- Check in with groups to ensure they are including the following areas of support for people with disabilities and their families:
 - Education
 - Nutrition
 - Communication
 - Medical referrals
 - Ways to educate their communities, including children with disabilities themselves, about the true definitions, causes, and interventions for disabilities
 - Ways to educate their communities, including children with disabilities themselves, about justice and inclusion for people with disabilities and their families
 - Ways to educate other CHPs who can propagate harmful beliefs and practices about disability
 - Direct support: helping with daily support, like feeding, washing clothes, checking in to see how families are doing, etc.
- As they are developing their action plans, remind the groups that we need to educate our communities about disability as well as other CHPs who can propagate harmful beliefs and practices about disability.
 - Ask them to consider how and when they can help other CHPs understand how to provide support for people with disabilities.
- Mention that many workshop alumni have found it helpful to give disability sensitization talks at one of their village's regularly scheduled chief meetings. These events are:
 - Well attended, including by various community groups and government ministries
 - Well received because the content has been approved by the chief
- Also mention that disability sensitization talks at burials and weddings, when arranged through the event's coordinators, are often well attended and received.





Action Planning (continued)

35. Presenting Group Action Plans and Completing Our Individual Action Plans

- Explain that, in addition to a group action plan, each participant will also write his/her personal action plan items on a worksheet (hold up the Appendix A-4 worksheet).
- Explain that participants will write down what they committed to in their groups and can also add ideas they like from other groups.
- Pass out one copy of the My Disability Outreach Action Plan Worksheet (Appendix A-4) to each participant.
- Then prompt the group to present their action plans one by one.
- Explain that others can provide feedback and ask questions after each presentation.
- Make sure that one of your co-facilitators takes a picture of each group's action plans for reporting purposes. The group leaders can take the flip chart home.
- During the presentations, monitor the room to make sure each participant is writing his/her own action plan activities on the Appendix A-4 Worksheet to take home.

Action Plan Follow-Up Logistics

36. Review the Weekly Reporting Form and Submission Instructions (Appendix A-7)

- Read the form together, especially the instructions at the top.
 - Emphasize that these should be completed each week and submitted monthly.
- Explain that participants will use this form to keep track of their disability advocacy activities.
 - Explain that individuals who have low levels of literacy can select a trusted family or community member to help them complete this form each week.
- Explain that these reports help the host organization know:
 - What's working well in the program
 - What needs to be modified in the program
 - How they can further support participants with resources, trainings, mentorship, etc.
- Answer any questions or concerns they may have.

37. Discuss Challenges That May Arise

- In addition to completing the reports, encourage trainees to contact the host organization if they face challenges in their advocacy work.
 - Explain that this is particularly important if a child has medical needs that could become life-threatening if they are not addressed.



Action Plan Follow-Up Logistics (continued)

37. Discuss Challenges That May Arise (continued)

- Explain that the organization can also help them to brainstorm strategies to overcome challenges, such as those related to families who need funding or transportation to support their child with a disability.
 - Spend a few minutes brainstorming ways they could help a family who is in this situation. Write participant answers on the board. Possible answers include:
 - Hosting a fundraiser for the family
 - Hosting a food/clothing drive for the family
 - · Asking the chief or elders for support
 - · Starting a Disability Advocacy Committee to help families in need
 - Helping the family start an income-generating project

Note: Funding and transportation challenges are common concerns raised by local leader child advocates trained by Kupenda and Kuhenza. Therefore, this discussion is a helpful way to address these concerns preemptively.

38. Select a Point Person for Each Small Group Who Will Report to the Host Organization

- Explain that they will now select a person from their group whom they feel is best suited for collecting and submitting their reports each month.
- Once each group has selected a point person, ensure those people understand that they will be responsible for collecting action plan updates from all the participants and reporting back to the host organization each month via WhatsApp, phone, email, or by dropping them off at the office.

39. Share Participant and Organization Contact Information with the Selected Point Person

- Provide the point people with their participants' contact information.
- Provide them with the host organization's contact information for report submission.

Disability Advocate Commitment

40. Distribute 2 Copies of the Disability Advocate Commitment to Each Participant (Appendix A-9)

- Review the content together.
- Answer any questions participants may have about the Commitment.

41. Ask Participants to Sign 2 Copies of the Commitment

- Collect one copy for your records.
- Let participants keep the second copy as a reference.





Certification Program

42. Show Participants a Sample Disability Advocate Certificate (Appendix A-8)

43. Explain the Certification Process

- Explain that participants who complete 3 consistent months of high-quality reports will become certified disability advocates.
- Explain that high quality reports are:
 - Dated
 - Complete
 - Indicate that the participant is actively fulfilling the commitments he/she made in his/her action plan
- Mention that certified disability advocates will receive both a hard copy and electronic copy of this certificate, customized with their preferred name.

