

Talking Heads Film Transcript

MH: Matt Harvey

CF: Caroline Fox

JB: Janet Betinis

JG: Julie Gosling

JT: Jennifer Thorpe

CS: Catherine Swain

CO: Claire O'Malley

SL: Shirley Lindo

VT: Viv Thomas

Video 2: How I want the world to see me.

MH: I want to be seen as conservative but funky, conservative with a small c. But then I realised that, maybe there was a bit more depth to it, but I do not know if I came up with anything profound. Diverse and mercurial, someone who can change which is definitely true and those changes are all right. It was also important to be seen as a good friend, sort of, to people and to be sort of supportive to people and helping to celebrate the good times and seeing them through the bad times. Um its sort of also thinking about, once again it is a bit of a superficial thing, but since I have been through times in my life where my ability to self care and sort of look after myself both through mental health problems and substance misuse problems, sort of..er..trying to look rarely well kempt is fairly important to me coz there have been times in my life when I have walked past and seen myself in a shop window and I have gone, who the fuck is that person, you know and er, so that's yea, for me keeping reasonably clean, is, I don't know, it might sound daft, but if you have been through experiences where you have lost track of you ability to care for yourself, that's quite important to me, to be reasonably well kempt, sort of yeah.

Video 3: How I want the world to see me.

CF: Um for me it is important to be seen as a whole person and not a stereotype or a diagnosis, um, that I am mad but I am not bad, I am not a bad person. I have done some crazy things, I am naughty but nice and um it is important to be seen as a kind person, I think I am genuinely a kind person. I would also like to be seen as a wise person, but maybe that's just being a little optimistic. JG: You are very wise, very wise.

Video 4: How I want the world to see me.

JB: I as I have got older I have started to feel really invisible, there was a time when I would walk down the street and people would look at me now you know I just feel that you know, I am invisible, basically and I think times that I have been on the ward I have felt the same too because you know you don't exist, staff will just come on the ward and not say hello, so I suppose I would like to be noticed more and I would like to be respected. I like to be seen as my opinions count for something, um respect those. I suppose in other roles as a mother I'd like to be seen as caring, you know that I can be depended on and like CF I would like to be seen as not a bad person because you can feel, you know with the label of having a mental health diagnosis you can feel like you know I am a bad person and the services unfortunately can reinforce that.

Video 5: How I want the world to see me.

JG: I also catch sight of myself self in shop windows and mirrors and I see an older person, I see grey hair and I see a person who has got bigger and er I want people, the world to realise that I am only ten in here, in my heart, in my heart I am ten years old, I am full of joy and hope and er exhilaration and sometimes I cant convey that physically but it there, it is in my spirit and that's really really important to me. I also want people to see my Irishness, I am very proud of being an Irish woman, an Irish woman who has survived and I am deeply proud of that and I want to celebrate my Irishness and I want people to celebrate it with me. I am mad and I do not want to be fixed, I am quite happy to be mad, I am peace with myself, I live with trauma, I live with pain, I live with fear but I am ok within my own heart I am ok with that and I want other people to be ok with it, I don't want other people to be scared or to fix me in any way. Um yea to see me warts and all, to see my wounds, to see my flaws, to see my vulnerable bits and to recognise that within me there is a vulnerability and there is a strength living side by side and both are incredibly important to me. And that's me thank you.

Video 6: How I want the world to see me.

JT: I aswell don't want to be seen as a label, I don't know if people create this label about me and er quite rigid about their views about me and what I am like because sometimes I am not that technical or erm advanced person or erm excels in certain areas and I like people to see my positivity my erm erm my understanding and charisma and I like them to accept that about me, I have got this thing about acceptance but being part of Making Waves has really helped because there is a diverse range of people and I am seeing how other people manage their flaws and problems aswell and erm erm again I just want to be listened to and I erm don't like people being discretional about the way I am and just being honest and erm I think that my confidence is getting there and I am accepting a lot of things about myself in a much better way.

Video 7: How I want the world to see me.

CS: Erm I always feel a bit sad when I talk about these things and I am not quite sure what that is, whether it is because rather like someone else has writen down that for a lot of my life erm I have been covering it all up and maybe I am not so good at doing it anymore and that's hard. And I never expect to get upset, it annoys me when I do..erm..erm..rather like someone else said I have been a cameleon a lot of my life so put me in a certain situation and I can blend in, I can appear to be fine..erm I have played the game in inverted commas for years and years...erm and I can still play the game but it takes more out of me I suppose and erm maybe that's just getting older...erm.. I don't know..erm I am sorry I did not mean to get upset.

JG: It's ok.

CS: So I would like people to..erm I had a conervation with my daughter and son in law recently and I don't know how it cropped up but my son in law was trying to say you know everybody goes through bad times and that's true but my bad times have been erm really bad and sorry its really hard to get across but then my daughter and I know she does accept me but she still struggles with it because she said something and erm your friend who's a nutter and so I played that back to her and said, well I am a nutter too...erm..and that's ok it's ok to be a nutter you know erm and I think she realised when I played that back what she had said and I was talking about this earlier with some else and it is hard because erm your family try and understand and they do accpet you but there is still that bit that is a real problem for them so it will suddenly come out like that and it shocks you

and thankfully at the time I did not get upset, its only now that I am getting upset erm..so you just don't know and then I had a time when I was beginning to forget quite a lot and my partner said I think you've got alzheimers, you are gonna have to go to the doctor, you are not remembering whats been said and then I was really relieved because I was talking to someone professional and he said that's part of your depression, is memory loss and that's just how it is erm..it's ok and so I was able to play that back to my partner and he has stopped saying that completely, because he used to take me to the doctor and in fact the GP, one GP that I saw did start asking me and I said that I was having problems remembering things and immediately he thought alzheimers and maybe that's also about me getting older so that's immediately what's in their heads so he started to say you can come in and we can do some tests and I thought I know what you are going to do, I know the kinds of tests you are going to do because I used to work in that field erm..so I thought I am not going to you again..erm.. so I have ended on a positive note, don't be ground down by the doctors.

Video 8: How I want the world to see me

SL: How do I follow that hahaha erm..erm..I can relate to a lot of what CS has said that it makes me sort of sad..angry..disappointed...because for me everybody has a potential, it does not manner what that potential is, we are all human beings and we all have a certain amount of potential and our aim in life is to reach our potential..that is what I believe and for me I have always felt that way, everything that I am capable of doing, just let me achieve it whether it be in terms of relationships or children or a career or a job or something, let me achieve it and I actually feel that since I was diagnosed when I was 19, which was a long time ago erm people..the world.. just.. society in general, family and friends and partners took all my potential away and said I have got no potential now, what can you do now? Well you can't do anything.. you can't get a job and you can't study and you can't have children and you can't have relationships and I thought what can I do? And I would like the world to see me and allow me to reach my potential despite whatever label I might have or whatever medication I might be taking and whatever my mental health experience may be..for them to see that I still have a potential and each and every one of us has a potential, irrespective of our experiences. I remember in the 1980's when I used to go for jobs I never mentioned mental health, never..I just would not say a word about it and I would get the job and pretty much I would be a good worker and nobody would have a clue, for the whole time I was at work I had to keep myself together, not even have half an hour when I was a bit shaky I had to be strong the whole day at work..Not a single colleague knowing a single thing and that was pressure and then the dicrimination act came out and people said SL you can share your experiences you know...you know it's it's they are breaking the law if the discriminate against you and I started to share my mental health and it was not as bad coz I was at least able to get some support at work. But what I did at least over the last eight or nine years was to work in mental health organisations.. Rethink...Mind in Camden City and Hackney Mind..erm.. National Mind and there there were other mental health service users who support each other at work so it is different and now I have got my social work degree I am finding it really hard to get a job and when I go to interviews I know it is fact that it is my mental health that is holding me back and I say can I have some feedback about why have I not got the job? They say..oh SL..its this..this and this and I think it's not true what you are saying, I am not an idiot, I know what is it but I can not prove it and you know I can't prove it and it is so demoralising. Since 2014 I have got my degree, I've got my experience, I've got everything but you still won't give me a job, so somebody in our group was saying how far do you think we have gone? And I was saying that we have gone far in terms of discrimination, we are going in the right direction but we still have a long way to go and for me I just want the mental

health community to get together, really get together support each other and start really challenging some of that discrimination out there because we have got a long way to go.

Video 9: How I want the world to see me

CO: Again, how do I follow that? [group laughter] 'Cause I think, like, even though we're coming from different, like a different stage of life, like I can see where what we want overlaps a lot. Um, like, I find this a very difficult question because um my first instinct when I saw the question "How do I want the world to see me?" was to think things like "I want the world to see me as happy, I want the world to see me as confident, I want the world to see me as cool" which um feels a bit like being a teenager again. But um I think maybe a wiser answer would be I want the world to see me as someone who's not confident all the time, who's not strong all the time, who can be vulnerable and that's okay and there is a strength in that like what we said, JG. But it is it is of course difficult to be vulnerable in its very nature because you wonder if it's safe to say certain things, like if it's safe to admit certain things as if you've done something wrong as that's what the word admit would indicate. Um and I think being vulnerable doesn't have to mean to tell all, it's okay to have different roles and to disclose different things to different people at different times. Um, I've run out of steam...

JG: That's okay, that's fine, yes, great.

Video 10: How I want the world to see me

VT: I want to be seen..how can I put this..despite my label not inspite..no..erm.. I want to be seen with my label but not my label taking over my entire life..erm..my label is an integral part of me..I have grown to be comfortable with it. The diagnosis itself isn't important to me..erm..what is important is that I recognise that something functionally has gone wrong but that's not the entire me, I can still take responsibility, I can still follow world and current affairs, I can still be on time, it is very important that I can tell what time of day it is, I can empathise, I can show empathy, I can do so many, I have got so many other human traits which are not defined or restricted by my label and erm it's important for me that the world can see me beyond the person as a label that, just what label tells you who I am and not try and limit or define my potential based on just a label and that's really important to me.

Video 13: Picture Representations

CF: This is how I feel..erm..like I am in a box and I am locked up and I am very contained, a lot of secrets, a lot of things hidden..erm..and erm..I don't want to say anything, so it's all contained and then when I go mad, it all comes out so I am flying out of the box so there's all the religious stuff that goes on there, there's the talking to animals, the interconnection of the universe..theres lots of love, there's drinking, there's smoking, there's dancing naked, there's nature..so yeah that's kind of my experience's of sort of ..how I probably deal with my distress, so there you go in a visual representation.

