



Youth Mental Health Coalition
Submission to Senate Inquiry
into Mental Health
May 2005

PART 1 – SUBMITTED HEREIN

An Achievable Dream ~ Excerpt

- I** Introduction
- II** The Youth Mental Health Coalition
- III** Key Facts about Youth Mental Health
- IV** Gaps & Fills : Discussion & Recommendations
- V** The Voice of Youth – Interim Selection
- VI** References
- VII** YMHC Contact Details

PART 2 – FORTHCOMING (31MAY)

- ◆ The Voice of Youth – Full Listing
- ◆ Pathways – A Future Service Model

An Achievable Dream

"I got help early, and when I needed it, and so did my family.

Our insurance paid for the help we received.

We were able to see doctors and others who were smart, well trained, and knowledgeable about where, when, and how to make referrals.

We saw people who (liked and) respected us and who taught us. We saw people who liked their jobs and felt respected and valued in them.

I had a place to get away and regroup and hide out that was quiet, safe, gentle, and like a home away from home. People respected my privacy.

I never had to go before a judge, or a magistrate, and no one in my family had to act in a punitive way to get help for me or for themselves. No one ever locked me up or made me take medications against my will.

The people in my family understand that it's not all my fault, and not all their fault. They understand that everyone has a part in our lives and my troubles - and theirs. They understand that there are no simple answers and they don't see me as a disease.

I got to go to school, live in a decent place, get money, have my pets – have a life without giving up everything else like my dignity and my hopes for a future I'd want to be in.

No one hassled me about how sick I was or whether I deserved to get help. I just got it.

And when I talked, people listened. What I said, felt, and wanted made a difference. I didn't always get what I wanted when I wanted it. But people listened – no b.s.; honesty is what I got.

I know this all sounds too good to be true. It is.

That's the only tragedy here."

Excerpt from
Harmony in Three Parts: Why Is this a Utopian Scenario?,
Sue E. Estroff, 1999.

I YMHC & YOUTH MENTAL HEALTH : AN INTRODUCTION

In June 2004 a new voice emerged into the field of youth mental health. The Youth Mental Health Coalition was formed at a public meeting at the Melbourne Town Hall. More than 700 citizens of Melbourne attended and the evening was supported by more than 20 organisations involved in the mental health field in Victoria.



The 2004 Forum sought to “test the waters” to determine the level of grass roots interest in establishing a consumer-led group which could work towards a better approach to the provision of youth-focused mental health services in our city and across our state.

The attendance at a public meeting and the commitment of those present to participate in a newly formed “Coalition” reflected the deeply felt community feeling about the issue. The mood and the stories reflected the level of distress, anxiety, pain and heart felt need to finding a better way to help our young people experiencing the suffering associated with both the diversity of mental health illnesses and the absence of effective models of care - and in many cases the unavailability of any care.

It was the need to investigate, document and understand the weaknesses, failings and gaps in our system of care for our young people that has driven the development of the Youth Mental Health Coalition. We are still in our “emerging phase”. We are volunteers – consumers of youth mental health services, carers and supporters of young people with mental health conditions who are committed to developing a consumer voice.

Our submission is not academic. We know the facts about service deficiencies in our communities. We see the weaknesses in the division of services between “adult-focused” mental health services and the “child & adolescent services”. We experience daily the sense of abandonment of teenagers dealing with depression, and the absence of a youth-appropriate service to help them ride this storm.

Our submission seeks a fresh look at the division between child and adult, the broadening of the care we provide to include the burgeoning depressive conditions, and the need to cater for the longer term recuperative needs of our young people. And we desperately seek an integrated approach to the provision of care – the creation of places where young people can go and feel welcome, trusted and accepted, and work through their private hell and come the journey to adjusted contributing adulthood.



A DANCER AT THE YOUTH MENTAL HEALTH FORUM - MELBOURNE TOWN HALL 2004

We believe firmly that the basis of our vision is within the realm of current expenditures in youth mental health.

A rethink of boundaries & service provision will start a sea-change.

Here is our story, and our plea for a rethink of the barriers of & to service.

II YMHC : WHO WE ARE, WHAT WE DO & OUR DREAMS

We spoke of our birth, which was exciting . . . and remembered by all who attended but it is appropriate to outline our constituency

On June 29th 2004 an unprecedented number of Victorians attended the first ever forum on youth mental health in our state. It was an emotional and moving occasion – lightened by the energetic and active participation of many past and present consumers of youth mental health services, which provided an uplifting mood and a sense of the opportunity the evening.

