Key Informant Training Manual

Identification of Children with Cerebral Palsy in the Community using the Key Informant Method (KIM)

This training manual has been developed by CSF Global team.

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Introduction

This manual has been created to systematically train volunteers to identify cases of children with disability such as cerebral palsy (the leading cause of childhood disability globally) in their local areas, particularly remote rural communities in low- and middle-income countries (LMICs). It has been developed to serve as a structured guideline to train the 'Key Informant' volunteers following implementation of the method, i.e., the 'Key Informant Method' (KIM) in numerous studies and projects over the years since its inception.

According to the World Health Organization (WHO), 85% of children with disability live in low- and middle-income countries (LMICs) and the majority of children with disability have limited access to any basic or specialized healthcare, rehabilitation services, accessible environments, assistive devices, and other necessities.

Determination of the burden and causes of disabilities or diseases is a matter of importance to health policy makers and planners for proper resource allocation, planning, development and implementation of service delivery systems. It is also of importance to researchers and academics for their studies to generate knowledge to bring about public health improvements.

Challenges exist, particularly in low-resource settings, for studies aiming to investigate the epidemiology of diseases, in the form of data that is often unreliable or wholly absent, difficulties in mobilizing adequate resources, remote rural areas with poor transportation, lack of awareness and other barriers. Childhood disability studies are no exception to this, the mentioned factors along with other issues such as social superstition or stigma pose further obstacles to childhood disability research and service delivery programs. The absence of baseline data on childhood disability such as cerebral palsy and the need for large sample size renders conventional survey approaches as time-consuming and resource-intensive, thus ineffective in LMICs. The Key Informant Method (KIM) has been developed and tested to be an effective alternative method to identify cases at the community level.

What is the Key Informant Method?

The Key Informant Method, or KIM, is a novel method for identifying children with disability (such as cerebral palsy) in the community. It involves training local volunteers to act as key informants (KIs). KIs are people who live and/or work in their local community, who have a social role through their vocation, and who are, therefore, likely to know the local context as well as the people about whom the information is being sought. KIM is a social mobilization strategy with a community-based approach for the identification, diagnosis, treatment, and rehabilitation of individuals with disabilities.

Who are the Key Informants?

The Key Informants (KIs) consist of local volunteers such as community health workers, teachers, students, non-government organization (NGO) staff, government staff, religious leaders, traditional healers, local journalists, or other people who are actively involved in the social network of their communities to identify children with disabilities in their areas, educate families and other community members about disability, and forge linkages between children with disabilities and local services.

History of the Key Informant Method

KIM was pioneered and piloted in Bangladesh through field research by CSF Global (csf-global.org) to identify children with cerebral palsy, physical impairment, visual impairment, hearing impairment, and epilepsy in remote rural communities. The technique has also been utilized at projects in more than 21 LMICs including China, India, Iran, Ghana, Malawi, Indonesia, Pakistan and Kenya.

Aims and Objectives

This Key Informant (KI) Training Manual is designed to help project managers and planners to train community volunteers ton the Key Informant Method by:

1. Spreading knowledge among the KIs regarding disability and disability-related issues
2. Instructing KIs regarding the needs (or unmet needs) of children with disabilities
3. Orient and train KIs to aid in converting research into public health interventions
4. Encouraging KIs to promote inclusiveness and equality in society
5. Activating KIs to identify children with disabilities and inform their families regarding service accessibility and rehabilitation needs
6. Engaging KIs to serve as effective linkages between children with disability and service providers

How will the Key Informant Method work?

An implementation of a KIM study or project would involve an understanding of the existing social networks and institutions, wherever possible sincere efforts should be made towards working with existing community health workers and other socially connected individuals with whom the people are familiar and are likely to cooperate. Therefore, a comprehensive understanding of the prevailing social network and interactions is essential to ensure optimum outcomes from the KIM implementation. Simultaneous efforts to map the available services (health, rehabilitative, educational, vocational, etc.) and multi-stakeholder engagement efforts are also necessary.

Subsequently, KIs will be recruited based on the understanding of social networks and trained to identify children with disabilities using standard instructions and procedures. The KIs will identify children with disabilities in their own communities, after which they will contact the project/study personnel regarding their cases and at the same time inform the disabled child or their family regarding the available services (whether facility or camp based), i.e., they shall commit themselves to be the effective link between two parties.