Resources Review and Distribution

44. Present and Distribute the Disability Guidebook (Appendix A-10)

- Before distributing pages from the booklet, remind participants that you reviewed 5 disabilities in this guidebook earlier in the workshop.
 - Ask if they can remember which disabilities you discussed.
- Remind them that this resource:
 - Describes some of the most common childhood disabilities
 - Includes causes, interventions, and risk reduction information
 - Includes photographs of children with disabilities
- Pass out the booklet and ask participants to tell you with whom they might share this booklet. Write their answers on a flip chart. Ensure they include the following:
 - People with disabilities
 - Family members of people with disabilities
 - Teachers and special education teachers
 - Doctors, midwives, and physical therapists
 - Traditional healers, soothsayers, and traditional birth attendants
 - Other CHPs
 - Other religious or local leaders in their communities
 - Government officials



Resources Review and Distribution (continued)

45. Present and Distribute the UNICEF Module: Identifying Disability (Appendix A-15)

• Before distributing the UNICEF Module: Identifying Disability (Appendix A-15), explain that this resource is based on a resource by the United Nations Children's Fund (UNICEF). This resource can assist CHPs in assessing functional difficulties in speech, language, hearing, vision, learning, mobility and motor skills, and emotions.

46. Present and Distribute the Local Disability Law Summary (Appendix A-6)

- Before distributing the Summary of the National Act or Local Laws Regarding Disabilities (see example in Appendix A-6), explain that this resource:
 - Describes some of the local laws related to disability
 - Includes citations and related penalties for breaking these laws
 - Provides contact information for where to refer children with disabilities for support
- Pass out the booklet and ask the participants to tell you with whom they might share this booklet. Write their answers on a flip chart. Ensure they include the following:
 - People with disabilities
 - Family members of people with disabilities
 - Teachers and special education teachers
 - Doctors, midwives, and physical therapists
 - Traditional healers, soothsayers, and traditional birth attendants
 - Government officials
 - Other religious or local leaders in their communities
 - Other CHPs

47. Present and Distribute the Service Referral Guide for Children with Disabilities (see example in Appendix A-5)

- Before passing out the list, explain that this includes the names and contact details for organizations and entities that can provide medical care, financial support, nutritional support, educational services, assessments, legal support, support groups, and equipment for children with disabilities and their families.
- Encourage participants to review the full list through the link/materials provided and make copies that they can distribute to those in their community.
- Ask them to let you know if they have additions to the list.

48. Distribute the Abuse Prevention Resources (Appendix A-II)

- Remind participants that you reviewed abuse prevention earlier in the workshop.
- Explain that this resource:
 - Defines abuse
 - Lists the types and examples of abuse
 - Lists laws related to abuse
 - Lists the penalties for abuse
 - Lists steps for reporting sexual and physical abuse



Resources Review and Distribution (continued)

- 49. Distribute the Access to Healthcare, Insurance, and Birth Certificates Handout (see sample in Appendix A-14)
 - Explain that this document includes instructions on how to access national health insurance, birth certificates, assessments, healthcare, and how to register as a person with a disability.
 - Explain that they can use this resource when they are counseling families impacted by disability.

50. Present and Distribute a Copy of the Host Organization's Brochure (If Applicable)

• Explain that this brochure highlights the work of your organization and includes contact details.

51. Administer the Survey Again to Assess Changes (Appendix A-3)

- Explain the following before you pass out the survey:
 - We will take the survey again to determine if there have been any changes.
 - Participants have 10 minutes to complete the survey.
 - They should not speak to one another as they complete the survey.
 - They should be honest. They will not be judged.
 - The results will be used to assess the workshop, but their specific names and answers will be kept confidential.
- If some participants are illiterate, assign someone to administer the survey verbally and write the participants' answers.

Note: Remind the volunteer or staff member that he/she should not provide the survey answers to the participants while assisting them.

- Administer the survey.
 - Walk around the room helping people who are stuck or confused.
 - Ensure they answer every question.
 - Give them time warnings when there are 7, 5, 3, and 1 minute(s) remaining.

52. Distribute the Certificate of Participation (Appendix A-16)

• Explain that you will now hand out a *Certificate of Appreciation* (Appendix A-16) to each participant for completing the workshop.





Conclusion

53. Volunteer Reflection

• Invite a volunteer to close the workshop with a spoken reflection on the experience.

54. Closing Words

- As a facilitator, share your reflection of the experience. Remember to thank the participants, host, and co-facilitators.
- If any of the participants regularly use email, offer to send them electronic versions of the materials you have shared.
- If any of the participants would like to host or facilitate another workshop, encourage them to speak with you after the closing.
- If any participants are interested in learning more and having follow-up workshops, tell them to let you know after the closing.
- If any of the participants have remaining questions or concerns about the content, encourage them to speak with you after the closing.

55. Word of Thanks

• Invite a volunteer to give a word of thanks.

56. Closing Prayer

• Invite the lead CHP to say a closing prayer.

57. Collect Sign-In Sheet

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Appendix A: Resources



Full resources may be found at: bit.ly/3IX3cZk

- A-I. Sign-In Sheet
- A-2. Media Consent
- A-3. Survey
- A-4. My Disability Outreach Action Plan
- A-5. Sample Service Referral Guide for Children with Disabilities
- A-6. Sample Summary of the National Act or Local Laws Regarding Disabilities
- A-7. CHPs' Weekly Reporting Form
- A-8. Disability Advocate Certificate
- A-9. Disability Advocate Commitment
- A-10. Disability Guidebook
- A-II. Abuse Prevention Resources
- A-12. Facility, Communication, and Resource Accessibility Checklist
- A-13. CHP Guide Presentation Visuals
- A-14. Sample Access to Healthcare, Insurance, and Birth Certificates Guide
- A-15. UNICEF Module: Identifying Disability
- A-16. Certificate of Participation