Video 14: Picture Representations

MH: Yeah for me it did make me think of problem middle ground and there is part of me, maybe I am more of a visual person so I wrote down, this scum should kill himself and that is me and that definitely a feeling that I have and then there's you know we talked about a bit like maybe when your in quite altered states you know all is beautiful and how..yea and

actually drawing it made me sort of..you know maybe I have problems with the middle ground in which life is lived and I sort of want absoluteness I want things to be absolutely beautiful sort of well actually life is lived in the middle ground and I did think that is something, it sort of made me see that, so drawing it made me sort of think that you've drawn those things but actually much of life is outside of that and sometimes I think if you've experienced feelings of profound..we talked about the loss of self and sort of we can be disappointed by the rest of life, you know, you're a bit like oh...I wasn't on drugs but everything felt really really amazing, why the fuck can't it be like all the time? And sorry, pardon my language but erm yeah it made me think that I have a problem with the middle ground of life but that's where you have to live it most of the time and that maybe, maybe I get a bit in denial about that and that's just, its not actually the devil, its one of the devils helpers I call him the horny one, he's got horns, I am not a good enough drawer to draw the puppet that would be me that he is manipulating sort of coz I do struggle a bit with religious even though I am not religious I can have quite a lot of religious thoughts to do with demons and devils so erm and that's just one of them that sometimes I draw to just externalise it.

Video 15: Picture Representations

MH: Did we do any drawing for you JB?

JB: What I was going to say was that wne I am really really distressed about something my way out when I can't cope is to go bonkers, you know I can't cope with my own reality and similar to CF you know everything in the universe becomes connected and that can be, is a really beautiful place but unfortunately it progresses to the paranoid delusions and stuff like seeing the devil. And thinking the devil is taking all sorts of things, you tune in to all the nasty things that are happening in the world, basically and I won't say anything else because CF and MH, oh God I have forgotton your name.

MH: OH JB how many times have we met?

JB: M!!! Its these anti-psychotics effect your memory, sometimes with someone I know really well and I can't remember their name just errr.

JG: It would be really good..we were talking about that, in connection with what you said made you feel well J and what you said about your medication is really important.

JB: Yeah I was saying that sometimes it kind of blurs your feelings and you can sit there like this [sits back and rolls her eyes] you know numb really dumbs your feelings down which is quite difficult when you are supposed, when there is something you are supposed to bothered about and it just goes over your head and you don't bother about it, something that you really should be dealing with.

Video 16: Picture Representations

JB: What about you J?

JG: Well what about me? For years I was very good at hiding my distress, I came from a family that carried its sadness on their back like a huge secret. It wasn't ok to talk about things, it wasn't ok to be sad so for years I thought I was quite happy, I thought I was quite happy and erm I survived a huge amount of trauma in my early life and more sadness than I could bare really included extreme domestic violence and family viloence but I went along

and I was like I'm alright, I had my nice happy mask on and that was ok until I finally cracked in my mid-thirties..erm I am now very mindful of my distress I live with distress everyday of my life..erm I am not very good at sharing yet so I have drawn some very tiny pictures so I will just take them from the floor [cough] this is me in my lair it's a little dark corner I curl up and I go into my lair and I become completely uncontactable so one way of you knowing if I am not well is if you don't see me around..erm..and I won't phone, I won't answer my phone and I won't email I will just stay here until I am ready and I am feeling a bit more confident to come out..erm I neglect myself when I am distressed, I won't wash I won't change my clothes I won't take my medication and I am talking about medication I need for my heart and asthma so I am already starting to think about self harming coz I am not taking vital medication, at times in my life when it has got really bad I have cut myself and I find that a really powerful thing to do and a way to put me in control of my distress erm.. recently when I have been getting distressed I have been getting fearful visions at night very very frightening and high levels of anxiety which only come upon me as I am trying to sleep but I have found ways of dealing with this and I have to say being here at Making Waves and the support I get and validation I have got from other people has given me permission to start talking about this not only amongst my peers but also within a teaching situation and to feel ok about it and accepting that it's alright, that I am vulnerable and wounded but I am alright still. When I am happy, when I am well, I would not say I am happy, coz I believe sadness is an important part of my life but when I am well I am at peace with myself and I am highly productive so here I am with my car, I am on all four cylinders I am doing all sorts of work, all sorts of brilliant ideas coming out, I am socialising, I am singing and I am dancing. I will pass it on to you J.

Video 17: Picture Representations

JT: I am aware of erm.. positive and negativity and erm..erm.. throughout my recovery I have seen the differences and erm...and how I am coping with things..erm the coping strategies..erm.. delivering...erm help me to put that into place. I have drawn a picture of how I sometimes feel because when you know, it sort of reflects a sun, a sunny day because sometimes when the sun is out for a day or it might be out for three days, it might be for a week if we are lucky in this country but it is reflective of my mood and I feel happy and positive, motivated, alive and energy, I feel special and sometimes I feel gifted especially when I am around people who have similar issues to me and give me lots of things to think about..erm.. when I look at the negative side I have drawn a no entry sign because I am feeling that a lot today, loss of energy erm.. anxiety depression it's like, it's like a bar to getting through to be happy and I have to think of ways to break that down erm.. that sort of vicious circle and the time it takes me to do it, and like you I show certain signs, I stop doing certain things erm.. but I am taking time to erm go for a walk and get myself motivated again, I am worried if I get a job or something like that I will have days when I don't feel like going erm...but I think I have got what it takes to keep going and I know what to do so I am feeling a bit more confident in that sort of aspect now and that's about it really.

JG: And you got here today which is incredible, thank you.

JT: Yea.

Video 18: Picture Representations

CS: Erm..when I am well I have got energy I feel alive positive optimistic confident erm..and when I am not feeling so well I am feeling anxious sad fearful and loss of confidence erm.. yea not really any more to say.

JG: I think the face does say it [drawing] it is incredibly eloquent, the pain there, thanks C.

CS: thanks.

Video 19: Picture representations

CO: Um, I drew an avalanche because I wanted to show that when I start getting, um, having bad days I feel very overwhelmed, sort of buried by everything so it's, um... I think what someone said to me is "you seem to find it very difficult to only be upset about one thing, about the thing that's actually got to you" because that can get buried under everything else so if I get upset about one thing I can start feeling really upset about housework or about the idea of going outside or um, uh, like getting up in the morning and that'll sort of, like a snowball, keep coming and feeding off each worry and just create something that's um more powerful. What melts the snowball is um [laughs] uh um sort of warmth and um being able to admit to not being okay and um to seek support. I drew a snail as well, if anyone can possibly recognise this as a snail, um [MH laughs] because you can retreat into your shell, what you [JG] said about the lair and gradually peering out and going "yeah, okay, it's safe to actually admit to this" and then I drew a pair of lips with an X through them to show this, that with distress often comes a feeling of losing my voice and um that I can't say like even if I could find the words that nobody would understand them. So that's me.

Video 20: Picture Representations

VT: What makes me feel upset is..is..is being denied my rights to express my differences, not difference of opinion but culture difference as such..erm..a big part of me was not formed in the country it was formed overseas, back in the Caribbean and erm.. to be told to or to be asked..it is not usually verbal, it usually unspoken but asked to conform and to be more institutionalised makes me feel like I am cutting off, cut off, adrift from my roots..and erm it makes me feel invisible, it makes me really feel invisible and an invisible person, invisible thing and the best way to get your attention is to actually speak and I found it the louder I speak the more I feel I will be heard but people tend to shut down but still I recognise that I speak louder again because you shut down and you made me feel invisible or I feel invisible for some reason or another. And erm I raise my voice just to be heard, but I find it a converse with people, the lower you speak, the more intently they listen so that's it for me.

Video 21: Picture Representations

SL: With me what makes me really stressed erm..at different periods of my life, different things have made me distressed, it changes over time..but recently in the last 5 maybe 10 years I say maybe things like injustice, I say if I think something is unjust or something bad has happened to somebody unfairly that really distresses me, it always has.erm.. abuse if I have been abused in anyway if it be emotional or psychological or phycally or whatever that distresses me and if theres too much stress and I don't mean a little bit of stress I mean lots of stress or too much pressure, say for example in a work environment that can distress me and I got to make sure that I go home and unwind and if it gets to a certain point I have at certain points when I was younger resigned from work because the pressure was too much and I could feel my head was about to explode and I did not know

how to deal with stress or pressure which I have learn to do over the yearsa and now I can deal with stress and pressure a lot more. At the moment there is a lot of stress and pressure in my life right now and I do not feel that I am getting ill or anything, I feel fine but maybe 5 or 10 years ago I would have been in hospital by now so things are improving, but pressure and stress definitely distress me. And how do I show it, I show it lots of different ways, sometimes I get upset, sometimes I become quiet, sometimes I withdraw into myself and I don't communicate, don't look at people, don't communicate, don't respond, sometimes I get angry raise my voice..erm.. I don't get physical but I do raise my voice I shout maybe swear..erm...people will say that I'm aggressive and intimidating but I have never lashed out at anybody all these years...erm...that's me really.

JG: What about when you are well, how do you show it?

SL: Well, we I am well I am happy I smile a lot, I talk, I communicate, I laugh..erm..I'm confident, I'm full of energy, I've got lots of ideas, I like to see myself busy and occupied, I like to be really busy and doing lots of different things when I have got the energy when I am well and that's what I love about being well, the amount of enregy that I have, I can tell when things are going wrong coz suddenly I am always tired and I think mmm got to notice that it's the first sign that something not going right and you got to do something about it before it escalates into something much worse. So now I am much more able to recognise my relapse symptoms which is maybe why I have been well for so long.

Video 22

VT: When I become distressed it is not a reaction of what is immediately there, sometimes it is something, a seed that has been planted or something that has festered for while..and erm it just comes out like years later..erm...like I used to work for a big pharmaceutical company, retail company everyone from my bach year, my training year got taken on after training and I was the only one who was left without a job and years later the switch finally clicked [snap fingers] I was the only Afro- Caribbean in the group and happened to be the only one that there happened to be no job for at the end of the process..erm..did some locum work for a while for them and the same manager, the same guy who was in charge of our..our..intake he was the lead on the intake someone decided to ring him and say that I was bullying them at work and he dropped everything he was doing at work in the office to come down and see me straight away to discipline me and I was like I don't work for you, you are not in charge of me and I don't appreciate you coming down here and showing me off in front of the staff coz I have got to manage them for the rest of the day and years later it all came back and I was like if only I knew the law then. Because there is protection under the law for what he'd done but you're ignorant, you're ignorant.

JG: I really identify something you have said a while back to me, V, how very often at conferences and stuff you'd be the only Afro- Caribbean pharmacist and how it was only when you got onto a ward...

VT: I became part of a majority, the situation suddenly flipped and I observed today and since a lot of people have levers of power on those wards and not Afro-Caribbean, they do not identify with us erm..a lot of these people are not socialised with us outside of the wards and yet they are meant to make a judgement call when we have gone from a state of distress to a state of normality but what is normality? Normality is something you have only experienced prior perhaps doing an exercise book, perhaps you've got the

perspective of one friend who is Afro-Caribbean but that person will have their own individual traits, what's the rest of the community like?

