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HOW TO MANAGE COMPLEX ISSUES IN CARER'S RESPITE

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Mental Illness Fellowship Victoria

- NGO operating through 30 outlets in Victoria, one in Canberra and Cairns
- Work with 2,300 individuals with a mental illness
- Operate a helpline which takes over 6,000 calls annually
- Worked with over 500 families last year
- Focus on housing, employment, social inclusion and reducing stigma through community action supported by a budget \$16.5m



What are the complex issues?

- Mental illness: Target group, low prevalence, recurrent disorders
- Develops in late adolescence early twenties interfering with maturational adjustments
- Volitional, thought and affective disorders in the context of normal intelligence
- Delayed diagnosis



Issues

- Stigma
- Development of disabilities resulting in: life expectancy of 50-59, 72% unemployment, 48% unfinished secondary education, 42% tenuous accommodation, 85.2% government pensions,
- age inappropriate reliance on family support



Family issues

- Carers on average contribute 100 hrs per week
- Increased anxiety, depression, poor health & employment outcomes
- Differential understanding of symptoms with consequential misunderstandings
- Poor understanding of different systems interventions
- Concentration on symptoms reducing capacity to reward positive achievements



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Mental Health systems issues

- Funding leads to silo thinking and investment
- Continued focus on clinical models
- Neglect of physical wellbeing
- Limited engagement with employment, psychiatric disability and Commonwealth respite services
- Limited understanding of the life cycle of caring
- Negative attitudes about the capacity of consumers and carers



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General Health Sector issues

- Poor understanding of the impacts of mental illness on the individual and the family
- Transferring knowledge from one carer group to another without carefully examining differences
- Linkages to general health systems and limited relationships with mental health systems



What we know

- Research on mental health respite limited to 29 studies found
- Studies investigated focused on the aged and young people
- Focus on giving a break with time to rejuvenate
- Benefits did not endure



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What we know works

- Everyone needs support to enhance their wellbeing through managing life stress
- Capacity building creates long term strategies to increase health outcomes
- One off interventions impact on the here and now
- Be very clear what you are working on
- Consider one off interventions as engagement strategies



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What we know works

- Address the elephant in the room: We will be better if our person is better
- Targeted peer family education and support
- Understanding that adults with mental illnesses have normal intelligence
- Supporting and creating alliances and networks: knowledge is power



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What are the respite services

- Occasion limited: Usually to provide support over a specific period while the carer is away for a particular reason
- Short Notice: Urgent family situation.



What are the respite services

- Volunteer Visitors: Longer term, less formal support.
- Flexible short term: Regular – a block of 12 home visits usually involving an activity in a local community.
- Residential-Holiday: Planned extended breaks for carers.
- Family Education & Support: Well Ways
- Building a Future
- Well Ways Duo
- Snapshot



Evidence

- Involvement Evaluation Questionnaire was used as a measure of caregiver burden (AH Schene and B van Wijngaarden, Department of Psychiatry, Academic Medical Center, Amsterdam, The Netherlands.)
- Measures four subscales :Tension, Urging, Supervision and Worrying
- Includes General Health Questionnaire – 12 as a measure of distress



Evidence: Well Ways

Results - N = 459

- Reduction in tension, worry and distress - the results of which were maintained over time. Measured at 6 months.
- Trend the program is more effective with psychotic disorders.
- Survey of what helped in the program and what skills were acquired.

N150

- 76% improved self efficacy and empowerment.
- 87% reported information helped.
- 75% reported improved communication skills with the relative.
- 87% reported increased empathy with the relative.

Stevens, Farhall, Ratcliff and Farnan 2009



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How do we do it

- We work with the carer and the person with the mental illness.
- We work in collaboration with clinical services.
- A care plan is developed.
- A consumer intervention requires the care plan to demonstrate a clear benefit for both the carer and the care recipient.
- Most referrals involve high levels of social isolation.
- Plans focus on developing social confidence and links into a variety of social situations and activities.



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How do we do it

- We work with CRCs, with varying results.
- In regions where there is more than one provider meetings have been established between providers to reduce duplication.
- Issues are evident with interpretations between CRCs of who is the care recipients and thus who and what will be funded.



Summary

- Respite in mental health is a relatively new program.
- The models and purposes need further investigation.
- Programs are not always based on evidence.
- Capacity building should be an aim of the intervention.
- Where one off interventions are used they should be considered in the context of an engagement strategy.
- Analyse the purpose of an individual intervention to enable effective tailoring.