CONSUMER PARTICIPATION IN ALCOHOL AND OTHER DRUGS SERVICES TRAINING COURSE
Session 1.1

Introduction to Consumer Participation
What is Consumer Participation?
Barriers and Benefits
Family Participation
Dual Diagnosis
Session 1.2

Diverse consumer communities
Levels and Domains of Participation
Session 1.3

What is Meaningful Participation?
Principles and Practice
Audit current/past consumer participation
Improve existing practices
Session 1.4

Audit current/past consumer participation
Improve existing practices
Session 2.1

Build new activities
Session 2.2

Recruit Service users
Evaluate activities
Develop a Consumer Participation Action Plan
Course Outline

Session 2.4

Review course learning
Concluding activities
Session 1.1

- Introduction to Consumer Participation
- What is Consumer Participation?
- Barriers and Benefits
- Family Participation
- Dual Diagnosis
The process of involving consumers in decision making about:

- service planning
- policy development
- priority setting
- quality in service delivery
Someone who uses, has used, or is eligible to use alcohol and other drugs services

Those people who are refused services or who refuse services

Family, friends and significant others of people who use services, regardless of whether or not they directly use these services themselves

Others affected by AOD policy and laws
An ethical and democratic right

“People have the right and duty to participate individually and collectively in the planning and implementation of their health care.” WHO 1978
a requirement for all publicly funded alcohol and other drugs services, and is embedded in sector policy

ensures public accountability

to deliver the best possible services to those it serves

evidence-based benefits
BENEFITS FOR ORGANISATIONS

- creates greater cooperation
- consumers less likely to express resentment and suspicion
- untapped resource for feedback and solutions
- trust built between service users and staff
- greater staff job satisfaction as services improve
Benefits for Our Consumers

- Improves effectiveness of the service system
- Assists recovery through empowerment and psychological wellbeing
- Increases skills and confidence
- Improves capacity in the wider community
**Evidence for Consumer Participation**

- leads to improvements in health outcomes for consumers
- supports consumers in managing their own health.
- leads to more accessible and effective health services.
- facilitates participation by those traditionally marginalised by mainstream health services

- is integral to the success of the development, implementation and evaluation of health strategies and programs
- effective participation is achieved through the adoption of a range of methods

Consumer Focus Collaboration Organisation
BARRIERS TO CONSUMER PARTICIPATION

- Attitudes
- Resources
- Confidentiality
- Fear
- Beliefs
- Training
FAMILY PARTICIPATION

- Defined as spouse, partner, sibling, child or significant other of an AOD service user or consumer
- Not ‘carer’ – negative connotations
- Embedded in Victorian Consumer Policy
- Can occur separately from service user participation
- Participation confused with treatment – much more
- Identical to all other Consumer Participation
WHY FAMILY PARTICIPATION?

• Problematic substance use is a familial and social issue.
• Important for getting different perspectives.
• An emerging trend similar to ‘carer’ participation in mental health.
• Contributes to improving quality of care – enables services to systematically introduce person-centred practices.
HOW CAN FAMILIES PARTICIPATE?

Direct involvement in decision-making processes around

- Priority setting
- Service planning and delivery
- Policy development
- Education
- Training and research
BENEFITS OF FAMILY PARTICIPATION TO ORGANISATIONS

• greater cooperation leads to service quality improvement

• good will generated for organisation in community

• untapped resource for feedback and solutions

• trust built between family and staff

• greater staff job satisfaction as services improve
BENEFITS OF PARTICIPATION TO FAMILY MEMBERS

• A better service system

• Empowerment and psychological wellbeing

• Skills and confidence

• Improved capacity in the wider community
BARRIERS TO FAMILY PARTICIPATION

- Participation confused with treatment
- Family unwanted
- Waiting times/Exhaustion
- Lack of information
- Organisational culture
- Staff training
Barriers to Family Participation

- Confidentiality
- Organisational Resources
- Capacity of Family
- Stigma
- Prohibition
- Organisational Language
MENTAL HEALTH & DUAL DIAGNOSIS

- 75% of people with substance misuse problem may also have a mental illness (co-occurring disorder)

- Government response - Victorian Dual Diagnosis Initiative/ federal Improved Services Initiative

- Mental health sector consumer participation policy included in dual diagnosis policy

