

Topic guide: INCONTINENCE (PERSON WITH OR WITHOUT A DISABILITY)

Overview: Incontinence affects about 1 in 4 women over 35 years, and 1 in 10 adult men, but often people do not want others to know they experience incontinence. A person who experiences incontinence has specific WASH requirements. We are interested in understanding these so we can design WASH programmes in homes, schools and communities that meet these requirements.

Objective: to explore how people with a disability experience incontinence. In particular, to investigate:

- Caring support required and provided
- Access to healthcare services for incontinence issues
- Incontinence products used and experiences of using these
- Any additional challenges faced by people who experience incontinence when they are menstruating
- Personal hygiene
- Levels of participation and relationships with others

These questions should be used to guide discussion but do not have to be used in the sequence listed below. The interviewer should follow up on any additional issues that may arise and seem important in relation to the issues above. Under most questions there are reasons why we are asking them in *italics*. If a participant asks you why you are asking specific questions, use this text to guide your answers. Do not volunteer it if the participant does not ask for it.

Inclusion criteria: person with or without a disability who experiences incontinence.

Materials needed: information and consent sheet, voice recorder, spare batteries, notebook and pen, camera (charged) refreshments, incontinence products gathered through the market survey, bark and leaves.

Introduction

Good morning and thank you for your time. I am (Interviewer's name) from.....
Remind them of the issue of confidentiality and anonymity which is fully explained in the information and consent form that they completed. Reiterate that we will be asking questions about how they manage their urine and faeces. We are asking these questions because your experiences will help us understand the issues that people who have incontinence face. These issues may relate to water, sanitation and hygiene. World Vision



want to understand these so that we can develop water, sanitation and hygiene programmes that better support people who experience incontinence. The only way we can do that, is ask people like you, personal questions about how you manage incontinence. What you tell us about your experiences will be invaluable. These questions may be difficult to answer. If they don't want to answer any of them, they don't have to – that's ok.

Check if they have any questions from the information and consent form about the research. Remind them that they are free to decline to answer any of the questions or stop the interview at any time.

<i>Interview Date and time</i>	
<i>Interview venue and location</i>	
<i>Rural or urban</i>	
<i>Interviewer</i>	
<i>Participant's name</i>	
<i>Participant's code</i>	
<i>Age</i>	
<i>Gender</i>	
<i>Disability / no disability</i>	
<i>Functional domain: seeing, hearing, remembering/ concentrating, self-care, understanding/communication</i>	
<i>General observations: anything which might impact how the interview is conducted. E.g. a person interrupting the interview, if you feel that the participant is pressed for time, if they are uncomfortable answering the questions, if the interview is not conducted in private, levels of rapport you have with the participant.</i>	

QUESTIONS

RAPPORT BUILDING QUESTIONS		
1	Can you tell me a bit about yourself? Do you live here with others? Tell me about them.	
UNDERSTANDING DISABILITY		
2	Can you tell me about your disability?	<ul style="list-style-type: none"> • What functional limitations do you have? • How long have you had your disability?
WATER, SANITATION AND HYGIENE		
3	Where do you / your family get your water from?	<ul style="list-style-type: none"> • How long does it take to collect water? • Do you collect water yourself? • Is it easy to collect water yourself? If not, why not? (e.g. too far, inaccessible) • Do you pay for water? Probe into if it is metered or a flat rate is paid. How much is it?
4	Has anything been done to make your water point (tank, tap stand, handpump) easier to use / more accessible? E.g. water brought nearer the home, ramp to the water point, handrails next to the waterpoint etc	<ul style="list-style-type: none"> • How do you find using it? <i>Explore ease of use and any related barriers faced</i>
5	Has anything been done to make the handwashing and bathing facilities more accessible? E.g. seat placed in the bathing area, water inside the bathing area, water placed on a table, handrails etc	<ul style="list-style-type: none"> • How do you find using it? • Can other people see you bathing? • <i>Explore ease of use and any related barriers faced</i>
6	Do you use the same toilet as your family? What sort of toilet is it?	
	YES: Has anything been done to make your toilet easier to use / more accessible? E.g. built nearer the home, ramp to the toilet, handrails outside, handrails inside, raised toilet seat, movable toilet seat, more space inside, etc	<ul style="list-style-type: none"> • How do you find using it? • Can other people see going to the toilet? • <i>Explore ease of use and any related barriers faced</i>
	NO: Why don't you use the same toilet as your family?	<ul style="list-style-type: none"> • What do you use instead? Please tell me the reasons for that?