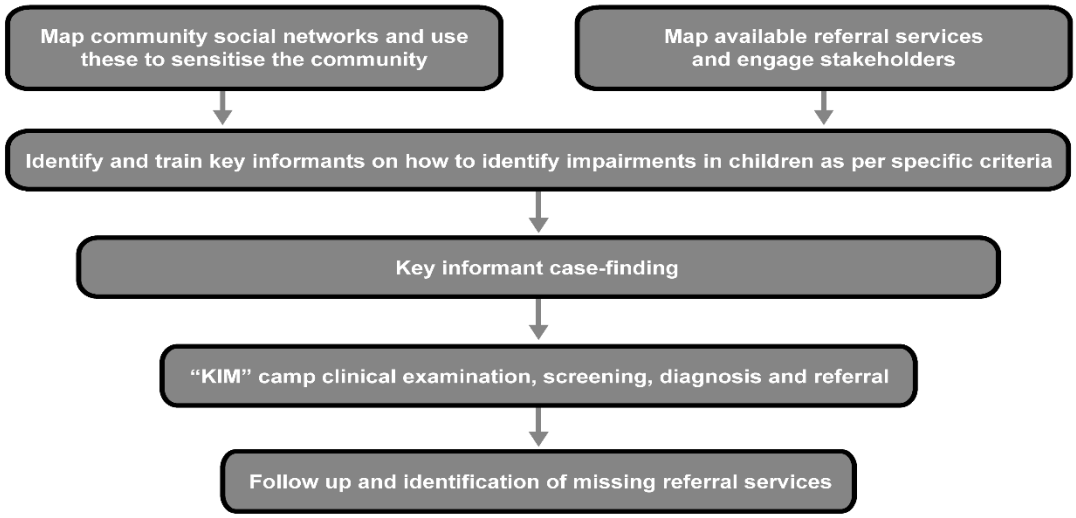

Figure 1: KIM flow diagram

Timeline

A project utilizing the Key Informant Method (KIM) by engaging a network of KIs can follow the devised model consisting of an 8-10 weeks long work plan. Appropriate modifications should be made depending on special requirements and context.

Activity	Weeks									
	1	2	3	4	5	6	7	8	9	10
1. Mapping social networks										
2. Networking and sensitization										
3. Organize local KIs										
4. KI training										
5. Case finding and health communication										
6. Supporting KI activities										
7. Planning and organizing camps										
8. Medical assessment										
9. Documentation and monitoring										
10. Referral and follow-up										

The series of 10 outlined activities with the specified timeframe constitute the standard operating procedures in conducting a KIM study. Project managers are advised to create a sketch of their own plan derived from this outline but based on their constructed logical framework.

KI Resources and Support Structure

The KIM requires resources; training and orienting the KIs to build their capacities for carrying out their activities, and inputs from the organization/project. Although a KIM study requires less resources compared to conventional methods such as door-to-door surveys, a structured and planned resource allocation must be made for the KIs.

- Proper training of KIs is fundamental for identifying children with disabilities such as cerebral palsy, a crucial matter for the success of any KIM study
- Training support and services; training session(s) must be facilitated with the organization/project resources, adequate materials (pamphlets, leaflets, etc.) to help identify the children with disabilities and access provided to address further queries or clarifications.
- The selected KIs must be reliable, mobilized, motivated and willing partners, they should be committed to maintain proper communication and networking with the community people as well as with the project team members (Figure 2). Otherwise it will affect the study outcomes.
- The work of KIs should be voluntary to minimize the costs of conducting the study, however the project should reimburse KIs for any expenses incurred while attending the training and any other subsequent sessions to ensure that linkages remain.
- Motivation and mobilization of the KIs will be carried out by Community Mobilizers (project staff) who will utilize their own networking, social and communication skills, motivation, and commitment to organize the KIs (Figure 3).
- A communication strategy is helpful for documentation and reporting purposes; KIs in the field will regularly communicate with community members and the Community Mobilizer(s) while a Field Project Coordinator will oversee activities in an area under the overall leadership of a Project Manager (Figure 3).

