



Topic guide: INCONTINENCE - PROXY

Objective: to explore how people with and without a disability experience incontinence through a proxy (carer). 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 suffer from 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.

Inclusion criteria: A carer of a person with an intellectual or communication impairment who experiences incontinence, but is unable to fully understand the consent process.

Materials needed: information and consent sheet, voice recorder, spare batteries, notebook and pen, camera (charged) refreshments.

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. 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>Code</i>	
<i>Interview Date and time</i>	
<i>Interview venue and location</i>	
<i>Interviewer</i>	
<i>Participant's name</i>	
<i>General observations (anything which might impact how the interview is conducted)</i>	

RAPPORT BUILDING QUESTIONS	
1	<ul style="list-style-type: none"> • Can you tell me a bit about yourself? Do you live here with others? Tell me about them. • What is the name of the person you care for? • What do you enjoy doing together?
UNDERSTANDING DISABILITY	
2	<ul style="list-style-type: none"> • How long have you been caring for [name]? • What is the nature of their impairment? • How long has [name] had their impairment? • What sort of care do you provide?
WATER AND SANITATION	
3	<p>Where do you / your family get your water from?</p> <ul style="list-style-type: none"> • Does [name] collect water themselves? • How long does it take [name] to collect water? • Is it easy for [name] to collect water yourself? If not, why not? (e.g. too far, inaccessible)
4	<p>Has anything been done to make your water point (tank, tap stand, handpump) easier to use / more accessible for [name] to use? E.g. water brought nearer the home, ramp to the water point, handrails next to the water point etc</p> <ul style="list-style-type: none"> • How does [name] find using it? <i>Explore ease of use and any related barriers faced</i>
5	<p>Has anything been done to make the handwashing and bathing facilities more accessible for [name]? E.g. seat placed in the bathing area, water inside the bathing area, water placed on a table, handrails etc</p> <ul style="list-style-type: none"> • How does [name] find using it? • Can other people see [name] bathing? • <i>Explore ease of use and any related barriers faced</i>
6	<p>Do [name] use the same toilet as the family? What sort of toilet is it?</p>
	<p>YES: Has anything been done to make your toilet easier to use / more accessible for [name]? E.g. built nearer the home, ramp to the toilet, handrails outside, handrails inside, raised toilet seat, movable toilet seat, more space inside, etc</p> <ul style="list-style-type: none"> • How does [name] you find using it? • Can other people see [name] going to the toilet? • <i>Explore ease of use and any related barriers faced</i>
	<p>NO: Why doesn't [name] use the same toilet as the family?</p> <ul style="list-style-type: none"> • What does [name] use instead? Please tell me the reasons for that?
<p>Ask to see the water point, bathing / handwashing area, toilet after the interview (if the participant has time).</p>	

UNDERSTANDING INCONTINENCE		
7	Now I'm going to ask you some questions about how [name] manages their urine and faeces. Is it hard for [name] to hold onto their urine?	<ul style="list-style-type: none"> Is it hard to hold onto the faeces? Is it hard to hold onto both urine and faeces?
8	How long has [name] been unable to hold [urine, faeces, urine and faeces]	<ul style="list-style-type: none"> How old was [name] when it started? How long can [name] 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 [name's] difficulty?	<ul style="list-style-type: none"> Who?
10	What do you call the difficulties [name] has 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 [name] couldn't hold it?	<ul style="list-style-type: none"> Where were they? What did they do? What did you do?
13	Did anyone help [name]?	<ul style="list-style-type: none"> Who was that? Do they often / always help them? What do they help [name] do?
14	Are you always there to help [name] when they need help with your incontinence?	<ul style="list-style-type: none"> What do you do if you are not around to help?
ACCESS TO HEALTHCARE		
15	Have you ever talked to a medical person (traditional healer, nurse, doctor) about [name's] 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	Does [name] 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 happens when [name] does not use 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 [name] uses and their 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"> Does [name] 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 does [name] use this product? E.g. lying in bed, sitting on it, being supported by another person?	
b	When does [name] use this product?	<ul style="list-style-type: none"> How often does [name] use them? E.g. 'just in case', every day, at night, day and night
c	Where does [name] use this product (e.g. inside the home, outside the home?)	
d	Why does [name] choose to use this product?	<ul style="list-style-type: none"> What does [name] like about it? What do they dislike about using it?
e	Do you support [name] use it?	<ul style="list-style-type: none"> How do you help? How often do you change it?
f	Where does [name] or you 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 / [name] 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	Does [name] use it once, or can they use it again and again?	
	ONCE: how does [name] / you dispose of it?	<ul style="list-style-type: none"> Where do they dispose of it?
	Reusable: how does [name] / you 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 is it dried? Are there any issues with drying it?
20	Introduce other products that are available on the local market. Ask the participant if [name] has 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 [name] feels 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 [name] most like to use? Why? (Probe into physical accessibility, acceptability, affordability, appropriateness and quality)?

		<ul style="list-style-type: none"> • What would other people (ie you, family members, community members) think of these products? • Could [name] 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. State what these are into the audio voice recorder. Ask the participant to:</p>	<ul style="list-style-type: none"> • Reorder the products in [name's] 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 does [name] wash their body and keep clean?</p>	<ul style="list-style-type: none"> • Can [name] wash independently or do you need help them keep clean? • What kind of support do you give?
24	<p>How often would [name] like to bathe?</p>	<ul style="list-style-type: none"> • Can they 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>Does [name] use anything to help them 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>Is [name] able to do everything they want to do? E.g. go to church every week, socialize and drink kava with others, attend weddings, funerals?</p>	
	<p>YES: how does [name] manage the incontinence when you are away from home?</p>	<ul style="list-style-type: none"> • Do friends / community members know about their 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>Does [name] go to school / work?</p>	

	YES: how do they manage the incontinence when at school / work?	<ul style="list-style-type: none"> Do teachers / other students / people [name] work with know about their 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 that incontinence stops [name] 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	Does [name] menstruate?	<ul style="list-style-type: none"> YES: move to next question NO: skip to 'recommendations' section.
31	In relation to managing incontinence, does [name] do anything differently when they are menstruating?	<ul style="list-style-type: none"> What does she do differently? Why? How does that make her feel?
32	Do you do anything differently when [name] is menstruating?	<ul style="list-style-type: none"> What do you 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?	

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	