

Consent to Intervention in Mental Health Rehabilitation: Who knows best?

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This paper attempts to stimulate thinking and discussion about the issue of consent in adult mental health rehabilitation services.

Being a 'good patient' helps you to get out of hospital, being a 'bad patient' helps you get a life.
(Judi Chamberlin, 1998)

All too often psychosocial rehabilitation services tend to process individuals. There is a confidence that we know best and that there is one (psychiatrically determined) way to recover. In this way services tend to sell a set of values, a combination of the medical model and the idea of a psychosocial 'stepwise progression' to health. Services aim to construct what is called a "better quality of life", or to "maintain quality of life" (see Rapley, 2001). This includes the concept that someone's 'condition' is static, his or her life can be held on a plateau and this constitutes a success.

All this occurs within or against the backdrop of the Mental Health Act (MHA) and clients' knowledge that they could be compelled to receive 'treatment' whether they want to or not. It becomes important for clients to be perceived as being good and respectful of mental health services' efforts, as to cause 'bad feeling' with workers could have direct consequences on their perceived 'fitness' to be free from the MHA restrictions. The Mental Health Act Code of conduct defines consent as being agreement in the absence of coercion. Whatever explicit messages are given, implicitly coercive power is ever present within all relationships between mental health workers and service users, due to the very existence of the MHA. In this context the process of seeking consent could be considered flawed from the outset. Nevertheless, power imbalances are present within all relationships and it is important that whilst recognizing the powerful position of mental health workers, we do not disrespect service users by dismissing the power that they do hold.

The pressures to comply can be subtler, but just as powerful. Clients can feel the need to go along with what is proposed by mental health professionals, not simply because of the powers bestowed by the MHA but out of a sense that the 'doctor knows best' and the belief, reinforced by Western culture, that as victims of ill health, their role is to be a passive recipient of the care prescribed. Through this process, rehabilitation services often consistently and faithfully offer services to people, over many years. People are recruited into the special world created by the service. There is considerable debate as to how special to make this world and whether individuals need the artificial world that rehabilitation services can create. The normalization and Social Role Valorization movements have raised challenging questions for such services. Normalization, however, has been appropriated by services wishing to process people back into mainstream life rather than helping people to live the life they might actually choose.

Within this system, the role frequently offered to the psychologist is to help people adjust to both the artificial world of rehabilitation and the aims for re-integration that the service has defined and hence to avoid the use of MHA compulsion.

Consent process within the system

Informed consent in mental health services has a long and challenging history (see Fennel, 1998). Recently this issue has been examined in relation to E.C.T. (Arscott, 1999), drug treatment (Baldwin, 2001; Cohen, 1998), child services (Shalan and Griggs, 1998) and addressing the power imbalance in the area of consent (Gelsthorpe, 1995). It is, however, a topic notably absent from the subject indexes of a number of key texts in psychiatry and clinical psychology (e.g. Baum, Newman, Weinman, Wets, & McManus, 1997; Birchwood and Tarrier, 1994).

In rehabilitation services the starting point can be, "Please help me (them) to get better/be normal". The, sometimes explicit, response is, "Conform and buy in to this system and hopefully you will reap the benefits in terms of a 'better quality of life'". A particular model of rehabilitation is sold as an absolute, and the consequences of this are little understood in terms of the effect on the individual. Rapidly the contract in terms of what you can ask for and what is on offer is closely defined; with no question of any alternative:

I asked the psychiatrist I was working with, 'What's wrong with me?' He said, 'You have a disease called chronic schizophrenia. It is a disease that is like diabetes. If you take medication for the rest of your life and avoid stress, then maybe you can cope.'... In essence the psychiatrist was telling me that my life, by virtue of being labeled with schizophrenia, was already a closed book. He was saying that my future had already been written. The goals and dreams that I aspired to were mere fantasies according to his prognosis of doom. When the future has been closed off in this way, then the present loses its orientation and becomes nothing but a succession of unrelated moments. (Deegan, 1996: p. 92)

Pat Deegan goes on to expand upon what happens within this shamefully common process which touches the essence of who we are. She quotes Heidegger's definition of what it is to be human: *To be human means to be a question in search of an answer.* By closing the book, this essence is squashed, and in doing so hope is stripped away. When hope is removed in this way, protecting the self from ever hoping again (and being vulnerable to this being destroyed again) becomes one of the best survival strategies: 'If I don't care then you can't hurt me and everyone can do as they like to me, as it doesn't make any difference'.

