

INDEPTH INTERVIEWS – CARERS

Use of these questions:

These questions were developed as a guide only. Interviews with carers are normally only relevant when a) the primary participant is unable to give detailed responses to questions due to communication barriers or b) when the caregiver is substantially involved in the WASH related activities of the person with disabilities. If you are conducting the interview because of reason a) it is important to cover all sections (not necessarily all questions). If you are conducting the interview for reason b) and have already obtained a good deal of information from the primary participant, then the focus of the interview should be around the experience of the caregiver and the potential challenges that WASH issues and caring impose on their lives.

In practice field staff should familiarise themselves with these questions and adapt them to suit the participant and their responses. This responsiveness is important to ensure that the participant feels at ease and able to talk about these topics. The interview should feel more like a conversation rather than a question and answer session. It is important to establish a rapport with participants and therefore it is advisable to begin with some general questions about their family and their interests before delving into what are quite private topics relating to WASH. Questions should be added where a participant mentions something of interest or touches on something that needs further clarification. Questions can be skipped where a participant answers the question in a previous response. It is not normally necessary to go through all questions.

Introduction

Thank you for agreeing to take part in this interview. My name isand I am a data collector from I am part of a team conducting a research study on disability and access to water, sanitation and hygiene. I am now going to ask you some questions regarding your participation in community meetings and events around water, sanitation and hygiene, changes to your personal use of water, sanitation and hygiene facilities in and around your household and community and any difficulties you may face when using such facilities and what you perceive to be the community's attitude towards you. As explained, you are free to stop the interview at any time.

District	
Village/settlement	
Area/Sub County/Parish	
Household No	
Name of Carer	FIRST NAME SURNAME
Gender	Male <input type="checkbox"/> Female <input type="checkbox"/> <i>Tick as appropriate</i>
Age	
Name of primary participant	FIRST NAME SURNAME
Relationship to primary participant	
Date of Interview	
Interview number	
Additional information	

1. Could you tell me a little about the condition/impairment/disability that [Name of primary participant] faces?

Discuss:

- How does this affect their life
- Does this limit the things they can do independently?

2. How long have you been caring for [Name of primary participant]?

3. What are the main tasks you need to assist [Name of primary participant] with?

Discuss – how much of your day do you spend caring for [Name of primary participant]?

4. What aspects of caring for [Name of primary participant] that are the most tiring or which aspects do you like least?

Describe and give examples where possible.

5. In what ways have you had to change or adapt your life so that you can care for [Name of primary participant]?

Discuss:

- Do you feel like you have had to make compromises in other areas of your life?
- How do you feel about having to make these changes/adaptions/compromises?

The next set of questions are going to be about [Name of primary participant]'s ACCESS TO WATER.

6. Do you have to provide any help to [Name of primary participant] so that they can any access water to drink or to use for daily tasks, tell me more about this:

If so, discuss - A 'Moment in Life' - have them describe how they assist the primary participant to fetch water and what the difficulties are with this, or whether they do this for them.

5.1 If you collect water for [Name of primary participant] what are the challenges with this?

If so discuss -

- How do you feel about having to collect additional water for them?
- Are you always available to get water when [Name of primary participant] needs it?
- Are you able to collect enough water for them (and other in your family)?
- Do you ever wish they used less water so that it was easier for you?

5.2 Are you aware of [Name of primary participant] ever having to use unclean water due to problems with accessing clean water?

5.3 Have you had to adapt your water facility or water storage accommodate [Name of primary participant]'s needs or get them to use the water facility differently to other members of your household?

Discuss:

- What adjustments did you have to make to your water facility or the way you access and store water ?
- Are you happy/comfortable with this method of accessing or storing water?
- Can you think of ways to further improve the water storage so that [Name of primary participant] can access water entirely independently or with reduced support?
- If you made adjustments to the water facility itself, how did you arrange for this to take place? Did anyone in your community or family assist you? Did the adjustments cost money?

- If you made adjustments to the water facility itself, how do the other people that you share the water facility with feel about these adaptations?
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7. The next set of questions I am going to ask you are about [Name of primary participant]'s ACCESS TO TOILET FACILITIES.

2.1 Do you provide any help to [Name of primary participant] to using the toilet, can you tell me more about this:

If yes, discuss - A 'Moment in Life' - have them describe how they assist the primary participant to use the toilet and what the difficulties are with this?

2.2 What happens if you are not there when [Name of primary participant] needs to use the toilet?

Discuss-

- Does anyone other than you sometimes help [Name of primary participant]?
- Does [Name of primary participant] sometimes have to wait for you to return? Have there been occasions where this has not been possible? Did this result in them trying to go themselves/ soiling themselves?

