

A photograph of a woman, likely a teacher or volunteer, smiling and leaning over a desk to assist three children with their schoolwork. The children are focused on writing in their notebooks. The scene is set in a classroom with a wooden ceiling and windows in the background. The entire image has a warm, orange-toned overlay.

Key Informant (“KI”) Volunteer TRAINING

KIM Malawi

Caring for children with disabilities

2013

Key Informant Training

1. Background to project
2. Understanding Disability
3. How to identify children for the project
4. Disability Rights
5. Next steps
6. Responsibilities
7. Contact details

Aim of project

To find out the number of children with disabilities living in communities in Thyolo and Ntcheu using the *Key Informant Method*



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Specific Objectives

- To count the number of children with disabilities, including how many have different types of impairments or difficulties, and what services they have access to
- Use this information to improve the range of services available for children with disabilities in Malawi
- Refer children to medical and other services that can help them take part in daily community life

How it works

Volunteer Key Informants (YOU!) go into your own communities to find children with disabilities and inviting them to attend screening camps
(July and August)

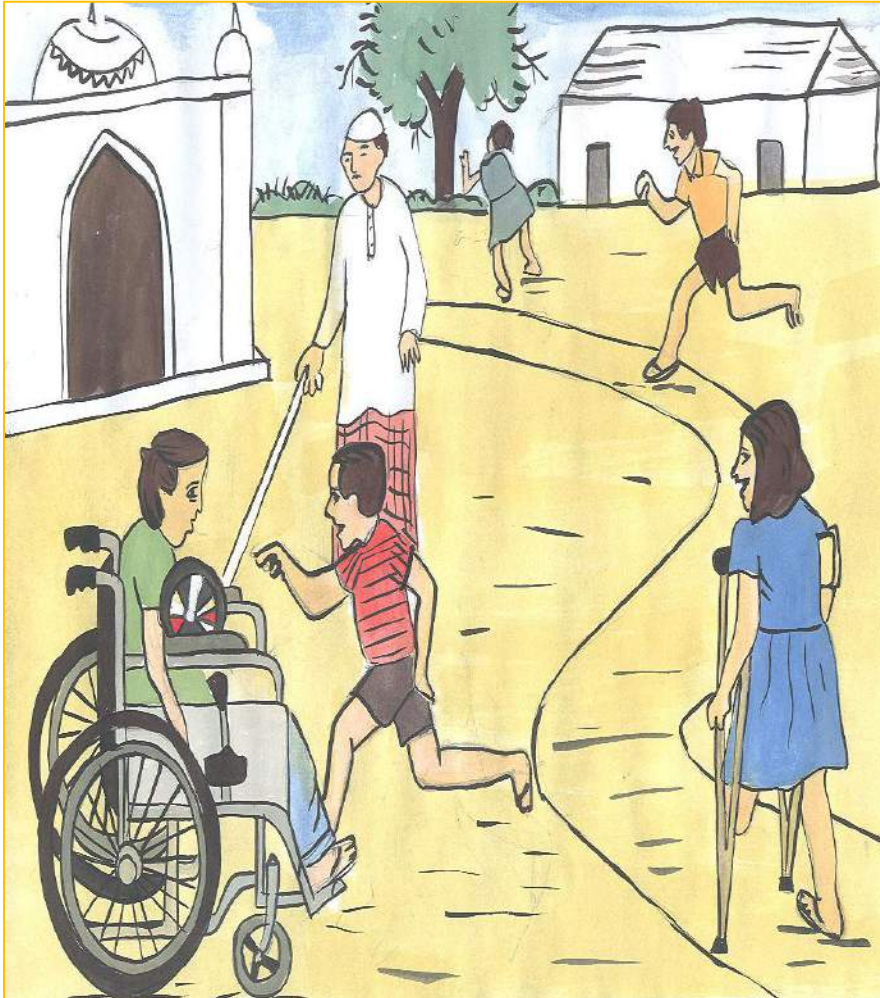
At the screening camps children will be screened by clinical officers to see if they can identify what is causing the child's impairment
(September and October)

Where problems are found, children will be referred to available health and support services

Activity

- Brainstorm: What do we mean by disability?