If (or when) an individual loses hope or in, 'rehab speak', becomes 'unmotivated' the process of consent at best becomes compliance, tolerating the system and being 'done to', without any hope of change. The sight of someone with long-term mental health problems sitting day after day, smoking and staring into space, might be viewed as 'the stuff of rehabilitation problems'. However, such withdrawal is in fact the very *solution* needed to protect from the pain of hopelessness:

'Rebecca'

In her early teens Rebecca had been admitted to a child and adolescent unit with a diagnosis of severe anorexia. She eventually began eating but became increasingly quiet and withdrawn and was finally labelled 'elective mute'.

Rebecca attended a day hospital for many months, attending individual art therapy sessions, but for the rest of the time sitting in the day room. The multi-disciplinary rehab day hospital team (MDT) were at a loss as to what to 'do' with Rebecca. Eventually she appeared overwhelmed by the bus journey to the hospital and stayed at home. The MDT insisted the family get her to the day hospital and then they would try to offer treatment. The psychiatrist planned a symptom by symptom approach: physiotherapy for posture and rigid movement; art therapy for inner expression; occupational therapy for practical skills and medical intervention for mood disturbance:

'there could be drug trials, and what about ECT?' They were also hopeful that the new clinical psychologist would answer their frustrations in coaxing Rebecca back to the day hospital, so she can receive this 'treatment'.

On my arrival I was faced with staff demands and parental expectations, but Rebecca herself was silent.

The Oxford dictionary defines consent as, *saying one is willing to do what someone wishes*.

Compliance is defined as an *unworthy submission* and coercion as *control of voluntary agent or action by force*.

As power imbalances increase, so does the danger that apparent consent is actually compliance or the manifestation of coercion.

Within the sea of others' (often powerful others') wishes, which frequently surround people who are 'stuck', power for the client can be reduced to the smallest denomination, down to what happens within individual interactions. Seeking, giving or withholding consent becomes a moment-by-moment process. If the worker invests in this process, within the relationship, they will almost inevitably tend to move away from being the instrument of the system and others' wishes. Through focusing on the shared experience of what happens within the relationship, both client and practitioner enter new (and uncharted) land. This landscape is formed through negotiating agreements between those wishes held by the worker and most importantly, those wishes held by the client. There is the uncertainty of not knowing from the outset how the relationship will develop, but hope that the shared experience will give power and carries a therapeutic authority that puts others' wishes in their proper context. In this way of working 'intervention' is a two way process.

In meeting with Rebecca I immediately started to step into this uncharted territory. I went to her home and explained what I had been given in way of background and the hopes for her to return to the day hospital. I tritely suggested a desensitization program to help with getting out of the house and back to the hospital. I was onto a loser; Rebecca would not go for this.

Looking for any way of relating, I suggested that drawing might be a way forward and Rebecca nodded. I gave her some pens and paper; I had noticed there were several pets around the house and I asked her if she was able to view herself as an animal, what kind of animal would she be?

After 15 minutes Rebecca picked up a pen and started to draw a rabbit. The next week Rebecca drew her 'family as animals'.

We seemed to have found a mode of communication in our relationship. From Rebecca's perspective, I felt she needed me to meet her where she was, both physically and emotionally; to abandon the brief I had been given; to be prepared to stick with her, and for me to be able to tolerate both silence and waiting. An important factor for me was that I liked Rebecca — I admired her honesty — I was pleased that she had not simply gone along with my initial brief and I felt anything she would say 'yes' to would be honest.

