

# Schizophrenia Ireland - Lucia Foundation

## 13<sup>th</sup> Biennial Conference

Newpark Hotel, Kilkenny

Friday November 29<sup>th</sup> and Saturday November 30<sup>th</sup> 2002

### S T I G M A

#### Breaking Down the Barriers

##### Conference theme & format

The aim of this conference is to look at stigma and mental illness in a number of distinct ways and to provide some practical responses.

- We aim to provide a general overview of what stigma is in a global sense.
- An exploration of institutional stigma where it occurs on a day to day basis in a variety of settings and relationships (such as organizations, the media, the workplace ).
- The impact of self-stigmatisation from the perspective of both service users and relatives.

##### Friday 29<sup>th</sup> November:

**11.00 – 1.30 Registration:**

**1.30 - 1.45 Welcome and Introduction** *Kevin Jones, Chairperson, Schizophrenia Ireland*  
*John Saunders, Director, Schizophrenia Ireland*

**1.45 – 2.00 Official opening** *Tim O'Malley TD, Minister of State at the Dept. of Health and Children*

**2.00- 3.30 Panel Discussion**  
**The Media and Mental Illness.**  
*Chair: John Saunders, Director of SI*  
*Fintan O'Toole, Irish Times*  
*Peter Byrne, Consultant Psychiatrist*  
*Sue Nunn, Head of News and Current Affairs, Radio Kilkenny*  
*Fergal Bowers, Editor, Irish Health.com*

**4.00 - 5.00 Working Group Sessions**

**1.Mental Health Awareness**  
*"Working with the Police"*

**2.Patrick Corrigan, Prof. Of Psychiatry (Chicago, USA)**

*“Addressing the Self-Stigma of Mental Illness”*

**3.Relatives’ Experience of stigma**

*A personal exploration of the impact of stigma by three family members*

**8. 30            Conference Dinner**

## **Saturday 30<sup>th</sup> November**

**8.15 – 9.15      Registration**

**9.15-9.30      Opening Address**                      Pat McLoughlin, CEO, South Eastern Health Board

**9.30 – 9.45      Ann Donnelly, Rethink**                      *“A New Prescription”*

**9.45 – 10.00    Chairpersons Address**                      Donncha O’Connell, Lecturer in Law, National University of Ireland, Galway.

**10.00-11.15    Plenary Session 1:**

**10.00 – 10.30** Paddy McGowan and Mervyn Tierney, Irish Advocacy Network  
*“Stigma – A user Perspective”*

**10.30 – 11.00** Tom Cooney , Lecturer in Law University College Dublin  
*“Equality, mental Illness and the Law”*

**11.00 – 11.15    Questions & Answers Session**

**11.15-11.30    Tea/Coffee**

**11.30-12.30    Working Group Sessions**

1. Irish Advocacy Network  
*“Stigma – A User Perspective”*
2. Mental Health Awareness  
*“Working with the Police”*
3. Service User Experience of Stigma  
*A personal exploration of the impact of stigma.*

**12.30– 2.00      Lunch**

**2.00 – 2.15      Chairperson’s address** John Owens, Chair of Mental Health Commission

**2.15 - 4.00 Plenary Session 2:**

**2.15 – 3.00** Peter Byrne, Consultant Psychiatrist (UK)  
*“Prejudice and Pride - What we know about beating stigma”*

**3.00 – 3.45** Patrick Corrigan, Prof. Of Psychiatry (Chicago, USA)  
*“Don't Call Me Nuts! - Coping with the Public Stigma of Mental Illness”*

**3.45 - 4.00 Question & answer Session**

**4.0 Conference Close**  
Mairead O’Sullivan, President Schizophrenia Ireland

## **WELCOME by Kevin Jones, Chairperson of Schizophrenia Ireland**

Good afternoon Minister, friends and colleagues. First of all I would like to welcome everyone here to the Newpark Hotel for the 13<sup>th</sup> Biennial Conference, which is hosted by Schizophrenia Ireland.

For the next day and a half the event promises to be both informative and interesting I believe and hopefully each one present here today will go away with at least one positive thing whether that be a new idea, a lesson learned or something else which will help each of you to proceed along life's journey.

Now we have a very interesting line-up of speakers who come not only from Ireland but also from the United Kingdom and the United States of America and firstly I would like to extend a warm cead mile failte or welcome to all our speakers

The theme or the subject matter of this conference is called 'Stigma – Breaking down the Barriers'. I think first of all it would be interesting to define the word 'stigma' and from the dictionary it means 'a mark or sign of shame, disgrace or disapproval, of being shunned or rejected by others'.

Now as we are acutely aware the stigma surrounding schizophrenia is strong in our community, so strong in fact that people with schizophrenia find themselves discriminated against at almost at every turn in their life, from finding employment to accommodation or simply making friends. As most of you here present are very well aware, stigma not only affects those who suffer from the illness, but also their families as well. And the consequences of stigma are far reaching because stigma maybe one of the most oppressing factors confronting the person with schizophrenia. It's impact can be devastating, feelings of isolation and depression are common and the negative effects of stigma include such things as discouragement or hurt and anger, lowered self-esteem, broken or disrupted relationships, negative labeling, decreased chance of employment and so on.

I'd just like to take a few moments to read a few extracts from a talk that was recently given by a mother who had three sons who were all in their twenties and who were all diagnosed with schizophrenia. And, of her second son she said 'he was able to complete his studies and had been in employment since January 1994, he was a valued member of a work-team and nobody knew about his problem, if they ever had found out he would have lost his job, but his illness was disclosed and he did lose his job two years ago, it destroyed his dignity, for a long time we've had to nurture him to rebuild some of that self-esteem'. And then she goes on about her third son, 'my third son, then twenty three had the benefit of effective medicine and nurturing support right from the start, he has been in full remission since '94, and he was after eight months of tender loving care and total rest able to return to his studies, he obtained his degree with distinction, being the top student in one of his major's, for which he received a prize. Last year he completed a year-long course and won the top student trophy, gaining an average of 93%. Very

occasionally, when stressed, he thinks he hears voices, suffers some paranoia or feels deep guilt about unimportant things, and then, likewise I, or one of us nurture him through.

He has recently found a job, which he hopes to start soon, but his biggest fear is exposure of his illness and he writes 'I cannot disclose my true story, I sit convicted of the heinous crime of mental illness, maybe one day you will all understand, for now I must simply hide, but with the hope that I will be found trying to pass as a human being who can make a valuable contribution. At least I know that life can and does continue after schizophrenia'.

I just want to touch on some of the aspects and topics, which need to be addressed in order to reduce stigma and the stigma which surround schizophrenia. Now, in a perfect world I would probably say eliminate stigma, but obviously it is not a perfect world so we have to do as much as possible to reduce. Many of these will be explored and discussed in more detail over the next day and a half.

Firstly education, educating the community on mental illness, both at school and in the wider community settings, is an effective way of increasing awareness and changing the negative attitudes. It is important for people to learn to think about mental illness in the same way as they think about other illnesses or conditions. Talking openly about mental illness is important, it is surprising how many people who are affected by mental illness or who have a family member with mental illness and are afraid to discuss it openly. The problem should not be swept under the carpet.

Then there is the aspect of quality support in treatment. For people with schizophrenia to participate fully in all areas of community life, it is important to provide high quality support and treatment services and so advocacy groups such as Schizophrenia Ireland need to be pro-active in their fight against the stigma surrounding mental illness both for people with schizophrenia and their families. And then on a personal level, it is important for people with the illness to play an active role in challenging stigma. It is also important for the person with schizophrenia to develop the skills and strategies to cope with the stigmas they face.

And then on the subject of the mass media, the media plays a pervasive role in influencing the public's opinion and when used effectively mass media can inform and educate people on the facts about mental illness. Unfortunately in many cases the media tend to portray people with a mental illness as unpredictable and often violent. As such it is important to keep a check on the media's representation of schizophrenia and to confront where possible and where necessary, those involved if poor practice is observed.

And finally the whole language surrounding schizophrenia, the use of particular words often portrays the idea that people with schizophrenia are somehow undesirable. Labeling someone as schizophrenic suggests their illness defines who they are, because it puts the illness before the person and it also suggests that the illness is life-long and that the symptoms evident in a psychotic episode will always be present. To reduce stigma, a

person with schizophrenia should be referred to just as that, a person who happens to have schizophrenia. As I said, these topics and more will be explored in a lot more detail in some of the sessions over the next day and a half.

Our organization Schizophrenia Ireland has a major role to play in this area and it is very much aware of it's responsibilities and it is facing up to these responsibilities and hosting this event today and tomorrow is part of that programme. I'm nearly finished but before I go I'd like to spend just a few moments and would you please indulge me, I'd like to read a poem which I came across recently. It was written by a young Indian girl and she suffers from schizophrenia and she titles the poem 'Harmony', and she speaks about her state and her state of course is schizophrenia so she uses the word state and she means schizophrenia, and it goes:

The state, which I couldn't understand for long  
Once understood, I always cursed it, abused it  
Blamed it for all wrong to me, tried to pretend  
That I never had it, tried to hide that I ever had it  
Perhaps I would have wasted the rest of my life doing that  
But now such a thing is no more, I have befriended it  
Accepted it as it is and it will be part of my life  
I understand that on no count I can blame it because  
It is the reality, it is the truth, because it has stayed for me  
For a major part of my life, how can I be disrespectful to it?  
Now I have understood that it has subtly given me inspiration  
To fight back  
Perhaps I might have lost years and the prize at which world values you  
But the state has given me an insight, helping me to enjoy things wholly  
I have deep faith that this state has perhaps a purpose in my life  
And to make my life more meaningful and purposeful and  
Hence I have no quarrel with my state  
Rather full respect and friendliness, so I could live in complete peace and harmony.

I'm delighted to welcome Mr. Tim O'Malley, TD, who is the Minister of state at the Department for Health and children and I will ask him in a few moments to officially open the conference.

Mr. O'Malley has special responsibility for mental health, a decision of this government which I warmly welcome and we hope in his course of his tenure, that Minister O'Malley will be able to articulate clearly at government and at government level the many and varied needs of mental health care services and particularly the needs of family members and people with the diagnosis who are using the mental health care services.

**Minister Tim O'Malley T.D. Minister of State at the Department of Health and Children.**

Mr. Chairman, ladies and gentlemen, first of all I just want to thank you Mr. Chairman and Schizophrenia Ireland for asking me here today to open your 13<sup>th</sup> Biennial Conference. I am delighted to be here.

I welcome the opportunity to contribute to this conference, which will focus on stigma. An occasion such as this provides us all with an opportunity to acknowledge and recognize the importance and value of the work of Schizophrenia Ireland, in responding to the needs of the vulnerable and people with schizophrenia and obviously to their carers and their families.

Schizophrenia has traditionally been a hidden illness that people were embarrassed to talk about. I am confident that events like this one here today will assist in breaking down the barriers and go a long way towards a better understanding of the problems surrounding schizophrenia and other mental illnesses.

People with mental illness were excluded for many years from full participation in community life as a result of widespread stigmatization of mental illness. A history of mental illness should never be a cause of discrimination, stigmatization or prejudice in any form, nor should it inhibit an individual's right of access to training, education or employment.

We all know that good mental health is an integral component of general health and well being which allows a person to realize his or her abilities. With a balanced mental disposition, what is more effective in coping with the stresses of life can work productively and fruitfully and is better able to make a positive contribution to his or her community. Thankfully society now recognizes more fully the burden that mental illness places on sufferers and their families. While researchers and clinicians have made important advances in reducing suffering and accompanying disability, the battle against the stigma and social exclusion caused by mental illness is on going. I am very conscious of the importance of fostering an awareness of mental health practices and highlighting the services that are available locally to people particularly in times of crisis. It is in this area that the work of Schizophrenia Ireland is so important. I want to take this opportunity to reemphasize the government's commitment to encourage in anyway it can, the activities of our many voluntary organizations both at national and local levels

**Patrick Corrigan, Professor of Psychiatry (Chicago, USA)**  
**“Addressing the Self – Stigma of Mental Illness”**

Self-stigma is what people do to themselves because they agree with the stigma and they apply it to themselves. In particular I want to talk about three things. One is actually how to deal with self-stigma, so if you are a person with mental illness or you have a friend or a family member with mental illness and they are beating themselves up with it, how to try to change this so that they don't see it as their personal sin.

The second issue is disclosure, a very important issue about mental illness stigma is that in this audience, just because I know this is a Schizophrenia Ireland Conference, I have good reason to bet there is many people here with schizophrenia, but I cannot tell is that mental illness, like being gay, or like religion is a private stigma, you cannot tell unless you decide to come out about it. So one of the important things that people have to decide for themselves is, do you disclose or do you not, and what are some of the decisions about?

Thirdly, I'd like to talk about the best way to beat self-stigma, and this is to increase personal empowerment and there are seven ways that we have come up with which can increase personal empowerment and I want to end the discussion with that.

Let me say that if you have any interest in what we are talking about today, we have summarized it in a book, which I had the privilege of writing with Bob Lundeen and Bob Lundeen is a gentleman who has struggled with schizo-affective disorder for the last twenty years and Bob and I wrote a book called 'Don't call me Nuts, coping with the stigma of Mental Illness', and in particular the book deals less with all these bad examples of mental illness, because we know they are there, and deals more with how to fix it and what I want to talk about today is this issue of how do we try to fix the self-stigma of mental illness?

Let's talk about the pain of it first, and my simple definition of self-stigma is that it's agreeing with the negative attitudes about mental illness and turning them against oneself. Again, let me talk about being an Irish man in America, you may not be aware that at the end of the nineteenth century and the beginning of the twentieth century, being Irish was a hugely stigmatized ethnicity and not so anymore but back then many people were in the closet and embarrassed about it. For me to self-stigmatize, I would first have to be aware of the stigma of Irish men – that they are all drunks, I would have to agree with it, yep they are all drunks, I would have to apply it to myself, therefore I am bad because I'm an Irish man and a drunk and I would have to feel bad about myself and therefore I'm a bad human being.

There are many people with mental illness who say, yep I agree all people who are mentally ill are dangerous, I'm mentally ill so I must be dangerous and therefore I must be a bad person. Here are some of the examples of self-stigma that I have heard over the

years, 'I'm really unable to hold a job, because I'm mentally ill'. 'I'm a danger, I could snap at any minute, I can't handle responsibility' or 'my life is a complete loss.' Mental health providers, psychiatrists and psychologists have taught people with mental illness that for a long time, 'you can't get better, you can't recover, you might as well get used to it, you are going to live in a state hospital for the rest of your entire life'

That is a stigma because firstly it hurts the person and secondly it's a lie. 'And I'm a thoroughly undesirable person, who would want to marry me? 'Anyone can plainly see I'm a misfit and I have a weak personality'. There is a strange phenomenon in the States called 'Talk Radio' where right now we have really moved to the right and there is this view that people are choosing to be mentally ill because they have a weak personality and I always think how silly that is for any of us in the room who has ever experienced depression. Now, could you imagine you choosing to be depressed? But that is sort of the view is that people are weak and have no backbone.

We have actually come up with a scale by which people can tell in themselves whether or not they are self-stigmatizing. We give them these six items, if you are wondering if you are self stigmatizing, you might try it now. I want you to rate the six items on a scale of one to five, where one is highly disagree and five is highly agree.

1. Person's with mental illness are morally weak. (five is highly agree and one is highly disagree).
2. I am morally weak because I have mental illness.
3. Person's with mental illness are dangerous.
4. I am dangerous.
5. Person's with mental illness cannot handle responsibility.
6. I cannot handle responsibility.

The purpose of this measure is to distinguish people who stigmatise against mentally ill versus who stigmatise against themselves. Add up all the even numbers (and to remind you the even numbers are 'I'm morally weak, I'm dangerous, I cannot handle responsibility') are all statements about yourself being bad because you are mentally ill. Add up the odd numbers and that is just about the public as a whole. What you find in a lot of people with mental illness unfortunately is a lot of people with mental illness buy into the stigmas about the mentally ill, that they are bad.

If your score is above a nine on the even side, that would suggest you are beating yourself up somewhat. This is a sort of an easy way, if you are with a group, to identify people who are hurting themselves because they are agreeing with the self-stigma.

Self-stigma has a nasty impact on people, it tends to worsen the course of the disorder. Research suggests that self-stigma all by itself makes schizophrenia worse. So that people with schizophrenia, people with bi-polar disorder, especially people with depression tend to have a worse illness because of self-stigma. It leads to poor self-esteem, to thoughts of 'I am a bad person', it leads to feelings that 'I am not worthy', loss of hope and again the one that I am most concerned about is 'why try'. And to give you a

little sense of my background, in addition to doing work in research on Stigma, I'm a rehab provider in the Chicago area and I have what I consider the 'Big 3'.

- To help people with mental illness get back to what ever kind of job they want
- To get back to whatever kind of housing they want
- To get the kind of relationships they want

And what you find with some people I've had the privilege to work with, they say 'Why try, why should I try to go and get a good job, I am a bad person, I am a weak person, I am an irresponsible person'. And we have to help those people tackle those statements they are making about themselves, so they handle the stigma better.