Different types of disabilities



- Physical Impairment
- Cognitive Impairment
- Hearing Impairment
- Visual Impairment
- Mental health problem
- Multiple impairments

Here are different impairment groups and what they mean:

1. Physical Impairment

- can mean problems walking, picking up objects

2. Cognitive Impairment

- can mean problems understanding or behaving in the way that people expect

3. Hearing Impairment

- not being able to hear people talking and other sounds

4. Visual Impairment

- not being able to see enough to read or carry out daily activities the way most people would expect

5. Epilepsy

- An illness that, without medication, can prevent a person carrying out daily activities because of frequent seizures (fits)

6. Mental Health Problem

- can cause difficulty interacting with people and accomplishing daily activities)

7. Multiple Impairments

- some people have many impairments together, such as not being able to walk or speak)

Identifying boys and girls with **visual impairment** (aged from 3 months to 17 years)

Who are we looking for? Children who...

- Cannot not see properly since birth
- Could see when younger but have since lost their ability to see properly (for example due to illness or injury)
- Can see well with glasses but can not see properly without glasses

Don't forget

Some children cannot see properly even though their eyes look normal on the outside!



When do I invite a child with a visual impairment to a screening camp?

- If one (or both eyes) or some part of them do not look normal
- If the parents think that the child cannot see because of a serious problem in the eye
- A child who has a difficulty seeing that is causing serious problems with daily activities
- A child with a permanent eye problem since birth or since illness

For children under 5 years:

- When a child does not look at or follow an object that is moving in front of them

For children between 6 – 17 years:

- When a child can not count, with open eyes, the fingers of a person standing about 6 meters in front of them



Identifying boys and girls with **hearing impairment** (aged from birth to 17 years)

Who are we looking for? Children who cannot hear well; who may have difficulty speaking properly; who often ask people to repeat what they are saying to them; who get teased or disciplined for being 'slow' or 'stupid' at school; children with a discharging ear (or ears).

Did you know??

Many children with hearing impairments miss getting help because teachers and parents think they're just not listening!

What are the signs of a hearing impairment?

Under 2 years

1. If a baby does not react to loud noises (clapping, whistle, loud speaker)
2. If you speak normally to your baby and she/he does not turn to look at you
3. If child is over 6 months and makes no sounds

2 year olds

4. If a child cannot name familiar objects

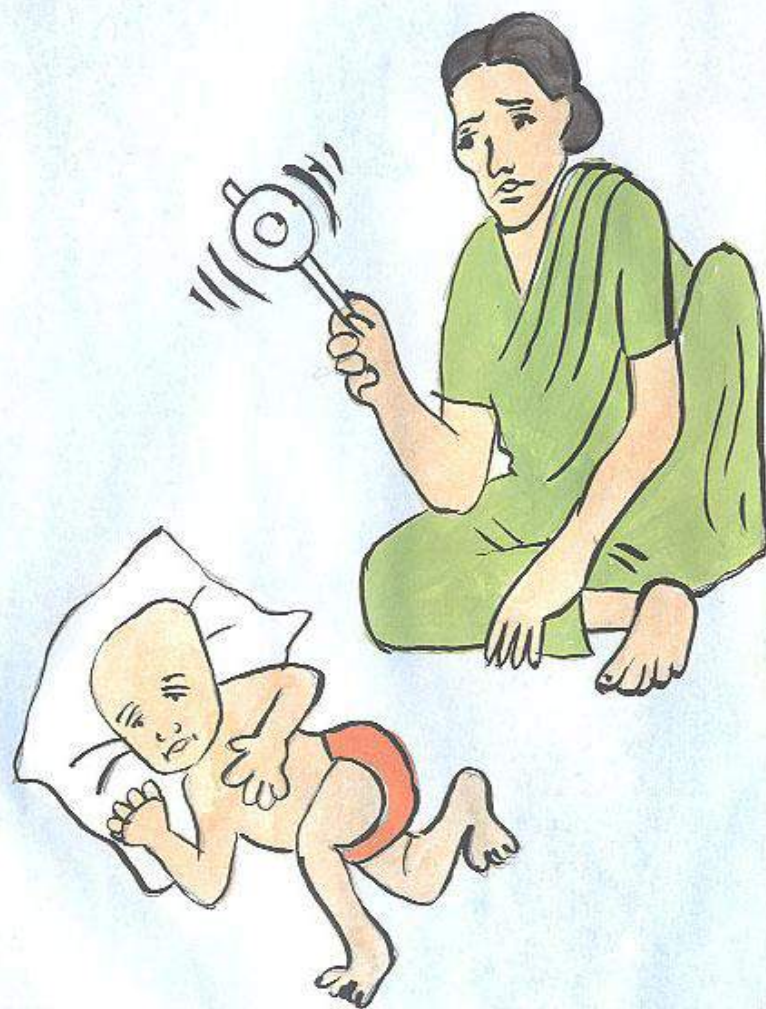
Signs of hearing impairment (continued):

