



## **Community Social Care**

*Normal Lives, Different Lives*

**v/o**

Normal lives, different lives. You will hear Jane Hubert's assessment of life on a locked ward for adults, and with challenging behaviour and learning disabilities. Dr. Jan Walmsley went with her to a hospital site which has played a large part in her research.

**Dr. Jan Walmsley:**

OK Jane, well we're here at this hospital site – can you tell us a bit about why you got involved in research here.

**Jane Hubert:**

I knew that these men who lived in a locked ward of an old mental handicap institution were about, or supposed to be about to moved into a smaller unit. I wanted to come and find out what they were like and how they lived in order to inform the transition into these other units because nobody had really tried to find out what they were like and who they were as human beings. So would you like to come in and see the ward? There's nobody in it now.

**Jan:**

Yes I would, very much. So Jane we're just going into the ward now, what were your first impressions when you came here.

**Jane:**

I was absolutely appalled when I came in. I hadn't expected to see what I saw. There were twenty men in huge, empty spaces, throwing themselves around, hitting the walls, screaming, shouting. I was completely overcome by the sounds and the sight of this mass of people, and I was afraid, I was frightened, it was so strange, and when I went home that night I wrote down that I'd been alone in the ward because I hadn't seen any staff and I was, found that I was excluding them from my own social world, which I hadn't expected to do. I thought that I would see them as other social beings and I didn't at first, and I realised that this is what happens to everybody who sees these people, and who doesn't know them, that they see them as strange and other, and it's only after a long time that you come to know them as people like everybody else.

**Jan:**

It seems quite a bleak environment, there's no carpet on the floor, there's plastic across all the windows, there are no pictures or anything, there are a few armchairs around. You were shocked by what you saw. What did you expect to see before you came?

**Jane:**

Well I'd been told that the ward was a dangerous ward, that everybody in it was dangerous in terms of physical violence and sexual dangerousness, and though my first impression was one of shock, none of what people had told me before was borne out by what I then learned about the men. They were not a separate species as they were spoken about by people outside. They were very troubled, very disturbed people, but only very, very occasionally was there violence actually directed against other people. Although they were seen as violent people a lot of the violence was inflicted on themselves either through throwing themselves or hitting themselves against walls, or the floor. If they did hurt other people quite often it was seen to be just something which was to do with their characters and things that they were suffering, rather than they were attacking somebody else.

**Jan:**

So we're in the room where the men lived, do you say?

**Jane:**

This is where they spent most of their time, one of three rooms, and each person had their own ways around the ward, their own tracks that they would go backwards and forwards on, or their own chairs that they would sit in. For instance that chair a man called Philip would sit almost all day without doing anything.

**Jan:**

I can see some screw holes on that floor – what's that?

**Jane:**

The chairs were all screwed down to the floor so that people didn't pull them around, and so were the tables. The perception of people here as unthinking and unfeeling was something which I found was totally wrong, and as you get to know people then you got to know how they felt and some of them much more rounded way. There was one man who would take his clothes off all the time and pound around, he was usually naked, and was not made fun of exactly, but was teased and treated as a child when in fact he was an adult man, without being allowed any dignity at all as a social being or as an adult male. And one day I sat next to him and talked to him and told him I'd visited his parents, and he stopped roaring and he kept very still, and when I told him about his family, I told him that I expect he missed him. He suddenly said quite out of the blue, "Bless you", and those were the first sort of meaningful words I'd heard him say.

**Jan:**

What do you think the staff knew of the men in here?

**Jane:**

I think it was difficult for them to get to know them too well. It was a very disturbing place to work, and mainly because the environment in which these men lived was so appalling, and in a sense by working here I think they felt in a way that they were condoning the situation that these men lived in, and so it was hard for them to show any sympathy or understanding, although some of them did.

This door is very significant because when the men first moved in here, stepping across this threshold meant that they were stepping out of the world, out of the social world, into their own locked environment which meant that they became socially invisible, they ceased to exist for everybody outside, and nobody knew any more about them and their .....

**Jan:**

Yes, I've been very struck by how this ward is shut away even from the hospital of which it's a part.

**Jane:**

I think now we'll go and see the newly built house where some of the men who did live in here have moved to, and see the difference in the way they live.