Let me clear one thing up though, it's that, it's a mistake to assume that because the person is mentally ill, they self-stigmatise. It is wrong to assume because a person is mentally ill, they beat themselves up with stigma. In America there is a famous psychologist – Gordon Allport, who during the first half of the century used to go around saying that if you were black, that there was no way that you couldn't feel bad, because you lived in a culture, the white culture that disrespected you all the time. And so we have this theory that all black people actually have lower self-esteem than white people. Even though this theory was going around for fifty years, somebody finally bothered to test it and asked a bunch of black people and a bunch of white people what they feel about their self-esteem and generally the research suggests that a lot of black people tend to have a higher level of self-esteem than white people. So it is wrong to assume because you are black, you have lower self-esteem or another one in this room is there is a theory, that women would naturally feel inferior to men because they live in a culture where women are viewed that way. Well, if we actually ask women, what you would find is the level of self-esteem in women is not necessarily lower than in men.

And similarly, with people with mental illness, not all people with mental illness have loss of self-esteem for it, not all people feel bad or beat themselves up. In fact my hunch is, the people in the room here with mental illness who are Schizophrenia Ireland people, by desire are somewhat out and have accepted who they are and do not beat themselves up with it.

The interesting thing about understanding self-stigma is why is it that some people with mental illness hurt themselves, have low-self esteem? Other people with mental illness have righteous anger, 'I'm sick and tired of the public disrespecting me and I'm not going to put up with it anymore'. And you can hear that kind of message in the previous session and some people with mental illness are indifferent to the whole thing. If you go back to me, with my Irish heritage, there is some pride in it, but in terms of the stigma I'm sort of indifferent to the whole issue of the stigma of being Irish and so similarly there are a lot of people who are indifferent to the stigma of mental illness. What we've been trying to do is understand is, when self-stigma seems to be bigger and when it seems to be lower.

One is, it depends on the situation the person is in. It's that stigma tends to be worse in some situations than others. For example if you had a Schizophrenia Ireland meeting, my

hunch is the level of schizophrenia you experience and the amount you beat yourself up is down because you are in a place that people are welcoming you to come-out and have no problem with that sort of experience.

If on the other hand as our research suggests you are on a job, somebody earlier talked about the person who is mentally ill being in the closet and did not want to come out. Then that level of self-stigma goes way up because you have to keep it hidden 'boy I must be bad because I have this secret I'm not trying to tell anybody'. So the situation tends to define whether people are likely to more self-stigmatize or not.

The second was legitimacy of the attitudes, whether you as a person with mental illness sit down and say 'you know those attitudes are right, a lot of mentally ill people are dangerous, all you got to do is read the newspaper.' Or, 'you know those attitudes are right, a lot of mentally ill people are lazy or irresponsible'. If you agree with the attitudes, if you think they are legitimate, you are more likely to beat yourself up with the attitudes.

Finally, 'Identification with the group'. And this one, before we did our research, we didn't really know which way would go. Let me ask you, if as a person with mental illness, do you think it is better to say? 'I'm mentally ill and I'm with you guys', or do you think it is better to say 'not me, I don't identify with a group of mentally ill, your turn'.

I'm mentally ill – research clearly says that maybe people are not 'out', but people who identify with the group and people who feel good about the group and people who are proud of the group are less likely to stigmatize and beat themselves up. So, the kind of groups that Schizophrenia Ireland keeps going is the kind of thing that is taking self-stigma away from people. Despite that, there are too many people out there who live in a culture where they beat themselves up with self-stigma and I think what you are going to find tomorrow, I have what I call my Aunt Lillian criteria. Aunt Lillian is an 85 year old lady who worked in the Dual Food Stores all her life and learned everything from T.V. and believed that mentally ill people are basically lazy and shiftless and you know there is no way she could get to 85 years old in my culture and not think that, because everything you see on T.V. and everything you read in the media perpetuates this idea that people with mental illness are lazy or dangerous or morally weak. And so, it is not surprising that a lot of people in this room, a lot of people you know, grew up in a culture where you thought people who are mentally ill are weak and then 'wham' at young adulthood you get schizophrenia and you find out that you are in that group and so you start thinking you are weak.

And so how I wanted to use the remainder of this time is to talk about how we change self-stigma, what are the strategies to try to fix it.

One strategy is just to understand what the myths are about mental illness and what the corresponding realities are. So what I want to talk about is one of the eight lies about

mental illness, for people in the room who think these prejudices are true and what the evidences are against the lies.

The first myth is *'Once crazy, always crazy, people don't get better'*. The public believes that people with schizophrenia doesn't get any better. I'm a Clinical Psychologist and if I based my understanding of mental illness on my practice, I would not think people get better because I only see people when they are really sick, the minute they are doing fine, they are out of the system and they are in the rest of the world. Research would suggest that two out of three people with schizophrenia with the worst illness, will get totally out of the system and live a normal life. And out of that last third of the people, two out of three of them with the services that are provided in the world will do just fine.

Now sometimes people (and I'm not sure where you folks stand) just say that is garbage, people just don't look that good. Well the reality is that about 60% of the people with schizophrenia never get into the mental health system. And the way they do this research is they go out on the street and just stop people on the street and they ask them questions and you find out the rate of schizophrenia is about three times higher than what you would think from the mental health system. So, the reality is not that people always stay crazy (this is false) but many people with the disease are living competent and fine lives, thank you.

*'All persons with mental illness are similar, they are all alike'*. It's just amazing when you go back to hear what people tell you. I once had a doctor tell me (she was a teacher of mine) that she could smell people with mental illness – ridiculous.

The first thing I would say to my students is the first thing you need to learn is that people with mental illness are as different as everybody is. That perhaps if there is 100% of the personality, 1% is defined by the mental illness and the other 99% is their unique part, just as I'm unique from you.

They are rare – I call this the *'Leprosy Myth'*. The 'Leprosy' (being a good Irish Catholic) I learned from the nuns that leprosy was this thing that God did to the bad people, forcing them out of town and it's just this handful of rotten people that had to be out of town where Ben Hur would come at the end of the movie and they would get lightening bolts and they would all get healed. Well, the reality is that mental illness is not rare, in fact one of the things I wanted to say to our colleagues earlier is that I don't think mental illness is special and I think what you want to do with the stigma of mental illness is you want to say it's mundane, it's everywhere, it's all over the place, it's not something weird. Take schizophrenia eight tenths of 1% of the population has schizophrenia, now if my mother were here she would chastise me because you can't see eight tenths of 1%, but if you translate it to an area like Chicago at any one time, 640,000 people have schizophrenia, that's a lot of people and that's just schizophrenia, add to that bi-polar disorder which has about 5 times the rate and major depression which is about 8 times the rate. The rule is that no matter where you are, the fact that there are people

with mental illness in that crowd is much more the rule than the exception, by no means are we a rare group.

How about this one '***people with mental illness are dangerous, one step away from a killing spree***'. Research suggests that people with mental illness beat themselves up with this a lot and the public use it against people all the time. There is a lot of research that has gone out about this and the facts are that people with mental illness are more dangerous than the rest of the population. When they are acutely ill and when they are abusing drugs and alcohol they are about 2 to 4 times more dangerous, but let us put it into perspective, when I'm abusing alcohol, I'm about 2 to 4 times more dangerous than normal also and actually if you want to do a study in this room, if you want to know what the best predictor is of who is dangerous in this room and who is not, it's not those of you with mental illness, it is gender. Gender predicts 7 times better than mental illnesses, so all you men, if you want to check into the psychiatric hospital at the end of the day, I'd be much more accurate on who is dangerous and who is not.

Once study showed that if you had a magic wand and could fix mental illness tomorrow, you would change 3% of the crime rate in the United States, so this dangerousness is trumped up by the media much, much more than it is in reality.

***'People with mental illness can only live in the hospital'*** - obviously false. There is a concern that hospitals are not moving their resources to the community, as we talked about earlier 2/3 of people with mental illness actually live fine on their own.

***'They can't benefit from psychotherapy'*** – you can't talk to a person with mental illness, so don't give me a psychologist because I'm mentally ill because I'm not capable of doing talk therapy – rubbish, people with mental illness can benefit from supportive therapy, talk therapy, peer therapy, family therapy as much as the rest of the population. That does not mean that because they benefit from psychotherapy that we should throw out medication, but it also does not mean that the *'Worried Well'* doesn't benefit from medication, so the lesson is that everybody benefits from some kind of medications perhaps for some illness and more importantly everybody benefits from some sort of psychotherapy or working closely with a counselor or a therapist.

***'If mentally ill people are able to get out of the hospital, they are not capable of doing anything other than working in a 'McDonalds' or working as a janitor'*** – wrong. Firstly we need to realize that the vast majority of the population do work at entry level jobs, whether you are mentally ill or not, a lot of people work at McDonalds, a lot of people work in Kaymarts and stores and there is nothing dishonourable about that. People with mental illness work at higher-level professions at the same rate as the rest of the population. So if lawyers are about 3% of the population and about 3% of people with mental illness are lawyers and if doctors are about 2% of the population then about 2% of people with mental illness are doctors.

Here is a list of famous people – Clifford Biers who is frequently credited for starting the pro-consumer movement in the United States. K. Jameson who is an author. John Nash

– a person with terrible schizophrenia who got the Nobel Prize. Thelonious Monk – a jazz musician, most of these people are Americans, I’m sure it wouldn’t take much for you to come up with a list of Irish or U.K. people who similarly had distinguished themselves in addition to having mental illness.

The last myth is that *‘bad parenting and bad parents caused this whole thing’*, that bad parents, because they were mean or nasty or aloof, caused their children to have serious mental illness. Well, this is as wrong as saying that people with mental illness chose themselves to have this kind of mental illness.

There is some evidence that if you are an abusive mother or father in the sense that you are sexually or physically abusing your kids all through their childhood, that would have a pretty big impact, but that is not, that is not, that is not what we are talking about with schizophrenia. It’s that there is this small percent of people with schizophrenia who have this kind of background. So, this is an obvious myth.

So, I’m saying that self-stigma is an irrational belief that people apply to themselves, take those 8 beliefs that we just went through. Some people tend to agree with those beliefs, RIGHT – I AM WEAK, RIGHT – I AM A LEPPER, RIGHT I AM DANGEROUS and tend to apply it to themselves. And so, the goal is to help them understand how this belief is interfering with them and more important, how to come up with a way to challenge it.

I’m going to make you all psychologists for a minute, this is a cognitive behavioural model of how we think people get depressed or beat themselves up. Take this normal upsetting situation – my girlfriend breaks a date with me. I could have a reasonable reaction to it – I’m not always the best partner in the world, or she had something else to do and I could have sort of momentary feelings like ‘oh Gosh that’s not too bad’, but they’ll go away.

People get depressed when in the course of a normal event like I’m late to a football game, they say ‘what a rotten person I am, I’m always late, I’m lazy, I’m incapable of doing well in the world, see how this is just another example of a moral incompetent I am and that makes us depressed. This is what happens to people who self-stigmatise and like many job interviews the person asks them tough questions and they are done and they say ‘boy the boss asked if I’ve ever had a hard time in school and I said yes – it goes to show you that I’m a bad person, that I’m mentally ill and incompetent and rotten and the like.

And what we want people to do is to try to replace those irrational beliefs, those hurtful beliefs about themselves because they are mentally ill with more reasonable beliefs.

We are more likely to give up irrational beliefs like ‘I am a sinful person because I’m mentally ill’ or ‘I’m incapable of getting married because I was depressed once’. We are more likely to give up those beliefs when we meet with people that we believe are mentors or respected people and they help us challenge it. And so, if I have the privilege of working with a person with mental illness, who is beating themselves up with self-

stigma, I'll ask them, 'you say you are not worthy of dating because you are mentally ill, well who are some mentors in your life, who are important people, who are people who you really think have got it all figured out?' It frequently comes up – pastors, parents, friends, business leaders. And, I want you to go to your pastor and I want you to ask your pastor whether mentally ill people should date because they are bad and I want you to ask your friends whether mentally ill people should date because they are bad. And, what you want them to do is find a group of people that will help challenge that bad thought, that irrational belief, so they can carry it around in the future and next time I see an attractive woman and I want to ask her out and I say to myself 'you are a bad person because you are mentally ill', no, I can counter that with 'well I may have had troubles in the past like everybody else on the planet, but I'm as worthy of asking somebody out as any other male'. It's a very private journey, so it's up to everybody in the world to come up with your own counters, but the idea is that beliefs can be beat up and fought back just as much as they were learnt over the course of time.

One of the ways we do it is the 'I must' paradigm.

I must be dirty, because I keep secrets. I must be weak because I need a therapist. I must be bad because I have to go to the hospital sometimes, that's the irrational belief. Seek out people you know – your friends, your parents, your pastors – people who confide in you about the fact that sometimes they have secrets and they don't think they are dirty or sometimes they have problems and need to talk to a doctor or a friend or a priest and they don't think they are weak. They come up with these counters that help you change your attitudes.

And so the first goal to leave you with is perhaps one of the best ways to change self-stigma is if friends of yours are walking around with attitudes that they are bad because they are mentally ill, you try to help them find some counters to it.

Second issue, should you disclose or not? In America we would say should you come out of the closet or shouldn't you? And the first thing I would say is that this is an extremely difficult decision and there is only one person on earth that can make that and that is the person with mental illness. There may be loved ones and employers etc who have strong opinions about it but if you are trying to decide to come out of the closet, to disclose, the impact is almost entirely on you and you need to be aware of the benefits as well as the difficulties to it.

We always educate people first on what the confidentiality is so they know what their protections are, and it's important to realize what your protections are. In America your protections are from the mental health community so if I am your doctor and you tell me secret things about you, you are fairly strongly protected that I won't go and tell other people. If however as a psychologist, I am your neighbour and I find out that you have problems, there is nothing that prevents me from going around telling people. So, you need to realize that confidentiality only goes so far and only has so much protection.

What are some of the benefits to coming-out. Perhaps the biggest benefit to coming-out and they have done this research on Gay's and Lesbians is you no longer have this hurtful feeling and this anger that you have to be in the closet for something you never did. That not only is it not something you did, it is something, it is a part of you. Now I have black hair with a little grey in it. Why do I have to keep that a secret? It's just part of who I am. You can be more truthful about your life, you don't have to worry about the fact that once in a while you go and see a psychiatrist. Perhaps the other interesting thing is that if you are on the job and you are in the closet, statistically speaking there are about 8 to 10 people in the room here who have a serious mental illness and I would never know it if you didn't come-out. I couldn't benefit from that with my own depression unless I came-out and said 'you know once in a while I get depressed' and you would say 'so do I' and we could lean on each other. You are also promoting your own sense of personal power, I can say what I want and I don't have to keep it a secret. In the United States, we were talking about this at dinner last night, Ireland has the DDA (The Discrimination Disability Act), America has the equivalence called the America with Disabilities Act. It's an Act that not only protects me from being discriminated against because of my psychiatric disability but allows me to get reasonable accommodation and certain supports on the job and so I can come out, I can get that sort of thing.

Finally, I want to say that the best way to deal with stigma is for people with mental illness to come-out. That is what the evidence shows. It's that when you meet a person with mental illness and you find out that they do not have horns and they are not sexually abusing children and their head doesn't spin around and you find out they are just like me. That's the best way to change stigma, and so people who come-out are testimony against stigma.

If I were to be up here and say 'it's easy, everyone should come out', then you should go and get your money back for this conference because clearly coming-out has a lot of risks. One is that unfortunately a lot of people will disapprove. They'll either disapprove of you because you are mentally ill (you weak, moralist person) or they will disapprove of you because you are being politically correct ('here's another person on their high horse about a political correct thing and I generally don't like them'). The second thing is that people probably will gossip, what a juicy little tit bit, Mary over there has been in the hospital. Even if they don't gossip, you will worry about it. Some people might keep you from social gatherings. Unfortunately there are still African-Americans in the city where I live who don't get invited to certain parties because they are black. Some people won't employ you, some people won't rent to you and sometimes even friends and family members get upset. As I said while it's your decision to decide whether you come-out, a lot of times, parents in particular get very upset by it and again I can understand that because as we talked about earlier, family members get beat up by the stigma too. And, some family members just choose not to have all the neighbours and everyone in their business know that their son or daughter has a serious mental illness. And so if you choose to come out then it may have negative impacts on your parents and this is something you need to decide about. So we would suggest that coming-out is a decision, it depends on the situation and you need to decide for yourself, what are the short-term benefits and costs and what are the long-term benefits and costs. Should I come out at

work? Well if I come out at work, the short-term benefit is that I can get reasonable accommodations and I can get some support on the job and I don't feel like I have to keep this in the closet all the time. And the short-term cost is that guy over there who is always talking bad about niggers and spicks is also going to be talking bad about me too and I'm going to be worried about what everybody else is going to be saying. The long-term cost is I might not get a promotion. The long-term benefit is I'm not going to have to worry about coming out again.