The family wanted someone to do *something*; they were well beyond thinking there could be any quick answer and felt Rebecca needed 'her own space' and as she seemed OK about me coming to see her they were thankful for my involvement. The day hospital team were less enthusiastic and expressed frustration, disappointment and then resignation when I explained that I was planning to work with Rebecca, but not in the way they had hoped.

In the early days the process of giving and receiving consent was a constant thread. There was a range of things that we explicitly or implicitly asked of each other (on reflection I asked a lot). I asked Rebecca if she would be willing to open the door and meet with me in her home (she agreed); I asked for an indication on a chart of how Rebecca was feeling at the beginning and end of sessions (she agreed). Rebecca in effect 'asked' that I wait on her (I agreed). I often pondered silence and the different forms it can take. The silence we experienced did not feel confrontational or power charged; it was not a 'stand off'. Rather, for me it was a space to reflect. For Rebecca it seemed that she was stuck, never the first to speak or initiate, apparently worried about making mistakes. Nonetheless, she did respond to my questions, albeit 15-20 minutes later. I learnt that if Rebecca did not respond within 20 minutes, it was unlikely she would.

At the beginning and end of the session, Rebecca would fill in a chart indicating how she was feeling; it was invariably at the bottom of the scale and often worse at the end of the session than at the beginning.

Near the beginning of each session I would ask Rebecca what was happening for her, through the metaphor of animals: the most common theme of self was as a mouse.

At our six weekly review times, I rather arrogantly assumed that because my input was very significant in Rebecca's withdrawn life, she must be worried that it might be taken away only to discover that in fact Rebecca often cried because the thought of giving consent for us to *continue* was so painful. Allowing me to 'intrude', exposing herself to the 'hope' that next time she would be able to use the session as she wanted was an agonizing process. In effect I was asking Rebecca to dare to hope, as the sessions were so difficult, they could only be worth it for some longer-term gain, an enormous thing to ask of someone who is surviving by switching off and not hoping.

This sense of intrusion was apparent as I asked Rebecca how she viewed our relationship and me. Rebecca drew me as a golden retriever, walking around her mouse hibernating within a cocoon.

Making mistakes about consent and reenacting abuse?

A recurring thought for me within our relationship was, "Because I am constantly initiating, am I an intruder or an abuser or am I a helper?" I would ask myself, "Is this me being stubborn keeping going or is this me not giving up on Rebecca?" and then, "What good am I doing anyway?" I would console myself that although nothing seemed to be changing; at least the wider system was not intruding. As the 'pacing dog' I would from time to time overstep the mark and move beyond something that Rebecca was conceding to. I would possibly try a more open question or ask slightly more probing questions. The result would sometimes be that Rebecca would not open the door to me next session. It seemed important to somehow try to bridge this impasse so that it could become part of our process of understanding, rather than the end. I decided to stay in my car, initially to give Rebecca the option of resuming the session at any time, but in reality it gave us a chance for some kind of session to continue with the wall of the house between us. I would reflect upon how I might have 'overstepped the mark' and how this might feel (the dog becoming a little too close to the mouse) and describe this within a letter. I would acknowledge my mistake, but suggest that it was OK, and not necessarily abusive; as long as the dog stepped back and learnt from the mistake (in this way trying to model that it is OK to make mistakes) and then I invited Rebecca back to the next session. She always returned to our work through opening the door next time. Occasionally Rebecca would write back writing saying something about why she had not let me in at the last session and confirming that she did want to meet again.

Shared understanding

In the silences I finally started to understand that I needed to suspend my search for a 'way to connect' and simply sit along side Rebecca. It was a place of being, where I held great hope and simultaneously abandoned the necessity for change. Rebecca seemed to sense this shift in me and represented this with the pacing dog finally sitting down besides the cocoon. Eventually she drew a channel opening through the wall of the cocoon, between the mouse and the dog.