Ask to see the water point, bathing / handwashing area, toilet after the interview (if the participant has time).

UNDERSTANDING INCONTINENCE

7	Now I'm going to ask you some questions about how you manage your urine and faeces. Is it hard to hold onto your urine?	<ul style="list-style-type: none"> Is it hard to hold onto your faeces? Is it hard to hold onto both urine and faeces?
8	How long have you been unable to hold your [urine, faeces, urine and faeces]	<ul style="list-style-type: none"> How old were you when it started? How long can you hold on to it? How often does it happen? Is it getting better, worse, or staying the same?
9	Do you talk to other people about this difficulty?	<ul style="list-style-type: none"> Who?
10	What do you call the difficulties you have in holding onto your [urine, faeces, urine and faeces]?	
11	Is that a term other people use?	<ul style="list-style-type: none"> YES: skip to next question NO: What do other people call it? Do you have any feelings about that word?
12	Can you tell me about the last time you couldn't hold it?	<ul style="list-style-type: none"> Where were you? What did you do?
13	Did anyone help you?	<ul style="list-style-type: none"> Who was that? Do they often / always help you? What do they help you do?
14	Is your [insert carer's name] always around to help you when you need help with your incontinence?	<ul style="list-style-type: none"> What do you do if they are not around to help?

ACCESS TO HEALTHCARE

15	Have you ever talked to a medical person (traditional healer, nurse, doctor) about incontinence?	
	YES: Can you tell me about the <u>first time</u> you talked to a medical person about it?	<ul style="list-style-type: none"> What support did you hope for? How did they react when you told them? How did that make you feel? Why do you think they reacted that way? Did they give you any support or advice? Please explain (e.g. assistive device, recommendations on what materials to use and how to use them)

		<ul style="list-style-type: none"> Do you think they had enough knowledge about the issue to be able to support you? What has this meant for you?
	NO: Can you tell me why you have not talked to a medical person about this?	
16	Since that first time, have you talked to a medical person again?	
	YES: Please can you tell me about that?	<ul style="list-style-type: none"> What support did you hope for? How did they react when you told them? How did that make you feel? Why do you think they reacted that way? Did they give you any support or advice? Please explain (E.g. assistive device, recommendations on what materials to use and how to use them) Do you think they had enough knowledge about the issue to be able to support you? What has this meant for you? Did you seek help elsewhere? Please tell me about that.
	NO: Can you tell me why you didn't talk to another medical person?	<ul style="list-style-type: none"> Do you know of anywhere you can get help?
PRODUCT ATTRIBUTE ASSESSMENT		
17	Do you urinate or defecate into anything else, or use something to soak up the urine / faeces? E.g. bed-pan, commode, sand, leaves, cloth, underwear, clothes, nappy, menstrual pad?	
	YES: Go to next question	
	NO: How do you find not using anything / what is it like not using anything?	<ul style="list-style-type: none"> After answer give, skip to question 21
18	Can you show me those products please? <i>If the person does not want to show you, say: I have some things that are used in this area. I'd like to talk to you about which you use and your thoughts on them and the other materials.</i> <i>Lay the products out in front of the participant</i>	<ul style="list-style-type: none"> Do you use any of these? YES: ask next question NO: skip to question 21
19	Ask about each item displayed: State which product are being discussed into the audio voice recorder. Discuss one item at a time.	