About The Youth Mental Health Coalition

Vision

From the June 2004 meeting, our volunteer committee set to work upon the basics. The Youth Mental Health Coalition's works for a future in which:

1. Every young person in Australia is supported to enjoy optimum mental health.
2. There is timely recognition and treatment of mental disorders and substance misuse in young people.
3. All young people have access to high quality, effective mental health services that treat them with respect and are appropriate to their needs.
All carers and families of young people with mental disorders and substance misuse have access to appropriate supports

Purpose

In defining its purpose, the Youth Mental Health Coalition committed to :-

1. promote social, political and economic changes to enhance the mental health of young people in Australia.
2. engage in activities to increase the capacity of members to achieve positive outcomes in youth mental health and substance use.
3. provide networking and knowledge sharing opportunities to all members.
4. provide a forum in which members who wish to co-operate further are supported in co-ordinating activities and pooling resources.

Representation

The coalition exists as an informal network of individuals and representatives of organisations. It is not an organisation or association - rather it is an agreement by its members to work together towards the common goal of enhancing the mental health of young people in Australia.

Formation

The Youth Mental Health Coalition was formed when over twenty agencies came together on 29th June 2004 to call for major reform of youth mental healthcare provision. The agencies who made this call are:-

- ◆ Alcohol and other Drugs Council of Australia
- ◆ Anglicare
- ◆ Australian Medical Association Victoria
- ◆ Beyond Blue
- ◆ Butterfly Foundation
- ◆ Brotherhood of St. Laurence
- ◆ Centre for Adolescent Health
- ◆ Jesuit Social Services
- ◆ Mental Health Council of Australia
- ◆ Mental Health Foundation of Australia
- ◆ Mental Illness Fellowship of Victoria
- ◆ Our Community
- ◆ ORYGEN Research Centre
- ◆ Royal Australian and New Zealand College of Psychiatrists
- ◆ The Salvation Army
- ◆ Sane Australia
- ◆ Victorian Health Promotion Foundation
- ◆ Victorian Mental Illness Awareness Council
- ◆ Wesley Mission Melbourne
- ◆ Youth Affairs Council of Victoria
- ◆ Youth Substance Abuse Service.

Membership

Of the 700 attendees at the April 2004 forum, more than 250 attendees indicated their willingness and commitment to participate in a campaign which would contribute to improvement in youth mental health services. A highly positive level of commitment . . . which has followed through to this submission.

The Management Committee

From the attendees of the forum and subsequent meetings and development fora, a Management Committee has been appointed, providing a mix of people with an interest in the area of mental health and consumers of youth mental health services.

The membership is :-

Anastasia Spathis
Ellen Flint
Kirsten Jones
Susan Betson
Maree Wilson

Frank Filardo
Gina Haebich
Jess Murphy
Gina Riley

Resourcing

The coalition currently has no funded resources. All activities happen as a result of volunteered time, money and other resources from members and supporters. A sponsoring organisation (ORYGEN Research Centre) acts as Secretary and assists with administration.

III YMHC : YOUTH MENTAL HEALTH - 10 KEY FACTS

1. Mental health issues are responsible for 65-70% of the overall burden of disease for young people between 15-25. One in four young people in this age group will experience a mental disorder in any 12 month period.¹
2. Only one in four young people with mental health problems receive professional help.²
3. 75% of mental illnesses first occur in people aged 15 to 24.³
4. Two-thirds of all disability in people aged 15-30 is caused by mental illnesses.⁴
5. Over half a million young people aged 12-24 years are hospitalised in Australia each year.⁵ Almost 9% of this figure (representing 43,500 hospitalisations) result from mental and behavioural disorders.⁶
6. The most common causes of hospitalisation for mental disorders among young people aged 12-24 were depression (6,264 hospitalisations), schizophrenia (5,514), reaction to severe stress (4,073) and eating disorders (3,701).⁷
7. About half of all individuals with psychiatric disorders will develop drug or alcohol abuse or dependency at some point in their lives.⁸
8. In Australia in 2001 those under 25 made up almost 30% of prisoners. About four in five of these are incarcerated for offences relating to alcohol and other drug use, two in five meet the diagnosis of personality disorder and one in five attempt suicide.⁹
9. Substance abuse disorders account for 1.1 million person days out of role as a worker, parent, partner or carer every month. Anxiety disorders and depressive disorders account respectively for 2.7 million and 2.1 million person days out of role.¹⁰
10. Over two thirds of people with bipolar disorder are likely to be misdiagnosed, on average 3.5 times, with the average time from onset to accurate diagnosis being over ten years. Of those who commit suicide, 60% are estimated to have received inadequate treatment.¹¹

IV GAPS & FILLS : DISCUSSION & RECOMMENDATIONS

Mental health is the number one health issue facing young people. Mental disorders tend to first emerge between the ages of 15 and 24 years, which is also the best time for detection and effective treatment. Early treatment of young people in a youth appropriate manner saves lives, money and distress. It's time that every young person in Australia had access to appropriate help for the health problem most likely to affect them.

The incidence of mental illness in young people is the highest of any age group. A recent landmark survey has revealed that the onset of major mental disorders, such as schizophrenia, bipolar disorder, depression and anxiety, substance use disorders, eating disorders and personality disorders is most common in adolescence or young adult life, between the ages of 12 and 26¹².