- Many AOD services becoming dual diagnosis capable
MENTAL HEALTH & DUAL DIAGNOSIS

• Create culture of openness about mental health issues

• Mental health issues as relevant as AOD issues

• Contact APSU to recruit dual diagnosis consumer participants

• Contact VMIAC to recruit mental health consumer participants
Session 1.2

Diverse consumer communities

Levels and Domains of Participation
DIVERSE CONSUMER COMMUNITIES

- Aboriginal Australians
- CALD
- GLBTIQ
- People with a Disability
ABORIGINAL AUSTRALIAN PARTICIPATION

Need to have:

• Respect for cultural heritage

• Knowledge of history of Aboriginal cultures

• Knowledge/understanding of specific needs

• Organisational policy and procedures
ABORIGINAL AUSTRALIAN PARTICIPATION

Need to Do:

• Cultural audit

• Cultural sensitivity training

• Appropriate systems in place

• Consult specialist Aboriginal AOD services
Barriers to Participation -

- Language
- Cultural misunderstandings
- Lack of understanding /awareness of available services

Barriers to Participation –

- Lack of culturally sensitive services
- Fear of stigma and ostracism
- Fear of persecution
PEOPLE FROM CALD BACKGROUNDS

How to improve Participation

• Understand clients and their needs

• Partner with multicultural/ethno-specific agencies

• Develop a culturally diverse workforce

• Use language services effectively

• Encourage participation in decision making

• Promote benefits of a multicultural Victoria

• Utilise other organisations/resources
People who are GLBTIQ

Barriers to Participation:

- Negative attitudes
- Lack of GLBTIQ sensitive services
- Fear of stigma and ostracism
- Confidentiality/ disclosure issues
People who are GLBTIQ

Improve Participation by-

• Staff education & training

• Staff/client communication promoting acceptance

• Documentation and recording protocols

• Database of resources and support groups

• Specific disclosure and confidentiality policies/procedures/statements
Barriers to participation

• Physical disability - wheelchair access, disabled toilets

• Hearing/vision impaired – interpreter services, access for guide dogs

• Intellectual disability – respect, patience
People with a Disability

Improve Participation

- Identify client needs
- Educate and train staff
- Provide access
- Be inclusive, welcoming, respectful
- Provide disability services resource material
<table>
<thead>
<tr>
<th>Level of Power</th>
<th>Level Type</th>
<th>Description</th>
<th>Activities</th>
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</table>
| High           | Control      | All decisions are made by consumers and consumers have control of resources. | • Consumer run organisations  
• Self help groups                                                  |
| Medium         | Partnership  | Consumers and providers are joint decision makers.                           | Peer workers, educators, trainers  
• Staff selection panels  
• Steering committees                                                 |
| Low            | Consultation | Consumers are presented with a plan or directive designed by the service provider and invited to give feedback. Control is firmly with service providers. | • Suggestion boxes  
• Surveys  
• Focus groups  
• Service user groups                                                  |
| Information    |              | This is not consumer participation but it increases power, enables service users to make decisions about their own treatment and supports consumer participation. | • Information to service users about services and treatment options  
• Charter of Rights  
• Complaints systems  
• Consumer participation Policies                                         |
DOMAINS OF PARTICIPATION

- Policy
- Research
- Education
- Organisation
- Individual Care
Session 1.3

What is Meaningful Participation?
Principles and Practice

Audit current/past consumer participation

Improve existing practices
Meaningful Participation

- Be clear about your organisation’s capacity to involve consumers
- Don’t promise what you can’t deliver
- Must be supported by management at all levels
- Listen to and act on feedback, make decisions and accept any changes.
• Be clear about your organisation’s capacity to involve consumers

• Don’t promise what you can’t deliver

• Must be supported by management at all levels

• Listen to and act on feedback, make decisions and accept any changes.
Meaningful participation equals change

Organisational Process

Consumer Input

Positive Feedback

Negative or No Feedback

CHANGE

NO CHANGE
PRINCIPLES AND PRACTICE

- Timeliness
- Honesty
- Inclusiveness
- User Friendliness
PRINCIPLES AND PRACTICE