2.3 Do you try to limit the number of times a day you use toilet?

If yes, discuss -

- Is this because of difficulty in getting to/from toilet?
- Because you do not want to ask for help too often?

2.4 Do you limit the amount of food / water so you don't need to go to the toilet as frequently?

If yes, discuss - Ask them to describe i.e. I don't drink anything until later in the day/ I eat only at dinner

2.5 If you have difficulties with movement, do you have to crawl or touch surfaces which you feel are dirty or unclean in order to use the toilet?

If so, discuss -

- Can you describe this in more detail? I.e. what surfaces you usually have to touch and how?
- What do you normally do to prevent yourself from getting dirty?
- How do you normally clean yourself after using the toilet?
- Do you require assistance to clean yourself after going to the toilet?

2.6 Do you use the same toilet as everyone else in your household? If not, how and what do you do that is different?

Discuss -

- Why are you not using the same toilet?
- Are you ever discouraged from using/ told not to use the same toilet because people think that you cannot be as clean/ that others can become sick/disabled from using the same toilet - (or other reason)?
- If yes, does it happen in your household? In the community?
- Does lack of toilet you can use keep you from travelling around/ doing things in your community? (i.e.: not going to the market/shopping/ church?).
- Kept you from going to school/ looking for job/ working outside household?

2.7 If you don't have any trouble getting to or using the toilet is this because you have had to adapt the toilet to accommodate your needs or use the toilet differently to other members of your household?

Discuss:

- What adjustments did you have to make to the way you use the toilet or to the toilet itself?
- Are you happy/comfortable with the way you use the toilet? Does the way you use the toilet allow for adequate privacy and dignity? If not, why? How could this be improved?
- Do you think the other people you share a toilet with happy with the way you use or access the toilet?
- If you made adjustments to the toilet itself, how did you arrange for this to take place? Did anyone in your community or family assist you? Did the adjustments cost money?
- If you made adjustments to the toilet itself, how do the other people that you share the toilet with feel about these adaptations?

Would you prefer if [name of primary participant] didn't have to use the same toilet facility as you or the rest of your household?

8. These next questions are going to be about WASHING YOURSELF AND KEEPING YOURSELF CLEAN.

3.1 Do you have any trouble washing yourself or keeping yourself clean?

If yes discuss: 'A moment in Life' - describe what you have to do when they want to wash yourself?

3.2 Does someone help you bathe/clean?

If yes, discuss –

- Does this limit how clean you can keep yourself? (Ask if this is also linked to trying not to use too much water – above)
- If you cannot bathe or clean as often as you would like, do you think this leads to infections/ other problems? (i.e.: pressure sores/infections)?
- If you cannot bathe or clean as you would like do you think this effects the way others perceive you?
- Do you use the same washing facilities as the rest of your family? If not why?

3.2 Do you have any trouble washing your clothes or doing other cleaning related activities?

If yes discuss -'A moment in Life' - describe what you normally have to do when you want to wash your clothes.

- Does someone assist you with this? Who?
- Do you wash your clothes less or more than other members of your household? Why is this?
- If you cannot wash your clothes as often as you would like do you think this effects the way others perceive you?
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3.3 [THIS QUESTION IS TO BE ASKED OF WOMEN ONLY] Do you have any trouble managing your menstrual period or cleaning yourself during this time?

If yes discuss - 'A moment in Life' - describe how you normally manage your menstrual periods or whether you do anything different in the way you clean yourself/other assist you to clean yourself.

- Is it easy for you to access sanitary pads/tampons/ locally produced cloths/ other products while you are menstruating?
- Are you able to buy these yourself or does someone get them for you?
- Have you ever been in a situation where these items were not available to you? Why was this?
- Do you have any troubles changing sanitary pads/tampons/ locally produced cloths/ other products?
- How do you normally dispose of your sanitary pads?
- Did you know about menstruation before you got your first period?

3.4 Do you have any trouble washing your hands?

If yes, discuss - 'A moment in Life' - describe how you normally wash your hands and at what points during the day you usually wash your hands.

- Does anyone help you wash your hands? Who? What happens if they are not there?
- Do you normally wash your hands with soap?
- Do you normally wash your hands after using the toilet? Is the place where you wash after using the toilet nearby the toilet?

3.5 If you don't have any trouble washing yourself or keeping yourself clean is this because you have had to adapt your washing facilities to accommodate your needs or use washing facilities differently to other members of your household?

