

STRUCTURED QUESTIONNAIRE FOR CAREGIVERS:

ID number _____

Date and time of interview: _____

Name of interviewer: _____

SECTION A

Socio-demographics of interviewee (Caregiver):		
<i>First, let me confirm some information about you</i>		
1.	How old are you?	a. < 20 years
		b. 20-30 years
		c. 30-40 years
		d. 40-50 years
		e. 50-60 years
		f. Older than 60 years
2.	Sex	a. Female
		b. Male
3.	What level of school grade have you reached?	a. Primary level
		b. Junior/ O-level Secondary
		c. Senior/ A-level Secondary
		d. Post-secondary/ University/Vocational institutions
4.	What is your marital status?	a. Single
		b. Married
		c. Divorced
		d. Widowed
5.	What is your average monthly expenditure?	a. 0-50,000ugx
		b. 51-100,000ugx
		c. 101-500,000ugx
		d. Above 500,000ugx
6.	What is your relationship to the child?	a. Mother
		b. Father
		c. Sibling
		d. Grandparent
		e. Other
Demographics of the child		
<i>Now, let me confirm some information about your child.</i>		
7.	How old is the child you care for? (write the age in years here)
8.	Sex of the child	a. Female
		b. Male
9.	What is your child's disability? (write the disability here)

SECTION B

Early Identification and Linkage to Care		
1.	<p>When did you realize that your child had any of the following signs and symptoms? <i>(Use this guide for them to understand)</i></p> <ul style="list-style-type: none"> •Late to Reach Milestones: Like sitting up, crawling, walking, or talking later than other children of their age. •Difficulty with basic movements like walking or picking things up. •Difficulty seeing things clearly or hearing sounds properly. •Difficulty in saying words or understanding what others say. •Trouble with remembering things, solving problems, or understanding new things. •Finding it tough to make friends, play with others, or understand feelings. •Having lots of tantrums, getting angry often, or being really quiet. •Being troubled by things like sounds, lights, or touch. •Struggling to learn new things or follow instructions. • Not liking to play or do things other children enjoy, or doing the same thing over and over. •Suddenly forgetting things they used to know how to do, like talking or using the toilet • Having health issues that seem to slow down their learning or moving around. •Being clumsier or uncoordinated than other children their age. 	<p>a. From pregnancy to 3 years <i>(Identified early)</i></p> <p>b. After 3 years <i>(Identified late)</i></p>
2.	When did you first seek help for your child regarding their developmental delay/disability?	<p>a. Within 1-6 months after identification</p> <p>b. 7 months and above after identification</p> <p>c. Never sought help</p>
Awareness and Health Literacy		
3.	Before your child was identified, were you aware of your child's specific developmental delay(s) or disability(ies)?	<p>a. Yes</p> <p>b. No</p>
4.	Have you received any information or education regarding your specific developmental delay(s) or disability (ies)?	<p>a. Yes</p> <p>b. No</p>
5.	If yes, from where?	<p>a. Antenatal classes</p> <p>b. Health talks</p>

		c. Radio/T.V
		d. Internet Peers
		e. Places of worship
		f. Outreach programs
		g. Others
6.	If no, would you like to receive this information?	a. Yes b. No
7.	Are you confident in understanding and managing your child's specific developmental delay(s) or disability(ies)?	a. Yes b. No
8.	If yes, to what extent?	a. Somewhat confident b. Very confident
Support Systems		
9.	On a scale of 5, How supportive are your family members in caregiving regarding your child's specific developmental delay(s) or disability(ies)?	1 (Not supportive at all) 2 3 4 5 (Very supportive)
10.	On a scale of 5, How supportive are your family members in making decisions regarding your child's specific developmental delay(s) or disability(ies)?	1 (Not supportive at all) 2 3 4 5 (Very supportive)
11.	On a scale of 5, To what extent do you rely on information and support from friends and peers in seeking help for your child's specific developmental delay(s) or disability(ies)?	1 (Not at all) 2 3 4 5 (Very much)
Relationship with Healthcare Providers		
12.	On a scale of 5, How would you rate your relationship with healthcare providers regarding your child's specific developmental delay(s) or disability(ies)?	1 (Very poor) 2 3 4 5 (Excellent)
13.	Are healthcare services for your child's specific developmental delay(s) or disability(ies) easily accessible?	a. Yes b. No
Trust in the Health System		
14.	Do you think the health system promotes timely identification and interventions for your child's specific developmental delay(s) or disability(ies)?	a. Yes b. No
15.	Do you have trust in the capacity of the health system to care for your child's specific developmental delay(s) or disability(ies)?	a. Yes b. No
Community-level factors		
16.	Are you aware of any community programs addressing developmental delay(s) or disability(ies)?	a. Yes b. No
17.	In the past 12 months, have you benefited from any of these programs	a. Yes b. No

18.	What cultural or societal attitudes towards developmental delay(s) or disability(ies) exist in your community?	<ul style="list-style-type: none"> a. Stigma b. Discrimination c. Blame and shame d. Superstition e. Others
19.	Are there any public awareness campaigns aimed at increasing awareness of your child's specific developmental delay(s) or disability(ies) in your area?	<ul style="list-style-type: none"> a. Yes b. No

IN-DEPTH INTERVIEW GUIDE

Number of caregivers: _____ Cluster name: _____

Date of interview: _____

Name of interviewer: _____

Introduction and Welcome

Welcome participant and thank him/her for their willingness to participate in the discussion.

