Family and carer participation in the recovery process
Aim of this session

- To explore the importance of family/carers and the role they can play in the recovery process
- To highlight the carer perspective on being involved in the recovery process
Session Overview

- Brief historical overview of family/ carer participation
- Current situation re. participation
- Reasons to involve family/ carers
- Barriers to involvement
- Best practice
‘Carer’ population

- One in five experience mental health problems in their lifetime
- 15% adults in a caregiver role

(Jane Pirkis et.al. (2009), Melbourne University)
Who are Carers?

- Someone actively caring for a person with a mental illness
- They need not be living with the person with mental illness
- May be a family member, friend or someone who has a significant role in the person’s life
- The caring role may vary over time according to the needs of the person and the carer
Historical Overview

- Deinstitutionalisation
- Western model of care
- Blaming families
- Issues of privacy & confidentiality
3. Step Guide to the Law
David Leggatt, lawyer

1. Respect confidential information
2. Treat the patient
3. Avoid harm

A reasoned use of information will always be supported
Current situation

- Carers often perceived by service providers as being of little importance
- MH policy suggests collaboration with carers
- BUT … carers often receive little education or support in their role
- Vital to keep carers in the loop
Impact of mental illness on family members

- The trauma model
- The caring journey – experiences & emotions facing carers
Impact of Excluding Carers

- Reducing carer well-being
  - Studies show negative impacts on carers
  - Added burden for the carer
- Compromising the carer-consumer relationship
  - Contributes to culture of blame between consumer & carer
  - Lack of information can lead to families potentially hindering consumer recovery
Challenges for families

- Mental illness – difficult to process cognitively, emotionally
- Family histories, traditions, values, beliefs influence attempts to cope and adapt
- Families not helped to manage impacts of guilt, blame, loss, grief
- Families of mentally ill have own needs – but not considered *per se*
Challenges for families

- Patient-centred focus by clinicians - no outcome measures for family members
- Many families unsure how to ask for help – often ignored & feel powerless
- Social stigma related mental illness – reluctant to reveal caring status
- Rural communities stigma more firmly entrenched
- CALD communities stigmas of mental illness even more deeply entrenched
CALD Communities & Mental Illness

- Consistently lower rates of access to public community & inpatient mental health services
  - e.g. Non English speaking countries – comprise 20% of Vic population, but only 13% mental health services, 15% hospital inpatients

- Represent higher proportion of involuntary admissions

www.vtpu.org.au
Evidence Research Base for Working With Families

- Evidence from over 40 randomised controlled trials over 30 years support inclusion family & other carers in treatment of mentally ill persons – better outcomes for all
Research evidence
Benefits from family involvement

- Decrease in relapse rates (up to 20%) through early detection of symptoms and early intervention
- Decrease in hospital admissions
- Better adherence to medication
- Reduction in psychiatric symptoms
Other Significant Outcomes

- Improved functioning of consumer
- > employment rates
- > involvement in community
- < burden experienced by family carers
- Improved relationship between family members
- Cost effectiveness - < treatment costs, significant savings for health system
Barriers to Implementation

- Issues of consumers not wanting to involve family/ carers
- Engagement of families can be difficult
- Professionals not trained to work with families
- Services feel under pressure without adding in involvement of families
Barriers (cont.)

- Systemic culture of excluding families
- Failure to identify carers
- Carer confidentiality often disregarded
Overcoming Barriers

- Promoting clinical attitudes re. value of involving families
- Prioritising resources to support involvement of family/carer
- Identifying practical ways in which family/carer can be involved at various points in diagnosis, treatment and rehabilitation
- Examples from co-design action plans
Overcoming Barriers (example)

- Support for carers
  - Accessible information for carers
  - Carer involvement in treatment and planning (eg early contact, review points, discharge)
  - Support for carers (eg peer support, access to services)
Dr Alex Cochrane

- Film Clip
Good information sharing outcomes

- Support needs of consumers & carers often interdependent
- Carer involvement & understanding of consumer situation assists better recovery
- This also associated with greater satisfaction for clinicians
- Carers can convey important information to clinicians
Key Principles for working with carers/families

- They must be recognised, valued & supported in care giving role
- Clearly defined roles and responsibilities for clinicians & carers – understood by all
- They should be consulted & engaged ASAP in an episode of care
- Clinicians, consumers & carers need to communicate effectively with each other
Key Principles for working with carers/families cont

- Clinicians must have sound knowledge what information may be given to carers under different circumstances
- Services need to ensure language & cultural needs of family are considered
- Consumer rights not to involve family to be respected – but explore reasons.
Benefits working with families/carers - summary

- Assessment – better diagnosis
- Service delivery – 2nd source of information
- Treatment outcomes – better care, support
- Relapse admissions – reduced
- Cost effectiveness – in improving treatment outcomes
- Carer support – < adverse impacts of caring

by

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- Peak body
- Awareness raising
- Info, education, training
- Ensure fed & state govt recognise carers
- Facilitation communication carers & key stakeholders
- Systemic advocacy for carers
- Encourage best practice research in carer support
- Support carer involvement
- **Support carer participation**