**Jan:**

Jane, we're in the new building on the same site, and some of the men have moved here. How would you say this place is different from the ward we've just been visiting?

**Jane:**

Well I think although it's still in some way an institution because it has seven men living communally, one of the greatest changes I think is the perception of the men by the staff, and the way that they treat them as other human beings, rather than as people that they have to feed and wash, and take from A to B, and I think that's the greatest change. There is, it is more like a house, it's supposed to be a proper house and it is gradually getting carpets and curtains, but they do tend to get pulled down. But it's much better, the staff and the men all eat together, they have access to the kitchen when they want it, they can go in the garden whenever they like, and they're taken out to the pub and to shops, and horse riding and things. It's a different way of live.

**Jane:**

Well Jan, did you see any difference between the two places?

**Jan:**

They're massively different, aren't they Jane? Hugely different. The new house is far more welcoming, the rooms are smaller, the noise is less intense, it's really quite pleasantly decorated, and people have obviously made a big effort to help the men feel more at home, it had more of a homely environment. It does seem a huge improvement, yes.

**Jane:**

You met Philip as we went in there. Perhaps we could go and visit his mother now.

**Jan:**

I'd really like that, get a better picture of Philip.

**Jane:**

Hello Jan.

**Jan 2:**

Hello Jane.

**Jane:**

This is Jan Walmsley.

**Jan 2:** Come in.

**Jane:**

Thank you. Would you mind telling Jan at what point Philip first went into hospital to live?

**Jan 2:**

Yes, Philip went into hospital when he was just a teenager at 13, 13½. He'd been at school since he was five and he went into hospital because we were finding that we couldn't cope with him really, if I'm really very honest about it, because things were happening such that he was taking ever increasing amounts of time and he had siblings, he had a brother and a sister, and we were looking forward to their teenage years and the difficulties that that might bring, so the time seemed right that we should make some decisions about how his life was going to be because obviously he wasn't going to be able to make those decisions for himself.

**Jan:**

Can you tell me a bit about Philip as a person?

**Jan 2:**

Philip's always been a very, I think a very happy, basically happy person. He has his off moments as everybody does. His expression of either dismay or happiness is to be quite noisy but he, yes, he's generally very happy.

**Jan:**

But what was life actually like on the ward for Philip from your point of view?

**Jan 2:**

I think I was concerned that Philip was part of a very large set-up whereas at home he'd been one of five. Now he was going to be one of something like twenty-five and that seemed a big difference to us, and so I would worry that those people that there were there, although they were very good and appeared very caring, I'm sure they were, they with the best will in the world we thought probably wouldn't be able to deal with him in the way that we had, and give him the same attentions, and I suppose that was our main concern, that things would get missed that were very important for him.

**Jane:**

Now recently he's moved into a different sort of environment nearby – what's that move been about?

**Jan 2:**

Well the move really is to get away from the sorts of things I've just been describing into smaller groups, caring smaller groups which is a national ideal, that's where we're going to look at it really, as an ideal, and I think it is much more ideal to have those smaller groups where there can be much more thought into caring for each as an individual, and so lots of the things to do with privacy and dignity can be addressed much better. I think there should be, one hopes, much more in the way of chances for Philip to take part in things, be part of something approaching a family atmosphere.

**Jan:**

Tell me a bit about how you feel about him moving.

**Jan 2:**

I'm frightened for him and I think I'm quite frightened for us because you know there's going to be more expectations and I'm not quite sure how it's all going to go. I think he's doing quite well now, but standards are very high in the home he's in and they cost a lot of money to keep those standards at a certain level, and will it be maintained always? I don't feel that we were part in any choosing of what might happen to Philip. I think decisions had really been made before we got there.

**Jane:**

What do you feel about the idea and the use of the word 'normal' and 'normalisation'?

**Jan 2:**

I don't like the word 'normalisation'. I don't think Philip is normal, and I don't think what ever anybody does is going to make him normal, but I am pleased that the people who care for him now are able to give him some normal experiences. Philip hasn't been shopping since he was about eight years old and he certainly hasn't been in a supermarket since he was probably much younger than that, so that's absolutely fantastic, and I hope things like that will continue.

**Jan:**

Thanks very much Jan, it's helped me get a much better picture of Philip and his life speaking to you.

**Jan 2:**

Thank you for asking me. It's important that people ask.