Explain the purpose of the discussion, which is to gather insights into factors influencing early identification and intervention for children with developmental delays and disabilities in Kabarole district.

1. Awareness and Understanding of Child Development

- a) What do you know about how children grow and learn?
- b) Where do you usually learn about how children grow and learn?
- c) Where do you usually learn about any problems children might have growing and learning?
- d) What signs do you know that indicate a child might be having trouble learning or growing? (development milestones and the signs of developmental delays)

2. Experiences and Perceptions of Developmental Delays and disabilities

- a) Please share any experiences in identifying that your child(ren) could be finding trouble learning or growing up (developmental delays and disabilities) like other children? (*Probe how they got their child diagnosed. Did she get any organization that reached out or did she go seeking for help?*)
- b) What do people think of children who might have challenges learning or growing up (developmental delays and disabilities) like other children in your community?

3. Access to Healthcare Services

- a) Please describe your experiences with getting healthcare services for your child(ren) who was/were having trouble learning or growing up (developmental delays and disabilities)?
- b) What are some difficulties you encounter when trying to get healthcare for your child's needs?

(Probe for challenges in decision making, financial difficulty)

4. Support Systems and Social Networks

- a) How do your family, friends, and other people you know help you take care of your child who might have trouble learning or growing like other children?
- b) Do you find it useful to share stories and learn from other parents who are going through similar things with their children? If yes, how does it make you feel? If no, why?
- c) How would you describe your relationship with healthcare providers who help treat your child(ren) experiencing difficulties in learning or growing like other children?

Probe for experiences talking to healthcare providers about your child's tests and treatments?

5. Recommendations for Improvement

- a) Based on your experiences, what do you think could be done to help find and help children with learning and growing challenges (developmental delays or disabilities) early in your community?

Conclusion and Appreciation

Thank the participant for their valuable insights and contributions to the discussion.

Assure the participant of the confidentiality of their responses and the importance of their feedback in informing positive changes for children and families with children with developmental delays and disabilities in Kabarole district.

KEY INFORMANT INTERVIEW GUIDE

Date of interview: _____

Audio no: _____

Name of interviewer: _____

A. HEALTH WORKERS

Introduction and Background

Hello, and thank you for participating in this interview. We're interested in learning more about your experiences and perspectives on identifying and supporting children under 5 years old with developmental delays and disabilities within healthcare settings.

- a. Please tell us about your role and responsibilities in dealing with children under 5 years old with developmental delays and disabilities at your healthcare facility?
- b. How long have you been in this role, and what types of services do you provide to children with developmental delays and disabilities and their families?
- c. How do you collaborate with other healthcare workers or team members in identifying and managing developmental delays and disabilities in children?
- d. How do you interact with members of the community in addressing developmental concerns in children?
- e. What are some of the communication channels you use when interacting with caregivers of children with developmental concerns?
- f. What resources or tools do you currently use to assess and support children with developmental delays and disabilities at your healthcare facility?
- g. Are there any additional resources or support systems you feel would be helpful in your work?
- h. Can you describe any community-based initiatives or programs aimed at supporting children with developmental delays and disabilities that your healthcare facility is involved in?

- i. Can you share any successes or positive experiences you've had in this area?
- j. What are some of the main challenges you face in identifying and supporting children with developmental delays and disabilities within your healthcare facility?
- k. Based on your experiences, what do you think could be done to improve early identification and linkage to cares for children with developmental delays and disabilities within healthcare settings?
- l. Are there any specific recommendations or strategies you would suggest for enhancing support systems and services for children and families facing developmental challenges within healthcare facilities?

Conclusion and Appreciation

Thank you so much for sharing your insights and experiences with us. Your input is invaluable and will help inform efforts to better support children with developmental delays and disabilities and their families within healthcare settings.

Date of interview: _____

Audio no: _____

Name of interviewer: _____

B. VILLAGE HEALTH TEAMS (VHTS)

Introduction and Background

Hello and thank you for participating in this interview. We're interested in learning more about your experiences and perspectives on identifying and supporting children under 5 years old with developmental delays and disabilities within the community.

- a) Please tell us about your role and responsibilities as a member of the Village Health Team (VHT) in addressing concerns about children that are having challenges learning and growing like other children?
- b) How long have you been in this role, and what activities do you engage in to support children and their families in the community?
- c) How do you collaborate with the healthcare facilities in addressing concerns about children that are having challenges learning and growing like other children?
- d) What are some of the communication channels you use when interacting with caregivers of children having challenges learning and growing?
- e) What resources or tools do you currently use to assess and support children with learning and growing challenges in the community?
- f) Are there any additional resources or support systems you feel would be helpful in your work?
- g) Can you share any successes or positive experiences you've had in this area?
- h) What are some of the main challenges you face in identifying and supporting families with children having challenges learning and growing like other children within the community?
- i) How do you engage with members of the community in identifying and supporting children with learning and growing challenges?
- j) Can you describe any community-based initiatives or programs aimed at supporting these children that you are involved in?

- k) Based on your experiences, what do you think could be done to find and help children with challenges learning and growing early within the community?
- l) Are there any specific recommendations or strategies you would suggest for enhancing support systems and services for children and families facing developmental challenges within the community?

Conclusion and Appreciation

Thank you so much for sharing your insights and experiences with us. Your input is invaluable and will help inform efforts to better support these children and families within the community.