Above 2 years

1. If you have to raise your voice to get your child's attention
2. You have to increase the volume of the TV or radio a lot

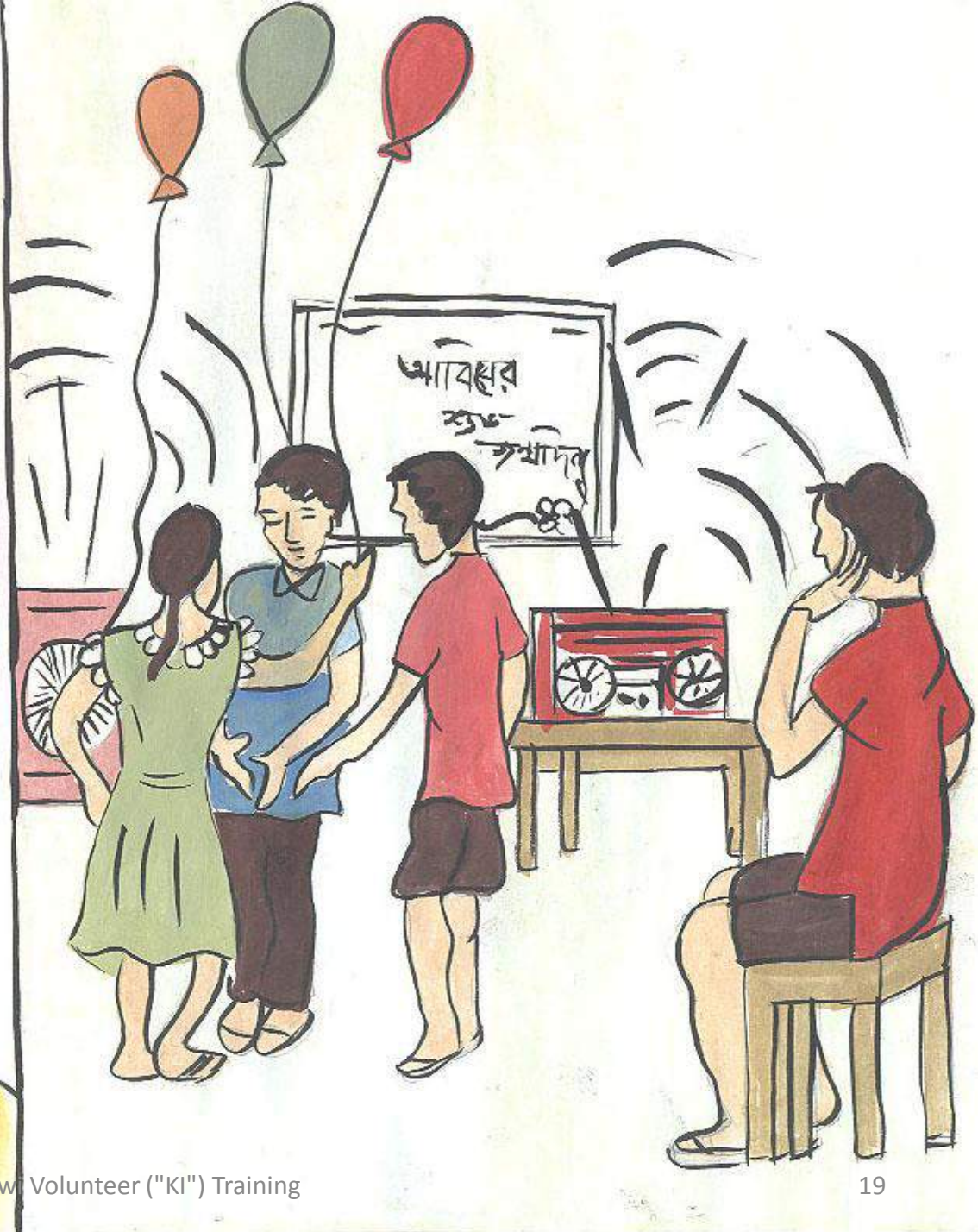
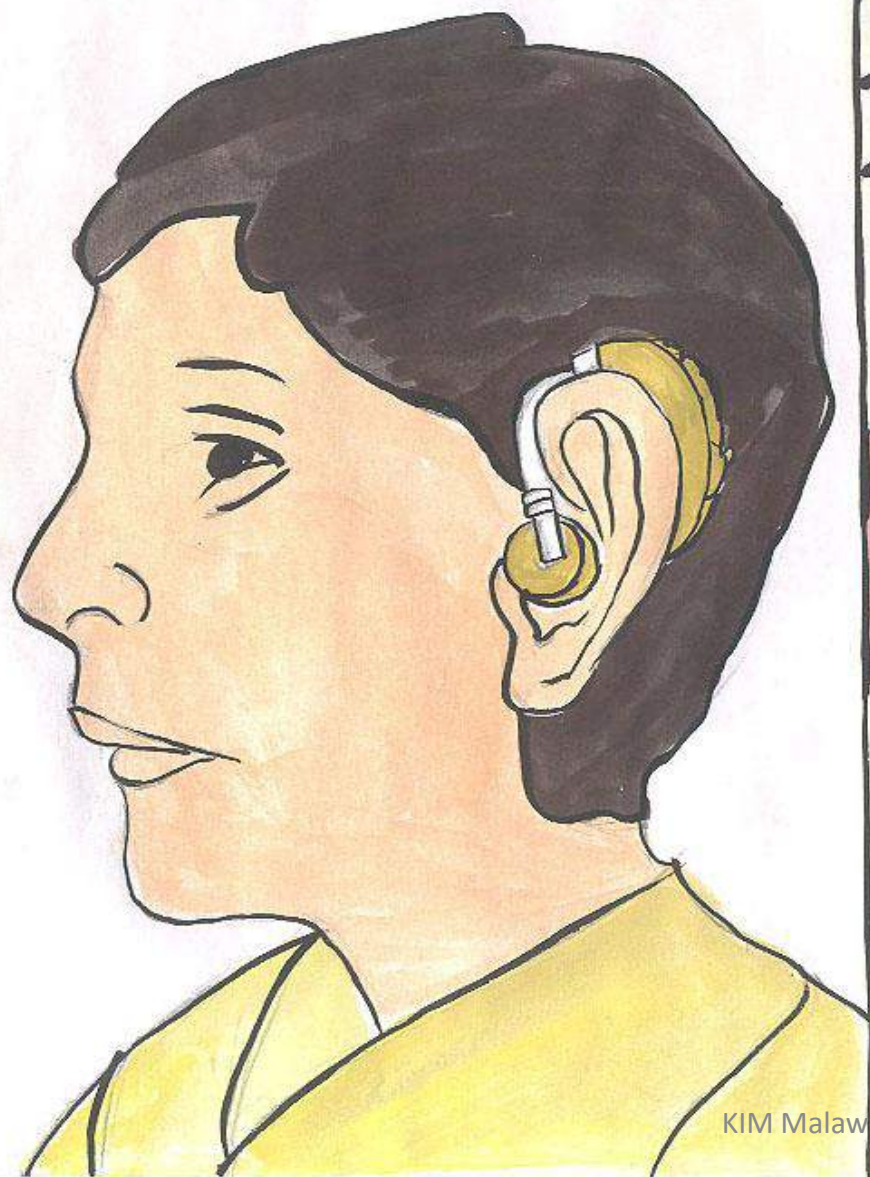
From 3 years and above (who do not have Cerebral Palsy or other forms of cognitive impairment)

