

THE FUTURE OF USER INVOLVEMENT IN DRUG TREATMENT DECISION-MAKING

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Presentation overview

1. What is user involvement?
2. Some problems of involving drug users in treatment decision-making
3. Recent developments relating to user involvement in treatment decision-making
4. The future of user involvement in drug treatment decision-making

Defining UI

- A broad term that encompasses many activities. It can occur when service users are involved in:
 - Making policy decisions about what services should be provided
 - Planning & designing new services
 - Delivering & evaluating existing services
 - Influencing their own treatment or care

Essentially a good thing

- Improve services
- Empower individuals
- A democratic right & an ethical requirement
- Improve treatment satisfaction & self-reported outcomes

But not without problems

- No clear definition of either 'user' or 'involvement'
- Entrenched policies & practices that fail to react to clients' views
- Limited resources
- Unrealistic demands
- Professionals' reluctance
- Tokenistic implementation

Our study

Fischer, J., Jenkins, N., Bloor, M., Neale, J. & Berney, L. (2007) *Drug user involvement in treatment decisions* (York: Joseph Rowntree Foundation).

Fischer, J. & Neale, J. (2008) 'Involving drug users in treatment decisions: an exploration of potential problems', *Drugs: education, prevention and policy* 15(2): 161-175.



JOSEPH ROWNTREE
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Aim

To identify some of the key challenges that can arise when trying to involve illicit drug users in making decisions about their own treatment

Methods

- 187 semi-structured interviews in 4 case study treatment services:
 - 79 new treatment clients
 - 59 follow-up interviews (3 months later)
 - 27 agency staff
 - 22 referrers

1. Perceived characteristics, needs & expectations of drug users

- Clients would exploit involvement processes
- Drug users have unrealistic expectations
- Lack of user interest in contributing to decisions
- Chaotic lifestyles prevent drug users from making informed choices
- Involvement would be stressful & a burden

2. Professionals' negative attitudes

- Undermine drug users' self-worth & self-confidence

- Act as a barrier to treatment seeking:

[My GP] was absolutely useless. He didn't want to know because I was a heroin addict. He just didn't want to know, so I carried on using for ages. [Community client]

3. The dynamics of treatment encounters

- Staff as 'the experts':
I'll let them come up with the treatment plan, because they are the experts. [Residential client]
- Power imbalance between treatment providers & clients:
Obviously he has got more power. He is the one that writes the prescriptions. He is the one that could chuck me off them at any time if owt went wrong. [Community client]

4. Treatment programme design

- Residential programmes are often designed to be directive
- Residential services tend to be based heavily on group work
- Residential treatment philosophies – based on the notion of addiction as a disease or faith-based approaches – inhibit user involvement

5. Structural factors

- Limited resources
- Other competing priorities for professionals
- Legal requirements
- Inflexible service remits

Conclusions: 2007/08

- The challenges of involving drug users in treatment decisions are neither inevitable nor insurmountable, but they are substantial
- 3 (fairly dull & uninspiring) recommendations:
 - i. More financial resources
 - ii. Improved communication between service providers & clients
 - iii. An investment in education, training & skills development for professionals & drug users



Recent developments relating to user involvement

Growth of the recovery community

- Difficult to define
- Peer-based recovery movement, incorporating diverse models of peer service that enable peers in recovery to meet service needs identified by people seeking & sustaining recovery
- Origins: North American/ Mental health
- UK developments: Wired In; Recovery Academy

Recovery community values

- Recovery: Recovery comes first
 - Inclusion: Room for everyone
 - Authenticity: Members use their direct experiences to identify problems & needs, & to find ways of addressing them
 - Participatory process: Full participation & commitment build strong vibrant recovery communities
 - Leadership development: Developing new leaders enriches the community & helps ensure the community's growth
- <http://rcsp.samhsa.gov/concepts/values.htm>)

