

**People with Learning Difficulties and Their
Healthcare Encounters**

Janine Owens

Department of Sociology

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APPENDIX I



How do *you* feel about Healthcare?

I need people who can tell me about their visits to the Doctor, Dentist, Optician, Nurse, Hospital, or Chiropodist.

All interviews are strictly confidential and anonymous.

Think you can help?

📞 07989 373988 📞

Jan - Researcher, Sheffield Uni.



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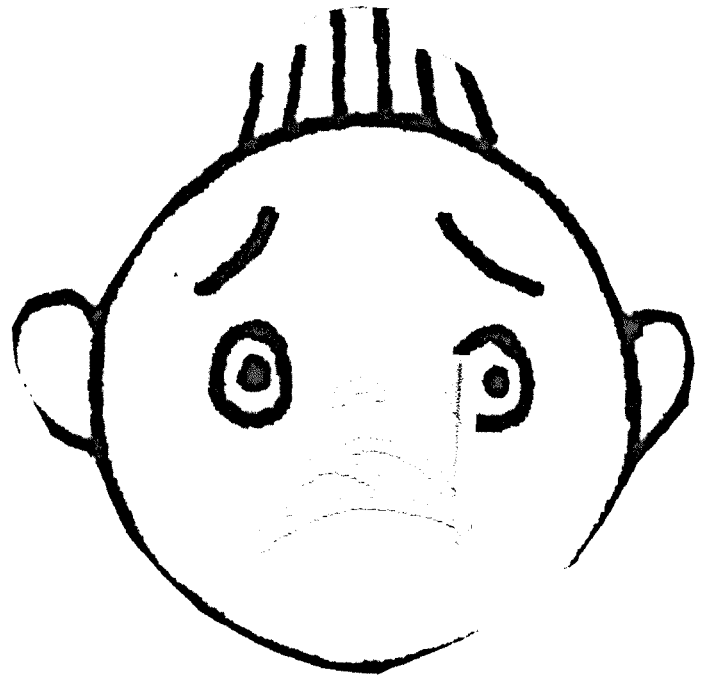
APPENDIX II

Aide memoire

1. Who are the people who help you with your health?
2. What helps you stay healthy?
3. Why is your health important?
4. What health people have you visited? (doctor, dentist, hospital, nurse, optician, are there any others I haven't said?).
5. What do you think about going to the doctor, dentist, hospital, nurse, optician?
6. What happens when you go to the doctor's, dentist, hospital, nurse, optician?
7. What helps when you visit?
8. What good things happen when you go?
9. What bad things happen when you go?
10. What makes you feel as though they want to help?
11. What makes you feel as though they understand what you need?
12. How do they make sure you understand what is being said?
13. What do they use to help you understand? (easy words, pictures, big writing, symbols, tapes?)
14. How are you helped to use the medical services? (Can you make an appointment easily, is it easy to visit, can you get there easily?)

15. How do you want your support worker to help you when you visit the doctor, hospital, dentist, nurse..?
16. What does your support worker do to help you?
17. What do you find hard to tell your doctor, dentist...?
18. What do you want to tell them?
19. What would help you to tell them?
20. What does the dentist tell you about looking after your mouth?
21. What does the doctor tell you about looking after your health?
22. What do you want to tell me about people who help you with your health?