a	How do you use this product? E.g. lying in bed, sitting on it, being supported by another person?	
b	When do you use this product?	<ul style="list-style-type: none"> • How often do you use them? E.g. 'just in case', every day, at night, day and night
c	Where do you use this product (e.g. inside the home, outside the home?)	
d	Why do you choose to use this product?	<ul style="list-style-type: none"> • What do you like about it? • What do you dislike about using it?
e	Does your carer/someone who supports you help you use it?	<ul style="list-style-type: none"> • How do they help you? • How often do they change it?
f	Where do you or your carer dispose of the urine or faeces? (i.e. in a toilet, open defecation site, outside)	<ul style="list-style-type: none"> • Can you tell me about that place please? (i.e. how far from the home is it? Is it near a water source? Is it buried?)
g	Where did you get this product?	<ul style="list-style-type: none"> • How easy is it for you to get them? • Did someone recommend you used it? • Have you always used it? • What do you think about the cost? • How often do you need to replace it or buy it? • Who buys / gets it for you?
h	Do you use it once, or can you use it again and again?	
	ONCE: how do you dispose of it?	<ul style="list-style-type: none"> • Where do you dispose of it?
	Reusable: how do you / your carer clean it?	<ul style="list-style-type: none"> • How often is it washed? • Is this easy / difficult? Why? (e.g. availability of soap and water, privacy) • How do you dry it? • Do you face any issues in drying it?
20	Introduce other products that are available on the local market. Ask the participant if they have ever used any of the products? <i>State what these are into the audio voice recorder.</i>	
21	Lay all the products available on the local market in front of the participant. Ask the participant what they feel about these products. <i>State which product are being discussed into the audio voice recorder. Go through one product at a time.</i>	<ul style="list-style-type: none"> • Would you be willing to pay the price of this? Show the costs of each product (displayed on the bottom of the packaging)? • Which would you most like to use? Why? (Probe into physical accessibility, acceptability, affordability, appropriateness and quality)? • What would other people (ie carer, family members, community members) think of these products?

		<ul style="list-style-type: none"> • Could you use, wash and dispose of these products independently and privately? If not, why not?
22	<p>Lay the products available on the local market and the product/s currently used to the participant in a line front of the participant. <i>State what these are into the audio voice recorder.</i> Ask the participant to:</p>	<ul style="list-style-type: none"> • Reorder the products in preference order. Left being the least preferred option. Right being the most preferred option • Ask the participant why they have ordered them in that way? • Take a photo of the product line and say the order for the voice recorder.
PERSONAL HYGIENE		
23	<p>How do you wash your body and keep clean?</p>	<ul style="list-style-type: none"> • Can you wash independently or do you need help to keep clean? • What kind of support do you have?
24	<p>How often would you like to bathe?</p>	<ul style="list-style-type: none"> • Can you bathe that often? • YES: skip to next question • NO: why is that?
25	<p>What things would make it easier to bathe? (E.g. assistive device, such as handrails, chair to sit on, having the water at the person's height, having water nearer)</p>	
26	<p>Do you use anything to help you feel / smell fresh?</p>	<p>YES:</p> <ul style="list-style-type: none"> • What do you use? • Does it help? • Where do you get it from? <p>NO</p> <ul style="list-style-type: none"> • Skip to next question
PARTICIPATION		
27	<p>Are you able to do everything you want to do? E.g. go to church every week, socialize and drink kava with others, attend weddings, funerals?</p>	
	<p>YES: how do you manage the incontinence when you are away from home?</p>	<ul style="list-style-type: none"> • Do friends / community members know about your incontinence? • What do they say about it?
	<p>NO: why not?</p>	<ul style="list-style-type: none"> • Is it anything to do with incontinence?
28	<p>Do you go to school / work?</p>	
	<p>YES: how do you manage the incontinence when you are at school / work?</p>	<ul style="list-style-type: none"> • Do your teachers / other students / people you work with know about your incontinence? • What do they say about it?