Australian surveys confirmed this, finding that the peak period for mental disorder is the young adult period of 18 – 24 years¹³. The rate among young adults (27%) is nearly double that seen in children and younger adolescents (14%)¹⁴. Youth is not only the peak period for the onset of psychiatric illness; it is also a complex and often precarious phase in the life cycle for psychosocial development.

The GAPS

The “Top Ten” and a myriad of outcomes of studies in the mental health of adolescents and young adult support the recommendations of the YMHC. Yet to date, what we have seen is largely a continuing investment in child focused CAHMS and Adult Health Services which are not structured to address and treat emerging mental health conditions – but more to manage established and longer term, low prevalence and high acuity disorders. The date of one’s 18th birthday defines which Service one is treated within – not the nature of one’s condition.

The method of improving primary care services in youth mental health has been to upskill GPs – yet there is a clear ceiling to the number of people and the level of complexity and severity of problems that can be managed within the structure of general practice¹⁵. A New South Wales Health Department study found that the most significant barriers to seeking help described by young people were concerns about confidentiality and trust in terms of the patient/provider relationship and having to deal with embarrassment and shame in disclosing concerns¹⁶. A clear message is that we need to look beyond the “parent-linked” GP clinic model as the best means of reaching young people in need.

From the GP to the secondary service level, we hit a diverse and diffuse range of providers – counselors, psychiatrists, social workers, justice, education, drug and alcohol, child protection, youth and family services – to name a few. The secondary services work largely independent of each other – there is no focus of the many available resources – no accessible “hub” for young people to turn to.

Young people are often reluctant to seek help and are very discerning about when, where and from whom they seek assistance. There is a critical need for youth oriented services. Young people who don't necessarily have a 'serious mental illness', and even those who do, must also deal with the stigma associated with attending a mental health clinic. The need is twofold; to provide mental health services with a 'youth' focus, and resource the primary care sector to better detect and manage the more high prevalence mental health problems.

In short,

- (1) We see a lack of youth appropriate services in our city

A model of youth-appropriate care exists for those in the north and west of Melbourne, in ORYGEN Youth Health, and we are informed that the Committee will receive a detailed submission from ORYGEN.

However, this model, which provides a breadth of inpatient and outpatient services, vocational, group and individual therapies is not funded to provide full support to its own catchment area population. Despite providing a model which caters for 15 - 24 year olds, which provides a youth friendly environment and a range of secondary support services, ORYGEN can not cater for the higher prevalence disorders such as depression.

- (2) We focus on GPs as the primary care provider – despite clear evidence that this is not meeting the needs of the youth and young adult community
- (3) We do not provide longer term care plans and accessible “one stop” services for the myriad of needs faced by young people with serious mental health conditions and their carers.
- (4) We know that “early intervention to address mental health problems in young people is vital (John Howard 29/09/04). We know that diagnoses are fluid and young people may take months or more to diagnose, and that their diagnoses may change over time – yet we arbitrarily break the child and adult services at 18 years of age.
- (5) We know the extent of depression in our community, and the high incidence of onset in adolescence yet we do not provide a youth appropriate service for our young people to access independently of their parents.

Our directions in service delivery are at odds with the needs of the young people they endeavor to serve, and this assertion is supported both in the literature and in the stories from youth.

The FILLS : Recommendations for Change to Youth Mental Health Services

1 Establish Specialist Youth & Young Adult Mental Health Services

The statistics about youth mental health tell a compelling story. About the onset of mental illnesses through the teenage years, and the need to treat young people from their early teens to mid twenties with a single service. The fact that 75% of first onset of mental illness occurs between the ages of 15 and 24 is just one clear indicator that we need to remove the artificial divide in our service model.

We need to provide access for all young people with emerging severe mental illnesses to specialist youth mental health services. Treat young people alongside their peers, provide therapies environments, group activities, vocational support, staff and work practices which are appropriate to the needs of young people.

The one working model to review is ORYGEN Youth Health – servicing the north and west of Melbourne. Its establishment as a clinical service was made possible by drawing on the Youth mental health funding from four Adult Area Mental Health Services. A dedicated unit was established in Royal Park, and the service has developed and provides a beacon of what can be done in high acuity youth mental health.

Remove the Great Divide!

2 Take a multi-disciplinary approach to helping young people with emerging mental illness of moderate severity

There is a high prevalence of depression amongst young people, where 50% or more of those who develop depression have their first episode before age 25. Epidemiological studies suggest that up to 24% of young people have suffered at least one period of major depression by the time they are 18 years old¹⁷ and between 15 and 40% of young people report symptoms of depressed mood and depressive symptomatology¹⁸.

We need to establish quality “youth friendly service centres where GPs are supported by teams of psychologists, occupational therapists, social workers etc where support is given to young people to return to work or study. Promote these services/centres widely so young people are encouraged and supported to access them. Take the Youth Centre model into urban and regional areas.