Emergence of the concept of responsiveness in health care systems

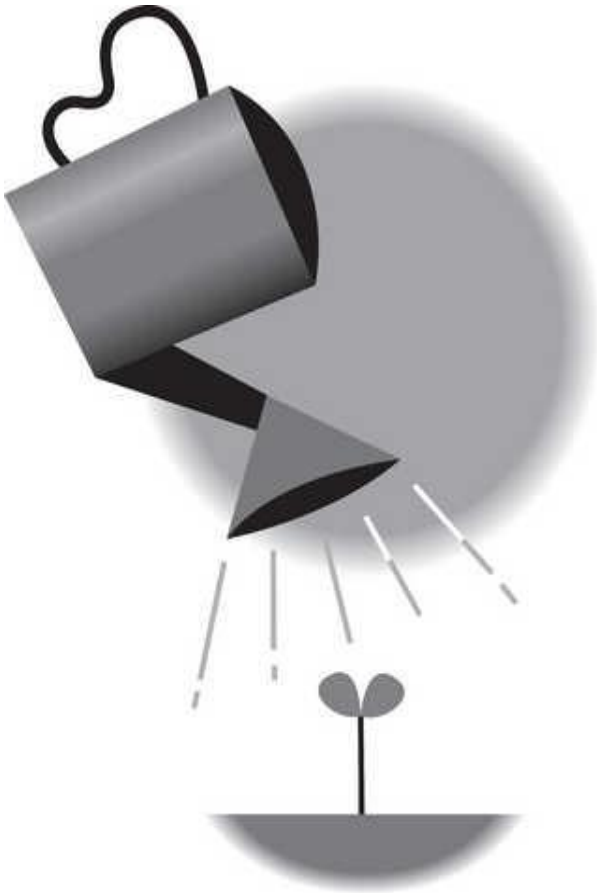
“Responsiveness is not a measure of how the system responds to health needs, which shows up in health outcomes, but of how the system performs relative to non-health aspects, meeting or not meeting a population’s expectations of how it should be treated by providers of prevention, care or non-personal services”

World Health Organization (2000) *Health Systems: Improving Performance* (WHO: Geneva)

Aspects of responsiveness

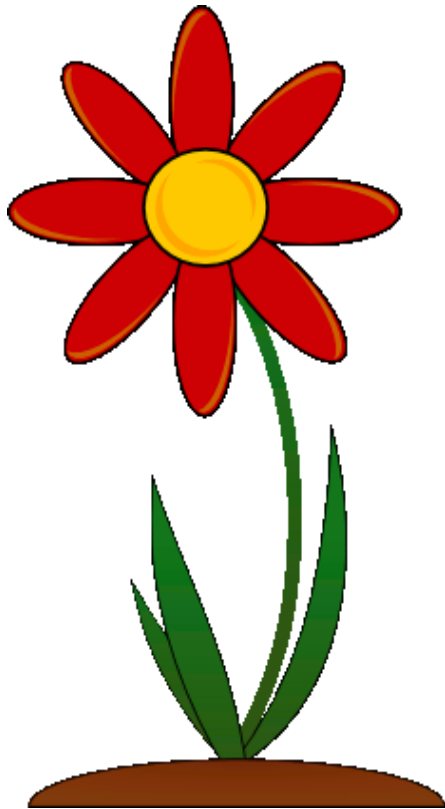
- Autonomy
- Confidentiality
- Dignity
- Privacy
- Clear communication
- Prompt attention
- Good basic amenities
- Choice of service provider

The outlook seems positive



- Recovery community: largely bottom up/ grass roots/ user-led; supports diverse approaches to recovery, but inclusive of more formal/ professionalised services & beginning to encompass research
- Responsiveness: largely top down, policy/ provider driven, but emphasises user involvement, user choice & the importance of good provider/ user communication

UI is a valuable concept: 2009



“My team that are looking after me have stepped back and let me tell them and not pushed me... I think that’s good, that I’m not being pushed, or feel like I’m being put in a corner to get clean... It’s on my terms, whereas before, and in other places, it’s been on their terms. A drug addict can’t, you can’t push them... You’ve got to go with the chaos first.”

(Female, aged 33, currently homeless)

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