Discuss:

- What adjustments did you have to make to the way you wash or clean yourself or to the facilities themselves?
- Are you happy/comfortable with the way you use these facilities? Does the way you use the washing facilities allow for adequate privacy and dignity? If not, why? How could this be improved?
- Do you think the other members of your household or people you share your washing and toilet facilities with are with happy with the way you wash and keep yourself clean? What makes you think this?
- If you made adjustments to your washing facilities toilet itself, how did you arrange for this to take place? Did anyone in your community or family assist you? Did the adjustments cost money?
- If you made adjustments to the washing facility itself, how do the other people that you share the toilet with feel about these adaptations?

9. These next questions are about THE WAY YOU VIEW YOURSELF AND THE WAY YOU THINK OTHERS VIEW YOU.

4.1 How would you describe [Name of primary participant]?

4.2 How do you think others in your community would describe [Name of primary participant]?

4.3 How do you think others in your community would describe you?

Discuss –

- Do think people view you differently because you care for [Name of primary participant]?

- Do you think other people in the community view your family differently because of [Name of primary participant]?
- Does this ever make you feel ashamed?

4.4 Are you concerned that the limitations [Name of primary participant]’s faces due to their condition mean that they do not have the privacy, dignity and basic human rights that others in your community do in relation to their access to water, washing and toilet facilities.

4.5 Are there any traditional beliefs about people who are elderly/disabled/sick in your community?

Discuss -

- What are these?
- How do these beliefs make you feel?

4.6 Have you ever felt like you have been excluded, treated with disrespect, teased, or bullied because of your disability/age/sickness?

Discuss: Can you give an example of this?

4.7 Was there an event/experience in your life where you sensed people’s opinions or attitude towards you changed/improved?

Discuss -

- What do you think has caused this change?
- How has this change made you feel? (e.g. dignity, self respect, self confidence)

10. These next questions are going to be about ADAPTATIONS THAT CAN IMPROVE ACCESS TO WATER, WASHING AND TOILET FACILITIES FOR PEOPLE LIVING WITH DISABILITIES AND YOUR PARTICIPATION IN COMMUNITY EVENTS.

4.1 Are there some groups in the community, such as women’s groups, Community Health Committees, church groups, charity organizations or others that help you by providing additional care or services?

If so, discuss -

- What do they do?
- Do you access their services?
- How did you find out about their services? Did they contact you or you/your family contacted them?
- Do you ask them to help? Do others in your family ask for help?
- Do these organisations also provide you financial support, medical support or other material items that you need?
- Are there other things you would like these organizations to do?

4.2 Do you as a carer feel that you need greater support?

4.3 Are you aware of any adaptations that you could make to your household environment that could improve [Name of primary participant]’s access to water, washing and toilet facilities?

4.4 Would you like more information about how to make adaptations to your household environment so that [Name of primary participant]'s access to water, washing and toilet facilities can be improved?

4.5 Would you be willing to spend money on these adaptations?

Discuss:

- Roughly how much would you be willing to spend on an adaption that meant that [Name of primary participant] could use the toilet a) independently b) with less support from you?
- Roughly how much would you be willing to spend on an adaption that meant that [Name of primary participant] could wash a) independently b) with less support from you?
- Roughly how much would you be willing to spend on an adaption that meant that [Name of primary participant] could access water a) independently b) with less support

4.6 Do you normally attend community events? If so does the person you care for normally attend as well?

- What type of events do you normally go to?
- What type of events would you not go to?
- Are there any events you would go to but the person you care for would not?
- What are the barriers for you and the person you care for to attend community events?
- What are the things that make it easier for you and the person you care for to attend community events?

4.7 Have there been any events or discussions in your community about people who may have a condition that restricts or makes it difficult for them to use household and other local facilities (e.g. latrine, collecting/using water and using bathing facilities) that you have been a part of?

If so, discuss –

- What was this event?
- What happened during the event?
- What made you attend (ie were you invited or did you volunteer?)
- Were you able to express your concerns/issues during this event and did you feel listened to/ were their ideas considered?
- How did you feel to be part of this process?
- Do you think this has changed the way that other people view you?

4.8 If such event was held would you like to participate?

If so, discuss –

- What would be the main points that you would raise?
- What changes would you recommend could be made to these water facilities, toilets, or washing facilities in your community to make them more accessible for people like you?
- What recommendations would you make for how local government/charity organisations/ community groups or networks could improve the way they relate to, engage and support people like you who may have different water and sanitation needs?
- What recommendations would you would you

4.9 Are you aware of any policy that relates to people with disability or their access to water, sanitation and hygiene?

- If so how did you find out about this?
- Do you think this policy has made a difference?
- If you felt that the rights of the person you care for were being infringed in relation to WASH, how would you go about raising this issue?