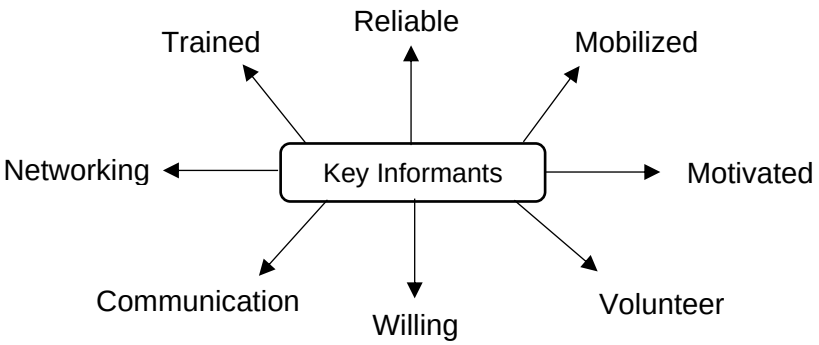

Figure 2: Characteristics of Key Informants

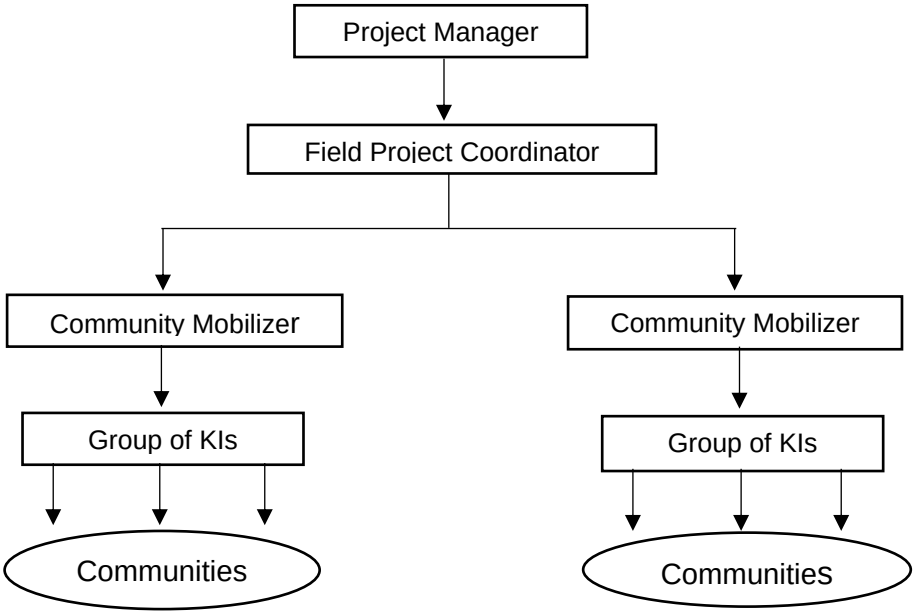

Figure 3: Team structure and plan for supervising key informants

Each KI (Key Informant) will be responsible for covering a certain area, a part of the community where they live or work or regularly visit for other purposes and have an existing social network that can be strengthened and activated to identify children with disabilities.

KI Training Structure

The KIs training should be a day-long session conducted close to the area in which they are based (i.e., live, work, travel for trade, etc.). General practice is to provide the training to the Key Informants free of cost (the organization shall bear all expenses associated with hiring venue, engaging trainers, arranging training materials and providing refreshments).

The following matters must be kept in mind and addressed accordingly while organizing KI Training Sessions:

- Appropriate **selection of venue**, date and time to ensure maximum attendance and minimum possible inconvenience.
- Provision of adequate and useful **training materials** to help the KIs with their work (booklets, leaflets, pamphlets, charts, etc.) for recognizing and reporting children with disability. They must be provided free of cost.
- Arrangement of **transportation** for the KIs, or reimbursement of incurred travel expenses.
- Lectures or sessions must be **understandable** by the KIs and modified according to context and capacities – this should include material covering the project itself, recognizing disabilities, awareness regarding disability issues, and familiarization with available services.
- Optional resources or support mechanisms in case of any additional roles and functions to be carried out by the KIs.

KI profiles: Personal profiles for recruited KIs including contact details and basic demographic data, education status, profession, etc. could be maintained by the project team. This process can be started during the mapping stage and finalized during the KI training sessions.

Identifying children with cerebral palsy: The primary focus of the training session will be on identifying children with cerebral palsy.

Cerebral palsy is an umbrella term for a broad group of movement disorders that affect movement and posture due to damage to the developing brain. While it is a life-long physical disability, the way it presents in a child can change over time.