We would suggest that based on this assessment everybody can decide for themselves in that situation, one of three options:

1. Yes I will come-out
2. No I won't come-out
3. I'm going to put it off, I still haven't decided, which in essence means no you won't come out

There is a rule about coming-out you need to remember and a very famous supreme court judge in the United States called Errol Warren once said 'it's hard to stop the clanging bell', which is once you are out, it's awfully hard to take it back 'I'm Gay, no I'm not', well everybody now thinks you are. 'I'm mentally ill', no I'm not, only kidding'. It's hard to take it back, so it's something you need to consider. I would also argue that coming-out is not a black or white thing, there is actually five different levels to coming-out. From staying in the closet altogether to broadcasting it on the street, social avoidance – there are so many people with mental illness that are so beaten up by the stigma that they want to stay away from all "normal people", they just only want to hang out with people with mental illness, these are the people we know who do not want to leave the state hospital. I know there are so many things wrong with the state hospitals but unfortunately some people get so used to it and are so afraid of the rest of us that they don't want to come out. It's not a great option but there are some people who just opt to socially avoid altogether. Next option is secrecy – 'I'm going to go and get a job, I'm going to get a job in a law firm, I'm going to get a job in a store, I'm going to get a job in a hospital, but I'm not going to tell anybody'. Again, it has a lot of benefits, I don't have to worry about people disrespecting me, the biggest cost it tends to have is that a lot of people find it very uncomfortable being in the closet. Selective disclosure is I can let some people know but not others. And, this is the one I'm a big booster on, because it's a pretty easy way to find out whether I should let you know or not. What I would do is I would take the gentleman here and he and I would go to the bar and I would say 'did you see on t.v. last night when Sally Field came-out with her Bi-polar disorder, what did you think of that?' And if he goes 'I'm sick and tired of those people coming out all the time', I guess he is not a person I would let know. If on the other hand he says 'You know, I can see it's a tough situation, I know some people like that'. And you say 'well so do I.' And you can work into it, you can find out if somebody is going to beat you up with kind of information or not. Again the good news is if you find a kindred soul, a co-worker, your boss, anybody you can be around that you can let them know about your history, that you don't feel so alone with it, and statistically speaking it's extremely likely that either they have a mental illness themselves or they know somebody closely who

does. And so you have a partner in this thing that you are choosing to keep selectively secret.

Indiscriminate disclose is you don't care who knows. If anybody asks, you are going to let them know. If you have to go and see the psychiatrist, you say 'I'm going to see the psychiatrist'. They say 'what is that funny little pill you are taking', 'that's a pill I take because I get depressed sometimes'. 'Why is your diet so strange?' 'Because I'm on medication and I have to watch what I eat'.

You don't care to keep it secret, you are not necessarily flying it up the flagpole but you are not hiding it anymore. Broadcasting your experience is what we in America would call 'coming-out flaming', which is you want everybody to know, there is a pride to it. Not only is it nothing I did wrong, but it's something that's a part of me and it's nothing that I should be ashamed of.

Again, these are five different options. The nice thing about it is that if people are uncertain about coming out, we would caution people (and I never liked number 1 as an option) to work at No. 2 or 3 of the scale and work down. Because as I said before it is really hard to take it back, once you have come-out.

Now, if you are a person who wants to go right out, and you have decided it's your choice and it may all turn out well for you.

Let me end by talking about beating self-stigma, by looking at empowerment. I believe in Ireland like in the United States, empowerment is a huge issue. I've been practicing in mental health for about 20 years and we have gone from the time 'the doctor knows best and I make all the decisions' to 'client knows best and they can decide to hire me for any or all of my services' and we are in this position now that all the power for people's services should rest with the person with mental illness and any other loved one that they want involved. So, I believe that if you are having some sense of empowerment, you are less likely to be beating yourself up with self-stigma. So, anything that boosts empowerment, decreases self-stigma. The consumer movement (users and carers/family members) has been the big boosters behind empowerment.

There are several different ways to improve empowerment. One way is to move the whole system from non-compliance to collaboration. A few years back the system was 'you do what the doctor says and if you don't you are not being compliant'. And, we realized that even if we have the truth which is a hit and miss kind of thing and we are???? with you on an issue, if we are forcing it down your throat and you don't even want to take the medication, and a lot of people wont because they don't like to be forced into that kind of thing. So, we need to move from this issue where people are being non-compliant to where people are collaborating with doctors.

I would argue that's even not far enough, that if the system could financially afford it, we should move from collaboration, which sounds like we are equals, to more where the consumer is driving the ship, that we are being hired by them. Now again, some people

would say that is political bull\*\*\*\*, that these are people with mental illness and they don't know any better and that you have to have a doctor to tell them what to do. Well the reality is that no matter how much power I have, except for the little bit of time when I can lock you up, the consumer has all the power over the relationship, and if I am stuffing things down people's throat, they will just opt not to do it and they'll just not come back. So, if I'm not partnering with the person and working for them, then what I'm doing for them is going to go for nothing.

A second issue and these seems like old hat 'Consumer Satisfaction' (and I hope it is old hat), in the United States up until about 10 years ago, nobody ever cared whether the consumer liked their treatment, which is kind of weird, it would be like opening a 'McDonalds' and nobody cares whether you like the food. Well, the difference is that system, at least in the States is that people didn't have a lot of choice about it and so nobody cared about whether they liked medication and all the side effects they were getting and if they liked being locked up in a hospital that was 50 miles away from their family and if they liked their parents being told that they caused all of this. Now, at least there is a desire and principle (although I think some systems are better than others) that the person that should be most satisfied, who you care most about, is not the doctors (which is the way the system used to be), it used to be whether I thought it was a good idea and satisfying, it should be whether the consumers are satisfied, which for us are the people with mental illness and their families.

There are Lodges and Clubhouses, Psycho-social Clubhouses are programmes that are run for people with mental illness by people with mental illness. Lodges are housing situations like that, there are a few of these in the United States, they have not taken off as well as they could. But, the whole idea is that the people that should be running them are the people that are living there.

There is a community treatment called Supported Employment and I'm here to say I'm a huge booster in supported employment. Supported Employment means that just like people in wheelchairs, people with mental illness should work wherever they are qualified to, because of their intellectual abilities. So, if a person with mental illness has been to law school and wants to be a lawyer, they should. If a person with mental illness has been through college and they want to go to law school and then be a lawyer, they should. And, the idea of Supported Employment is, it is up to me to work for them, to provide the job coaching and the on-board interventions, so they have the power to do this.

You know I am a good intentioned person, I think, but I'm still not a consumer and if you really want to change the system around you need to move in addition to good-intentioned people providing services, to consumers providing services for themselves. So, there is a big movement in the United States to hire consumers for jobs in which they are capable of, so if they are psychiatrists (and there are consumers in the States who are psychiatrists) – hire them for that.

Many people in the room here could service what we would call Case Managers or Job Coaches. What kind of special education do you necessarily need to go on the job and provide the kind of support to keep a consumer on that job?

There are self-help programmes, I heard them talking earlier about GROW and I just had the privilege of finishing a four year study of GROW in Illinois, as you know GROW is big in Ireland, big in Australia and big in Illinois. The interesting thing about GROW is it's a programme designed entirely for people with mental illness by people with mental illness. Self-help, as GROWers frequently teach me is a bad word, because self-help sort of sounds like everyone is in it for themselves and actually the power in GROW comes from mutual help. It's not only from me getting help from you but from me being able to help you. And, perhaps one of the highest level of services, one that we are struggling with in the States is to turning things more over to consumer-operated services.

Finally – Research, there is a lot of power in research, I say that not only because I'm a researcher but I because Government officials come to me and say 'what is the best way to do this, what does the research say?' And I say 'the best thing the research says is lock them all up in the hospital' or 'the best thing the research says is do electric shock therapy on everybody' (and you may laugh at those previous two) or 'the best thing it says is and this is a huge issue in the States now is mandated treatment', this is where (regardless of what you think you knew) you can go to court and get the court to decide what you need. So, researchers are one group who the policy makers come to and there is nothing about research (maybe there is a little bit about statistics) that Schizophrenia Ireland could not get involved in, hence this idea of participatory action research. We have just finished a 22 million dollar study in the United States, where half the people there were consumers and half the people on my project were \*Growers and they have a very different perspective on this and the reason why it's important to have them there is that research is not objective, research is political. When I start off with a project I start out to prove something, I prove medication works or I prove GROW works or I prove that consumers can be just as good a provider as somebody else or I prove that parents didn't cause the whole thing. So, it's a political agenda and there is no reason why people from Schizophrenia Ireland couldn't join in that political agenda as much as anybody else.

So, another way to help people with self-stigma is to build up their sense of power. This is not meant to be a complete list, this is meant to be a list of some of the ways to help people build that power.

I want to end with a point I made earlier – who's problem is it anyway? I most clearly am saying that Schizophrenia Ireland should not say 'you know who's problem it is? It's all those mentally ill people and they should learn how to live with stigma'. Well the racial problem in the United States is everyone's problem, whites and black's, the gender issues is men's problem as much as it is women's problems and the mental illness problem is that we should not just look to the mentally ill to fix their problem of stigma, we should be unhappy with it and try to change the public's view.

\* *Worried Well* – people who would attend counseling or psychotherapy because of an issue or problem in their life rather than because they have a mental illness.

\* *Growers* – People who attend the *GROW Programme* of personal growth. This caring and sharing community has been developed from the findings of former mental sufferers in the course of rebuilding their lives after mental breakdowns.

## **Stigma- Breaking Down The Barriers – Brendan Kenny**

As part of the S.I conference people with an experience of a mental illness explored the issue of stigma and how it impacted upon their lives.

There were three broad areas in which we explored the issues.

How does it feel to experience stigma?

How did you manage? Practical implications work/ hospital/ home, coping skills.

What can be done in society to eliminate stigma for people with an experience of a mental illness?.

We want to share our experience and to also develop a better understanding of other peoples' experiences which will hopefully bring about change.

Although every experience is unique to the individual it is useful to see if there are any experiences in common.

### **a) How it feels to experience stigma?**

Before developing the illness I had some negative attitudes to people with mental illness so am now very aware of how others including old friends may perceive people with mental illness including me.

After being hospitalised I did not want anyone to know that I had been hospitalised with a mental illness, there was an overwhelming sense of shame a feeling of being flawed.

Before my illness there was no experience of mental illness within the family so the focus was on being strong and fit.

There is a feeling of such low self-esteem of being worthless and due to my young age I had little experience of life and didn't feel able for the world.

I know that the illness is a vulnerability, rather than a weakness but other people have perceptions of why people develop a mental illness.

### **Language**

The language surrounding mental illness in the public domain is often derogatory and reinforces the stigma felt by people experiencing a mental illness. In other areas of life there have been improvements but mental illness is still portrayed in a negative manner.

Media, especially the tabloids perpetuate the negative stereotypes in mental illness, which has a devastating effect on people who have experienced mental illness.

It is hurtful that if someone with a mental illness commits a crime that the illness is linked with the crime, most crimes are committed by people without an illness, but this does not impact negatively on everyone without a mental illness.

When someone with schizophrenia is involved in a crime - feel that they are letting the side down because it will reinforce the myth that people with schizophrenia have a propensity to be violent.

People with mental illness are usually portrayed in a very negative light in films and in television programmes.

### **Family**

Family stigma will depend on the attitudes within the family, negative attitudes held within the family can be reflected back on the person with schizophrenia and can further lower self esteem. Some people find it easier to challenge the attitudes of family members and feel that one can agree or disagree with family members.

There is awareness for a person who has been hospitalised with a mental illness that there is stigma on the family.

It is very important that the family must understand the illness.

### **Social**

For some time before the illness spent long periods of time on my own was a loner. Isolated from friends during the onset of the illness and following the illness don't socialise very much.

It is not easy to break into new group and feel included.

Fear that people will have the same attitudes as me before illness.

There is also the dilemma when do you say it?

Fear of rejection

Tend to have couple of close friends

Family very very important

Some people that I met with mental illness I've moved on from now.

### **b) How did you manage? Practical implications social work, hospitals, home.**

Although it is often very difficult to get out of bed- don't use the bed as a crutch (yes it is very difficult!!).

Take interest in life and join in activities.

It is good to talk about the illness with people you feel that you can trust.

Always focus on recovery

It is important to have an advisor/ confidante – someone that you can trust to talk about feelings and any problems that you are experiencing.

Learn as much as you can about the illness, but timing is also important as the literature on schizophrenia covers all types of experience it is easy to see oneself everywhere, having all of the symptoms. Actually the severity in symptoms varies and some symptoms are transient. Illness is fluid it is continually changing, with different underlying trends.

Training programme with skills training and personal development are very important. Confidence building, assertiveness and raising self-esteem are very important. And it is also important to realise like everyone with or without an illness have to continually work upon social skills.

It is useful to secure a job that you feel is not too stressful

Support groups are?

Good to go out and socialise but should not go out under pressure.

It is very important to have a trusting relationship with your doctor and if you are feeling unwell that the doctor is accessible.

## **C) Society**

### Education

Education is the key for change and this includes education of

Self

Family

Public

Media/ Positive (through media adults are educated)

Schools transition year.

It is important that people with an experience of a mental illness are involved in education programmes.

### Employment

Employers are concerned that people with mental illness will be hospitalised and take time off, but this is discrimination, how can we predict the future? Who will need sick time, maternity leave, paternity leave etc.

### Lobbying

Other interest groups are a lot more organised than groups involved in mental health/illness and have created positive changes

Organisations working in the area of mental health need to be more active in promoting the rights of people with a mental illness.

### Language

The language in use surrounding mental illness needs to be challenged; derogatory language about other illness it is not tolerated so why is it tolerated in mental illness?

## 2<sup>nd</sup> Day

### **Kevin Jones, Chairperson of Schizophrenia Ireland**

Apologies for the slight delay on the 2<sup>nd</sup> day, it is always a problem to get everyone together and some others will be joining us as soon as they finish breakfast so welcome to everyone on the 2<sup>nd</sup> day of our Conference especially those who are joining today. I am very aware that there are people here who are joining the Conference for the first time this morning and if today and today's sessions can be judged on the sessions yesterday we are in for a very informative day. Yesterday went off very well, some very interesting sessions and today promises to be just as interesting. Some housekeeping rules in the unlikely event of a fire or any other such emergency please proceed to one of the exits you have some on your left, quite a lot of them and also on your right, follow me. Secondly there is a no smoking policy in and around the Conference areas so please adhere to that. Thirdly the mobile phones, yesterday we had the fifteen second wait while everyone took their phones out of their pockets so we will do the same again today. It is a full schedule today and we have to make up a few minutes, which we will do as we want to promptly finish at 4pm for people to get home in time. Please be prompt in returning from coffee breaks etc. so that's it

I am delighted to have the newly appointed Chief Executive Officer of the South Eastern Health Board, Pat McLoughlin here this morning.

### **Pat McLoughlin, Chief Executive Officer, South Eastern Health Board.**

I used to be told that the afternoon session was the graveyard session for speakers but I think Saturday morning in Kilkenny after a good night will make a good second. You are all welcome to the South East, we are delighted you are having your Conference here and it is a very very important issue, because the issue of stigma is very very real and I think all of us on the front line, and I include Managers in the front line, I know some people might not agree but I believe we are the front line and there is very real stigma and we notice that in relation to a number of groups who have difficulties in accessing services, so certainly I can say that as CEO of the Health Board I am extremely interested in hearing the outcomes and what we can do and what the international perspective on it is.

I think it is clear that SI need to have a very firm advocacy role and I think there are such significant vested interests in relation to all aspects of health services it is extremely important that all the Health Boards and health agencies work very closely with yourselves in that advocacy role, because there is no doubt that mental health services have not got their fair share of resources over the years and I note the good work that you are doing in relation to counseling, information, Helpline and the Jobclub and I am delighted that the South East have developed a Regional office and I would like to say that we will continue to support and develop that in the next number of years.

There have been significant improvements in relation to mental health services and that is first thing I would like to acknowledge. We have had a significant reduction in the number of patients in our large mental health institutions. In 1996 there were 5005, there

are now 3817. It is still far too many but I will come back to that issue later. We now have 407 community residences, that was in 2001 and there are now 3077 patients living in the community. There have been significant developments in old age psychiatry, child and adolescent psychiatry however I do believe that general adult psychiatry needs attention.

If one examines the various reports that have been issued and in particular the Inspector of Mental Hospitals reports the admission rates show that the highest board is more than double the lowest, so there are very significant differences in admission rates across the country in our mental health services. The number of people resident in our mental health institutions also the range is from .62 per 100,000 population to 1.52, very very significant differences in the style of practice and in the availability of services. In relation to community residential services there is 61 in the lowest board per 100,000 population to 144 per 100,000 population, so again very great differences. Outpatient attendances, which you would think would have a reasonable degree of comparison, again the highest is almost double the lowest.

