



Youth Mental Health Coalition

Submission to Senate Inquiry into Mental Health – Part 2

May 2005

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2.A INTRODUCTION

As outlined in Part One of our submission, The Youth Mental Health Coalition believes that it is crucially important that the voices of young people and their families are heard by the Senate inquiry.

Accordingly, we have included additional contributions from young people who attended the Youth Mental Health forum in June 2004. In addition, a young person suffering from depression prepared a video containing interviews of other young people, and this has been provided on a DVD.

One extended story also forms part of this submission. It is entitled "Michael's Story" and traces one family's battle with the "mental health system" and struggle to cope. It is a lengthy piece, but we have included it in full, as it touches on a number of key issues in addressing needs and services for youth and young adults in the mental health field.

The Coalition's Policy Sub-Committee is in the process of developing a Model for the delivery of mental health services for youth and young adults. Part 2 of our submission starts with "Youth Mental Health : A Model for Treatment & Learning", which is an exposure draft of the YMHC Model.

Contact details for Youth Mental Health Coalition members are provided at the end of the document, together with the required authorisations.

We thank you for the opportunity to make our submissions, and hope that we may be able to speak directly with you during the forthcoming months.

Ellen Flint & Kirsten Jones

for an on behalf of
the Youth Mental Health Coalition

2.B YOUTH MENTAL HEALTH : A MODEL FOR TREATMENT & LEARNING

1. Guiding Principle – Involving Young People And Their Families / Carers

Historically, the relationship between mental health care providers and young people and their families has relied on a model where power rested almost completely with the service provider, especially where they were a medical practitioner. The effective operation of this relationship to a large extent relied on the passive role of patients who placed significant trust in the doctor who was treating them and to the effective exclusion of family members from developing and implementing treatment plans.

One of the core beliefs of the Youth Mental Health Coalition is that young people and their families / carers should be involved as respected partners of mental health professionals. There are a number of ways of achieving these goals, including youth and family participation schemes that cover treatment plans and service design and delivery.

2. What Do Young People And Their Families / Carers Want?

A useful starting point is to ask what do young people with mental illnesses and their families want? Answers to this question will vary from person to person but some general themes that we have identified are:

Young people with a mental illness would like:

- ◆ Effective treatment (more than just medication)
- ◆ A safe place to live
- ◆ A job or something meaningful to do
- ◆ Study or skills training
- ◆ Friends to do things with
- ◆ A doctor or health worker who listens and explains
- ◆ Help with drug problems
- ◆ Understanding instead of discrimination
- ◆ Support to achieve a good quality of life

People caring for young people with mental illnesses would like:

- ◆ Effective treatment and support for their relatives
- ◆ Involvement in the treatment plans of their loved one

- ◆ Education and training in their role
- ◆ The opportunity to talk to others in a similar situation
- ◆ A break from the responsibility of caring
- ◆ Acknowledgement of the importance of the carer's role
- ◆ Understanding and support from the community
- ◆ Reduced stigma about mental illness
- ◆ Support for day to day living

3. Translating Expectations Into Practice

In order to demonstrate how some of the expectations and wishes of young people and their families can be translated into better mental health care, the Youth Mental Health Coalition is using this part of our submission to outline one potential model of care. It should be noted that the model outlined is not a one-size-fits all approach to youth mental health. That would be beyond the scope of this submission. Rather it takes one particular youth mental health issue – schizophrenia – and articulates a service that would meet some of the needs of the young people and their families that are affected by this illness.

It should also be acknowledged that the model that will be outlined focuses on treatment and education. As such it doesn't address either the social and economic contributors to mental illness or the manner in which research and policy priorities are set.

Although this submission doesn't tackle these issues it is important to note that recent research on social capital and inequality suggests that how individuals and communities feel - levels of trust, tolerance and participation - may be a critical factor in determining mental and physical health. Income inequality specifically is thought to damage social capital, eroding networks, cooperation and cohesion, which in turn contribute to poor health.