Video 23

JG: I think certainly being Irish erm...it's a culture which isn't validated very strongly coz people look at me and they see a white face, when I have been in hospital people don't ask, they just write down British and actually as Irish I have a very specific culture. We are loud we are tactile we hug we're over the top and that can be redefined as aggressive no boundaries erm it's been seen as an intrinsic part of how I say who I am so I sometimes feel my culture is invalidated misinterpreted redefined and not even visible.

Video 24

JG: In a word, CF, what is good support?

CF: For me, good support is, erm, being listened to, and, erm, people actually hearing what you're saying. Erm, I think for me my experiences of madness are really important and um [laughing] and really they have a lot of meaning to me so um I don't want my experiences to be um... like... dismissed or people telling me what I'm saying or what I'm meaning. So I want somebody to support me and keep me safe and to actually I want them to let me express what I have to express, let me express the story that I have to tell, and even if it doesn't actually make any sense to a person, um, to just be with it, and accept it and listen to it, and not judge me, just um, be there and be respectful um and um let me express what I have to say the way I want to say it, um and I might be saying some weird and strange and unusual things and they might not make sense to you but they do make sense to me so don't make me feel like um I'm an idiot or that um I don't know what I'm doing because I... there is a meaning in the madness, so that's all I have to say about that.

JG: Thanks.

Video 25

CF: Um I don't like being talked down to, I'm a very intelligent person, I don't like being treated badly, I don't like cruelty or being abused, I don't like being verbally physically emotionally abused by anyone. Um, I like to be treated like a human being not like a, um, like a, I don't know, like a "mental patient", an actual person and there's a person in here, just remember that and I could be um... that I may be acting really strangely and weirdly but at the end of the day um I'm not always like that, so...

Video 26

CF: If and um, actually, I think it's about actually asking um not forcing um... It's about um giving with a compassion with a genuine kindness um with a faith in me and that I can I can um become better mmm.

Video 27

VT: Um good support for me is um from a professional point of view and the interaction with the profession, a good professional is giving a little bit for a little bit for he has to take from me. Um, for example, tell me a little bit about your background before you ask about

mine um where did you go to school um where did you go up um what past-times do you like and I'll be more likely to share with you um not what's happening with me in terms of my illness but what happened to me and what makes me the person I am. Um, also good support is finding out things beyond um, things I'm interested in um or little bit what makes me human beyond my madness. My madness is an integral part of me but there's more to me than just madness. For example, one worker found out I liked football and one of our sessions, instead of us just sitting being at home drinking coffee and tea and whatever and talking, they did a session on the way up to Tesco Top Valley following from Radford, we went to buy a DAB radio so I could get Five Live. We could listen to the football and we'd always have something to kick off the conversation next time he comes around. Um, that for me was good support. I'd like to say his name but he'd probably get a big head from this so... [laughing, group laughter]

Video 28

MH: What for me is good support? Erm I think possibly good support takes place before I'm even in the room, it's about the attitude someone has towards me when they meet me and whether that is a unique occasion for them, as I think it should be, or whether they see it as part of a factory line as it can sometimes feel. I think there's some elements of that factory line approach tend to come more sometimes from psychiatrists than from nurses. I've found nurses sometimes are... a bit more appreciative of the three-dimensional person. I think the nature of, the prescribing nature of modern psychiatry can sometimes make you feel like you're just going down a tick list to certain medications, many of which you could predict you were going to be put on from spending ten minutes on the internet before you sort of went into the session. So, yeah, good support for me begins as soon as I step in the room by the way someone engages with me but I think the skill of good support begins before I even step into the room which is to do with the attitude... which is gonna be shown me as soon as I step in the room. Thank you.

Video 29

JG: In your own words.

SL: Good support, well it means a lot of different things. Basically, to be valued as a human being and being valued just like anybody else wants to be valued and not to be seen only in terms of my label, diagnosis or medication. But to be seen as a person who's got feelings, who's got aspirations, who's got hopes and desires like any other person. So good support for me really means someone who respects me, gives me a certain amount of respect and I expect mutual respect so I give them respect for the skills they've got and the skills they bring to me and I want them to respect me for the skills I have and my experiences. I want them to have... I expect nurses especially to have – not so much doctors but nurses – to have a certain amount of empathy towards me and to be able to think “well, how would I feel if it was my first time meeting this woman? How would I feel?” And if they can't then they won't, as far as I'm concerned, they won't be able to offer good support because they will never be able to see things from my perspective. And I think also as well as empathy I think non-judgemental, not to judge me, because they've read my case notes and they've read my file doesn't mean they know me, they know somebody's view of me, of the professionals' views of me but they don't know me. And if they want to get to know me they're gonna have to be non-judgemental and take me as they find me and give me a chance. Um I also think in order for us to have a decent working relationship, they're gonna have to learn to empower me, if I'm saying something to give me some encouragement and positive feedback, find some way for me to express

myself in a positive way, um, yeah, that's what good support means to me, it means a lot of different things but I think the key things like I said are empathy, non-judgemental and empowerment.

Video 30

JG: ... words mean to you?

CS: Good support to me means someone listening to me as if they really want to hear what I've got to say and then taking me seriously um in what I say so really believing what I'm saying, um, that it's how I see things, it might not be how they see things but it's how things seem and appear to me. Um... [pause] Yes, I think... I remember being very impressed with one psychiatrist who'd clearly read what he'd written after our last session and actually remembered that so instead of going through the tick list he actually said "And how is your brother?" or whatever it was – my brother was dying at the time. Um, and that really impressed me and enabled me to actually trust him, that he was interested. Um, and so I was probably able to be more honest than I might otherwise have been, I might just have the happy mask on and all is well, happy in the garden and off I went.

Video 31

JT: Ah something I've been thinking about is um somebody actually um somebody actually being very into – having a lot of intuition, understanding my um... my thoughts um... actually uh tangibly engaging in what I'm I'm thinking about what I want for myself and what sort of route that I wanna take and how I'm gonna go about it and um I never cease to be quite amazed at people who do that because I've met an awful lot of people who don't do that and I've lost a lot of trust in people so when people give me encouragement and they ask me what I want and they do what they – they go out of their way to help me try to get to where I want to be then I think that's that's wonderful and JG's like that and CS is like that, a lot of people here are like that and it's restored my faith in um human faith and um support as you know as well, as I see it.

Video 32

JB: [laugh] Um what is good support? Um good support to me is spending time with someone, getting to know them, and building a relationship of trust. ... And showing they're interested in me and making me feel valued as a person... and um helping me understand my experiences because for me. I mean you could think of support in a practical manner but where psychiatric nursing's concerned to me it's emotional support you need. It should be about giving emotional support to someone, like someone else already said, you know, it's about their attitude, it's about having compassion, you know, for people. And the understanding how difficult it can be to be on a ward, you're with people you don't know, you're with people who are having, you know, bad experiences, so kind of helping me in that environment. And also about them being positive and optimistic about my ability to recover. That's all from me.

Video 33

JG: ...from mental health nurses means to you?

CF: Um another thing I was just thinking based on what's been said about like um boundaries um nurses may have and I think it's quite an interesting topic that actually you

have to... I think nurses in a sense do have to give a little bit of themselves in order to connect. So I think it is very important, like has been said, about actually connecting with me as a person on a human level, so I think actually that giving and taking um is actually really important so I actually still think you can actually let that slip and actually see people on a human level and see them as a well-rounded person, as a whole person, and actually see me as a person and not just a mad person, seeing me as a person, and trying to come to me, come into my world, but you have to give of yourself in order to do so otherwise I will not trust you and I will not open myself up to you if you're not willing to give me anything back.

Video 34

JG: Good support for me recognises the power in helping someone. To actually help someone is a very very powerful thing to do and to be on the receiving end of help, to be needing help, can feel very very powerless. So good support will try and make a much more equal relationship. Um and I want support that recognises that I'm on a journey, um, but it's my journey, it's not your journey, it's my journey, and you can walk alongside me and be part of my journey and you can be there as an ally to me. You can offer me some guidance but at the end of the day it's my journey, it's my journey and I want to choose my direction. Um, good support won't judge me in any way and good support will be very kind and compassionate towards me. It might not always be easy and it's okay for me if good support isn't easy. It might prompt me to do things I'm resisting doing, um, but good support I guess at the end of the day, although I might want to resist it, good support is actually on my side and is actually in my best interests.

Video 35

MH: The importance of uh support involving you know, you may be mentally distressed, disturbed, ill, whatever you want to call it but quite often people also have quite practical things going on in their lives like paying bills. Life doesn't just stop 'cause you're in hospital, sort of, and I think it's entirely legitimate for people in hospital or in the community to be very worried and very concerned about those things and um and I think good support also recognises that life is still going on whatever your mental state. There's still what's happening with your electricity bill at home if you live on your own, sort of, and you're in hospital, sort of, and all those worries still go on and I don't think... It may not always be the nurse's role but I think it's the nurse has resources, be it social workers or whatever, people can talk to about practical problems. 'Cause often if you're in a very distressed state you can lose sight of those practical problems but they do exist and they can cause a lot of worry as well within so I think a nurse should be aware of how to support people with practical problems, 'cause those things can do your head in trying to sort them out if you're in a very altered state, if you're very depressed, if you're very manic, but they are still there, they don't go away, so I think those things do need to be made available for people to be supported with and nurses should always know how to help people with the nuts and bolts of life.

Video 36

VT: It's about um not being afraid to take a little bit of risk, to let me take a little bit of risk. It's about good risk management. Not risk management in terms of um... being aversive or avoiding a situation or um a scenario but um helping me recognise the benefits and pitfalls to a scenario, helping me rationalise that and make a reasonable decision. Allow me to

take risk because there will come a point where the support has to fall away and I will need the skills necessary to risk management in that situation I'm going into.

Video 37

CS: I'd like to add that for me good support is also about somehow giving me hope, that the situation I'm in isn't going to last forever, that things can get better and whilst I can't have that hope for myself, if someone else articulates it, it sort of stays in your head and helps you, um, you remember it, um, and the fact that someone else has said it and actually believes it – you know, it's no use saying it if they don't believe it or not – but if they say it then that can be incredibly powerful in the journey to recovery so um yeah hope is what I would say.