I have decided to pick up on some of the themes that were mentioned in the earlier session with the media. I actually would have liked to be on the platform with them to challenge and debate issues and I had planned to do it from the floor, but there were so many people trying to get in and I felt I had my own slot. I don't mind debating in public some of the issues that were raised, I do think that debate is healthy.

They did raise the issue of prisoners and that is an issue I have particular interest in, because I have always felt that the people who are on the lowest rung generally have the weakest access to services and recent studies do show that in prison 50% of males are in need of treatment, that aren't in receipt of them and 75% of females. Now I am glad to say that a group has been established comprising of the Department of Health & Children, Department of Justice, Equality and Law Reform, the Health Boards and the Irish Prison Service. I chair that group nationally and our intention is to try and improve the lot for prisoners and that is both mental health services and their general health and well-being.

I would like to deal with the issue of accommodation because there needed to be a lot of realism injected into the yesterday's debate in relation to accommodation. If Fergal Bowers thinks it is as easy as to knock on doors and say we would like to bring a service to your area and to say that the expectation would be that people would say "oh that's great we have been looking for a hostel or community residence for years", that is not reality. The reality is that it is extremely difficult to get services established in communities. For about two years of the past six years I was responsible for services for people with a drug addiction which is a chronic relapsing illness in the eastern region and I can tell you if we just didn't just go in, select and then negotiate, there would be a lot more people dead today from addiction because that is the reality of dealing with it. I do believe, and there were issues raised here yesterday in relation to selection of accommodation, that the Health Boards have to be careful in how they select accommodation, they cannot put too many residences and too many facilities for groups

who have difficulties in the same area and I do think that they have to be accountable for that and we are accountable in public arena at our Board meetings each month for that. My attitude to this is that we have to do this very carefully make sure that we do it right. We should, in my opinion, discuss how it should be done and not whether, because as far as I am concerned patients have rights and they have rights to services in the community. If Managers in the Health services and Clinicians and Carers and Advocacy groups aren't as one on this, well I think we will be left with the present system where might is right. I do believe we have a duty to liaise with the community, I do believe we have a duty to run these places properly, I don't condone where they are not run properly but as to whether they should be in the community, well then as far as I am concerned I have a very different view from the media on it. I would ask Fergal to link up with the Northern Area Health Board and discuss exactly what happened in Swords as I think it will bring a different perspective to him. I would like to compliment the Chairperson of that Board, Ann Devitt, who is a local politician, who went on, at political risk, and challenged what went on in that community. Things have settled down and are going well. Often it is fear and it is fear that needs to be addressed by the service providers. There was a very interesting point made yesterday by Fintan O'Toole in relation to the power that the Health Boards might have in relation to media. He raised the Mary Ellen Synon issue, it is not something the Health Boards have used as a weapon in the past, although we could have and there is probably no weekend that a Sunday paper isn't produced, that there isn't wrong information given out, as there has been in the past few weeks in relation to the South East, where journalists didn't even bother checking their facts with us. I think if we constantly used the weapon of advertising I think we would face serious difficulties. I think it is something that the Health Boards were very concerned with, having discussed it with voluntary organizations as a result of that report. But let us not forget that public service bodies, the Health Board at that stage, were criticized because the attitude was that it was the private sector and media and private taxation that was keeping public services funded, and bodies like ourselves funded. So this isn't necessarily a one-way approach. I hope that we would work much more with the media in trying to have a balanced view. In relation to that, I would just like to say we have no difficulty, as far as I am concerned, with local media. I personally have no difficulty with local media. I do believe they give issues time and it is up to us as Managers and as clinicians to debate those issues and to deal with the real concerns in the community. I think the national media is varied in terms of the communication, the tabloid is the tabloid and it is sensational and that is what drives it.

I see a lot of challenges for the future in relation to the provision of mental health care services and I will outline some of those now.

- Primary care needs a greater role and greater attention. There is still not an adequate integrated primary care service for people with mental illness and I would hope that with the establishment of the primary care teams that this would change.
- It is clear to me from the Inspector of Mental Hospitals Report that there is a need for an immediate clinical assessment prior to people being admitted to mental health institutions.

- I believe we need to examine the whole structure of how we provide services. There are certainly undoubted benefits to the catchment system but we still have a very underdeveloped sub specialist system in terms of rehabilitation, in terms of addiction and in terms of other services at a clinical level.
- I believe that there is a lot of evidence that our mental health services are not accessible to young people and I think we need to take a serious look at this and particularly so in the light of the number of suicides and the extent that people do not have contact with services. We have got to make our services much more accessible and accessible in the context of where some of our services are still on the sites of old Victorian buildings and simply not accessible in terms of how young people and people see them. So change is going to be needed in that.
- I think your own surveys have shown very interesting differences and regional differences and it is something I have had an interest in. We are supposed to have an equitable service, it is clear that there isn't an equitable distribution of services across the regions. Your own surveys show a different level of access for counseling, employment training, creative therapy and indeed the skill mix.
- Our buildings also need a very serious examination.

I am glad to say that, not as a result of today, I do have a determination to try and resolve some of the issues in relation to mental health services in the South east and at the first Board meeting that I took in October, I announced that I was taking a complete fundamental look at our mental health services. I am simply not happy with the quality of accommodation that people have here and the access to skill mix and other services. So the terms of reference for the review will be coming before the Board in December and it is my intention to move rapidly in relation to that.

It is going to be consultative. I want to get the views of patients, voluntary organizations like yourselves, staff and advocacy groups. I am determined that we will use the facilities which we have, which are considerable buildings and assets such as land, that we will use that as the means of driving forward a comprehensive programme in the South East.

That is all I propose to say at this stage. I wish you well and I hope that the rest of the day goes well. I thoroughly enjoyed yesterday, the part that I could attend, and again I would like to thank you for giving me the opportunity to speak on these issues.

**John Saunders Director of Schizophrenia Ireland.**

Good Morning, thank you Pat for taking the time to introduce today's proceedings. Just a few words to notice for you the Mount Southwell Social Club in Letterkenny, Donegal have kindly agreed to come down this weekend and are displaying artwork they have been developing over time. If people want to visit the exhibition it is in the Art Suite which is upstairs on the 1<sup>st</sup> floor and is for sale, it is well worth a visit. A private message

for members of Council of SI, there is a Council meeting scheduled for 1pm in the Chestnut Suite.

Without further ado I want to continue the programme for today. I was in the North of Ireland a few months ago, I was kindly invited to a meeting of Rethink of Northern Ireland and in the course of the day Ann Donnelly who is on your programme and I decide we had to have Ann down here for our Conference because it certainly was very inspiring and thought provoking presentation. So we scrambled very quickly when we went back to Dublin and asked Ann and she very kindly came down last night so she didn't get yesterday's session. So without further ado I would like to ask Ann to speak to you and then we will continue with the session proper with Donncha O'Connell.

### Ann Donnelly Rethink Northern Ireland.

Back in the 3<sup>rd</sup> century BC a Greek mathematician Pythagoras first put forward the theory that the earth was a sphere rotating on its own axis. The idea was a wee bit ahead of its time. For centuries afterwards, people still insisted that the world was flat. From the time Columbus sailed the ocean, the opinion was still divided. Although Columbus himself was pretty sure that the world was round, he just wasn't very sure about the distance between where he was and where he wanted to be. That is why instead of sailing around the world he discovered America.

For centuries scholars had debated the existence of a huge landmass on the opposite side of the globe. The name they gave it was Antipodes meaning people who walk with their head on the ground and their toes in the air. What was the largest island in the world before Australia was discovered? Australia, it just wasn't called that then. It was just a vague idea visited by some passing Chinese and happened upon by some Dutch sailors. They were way off course. They called it New Holland, but New Holland, Australia, Antibes they are just names for the same place aren't they; they don't change it, or do they?

The Aboriginal inhabitants of that part of the world have a different reckoning of the power of words. They believe that the land is shaped by song lines, every step that they take they describe what they see noting and naming land marks they see along the way. They believe that their world is held together through the creative power of words. According to the Old Testament "in the beginning was the word and word was God" God was the master namer and the creator of heaven and earth making things come into being by just giving them a name. Throughout centuries witches and wizards have cured and cursed through the power of spells, from the word shpeel meaning stories, sentences, words. You have all heard of stories of witch doctors who only had to point a finger and the person went off and died. So "sticks and stones may break my bones but words" what will words do to me?

There have been experiments conducted in schools in America where children who were very very intelligent, were told they were stupid, and children with low intelligent levels, were told they were very clever. Yet when it came to the exams people conformed to

what they had been told they could do, so the clever children who thought they were dumb did really badly and their slower contemporaries outshone them in academic results. So is it true then a rose by any other name would smell as sweet. What is in a name.

What do we do by naming something? A name clarifies and classifies, puts things into a category. That is okay for a rock, if I call a rock, a rock it doesn't change what it is, does it, but what about an individual, if you call me a failure what does that do to me? Maybe the first time, I can brush it off but if you keep persistently calling me, it is not very pleasant, it could stick, it could attach itself to some idea I have about my own abilities and if you keep calling me that over and over and over, there is a chance I could become what I am named.

So what effect does diagnosis have then in the case of severe mental illness? It is intended primarily to enable the person to seek appropriate help, but it has immediate repercussions. It bestows a new name, puts the individual into a new category. Lets simulate the response of a person who has just received such a diagnosis. Watch closely.....

There was a lot going on there but it was underneath the surface so I will do you an action replay in slow motion enhancing the underlying emotions.....

So clearly the individual is a little bit upset, what would make them feel that way? How would you feel to be treated like a loser, how would you feel to be pushed to the margins of society, how would you feel to lose your mind, lose your voice and lose your self respect all in one go.

A diagnosis is just a sentence, but it is a life sentence. Up until recent years it also represented a list of, you can't do this, and you will never be that. The name of the illness comes between you and me, between lovers, between friends and family, between an individual and the rest of the world. While some are working on a chemical miracle which addresses the symptoms of the illness, others will have to deal with the consequences.

The name of the illness, it is just a mask, a disguise, underneath the same face, the same body, the same person with all the lies and misunderstandings and superstitions and the burden of all those fallacies from all the centuries, descends on the shoulders the inheritance of everyone who is called mentally ill.

I found a Chinese poem which sums it up

The North Sea King was called 'act in a flash',  
The South Sea King was called 'act on a hunch',  
The King of the place in between was called 'no-form'

Now North Sea King and South Sea King used to go together often to the land of 'no form'. He treated them well so they consulted together, they thought up a good turn, a favour, for their friend 'no turn' in token of their appreciation. Men they said have seven openings for eating, seeing, hearing, breathing and so on. 'no form' has no openings so let us make him some holes so they made holes in 'no form', one a day for seven days, and at the end of the seventh day their friend lay dead.

The motto of the story is to organize is to destroy 'no form' into 'conform', squeeze the life clean out of him. As with an individual who stands small and powerless in the face of so many words, words of prejudice and ignorance, words of history and precedent, words of expertise and diagnosis. Before we attempt to fix our fellow men perhaps we should remember the words of Mark Twain, he said "to someone who wants to use a hammer badly, a lot of things look like nails that need hammering". Maybe it is time we stopped trying to make individuals fit into society and started to make society fit for us all as individuals. A person with severe mental illness goes to the Doctor he says

Doctor, I am worried about society.

What is the matter with it?

It has delusions, it thinks that I am without value and dangerous.

How does it say this to you?

Through the mass media, through TV and newspapers and films. It keeps perpetuating myths and misunderstandings about me.

I see.

It is paranoid, keeps looking at me as if I'm about to lash out as if I am dangerous and up to no good.

I see.

And then there is the social withdrawal, people are shunning me for no good reason.

I see.

The worse bit of all Doctor is the inappropriate emotions, it laughs at me when I am in pain when I don't feel well, that is hardly right is it?

Indeed.

What is the matter with it Doctor?

It is probably just going through a phase, if this persists doesn't work come back and we will talk about it.

Time passes

Well Doctor, any word, what word would you give it? I am not a patient person, I am an impatient person why are so many people are pushed aside undervalued, made little of? Is illness the excuse, is there ever any excuse?

There is a really amazing programme on channel 4 called 'Faking it' where ordinary people members of the public lifted out of their lives and made into something that is the opposite of themselves. A burger flipper, becomes a chef, a shy gay man becomes a butch bouncer, a ex soldier becomes a drag queen. With a wee bit of expertise and some coaching these people can totally transform themselves and in a few short weeks they have to pass themselves off in front of a panel of experts, set to spot the fake. Do you know what the amazing thing is, most of them succeed in fooling the panel. They have managed to totally change their lives. And what is even more amazing is that they go on

to be inspired by the experience and change forever, they have a new feeling of what their abilities are, an idea of what they can achieve, a new feeling about the power they have to change their lives.

Imagine what it would be like if people with severe mental illness were given an opportunity like that, a chance to move themselves from the fixed position in which society has placed them. Imagine it. A new prescription it might go something like this.

- Understanding , liberal doses, available on demand,
- a solution of acceptance washed down with respect to counteract all those years of swallowing bitter disappointment.
- Reconstructive surgery to replace lost goals and ambitions,
- vocal training would follow to enable the individual to regain a sense of confidence and communicate their ideas effectively,
- strong back support would be needed to keep the individuals head held high,
- cognitive therapy would teach the individual that their value as a human being doesn't depend on health or ill health.

What they would learn is that no matter how ill they become, they always had and always will have equal rights and equal value. We still have to deal with those unpleasant negative symptoms, those voices calling the individual with mental ill health a loser, a freak, treating them like an outcast. There is a massive campaign to inoculate the public against the spread of this type of symptom. Early experiments in schools and offices have proved very very successful. We are using information to immunize the population against ignorance and bigotry, the two great plagues of our time. Lethargy is a problem, people who developed hardened attitudes towards mental ill health should be treated gently but firmly. You know these problems didn't just appear just overnight, it took years to get them to this stage of severity. It might take them quite some time to get them fully under control but there is a new pill on the market now, it is called hope and has been under wraps for years but now has become freely available and I feel this will have a big part to play in bringing about a full recovery. That is the name we are giving to this journey, a journey which seeks to reclaim territories on the map of human experience where previously it was written 'here be dragons'.

When those early explorers set off, they had very little idea about where they were trying to get to. What they discovered had in fact always been there, they were just looking at it with fresh eyes. So in the struggle to map the territory of human existence, let us not colonize and abuse the inhabitants of the lands that we find. Rumour that some of them came there by accident rather than by design and some of them have had enough of living in the wilderness and would like to move on to more favorable climes, where life is a bit more hospitable and easier for human beings.

So now we all know where we are going, lets set sail. Recovery, it is an idea whose time has come.

**John Saunders- SI**

Thank you Ann. Without further ado can I ask Donncha O’Connell to come to the stage. Donncha is our chairperson for the 1<sup>st</sup> session. Donncha is a friend of SI working with University College Galway in the Law Department. He is a former Director of the Irish Council for Civil Liberties and in that role has worked with Schizophrenia Ireland so I hand you over to Donncha.

**Donncha O’Connell, Lecturer in Law, National University of Ireland, Galway.**

Thanks very much John, Ladies and Gentlemen. The next session I am not going to spend much time introducing because I think it is more important to hear the speakers and have a good question and answer session but we have tried to balance the panel. You are going to hear from two lawyers and from two human beings. The lawyers might be able to tell you something about stigma.

I should qualify that by saying of course to say that one of the lawyers Tom Cooney is in fact a great human being and someone it gives me great pleasure to introduce as a speaker because he ran the Irish Council for Civil Liberties for years in a voluntary capacity, long before I ever got to work for that organization for a salary and I had acute insight into what he and others did for very many lonely years campaigning for issues stretching from mental health concerns, gay & lesbian rights issues to issues to do with police accountability and the traveler community, very very broad range of issues and it is certainly great to have Tom here today to talk as a long time campaigner and advocate as well as a passionate scholar on legal issues, as they affect people who use mental health services and people with mental illness.

It is also great to introduce the two others speakers on the panel today, they will be coming before Tom, Paddy McGowan and Mervyn Tierney from the Irish Advocacy Network. I have known Paddy for a number of years and he is a really great guy and a really excellent speaker and a very consistent advocate and a very consistent advocate of advocacy, which I think is a hugely important issue in this country at this point in time. He is from Omagh and is now the Director of Advocacy for the Irish Advocacy Network. Mervyn Tierney is from Cork but has emigrated to Monaghan, which I think for a Cork person is quite some distance but I think he is doing very well up there and he seems to be happy and has made the adjustment. He is also from the Irish Advocacy Network and he is going to be doing a joint presentation with Paddy. So if Paddy, Mervyn and Tom could come up to the platform and we will start with Paddy McGowan. Thanks very much.

**Paddy McGowan – Irish Advocacy Network. – “Stigma – A User Perspective”**

Good morning.