Depression is often associated with high rates of associated health problems including substance use and dependence, anxiety disorders, non-fatal deliberate self-harm, eating disorders and a range of other health risk behaviors. Depression is also the most common factor associated with suicide in all age groups. The majority of suicide victims meet criteria for depressive disorder in the weeks before death¹⁸. This leads to proposals #3 and #4.

3 Integrate treatment for mental illness and substance abuse

It makes sense to provide treatment of both the mental illness and substance use disorders by the same team at the same time – and this has been proved to be more effective than non-integrated treatments for people with both mental health and drug and alcohol problems^{19,20,21,22}. The lack of integration of services has significantly contributed to the poor detection and treatment of mental illness amongst young people with substance abuse. We can avoid the waste of resources and long-term psychiatric and substance use problems for individuals who could otherwise be helped. The National Drug Strategy 2004-2009 committed to “build strong partnerships between drug treatment services and mental health services to enhance responses to co-existing drug and mental health problems.” It is important that these services are supported to meet this goal.

4 Tackle youth suicide by re-focusing suicide prevention strategies on the mentally ill.

Our existing suicide prevention strategy (LIFE) takes a broad, public health oriented approach. To make a measurable difference it is important to tackle populations we know to be at high-risk – the mentally ill (depression is present in 88% of suicides)²³, those who self-harm or have made previous suicide attempts (who suicide at a rate 100 times higher than the general population)²⁴, those in early stages of a mental illness²⁵ or recently discharged from a mental health service²⁶ and those with both mental health and substance abuse problems²⁷.

5 Intervene Early – Get In Quick!

Existing Commonwealth Government policy articulates the need to address youth mental health issues early, and our Prime Minister has been quoted on this topic!

A preventative focus involves early case identification and intensive treatment of the first episode of mental illness, and it is logical that this should reduce prevalence, cost and minimize the potential impact of such illnesses²⁸. Research has also pointed to both the short and long-term benefits of early intervention for clinical and personal outcomes. Early intervention has also been shown to reduce the need for inpatient treatment and is associated with better outcomes and subsequent cost reductions for the health care system²⁹.

V THE VOICE OF YOUTH – PART A

“Stories from The Community”

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. The following are an initial collection of comments, reflections, personal stories from young people, and those who care for them

The contributions came from people attending the Youth Mental Health forum in June 2004. Sources include a transcript of the evening, question cards filled in by attendees, and evaluation forms. An interactive sculpture was placed at the entrance to the Public Forum and more than sixty stories were pinned to it.



The Voice of Youth Mental Health

“I know a boy in Year 12 who has signs of psychosis. He has been waiting for help for over a year. How can I help him get through the systems or is there nothing I can do?”

“My son was suddenly diagnosed at 21 with schizophrenia. We found out that at 15 he had been telling our family GP, but the doctor didn't listen.”

“I want to say thank you to all the people who have helped me 'cos if it wasn't for them, I wouldn't be here and my daughter wouldn't be here”

“If we are going to talk about mental health in youth then the logical place to get to them is at school..[my son] was cutting himself at school and the school's response to that was we'll expel him”

“I am a 21 year old woman. I have depression and anxiety. I am terrified of my illness because when it gets bad the services available are not enough. I might die. It's too much for my family, partner to help. I have nowhere to live when it happens. I can't afford my medication because it costs over \$100 per month. Please Help! For me it can be like being strangled on the inside. People who have listened and helped me have saved my life. These people need more recognition and support. I dropped out of high school at age 14 after suffering a nervous breakdown. I was so anxious and depressed that I couldn't bear to face my friends and family or even the sunlight. I spent my Year 10 year studying (unsuccessfully) via distance education. However, I was barely able to get out of bed most days. My brain stopped functioning properly and every anti depressant I tried eventually ceased to ease the pain. The next two years were virtually lost in a haze of fatigue depression and pills. I was admitted to hospital on two occasions and found my experiences extremely traumatic. I was told on several occasions that I was uncooperative because I could not tell counsellors and/or psychiatrists what was wrong with me. Finally after 5 years of suffering I was given a plausible diagnosis. I was diagnosed as a maniac depressive. Life is still a struggle, at least now I can see a future and see a way ahead.”

JOLAN'S STORY

I first came to ORYGEN in 1999. The night I was admitted I reckon I had luck on my side. I thank whoever it was who knew about this place and referred me there. I believe had I not come to this service I would not be as well as I am today. Having a psychotic episode was traumatic for my family and me, not just because of how delusional I was but because none of us knew what was going on. The night I was admitted I was cold, shaky, had forgotten about eating and convinced I was going to die. I have never felt that much fear in my life. I had a whole community of voices in my head that I spoke with, people I knew and a few that I didn't know and the common rule was that no-one spoke about this form of communication in the normal world. I conversed with several gods and everyone could read my thoughts and in my imagination looked into my eyes like they were cameras. As you see my life became very busy. I had what I thought a very active social life. It took up much of my time talking in this way.

