THE VALUE OF THE "LIVED EXPERIENCE" VOICE IN POLICY, ADVOCACY AND SERVICE DESIGN IN CREATING THE BEST POSSIBLE AOD SERVICE SYSTEM

Annie Madden AO
Scientia PhD Scholar, CSRH, UNSW
Principal, 2SqPegs Consulting
Founder, Harm Reduction Australia

OVERVIEW

- Introduction
- Core principles
- Barriers to participation/engagement for PWUD
- Motivators for engagement (PWUD & Services)
- Specific area of participation/engagement:
  - *AOD services (service policy, systems & delivery)*
- Conclusion
  - *Principles for Engagement & Practical Considerations*

INTRODUCTION

INTRODUCTION

- PhD student, Centre for Social Research in Health, UNSW;
- Founder & Board Member, Harm Reduction Australia;
- Recently awarded Officer of the Order of Australia;
- CEO, AIVL (national PWUD network) 2000-2016;
- CEO, NUAA (NSW PWUD network) 1994-2000;
- Identify as a person who uses drugs;
- Currently on methadone but have broad treatment b/g;
- Speak from direct, personal experience;
- Draw on the experiences of my peers;
- Don't claim to represent all people who use/have used drugs;
- Do try to represent the issues that affect PWUD;
- Passionate advocate for the rights of people who use/have used drugs BUT…
- Have paid the price personally and professionally for being a PWUD advocate… understand impact it can have (+ & -)

CORE PRINCIPLES

… the voice of "lived experience"…

CORE PRINCIPLES

Nothing About Us Without Us

BARRIERS TO ENGAGEMENT

- **Criminalised** – by illicit nature of illegal drug use
- **Stigmatised** – 'others' and devalues PWUD as 'people', as 'citizens' and as 'members of the community' and stereotypes PWUD as liars, thieves, dangerous, etc – we cannot under-estimate/over-state how profoundly this impacts all areas of life and self-esteem for PWUD.
- **Marginalised** - drives PWUD underground away from information, services and support – fundamentally erodes trust in services and in government processes
- **Isolated** – away from the support of family and friends

BARRIERS TO DRUG USER ENGAGEMENT

- *Criminalisation cont…*

- **Compromises Health and Wellbeing** – put up with chronic, painful and even life threatening conditions rather than coming forward to engage with services

- **Shames** – makes PWUD too guilty and ashamed to come forward, too scared to come forward, too fatigued to face stigma again, etc.

- **Reduces Options** - take risks to survive, black market forces people to find ways to raise large amount of money and also results in debt and poverty and all the problems that brings, etc.

BARRIERS TO ENGAGEMENT

- **Process of criminalising, stigmatising and marginalising results in people who use drugs being:**

– *Sometimes difficult to identify and reach in relation to engagement (depending on who is asking ☺);*
– *Very fearful of coming to attention of police/Child Services;*
– *Suspicious of motivations of services/government/organisations;*
– *Frequently occupied by other 'priorities';*
– *Sometimes too ill to be involved or participate;*
– *Can feel/believe they have nothing to offer; and*
– *Do not deserve to be treated with basic dignity and respect (deserve what 'they get' or should 'expect less').*

WHAT MOTIVATES PWUD ENGAGEMENT?

To be engaged/involved PWUD need:

- To feel comfortable and genuinely welcome;
- To feel safe and trust the people, the process and environment;
- To be able to ‘prioritise’ being involved;
- To not feel judged, stigmatised or ‘othered’;
- To believe that they are ‘truly’ valued;
- To be treated with basic dignity and respect;
- To know that something will HAPPEN!
- IT IS NOT ROCKET SCIENCE!

WHAT MOTIVATES SERVICE /POLICY-MAKER ENGAGEMENT?

- Need to be clear on ‘why’ you want to engage/involve people who use drugs/service users in your service/policy process - how you will do it, what it will achieve and how you will ensure it is a meaningful experience.

- Too often it becomes about external agendas (strategy talks about ‘partnerships’, meeting performance/outcome indicators, accreditation standards for ‘consumer participation’ – these are principles underpinning your work – NOT REASONS!

- Too frequently about a genuine desire to involve PWUD/service users in the planning, delivery and evaluation of the service because it will make a *better service* or the policy process because it *will better meet people’s needs, etc.*

SERVICE USER PARTICIPATION IN AOD SETTINGS

- “Treatment Service Users (TSU) Project” – 2007-2009
- Examining consumer participation in drug treatment settings
- First national research project and some of the only international research on this issue
- Qualitative social research project – collaboration with AIVL & CSRH/UNSW
- Funded by Commonwealth Department of Health, Drug Strategy Branch

SERVICE USER PARTICIPATION IN AOD SETTINGS

- Policy Audit – consumer participation policies
- Research stage – qualitative interviews with service providers (n=64) and service users (n=169) drawn from the services interviewed.
- Across 3 states (NSW, Vic & WA)
- Across Resi Rehabs, In-patient Detox & OST
- Consumer participation model – broad model used in other areas of health service delivery based on a ‘scale of participation’
- Focus – views on consumer participation

SERVICE USER PARTICIPATION IN AOD SETTINGS

WHAT DID WE FIND?