Video 38

SL: Um I think someone believing in me when I don't believe in myself, someone believing that I can recover, and quite often unfortunately when I have been in hospital or I've been in crisis in the community or with my family, people have said "oh that's it, Shirley, Shirley's never gonna get any better, you do realise that, that's the end of her now, she's she's not gonna make much progress beyond this" and when you hear that you just think to yourself "well, what do I do now?" And even though you're in whatever state you might be in, how confused, how frightened, how mixed up, whatever's going on for you, you are still aware of what people are thinking of you and if someone doesn't give you hope and a straw to cling to then you might as well not exist, you might as well not be there. So for me it's vital that people believe in me as a person, that I can recover. And I don't mean "recover" necessarily in get completely well, not take medication, not have a label, never have another crisis, but recover to some point where I can have a decent quality of life. 'Cause if I don't have a decent quality of life I might as well not be here. [pause] So for me I think hope and believing in me and believing in mental health service users, as nurses believe that people can recover no matter how desperate and how dark and how lonely and how frightened they may feel, to show some light at the end of the tunnel is so important, and people no matter what their condition is can sense it, they can sense that you believe in them or they can sense that you don't believe in them. I can sense it.

Video 39

MH: I think yeah what sounds good about that or resonates with me is having some belief that you can have some quality of life. 'Cause there's times when, yeah, I've despaired of that and having someone who can just say "look, things might be okay again" can be a really powerful thing, you know, not that everything's gonna be all-singing, all-dancing bells and whistles but your life might be all right, sort of, it might contain some pleasure, some sadness, but yeah, having someone who believes that things can be all right can make a massive difference 'cause I think... I think sometimes extreme states of mental distress can be a profound sense that things will never be all right again, you know, just a really deep sense that I'm fucked, and being around people who believe that things can be all right again can be one of the most profound things you can have, just someone who can say "yeah, no, good things will happen again" sort of um, you know... I remember going walking in the Peak District with a friend last year. We went for a ten, twelve mile walk and she reminded me that when I was in a very very dark place I used to say "I'll never go for a walk in the countryside again" and she'd always say "You will one day, MH, you will one day go walk in the countryside again" and she was right but there was a long time when I believed that was impossible so this, just someone believing that something

simple and good might happen that you like can be incredibly powerful sort of and I think if it can come from nursing services that can be very powerful, to get away from the feeling which we probably all of um... being in the revolving doors of mental health services , you're going in, you're going out, you get on what I call the medication-go-round where you're going around all the medications so um... I'm being long-winded but um I think there's something very profound in someone feeling that things can be all right, that you can have some quality of life again.

Video 40

JG: Um I'd like to talk about the best support I think I can ever remember receiving was somebody who sat at the side of me and gave me permission to cry. I'd held my tears in for many years and to actually be given permission to just cry and cry and cry was deeply healing at the time and I think there's something in that for me about support. Um, support won't be frightened of my pain and it won't want to dampen my pain down with medication or quieten my pain. I need permission to howl if I've got to, to scream and cry, and good support will allow me to do that, good support won't shrink away from it, good support won't say "ooh, that's assumption, you've got to suppress it, you've got to dampen it down". Um, I want the quality of support that hears my pain and hears the truth of my story within my pain and can respond to that pain with understanding, with empathy, um... and recognise that the pain in itself, although very distressing, is ultimately gonna strengthen me. If I'm given good support it will carve out understanding in me, it will call out compassion within me... so there's some permissions there and and it's permissions that may be the "tolerate the intolerable together".

Video 41

VT: I remember I am just going to use an example here but I'll explain at the end I remember erm...when I was at EIP first few times the nurse came round I'd look at him through the window and I just would not open the door, I just would not open the door. He'd knock for a few minutes stand around for a few then he'd go but guess what? Following week he was there still did not let him in, week after that same time he was there and the week after that..Good support is persistent not pushy..good support is reliable..and above all good support let you know when they are gonna be late, if you are running late, I understand that you are a human being just like me, I understand you don't have control over the traffic, I understand you may have had a late running last appointment but just keep me in the loop, show me that respect by keeping me in the loop and for me that's part of good support.

Video 42

JG: Can I add something about culture erm.. I want the sort of support recognises with me you get the whole package erm...I want support that recognises and celebrates my culture erm.. I am from a minority ethnic culture, a non-visible minority ethnic culture but my culture is very important to me..erm.. and it defines the way I think and feel about things and it's not helpful for me er..if people take a look at a white face and write down British, I am not British I am Irish and because I am Irish we for example are very reluctant to tell you when we are not feeling good so if you ask an Irish woman how she is feeling, she'll say ohhh I am grand no problems at all, absolutely no problems at all nothing to worry about. I need support that is culturally sensitive and will dig a little bit deeper erm..but on the other hand I don't want support that stereotypes me..oh..this is how all the Irish behave so support that recognises true distress within my culture.

Video 43

VT: About culture erm...in regards to culture if you do not know I do not expect you to know..so ask simple just ask..erm..you may be clumsy with your words...erm maybe I initially angry with you but at some point I'll recognise even if it's three years four years down the line I'll recognise that erm..that person asked that question they were trying to get to know something about me, the person, me culturally, don't be patronising ask I think it is more patronising to assume that to put the direct question to me so don't be afraid to ask, you may be clumsy, you may need time to think about how you phrase your question but ask.

Video 44

JB: I have always feelled so disempowered when I've been on the wards because I have always feel that they know everything about me and I know absolutely nothing about them and there was something that CF said about giving a bit about themselves so you can relate to them..erm..there was one member of staff on the ward who when I was first on the ward and he was really good, he always acknowledged me, said hello how are you, it was not rocket science he was just treating me like another human being and one day he come on the ward and he said Janet I have got something to show you, he showed me pictures, sorry I get upset about it, he showed me pictures of his new baby at it erm..really touched me coz he is sharing a bit of himself..he trusts me enough with something about himself which I thought was really powerful [wipes away tears].

JG:Thank you.

Video 45

CS: I think that one of the things that I find is that erm....if I, partly because of the culture I was brought up in, which was English stiff upper lip, you don't reveal your emotions [tut] no you don't even dare say that you are tired, I remember that was one particular thing that was not allowed in my home ermm you certainly could not be angry so you know there were no emotions really allowed to be expressed so erm.. I learnt very early on shut everything down and put them all in a box in the basement, tie them up tight and keep them there so erm.. if I begin to get upset and erm.. begin to express my emotions particularly erm..through tears that makes me feel incredibly vulnerable, incredibly powerless erm..and open to being exploited in all sorts of ways erm.. and that's perhaps because of my generation or whatever might not be something that would be naturally erm..or immediately understood by erm.. health professionals erm.. and that something that I've come to understand that erm.. the world is, something also about them, the person listening being able to contain like my emotion or my distress so, like we said earlier it's not like going to disturb them and they are not going to feel oh my gosh she has suddenly fallen apart or this is very distressing, we need to clamp her down, to some extent I do still feel that medication is a form of control erm..however I would not be as well as I am without it so it's a... double edged sword thing erm.. but yes so it is that power thing and I think that often health professionals don't realise they have that power they think that they don't have which is great but really the more honest thing is to accept that they do have that power erm..they have the power to change our medication, to ring the doctor, to put somebody on a section erm..or to start the process of putting someone on a section, they have a lot of power erm.. and I think the honest thing erm is if they admit that they have that power.

Video 46

JB: I think it is historically it's always been ok to treat people with a mental health you know.. badly coz it seems to be par for the course and that kind of filters down you know to the nursing staff and I agree with what CS was saying about mental health law is so powerful..I mean they can take you off the street, lock you up, you know without a judge and jury so it is a really powerful system but obviously you know its going to effect the kind of nursing you receive, it trickles down that power so I don't know how you can change that kind of culture, I know a lot of nurses start out with really good intentions but unfortunately they get socialised into the system.

Video 47

JG: I'd like to talk about the power of words erm..words have a huge amount of power to take chunks of my life and turn them into illnesses to be controlled or cured by other people and erm.. I would like nurses to be very careful about the words they use about me..erm.. I'm not at all certain about diagnoses whether we need diagnoses.. I have a story, I certainly have a story, I have a story of trauma and distress and I would like to tell my story in my own words and to have my story heard and to have my story validated erm.. I think the most frustrating thing about words for me is, and it certainly makes me recognise the power of words is how a behaviour that may be very valued erm.. amongst people who don't wear my labels, for example say assertiveness, I am sure most nurses would value assertiveness as a professional, the right to be assertive, erm when I am assertive it is called confrontational erm..it always amazes and amuses me that exactly the same value in two different ways and there is a huge amount of power there because once I am labelled as confrontational then I become a problem [murmurs from others] so I would like nurses to be very careful about the words that they use and to think that particularly if they are putting a word on me that becomes a label that will stick with me and travel around with me on my case notes, in my reviews huh.. I can't just take it off like a luggage label, it sticks.

Video 48

JB: I quite agree with that because I had a CPN..well my CPN was going off on maternity leave and she brought this new CPN to see me and straight away she was telling me oh you should be doing this course, you should be doing that and I thought, she hasn't meet me, she's only read my case notes and what the CPN has told her and erm..if she'd have known anything about me, she would have know that the reason why I had become unwell was because I had taken on too much, I was doing too many courses, anyway they went away and when I saw my psychiatrist he turned around and said oh you're a difficult..you're really difficult aren't you and argumentative and I hadn't been angry or anything like that I had just told her what I thought you know and straight away I was given that label, someone in the future might have read my notes and think she's a real trouble causer so mud does stick you know basically.

Video 49

SL: I think it is important for people to be really aware of their words that they use to describe you verbally, words that they use to write about you and actions towards you, you've got to be aware of all those three things because they are all powerful, words are all powerful and all you need to say is S is aggressive and you think oh ok S is aggressive and straightway write that down S is aggressive and forever that's on my file I am aggressive, wherever I go anywhere in the whole country, people who don't know me will

read my file and you know aggressive oh you've got to be careful of her so for me the whole thing for me is what CS was saying about to be honest about the power over mental health service users, they do have power, let's not deny it, it's how you use that power, are you going to use that power in a positive way to empower your service users, to empower people with mental health problems, are you gonna use it in a constructive way, in an empowering way to empower your clients or are you going to use it in a way that is offensive and oppressive, to oppress your clients and to keep them down and as a professional you have to make up your mind, be it a student nurse or a psychiatrist or a mental health social worker, occupational therapist what ever, you have to make up your mind somewhere along the way, how am I going to use this power that I have and I must acknowledge that I do have power, how am I going to empower my client, how am I going to use it in a constructive way so that I am going to make their lives better and richer rather than oppress them with my language and the power that I have and use it in a negative way and that is the choice that people have to make, there is not point in pretending that it is not there because it is there, it is not equal, we can't section, I can't section the psychiatric nurse can I? [laughter from group]

JB: What about medicating them?

[Group laughter]

SL: Lopromozene...lopromozene

[Group laughter]

Video 50

JB: To me it feels that controlling your emotions really that you're not allowed to have these feelings.

VT: You are not allowed to vent.