3. If they are not able to describe an object in meaningful sentences



When do I invite a child with a hearing impairment to a screening camp?

1. If there is any **discharge** coming out of the ear
2. Has a child ever had discharge for more than 3 months (even in the past)
3. If the child has discharge from the ear once a year or more for 3 or more years
4. If one needs to sit on one side for the child to hear or the child is often asking people to repeat questions
5. If the child has **breathing difficulties** at night? (Such as snoring)
6. If the child is suffering an ear problem for 6 months or more
7. If a child has serious ear/hearing problems since birth or has permanent hearing loss



Identifying children with **epilepsy**

Epilepsy is a brain (neurological) condition which causes a person to lose consciousness. It is due to a malfunction in the brain.

What do you do when a person has a fit (seizure)?

Make sure the person is safe, move objects away from the persons' head

Do not put anything in that persons' mouth

Do not hit the person or force them to sit up

Comfort the person when they awake, allow them to rest quietly

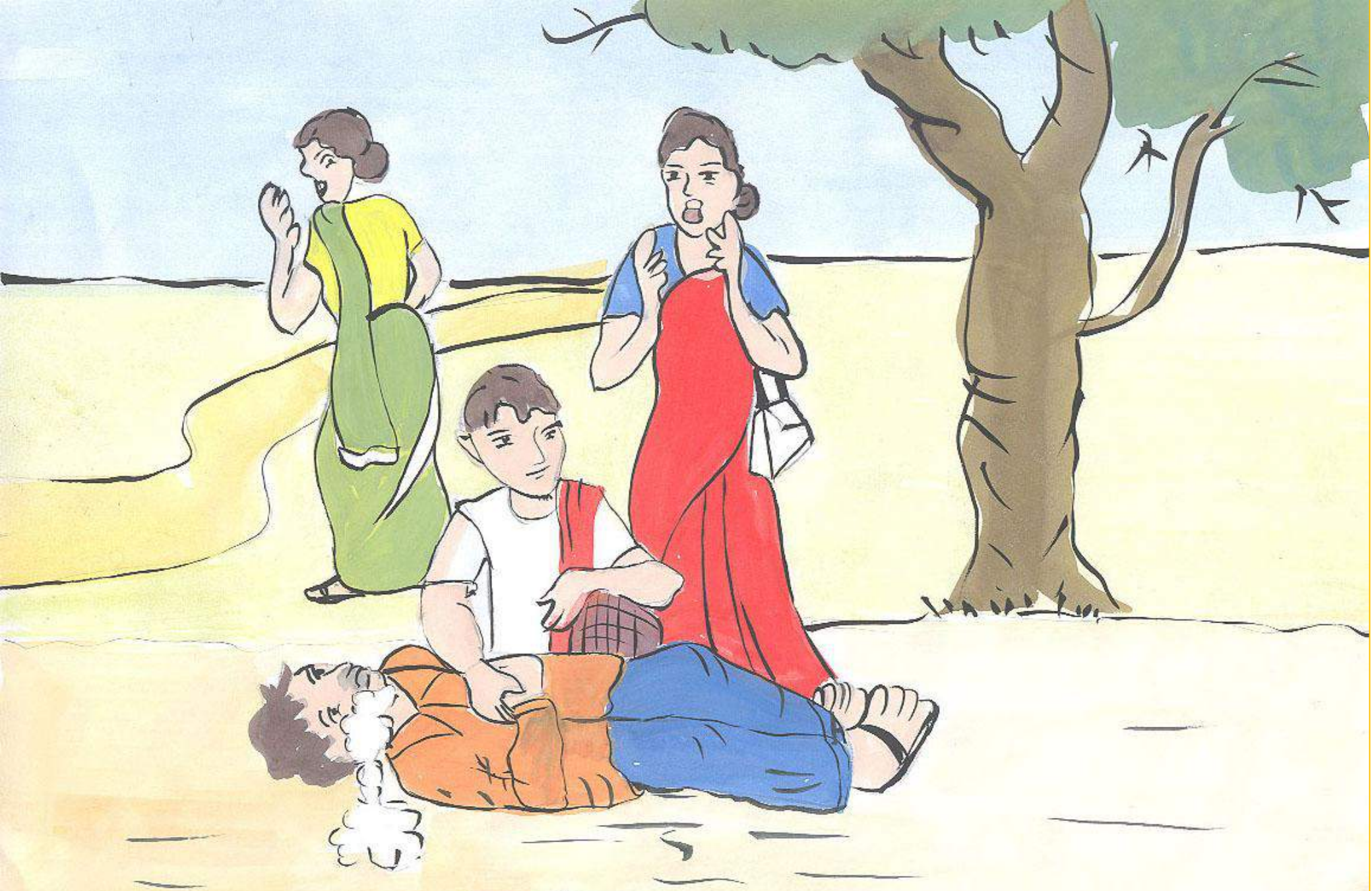
What are the signs of epilepsy?

1. The child may have had fits, become stiff, or lost consciousness
2. The child may have spasms or jerky movements of arms, legs, or the whole body
3. Sometimes, there is frothing at the mouth during an episode
4. A child may suddenly fall over and bite their tongue



Which children should be identified?

1. Children who have had seizures or fits more than once over the past 6 months or more
2. The children who have seizures or fits incidents consistently since birth or started to have them soon after



What are the signs of **physical impairment**?

1. Compared with other children, there was some delay in sitting, standing or walking
2. The child has weakness, stiffness, or floppiness in the arms or legs
3. One of the following got more difficult as the child gets older: walking, running, climbing stairs, getting up from squatting position or child has frequent falls

Other signs of physical impairment?