Furthermore, even though people with mental illnesses face social as well as clinical issues, current research funding often concentrates on clinical issues, especially pharmacological therapies. While research is needed to improve our understanding of mental illnesses and to develop better medications, we must research social issues more equitably. Researchers and funding bodies must heed the concerns of people with mental illnesses and their carers.

4. A Project To Meet The Needs And Expectations Of Young People With Mental Illness And Their Families / Carers

This section imagines a project to achieve the best “whole of person” outcome through evidence based programs that are driven by young people and that involve and support families / carers.

4.1 Brief Description

A dedicated facility will provide treatment, accommodation, rehabilitation and training supports for 6-10 young people (15-24 year olds) diagnosed with schizophrenia at any one time. This initiative will accomplish the transition from "Mental Illness" to "Mental Health". It will represent an integrated approach that brings together, under one roof, five critical life elements:

- ◆ Medication (stability, maintenance, etc.)
- ◆ Accommodation (safe, stable and friendly, etc.)
- ◆ Rehabilitation (cognitive-behavioural therapy, life skills, etc.)
- ◆ Employment / Education (supported work/study environment, economic participation, social connectedness, etc.)
- ◆ Support for Families / Carers (education about mental illness, crisis back-up for families, etc.)

4.2 Target Group

The target group for this project is young people (15-24) who have schizophrenia. The family / carers of these young people will be provided with services to support them in their important role in assisting their loved one's recovery. Young people participating in this program will need:

- ◆ to have been diagnosed with schizophrenia
- ◆ to be stable
- ◆ to be on medication
- ◆ to have a personal “going forward” plan
- ◆ to abide to their contract rules and regulations

Currently, the costs associated with supporting this group are significant. Based on first hand accounts, we estimate the following costs for a young person with schizophrenia:

	Annual Breakdown	1 Year	10 Years	20Years	30 Years
Disability Support Pension	\$379x26	\$9,854	\$98,540	\$197,080	\$295,620
Rent assistance	\$54x26	\$1,304	\$13,040	\$26,080	\$36,120
Hospital	ave2ldays @ \$196day	\$4,116	\$41,160	\$82,320	\$123,480
Medical	\$105x16	\$1,680	\$16,800	\$33,600	\$50,400
Medication	\$7x365	\$2,555	\$25,550	\$51,100	\$76,650
Total		\$19,509	\$195,090	\$390,180	\$582,270

The costs listed above do not include additional items like study assistance, sickness allowance, concession cards, carers payments, etc, which probably increase the totals by somewhere around 10-20%.

4.3 General Approach & Environment

The physical environment will both be youth-friendly and conducive to development of personal wellbeing. It will not have the feel of a “medical environment” and will use warm colors within and green landscapes outside that incorporate unobstructed long distance views.

Programs provided will be driven by the young people themselves:

- ◆ Participant is part and parcel of his/her own education and training program
- ◆ Participant elects and implements what works for him/her
- ◆ Participant keeps his/her own record of what works/does not work
- ◆ Participant sets their own program targets and achievement rewards
- ◆ Participant services to be delivered on site
- ◆ Participant achieves best outcome because of the timing and personalized nature of service delivery
- ◆ Participant learns at own pace as well participating in group activities

Programs will comprise a combination of support group meetings for young people, carer forums and family meetings and specifically target the development of the consumer's “whole of person” wellbeing. The team-learning dimension to programs is crucial. The group of young people offer mutual support, advice and make constructive

criticism to each other. The process, therefore, fosters team learning skills and a cooperative, collaborative culture:

- ◆ Team learning skills are refined in a supportive environment.
- ◆ A forum is provided where people can share difficulties and problems without fear.
- ◆ Problem solving, listening and communication skills can be enhanced.
- ◆ Motivation for ongoing learning can be increased.
- ◆ The process contributes to a cooperative and collaborative culture when participant, staff and the collective partnership share insights and problems.