I would like to start by thanking SI for inviting us along to this conference and I would also like to thank Ann for that presentation. It was the right way to start and it has left us with a hard task to follow. Just while I was listening to her, it reminded me of something I heard years ago, I can't remember by who, we were talking about mental illness someone said to me "they said I was mad, I said they were mad, God damn it they all ganged up on me".

The Collins dictionary definition of stigma is a distinguishing mark of a social disgrace. What does stigma represent, shame, disgrace, dishonor. Stigma has in the last few decades become a buzzword and we who are involved in the mental health field have tried to tackle the subject. We have failed, we simply spent our energy largely talking to ourselves and in many ways have excluded the very people for whom stigma is part and parcel of their everyday life. We have had good intentions, our hearts were in the right place. We have unwittingly fed more fuel to the fire by using the language of madness. When we use terms like schizophrenia, manic depression, personality disorder, high support hostels, institutionalized care, chemical imbalances, genetics, non-compliance the list goes on. These words strike fear into the very heart of society, and in the process make prisoners of the very people they are attached to.

We take it a step further by reinforcing to people that they are different. We educate them to become stigmatized and to be good patients. If we take people and separate them from their families and communities, by placing them in institutions regardless if its one of the old type psychiatric hospitals or indeed one of the new institutions attached to general hospitals, we are breeding stigma. If our thinking has not developed past the mind set of our forefathers, who were the guiding influence on designing stigma and the need for exclusion. No doubt they had good intentions, unfortunately we now live with the legacy.

It could be argued that stigma has been created out of need. Right from our early days psychiatry struggled to be part of the medical science family and in many ways still does to this day. We are still the Cinderella of medicine and within health services. By having to justify its existence, it had to be imaginative in creating the need. It became involved in moral and social control. It became a tool of the government and society and was armed with legislation and the right to disregard peoples' civil and human rights. We undertook probably one of the largest building programmes in this country to date, right across the 32 counties and in a relatively short space of time, given the tools and machinery available at that time. We filled these institutions with people with no thought of care but with the emphasis on containment. We equipped staff with no training, we gave them uniforms that resembled that of prison officers, and keys on long chains. We called male staff 'keepers' and female staff 'nurses'. We used some of the most barbaric procedures and called them treatments.

One of the first institutions in England was the house of Bethlam, hence the saying there is bedlam here, where on Saturday the upper classes of society used to pay to view the inmates in their despair and then would come out and remark that these people were no better than animals. They behaved in the same manner. Is it any wonder when we treated them like animals and that was in the early 1600s, and just as a matter of interest in the

year 1620 the first user led advocacy group was formed by the inmates and former inmates, so we in the user survivor movement have a long history.

The Board of Management in Bethlam at that time had foresight they were brilliant at marketing madness, they used the visits as a way of selling their product by creating a human zoo, which has now become an industry. We have large pharmaceutical companies now cashing in on the concept of madness. We have medicalised a theory of mental illness and we live with the profits. Everyone who is involved has become rich at the expense of human beings, who are selected to become victims to feed the industry.

So my friends if we are really going to tackle stigma then we must examine ourselves and the role we play in keeping it alive. We will have to think about our beliefs and language and how we treat people with so called mental illness. The media have played their part in hyping up the public to a frenzy to sell their product and to promote stigma as a tool of oppression by the powerful over the most vulnerable amongst us. It has to be eradicated and the only way to do it effectively is by demystifying mental illness, by normalizing the experience of those who are labeled with a mental health diagnosis. When we in society engage honestly in the process of challenging stigma, then and only then, will we break the chains of oppression, which will lead to the liberation of the person and indeed society as a whole. No longer will we condone or accept exclusion, marginalisation of citizens of this land.

History has recorded our past and we now talk about how we have moved on. Have we moved on, or are we living in a psychotic state of mind or a figment of our own imagination, so we can feel comfortable and not have to accept any responsibility for what we all know to be wrong. Things have not changed, some would say things have got worse. We have become experts in the art of spin and illusion. In years to come when historians look at our time, they will no doubt judge us in the same light as our past, and may well record our time as being more inhumane, because we proclaim to have science academia available to us and that we supposedly live in a more technical age. In the whole evolution we have failed to understand the human element, our developments and dare I say it, lost our capacity to relate to people as people and not as someone with a disease.

We need to start to see people where they are and not where we want them to be. Understanding and compassion are the key components for defeating stigma and we can do this together. Thank you.

## **Mervyn Tierney.-Irish Advocacy Network – “Stigma – A User Perspective”**

Good morning

“A civilization is judged on its treatment of its most vulnerable citizens. Citizens in care are no less citizens. Their voices should be heard, their views respected and their interests

defended.” That was a comment on pure advocacy by Edna Conlon in 1989 when she set up Ucamp. That is what the Irish Advocacy Network is all about, hearing the voices, respecting the views and defending the interests.

It is most unusual to stand before you today to speak on stigma, normally myself and Paddy, when we are invited to a conference, have to work out what we are going to say and what we are going to do. But on this occasion we didn't have to do this because what you are hearing this morning, are the views of fellow users and sufferers, through needs assessments we have carried out throughout the country. Every comment that I will pass here this morning, are comments of service users throughout the country.

Basically what I would like to cover over the session is what our friends have to say about stigma. How does it make them feel, who do they say feeds into stigma, what do they say has to be done to reduce it.

From time to time people have said to us, throughout the service there is a total sense of shame and indignity. These are huge words and they feel that if they go that bit further and do one small little thing wrong they become a person of notoriety. They become a person of ill repute, with a reputation, with a bad name and become renowned for the smallest of little things and eventually it is total loss of face and they are easily slandered and easily libeled. So the following comments, as I said, are coming from the individuals.

- First comment – ‘nobody understands, you must go through it yourself to understand.’ Nobody understands, how all inclusive is that comment, actually this individual felt that there was nobody out there who could understand where he was coming from. He went on to say that it knew no boundaries, male, female, professional, ordinary person, it knew no boundaries and that at the end of the day to know exactly what stigma is all about, it had to be a lived experience. You have to actually live the experience to understand what stigma is like.
- Another comment – ‘they say we need a good swift kick in the ass’ don't they. How embarrassed that makes some people, especially if you were 6ft. 2” like myself. It was said to me at 35 years of age and when you were told because all you need is a good swift kick in the ass, all of a sudden you really believe you are responsible for what has happened. A lot of things are completely outside of your own control and when you can do nothing about it, you become ashamed, completely ashamed.
- ‘I have been in hospital and they think I am mad’. They think I am mad and what does this do. It equates the whole situation of institutionalized care as we have it today, in that the hospital itself is the stigmata, it feeds into the system. What has happened over the years is from asylums as they were set up, it has changed. Hospitals in itself is all about stigmatization.

- What do they think of the staff? It is interesting but we have never had to come back to think about it.
- ‘They are afraid of me and I am dangerous’. Again I reiterate these are comments said by people. The whole fear I am a dangerous person they feel they are utterly and completely defamed and they have a bad reputation, as I said before a bad name. It is the process, the process that leads to stigmatization.
- ‘You are mad as one individual said, and it is horribly’ at the names I am being called. This is the next step moving towards resignation, giving up. It is not worth living, you are starting to lose your dignity, every small little bit of dignity that you actually had and you begin to feel worthless and eventually you end up labeled, you are mad, and it is horrible the names I am called. Then everybody is painted with the one brush, nobody is different. How unfair is that. How much understanding does it actually show the public has. How out of date is it, we have moved on so well, as Donncha has said, in many other areas over the years gay & lesbian movements, traveler movements etc. they have all got their rights but we are still coming from 150 years behind. And it is exclusive and we have not got equality and we know that, totally out of touch with reality

So who do not understand, who do the people say do not understand or care.

- The general public need to be more aware of what mental illness is really. The public have no idea of what my illness is.
- Doctors, you read it but I feel it. Basically we are experts through our own experience.
- Nurses just do not care, they only care for themselves.
- Drug companies, no drug to destigmatise, interesting and that is a comment from a service user.
- Politicians criticize and you know what time of the year we were carrying out this survey.
- They do not understand me, not even my own family, and that possibly is one of the areas that causes most concern and which is very very sad.
- The local community look at me as being funny, they know I have been in hospital but plenty of us have been in hospital, but it is the type of hospital you have actually been in.
- Look at what the papers and TV say, it is not true.

These are all comments of service users.

What needs to be done and I am using comments here again.

- What needs to be done to stop me hiding my illness to avoid being laughed at?

- What needs to be done to stop the feeling, that people are looking at me and talking about me?
- What needs to be done to stop the feeling of being isolated?
- What needs to be done to stop people not understanding me at all?
- What needs to be done to stop people being narrow minded and selfish?
- What needs to be done to stop people looking down at me and making me feel lousy about it?
- What needs to be done to stop people feeling alone and sad?
- What needs to be done to stop employers who won't give me a job because of where I have been treated?
- What needs to be done to stop society believing that I am mad and that I am dangerous, that they are afraid of me because I am dangerous?
- What needs to be done to stop society seeing me as just not normal just from hospital?
- What needs to be done to stop the media playing that negative role?
- What needs to be done to stop staff nurses who don't care, they don't want to meet my needs only their own?

This shows that right across the spectrum of society these comments have actually said that nobody, going back to the first comment, nobody understands me.

What do the individuals, that we have interviewed, say needs to be done to address this?

- People need to be more informed and we hear this day after day after day.
- We need awareness training,
- We need to dispel the myths out there about mental illness
- We need to educate our children at a young age
- We need to educate our families,
- We need to educate the public.
- We need to medicate properly, how come nearly 62% -6 out of every 10 people who are here today, are in hospital, have no idea of what their diagnosis is. What chance has the word recovery to any individual if they don't even know what they are suffering from. Why is it hidden, why are 70% of individuals not informed fully of information re their medication, particularly the side effects.
- We need better service information and communication.
- We need better information within the services and we need far more effective communication and we need a more positive media.
- They also say that the services need to stop researching and put money into action.
- We need to be more active if we are to deal with stigma, we need to be more active not just an effort it is activity we need.
- We need an effective community based mental health service, but in that move, as we have seen it two community services, let us not institutionalize that type of service as we have with our previous services. We need to keep a very close eye on it.

- We need to expand our mental health services into the community but people working in the services can't do it alone themselves. To move into the community, the community is part of the problem, but to move into the community we have to effectively network, become involved with existing statutory organizations, voluntary organizations and community organizations, who know best. Let us use the good facilities that are there but let us not try to be all.
- We need to tailor the treatments from a clients needs prospective. Some 83% of people have asked for alternative treatments but it goes unlistened to.
- We need a more fair and equitable service as was mentioned earlier on this morning,
- We need to effectively work in partnership and at all times with the service user at the center. We have to become client centered.

So the questions that needs to be asked as we move on this morning and we would hope to address later on in the next session is:

- Who is best placed to make these changes?
- What needs to be done and what needs to be put in place?
- How should it be implemented?
- Who should implement it, who is best placed to implement it?
- How will it be resourced, who will monitor and evaluate it?

As we move forward I believe that we need to ask, each and everyone of us need to ask ourselves, what can we do, because when you ask a question it eventually changes your attitude, it increases your skills and it gives you more knowledge. The time for change has come. Let us not forget the past, we can read from its pages but let us not forget it. The time for change is now it must not and will not fail.

Thank You

*I think that is an absolutely brilliant presentation Mervyn has described stigmatization as a process but has given us immense human and experiential insight into what was going on and Paddy prior to that I think painted a very eloquent picture very sadly describing the present as being one but pointing very accurately to our complete failure to understand humanity which contrasts sharply to our failure to understand things like things like technology and other wonderful outputs of human endeavor and I think that has given us immense food for thought. We will have the questions and answer session later.*

*The next speaker is Tom Cooney who is a lecturer from Dublin and he is going to talk to us about equality and mental illness*

**Tom Cooney, Lecturer in Law, University College Dublin – “Equality, Mental Illness and the Law”**

Thank you Donncha and thank you for the kind words earlier on. The kind words said about me are nothing to the kind words that needs to be said about Donncha in the role he has performed as I think, a leader in Ireland in terms of civil liberties right across the board and I will say with my hand on my heart and I will say unabashedly that I do not know of anyone who has contributed so much across so broad a zone as civil liberties as Donncha and I am glad to see him here today.

I am glad to be with you today but I would rather be at the Flood Tribunal representing a crooked politician but I am not and I accept that so I am here today.

I have a very narrow brief today, my brief is to speak about stigma and equality and rights and the law and that is narrow brief because the law in Ireland, and you don't need me to tell you, the law in Ireland is still in terms of equality and the right to be respected as an equal, if you are a person with a mental illness or if you are labeled with a mental illness, the law is your enemy not your friend. That is the struggle you face and listening to Ann when she was talking earlier about stigma, I learned from Ann that part of stigma, that process of stigma, is recreating somebody not in their own image, in a negative image, an image that you impose upon them and of course one meets that everyday. One still hears psychiatrists, one still hears nurses, one still hears social workers and psychologists speak about a schizophrenic not a person with a condition, but a schizophrenic. One hears about the manic depressive, that is still part of the currency of our language and as Ann said words aren't just words, words are used to change the world, words are used to recreate a person and when they are used to recreate a person in a negative way, what it does is it violates its most fundamental right which is the right to be respected as an equal. You have learned from Paddy and Mervyn that stigma is something that operates in our society, it is a social thing it is where people use various processes, various ways, various techniques various conventions, whether it be professions or just ordinary community to stamp a badge of all consuming inferiority on people, an undeserved, an unjust, an unwarranted badge of inferiority. The positive thing I learned from Paddy and Mervyn was that you struggle against it, that is where the dignity is, struggling against it and that is what was great to hear that sense of empowerment, that you struggle against it. It reminded me of the old black freedom song that the only chains that the human soul wants to bear is the chain of hand in hand solidarity to fight against injustice. That song ends somewhat like "keep your eyes on the prize, keep your eyes on the prize, keep your eyes on equality that struggle."

Now stigma, the answer to it of course is equality and some people think we are going through an equality revolution in our legal system at the moment and in a sense we are but it is slow, it is partial, it's gradual, it's piecemeal, it isn't really fundamental yet that is the problem. Take the Equality Act, we now have an Equality Act and it is an important Act, and it does good things, but with stigma we loose out on certain things. What do we lose, well in the immediate sense we are discouraged. If there are health services and personal services that we want to access, we do feel discouraged out of the fear of stigma, that is understandable, that is not being silly, that is not being cowardly, that is not being crazy, that is being human. The second thing is if we experience a

disadvantage because of inequality, disadvantage never comes in ones, it comes in ones and twos and threes and fours, it is a sequence, it is a cumulative process, when you experience it once you experience it again.

Lets take that Equality Act that I mentioned this magic Act, which politicians have been saying is a great Act, it is a good Act, not a great Act. One of the weakest parts of it is in relation to education. If I am a child and my parents want to send me to a local school and the manager believes that I am mentally ill, the manager, if he or she can find their own reasons, their own apparently respectable reasons to refuse me access to that school then that Act is useless, absolutely useless. The problem is if you are denied a proper education, if you are denied a respectful education, if you are denied every opportunity you are entitled to just because you are labeled mentally ill, then inevitably you will suffer disadvantage after disadvantage. You will suffer disadvantage in employment and that is one of the problems with equality in our society at the moment, but the answer is still inequality, I am not going to be pessimistic, I could be pessimistic. What is the most important article in our constitution of 1937? It is article 40 section 1 what does it say you are guaranteed equality before the law. What is the article of our constitution that the judges have done nothing about, they have made it into a vacuum of nothingness? Equality that is the one article that our judges have been fearful of developing. That is the one disappointment in our constitutional demographic law that is a real pity but the answer is still equality. Now the question is what do I mean by equality? There is a debate in Ireland at the moment, for example Kevin Myers in the Irish Times says equality is a silly work, get rid of it, because he thinks equality means treating everyone the same. Nobody wants to be treated the same, we are all different but we do want to be treated as equals.

Now if it doesn't mean being treated the same what does it mean? I think there are two sides to it, one is respect. Equality recognizes that there is a tendency in our community to grade people, to say you are inferior, to say you are possibly dangerous, to say you are unreliable, to say you are crazy. All that is grading, all that is stigmatizing and equality recognizes that and equality says no no. The first thing is we must respect the right of each individual to be independent, to be the maker of his or her own life, according to his or her own values. Imagine your life is a book, your right is to be the author of your own book, to write your own book that is equality. Our mental health laws do not respect that fundamental right and I will point out in a moment what I am supposed to be pointing out, how it fails to do that. But the second side of equality is this, concern, concern goes with respect. It is a reality in life that some of us will experience illness, there are lots of things that we will experience that will make life much more challenging for us and this is the reality and we all recognize that. The right to concern says okay if people experience illness, or experience setbacks, or whatever, then we structure society in such a way that we use whatever resources we have, to distribute them fairly so that people can get the resources, whether it be health services, personal care services, whatever they require in order to live an independent life as far as possible. The idea is that health services and personal care services are not just about meeting needs, yea they are about meeting needs, but they are about meeting needs while respecting abilities and the most fundamental ability is the ability to live an independent life in the community, an

inclusive community and I heard Pat McLoughlin make that point, the inclusive community where people have the right to live. That is concern, so equality I am suggesting has two sides respect and concern. Your right, your unconditional right, to have respect from your community for your right to live a life, you think worthwhile, and your right to concern that if you meet setbacks, as we all do in society, society should have a policy of justice, a policy of redistribution of the resources so that you should be able to live up to that challenge. Does our mental health law stigmatize people because of mental illness or does it actually respect them and resource them? What I want to do, I want to pick just five examples, as briefly as I can, where I am suggesting that our mental health law stigmatizes. Lots of things stigmatize what I am saying is the law does it too.