A brief information sheet on cerebral palsy will be provided to the KIs at the training session (*refer to Short Information Sheet 1 at the end of this manual).*

KI Training Schedule[1]

Sl.	Activity	Duration
1.	Welcome address, introduction and ice-breaking session	30 minutes
2.	Objectives of training and brief project overview	15 minutes
3.	Session 1: Discussion about key concepts, children with disabilities, social stigma, and other problems faced, video presentation	45 minutes
4.	Refreshment break	15 minutes
5.	Session 2: Presentation on cerebral palsy among children in LMICs (using flipchart/ multimedia)	45 minutes
6.	Experience sharing by serving/working KI	15 minutes
7.	Session 3: Discussion about the role and function of KIs, finding cases (using flipchart/ multimedia)	30 minutes
8.	Session 4: Organizational, logistic and administrative matters	15 minutes
9.	Question & Answer (Q&A) session	30 minutes
10.	Summary, evaluation and vote of thanks	30 minutes
11.	Closing and lunch	

[1]The training outline can be modified as per the project activities.

The KI Training session will commence with an introduction and welcome address by project staff, followed by a round of introductions among the participants consisting of sharing basic information about their areas, profession, etc. for icebreaking purposes. A brief presentation about the organization might also be shown. The training program objectives and a brief overview of the project will be made known to them. The session details are available in the subsequent sections.

Session 1: This will be an interactive session with the trainers engaging the participants (KIs) on their knowledge and understanding of childhood disabilities, their needs, social stigma, obstacles or barriers faced by children with disability and their families. Emphasis will be made on their existing comprehension of childhood disability matters. The following questions can be asked and answers collected from the participants orally or on paper:

Q: What do you think disability means?

Q: What obstacles do children and adolescents with disability face?

Q: What do parents do when they think their child has an impairment or disability?

Q: What do feel can be done to improve the life of disabled children?

Additionally, a few short videos will be shown to them for educational and awareness-raising purposes. *(Refer to the Selected Videos page at the end of this manual).* Other videos, as deemed appropriate and relevant by the project planners can also be shown if needed.

Session 2: Discussion on cerebral palsy among children in LMICs. This session will focus on the basic understanding about what is cerebral palsy, the known risk factors of cerebral palsy among children, the current status of health, rehabilitation, education, social participation and vocational needs of children with cerebral palsy in LMICs. *(Refer to KI Training Flipchart)*

Session 3: The role and function of KIs in the identification of children with cerebral palsy from their community will be discussed using a flipchart. The discussion will primarily focus on different clinical presentations/ signs of cerebral palsy among children (using flip chart/ photos/ video) and how to identify them. They will also be oriented towards raising awareness and providing information to children with cerebral palsy and their households. A currently working KI or one who has previously served in this role will be invited to share his/her experiences. *(Refer to KI Training Flipchart and short information sheet)*

Session 4: This session will consist of discussions regarding organizational, administrative, and logistic processes of the KIM study and how the KIs, project staff (e.g., community mobilizer), and the community shall work cohesively. This section will include matters about communication, documentation and reporting, medical camps, health facilities, etc.

Before concluding the session, a Q&A session with an open floor discussion will be conducted to clear up any confusions or queries as well as obtain comments, suggestions and feedback from the participants. The project staff shall provide a short summary of the session and distribute evaluation forms among the trainers to test how the workshop has affected their understanding of the subject. *(Refer to KI Training Evaluation Form at the end of this manual)* Project staff will deliver closing remarks and give brief instructions (if any).

Follow-up and Assessment

The KIs while carrying out their work in the local communities shall be encouraged to actively inform people regarding cerebral palsy and the specialist medical assessment camps that shall be conducted by the organization as part of the project. They will also help refer cases to various

health facilities (private clinics and hospitals, government health complexes and hospitals, community clinics, etc.) to receive appropriate medical treatment.

The Key Informants will be asked to maintain a record of the suspected children with cerebral palsy (including unsure cases where the KIs or the families themselves perceive the child might have cerebral palsy even though it is not evident). A format has been provided in this manual that can be printed out and distributed to the KIs. (*Refer to Child List for Key Informants at the end of this manual).* The Community Mobilizers (i.e., paid project staff) will in turn create their own list of children in their areas by compiling the lists of KIs in their respective teams. (*Refer to Child List for Community Mobilizers at the end of this manual)*

The specialist medical assessment camps will be conducted by the project on pre-announced dates at locations that are conveniently accessible by the target group who are predominantly situated in remote rural areas with poor transportation systems. The medical assessment team will consist of experienced members including pediatricians, physiotherapists, and other specialized personnel with assistants who are oriented about the study.