JB: Medication for the nation [Group laughter]

SL: It is true though..it is controlling.. I remember once, I was on the ward I was at Q's actually now this was about maybe 15 years ago maybe longer, I was at Q's and I on this ward and I was black person on this ward believe it or not and erm...people were insulting me left, right and centre and they said don't take it seriously she's not very well and don't take her seriously and this woman really insulted me and I got really upset and I raised my voice and I wasn't screaming or swearing but I raised my voice and I was upset and I was ranting a bit and the nurse just said get here and I said what? And she said get here, right take this and I said but I don't want to take anything, why do I have to take a pill because somebody has just insulted me and I have got angry? Take it otherwise we will inject you and you know I had to take this pill and go sit on my bed, all because somebody had racial abused me.. and I thought where is the logic in that? Dampen me down because you can't deal with racism on your ward.

CS: They probably never dealt with a person who had been racist.

SL: [shaking head] It was terrible, I'll never forget that as long as I live.

Video 51

VT: But um you've got to remember that we live in Britain um... there is a huge British empire, a lot of what was done in the name of empire wasn't very good and um resonating as a male, African Caribbean and the African part is very important um I may be of mixed heritage, I know I am of mixed heritage but I am predominately African Caribbean, when you look at me you first see the African Caribbean aspect of me..um you have got to remember that for, you have got to put things into historical perspective as well, for well over 400years I have not had any power, I have not had any say, my viewpoints have not been valid..um Professor Whitaker put it good last year November when he was last here..he said if for 400 years you have told to shut up, you've got nothing to say and suddenly you are give a chance to speak, you will speak coz you have got a lot to say, for 400 years you have had to keep quiet and for me when particularly I will be honest with you here, I feel that I am in a safe place to say this..um..particularly when a white, middle class British male is going to misinterpreted my um... vocalism as being anger it really, really, really grates me, it annoys me, it puts my back up and it makes me more angry than if you just give me a little space to vent and come and speak to me later or even invite me to sort of seclude myself, I would have happily gone into seclusion when I have calmed down, keep checking on me, when I have calmed down you let me out and we can discuss what was upsetting me, but to me to medicalize things to me is the physical factors have been replaced by medical factors in..in..in my particular circumstance and scenario and view and that is what I have got to say about power when it comes to African Caribbean males, some of us may not vocalise it, some of us may not say it but it is some great and deeper than just one generational or two generational looking back, it is something going back well over 500-600 years and um..it cuts deep, it cuts deep and um.... Give me the space to speak and I will speak um.. as I said for well over 400 years I have had to be quiet even post abolition I had to be quiet until the better part of the 70's 80's.

Video 52

VT: Um when you see the police taking us in on a 136 for behaving violently or what you would call aggressively is because of what that police officer symbolises, it is not the police officer himself, he could have been the nicest person in the world but it is the institution which he symbolizes that gets my back up. I don't know if any of the African Caribbean females got anything to add to that but that is just me, as a male, young African Caribbean male who finds himself being sectioned um.. the thought processes that go through my head.

SL: To be honest with you V, it's certainly, what you just said there in terms of racism in this country and racism in the mental health world and the psychiatric system is true, it's very true and I think anybody who knows anything, whose read anything or mixed with anybody in the mental health world should by now, hopefully be aware of what you just said because people have been saying that for a long time and it needs to be continued to be said because there are still people who don't know about it, which I always find shocking, but my perspective has not been that different even though I am female my perspective has not been that different.. a few years back I used to have dreadlocks all the way down to my back, I used to smoke roll ups and the police would be on my case, thinking I am smoking weed and I am causing trouble, they check..yes we know S, she's been in Q's a few times, I spent hours and hours in the police station, get dragged over to Q's, get assessed, get kept in and then get sectioned, get medicated and my whole life would fall apart, from what? Just because I was walking down the street and smoking a cigarette and acting suspiciously and the only suspicious thing I done was have dreadlocks and have a roll up in my hand so I do know what that feels like because to be

honest with you, some of these experiences that African Caribbean females face are not that different to their male counterparts, it is just not that extreme, the violence, that is used on them is not as extreme as what is used on the males, but the perceptions and the fear of anger and aggressiveness is just the same.

Video 53

SL: Well I can remember an Asian guy getting really angry with me and shouting abusive terms at me and I thought I know this guy is a bit confused at the moment and everything so I said to the nurse you need to do something about this because he can't be just there screaming all that [shaking head] stuff at me, that abuse at me, it's just not acceptable, she told me to shut up and go away before she injects me so that was her response, so I just shut up and went away, what else could I do? You are powerless on those wards that's the thing, I felt absolutely powerless, if you want to talk about power dynamics I felt like the nurses, the healthcare assistants, the nurses, the psychiatrists, the junior doctors, the social workers, the occupational therapists had all the power and I was completely, totally, utterly powerless and the only people really I can say over the years on the wards that I have been on, the most compassionate people have been the healthcare assistants, I found them to be the most caring, empathetic..um empowering has come from the healthcare assistants, not from the nurses and not from the doctors.

Video 54

CS: I'm sorry.

VT: It's ok haha I will get it back, you can speak if you wish.

CS: Thank I just wanted to broaden it out as well, that um whether it is something to do with Nottingham being a small city and people knowing each other and we have more CCTV cameras in this city than in any other city why I have no idea, it seems to me very extraordinary, but there is this sense I know there are white men who have experienced um.. oppression, being picked on by the police because they are different, they look different, perhaps their hair is longer, they wear different clothes perhaps, you know and.. and they get approached by the police, they get pick up and questioned and to the extent that I know quite a few white men who cannot go out into the city through fear of being picked on or picked up by the police..um so there is something quite strange that happens in a city, it probably happens other cities, I have lived in London, there is a different kind of feeling there.

VT: Culture.

CS: Yeah.

VT: Culture of policing.

CS: There is a more appreciation difference.

JG: I am just going to focus back in.

CS: I am sorry.

JG: No because I think it is very relevant to the discussion we have had so far but just focus it back in again to the relationship with mental health nurses whether it is in the acute wards or within the community and the power within that relationship.

CS: Actually as I have just remembered something about when I was visiting on the ward um...there was a nurse and I have to say it wasn't just me who felt this but he looked like a security guard, he had a walkie talkie which he was speaking in to, he was standing at the entrance to the garden area and it was unbelievable because a I did not understand why he had a walkie talkie and b so we talked about words, actually body language is really important and this guy was, his whole body language was I am here to, you are in prison or whatever and I am going to make sure that you don't step out of order any of you, I was visiting someone, I wasn't even a patient for goodness sake, I felt that, how awful for patients to feel that um and I don't know what that is but I will leave it in the air.

Video 55

VT: Regardless of your creed, your class, the colour of your skin, your background um.. for someone to, because you are in the psychiatric hospital verbally threaten you, it's just not on.

CS: No.

VT: It's just not on.

SL: To be honest, there was this nurse, this community psychiatric nurse and this was a while back um.. the psychiatrist said to me, 'you know you are doing really well' and I said I am fine and I want to withdraw from my medication, some of it, maybe not all of it, not all at once but the aim is to be drug free at some point in my life, anyhow he said fine and he seemed happy with that and I was really pleased my psychiatrist agreed that at some point perhaps I could be drug free, anyhow he said we are going to put you in touch with this community psychiatric nurse who is very experienced and she is going to help you with the withdrawal, so I said ok great, anyhow met up with her I came round, went to her office and she erm said to me, right here's the programme, this is what you are going to do, this is how much you are going to cut down by, blah, blah, blah no negotiations, no discussion, no debate and when you get down to the last 10mg it's up to me to decide what happens then, because it is my judgement, I am going to decide whether or not you are going you are going to be well enough to stay on them, and I said to her, why is it your judgement? You hardly know me, you barely know me, so how can it be in your judgement. Well I have over thirty years clinical experience of blah, blah, blah [group laughter].

VT: How much lived experience does she have?

SL: I said ok, fine, I never argued with her, I just said fine, I thought you know something S, sometimes you got to be wise, you got to be wise with these so called professionals who are not very professional at all and you have got to take from them what skills they do have and acknowledge that they do have skills and some of them do have skills and when you get to a certain point do your own thing and that's what I did, I stayed with her for a while cut down, cut down, cut down and then I put in a complaint against her because she got more and more oppressive towards me and more and more abusive of her power towards me and um.. I did my own thing and got off that particular drug.. but it wasn't easy and she was telling me right from day one I am in control here S.

Video 56

CF: There was this young girl and um.. she wanted to have a..a. cigarette and um.. the staff said no you have been um.. badly behaved so you can't smoke now, you can't go out and have a cigarette, we are not going to allow you to go out and have a cigarette um... and then she was very upset, she was crying saying I just want to have a cigarette, why won't you let me have a cigarette and she was getting very angry at this point, now smoking actually relaxes people and I don't see why she not have just gone out, they had a courtyard, where she would have gone out and had a cigarette with one of the staff members, however they did not want to do that and she was sort of crying and crying and crying then three members of staff, who were involved with giving her the medication went outside, in full view of her and had, smoked three cigarettes, in front of her, so she had to watch um.. while they were smoking cigarettes and I had been there and I was a friend of hers on the ward and I just, comforted her and took her away and said look just leave them alone, there's just being horrible, just ignore it because, but otherwise if I hadn't of possibly been there she would have actually been sectioned or worse, coz she was getting really, really upset and I think if the staff had just diffused the situation, all it took was for somebody to go, lets all go out together and have a cigarette together, because actually sharing a cigarette is a way of actually, sharing a human, sort of common humanity of life, like having a cigarette outside together um.. so I think that situation was handled really badly and it was such a simple way of dealing with it but it was almost, they were misusing that power and I mean even now that I am out of hospital, I um.. I am sometimes like on the bus and the actual simple fact that I am on a bus and that I am free and I can do what I want is such an incredible feeling to me, which is strange because I have been in a situation where I have been completely powerless and being, not being able to make the most simple of requests without asking someone for permission, it just um I find it quite um.. remarkable that, that you have no power what so ever and you become a very, very, very small, they make you very, very, very small and your life becomes very small and very under the control of the important people who isn't me.

Video 57

JT: I just echo a very similar thing to that um CF just said um.. is that immense feeling after I had been sectioned, it just feels so wonderful to be able to go on a bus or be able to..to.. go where you want to be and it just, you know its what the reason that I just don't really go back, it might sound a bit sad to say that [group laughter] because I did not have that choice, because my parents are my main carers you see and if anything goes, anything happens then they'll go back to the GP so I'll not say anything so um..um yeah I..I..I just thought that that a section was one of the most traumatic, very traumatic period of time of my life and it is something that I carry around with me, it's diffused in a way, its fading away, but it's something that is there every day for me and it is that disempowerment thing.