	NO: why not?	<ul style="list-style-type: none"> Is it anything to do with incontinence?
29	Is there anything you feel that incontinence stops you doing? <i>This may have been answered in the previous questions</i>	<ul style="list-style-type: none"> YES: Can you tell me about that? NO: skip to next question
ADDITIONAL QUESTIONS FOR PEOPLE OF MENSTRUATING AGE		
30	Do you menstruate?	<ul style="list-style-type: none"> YES: move to next question NO: skip to 'recommendations' section.
31	In relation to managing incontinence, do you do anything differently when you are menstruating?	<ul style="list-style-type: none"> What do you do differently? Why? How does that make you feel?
32	Does your carer / person who supports you do anything differently when you are menstruating?	<ul style="list-style-type: none"> What does she / he do differently? What does that mean for you?
RECOMMENDATIONS		
33	In your opinion, what do you think could be done to help you manage better?	
34	Thank you very much for talking to me about your experiences. Before we finish is there anything else you want to tell me? Is there anything you would like to ask me?	
<i>Now ask to do an accessibility and safety audit.</i>		

If the participant has time, ask to see the water point, handwashing, bathing area and toilet that the participant uses.

ACCESSIBILITY AND SAFETY AUDIT

Use this checklist to review the latrine, bathing area, water point. Make a note of any features that might make it difficult to use. Write these up after the interview. Take photos of the facilities. Add the jpeg number to the participant spreadsheet. The photos will be used by Jane to understand the situation. They will not be used in any reports.

Switch on the voice recorder and explain what you see.

Type of facility (i.e. latrine, wash room, behind a bush/tree, water point):	<u>Latrine:</u> <u>Wash room:</u> <u>Water point:</u>
Location:	
General description of the facility:	
Getting there:	
<i>Checklist</i> <ul style="list-style-type: none"> • Distance from house to facility. • Is the path wide enough for the primary participant? • Is the path level and firm, with nothing to trip up? • Is the path surface slippery when either dry or wet? • Are there obstacles that block the path, or make it easy to trip especially for visually impaired people? • Are slopes too steep? • If used at night, is the path lit? • Are there any parts of the path which make people feel unsafe when using it? If so why? 	
Getting in/on/out:	
<i>Checklist</i> <p><u>Steps:</u></p> <ul style="list-style-type: none"> • Are they even or uneven, firm or broken, non-slip or slippery? • Is there a handrail for support? 	

Entrance:	
<ul style="list-style-type: none"> • Is it wide enough for the user to enter? • Is the door easy to open? • Is the door easy to lock and unlock? • If someone faced harassment or other safety risks when using the facility would they be able to safely get away from the facility? 	
Safety of use (ask the participant)	
Checklist	
<ul style="list-style-type: none"> • Do you feel safe when using the facility? • Are there any particular times of day or night when you feel less safe? • Is there any way that anyone can easily see inside the facility? 	
Inside:	
Checklist	
<ul style="list-style-type: none"> • Is there enough space inside for a participant and her Carer (if she needs support) to move around easily? • When the door is closed is there enough light to see? • Do the roof / window (if applicable) provide adequate privacy for user/s? 	
Water (observe and ask the participant)	
Checklist	
<ul style="list-style-type: none"> • Is there an internal water point? Describe. • Can the water be used to wash the body and the menstrual / incontinence product? • Is soap or ash available? • Can the water and soap be easily reached by all users? 	
Disposal: Is there a place where washed reusable menstrual / incontinence product be dried, or where it can be thrown away (observe / ask the participant)?	
Checklist	
<ul style="list-style-type: none"> • Can the product be hung up? • Is it in sunlight to dry the product? • Is there a bin with a lid for disposal? • Is there a safe location for the final disposal of the sanitary waste (i.e. incinerator, a place to bury it or disposal into municipal waste collection systems)? 	



Any additional information or comments	
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