The first example I want to pick is a piece of law reform, a piece of modern law reform the Mental Health Act 2001. There are many aspects of this Act that one could go through, but I just want to pick one piece to illustrate how it stigmatizes. You will see in the Mental health act, part 4, that it deals with treatment and consent to treatment. For the first time in our law we have a definition of consent. It is a poverty of a definition, a defamation of a definition, a terrible definition and it's notion of respect for the individual really is the opposite of respect. Now what do I mean? Under part 4 if I go into hospital, I am committed to a hospital, for three months I must take the drug treatment, it calls it medicine, that the treating psychiatrist gives to me. At the end of the three months the treating psychiatrist must consult with me to continue with that treatment and I say no. I give the psychiatrist perfectly understandable reasons, relative to my values, relative to my experiences as to why I don't want that particular course of drug treatment. So that psychiatrist then calls in a second consultant psychiatrist and if the second consultant psychiatrist agrees with the first, my treating consultant, that I should take those drugs anyway, regardless of my refusal, I have no choice. I am no longer a human being, I am an object of treatment. Some people will say that is excessive, well why is it excessive. There is a basic principle of self-determination in our law. It is a constitutional right of self-determination that relates to the right to respect, respect doesn't equal means, you are a self-determining human being. Now what does it mean to be a capable person, a competent person with regard to treatment.

1. You have got the capacity to understand what has been proposed, you have the capacity to understand the implications of taking it and the implications to refusing it and most important you can relate your decision to your own values. In your heart, in your soul, in your being, you know why you don't want it your values so you know why you don't want it, so you have got the capacity to understand
2. You can make a voluntary decision. You are not being duressed, you are not being forced, you are making your own mind up.
3. You want information. Mervyn pointed out the problem in society for so many people, psychiatrists don't tell you what your condition is, they don't tell you what the material risks are of certain drug treatments, they know but they don't tell you. The third aspect of a genuine consent is information. You

are entitled to that information. If you have the capacity to understand, there is no reason why you shouldn't be given the information

4. Your consent should be about a specific proposal a specific treatment.

Now what the Act basically says is, if you meet all those criteria, you've got that basic capacity, that human capacity to make your own decision it doesn't matter. Psychiatrists can make you take that drug treatment and the experience in England where they have a similar position is, that the second consultant psychiatrist nearly always back up the treating psychiatrist. Some people will say but don't you have the rights to go to the courts, well you do but that is all very fine. What is the practice of the Irish judges with regard to Doctors, Judges say we are not Doctors, if this is a general and approved practice among doctors, we won't interfere, so if that particular remedy in the Act is an illusory remedy, what it will mean is people going to court thinking they have a remedy but finding the judges will rubber stamp. The point I am making is part 4 of the Mental Treatment Act recent reform what does it do? It rubber stamps violation of a person's right to equality. The second example, one of the biggest scandals in our legal system, has been the discrimination against people who are labeled mentally ill with regard to access to the courts. If I am confined to a psychiatric hospital and I believe that I have been illegally detained, I cannot go to court and sue whoever put me into hospital, I cannot sue the doctors the nurses whomever was involved. If I believe I have been illegally detained I can't do it. Why, because in Victorian times psychiatrists went on strike, they said they wouldn't put anyone in hospital unless they had protection against their patients, Irish psychiatrists adopted that law, and they have insisted that it be preserved with one minor modification that I will mention in a moment.

What does that law say, it says if you believe you have been illegally detained what you have to do is, you have to go to court and ask for permission to sue and when you go to court you can't bring your witnesses, you have to swear your whole case on paper to the court. What is more you have to prove that you have a substantial case. Now in ordinary law if somebody runs me down with a bicycle and they injure me and I want to sue them, all I have to prove is that it is probable that they did injure me. But with this law you have got to prove a substantial case, almost beyond reasonable doubt. OK there is reform, what has the reform meant? Now you have to prove that there is a reasonable case, not a substantial case and does that make any difference. The answer is no, it doesn't make any difference. Judges have been interpreting substantial to mean reasonable, interpreting against patients in favour of doctors. That is the reality and that is an inequality, a real inequality. One example of a case that illustrates the inequality, in such a horrendous fashion and is a disgrace on our judges who made such a decision. It is an example of prejudice amongst our judges that they made this decision, a case called the O'Dowd case. A man brought into hospital, legal procedures weren't gone through, he was drugged, put into a room, where he fell asleep from sedation. Then the medical director came down and examined him. Now what is an examination? Well in this case an examination was he looked at him and he signed the form and he was committed. The man sued right up to the Supreme Court and he didn't get permission to sue and the reason that he didn't get permission to sue was because he had been examined. Now if

that is the way the law is stacked against the individual, who is labeled mentally ill, then that law is a bad law, the reason it is a bad law is because of the inequality.

I will do the other examples a little more quickly. The Disabilities Bill died, you recall that. And it was good it died because it was a lousy Bill. I want to raise the question. It dealt with important matters but I want to raise the question, what should be the key note to a new Disabilities Bill. I think equality and in what sense is equality important here. We have talked about equality of respect and equality of concern. Equality of respect is your right to live an independent life and if you need resources to do that, equality of concern is your right to those resources. That should be a rights based Bill, no more, no less, a rights based Bill. That Bill wasn't. What types of things are needed? In terms of health care services and personal care services and resources, I think there are a number of things that need to be examined.

1. The right to an individualized assessment, each person gets his or her own personal assessment.
2. The right to personal participation in any assessment including having an advocate present if that is your desire.
3. The right to have services, and Ann mentioned this, in terms of society, how society tries to match the individual to its preconceptions, isn't that what you said. Well I think this applies here because there is a fundamental principle which needs to be in that Bill. The principle should be that you match services to the individual and not the individual to the services. That when you provide resources, you provide resources not just to meet needs but also to respect abilities, respect the person's own abilities, enhance his/her independence, his/her ability, his/her right to live as far as possible an independent life.
4. The next thing is the right to reviewable plan, the plan should be reviewable periodically, automatically.
5. As well as that, and this is the final thing I will say about it, the right to legal enforcement. If you have certain rights and they are in your services plan and you are not getting them then you are being denied equality. So what is the remedy name, blame, shame, you should be able to go to a tribunal or court and have it confirmed that you are entitled to those because you are a citizen, not because you are begging, not because you are an object of charity, not because you are dependent but because you are an equal citizen and that is what it should be.
6. Advocacy and I will finish here. The Government has run away from the challenge of advocacy. There are different kinds, self-advocacy and so on and all these things are important. What I want to mention here is the idea of an advocacy service and by mentioning it I am in no way trying to diminish the importance of self-advocacy. What is the crucial requirement for a true advocacy service? I think the crucial thing is that it be based on statute, it would have a statutory footing. That it be independent, independent of Health Boards, independent of the Dept. of Health. Let it be a body which has the passion and commitment and legal independence to pursue justice on behalf of individuals and doesn't have to take it's cap off to a Minister, or anybody in the Health Board, or to any politician, that

it can go to court and assert people's rights. If an advocacy service provided by the state doesn't do that, then it is no good, there is no point in having it.

So the final thing I want to say is this. I am speaking to people who are struggling for justice. Today we hear that Charlie McCreevey has more money than he thought he had. I don't know how he didn't realize he had the money, but apparently he has more money. There is an ugly reality isn't there at the moment, the ugly reality is that if you are a horse in Ireland, your owner will get tax relief, get what he wants, get what she wants, it doesn't matter if every stud owner comes from a country, a regime, where they wouldn't recognize a human right if it stood up and asserted itself. That is the reality, no taxation for these people who own huge studs but the money isn't there for proper health services, proper personal care services.

So the road isn't straight, it isn't smooth, it isn't wide but it is a road you must go down, and I think when you meet like this, you give yourselves the energy to do that, to pursue that. Otherwise what lies at the end, well a road that is paved with prejudice and stigma and leads to a bleak cul de sac of misery and injustice and a sense of worthlessness, and that is nowhere to go. Where you are going is the place to go and as I said in that old freedom song the only chains the human soul will bear is the chains of hand in hand, that is solidarity, that is struggle. That song finishes with the words "keep your eyes on the prize" and I say keep your eyes on the prize.

I always marvel at how Tom can present such an honest picture which does not depress you but leaves you very hopeful. I think the key point that he made in the earlier part of his speech was the dignity of struggle and dignity of solidarity not to mention the necessity of solidarity within groups and across groups and I think that is a key message in what he had to say bearing in mind the great truths that he uttered about what we perceive to have been progress in the law. Now we are very tied for time but I think it would be an absolute shame not to have some questions and answers. What I would like to ask is I am going to try and take some questions together rather than referring them directly back to the different speakers but if you want to indicate who your question is if it is not for the generality of the panel. Again at the risk of being a bit bossy I ask that you be brief in your question or your comment because we are really up against it. There are roving microphones from the back of the hall so if there is anyone who wants to speak hold your hand up.

1. I just wanted to ask Tom where do you go to get this justice, who do you ask, you said about this man signing the form and but who do you go to to find that out?
2. For Tom he mentioned in part 4 of the Mental Health Act when someone is committed to hospital that they are entitled to a review of their medication after three months and the psychiatrist can call in a second psychiatrist in that situation if the patient isn't happy, now what I find very strange is the psychiatrist can call in the second psychiatrist instead of the patient, I think in any normal court if there is a disagreement, that the person concerned would be entitled to call in their own expert, their own psychiatrist, rather than for the person who is already

- prescribed another psychiatrist nominated by themselves, that doesn't seem fair or equal to me.
3. Good morning it is just a general question on foot of what Mr. Paddy McGowan actually referred to and indeed the other members I am just curious to know if there is any strategic plan, the very first man was Mr. McLoughlin and I know he isn't here at the moment but he is Chief Executive Officer of the South Eastern Health Board . I was wondering is there a strategic plan in relation to the various Health Boards I am of the opinion myself that there are too many Health Boards in existence in Ireland. So I would like to know if there is an overview where one Health Board is actually doing the same as the other or what varying degrees, we don't seem to have any answers in relation to that. Also if I may say Mr. Tierney referred and made a number of excellent questions but unfortunately due to time didn't get around to addressing the issues e.g. who is best placed to make the various changes I wonder would the panel offer any answers or solutions in relation to those questions.
  4. What is the panels opinion on the need for a National Strategic Plan with regard to mental health services, particularly over the next decade and secondly with regard to what Tom was saying about having the whole advocacy network given some statutory backbone, it would say so it would be good to know what your opinions about other ancillary services, respite services in the country for carers or for users and particularly with the new Mental Health Act it is very good in the sense of putting forward in a legal concepts about diagnosis and treatment but my question would be your opinions on all the shortcomings with regard to building the services in there to be able to implement this new philosophy.

*Tom Cooney:* In regard to who you go to for advice, well when the 2001 Act comes into place, and it is not in force yet, there is a provision there which says that everyone who has been committed to a psychiatric hospital has a right of access to a lawyer. The state will have an obligation to provide a lawyer. Now that is a good thing I think, it is not as good as having an advocacy service, an advocacy service would be there all the time, you can build a relationship with an advocate and they would know things, how to get around the bureaucracy better than a lawyer, that is what will be provided.

Expert witness: I agree with you, that is a flaw, what it means is that a person is going to be very disadvantaged under the new Act as they won't have a right of access to an independent consultant psychiatrist, that you can bring in and say look this is my view. The experience in England is that the system we are adopting is against the service user and I think you are right it is unfair.

Ancillary services: I think that is a weakness in the Act. One of the telltale signs is the absence of the right of treatment plan, a review, and that it seems to me is something essential that a person should have the right to a treatment plan and a right to participate in that, it should have a periodical automatic review and they should have the right to question if they wish to question., that is not in the Act. The other thing is there is nothing in the Act to say one has a right to a plan after one is discharged and there should be because if one is discharged there are questions relating to accommodation and various

other aspects of living an independent life and I would agree with you it is defective in that way.

*Paddy:* As far as I am aware the Dept. of Health and the Minister have said next year 2003 there is going to be a complete review of mental health services , a new strategic plan that is what has been talked about and that will be a national strategic plan following “Planning for the future” 1984 so that is welcome in a sense that there might for the first time get everyone around the table , service users included to talk about developing a strategy, We have been involved the Irish Advocacy Network with the Southern Health Board and the Midlands and North East at an earlier date doing an audit and research on what service users believe want and require and need . I would be happy in the the sense that the Southern Health Board and indeed the North East have actually listened to what people are saying some of the things that they heard they didn’t want to hear and some of the things you could try and dismiss and walk away from but they didn’t and for that approach I commend them because it shows they are trying to be genuine. This is what we need to do we need to work in partnership, we need everybody that has mental health in their heart to drive this process forward. Strategic plans have to be done but they must be done with everyone at the table, no exceptions.

*Mervyn:* I haven’t much more to say than what Paddy has said I am very interested in your comments there on the 2001 Act in that one psychiatrist looking after another surely natural justice does not apply there and that you be a judge in one’s own cause and if the file is not handed over from one solicitor to another it may lead to censure. Strategic plans, it is the way forward. There will probably a lot of planning to plan for the National Strategic plan and knowing this country but as Paddy says there are “focusing minds” from the Southern Health Board perspective which was an excellent document which was launched back in Sept and is well worth reading and there are other health boards coming through such as the Midland Health Board so all we can deal with is what we deal with at the minute /. As to who is best placed to deal with it , we would hope to take that up in the later sessions.

*ECT:* If someone has a concern around ECT as a procedure or a treatment I think that that person has the right and the ultimate right to decide whether they want that treatment , or not I don’t think there is any ifs or buts about it I think that decision has to lie with the patient, we can’t argue that or diminish it it has to be their choice

Q

Ect I am going going back many years when I was in hospital myself, luckily I had my family to stand up for me at the time. They asked my parents to see if this would help my illness but my family were against it, they said you can give him one but that is it then, it didn’t work for me at all. My family watched the doctors morning, noon and night they were very concerned about me because I was not in my right mind I was very sick.

Q

Earlier on this year my son suffered a serious illness and after 5 weeks at home he decided to go into a private psychiatric hospital. Within 48 hours of going in he was

sectioned under the mental health Act into the high secure unit of Dundrum hospital and spent 8 weeks at which time we were very concerned. To make a long story short the psychiatrist from the private hospital decided to take our son back under duress. What is the criteria for doing this and is it legal. My son didn't want to go to Dundrum and he was traumatized by the experience.

*Tom:* there is as you pointed out a procedure under the 1945 Act for making that type of a transfer but I sense the problem there was as I see it the lack of proper consideration on the part of the psychiatrist in the private hospital, that in a sense he or she had a responsibility and in a sense you were left feeling that that responsibility was being abandoned, that you had to stand up and fair dues to you for that meant that your perception seemed to be correct . At the end of the day I suspect taking you son back in fear that if he didn't and something happened that he might have to face the consequences in court.

The psychiatrist used the excuse that he used was that he had a very disturbed patient in his acute ward that it might set my son back and our concern there was that where our son was actually being detained in Dundrum was their high secure unit that he might suffer irreparable damage spending 8 weeks in an environment that really wasn't suitable for him.

Q. I just want to come back to the court procedures where the judge says he is not a doctor and it is the doctor's opinion for treatment for people with mental health disabilities I am talking about re-education for working with the police, do we need something for judges now something like that

*Tom:* We need less arrogance and more humility from the judges

*John Saunders:* Two comments:

The ECT issue has been raised by John Owens who will be here later, the Chairman of the new mental health commission and he has publically pointed out the rate of ECT usage across the health boards is inconsistent and there is a problem there in terms of who is using it and why. Maybe Dr. Owens will address that later if he has the time.

The second issue is the transfer to Dundrum Mental Hospital, as far as I remember every Inspector of Mental Hospital report has condemned the behaviour of transferring people to Dundrum and his point is that psychiatrists are using it as a way of moving people on that they feel they can't manage in the so called ordinary mental hospital. He has consistently said that this is bad practice and they are probably illegal in terms of using that power to send people to Dundrum because at the end of the day the treatment you get in Dundrum is no better or worse than you get anywhere else.