- 4. He/she finds it difficult to pick up or manipulate small objects
- 5. There may be an part of their body (head, mouth, chest , limbs or whole body) which is larger and smaller or shaped differently than other children their age
- 5. Children who have wasted or abnormal muscles due to polio, cerebral palsy, dystrophy, burns, or some other reason



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Some specific conditions

Club Foot

- Foot deformity since birth
- One or both feet curving inwards
- Children with club foot find it hard to walk properly



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Chronic osteomyelitis

An infection of one or several bones. Is painful and may cause sores on skin as the infection moves out from the bone, through the skin.



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Cleft lip and/or Cleft palate

- A condition children are born with
- These children may have difficulty eating or speaking clearly like others
- These children may look different from others and may feel shy



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Limb deformity

(leg or arm disability)

- If any part of the child's body is small or absent
- The body part may cause imbalance or difficulties in function
- Most children are born with limb deformity, though some can be caused by an accident, burn, or other trauma.

Chilema pamwendo kapena nkono (leg or arm disability)

- Ngati chiwalo china cha mwana ndi chachingo'no kapena palibepo kapena mawonekedwe a chiwalocho ndiwosiyana ndi ana ena, .
- Chilemachi chimabweretsa mavuto osiyanasiyana kuphatikizapo machitidwe a zinthu kapena kagwiridwe ka ntchito.
- Ana ambiri amene ali ndi chilemachi amakhala kuti anabadwa nacho.





Cerebral palsy (CP)

- A child has difficulty controlling his or her movements; some limbs may be very stiff; they may have trouble holding up their head
- A child may be unable to speak, or to speak clearly



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15.05.2008

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Even more specific conditions:

Hydrocephalus

- Hydrocephalus will be clear at birth or during the growing stage
- Their head is much larger than their physical structure
- The child's head growth is quicker and abnormal for their body
- The head looks much bigger than other children

Microcephalous

- A very small head for that child's age
- May mean that the child will have problems understanding and learning or other developmental difficulties



Identifying children with **intellectual disability?**

Who are we looking for?

- Who are the children with cognitive/intellectual impairment in our communities?
- Often called intellectual disability, cognitive impairment, mental retardation...
- Brainstorm of Chewa terms...

Don't forget

Children with cognitive impairments still have a right to be loved and cared for by their family, a right to take part in their community, and to get an education!

How to recognize children with **intellectual disability**?

There are many signs of cognitive impairment (or intellectual disability). For example, these children may:

- Sit up, crawl, or walk later than other children
- Learn to talk later, or have trouble speaking
- Find it hard to remember things and to take care of themselves
- Have trouble understanding social rules or “fitting in”
- Have trouble seeing the results of their actions
- Have trouble solving problems
- May have very aggressive behaviour compared to other children of their age and gender



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Other conditions

- Albinism
- Discussions of Chewa terms for other conditions...



Which children with impairments should be identified?

- Children who have moderate to severe problems since birth or for more than 6 months
- Children who can NOT do daily living activities easily: for example dressing, washing, going to the toilet, talking, seeing, hearing or moving about
- This is NOT about being eligible for a project. This is about trying to get good information on the number of children with disabilities – children who have trouble with daily activities due to their impairment or condition

Expectations

Expectations

Respect

Confidentiality

Child protection

...Next Steps...

- How to collect information on families
 - Journal and spreadsheet
 - Information required
- Planned date of Screening Camp
 - At _____
 - On _____
- How to communicate with parents
- Parents should bring along the child's HEALTH PASSPORT (but children without one will still be seen)

Project Staff in Malawi

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Stakeholders

Funders

- The Health Partnership Scheme (COOL Programme)
- CBM
- CURE International UK
- Lilliane Foundation
- Fight for Sight

Advisors

- Mr. Action Amos, Ms. Miriam..., Dr. Mac Mallewa, Mrs. Dorothy Chinungo, Dr. Ntcheu, Dr. Amber Majido, Dr. Margaret Wazikili, Dr. Colleen Adams

Collaborating Research Institutions

- Beit CURE International Hospital
- London School of Hygiene and Tropical Medicine
- The College of Medicine (Malawi)

Partners

- FEDOMA, PODCAM Ntcheu District, Thyolo District, MACOHA's Ntcheu CBM programme, CBM Malawi office, QECH, Lion's Eye Hospital (QECH)

Thank You



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