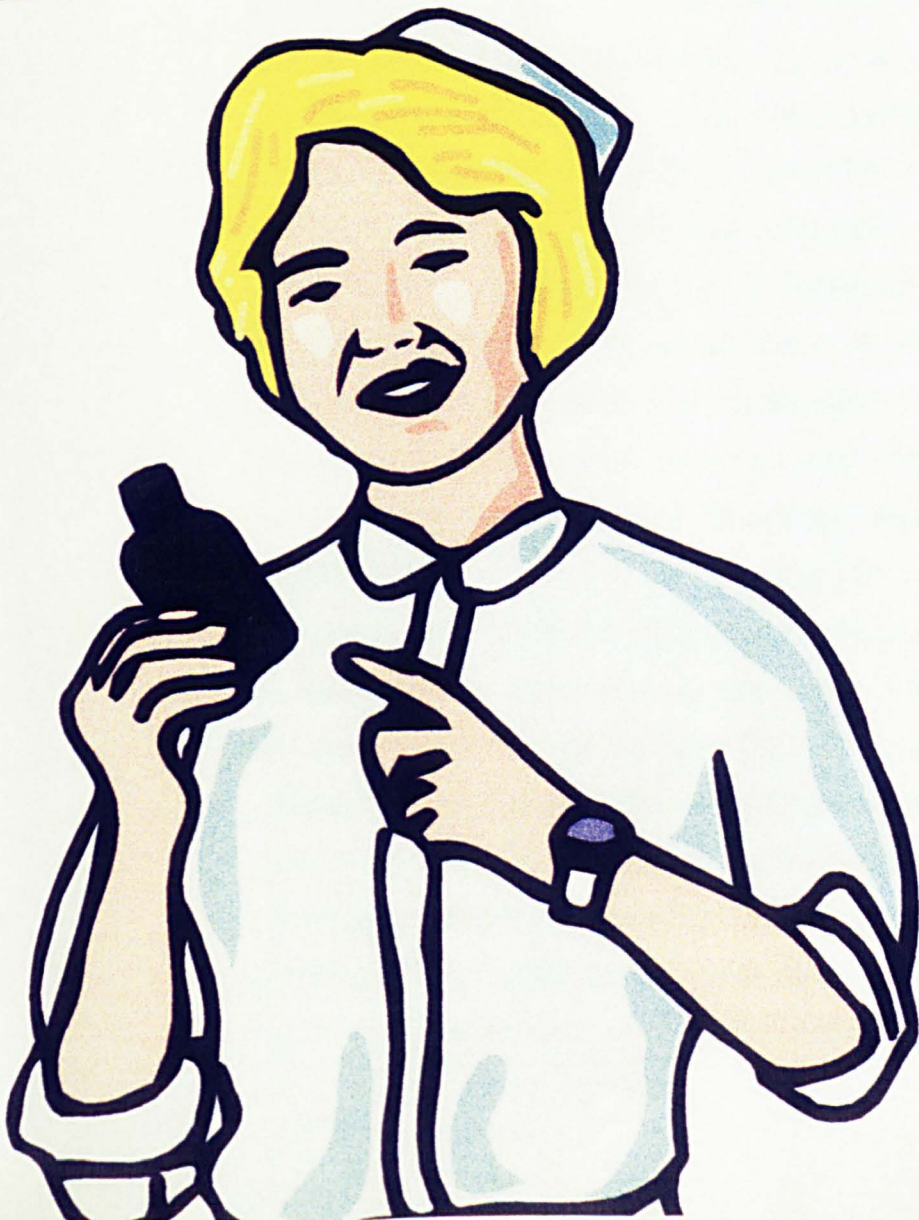
APPENDIX III











APPENDIX IV

St. Francis' Hospital Unit

Place stunk of urine, terrible state of repair, dirty, battered, and staff looked worn out. Crisis occurred with one young client put into this centre, quite high functioning but transferred from private sector because things not working out. I think I would go into crisis if placed in a unit like this with screaming wailing people around me, it must be terrifying for the poor thing. Felt off balance with people running round, residents screaming, wailing, banging doors. Sat with one resident who was rocking in corridor, realised he liked the Beatles music because nurse kept singing to him when passing and trying to sort out two other residents. Sang an awful rendition to him and he stopped rocking. Just sat with him and talked quietly about nonsense until the screaming stopped. When it was quieter, he just got up and went to his room. Went in lounge, spoke with senior nurse, rubbing the feet of young female resident. Another resident became angry with the attention and hit the young girl. Another crisis, young girl started screaming, sank her teeth into her arm and bit it, ripped her dress, male nurse came to assist and she went off the wall. She ripped her arm open with her teeth, blood running down her arm and over her dress. Ran round room overturning furniture and throwing what she could. Senior nurse sent male nurse out, young girl ran to me and hugged me, hugged her back with lump in my throat, this wasn't in the researchers guide to doing interviews! I felt frightened and had to force myself to remain calm. Everything started to calm down and young girl went to senior nurse sobbing and begging not to be held down. Senior nurse talked quietly, didn't invade her body space and told her that nobody was cross with her and nothing would happen, gently coaxed her to change into a new dress and said she would need to go shopping for new