I had no idea that I had actually become quite withdrawn socially, in fact I had so much going on in my head I had no space to reason with anyone.

I was at Uni doing honours and the struggle was actually knowing which space was mine. I couldn't study any more and it wasn't until I had lost my memory and thought I was going to die that I got help. My life had become a bizarre mixture of the Truman Show and The Matrix. My first admission I spent 4 months in hospital. Once I realized I was psychotic I had lost belief in myself. I couldn't trust my mind and had to learn to trust and rely on others. I don't think I would wish this on my worst enemy. Imagine being told right now by someone that you are not really here. There is no such thing as this Melbourne Town Hall and this public forum and the person that it talking to you now doesn't exist. You are told you won't be able to leave this building until you believe this to be true. How do you feel? By the time I got out I had become institutionalized. I lost my independence.

For 4 months I had all meals cooked for me, I had to ask for everything, I couldn't leave the building and after a while after I got permission I could go out for a few hours or the day. Linen was changed regularly, fresh towels everyday, dishes were washed and the ward was cleaned by cleaners. I didn't have to do anything except get well and get out of there.

From then to now has been a slow road uphill, in fact I wouldn't call it a road I would call it a track. In the first 18 months I had 8 admissions. When I was home I had forgotten how to do things on my own and was in the habit of asking for everything from a carer. I struggled with reality. I was used to getting up at 6am which is great but with no motivation it is a nightmare. And the side effects of medications ranged from feeling hungry, stiff or lethargic to not being able to stand still. It has taken me 5 years to get to the point of where I am now and it is a full-time job to maintain this. I think a lot of people don't realize it and even I forget it sometimes. Every now and then I have a gentle reminder of psychosis and realize it is very easy to let go and into that realm, but I know as soon as I let my guard down I will end up having to rebuild my life again.

I have respect for my illness, even though it has caused me no end of grief. I believe it has made me stronger and better equipped to deal with life's ordinary hurdles and stressors. I have to look at it this way otherwise I would be constantly held back by negativity. Its so easy today to focus on negative things or feel that we aren't coping in some way. I know there are things I'm not able to do right now and may never be able to do again. It's important for me not to forget these things but if I put them to the back of my mind so they don't restrict me what's left in front of me is endless opportunity.

I have been lucky I have not experienced stigma in the broader community. Everyone that I know and have met since my first episode has accepted and embraced my openness about it. Where I have felt like less of a person is within the adult mental health system. There is a general atmosphere there that you have no

future, your illness means you can be ignored, spoken to rudely, be made to feel like you are taking up too much time and you don't deserve any patient respect because you are struggling with living. This concerns me because these are the services I will need if I become unwell, these are the services that many young people will encounter because there is not youth services in the area they live. One thing that drives me to maintain my health is that I refuse to be part of a service that can't see me as a person, and believes that I am only a schizophrenic that speaks "schizophrenise". There are services out there that adopt a caring and responsive philosophy, if these places do it, why can't they all? It is important to have services that are specifically for young people as it gives the opportunity to recover amongst your peers and share similar experiences. Experiences that are related to mental health but also stuff that is related specifically to young people, like sharing music, interests, expressions and dress codes.

I like to think of myself as an ORYGEN graduate, not a mental health patient, yes I am one of those crazed and deranged people that society is so cautious about. Its funny that, because when I look at what's happening in society today it seems to be on the brink of madness, materialism, consumerism, terrorism, genetics and morals. You must have viewed or at least heard of the saying "the worlds gone mad". Maybe a bunch of people like me in society should get together sometime, us crazy people know our stuff, we could help out.

CHRISTINE'S STORY

I have a very vivid memory from when I was 5, I was sitting cross-legged on by bed with a book in my lap and a nagging voice in my ear, it was mum. She was sitting next to me with an earnest expression on her face telling me about the tales of her and Elvis. Apparently he used to be in love with her and even postponed one of his shows to be with her. I remember thinking that that just couldn't be possible, but also somehow knowing that she wasn't actually lying to me, she really did believe it. Growing up with a parent suffering from schizophrenia was an experience that was both challenging and rewarding.

There were many times when it felt as though things were made harder for me because of my mother's illness. I remember as a young girl having the implicit knowledge that when my Dad went to work it was me looking after Mum and not Mum looking after me. At times I resented the fact that she was different, visiting my friends families made me feel jealous that my mum didn't do the kind of things that other mums did, like pack my lunch before school or make sure my uniform was clean and ironed, or even just be up and out of bed when I got home. As I got older I sometimes felt sad that I couldn't have the kind of conversations with Mum about school, work and relationships that I knew that other girls had with their mums. All of these things did make life difficult at times although there were lots of good times as well. I always loved listening to her stories even if I didn't believe many of them and I always knew that she loved me.