Video 58

JT: It's awful, the only small thing, I noticed you were talking about the racism thing. I was talking to you a bit earlier, I do get it but I in a way, have that in a way but mine is a bit more invisible, I think you had a term for it, a terminology for it that you used one time, I can't remember what it was, it is sort of something that it doesn't, not so violent, people aren't so violent, they just ignore me or they are very discretionary, they do things which are a bit more discretionary but there is also um.. some sort of um..um sexual orientated comments and things like that which upset me aswell, the doctor asked, the doctor said to

me um.. I think it was a trainee doctor but he said I was there because I was a danger to myself or others but he also asked me if um if I um... aware of my um... what did he say..um....am I aware of my sexuality, he said which I found, perhaps looking back I think maybe he was just saying that, but at the time I was quite horrified at it and I did not know why he asked that and I don't know that thing going on for me and that wasn't very nice and I was horrified that that sort of thing goes on in a hospital.

Video 59

JB: Can I just say so..the last time I was on the ward it was just over three years ago and I was on 6 months section and I, you know really thought, you know, I was never, ever going to get off it um like CF said it's terrible because you are taken out of your life and I've been sectioned, you know three times all together and a couple of times you know on a 136 where you are brought in by the police and me being a white woman I was treated, one time I was just walking up my path and I rang the police because I thought there was something going on in my flat and I was just walking up the path, next minute this policeman jumped on my back, I just couldn't believe it, he handcuffed me, he took me down to you know Bridewell and I just couldn't believe, I was just left in a cell all night without even any water, nothing what so ever and er.. another time, I mean I just couldn't believe this I got followed by a helicopter, I mean some people might have thought I was delusional...I was late back to the ward and they rang me after two hours, I mean they had let me go for two hours and there was no way I was going to get home and back again in two hours, where I live, especially on public transport, but little did they know I got my car hidden away [laughs] but anyway so I went home had a bath and they rang me and I said ooohh I am really sorry I am going to get the bus now, but I had no intention of getting the bus, anyway I went to Sainburys, filled up with petrol, then the next minute I saw a blue flashing light behind me so I thought oooh I will give them a run for their money [group laughter] and er.. they followed me and I went on, I made sure they could not overtake me and then I went off this fast road, then next minute I thought.. I will go home, you know, we've had a bit of fun and there was this flat, white light and I thought what's that? You know, what's happening? [Group laughter] It's only a police helicopter and I thought, well I am not going home now so you know I drove up the road and I had to stop at some traffic lights and I couldn't believe it, there were three police cars there, two at the side and one at the back and I had locked myself in the car, come on get out...and they took me back to the Queen's and the police were laughing but I thought haven't they, it was like I was some kind of dangerous criminal, you know and I was well on my way to recovery, I just thought it was absolutely unbelievable, really they probably had nothing to do that night, but the thing was that my car was just left and my son had gone to the police station to say where's my mother's car and they told him on this council estate somewhere, there was no sign of it, so it took him two weeks to find it and by then it had been vandalised a bit, but the police did say, oh yeah that was a really good car chase, you kept to the speed limits, you stopped at every traffic light [group laughter] but the staff had said on the ward, you know, coz I said have you seen that how ridiculous and they said, that's nothing, they bought a little, old, six police men brought a little, old lady in the other day and I thought [shake of head].

Video 60

MH: Just wondering in terms of nurses and in terms of nursing teams are we as a group of people with lived experience saying that it is really important that on a regular basis, a daily, a weekly level they ask what's happening with the power thing? You know, coz we know potentially we have all the power in this situation are we abusing it? I'm just, just

wondering if that's the thing which nurses and teams in hospitals just as an every day thing, have we abused our power this week?

SL: The thing is, it is kind of like it's every single instant, everything you do, at every single point, there needs to be certain markers that need to be in your mind in terms of racism and culture, gender and sexuality, along with age and other forms of discrimination, along with discrimination which has been drilled into peoples heads since the 1980's and 70's, power need to be there on the same level, on the same significance, are we, everybody time you are in a relationship, in contact with a patient or a client, you are going to be asking yourself, you know, you were saying before, the work that you do before you meet, to be thinking what's the power dynamics here? What's this persons history, where's this person come from, how am I going to introduce myself, how am I going to use my power in a constructive way? And these things you are going to be saying every day, every minute of every day until it becomes second nature to you.

Video 61

CS: It strikes me that um..over many years that, psychia..and I think it has become more so for some reason um,, that there is a culture on the wards of reducing people and this is not to denigrate children but actually making the power, we are the parents, and you're ill so you are the children and so you tell people off, you tell them they can't do this, you tell them you have to ask them for this, all completely robbing people any sense of dignity, self-respect that they might just have when they come into hospital, and it can so often be a double whammy coz some of the reasons why some people may be in hospital maybe just because they their voice hasn't been heard, they have been oppressed, they've been discriminated against and they come into hospital and what do we do? We just give them more of the same because we think that is just such a good idea..um..its really completely outrageous and I think that you know its well time that we should really look at it..um and turn it right round so that people are aware that this, that health professionals are aware of much more what it is like for patients.

Video 62

SL: What really gets to me is, just the thing about, just to follow on from what you was saying, the thing about children, we are not children, no disrespect to children, I'm very pro- children and children's rights, respecting the child and the right of the child and every child matters, I really care for children but what I am saying is we are not children, we are adults and we have to make choices and we have rights , we have responsibilities, you know and to turn around and treat us as if we are children who can't make our own decisions about anything is terrible and the other thing I don't like is vulnerable adult, what is a vulnerable adult? Where did this thing come from? It is just so annoying because any adult can be seen as vulnerable, any adult at some point in their life can be seen as vulnerable, why am I suddenly any more vulnerable than any other adult, somebody described me as a vulnerable adult the other day and I thought, what do I have to do in order to be seen as just like a regular person? What, what more do I have to do? But because I am taking medication I am a vulnerable adult and I am thinking you can't win, so if I take medication til I am eighty I am going to vulnerable all that time, no matter what I achieve in my life, I could go on and get a PhD and still be a vulnerable adult.

CF: I've got a PhD and I am a vulnerable adult.

Video 63

JG: I just wanted to widen it out to maybe look at the way nurses respond to our distress and from the sort of things we have been saying you know I think we all feel that distress is something that is part of us, part of our lives and it isn't something to be feared, but I just wondered whether particularly around the experience you've given of escalation whether there is a culture of fear and just ask the question do we think maybe nurses fear our distress?

CS: I think maybe they fear that maybe that it can get out of control and I think that is what they are frightened of..um.. perhaps so that maybe we will become extremely angry and may want to throw um.. a plastic cup, whatever actually so what? Um.. when I was having therapy at one particular point my therapist actually said get a rolling pin and go to the sofa and beat the hell out of it, well if you did that on a ward my gosh can you imagine? Well you wouldn't be even allowed to have the rolling pin but if I took my shoe to the sofa and started hitting it [group laughter] what would they do? Yet actually that is a hugely therapeutic thing for me to do and I still use it, I should probably go back tonight and bash the sofa because I am angry about all the things I have heard today, so it is somehow not understanding, not understanding our..humanity what do they do when they get angry? Perhaps they drink, perhaps they smoke, perhaps they.. that's fine, that's their coping strategies but they really need to look at.. at what, and that's one of the things we talk about is coping strategies, that that's a perfectly viable place, situation to have a room where people could go and just...

SL: Bash things.

CS: Yes.

SL: I think it is just fear.

JB: The thing is the nurses are working within a system and very often they'd like to be able to do something for someone, but they are in that system, they've got to work in that system and you know having been on the wards quite a bit you know you do get really frustrated you know because you can't do anything, you know you can't do the kind of things you do at home.

Video 64

JG: One of my colleagues who can't be here today because he has had to go into hospital, that he talked about um.. the nurses response to him and his distress and what he said was that they didn't want to take it personally that he was angry or agitated that it was possibly his distress that was making him angry and agitated and angry and it wasn't them necessarily and he thought, because he is quite a big guy, he says I know they are frightened of me um.. but it isn't them I am angry with, I am just angry because I am not feeling well, I am feeling distressed, but they take it personally and then they punish me.

SL: I think there needs to be a different strategy that nursing staff um.. are given in terms of the way that wards are set out, wards need to be set out differently that people can go somewhere when they are really angry, they can go to a room or a couple of rooms or spaces where they can rant, really raise their voice, throw soft things around, bash settees, just whatever and then come and when they're in there to be left alone to express, people can check they are alright but to be left alone to express whatever and when they come out the nurses to be equipped to know how to deal with someone who is that upset

or that angry or that annoyed, how do you communicate and I don't think they know that, I don't think they're trained in that way and that's where the fear comes from because all they are thinking all the time is, they're going to hit me, they're going to lash out and they're going to hurt me and hurt somebody else or they're going to hurt themselves and that is all that is going on in these professionals heads, that they are worried about hurt and harm and harm minimisation and instead of trying to control and clamp down on that if they know how to talk to somebody and communicate with eye contact and the tone of your voice, body language and be train to deal with that then maybe some of this over use of medication, fear of peoples anger and emotions wouldn't be so.. such a big issue.

Video 65

MH: There is 70's utopian fiction novel, I don't know if you have read it called "woman on the edge of time" by Marge Piercy.

SL: Yeah, yeah, yeah Piercy yeah.

MH: And you in this sort of utopian future they still have places like asylums but they are places where you go, not to be cured from your madness but you go to be mad, so they are safe places for people to be mad in and I always thought that is quite an interesting sort of changing of the narrative, yeah you can be mad and it might be three months that you are mad for, it might be a year you are mad for but you can go and be mad in a place and maybe that's the sort of mini- version you were talking about, can people have a place they can just go and vent for an hour or two and be if you like mad, sort of and then come back out, but.

CF: You can't be mad in a mental hospital, you have got to conform and comply.

MH: Yeah.

SL: You can't show any form of emotion, if you are happy it a problem, if you are sad it is a problem, if you are up it is a problem, if you are down it is a problem, you can't win.

CF: If you are expressive, if you are creative, if you laugh to much.

SL: If you laugh to much you are too happy, you're high.

Video 66

CF: With all the staff and I was being enthusiastic about it, was expressing this to the staff and I was told by the ward manager [laughs] you're too happy, you're too happy, why are you so happy, you're high, we'll have to give you some medication [laughter] and I was actually reducing my medication and in the end I came completely off that medication coz I did not listen to her and I said not I am not any medication, I am not high, I am actually happy because it is New Year and I am having my grapes and I am trying to make the most out of a difficult situation coz I tell you what it is not the easiest things in world to be Christmas and New Year in a mental hospital but I just thought it was remarkable [laughter] that because I was happy and I was celebrating that that obviously, you can't even be happy on a ward..

SL: No you can't..

CF: ...because then you are manic.

SL: No you can't be happy.