*Tom:* I am glad the ECT question is being addressed, just two things one there is a study in England shown that a psychiatric hospital which were using ECT, sequence of patients and they recorded that they were improved only to discover that the plug hadn't been put in.. That raises the question of efficacy of ECT, I am not saying it isn't effective in some

cases. Secondly there needs to be study as well it raises the question of difference of practices. It is interesting in the past that if a person went to St. John of Gods hospital and was diagnosed with schizophrenia and they would be given ECT where if they went with the same symptoms to Pats they might be diagnosed with depression and given ECT, so what is it about. I will finish with this when hospitals build units with ECT it creates the impetus and pressure hey bring them in this is our job.

*John S.* It gives me great pleasure to introduce Dr. John Owens who has kindly agreed to Chair the plenary session. Dr. Owens is a friend of SI. He is honorary Clinical Director of SI is also well known as a consultant psychiatrist in the Cavan/Monaghan region in the North Eastern Health Board and recently has taken the Chair of the new Mental Health Commission which has been formed under the 2001 Act. Many of you have read his public comments on the role and aspirations of the Commission. It is a great pleasure to have him here with us for this afternoon. So without further ado I will hand you over to Dr. Owens.

### **Dr. John Owens- Chair of Mental Health Commission.**

Thank you very much John. The first thing I want to say it is great to be here I arrived unfortunately only this morning, but I arrived in time to hear Paddy McGowan's session and the discussion after that I must say it was of great interest, it was enthralling. I know some people might find this kind of strange but not all psychiatrists and therapists in general get to hear about the services that they provide themselves. It can often be a most humbling experience and certainly some of the comments, which were made here, this morning went right through my armour and it resonated with some of my own views about the difficulties within the Irish psychiatric services.

As John says recently for my penance and in my old age I have been appointed Chair of the Mental Health Commission. This is a new body which has been formed, which has very broad responsibilities and a considerable degree of independence, which is what attracts me to it. It is a body which was set up in essence to introduce and police the new Mental Health Act. We all know that there is a new Mental Health Act 2001. Our previous Mental Health Act which was a very old Act of 1945 and that in itself speaks volumes about the priority that has been given to Irish mental health services, to Irish psychiatry over the last number of years. It was by far the oldest Act in Europe so things have changed and hopefully not only have things changed but hopefully the pace of change has changed as well. From now on we can expect a lot of new and hopeful beneficial and radical things to take place.

The Mental Health Commission was set up under the Act and has the responsibility to bring into being the new Act. The new Act is an Act which is much more respectful to basic human rights and in many ways it gives much more responsibility and much more autonomy back to the actual users of the service. The previous Act by no means did that. It was an Act reflective of very different times and very different attitudes towards mental illness and how it should be managed.

The other responsibility that the Commission has is to advance the whole quality of the mental health services and the Commission takes that aspect of the responsibility very seriously indeed. I don't think I need to make you aware that there are lots of problems, lots of deficiencies in the Irish mental health services. Our services need to be changed in very very major ways and I would hope in the first 5 years of the Commission that we will be responsible in trying to move things in that direction.

The Mental Health Commission isn't the only player in this, everyone has a role to play in it as well, not least the actual users of the service. In many ways these are the people who perhaps know best of all, the sort of services which are relevant, the sort of services which makes sense to them. Very few people in the past have listened to what users have to say. Hopefully those days are gone. Now I can't give you a guarantee that in 5 years time you will have a dramatically improved service but what I will say is that we will have a different service and I would hope it would be a much better service, a more effective service.

Now the theme of this conference today is stigma and this is something which is a problem not only in Ireland but the world over. Within Ireland, like everywhere else, it has been a major factor in holding back the whole prioritization of the mental health services. If mental illness didn't have the stigma it has, it would be treated much more as it should be like an ordinary general illness, physical illness if you like, though that isn't a proper distinction to make anymore, and would be much better funded. People would feel that they wouldn't lose their dignity by becoming ill and would feel that in no way are they diminished by their illness, openly acknowledge and talk about it and solutions can be found and proper funding can be found as well. One of the major reasons why funding is so low within the mental health system is simply because of stigma. Nobody gives it that much importance, everybody knows about it, people talk to themselves about it and they talk behind closed doors as it were. Nobody is prepared to openly acknowledge the problem and as we all know the problem is a major one. In any one time around 17-20% of the population have substantial psychiatric problems. That varies a lot and we all know that some people have a lot more serious problems than others. In the case of schizophrenia you are talking about a smaller group, but still a substantial group, and a group of individuals who are very disabled indeed, not only in the context of their own personal suffering and misery, but all the difficulties that are contingent on them in terms of their families, the economy, all that sort of thing. So it is something which ought to concern us all and to have a stigma about something which is shared by one in five and that one in five may very well move through the other 4 over the period of a lifetime, you can see how silly the whole stigma process is, but it is there and we can't do an awful lot about it. People notoriously confuse or character problems with mental illness problems simply because you cannot see an obvious sign of illness, people just behave differently, or feel differently or do odd things. People are intimidated by that and frightened by that, the stigma builds up and all the hysteria typing, lampooning, jokes, fear, guilt and anxiety and all that sort of thing. People have been talking to you about this and will be talking to you about this in this session as well, in a much more aureate way than I will.

But getting back to what is the role of the Commission here. One of the reasons why the service is so badly funded is because of the stigma. If there wasn't the stigma there wouldn't be the same degree of neglect, the public would not put up with it. In the health services this year 2002, our budget is €8.04 billion that is for a population of just under 4 million, the mental health spend is about 420 million that is about 5%, it used to be higher but it has progressively fallen over the last number of years, mainly because the institutional base of psychiatry has fallen. But I think most people would accept that mental illness in general probably contributes something around 20% of total disability and in fact some of the literature on this suggests that mental illness, after cardiovascular disease, is the highest percentage of what is known as disability years attached to it. So 5% of the health budget, 20% of the disability you can see easily the mismatch there.

Now stigma is an important factor in that. Why can't people do something about it. Well I suppose some things are being done about it, but people who have psychiatric problems for a variety of reasons, are no great advocates of themselves. People feel embarrassed because of the stigma and say I've got a psychiatric problem and I went to such and such a hospital and think I was treated very well, or I could have got better treatment, or I should have not had to wait for outpatients, or whatever it is, or I should have had an opportunity to consult a specialist in my particular problem, but they won't say that because they feel embarrassed or because they are too ill to say it. The advocacy for psychiatric services has largely got to depend on the individuals who actually provide the services themselves, the actual doctors and nurses and other therapists. I think perhaps over the years we might have advocated, I think we did and a lot of psychiatrists might have felt they were talking into the wind, as it were, nobody listened. Maybe we could have talked in a more effective way or maybe we could talk in a different language, if you like, but I think perhaps the most effective language of all is people themselves, the families of people with illness, particularly people with severe illness. So what we are conscious of, as far as the Commission is concerned, is trying to do something fundamentally to affect stigma, to reduce stigma, to normalize the whole notion of psychiatric illness, to make it an illness like any other illness, to demand a degree of resources which it requires, in the same way as any other illness does and I think we are some way from doing that, but we would have that as one of the major objectives of the Commission. Another reason for stigma, apart from the notion of people not being able to get their head around what abnormal behaviour is all about and tend to see it as a character problem rather than a mental illness problem. Another reason is the actual quality of services that the mental health services provide. It is very hard not to be frightened of an illness if you have to go to a separate mental illness hospital for treatment, and there is still a lot of those around, about 50% of all admissions to Irish psychiatric inpatient services or inpatient units in the traditional mental hospitals. They are grim looking places, I don't have to tell you that, they should be all closed down, they should be all closed down tomorrow. People have been advocating for closing them down for twenty years at least, but they are still there and it looks like they are going to be there for some time yet. There is a movement towards acute units in general hospitals, but that movement is slow. It is planned by 2006 all acute admissions in the psychiatric services will be units in general hospitals but that is some time yet and there will probably be financial slippage in that. Really though these places do affect peoples attitudes towards

mental illness if you go into a place like that you tend to think of “lose hope all you enter here.” Why should it be separate from general hospitals anyway, what is so separate about it, it is an illness like any other illness but clearly it is not if the buildings are dark and forbidding and not inviting. It is quite clear how the actual service has perpetuated the notion of stigma. The other thing which will be very affective as far as stigma is concerned is having effective treatments, I mean I am very conscious even in my time. When I was a young lad everybody was stigmatized towards TB, consumption, whatever it was and there were families that had consumption in them and houses that were riddled with TB and people were frightened and concerned and there was considerable embarrassment about it all and that is the extent of the position within mental illness now but clearly as far as TB is concerned is getting an effective treatment and there is no point in wishing mental illness away and I don’t wish to offend anybody by saying this but mental illness is very real and severe mental illness like bipolar and schizophrenia is very real. What would be most effective in doing something about the stigma is if we have effective treatments to treat people and get them well, or if not being able to get them the services could be developed to the extent that these people are treated in pleasant normal surroundings like people with any other illness, or preferably not treated within hospital at all. Certainly as far as the Commission is concerned the two things that the Commission will be pushing more than anything else, well three things, one would be an educational programme where we will be working with groups like Schizophrenia Ireland to do that and to encourage that to happen to the maximum extent. The other two things that we will be doing, first of all we will be trying to radically change services and to radically improve services and we will be trying to get people treated without going near hospitals at all, nobody wants to be admitted to hospital, they are awful places. I am not talking about units in traditional mental hospitals but even in general hospitals, nobody wants to go into hospital, it tends to be a traumatizing experience, a frightening experience and women in particular find it so. There is no longer any reason for most people with psychiatric disorder to go into hospital beds anyway, most people can be treated in the community even when they are quite acutely ill. It is a question of mobilizing resources and having it available outside in the community, where you can diagnose their illness early and you can have home based nursing and that sort of thing. Within groups of individuals who have more chronic severe illness, and many schizophrenics might perhaps be like this, there is need for a specialized rehabilitation service. Professor Corrigan will be talking about that later on. We need to match services to individual peoples needs and that has to be done and there is no reason why it can’t be done very quickly, it is to a certain extent a question of finance but more than anything else it is a question of model of care, it is a question of looking at our services, seeing that they are not satisfactory and move in a very radical direction to a very communitised model of care of illness, whether it is acute illness or chronic illness. Now that at the same time has to respect things like pressure on families and that sort of thing. Anyone can discharge a patient from the hospital, patients are often not well when they are discharged from hospital into families who are burdened and can’t cope and find it very difficult. I have talked to a lot of users groups quite recently since coming on the Commission particularly in the Dublin area and I have talked to them about services and they all say the same thing. They are all very critical of the service, all they can do is admit and they can’t even do that, no one wants to admit, no one wants to give up a bed

and when they are admitted, they are discharged a few days later or a week later back into the same situation. The care doesn't include other aspects of people's lives, home, family, work, housing, education, all those sort of things and really when you think about people's illnesses, to have a very narrow and medical type of approach misses the point and you are simply not addressing the issue at all. So the Commission is very anxious indeed to move towards that model, where as much as possible, people are treated outside in the community and that there is a range of resources and properly resourced multidisciplinary teams to provide that sort of care, it is all possible, it can be done, it can transform services, it can transform individuals. I am putting it at a very simple level if I am John Smith or whatever my name is and while I have schizophrenia I am still John Smith, and I have a mother and father or I don't, I should have a job or I don't, I have a house or I don't, I am still a person and I have got to live with myself whether I have schizophrenia or not. All these issues interact and treatment packages should include all those sort of things. I have seen people who have been in specialized services for chronic illnesses like that and I have seen them transformed from individuals who go in and out of traditional model of care, in a kind of whirling door way, in and out, in and out, demoralizing to them and to staff and to everyone else and I have seen those individuals in a specialist rehabilitation service, which addresses in that very broad way a whole range of problems and difficulties that they have in their lives and I have seen them very different. I have seen them dressing well, I have seen them have the dignity of some sort of work, to be able to communicate, to be able to talk openly about their illness without feeling they are losing dignity in any way, to be able to be on equal terms and contribute to the doctors and nurses in deciding what their own treatment programmes ought to be. This isn't rocket science, this is something that has always been there, problems with models of care and those models have to be very profoundly changed. If the Commission has any role, it is going to be moving things rapidly in that direction. It is not so much a question of funding, there is a fair amount of money, we could always do with more money in the psychiatric services, €420 million, 5% it is not great but there is a lot of that money that could be more effectively used and targeted at individuals with specific problems.

The other thing that is inclined to characterize the Irish psychiatric service is the limited user involvement. Users are not asked to the extent that they should be, to talk about their illness, to talk about their treatment, to talk about the sort of programmes that they would like to be developed in services around the country. Hopefully that will gather pace.

These are just some of the remarks I would like to make to you today. There is one final thing that I would like to say that is apart altogether from services for people who acknowledge illnesses and they need to be improved, there is a problem also because of stigma in people acknowledging illness at all, only about 60% of people with psychiatric illness go along and get anything done about it. They keep it to themselves, a personal secret in an ashamed way but whatever services there are there, cannot address at all. So it is a very central thing it is a very disabling thing all along the line and something that has to be tackled and tackled very vigorously. The Commission will be interested in it in the ways I have described but if it is putting emphasis on anything the Commission is going to put emphasis on reducing stigma, by trying to encourage a vast improvement in

the actual quality of the services, so watch this space. I hope you don't watch it in vain, hopefully over the next five years things will improve.

Thank you very much

*It is my job to Chair the afternoon session. I want to introduce the first speaker Peter Byrne whom I have known over the years, we have been at conferences together and while you can see in your brochure where he comes from, where he has been trained he has been very actively involved in campaigns against stigma and in the media and how the media in general talk about mental illness, how they portray it which is such an important part as of how people see psychiatric disorder. He is very learned in this area, very well thought of, very well published and let me introduce Peter Byrne.*

### **Dr. Peter Byrne, Consultant Psychiatrist – “Prejudice and Pride – What we know about beating stigma”**

Good afternoon everyone, as you know in the description in the handout I described myself as someone who was trained in Ireland, and I have worked pretty much for all the Health Boards including the South Eastern Health Board, but having trained in Ireland I now work as a consultant in England and I was explaining this to Pat that Irish people have a long tradition of missionary work in less developed countries so I think that is the best way of saying that.

Although some of the experiences I am going to show you here are stuff I have done in England. What I thought would be much more useful, would be to present to you surveys and research done here in Ireland and initiatives that have been taken here in Ireland and using examples from Ireland because you don't want to hear a lecture about how things are across the water and inevitably when you decide as Schizophrenia Ireland have so bravely done, to have a conference on Stigma, some people will react, even people with mental health problems and they will say what stigma, what prejudice, there isn't a problem, I don't have a problem. They will say people with schizophrenia are no different than you or I and of course that is true, the problem is the perceptions of them are different. Diagnosis of schizophrenia isn't just about the symptoms, it doesn't just have medical consequences, it has social consequences, it has familial consequences, relationship consequences, economic consequences, political consequences so psychiatrists even though we deal with people with schizophrenia, our training doesn't cover all those and that is why I have ended up in the area I am in now.

We often draw the parallel with physical illness and that is not working for schizophrenia so maybe it is time to do something else. When we stand up and we say oh schizophrenia it is just funny or abnormal brain chemistry, it's a chemical imbalance. The response that gets from the general public is, I see so that means we have an imbalanced or unbalanced person. People then associate that with criminality, with danger and with someone who has a get out of jail free card, so chemical imbalances do not, I think and we know this from research, reduce stigma and discrimination.

It is interesting in the 1980s the American Psychiatric Association, and of course America is light years ahead of us here in Ireland and the UK, they thought the word stigma might upset people so they should avoid using it. I think that is an interesting parallel with the word schizophrenia, and you will have heard many spirited discussions about the use of that word. Then other people will say there is no stigma, because a lot of people say I have no problem at all with people who have mental illness, pretty much it is the same if someone asks you in a survey, are you a racist, of course I am not, are you sexist, of course I am not, people say I have no problem at all with people with mental illness. It was Jonathan Swift who wrote “ You should judge people not by what they say but by what they do” I think stigma is not just about language but it is about the end result, which is about discrimination. In my direct experience of learning from people with mental health problems, if you tell your landlord that you have just come out of the psychiatric hospital and attend a psychiatric day center, you will not get that place to rent, it is as simple as that, so you learn to lie to your landlord. In almost every Health Board that I have worked in, I have been involved with a local residents group objecting to a group home, objecting to a psychiatric hospital and that is the manifestation of stigma. Only last week I had to advise a patient to lie to his employer about mental illness because if he had told his employer, he would have lost his job. When I worked in Dublin I had a man who had had a problem with anorexia in his twenties and his insurance policy was loaded for the rest of his life. He happened to work for the company that produced the policy so he challenged it and lost his job. This is the reality of stigma.