Respectfulness

Remuneration

Training and Support

Other issues
CONSUMER PARTICIPATION PLANNING PROCESS

Audit
- Identify all current and past consumer participation activities including those that support participation
- Decide what is working and what isn’t

Improve
- Educate staff and recruit interested staff and service users
- Improve, existing activities especially ones that support participation (complaints systems, consumer rights)

Build
- Implement new consumer participation activities
- Evaluate new activities
- Incorporate new activities into organisational documents

Recruit
- Recruit and train service users
# Current and Past Practices

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<thead>
<tr>
<th>Information Level</th>
<th>Consumer Rights</th>
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<tbody>
<tr>
<td></td>
<td>Complaints Process</td>
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<td>Information Provision</td>
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<table>
<thead>
<tr>
<th>Consultation Level</th>
<th>Suggestion Box</th>
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<tr>
<td></td>
<td>Surveys</td>
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<td></td>
<td>Interviews</td>
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<td>Focus Groups</td>
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<td>Service User Groups</td>
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</table>
CURRENT AND PAST PRACTICES

Partnership Level

- Peer workers, educators, speakers, support groups, volunteers
- Experienced Workers
- Staff selection
- Quality Assurance
- Strategic Planning
- Committee Membership
CURRENT AND PAST PRACTICES

Control Level

• Self Help Support Groups

• Service delivery organisations

• Promotional organisations
AN IMPROVED INFORMATION SYSTEM

• Provide information on ALL services
• Include other services and allied information
• Must be easy to access and read
• Survey consumers on information wants and needs
• Involve consumers in development of information resources
• Use multiple delivery systems e.g. hardcopy, website, email, social networks
AN IMPROVED COMPLAINTS SYSTEM

- Ask consumers and staff about pros and cons of current system
- Look at systems in other organisations
- Invite consumers and staff to have input into system design
- Make the system user friendly - access, process, language
AN IMPROVED COMPLAINTS SYSTEM

• System must be written as policy and procedure

• Educate staff and consumers on benefits and use of system

• Ensure complaints are followed up and actioned

• Ensure consumers and staff are informed of complaint resolution
AN IMPROVED SUGGESTION BOX

- Survey consumers on current process
- Develop a Suggestion Box policy and procedure – involve consumers
- Must be displayed prominently and equipped
- Consumers must be informed of it
- Consumers must be encouraged to use it
- Suggestions must have follow up and action
AN IMPROVED CUSTOMER SURVEY

- Develop a survey policy and procedure
- Define and justify purpose and use
- Involve consumers in design
- Use plain ‘user friendly’ language
- Have incentive for completing
- Assist people to complete
- Provide feedback on results and how they will be used
Session 1.4

Audit current/past consumer participation

Improve existing practices
Build new activities
BUILD NEW ACTIVITIES

• Start small
• Involve consumers early
• Ensure activities are sustainable
• Develop a pool of consumer participants
• Train and support consumer participants
• Become a member of APSU
INTERVIEWS

• Helpful to gain detailed consumer feedback
• Best used for defined purposes
• Used where consumer literacy is an issue
• Builds rapport with consumers
• May provide more accurate information
• Best conducted by non-service delivery staff
• Can be time consuming
FOCUS GROUPS

• Good for specific issue
• Chance for consumers to voice opinions
• Best to gain qualitative information
• Series of focus groups ensures wide consultation
• Run by external trained facilitator
• Ideal with 8 – 12 members
• Protect anonymity
• Must get feedback
SERVICE USER GROUPS

- Must have clear role
- Feedback must be reviewed and acted upon
- Must get feedback and organisation’s response
- Must be formally established (policy / terms of reference/ procedure)
- Remuneration required
- Training required
- Self run
- Draw on focus group members to start
PEERS IN SERVICE DELIVERY

- Creates sense of identification amongst other service users
- Gains trust and credibility for organisation
- Greater understanding of issues
- Extra knowledge and skills to service users
- Need education and training (APSU)
- Benefits peer
- Roles include:
  - Peer helper, support, worker, educator, experientalist
11% of AOD services involve consumer in process
Must be well planned
Training required
Educating staff required
Improves relationship between service and consumers
Improves support for consumer participation
Can assist with Position Description, developing interview questions, in interview and selection process
QUALITY ASSURANCE