A coordinated approach, through group/individual consultation and collaboration supports the families/carers of the young people, focusing on specific mental health issues. Support of carers includes:

- ◆ Increasing awareness of mental illness, its causes and effects and how services can be accessed
- ◆ Collaborating with service providers to promote shared care, and facilitate the development of effective partnerships between the medical/clinical care, carers and families
- ◆ Acting as an advocate for individual carer groups so that their needs are recognised and met by professional and service organisations
- ◆ Working collaboratively at local level to develop models for service provision and education strategies
- ◆ Providing support and advice to carer group/individual experiencing difficulties and grief
- ◆ Working collaboratively with carer support groups and local support organisations to develop, implement and evaluate programs and strategies

4.4 Education Programs

- ◆ Young people and their carers are provided with education to enable them to better understand and manage the schizophrenia illness. Eight sessions of one and half hours each over eight (8) weeks cover issues such as:
 - ◆ What is the pathological mechanism
 - ◆ How does it work
 - ◆ What caused the problem

- ◆ What does the problem do to the person and carers
- ◆ How does it work
- ◆ Why did it start when it did
- ◆ How severe is the problem
- ◆ How long does it last
- ◆ What treatment is needed
- ◆ What needs to be done
- ◆ What outcome is expected from the treatment etc.
- ◆ What other services need to be involved, who is to arrange them, is the consumer/carer going to be involved etc.
- ◆ The illness relapse risk management
- ◆ The sectors of the health care system
- ◆ What are the consequences of ignoring a young person's illness experience

The education program will take into consideration the group's language, traditions and culture. The program content will be relevant to both young people and carers and will start as soon as possible following discharge.

4.5 Innovation Objectives Of The Program

The program aims to constantly innovate and in addition to providing treatment and education, aims to contribute to new knowledge about effective interventions. Specifically, the program aims to :

1. Study the behaviors of the group of young people, their self-sufficiency and the differentiation of illness phases and progressing aspects of health status (e.g. stable and on medication, rehab ready, etc)
2. Document an individual's program progress for long term rehabilitation outcomes
3. Assess the program's overall effectiveness, both clinically and in terms of long term cost savings (e.g. progress in consumer's self sufficiency)
4. Research the mechanisms by which the self-management program affects the health status of participants. i.e. Disability Adjusted Life Year
5. Research the behaviors and the utilisation of available health services by the participants, e.g. accessibility, effectiveness and efficiency of services

6. Assess a young person's progression to achieve "whole of person" progress benchmarks
7. Identify the most influential stakeholders that need to participate - carers, health professionals, employers, etc.

4.6 Outcomes and Benefits

The outcomes and benefits of this model will include:

- ◆ Learning about each stakeholder's role, requirements and information needs
- ◆ Breaking down the existing/perceived barriers to collaboration
- ◆ Equity, equality and prompt access to professional care and other supports
- ◆ Assisting a young person's full integration into the community

2.C DVD BY FLICKA JONES

Flicka Jones is 19 years of age and has been diagnosed with depression. A keen diarist since her early teenage years, Flicka now keeps an online journal.

Through her journal, Flicka wrote about the work of the Youth Mental Health Coalition and her desire to create a submission on film, to help young people tell their stories.

She arranged to meet eight total strangers "under the clocks" at Flinders Street Station and to film their stories at the station and in nearby Federation Square.

Three people came on the day agreed for filming, and the enclosed DVD tells their stories and the stories of their families.

2.D MICHAEL'S STORY

Michael's Story is a lengthy piece which traces one family's story and interaction with the mental health system over more than ten years. The Story was written three years ago by his father, David, and originally the family intended to publish it in *The Age* – to help place a spotlight on the failings of the mental health system in addressing the needs of young people. It remained unpublished until its inclusion in this Submission.