CF: And it wasn't that I was because I um.. ended up leaving the hospital um.. about 4/5 days later so how could I have been high if that was the case so it was just um.. a way of seeing me and my happiness as a symptom which was just being a human being and being happy coz it's New Year.

SL: It completely dehumanises you doesn't it?

CF: You've just got to be a ... robot, like a patient, a good patient robot, compliant patient who does exactly what is said on the tin, you learn the rules of how to be a good mental patient, that's what being in a mental hospital teaches you how to be a good mental patient, that's all I learnt from in a hospital [laughter] I learnt how to be a mental patient and play the system so I could get out of the hospital and know what to say and what to do and how to behave in front of the nurses, be polite to the nurses, even if I don't mean thank you, I will thank you and I will say please and I will ask for my plate and I will ask for my cup and I will ask please may I have towel and thank you for a towel and even if I don't mean it I will behave in this programmed sort of way so I can get out and that so that I don't have to see you anymore.

Video 67

CF: But what I really needed was actually a space to express my story and my sadness and I needed a place to mad in so actually what you were talking about a place to be mad in, that's where I needed to be, and sometimes the pain of my life and my story gets too much that I need a place to go to, which is safe, where I can be with people who, well I get, I know I get, I am actually vulnerable, I get very vulnerable and I need a place where people look out for me but I need a place to express the great sadness in my life, past, the great pain I've been through and I don't want it to be silenced by drugs and I don't want to be told to be quiet, I don't want to be told to be compliant, I don't want to be told, threatened with section, I don't want to be abused by staff, all I want is a place to be mad and [laughter] accepted as a madperson and when I am done with being mad I will come back and I be fine and that's cool.

MH: So so sanctuary really.

CF: A safe place.

MH: A sanctuary really, sort of coz.

CS: Which is what asylum used to be.

MH: Which is sort of a, you know, coz I remember once, asking, you know, can I come into hospital? And the psychiatrist [shaking head] said 'you don't want to come in here mate'. [Group laughter] I said I just want a place where I can just have a, I want to be away from, 'well don't here mate coz it'll just do your head in.' [Group laughter] And thank god he said it. [Group laughter] Sort of just a bit like really 'if you want a bit of sanctuary from the world don't come here.'

[Group laughter]

CF: Go to a spa.

[Group laughter]

MH: 'Go to Brighton for the weekend, but don't come here.'

[Group laughter]

Video 68

VT: What I found unhelpful was firstly um.. I remember when I had just been diagnosed and having struggled from April to the October before I was sectioned trying to do it on my own um.. just been diagnosed, released the following April because I had a section 2 then a rapid section 3 afterwards, released round about April 2006, nurse kept saying to me come meet me in town, come on I can't even get out of bed, much as to come meet you in town, um I don't want to socialise, I don't want to interact, it's enough that I have got to meet you, don't ask me to go that extra mile, meet me at the threshold um.. good practice was that same persistent nurse JG knows who he is we'll keep him quiet for now, I am sure if he watches this clip he will identify himself um... he came and met me at the threshold, he didn't invade my space, he respected my space when he came in, my carpet was a mess but he was if I cleaned up that day he would recognise and take his shoes off, and it's little things like this and um.. he would meet me at the threshold and we would go and to the coffee shop at the end of the street first and then we'd go two streets down then we'd go to the edge of the community and before we know it we'd be going to Top Valley to buy a transistor radio, you know I am, its just good practise to tease me out of my comfort zone, a zone I had found myself comfortable in after being I would say totally institutionalised, 6 months is not a long time but each person react differently in that situation but I was to some extent institutionalised and your um.. don't ask me to come and meet you in town, don't ask me to come and meet me at at a far flung corner café from my house, yes um.. I am worried about having you around um.. I don't want you around my space yet but just come and meet me at the door, ask me to meet you at the door, drive your car up to the door or as close as you can get to the door and ask me to come out and that would be a shorter leap than getting on a bus or tram into town.. yeah.

Video 69

JG: I have got two examples of attitudes I don't find helpful and the first one is when a practitioner introduces themselves to me as my new friend, actually you have to work hard to be my friend um.. I am not that desperate that I will give my friendship away, you can be my ally, you can be my supporter but please don't ever introduce yourself to me as I am going to be your new friend.

CS: That is a terrible assumption.

JG: And the second attitude that I find really unhelpful for me is when someone says cheer up it's not that bad, when actually it is that bad um.. I don't expect um.. people to know what I'm going through, it's my journey, um.. but I expect to understand if I say that and I don't want that dismissed, I reserve the right to be sad if I need to and I don't want to be told to cheer up.

MH: I remember doing some cognitive therapy off a psychiatrist once and they were always trying to reframe all experiences and I was just a bit like, no you're wrong, it's fucking shit, my life is awful sort of, she got very frustrated, sort of and um.. yeah and it was just quite funny, things aren't that bad, no they really are, don't patronise me, they really are that bad.

JG: Yes.

Video 70

SL: Attitudes I don't like to be dismissed and I don't like.. I got this thing about potential, like I think we've all got potential like I said earlier um.. I don't like being dismissed and I don't like being denied my potential by anybody especially professionals, so don't dismiss me and don't um.. underestimate me and don't think that I'm stupid, I want to be recognised as an intelligent woman with a lot to say and a lot about her and I like to be recognised for my skills and abilities and experience..um so don't dismiss me that's what I don't like, to be dismissed.

JG: Good, thank you.

Video 71

CS: I don't like any attitude that smacks in the beginning of bullying me, of which I have experience quite a lot by people in authority um.. in work um.. so it is almost as though if you can see that I might be a bit vulnerable just respect that and tread carefully um.. don't go in with your big boots and kick me around.

Video 72

Yeah um... I think especially in the early days but to a small extent now I have been told that I'm not, not um.. I haven't got the capability, I haven't got the ability to um.. I don't know um.. do things like um.. I don't know go to college or go to work or something like that um.. told that I was lazy and make excuses not work, I don't like that, I thought that was very, very rude um.. and also but then again at the other end of the spectrum people thinking that um.. I think I'm I know it all or that I am better than other people and that sort of thing, when I think that I am a survivor like a lot of people and that's it really, thank you.

Video 73

JB: Well I don't like someone who's kind of bossy and pushy and too questioning... I think like someone else said I mean you will speak to someone about stuff in your own time if you trust them but if they haven't built a trusting relationship with you then that no.. but just as equally not liking someone who's pushy, I kind of don't like some one who is a bit kind of too gentle and not very assertive, so I did have a social worker for five years and he used to come in quite mouse like and he always used to say to me J, you've got more knowledge of the mental health system you know, he kind of always put himself down and then one day he says to me, if you are starting to feel unwell, go and start to clean behind your cooker, and I thought in five years that's the only thing he ever told me to do which.

CS: Have you looked behind your cooker?

JB: No, I make a point now keeping it clean now.

[Group laughter]

CS: Have another look.

JB: Um.. I mean I just thinking about when I was attending the day hospital aswell um.. they had a different psychiatrist you know and I saw him, you know it's my first episode and I was determined I was going to get back to work, I was going to get a job because to me normality was getting out there and getting a job and feeling you know, valued, and he said oh no, no, no he said you want to get a nice little job in an office and I thought what about putting a dampener.. you know on your aspirations, I thought... you know that was really, really bad and another thing I don't like someone else making assumptions that they know best, you know, what is good for you because I think everyone is their own best advocate and they should involve people in decisions which are made about them. That's me I will pass you over to C.

Video 74

CF: What I don't like, well I've seen a lot of cruel behaviour on wards so I don't like cruelty, I don't like being dismissed, being um..um.. treated like I am nothing coz I have been treated like I am nothing or treated like I am an idiot um.. I don't like being ganged up on by groups of staff, so I don't need four people to come and give me my medication and two men standing up while two women emotionally blackmail into taking my medication, you know what, just leave it there I might take it, might not you know it's um, is it really um..... is it really... is it really a place... I do not want to be in a place where I feel bullied and forced into doing things, as somebody who has been um.. abused I don't want to be abused by the system as well and that's what happened to me, I have been abused once and then I have been abused by the system twice so its kind of like I go for a place of safety and I end up getting abused by it so its kind of a ridiculous thing, ridiculous thing coz at the end of the day I did not feel safe in my home and then I did not feel safe in hospital so what, what the hell is that about so I think...um create a place of safety fro me that would be my plea.

Video 75

CS: What I have found really good and supportive is when the practitioner has said to me what do you want me to do? And although I may not know what I want her to do the mere fact that she's asked me shows a willingness to respect what I might answer with is worth listening to, she's not promising she can do it but she's giving me the courtesy of asking what I want her to do and I find that is very powerful mmm.

Video 76

SL: I can think of an experience when I was on a ward some time at Queen's and there was a ward manager there who is female and she is one of the best nurses I have ever met since I came into the mental health world all those years ago, she inspired me and she helped me to believe in myself again, she'd come on ward and if I wasn't dressed and ready she'd come round to where I was sleeping and say S are you going to get up today? And I say ohh and she said come on get up and we can have a chat... I I I just wanted to spend the whole day in bed, I was that depressed, I did not want to see or talk or anything but she encouraged me to get up, get shower and get ready, get dressed and I ended up having a really brilliant day, a really good day because she was so much fun and so when she was on the ward I looked forward to her being on duty, making an effort, getting

dressed, getting ready to have a conversation and to do something exciting, to sit down and talk and she kept me going for about 6 months, she kept me going on that ward when she was there, it was really, really good and she is such a positive person, she was saying things about me years before things happened, predicting that I'd do well and saying that I was intelligent and saying that my experiences, that I would use my experience in a really good way, that I was a strong woman, she said lots of really good things about me, which I remember to this day, she really, really inspired me, I can really say that, a brilliant nurse, if there were more nurses like that the wards would be a better place.

Video 77

VT: Oh yeah positive support that I received from practitioner is to co-author, co-produce um.. solutions whether it be from.. medication regime to a simple daily solution like dealing with my debts um.. or paying my electric bills on time um.. if you give me a chance to co-produce the solution it increases my buy-in to the end result and I am more likely to preserve with whatever solutions come up, I am more likely to be amenable to, to the solution and be more receptive of, of what you are saying, if I have, what I feel not even, I am not asking for equal input, I am asking for some input to the solution um... there's states, when I am in certain states um.. I won't be 100% willing or capable of making those decisions myself but if I get that buy-in I am more likely to go along with it.

Video 78

JG: I would just like to reiterate at the beginning of the afternoon that the best the support I ever received was the person who gave me permission to cry, to cry without shame, to cry without fear, just to cry and cry and he didn't try to stop me, he didn't try to make it better he just said go ahead um.. I am very, very much, deeply value that support and I think the other example of good support I'd like to share is a practitioner who focussed on my strengths, yes I'd got needs, yes I was vulnerable, fragile, yes I was in distress but she also saw that I was resilient, she saw I'd got strength and she and she didn't just see me as a bundle of needs and weaknesses to be patched up, she saw something strong inside me and she helped me see that strength as well.

