NCOSS Conference Paper

Working Together for Mental Health

Negotiating the System

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BOBBY GOLDSMITH FOUNDATION INC.

- BGF is the oldest charity for people living with HIV in Australia. It has provided services continuously since 1984. In 2004 it will celebrate its 20th anniversary.
- Our services include direct and practical assistance, a no interest loans scheme, financial counseling, positive employment support, life coaching/choices, and accommodation support for 30 people in both our ten unit facility Bobby Goldsmith House and in properties across Sydney leased from community housing associations and the AIDS Council of NSW.
- In 2002/03 we provided 30,000 occasions of service to 1800 people across NSW

THE INTERSECTION BETWEEN HIV AND MENTAL HEALTH ISSUES

- Recent improvements in treatment have meant that people living with HIV/AIDS in Australia are living longer than at any previous time in the epidemic
- Some people with AIDS Dementia Complex, HIV related psychiatric illness, other mental illness and other behaviour management issues have complex support and housing needs
- There is a clear correlation between secure housing and the capacity to achieve and maintain good mental and physical health
- There is no definitive answer to how many people with HIV may have a significant mental illness – independent of their HIV status or associated with it.
- Recent research in Sydney by Donna Waters (2002) into *mental health concerns and maladaptive coping styles among HIV+ men accessing volunteer social support* presents a review of literature on the intersection of HIV and mental health.

- Ms Waters reports research indicating issues of loneliness, isolation and psychological difficulties continue to be pressing concerns for many with HIV. In particular, unemployment, financial stress and low incomes, a sense of helplessness, less adaptive coping resources, and poor physical and mental health may compromise the capacity of people with HIV to achieve and maintain wellness.
- Ms Waters argues that emotional distress and psychopathology among people with HIV have been consistently present since the beginning of the epidemic – it appears that depression is generally double the rate in this cohort compared to age and sex matched total population rates
- In the US one major study found that half the sample of almost 3000 people had a major psychiatric disorder.
- Ms Waters own research in Sydney found that 20% of the cohort she was investigating had elevated rates of psychological symptoms and levels of distress that were well above the adult community norm. 76% of the group were taking treatments for HIV and 68% were taking anti-depressants or psychotropics.
- This research does not consider the fact that for a proportion of people with HIV their mental health comorbidities prevent them from accessing mental health services, drug therapies (including HIV), and in many cases other community based services (like GP's).
- In summary then, many people with HIV are living with significant mental health issues for that arise from HIV related conditions, from pre-existing mental health issues, or as a consequence of living with HIV.

FLOATING CARE INITIATIVE (FCI): THE MODEL

- BGF observed over time that people with AIDS dementia, and people with HIV or non-HIV related psychiatric illness, and other behaviour management issues have more complex support and housing needs and require medium to high levels of support.
- In response to this need BGF established Floating Care in 1999.
- Excluding their HIV diagnosis, 33% of Floating Care clients have triple diagnosis, and 43% of Floating Care clients have a dual diagnosis.
- The Floating Care model links community based accommodation to a range of support services coordinated through case management and brokerage of a range of support services – including specialist mental health services.
- Floating Care provides up to 20 units of community based rental accommodation
- Floating Care is based on the principal of providing support to clients that moves or 'floats' with them wherever they choose to live. Floating care can also work with people who are homeless to assist them to find, secure and maintain affordable and appropriate tenancies.

- Level and type of support is flexible too, adjusting to an individuals needs at a specific point in time – there are three levels of support of between two and eight hours per week:
  - Level one: intensive support in locating and moving into property, reviewing problems in previous tenancies, develop strategies to prevent recurrence, assistance in accessing community based services, development of an exit plan which allows monitoring and follow up as needs.
  - Level Two: initial support if eviction is limited and access to interim accommodation if homeless, intensive support in locating and moving into tenancy, provide intensive support in sustaining the tenancy including prevention of rental and utility arrears, property damage and relations with neighbors, engage with client to explore options to change behaviors where possible, facilitate access to services (mental health and drug and alcohol), negotiate with service providers for access, provide ongoing support through relapses of behaviour that threaten tenancy and alternative problem solving strategies
  - Level Three: initial support to construct clear boundaries around interventions, intensive support focusing on establishing and then maintaining the tenancy, provide intensive intervention to establish and maintain integrated support network, and generate multiple referrals – often to address complex issues one at a time.
- The model identifies a range of roles necessary to support the client including the housing provider, a case manager and the support agency – BGF. BGF does not act as case manager.
- Floating Care has developed partnerships and referral relationships between housing providers, support providers and case managers – all focused around the expressed needs of the clients.
- Clarity about roles, responsibilities and mutual expectations is essential for the maintenance of successful partnerships in the provision of services to clients with this level of complexity.
- The cost of provision of this service by BGF is around $10,000 per client per year – significantly less expensive that incarceration, acute in-patient care, a disability group home, or a nursing home.