As members of the local community, the Key Informants (KIs) can play a role in follow-up by helping project personnel and health workers establish contact with children with cerebral palsy and their families.

Short Information Sheet 1: Cerebral Palsy

What is cerebral palsy?

The brain controls all that we do. Different parts of the brain control the movement of every muscle of the body. In cerebral palsy, there is damage to, or lack of development in, one or more of these areas of the brain.

'Cerebral' refers to the brain.

'Palsy' can mean weakness or paralysis or lack of muscle control.

Therefore, cerebral palsy is a disorder of muscle control which results from some damage to part of the brain. The term cerebral palsy is used when the injury has occurred early in life, to the developing brain.

What are the common signs?

A child may be described as having a cerebral palsy if s/he has any or some of the following signs:

- Compared with other children, s/he was very delayed in rolling, head/neck control, sitting, standing or walking
- The child has weakness, stiffness or floppiness in the arms or legs
- Some of the following movements have gotten ***more*** difficult: walking, running, climbing stairs, getting up from squatting position, or the child has frequent falls.
- He/she finds it difficult to pick up or manipulate small objects
- The child may have difficulty in understanding speech (receptive language difficulties) or with oral speech (talking or expressive language difficulties).

What if the child has these signs but only very mildly?

These children are unlikely to be considered as having a disability unless it is of a serious nature, that has been there for at least 6 months or from birth. Only if there are some real difficulties in carrying out an everyday activity such as dressing, eating, self-care or moving about, etc. would they be described as having a physical disability.

What causes Cerebral Palsy?

There are many different risk factors and some known causes. A problem with the brain can occur:

- If the brain does not grow or form properly. The result is that children may have brain malformations.
- In the early months of pregnancy, for example, if the mother is exposed to certain infections such as Rubella (German Measles), or Cytomegalovirus (CMV).
- During labour or at birth, for example, if the baby does not receive enough oxygen.
- In the period shortly after birth, for example, when an infant develops a severe infection, such as meningitis, in the first few days or weeks of life.
- In children having accidents in the early years of life, causing permanent brain injury.

Can it be cured? Does it get better, or worse?

Cerebral palsy cannot be cured, the impairments are permanent but early diagnosis and early initiation of interventions can substantially improve the functional outcome, health, nutrition participation and quality of life of children with cerebral palsy. For example:

- Need-based therapy/ rehabilitation (e.g., physiotherapy, speech and language therapy, occupational therapy, orthosis) can reduce the severity of impairments and associated conditions.
- Adequate management of feeding/ dietary intake could prevent malnutrition, digestive issues such as constipation
- Assistive devices such as walking sticks or crutches, leg braces, wheelchairs, special seats, artificial limbs, etc. could help the child in daily movements and participation in different activities
- Surgery in some cases can correct a deformity or help a child move better
- Plastering and splinting in younger infants may be enough to correct a deformity

Can children with cerebral palsy go to school, get a job, get married and have children?

YES! They can do all of those things and it is good for all children to go to school and participate in everything. Sometimes, they will need extra help from teachers or other children to move around or carry things. Often some assistive device or adaptation at school (e.g. wheelchair ramps) will allow them to attend. Most children with cerebral palsy still get married, have children and find work depending on their abilities, skills and interests, and extent of disability.

It is important to include them in all activities since education and other skills will help them to participate in daily life in the community and find work later.

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Short Information Sheet 2: Different types of clinical presentation of children with Cerebral Palsy

PHOTO 1

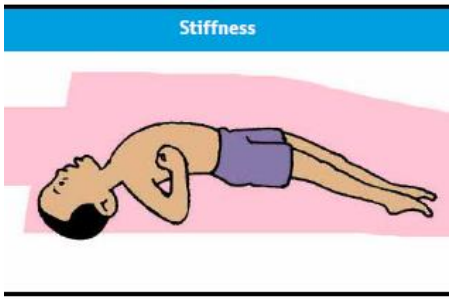
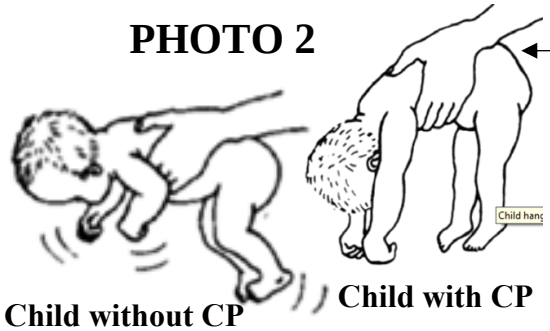