We continued to explore Rebecca's inner conflict, and the battle between her early self (sheep), the part of self in sessions (mouse) and her abusing self (elephant). Eventually Rebecca drew her final drawing of this unseen self being split apart. And then, there was just silence.

This felt our darkest period. There were no drawings, just silence and tears. Then one day my car broke down. I had to come back to the house to ask if I could phone the RAC. They asked for the telephone number from where I was calling, I turned to Rebecca and she gave it to me. It was the most she had said in the 18 months we had been meeting. I now felt I had been given the permission to raise the question of whether Rebecca would like some help in trying to talk more.

In the following sessions, I suggested that Rebecca tried out words that might be useful in giving her more control in her contact with others. Words such as, 'Yes', 'No', 'I don't know', 'I'm sorry I didn't hear what you said' etc. I suggested she tried saying the words softly and then more loudly. This was all somewhat artificial, but it broke the ice. I also suggested Rebecca have a go at looking up again, so that she could see the world around her, and feel less fearful and more in control. I suggested stages, little by little with her finally looking at me, with me looking ahead, so that Rebecca did not have to meet my gaze.

Although these exercises did have some merit in their own right, they also gave us a medium for our relationship. The common pattern was for us to try out something to point where Rebecca indicated it was too much by being silent, crying and sometimes writing. Although it was still difficult for Rebecca to let me know directly when I overstepped the mark, Rebecca was now able to make herself heard somehow within or between sessions, so that we did not have to miss a session for me to get the message.

I started to ask more about her background. It was clear that Rebecca had been very unhappy for many years, particularly at school. She was angry with herself for withdrawing; she felt there was no good reason for her feelings, she could not remember why she first became so distressed, and her memory was fragmented.

It was an important lesson for me that movement forward for Rebecca at this point in her life was not dependent upon discovering some core underlying explanation; it seemed important that Rebecca's feelings were simply validated.

Rebecca felt her fears and worries were trivial and no one would want to hear them. She suffered excruciating social embarrassment and she simply didn't understand why she got into the situation of not eating. She had felt everything had fallen apart in her life, and that she had become stuck, and felt left behind by her peers.

During this period, Rebecca started to mirror work we had done with her pet rabbit: from stroking her in her cage, to taking out of the cage, to bringing her into the home. At the same time she tried further education courses (GCSEs), doing the work at home, and she even made the decision to pack in one course so that she could succeed by concentrating on the others.

Saying 'no' and saying 'yes'.

After almost three and a half years of us working together, a letter arrived from Rebecca. She was interested in Community Volunteer Service (CVS) work, and wondered what I thought, would I give a reference?

Rebecca got herself to the interview and she was given a place working in houses supporting young people with physical disabilities, several hundred miles away, alongside workers of her own age. She decided that she did not want another therapist in the new place, but we agreed that she could write to me and I would respond each week, if it proved useful. At the last session, Rebecca gave me a thank you card and some presents; a wooden heart with wings, a fridge magnet cat and a tape of her favourite music.

For two months I heard nothing and was convinced that everything would have been too much and that Rebecca would be sitting at home desperate. Finally, I contacted her parents (after having written a cautious feedback letter to GP and psychiatrist); she was OK, still there.

And now it is six years later, Rebecca worked there for several years, then moved back home, backpacked round Japan and is now working whilst studying for a higher education access qualification and applying to study veterinary nursing.

Conclusion

It seems that at different points in anyone's life, it might be helpful for different parties to initiate an offer of help; the individual might be stuck without such offers. The most important question seems to be, 'what help is best?' This question belongs to the individual, in the same way that we all carry 'questions looking for answers'. Pat Deegan comments that we talk about 'outcomes', but for the individual an 'outcome' is 'my life'. The question belongs to the individual and it is within that context we should approach and make our offers of assistance. In this way, rather than consent being a 'one off' event it becomes a constant theme of intervention.

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