A NATIONAL CARER PERSPECTIVE ON PERSONALITY DISORDERS: 
*Engaging Carers and Services*

Eileen McDonald  MCouns, GradDip DMT, BACommunications
Carer Representative & Advocate

4 November 2011
Carer Facts And Figures

- Nationally: 2.6 million carers
- 90,200 Young Carers under 25 (ABS 2003)
- 72% female
- 91% were caring for a close family member,
- 40% care for a partner,
- 29% for a child
- 32% for others

From estimates based on ABS 2003
Carers have the *lowest* collective wellbeing of any group the Deakin 2007 survey studied.

The survey found:

- More than 1/3 carers were found to be severely or extremely depressed
- More than 1/3 carers were found to be *experiencing severe or extreme stress*
- Almost twice as likely as the rest of the population to *worry* that their income would be sufficient to meet their expenses
- Almost twice as likely to *experience chronic pain.*

(Deakin University/Carers Australia/Australian Unity October 2007)
Mental Health Disorders Affect The Whole Family

• Due to stigma in the family, community, and cultural / religious community
• Due to stigma and discrimination from service providers

Hidden Carers are:
• Family members who consider their carer role to be the normal part of being a spouse or family member
• Those who are usually not considered the primary carer such as children and youth, grandparents...
Dimensions of Caring

1. Continuum of Care
   - start of caring
   - Caring life-course*
   - end of active caring role

2. Level of need of the Carer
   - Low
   - High

3. Carer's Life Stage**
   - Young
   - Marriage/Partnering
   - Children
   - Ageing parents
   - Aged

*Carers may undertake more than one caring role/life-course during their life and/or may have multiple caring roles

**Life Stage includes age-related and life events of the carer
Carer Life Course Framework

Phase 1: "something is wrong"

Phase 2: confirmation of mental illness

Phase 3: adjustment/readjustment

Phase 4: management

Phase 5: purposeful coping

Phase 6: end of active caring role

(Pagnini D 2005)
Dimensions of caring - impact on the carer

Carers’ needs:
• Separate to, but intertwined with, consumer
• Sometimes at variance with needs of consumer—
Impacts of caring

Dimensions of care

Influences

Carer

Transition to employment

Education

Financial

Health and well-being

Housing

Employment

Social exclusion

Physical

Community connectedness

Relationships
Elements of carer support

- Impacts of caring
  - Choice
  - Recognition
  - Early Intervention
  - Education & Training
  - Information
  - Flexible work practices
- Influences
  - Dimensions of care
  - Carer
- Financial security
- Emotional support & counselling
- Practical support
- Care planning & co-ordination
- Flexible respite
- In-home support
- Flexible support

Carer Dimensions of care Influences Impacts of caring

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer

Carer
Outcomes

1. Care recipient
2. Carer
3. Three dimensions of care
4. Factors which influence the three dimensions of care
5. The impacts of caring on the carer
6. Elements of carer support
7. Outcomes of carer support

- Prevent/minimise negative impacts
- Sustain informal care where chosen
- Carer Support
- Impacts of caring
- Influences
- Dimensions of care
- Carer
- Social inclusion
- Enable choice for carers
- Culturally appropriate responses
- Reduce cost to government
- Maximise quality of life of carers and the person they care for
- Social inclusion

Outcomes
What is family recovery?

Recovery will mean different things to different consumers and families

‘Recovery is a process of adjusting one’s attitudes, feelings, perceptions, beliefs, roles and goals in life. It is a process of self discovery, self renewal and transformation’

(Spaniol, Koehler & Hutchinson 1994)
Systemic level

• Ensure carers have a voice and are present at all levels of policy making, service delivery, evaluation

• Ensure the concept of family recovery and the interdependence of family and consumer recovery is understood and incorporated into undergraduate, postgraduate and ongoing training for health professionals
Individual level

• Ensure carers are genuine partners in care. Ensure that they participate, with consumer’s agreement in:

  – Discharge planning
  – On-going care plans
  – Education & employment planning

(NSW Mental Health Act 2007)
Engaging Carers

• It is not difficult to engage and include carers
• Engaging with carers increases chances of success for recovery

• Significant improvement in outcomes for:
  – Consumers
  – Carers
  – Health professionals & service providers
What is family recovery?

• instilling hope in consumer family member
• not seeking to inhibit self determination of consumer family member
• being able to withdraw - ‘dignity of risk’
• a strong belief that their own needs are important – that pursuing an independent life assists consumer and carer recovery
Why is recovery needed for families of persons experiencing Personality Disorders

• 58 – 73% of mental health consumers live with their families – (notion of interlinked lives)

• Family recovery needs to be identified as important for the family itself and the consumer family member
Families a recovery resource

- Families and carers need to be considered as a recovery resource for consumers
- Families need nurturing and care if they are to be a sustainable resource
- Families need information, education & support
- New methods of communication
- Skills for effective relational styles
- Skills to cope in crisis
Family recovery *is* possible – what are the implications for Service Providers?

- Identify the values that support recovery
- Provide information and education
- Focus on strengths
- Ensure services are family sensitive and inclusive
- Integrate the *Carers Lifecourse Framework* (Carers NSW) into thinking and planning for interactions with and services for families
How?

• Consider carers and hidden carers when taking family history from clients
• Refer families to the counselling, resources and supports for mental health carers including specialized support needs such as Aboriginal, CALD & youth networks
• Have carer information in your practice
• Be an information resource for families
• Engage carers as partners in the solutions for Personality Disorders
Anyone, Anywhere can become a Carer Anytime