But looking back now one of the hardest things to deal with is the lack of understanding surrounding mum's illness. I didn't find out that my mum had been diagnosed with schizophrenia until I was 15 years old. Approximately 15 years after she had received the diagnosis, I remember once when I was about 10 after mum had locked me out of the house when I got home from school, asking my older sister what was wrong with mum. She replied that mum had the mind of a 2 year old. Needing some sort of explanation for mum's behavior I latched onto this, and this was the explanation that I gave my friends when they asked about mums weird behavior. She has the mind of a 2 year old I'd say, its been clinically proven.

When I finally did find out by accident that mum had been diagnosed with schizophrenia some 15 years ago I was livid. How could no-one thought to tell us. Surely mum's doctors had known that she had 3 children, why did nobody think to ask us if we were OK. I never got to ask Dad why he didn't tell us because he passed away shortly after I found out. Knowing Dad though I can imagine that it was something he too found hard to deal with and not having any support himself I think that he did what many others of his generation did faced with mental illness, pretended that it simply wasn't there.

I had known for a long time that Mum had to have a needle every month but I never questioned what it was for. It had been like that since I was little so I just never thought to ask. When I later started looking into the syndrome of schizophrenia I was shocked to realise that I could have diagnosed mum myself had I known about the disorder for she had all the classic symptoms. Just knowing that mum had a recognised mental illness would have helped to explain a lot of her behavior and would have reduced the feelings of resentment that I had sometimes felt towards her.

Moreover, the most important thing that recognition of mum's illness would have done for me would be to allow me to realise the role that I had as a result of her illness was a difficult one. Not knowing what was wrong with Mum precluded a realisation that this was a difficult situation that anyone would find hard to deal with. Instead I was often left wondering why things were the way they were and why home life seemed so much harder for me than any of my other friends at school. Looking back now I sometimes wonder how it was that I managed to get myself off to school every day, do my homework every night and deal with the bullies at school that teased me about my retarded mum. There were lots of things I had to be to get this done, responsible, resourceful and independent. All qualities that I now attribute to growing up with a parent with schizophrenia.

When I was first asked to give this talk today I started thinking about what the main message was that I wanted to get across. It occurred to me that everything I have heard so far in discussions of the issues surrounding children of the mentally ill parent described the negative effects on these children. We know now that these children are faced with a lot of hardship and that its important to give them the support they need. The fact that this is now recognised and procedures are starting to be put in place to give support to these children is an excellent starting point.

There is however, another side to the situation to be faced by this group of people. There are also positive aspects to caring with a parent with a mental illness and its these that I think we should focus on in trying to help young people in this situation. We need to be proactive in our approach in order to promote resilience in a group of young people that we know are at an increased risk of suffering from mental illness themselves.

One important aspect of caring for a mentally ill parent is the increase in responsibility. This can certainly have negative aspects at times. When I was only 15, I flew with Mum to the Northern Territory to see her father before he died. It wasn't long since my Dad had passed away and I felt scared and alone because I knew it would now be my responsibility to take care of Mum. On a positive note I did manage to take care of Mum and I knew that she and the rest of my family were thankful to me for going. Experiences such as these allowed me to accept the responsibility and gain a sense of mastery that I was actually able to cope.

Experiences such as these allowed me to accept the responsibility. Learning to deal with responsibility is an important part of growing up and I think that its essential that we recognise that children with a mentally ill parent do have these extra responsibilities and for the most part deal with these exceptionally well. These children should have this responsibility recognised and furthermore be encouraged to use this skill in a positive way for their own lives.

The second important skill that is required to care for a mentally ill parent is resourcefulness. There are many situations that I can recall where I initially had no idea what to do. Not long after Dad died, Mum became convinced that my brother was plotting to kill her and it was left to my sister and me to do something about it. I called the community mental health service and had the crisis assessment team come out. They suggested that she be admitted to hospital so I took her down and waited with her until she was admitted. Several times I had to explain to her the reason that we were there and try and stop her from leaving. I remember feeling very unsure about whether or not I was doing the right thing. I now know that many young people are faced with this difficult situation. The need to be resourceful in these situations and to recognise when and how to help are again important skills that should be recognised and fostered. In my experience these skills were invaluable to me when I later went on to undergraduate and then postgraduate education.

The third skill that I think is important to recognise and support is that of independence. I was often left to myself as a young child when Dad was at work and Mum was still in bed. I learnt to take care of myself and I soon learned that if I wanted my clothes to be ironed, my lunch to be made and my homework to be done then I had to organise to do them by myself. The need to be independent and organised in this way became especially important after Dad died because then there were bills to be paid, groceries to be bought and dinners to be cooked.