- Strong support among both service users and service providers for the concept of consumer participation but…
- Service providers believed that service users would not want to participate in service planning and delivery
- Service users believed that service providers wouldn't want them to participate in service planning and delivery
- Overall lack of understanding among service providers and service users about what consumer participation in drug treatment settings is in practice, which resulted in…
- A lack of support among service providers for 'higher level' engagement – the more the service users was involved in decision making roles within the service the less support there was from service providers for that type of participation (happy with suggestion boxes but not involvement in decision making)

SERVICE USER PARTICIPATION IN AOD SETTINGS

WHAT DID WE FIND?

- Reasons service providers did not support higher level engagement:
  - *Clients lack the necessary skills*
  - *Issues too complex for clients to understand*
  - *Clients cannot be trusted with issues of confidentiality*
  - *Could represent a conflict of interest for clients*
  - *Clients aren't interested*
  - *Clients lack confidence*
  - *Not practical for the service to support involvement of clients*

SERVICE USER PARTICIPATION IN AOD SETTINGS

WHAT DID WE FIND?

- These 'higher-level' decision making consumer participation activities are standard practice in mental health, disability services and aged care
- They have been found to be highly successful, without evidence of the 'concerns' expressed by service providers in TSU Project – addressed through training & support and policy frameworks.
- While a few service users agreed with service providers, the majority of service users said:
  - *They were very interested in consumer participation*
  - *They would be willing to participate if given the chance*
  - *But lack confidence and sometimes lack skills*
  - *But mostly, they did not believe that service providers want them involved*

SERVICE USER PARTICIPATION IN AOD SETTINGS

TREATMENT SERVICE USERS PROJECT – STAGE 2

- Followed with a series of demonstration projects in drug treatment settings in 3 states
- OST, Resi-Rehab & In-patient Detox
- Services could plan their own CP projects and were provided with a seeding grant from AIVL
- ***What Happened?***

– *None of the services completed their self-designed projects*
– *All services entered the projects thinking their biggest problem would be the skill levels of service users*
– *All services ended the projects realising it was the services not the service users that were not 'fit'*

SERVICE USER PARTICIPATION IN AOD SETTINGS

WHAT DOES ALL THIS MEAN FOR ENGAGMENT?

- Services need to be clear about *why* they want to engage service users – not just to meet indicators or accreditation;
- Service users need education and training to participate *meaningfully* in services – this is how you address skills and confidence deficits;
- Service providers and service users can work effectively together even where 'sensitive' or 'confidential' matters are involved as long as there are clear policies and procedures
- Service providers need education and training to understand consumer participation in service delivery and how to work with/involve users in *practice*;
- Services need to have support ALL levels (partic. management) and appropriate policies if consumer participation is to work effectively.

PRINCIPLES FOR ENGAGEMENT

WHAT DOES ALL THIS MEAN FOR ENGAGEMENT?

- Drug users are *no different* from any other service users – they are interested and have expertise offer
- Service providers should not based decisions about interest in and capacity for involvement on unfounded *assumptions and beliefs* about service users
- Service users know when their involvement is *not really wanted* and will respond accordingly – they will disengage from services/organisations
- Treat people with basic dignity and respect – how you would like to be treated in the same context

PRINCIPLES FOR ENGAGEMENT

- Work with & engage PWUD but only if you are ready to accept us as *we are* not as you would *like us to be! (not 'on the road' to becoming someone 'better')*
- Know why you want to engage with people who use/have used drugs and make sure you/your service is prepared/ready (policy frameworks, training, ensuring high-level management support)
- Respect that not everyone will share your agenda or want the same things you do
- Be prepared to change the way you do things as a result of engaging with PWUD/service users – or don't bother!
- Recognise the value of people's personal experience and expertise - people may have a great deal more to offer than you know (incl. formal skills)

PRINCIPLES FOR ENGAGEMENT

- Avoid making assumptions based on unfounded beliefs, stereotypes and attitudes;
- Remember that PWUD/service users have their own lives, families, jobs, commitments, etc., and are not just available to engage with services/organisations when/wherever;
- Recognise that as a service provider or organisation you have power in the relationship particularly if you provide something the PWUD/service user needs/wants;
- Don't view PWUD/service users as 'the problem' but as part of 'the solution' – the solution to how to make your service/organisation a better service/organisation, etc.
- ALWAYS – avoid 'lone' representatives, pay people for their time and expertise (in a way they value and as agreed), ensure transport costs are covered, PWUD/service user reps have access to the same information, b/g papers, etc., as others and that they are familiar with meeting procedure and any protocols.

PRINCIPLES FOR ENGAGEMENT

- Never under-estimate how difficult it is to be the ‘PWUD/service user representative’ at the table;
- Enormous sense of responsibility to represent an under-represented community;
- Years of stigmatising and othering that can make people question their entire right and reason for being at the table;
- You have asked me to speak today on the value of engaging with people who use drugs/have used drugs in policy and service design… but…
- We are in the midst of a war – a global war against people who use drugs – not just against our right to have a ‘voice’ or a ‘say’ – but against our very existence as other people in society…
- And it is this that we must change – fundamentally and utterly if we hope to engage PWUD meaningfully in policies & services…

CONCLUSION

There can be:

Nothing About Us… Without Us