Photo 1: Muscle stiffness. This causes part of her body to be rigid, or stiff. Movements are slow and awkward. Often the position of the head triggers strange positions of the whole body. The stiffness increases when the child is upset or excited, or when her body is in certain positions. The pattern of stiffness varies greatly from child to child and she has no control over these movements. Muscle stiffness is the most common way that individuals are affected by cerebral palsy

PHOTO 2

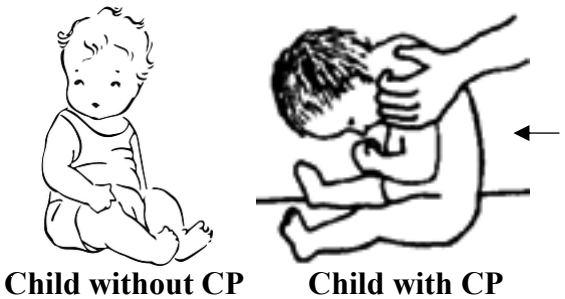


Child hangs in upside down 'U' with little or no movement

Child without CP **Child with CP**

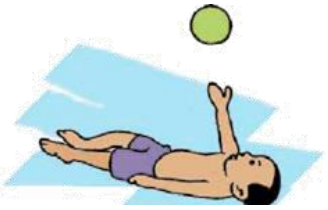
Photo 2: Floppiness. Another type of cerebral palsy is when the child's muscles are very floppy. Children who have very floppy muscles often look like the children in these pictures. The floppiness of the muscles can make it difficult for the child to move easily, and she may get tired quickly, for example when trying to sit by herself. When she lies on her back, her legs will often flop outwards.

PHOTO 3



Child cannot sit at the age that normally a child should sit.

Child without CP **Child with CP**



Child may not use his hands. Or he only uses one hand and does not begin to use both

Photo 3: Slow development. Learning to lift her/his head or to sit or to stand or to walk takes longer than expected, and s/he may neglect some parts of the body.

PHOTO 4

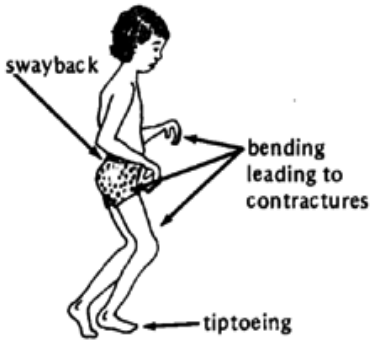


Photo 4: The child who learns to walk may do so in a stiff position with the knees pulled together and bent. Feet often turn in.

PHOTO 5(a)

PHOTO 5(b)

Photo 5 (a)

- **Stiffness in the legs**
- **Difficulty in seating without support**
- **Poor head control**
- **Difficulty in closing mouth**

Photo 5 (b)

- **Stiffness**
- **Wasted muscle**

Ref: Getting to Know Cerebral Palsy. Available from: https://www.lshtm.ac.uk/sites/default/files/2019-06/Getting-to-know-cerebral-palsy-english.pdf

Template for key informants (KI) to list children with suspected cerebral palsy from community

Details about the data collector (KI)

Name of the KI: KI code: Phone number of the KI:

Location of the community where the screening was completed:

District:_____ Sub-district:_____ Union:_____ Village:_____

SL	Name of the child	Gender (Boy/Girl)	DOB/ Age in years*	Father's name	Mother's Name	Address	Contact number	Presenting problem
1.								
2.								
3.								
4.								
5.								
6.								
7.								
8.								

*** Write age in completed years and if less than 1 year write number of months (e.g. 5 months)**

KI Training Evaluation Form

Sl.	Question	None	A little	A lot
Q1.	How much knowledge did you have about children with cerebral palsy before you attended the training?	☐	☐	☐
Q2.	How much do you feel you know about this subject now?	☐	☐	☐
Q3.	How much of the content was important & relevant to you?	☐	☐	☐

Q4. Which aspects of this session were most useful and interesting for you?

Q5. Were there topics that you did not like or find useful? – Please specify below:

Q6. Please give examples of how you are going to use the information in your work or community

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THANK YOU FOR COMPLETING THIS FORM AND ATTENDING THE TRAINING