Organisation is now a big part of my life, juggling 2 degrees and 3 part-time jobs and its something that now comes naturally to me. My ability to do well in situations requiring independence and organisation can be attributed to my early experiences in life and they have become invaluable skills both in study and work. Children and young people with a mentally ill parent should be given more opportunities to further enhance their independence and organisational skills so that they can use these skills to provide structure and support for themselves.

In summary, responsibility, resourcefulness and independence among others are all skills that are important to have when caring for a mentally ill parent. In some ways I was very lucky because these skills came relatively easy for me. Many children and young people are not so lucky however, its easy to feel overwhelmed and focus on the negatives, the stigma, the uncertainty. Its easy to get stuck in the cycle of saying things like, life sucks, things are never going to get any better, I don't have any support, I'm alone. For these children we need to be proactive in providing them with the support and resources that they need to foster these skills so that we can help them to help themselves. We know there is an increased use of substance use, depression and other mental illnesses in this group, but hopefully by rewarding their strengths we can break this cycle of negativity, by rewarding their strengths we can empower them to deal with the situation in a positive way.

BRONWYN'S STORY

Firstly I would just like to thank Pat McGorrey and ORYGEN for giving me, a care giver, the opportunity to come and talk and so I dedicate this talk on behalf of all care givers who are struggling and coming to terms with young people with mental illness. I want to start with a poem I wrote 5 years ago entitled "Psychosis".

What is this word "psychosis" that tears our lives apart
Why is it so destructive?
Disruptive, tormenting, creating havoc in its path
Rollercoster that never seems to stop
Broken minds, broken hearts
Lost in a world torn apart
Whispers in corners, sadness in hearts
Tears in showers, doctors, hospitals, pills
Total helplessness, when you can't stop the fall
Fear from uncertainty when they're often world
Anguish when they're frightened from what's in their head
Nothing you say is comfort
No words can negotiate reality
Nothing seems to help
Empty arms, broken hearts
Tiredness, stress, distress, frustration, sadness, fear
All play their part
What is this word "psychosis" that breaks a mother's heart

That poem can only describe a small amount of emotion that you are thrown into when your child becomes mentally ill. It is overwhelming, the disbelief and gut wrenching anguish you feel, no words can describe, the barrage of grief, shock and fear can almost be paralysing but somehow you have to find a way through to support and care for your child and other family members. There was no time for me to explore my grief, I was suddenly thrown into a role of being a psyche nurse, a case manager with no previous experience and left to deal with my then 17 year old son's illness. That was so traumatic and so very serious. His world and ours was totally torn apart and as a mum I thought my heart would just break into a million pieces.

I had a million questions - "how did he get it?, why, how long will it last?, the list went on and on. Where do you get help? Why am I feeling like this? I wanted someone to come in and rescue me, I wanted someone to take away the illness. I felt helpless. I couldn't stop what was happening to my boy, my beloved son.

As time passed I learnt very quickly how to find strategies to help him and to grow him through that initial onset of the illness. We battled with his drug taking. Doctors would not always listen to my observation of him. He could mask his illness. I battled with clinicians for 3 months before they recognised he was unwell again. It took 2 years for things to start to settle, guess what? Bang. My then 17 year old daughter came to me and said she was experiencing symptoms. With out delay I moved very quickly to get her assistance because this time I had already had an insight. My daughters experience was totally different however, the grief was even worse for me. I now had to come to terms with two with a mental illness. How was I going to manage? Again questions.

Here and now my life is consumed by mental illness. Not only in my caring role but also because the services are not always available due to lack of staff caused by inappropriate funding and therefore we, the care givers, are expected to carry a lot more. I struggled to get beds in hospitals, at times there are no beds available when my children are unwell. An intervention doesn't happen straight away, sometimes with long delays. I get very little respite, but except from an organisation called Carers Links West who have been absolutely wonderful, but they themselves are limited with access to funds. Even now my son is very unwell and he has been unwell for nearly 12 months and I can't get the intervention that he needs and he no longer has trust in their care and they are failing him. They are failing him. We have our hands up, we don't know what to do. I never give up hope though that the system can change. We have seen our own personal changes through this journey, this epidemic, youth mental health is enormous. You only have to sit in the waiting room at ORYGEN to find that out. But, we thought it would never happen to us. You probably think it will never happen to you. But chances are 1 in 4. This is not just our own personal problem, this is the nation's youth. This is our youth, and they are being afflicted. What can we do together to provide better care and intervention of our young sufferers with mental illness. I pray to god that help comes soon.