- Opportunity to evaluate effectiveness of programs
- Engenders feeling of personal value and worth
- Views relevant and worthwhile
- Organisation has ‘outside’ perspective
- Leads to greater consumer participation
- Must be trained
- Independent feedback required
- Involvement needs to be planned
- Participants must be given preparation
- Personal attendance is ideal
- Can include surveys, focus groups, other feedback
COMMITTEE MEMBERSHIP

- Provides valuable service user representation
- Formal selection process - terms of reference
- Fair, transparent selection
- More than one representative is best
- Direct experience of the service
- Remuneration
- Training and support
- Ongoing role
- Variety of committee styles – steering, projects, reference groups, service users
Board of Management Membership

- High level consumer participation
- Contribute to governance of organisation
- Usually a requirement of organisation’s constitution
- Experts by experience
- Bring specific skills and expertise
SELF HELP GROUPS

- Run exclusively by service users/ ex service users
- Full control over decision making and resources
- Provide support, resources, helpline information services
- Health promotion
- Education to reduce drug related harms
- Research collaboration
- Advocacy, policy advice, community awareness
  - Narcotics Anonymous
  - Harm Reduction Victoria
<table>
<thead>
<tr>
<th><strong>EDUCATION AND TRAINING</strong></th>
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<tbody>
<tr>
<td>Consumers provide input into training</td>
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<tr>
<td>Less stigmatised attitude towards consumers</td>
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<tr>
<td>Encourages practitioners to consider consumers before potential adverse action</td>
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<tr>
<td>Gives consumer perspective - key messages</td>
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<tr>
<td>Formal process for recruitment</td>
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<tr>
<td>Require training and support</td>
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<tr>
<td>Must be remunerated</td>
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**Policy Development**

- Great capacity to improve services
- Need training and support
- Avoid token participation
- Involve consumers early
- Have clearly defined role
- Use surveys, focus groups, interviews
- Provide feedback
• Community based participatory research
  - equal partnership in decision on research priority, methods used, and analysis and dissemination of results
  Leads to:
  - New insights and approaches
  - Higher priority issues addressed
  - Improves data quality, validity and reliability
  - More accurate and culturally appropriate
  - Better health and community outcomes

• Consultation level - Organisation
  Use variety of focus groups to get information and develop research activity
Session 2.2

Recruit Service users

Evaluate activities
Recruitment

- Must be systematic and ongoing
- Develop recruitment and training procedure
- Devise consent/application form
- Establish a pool of service users (APSU has state wide database resource)
Training

- A must for higher level participation
- Train ONLY as need arises – project/activity based
- Sign clients to APSU membership (offers training opportunities)
- Support and supervise (APSU can help)
THE ACTION EVALUATION RESEARCH PROCESS

Plan

Reflect

Implement

Fieldwork

Design
(Based on Wadsworth’s Action Evaluation Research Process)

- Plan for evaluation as part of your project
- Include Indicators (Outcomes/Activities) to be measured
- Establish understanding of what consumers/colleagues think
Establish appropriate evaluation tools such as:
- Focus Groups
- Feedback Forms/Surveys
- Journals
- Reports/Reflective Evaluations

Provide feedback on results to consumers/colleagues

Plan for changes to work practices and policies as a result of feedback
**Step 1: Audit Past & Current Activities**

Decide what is working and what isn’t

Identify past and current consumer participation activities including activities that support participation.
STEP 2: IMPROVE CURRENT ACTIVITIES

• Think about what works

• Think about what doesn’t work

• Get others involved:
  - Who else is interested in your workplace? Is the management team on board?
  - How can you get consumers involved in your improvements?
Step 3: Build New Activities

- What activities complement present practice?
- Think about organisational readiness – eg training, address barriers

- Think about structure and size of organisation and who uses your organisation – types of participation achievable, available resources

- Recruit/train service users
STEP 4: EVALUATE NEW ACTIVITIES

- what to measure
- tools
- feedback
- action
CYCLE OF CONTINUOUS IMPROVEMENT

Evaluate → Audit

Recruit

Build → Improve
Develop a Consumer Participation Action Plan
Session 2.4

Course review

Final Activities

Course Close
CONSUMER PARTICIPATION
IN
ALCOHOL AND OTHER DRUG SERVICES
COURSE

End of Course

Thank You