FLOATING CARE: THE EVALUATION

- The Department of Health and the Office of Community Housing commissioned an evaluation of Floating Care which ran concurrently with the pilot period and had been designed as part of the project itself.
- The **evaluation** found that Floating Care enables clients to maintain tenancies where in the absence of the service they would not be able to do so; and
    - that the provision of secure and subsidised housing has enabled support providers and clients to successfully focus on identified/agreed issues in the lives of clients – in particular their mental and physical health needs
    - Floating Care has been successful in linking clients with other community support services
    - two thirds of clients have substance abuse issues combined with personality disorder or other psychiatric disorder;
    - 76% of clients had either a triple or double diagnosis
    - 25% of clients had AIDS dementia complex;
    - more than 50% of clients had sensory or physical impairment.
    - Floating Care increased the access of clients to the specialist and generalist services for which they are eligible.
    - Significantly, service providers argued to the evaluators that without floating care many of the clients would be in jail, in institutional care, in inappropriate accommodation, or may even have died.

WHAT THEN DOES THIS TELL US ABOUT NEGOTIATING THE SYSTEM?

- There is no single point of access to the broad network of Government and non-Government services that exist to meet the needs of people with mental illness.
- The array of services needed to meet the needs of people with mental illness and statutory interventions that impact on their lives or liberty include: health services and specialist mental health services, disability services, community care providers, drug and alcohol services, the legal system, courts and criminal justice services, the corrective system, and substitute decision making authorities including mental health, guardianship and financial management processes.
- The experience of BGF is that consumers are not particularly concerned about where the get a service from and don't usually have a clear sense of alternative sources of support. They are even less interested in the challenges faced by services in creating and maintaining comprehensive community care planning and delivery.
- For these reasons, BGF does not place on the client an obligation to understand and negotiate the system. Rather, we act as **navigators** to facilitate comprehensive assessment, integrated service access, collaborative case planning, implementation of outcomes and evaluation.

- Modeling this navigation occurs formally through case management, case conferencing and a shared structure for community care plans and informally through working directly with clients.
- The experience of BGF is that where an individual worker or case manager approaches a client within their own professional frame of reference without appropriate consideration of the global needs of the client, their lived experience, and the array of services that might contribute to solutions – is potentially the extent to which the client is left to fend for themselves.
- The experience of BGF that the provision of support that is broader than any single discipline or even service system, is the approach that is most likely to achieve positive outcomes: in many cases this will require workers to adopt and maintain a **negotiation** position, combined with an informed sense of **navigation** possibilities.
- Another important role in assisting clients to successfully navigate the system is that of **mentor**. The lived experience of clients who struggle with mental illness may be seen by the client as repeated failure to succeed. This belief can be reinforced by services.
- **Mentorship** with these clients involves modeling behaviours that are different from those used by the client to date, and are likely to be more successful in achieving outcomes articulated by both the client and the case conference process.
- This FCI model is not a quick fix and may not work for every client, every time.
- However, the important issue is engagement with the client over time rather than connecting with as many services as possible in a short space of time.
- A critical component for achieving sustainable interventions is incremental success that demonstrates to the client and services that change and improvement in health is possible.
- Any intervention must be also be disciplined. This is not easy. Effective supervision and training for staff is essential. Clarity of role and responsibility at a worker and service level is equally important. Again, in the experience of BGF, case conferencing, care plans with clearly articulated outcomes provide the framework within which navigation, mentoring and professional self-management is best performed.
- Even for committed workers or service providers it is possible to adopt a nihilistic view of the mental health system, one in which we come to believe that it cannot help an individual client or a group of clients. So, it's the systems fault. Systems need continuous improvement but the reality is that at the time of planning or delivering an intervention – the system you're working with or within is the one that we have.
- Our experience is that often many options need to be explored and each option is an opportunity for success. In the presence of complexity every small success counts.

- In addition, a discipline by workers that views lack of demonstrable success as a step towards success is potentially more helpful to the client that adopting a position of failure.
- Over time, failure or perceived failure becomes merely an alternative that was explored and a step towards success – particularly given the length of time it may take to achieve outcomes for people with complex needs.
- A significant challenge faced by Floating Care is that clients are geographically dispersed across Sydney and move across system access points – our clients are mobile.
- This movement is geographical, but also crosses health areas, service catchments, community or institutional sites, and may intersect with statutory criminal justice or scheduled facilities.

ARE THERE ANY ISSUES THEN FOR OUR SHARED ACTION PLAN FROM THIS CONFERENCE?

- In 2003 deinstitutionalization is more than a decade old - it may be that it is time to examine models of service provision in mental health that are still based on institutional or large congregate settings;
- I'm not talking about scheduled in-patient environments – they don't constitute the majority of the settings.
- I'm really talking about provision of supported accommodation in SAAP services and some specialist disability services.
- In conclusion, what is it that is keeping us from integrating people with significant mental illness into community based accommodation with effective supports?
- I would want to argue that it isn't the absence of effective models of support, it doesn't seem to be a reluctance on the part of services to work together to achieve independence and good mental health in the community, and it certainly isn't the needs and desires of clients who engage with services to achieve changes in their mental health and their lives.
- It may be that in some cases funding structures or Government purchasing decisions are responsible. It may also be that in some cases staff in services can't see or don't want to see that vibrant models and services are available to assist in negotiating the system.

References:

Donna Waters (2002) *Mental Health Concerns and Maladaptive Coping Styles among HIV+ men accessing volunteer social support*, dissertation for Master of Psychology (Clinical), UNSW

NSW Health and NSW Department of Housing (2002) *The Evaluation of Floating Care*.