Video 79

SL: Points I think C and I don't know who else made these points, as far as I can recall CF made some points and VT made some points about sharing something of themselves in order to start that relationship with service users and I know of one practitioner who um.. who worked with me for about three, four years and she always shared a little bit of herself with me and um.. it made me feel human, she made me feel human, she made me feel valued, she made me feel important.. because she was, she would talk about her partner, going away on holiday, nothing.. she never told me I live at such and such a house and we go here and there shopping, she never disclosed anything that would mean I could stalk her or whatever their fear is, but she shared important things like we're going to get married in couple of years time and we're going to start a family, it was just so.. she shared things with me, oh this week we're going to do some decorating and it made me feel if you are going to share with me, I am going to share with you and from the very first meeting, when she first met me, she shared and it just changed the whole dynamic in our relationship from the day one, it was really, really good, one of the best and she was the one who said to me why don't you think about doing mental health social work, I think you'd be really good S.

JG: That's great, yeah.

SL: She was good, she was good and she was quite a bit younger than me as well but she was good, it taught me a lesson not to dismiss someone because they are younger, you know.

Video 80

VT: If you are sceptical about sharing anything personal or you don't know what boundaries to pick up, what about, what about finding an interest I like, a mutual interest we both like and we or you pick up an interest I like and we can start sharing along that basis, that way you are not disclosing anything private and you don't run the risk of, of, of running foul of your employers rule or your professional body rule because it is something that you and the client came together and um.. started an interest in, it would do a lot for the client's ego and you just may learn something new.

Video 81

MH: I think it is just that general one, when someone treats you with respect and as a person who has potential that it makes an enormous amount of difference and someone who... it's very difficult coz I think people can get worn down by the system on both ends of it but I can think of one particular practitioner who I had contact with who er... he just always, he was a ray of sunshine, sort of [laughs] you know, he was almost better than the drugs he was giving out [laughs] sort of coz I'd be a bit like can't we just hang out for days, I'm sure I'd be better if I could spend three or four days with you coz he was such a positive person and um yeah and it doesn't..... it's funny how sometimes even in very disturbed and very distressed, sometimes, I don't know if anyone else has this experience that is a random positive experience in a day, where you just chat to someone for a minute and it's somehow uplifted and you're just a bit like oh, I was only chatting to an old lady at the bus stop or sort of and um.. human contact can make you feel better and working out as a practitioner which this one I was talking about he had worked out, I don't know how, but how to be a really sort of, positive effect on someone's life so yeah I think working out how you can be positive and I think another thing I have noticed with people is.. the people who do have a good effect I get the sense that they believe that they can do their job well, and I think a lot people, a long time ago I worked in community care with adults with learning disabilities and used to do a lot of training and um.. the first thing we'd try and get people to think about was what it meant to do your job well, coz you'd find a lot of people just thought you know, it's cleaning up shit, it's sort of listening to people talk nonsense, and I've just got to get through it, so the first thing you'd try to do is to instil a sense that there is such a thing where working with this diverse group of people as doing your job well and I think anyone who works in human services needs to have some sense and believe that there is a thing of doing their job well because if they don't they'll never gonna do it well, you know if they don't believe that there is such a thing as doing a job well it's never gonna happen, it's always going to be drudgery and you probably are going to end up working in an oppressive way.

Video 82

JT: I think that one thing that helped me when I was at very, very low ebb some, some years ago um.. looking back at the 97/98 um.. a social worker, um I had a couple of social workers who were very good and um.. around all the negativity and the stereotyping that was around me, and they helped me to get into my flat and everything, once that

happened it, it was like a sense of being part of community and society again, rather than being cut off and isolated and feeling odd and that sort of thing um.. introducing me to holistic things and um.. taking me out for things like dinner, it was lovely to be take out for a meal, a French meal I was taken out and also for a facial and a massage and that was really nice um.. treat with some respect and er.. that started to make me sort of weave back that sort of, thing back into my life where I thought I was worthless and I was started to give some value and um.. I think that helped me become, sort of think that it get me back on the journey um.. with my recovery and um.. realise that I am someone

Video 83

JG: Thanks Jen.

JB: Um.. [coughs] well after my first psychotic episode I had a CPN, I won't say his name, and I, he was really positive and I was feeling completely decimated especially after the experience of being on the ward coz that wasn't helpful and he was just saying 'look, you know lots of people have recovered' and he's reeling off all these names of people who have had episodes um.. and he made me feel that he really believed in me and one day he said 'J. come on you know why don't you do some volunteering, you know.' But he wasn't pushy, you know, he was really enthusiastic and he said, 'what about volunteering at such and such a place' and he took me along there and I thought he would hold my hand, he didn't he just dumped me there basically [group laughter]. And he said 'right I will see you in half and hour' [laughs] I thought you know he was going to come in with me, but you know I found his attitude really helpful.

Video 84

CF: I think for me it has been little things that people have done so um.. little things that are done with authenticity and um.. kindness, so I think I can tell the difference, I am now incredibly good at telling if somebody is not being authentic with their kindness, if they are just putting it on, so I mean nurses who have been incredibly kind to me, who when I have been upset and they have just sort of held my hand or they have listened to me with.. with um.. sort of attentively and had a sort of ... gentleness about them with me which has allowed me to open up um.. I think also being humble about it and not self-gradulating about it..oh I've got anything from this person..um like..if you..um going for a walk with somebody and just being able to, actually share life stories with that person um.. and giving something um.. they give you something back..um.. so I think like the first time I was in hospital when I left hospital, just before I left um..one of the nurses who, just came up to me sort of, like a hug and it was so genuine and she said, 'I am so happy that you have got better and that you are going out now,' and it was just, it wasn't false, coz I have had hugs from a lot of nurses [group laughter], but it was and their kind of like 'oh she's going, good, the trouble maker is leaving' not it was just like a authentic, so for me the most important thing is that it comes from a true place, so if the nurses if they be true to themselves and be authentic um.. and have that true compassion and that would be what I value the most.

Video 85

VT: Oh um.. I have been hanging on to this one for the longest time [group laughter].

JG: Well done.

VT: Um.. what I found out from this world um.. that say I contributed about 40% towards my recovery in the early days, was having someone who, who um... not necessarily further along the psychiatric path than I was, but someone who was treading that path um.. when I was in hospital there it was discouraged for you to keep in contact with anyone that was on the ward, I don't know if that still happens, but um.. when people have come out and they no longer vulnerable, no longer at risk of being exploited sometimes we just wanna.. um.. share our experiences with someone who is um... trod in the same path as us and that is as powerful as the psychiatric medication to the healing process um yes um.. I had a good friend, he has now passed, very, very good friend J's met him, always smiling, always had a big smile, I can still see his smile today um.. with whom I could sit, speak about random things or deep things or psychiatric related things, just anything without being judged, without being assessed, without being risk assessed um.. knowing that we've got equal power in the relationship and you can never have truly equal with someone who could always resort to having you sectioned or assessed for section, sectioning um.. so that me thinking out about, just thought about this, thinking out of the box.

Video 86

VT: Just throwing it out there.

JG: I think what.. the very clear message for nurses there, is to recognise the healing that patients give to one another.

VT: Yes, we are social animals.

JG: And not to dismiss that and to recognise the communities of survival.

VT. Yes.

JG: Um.. within the wards and within the communities and indeed here, we call it peer support but I think um.. nurses need to recognise how important that is to us.. um would you agree?

SL: I think what's happened in the past in my experience on the wards, is that when you strike up a friendship with somebody on the ward um...

VT: They separate you.

SL: They see that as somehow threatening to your recovery and they, they discourage you from keeping, maintaining that friendship and you really struggle to be friends and if you are determined once you leave you swap numbers and then you link up once you've both been discharged and try and maintain the friendship, but I think it's vital because for me, if I with other people who have been through the system then I value their um.. their opinions, their views, their attitudes more than anybody else, they're my number one source of support above any professional and they always will be because they've lived what I've been through and when I am saying something they can feel it, they are not hearing they are actually feel it and for that's so important to have that connection and that real grounding and that real support. I think it's vital and we call it peer support now but it has always been there with communities hasn't it? People of many years ago, even I used to attend er.. Black women's mental health support group and that was pretty good, when I first came to Nottingham, I was quite isolated, didn't really know anybody, didn't really

have many friends and got quite unwell and started to go to this group it stopped me from ending up in hospital, really, basically, that group.

JG: So there is another message there I think for nurse which I think is about signposting people, signposting people to appropriate groups and recognising that maybe that um.. when we are working with people, when we are looking at support that services may only be part of answer and we should be looking for solutions, solutions for nurses might be about signposting you to a black woman's group, to a coming off cannabis group, to a self harm group and that's, most partnerships are amazing and there's huge resources in the community that nurses can make use of.

Video 87

MH: It is interesting sort of, just as a, how I've been going to a wellness group at Manor Road in Carlton, sort of but it's quite interesting how, and it's it's done with a lot of integrity, sort of er.. you know it's it does give out a lot of power to the group, sort of, but I'm sort of, I wonder if people are more open when they're in a group, which doesn't have any psychiatric professionals in, sort of, and I think think people seem and I'm I can't it's really well run, I'm getting things out of it, just the contrast of coming here is that, maybe it's actually been a lot more of a constructive atmosphere, sort of, I wonder sometimes if the mental health professionals sitting there if people, sometimes people get a bit antagonistic and you can see people becoming a bit like oh they're the enemy, I don't like them and I wonder if sometimes in peer groups if the attendance of mental health professionals can sometimes affect the mood, I don't know, I am not sure but I am just been interested coz I have been very impressed with, well it's been lovely to be part of such a candid group of people sort of, yeah today, yeah its been really, really lovely.

Video 88

SL: I think it's a bit of both because I have been to groups where it's been service users together and that's got a certain vibe and a certain feeling, when I've been to the black women's group which had two social workers and the black women and that was the social group and that was great, we had a really good time and we supported each other, but the workers were there to stop anybody from falling over the edge.

MH: Right.

SL: Which was, which was good for my safety at that time, where my head was at, that was good for me, years ago I went to a black women's psychotherapy group in Brixton, in South West London and um.. I was working at the time and I was seeing a therapist individual one-to-one psychotherapist and I was also attending the black women's psychotherapy group and it was all black women, all Caribbean, African women but there was a black woman psychotherapist who facilitated the group and that group stopped me from going over the edge many a time and I think the power of groups, be it either with or without professionals you can't underestimate that really, where you've got shared experience, so powerful, really is.