VI REFERENCES

1. Andrews et al 1999; Sawyer et al 2000 and the Victorian Burden of Disease Study - all cited in *Innovating for youth mental health: planning for the next decade*, Albiston A & Moran J 2003
2. Mental Health Council of Australia
3. Mental Health Council of Australia
4. Mental Health Council of Australia
5. *Australia's young people: Their health and wellbeing 2003*, Australian Institute of Health and Welfare, Canberra
6. *Australia's young people: Their health and wellbeing 2003*, Australian Institute of Health and Welfare, Canberra
7. *Australia's young people: Their health and wellbeing 2003*, Australian Institute of Health and Welfare, Canberra
8. US studies in Epidemiology Catchment Area Study and National Co-morbidity Study cited in the NAAH Dual Diagnosis And Young People report, 2003.
9. Legislative Council of NSW. Select Committee on the increase in prisoner population: final report. Sydney, Parliament of NSW, 2001 cited in *A healthier approach to crime prevention in Australia*, O'Donnell, C, 2003
10. Australian National Survey of Mental Health and Wellbeing, Profile of Adults 1997, cited by Mental Health Council of Australia
11. *Bipolar Disorder Costs*, 2003 SANE Australia
12. Mrazek P.J. & Haggerty R.J. (Eds) *Reducing Risks for Mental Disorders*. National Academy Press, Washington, 1996.
13. Andrews, G. et al, *The Mental Health of Australians*, Mental Health Branch, Commonwealth Department of Health and Aged Care, April 1999.
14. Sawyer et al, Capt V. *Mental Health of Young People in the Australia*, Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged and Care, 2000.
15. Vines, R.F., Richards, J.C., Thomson, D.M., Brechman-Toussaint, M., Kluin, M. & Vesely, L. (2004). *Clinical psychology in general practice: a cohort study*. *Medical Journal of Australia*, 181 (2), 74-77
16. Booth, M., Bernard, D., Quine, S., Kang, M., Usherwood, T., Alperstein, G., Beasley, L., and Bennett, D., (2002). *Access to health care among NSW adolescents*. NSW Centre for the Advancement of Adolescent Health pg 6-8.
17. Barraclough B, Bunch J, Nelson B, Sainsbury P. *A hundred cases of suicide: clinical observations*. *British Journal of Psychiatry* 1974;125, 355-373.
18. Shaffer D, Gould MS, Fisher P, Trautman P, Moreau D, Kleinman, et al. *Psychiatric Diagnosis in Child and Adolescent Suicide*. *Arch General Psychiatry* 1996; 53:339-348.
19. Drake, R.E. and M.A. Wallach, *Dual diagnosis: 15 years of progress*. *Psychiatric Services*, 2000. 51(9): p. 1126-1129.
20. Mueser, K.T., R.E. Drake, and M.A. Wallach, *Dual diagnosis: A review of etiological theories*. *Addictive Behaviors*, 1998. 23(6): p. 717-734.

21. Drake, R.E., et al., Review of integrated mental health and substance abuse treatment for patients with dual disorders. *Schizophr Bull*, 1998. 24(4): p. 589-608.
22. Torrey, W.C., et al., The challenge of implementing and sustaining integrated dual disorders treatment programs. *Community Mental Health Journal*, 2002. 38(6): p. 507-521
23. Lonnqvist JK. Psychiatric aspects of suicidal behaviour: Depression. In: Hawton K, van Heeringen K, editors. *The International Handbook of Suicide and Attempted Suicide*. Chichester: John Wiley & Sons, Ltd; 2000.
24. Kapur N & Gask L Introduction to suicide and deliberate self-harm *Psychiatry*, The Medicine Publishing Company, 2003.
25. Appleby L, Shaw J, Sherratt J, Amos T, Robinson J, McDonnell R et al. *Safety First: Five-Year Report of the National Confidential Inquiry into Suicide & Homicide by People with Mental Illness* Department of Health, England, 2001
26. Goldacre M, Seagroatt V & Hawton K Suicide after discharge from psychiatric inpatient care. *The Lancet*, 1993 31;342(8866): 283-6.
27. Murphy G E Psychiatric Aspects of Suicidal Behaviour: Substance Misuse. In: Hawton K & van Heeringen K *The International handbook of Suicide and Attempted Suicide* (pp135-146). Chichester: John Wiley & Sons Ltd, 2000.
28. McGorry PD, Edwards J, Mihalopoulos C, Harrigan SM, Jackson HJ, EPPIC: An Evolving System of Early Detection and Optimal Management. *Schizophrenia Bulletin* 1996; 22(2): 305-326.
29. Mihalopoulos C, McGorry PD, Carter RC. Is phase-specific, community oriented treatment of early psychosis an economically viable method of improving outcome? *Acta Psychiatrica Scandinavica*.1999;100(1):47-55.

VII CONTACT DETAILS

Youth Mental Health Coalition

<u>Authorisation</u>	Ellen Flint Kirsten Jones Committee	Acting Chair, YMHC Management Committee Chair, YMHC Policy Sub-
-----------------------------	---	--

Mail	Locked Bag 10, Parkville, Vic 3052.
------	---

Phone:	03-83468230.	YMHC Secretariat (Matthew Hamilton)
--------	--------------	-------------------------------------

email	info@ymhc.org.au
-------	--