clothes, and some make-up. Young girl changed and started chatting about new dresses, make-up and nail varnish; diversionary tactics worked. Asked senior nurse about history and why young girl had been moved to this unit from the other home. Been in private home with poor reputation, mother very unhappy, managed to move her. Previous carers male, physically restrained her if she 'acted up', on heavy doses of medication, senior nurse questioning if it was necessary and contacting psychiatrist for full assessment.

Medication on the big spoon again with clients actively discouraged from tasking their own medication. Stayed all afternoon and helped with evening meal, everyone wore plastic pinnies, I refused. Helped residents who were less able to feed themselves, no joy in this mealtime, merely a function. Nurses behaved like nurses, not carers, everything very clinical and routine. Felt irritated that so little was being done to make life more interesting for the residents who appeared to function at such a low level. There was nothing interesting to do here, I felt bored helping because there was very little interaction from most of the residents, but there was little around to engage their interest. Everything was dull and depressing, 5 hours in this unit made me feel irritable and anxious, I wonder what it is like having to work here on a daily basis?

Severe behavioural problems for most residents here, with a reduced number of staff compared to the other units. Doesn't make sense, the residents would benefit from one-to-one attention. Clients mixed in ability level. Senior nurse working at 100 mph to get everything done and keeping her finger on the pulse, form filling a nightmare, again everything run to procedure. Every incident needs logging in quadruplicate, more focused on form filling than spending time with residents.

Everything is so regimented, just like it used to be when I worked in hospitals, rules with no apparent reason, petty routines with no flexibility, no wonder the residents are running around screaming. It's boring, there's little interaction, nothing to do, dull depressing, regimented, no choice in meals, what time you go to bed, when you get up, what you do, it's like being in prison, only worse.

Client base appears to need more one-to-one support. There's a high turnover of staff on this unit, they all look frazzled. Not surprised.

APPENDIX V

Samantha

Samantha is a young woman in her twenties. She lives in a hospital-based unit at St. Francis'. Previously she lived in a private care home a few miles away. When she arrived at St. Francis' she was frightened of every male carer. Samantha is a quietly spoken young woman who has recently formed a friendship with George, who lives in the next-door unit. Over the months, the friendship has deepened, and the nursing staff have monitored the relationship. Samantha has been counselled about sex and pregnancy. With the help of the staff and her mother, she has decided she wants a sexual relationship with George but does not want a baby. The doctor has prescribed the contraceptive pill. George has not been included in the decision.

Staff perceptions

Learning difficulty nurse 8;

Samantha was like a frightened rabbit when she first arrived, she came from a home with a poor reputation for restraining their clients. Samantha had been prescribed far too much sedating medication, there was simply no need for her to be on that amount of medication. We reduced the medication and look at the result, she's quite articulate minus the medication and a totally different girl. I've heard stories about the home she came from, I didn't want them to be true, but Samantha is evidence of how not to treat someone with her level of need.

Learning difficulty nurse 11;

Well you need to be careful with the clients because you have a duty of care for them, you don't like spying on them because they deserve some privacy, but if you end up with a pregnant client then how do you explain it to their parents?

Doctor;

Oh yes, Samantha, pity about the other home, but she's doing well now. She has a boyfriend and they seem happy together, she's made a decision to go on the pill because she doesn't want the responsibility of a baby. But, I think her mum has had a lot of influence in the decision.

APPENDIX VI

Transcript Seamus.

Interviewer; So you visit the doctor's dentist, opticians and chiropodist comes here to see you, anyone else?

S; Well, there's me mum and sister.

Interviewer; O.K., what do you think about going to the dentist?

S; It's alright

Int; What sort of things do they do?

S; Checking your gums and they take notes

Int; You've had work done on your teeth?

S; Yes

Int; Fillings?

S; Fillings and Check up every month

Int; Do you have your teeth cleaned there?

S; Yes

Shows interviewer interior of mouth to emphasise the fact the dentist is visited.

Int; Do they show you how to clean your teeth?

S; Yes

Int; What sort of things have you been shown?

S; Just cleaning with the toothbrush

Int; Any floss?

S; No

Int; Does one of the staff come in with you when you go?

S; Yes

Int; And they stay in with you when you have treatment?

S; True

Int; Is there anything you find it difficult to tell the dentist or doctors when you go?

S; Well yes

Int; What sort of things?

S; If there's a pain and I can't get it out

Int; Is it difficult because your mouth is swollen?

S; Yes, But it's not swollen all the time.

Int; Is there anything you don't like about going to the dentist?

S; I like the dentist because the old dentist did no good for us

Int; Why was that?

S; Because he did nothing for us

Int; He wouldn't do any work on your teeth?

S; No. This one will do anything for us.

Int; So you've changed dentists because they want to help at the new dentist whereas the old dentist didn't want to help.

S; Yes.

Int; How did you feel about that?

S; I think it's wrong

Int; What about your doctor?

S; This one's alright but the old one was worse

Int; So you've had a bad experience with your doctor?

S; Yes

Int; What was the difference between the old and new one

S; He was foul mouthed

Int; So he told you off and was rude to you? That's terrible

S; Yes

Int; What was he like that for, was he just a not a nice man?

S; Yes

Int; So how did you move, did you say I don't want to see you again?

S; The staff helped me and helped me to move doctors.

Int; So this doctor sits and talks and explains things to you?

S; Correct

Int; And the other doctor didn't talk, didn't listen and didn't explain?

S; No

Int; So you can see the difference between the two people?

S; Yes.

Int; So you have your eyes tested?

S; I couldn't see with my old glasses and I can see a big difference now.

Int; You needed glasses before and the other glasses weren't as good.

S; Yes, I've two pairs now, one for reading, the other for seeing.

Int; One for distance and one for close up?

S; Yes

Int; What's it like going to the opticians?

S; I think they do very well

Int; So they listen to you?

- S; Yes they listened when I said the other glasses didn't work.
- Int; The chiropodist cuts your toe-nails? Anything else?
- S; Yes, these people are no trouble, they are friendly and help. Like the new doctor's surgery, they are friendly and I wait my turn because there are other people to see.
- Int; Is there anything you find it difficult to say to them?
- S; Not all the time but sometimes cos some people go first and I'd like to go first.
- Int; Is there anything that would make the visits better?
- S; My family coming with me helps
- Int; When your carers come with you do they do some of the talking for you?
- S; Yes they do
- Int; Why is that?
- S; Because we don't interrupt anybody else because we can't interrupt staff because they're talking private. We are not allowed to say anything that's why.
- Int; So you are not allowed to interrupt them while they are talking?
- S; Correct
- Int; But if you are there for you, you can talk no problem?
- S; That's correct, yes
- Int; So why do they talk for you?
- S; Because it's bad manners to interrupt.
- Int; So are you afraid they will tell you off?

S; No, what it is is they like to talk in private and that's the way I see it.

Int; Have you ever been in hospital or visited?

S; No, everything's working fine.

Int; What do you do to stay fit?

S; I go to college and I make friends there and there a lot of people to talk to. There are people there from way back who I remember and I help the people get around in the wheelchairs.

Int; Does that make you feel good and useful?

S; Yes. Cos this is my job, I don't mind helping anyone, staff as well, because this is my life and I do what I like. At the college they say you do what you want to do and I do.

Int; Is there a time when you do what you don't want to do?

S; It's not that I enjoy helping and people say I've done a good job and not to let people boss me about.

Int; So you stand up for yourself, that's brilliant

S; Yes

S; Sometimes I go to the speech therapist and she shows me sign language so I can talk to other people who can't talk. I do my own washing and ironing and cooking, I look after myself and I do what I want to do, It's my life and I look after myself and I make my own decisions and I speak out because it's my life. This is what I say is right and true. I don't want to move form here, this is my home I'm happy here because I like it. F... is moving and I can't tell you why because that's the staff's job,