It isn't just about political correctness, it is about active discrimination, discrimination in the social welfare office claiming disability payments, trying to get housing as we heard yesterday, these are the real points of stigma, this isn't an academic subject this is very real. In the Health Service it is about access to services, we know they are patchy in Ireland but even the facilities themselves are carriers of stigma and I have worked in many of them, St. Ita's was mentioned yesterday and St. Otteran's in Waterford. I have worked in parts of Cork where the services are a barrier, the actual physical buildings, to people getting better. For people sometimes stigma is about those secrets that I have mentioned, also this incentive to lie to people about what is actually going on. I thought what was very useful in the book by Anthony Scott “Is that me” and just like as John Owens has been saying, I am not coming here to this conference as an expert, you go to the sessions and you hear stories for the first time that are incredibly powerful and Anthony Scott's story is incredibly powerful and these are his words not mine, he describes losing control of his personality and his intellectual and emotional infrastructure “It had become a giant maelstrom of mental turmoil and pain.” Someone yesterday was looking for a definition of schizophrenia, now I know this is quite a complicated definition, but that is a fabulous definition and it is certainly better than the text books that I have studied with. If you get a psychiatrist talking they will say oh he has positive symptoms and negative symptoms, now what does that mean, we should all have some of those, what does that mean. This I think is the language that we can all understand and he also comments throughout the book that after a while he realized that it wasn't just the illness, it was the reaction to the illness and he said that he felt good when strangers treated him with complete indifference that was what he expected, if he got hostility that set him back but if he got indifference that was a good day.

What does that say about someone? If we started haranguing people who had heart attacks, if just for a week we had anti heart attack week, there would be a huge public outcry, if we said to somebody oh you had your heart attack well you should just pull yourself together or you are a nuisance or you are a danger to society, or are you going to move in next to me, I think you should be disbarred from your job or whatever, there would be an outcry. But what he was looking for was indifference. What does that say when you are reaching out for support, you are trying to beat a terrifically severe illness that is what you get. He also hooks into a theme that I will pick up later, he said thankfully he never committed a crime because he was well aware of this popular misconception about schizophrenia, split personality, Jeckel and Hyde, Jeckel was the nice face and Hyde would go off and rob and kill and rape and murder and all these awful things. From my own perspective, I have an interest in the media, and that is not a media psychiatrist, I keep explaining that difference to people, I am a psychiatrist with an interest in media and Anthony says 'the picture I had of mental hospitals was the Hollywood version.' I think that is very interesting because when people get mental health problems, we are all members of the general public, and they have the same negative attitudes that are out there as well, and the whole total of what that book is about is self stigma, where he constantly re-evaluated himself in the light of the illness and people's reaction to that illness. I think it is interesting for me after quoting Jonathan Swift, Anthony Scott also had a link with St. Patrick's in Dublin, this is the best first hand account of schizophrenia that I have come across. Now there are many book chapters and many service user publications but this is very real, as an Irish person reading this man's own voice.

This is from the front page of the Irish Times and it was mentioned yesterday by Fergal Bowers and this is from the Irish Times of February last year. The Irish Times is the nearest thing we have in Ireland to a newspaper of record and it is a good paper to highlight issues like this, local residents picketed and harassed a building that was to be a group home and then it was broken into, every room was slashed and every carpet was poured with petrol. I don't want to incite or say something that crosses the line here, but do we really need to have somebody with schizophrenia murdered before something is done about this. This is a hate crime. So what I wanted to do was, always conscious of where I am coming from as a psychiatrist, I often say to people that in spite of my training in psychiatry I know something about mental illness, but generally people do not get a good deal in psychiatric services and the reason for that is the same prejudices that are in the general public, are there with terrific power in the professions as well. Psychiatrists are not immune from prejudice and from value judgments, and what I am showing you is research that was actually paraphrased by Paddy and Mervyn in this morning's workshop. This was research published in 'Psychological Medicine' it asked 88 medical students over two years a simple question "Do you think psychiatric patients are not easy to like?" in other words generally speaking do you not like psychiatric patients, compared to patients who have a broken arm, a heart attack whatever and as medical students 28% said yes I do not like these people. Two years later the same people as doctors this figure had not improved it had doubled. There is prejudice in the medical

profession and this isn't just having low expectations for people with severe mental illness, sometimes it is more serious.

This is study from Levingston in America done in 1993 and he questionaired the transplant units in the major cities around the US. Now there is no such condition as active schizophrenia but these people decided, these are medical doctors and medical nurses, transplant teams, they decided that there must be something called active schizophrenia, which means when you read the actual study, they looked mad, they looked different, they looked like psychiatric patients and when they had active schizophrenia they said in a medical language, total contra indication, is medical for no way were this group going to get transplants, heart transplants, liver transplants or kidney transplants. So that effectively is a life and death decision and what we heard this morning from the lawyers was about equality and this is a manifestation of a complete lack of equality. This is one rule for people without mental health problems and different rules for those with them and I think it is services like these, unfortunately now less and less of these services are being done because disability legislation is driving the prejudice a little bit under the ground but I think these studies are very useful. I am quite sure Irish doctors would be no different than this and I speak as someone who fought a kidney specialist, tooth and nail, for a transplant for a patient of mine who had schizophrenia.

So what I want to present to you in the next four slides are the results of a survey we did here in 1999 and this was part of the Royal College of Psychiatrists work. Again just to give you an illustration of stigma, I asked three drug companies for the money to do this and the three of them said no. I finally got another company to do it by lying and saying another drug company had just agreed to give the money and if you get in quick you will be able to do this. Here is an interesting result, we just asked people about the word schizophrenia "Are you aware of the term schizophrenia?" and this is now Irish people 32 counties, north and south and whereas 96%, almost everyone, said we are aware of depression, it falls to 85% of people when it comes to schizophrenia. Now I know we argue over the word etc. but that means something that out there, there is not just prejudice but that there is an 'I don't know' and sometimes 'I don't want to know'. Part of that 15% may be people who just say I don't want to talk about schizophrenia.

In Northern Ireland and we can say all the bad things we want about Northern Ireland, but that awareness is much higher than here in the Republic and we have to think about why that is, because we tell ourselves that we have a great primary and secondary school system but something is missing here this is a very common, the most important severe mental health problem today and the awareness of it in the Republic is much lower. When you get to rural Ireland outside of the cities that awareness figure falls to 76% and there is a range here where 95% of the group are between 73 and 80. I was quite interested in that because I looked at the area who just receives RTE, I have a big problem with RTE television, I call it rotten television for everyone, it is a dreadful station. Part of the study showing my own prejudice was to ask people well "Do you just get RTE?" and the people who did get RTE had awareness levels of schizophrenia in the 60s and that is a significant result and people are thinking why that is. BBC TV have a soap call Eastenders and when we took the survey they portrayed a character with

schizophrenia and this raised awareness globally and the people who didn't receive that station didn't even know about schizophrenia. We beat the media with a big stick, but many times and I would argue perhaps nine times out of ten, the media do give us a fair chance, okay so there are exceptions and I will show you just one of those. If you ask single men, I don't want to delay too much on this, that figure is down in the 80s and most worrying of all if you ask young people, people between 15 and 24 that figure is lowest than in any age group. That is the age group that get schizophrenia and what I have shown you here in this slide is replicated in some of the other questions we asked people. Here is a simple slide and again I don't want to bombard you with percentages, if you look at depression in the North and depression in the Republic of Ireland which are on the top here, on the group on the left they know a lot and they know something about depression so pretty much about half the population in Northern Ireland slightly know and the don't know over there on the right hand side. When it comes to schizophrenia that goes way down, so people are just saying we just don't know about this illness. We asked them about other attitudes but we are talking about pretty much one in four people in the Irish Republic having just a slight knowledge of schizophrenia and if I can qualify that, those figures exclude those 15% who said well I am not even aware of schizophrenia, so it is even lower than one in four, it is if you like 25% of the 85%. When you break that down again, the lowest age group is the 15 to 25 year old age group and that is the group, men especially who get schizophrenia, so none of their friends know about this and have any knowledge of this, so they are not going to turn to their friends and perhaps that is why they turn to cannabis or alcohol or don't see medical service for a year or two years. Again if you are a single man that figure is lower than if you are somebody that is married, particularly in all instances women knew more than men but at half of you would agree with that statement. It is interesting Dublin people think they know everything but only 25% of people in Dublin agree, that they have some if only a little knowledge of schizophrenia and that is way down in rural Ireland and pretty much the same for RTE.

So what I wanted to do as well, just briefly ask a question "Had you personal contact with someone with schizophrenia?" you all clearly have, okay so you are a biased audience but imagine if you never had that personal contact. Even though it is a 1% illness we have only 9% of the people in the Republic who have had any personal contact and that figure is significantly higher in Northern Ireland. We think in the Republic that we have a great sense of community, that we are great neighbors, we are very interesting people, well hold on a second in Northern Ireland it is much higher, so something is happening there. Again there is a great difference between people who are married and people who are single, in terms of that personal contact. This is the scary bit, only 6% of those people have personal contact with people with schizophrenia and right across the country, in the four provinces those figures are scary. Why is the rural area of Connaught and Ulster at 15% but Munster is down at 4% that says something to us about community and the sort of communities we have. One of the great problems of a psychiatrist is sometimes, especially in England, it is very hard to have community care when you don't have community. That is something politicians don't understand, that there isn't that sense of community that there is here, we can have community care. But for some reason this illness causes isolation, which is a two way street where someone is afraid of the reaction

by telling somebody that they have schizophrenia and ditto the general public don't know about it and sometimes they don't want to know about it.

Let me move on from personal contact just to give you the best definition, I think, of stigma and it is Pat Corrigan's definition. The best three-word definition of stigma is 'them and us'. That covers everything in terms of what stigma does to people and in mental health that works so well 'them & us', the doctors and nurses versus the patients, sometimes it is 'them& us' the people with the illness versus the family but it is definitely 'them & us'. The definition I use, and it works well, is that stigma is a prejudice based on stereo types, that results in discrimination and the discrimination that I have listed for you, and it basically means that discrimination happens in a situation of power, that people with this label lose power, they have stigma, they are stereotyped, they become the victims of prejudice and then comes the discrimination. What I want to do just briefly is talk about those stereotypes and I made these slides before Fintan O'Toole's remarks that insanity is, trust Fintan to blame the church and religion, but certainly in early Christian times insanity was equated with possession, and then it was equated with promiscuity so there are a lot of negative connotations. The word lunatic comes from a theory, a stupid theory that people with mental illness are controlled by the moon. My psychiatric textbooks had these phrases, it talked about schism and schew families, that schizophrenia was caused by families and we now know that is a completely bogus theory. There was even the word schizophregenic mother which I think in terms of stigma is just up there as number one, number one because it is nonsense.

We knock the media because thankfully the media are available in print, are available in tape, available to listen on a playback and they are the visible and audible carriers of stigma. Our Home Secretary, who is Minister for Justice or Homeland Security as Pat would call it, decided Bin Laden was psychotic and he said it in a press interview and he said I know there will be letters because these people are always writing to me but I know what I am talking about. That was Jack Straw, who clearly hasn't a clue what he was talking about, because we got a chance to ask him, well should we go over to Afghanistan and section him instead of blowing up half the country and forcing him into Pakistan. The bit that isn't funny is that Jack Straw drafted new mental health legislation for the UK, he was Home Secretary and that was his job, so this man doesn't know the difference between psychotic and psychopathic. I know they are words and maybe they are terms that we don't like throwing around but there is a huge problem here because we can't give out to the journalists who reported those remarks, in fact one of the papers published a proper explanation of what psychotic meant along side his words and made him look an even bigger fool than he is. It is also interesting that UK mental health policy is entirely driven by control and risk and murder than by actual care, and a colleague and friend, Jeremy Lawrence who writes for the British Independent, has just written a book about that. He has actually gone right around the country for a year and he has looked at the fact that people are being sectioned, as Ivor Brown used to say "not because they are suffering but because they are insufferable". I think that is a huge worry here with your new Mental Health Act, the rate of certification will go up and that won't be in the patients' interest that will be in the perceived 'lets take all the risks out of society's interest'.

When we did our survey, and this the same survey of 2500 people in Ireland, North and South there is great news I think from the survey that we ask people “Do you blame people who have schizophrenia?” and only 6% of the population say no. I think that is a very good low result. 6% is believable you would not believe if it was at 0%. We asked people “Well should people with schizophrenia pull themselves together?” and that figure was as low as 8% and that is both north and south. We also asked people do you think if people had proper treatment, we didn’t say what treatment, would they greatly improve and well over half the population said that. We asked about a full recovery and that number was low and I think that is quite a realistic number because many of you and I would probably say yes, most people will make a recovery that is a tough one to answer. I think having seen the best treatments and proper treatments and working in the UK, I would argue that most people will make a full recovery. Anyway it is interesting that Irish people are able to say well we don’t know that, and I think that is a very humbling thing to say, because in the UK the same question gets a 50% response, that is 50% of people in the UK say that most people will not make a full recovery.

Here is the bad news from our survey I am just going to show this as the last two areas, is that there is this link with danger and violence when we asked people about schizophrenia that isn’t there with the other mental health conditions. Just about 50% of Irish people in the Republic say yes there is a danger link with schizophrenia. That figure is higher in the North two thirds and higher again in the UK the exact same question and the word unpredictable has a parallel response to that. I mentioned this yesterday, back in the 1950s when the US had McCarthyism and was worried about flying saucers and the Cold War there was only 13% worried about schizophrenia and violence, now that figure is way up at 70%. In fact in the UK the very very rare instances of violence and homicides by people with mental illness has fallen every year since 1957 so the risks aren’t rising, but it is the perception that is rising and this is something that we have to deal with. I want to just pause briefly, we talked a lot about language at the workshop this morning, all the words on the left I am not going to read them for you, you have heard them before, they are all the insulting words that we use to describe people who are different because of mental health. My point here is this, that we have a new one, Islam phobia. Since September 11 there is quite clearly a breed of people who are absolutely convinced that everybody who is Muslim is going to be strapped with dynamite whatever, but that is the nature of fear and prejudice but we have all these words to describe ageism, racism, sexism, bigotry but we don’t have any word to describe the prejudice and the stigma against mental illness. There is no one word to describe that, so if people often think of themselves as being empowered, well we are not empowered with language here, because the language on the left is the language of insult and stereotype and we don’t have the language we need and we are struggling even as professionals, users and family to agree well should we call it schizophrenia. So language is a tough one.

Just to show you how newspapers sell I am only going to show one example of terrible headlines. This is the Evening Herald Christmas edition and a completely made up story, a woman if you remember she was a taxi driver, she was robbed and stabbed and she

bled, this wasn't a frenzied attack this was a robbery and assault on her and she died. But across the city a woman was going home late at night and a man followed her for a bit so she rang the news desk and that was enough for the news desk to believe that there was a psycho on the loose in Galway. The fascinating thing about this headline, and I have shown this around the world, is just to the left of this they have released 9 IRA guys. It is extraordinary that 9 IRA guys who have killed and maimed almost collectively 80 people and they have done it and they are less scary than one guy who has mental illness and I think that says an awful lot about our society. Now I should say this is from 1997 and good things happened and we engaged with the media, I couldn't find the sub-editor who would admit to that headline in the Evening Herald but I'm afraid that is out there and we have to be aware of that and we have to do something about it.

Again taking from Pat Corrigan's work with David Penn they believe in three strands protest, education and contact and it is good to let journalists know that you exist. You are not just Schizophrenia Ireland you are there to support each other, to find out, to exchange information, you are also an important lobby group and that lobby group should button hole journalists, grab a journalist, engage with them, have a dialogue, I think you will both learn from each side of that. Things like media watch are very important. It just so happened that when I lived in Ireland my newsagent's daughter had schizophrenia and he knew the business I was in and we used to chat about it and he used to keep all the newspapers for me, so he used to do a media watch for me for nothing, so it is well worth doing them. With journalists there is the carrot and stick, usually when a journalist writes a really terrible piece we ring them up and tell them we love their work, they're a great journalist, that was a great piece, it really got me, can we meet up and whatever and then you slip in the comment well actually one person I met didn't really like the schizo/cannibal/murderer headline you wrote and then sometimes you know you can effect a change. I took the Health correspondent from the Sun out to lunch, there you go that is my claim to fame. I said this yesterday and I am saying this directly to families and to service users, tell your own stories, it is pointless for someone like me to rabbit on at journalists and talk down to them because I am a vested interest, of course a psychiatrist will want to create more funding for psychiatry. Tell your own stories, they are so powerful and when they get out there people aren't able to turn their backs on them because the stories you are telling have emotion and charge and reality that nothing we can dream up from the professional end can ever match.

I would also say that education is very important here with the media and it is a two way process. If you do a media watch you begin to understand the media. The more you watch of films, the more you tape of radio programmes, the more you learn about this area is incredibly important. You will get to know about the media, meanwhile the journalists, the broadcasters will get to know and get more understanding about the complexities of mental illness. Personal contact is the best single way to fight stereotypes there is no doubt about that. I won't steal Pat's thunder from him, but if a journalist who has prejudice meets one or two people with schizophrenia and realizes what is going on for them and doesn't feel the fear and bursts the bubble, that is when you effect the best change. This is one of the best things I have done with Schizophrenia Ireland, this is the guide for journalists and broadcasters reporting on schizophrenia. We released this in

1999 and it is a booklet I highly recommend to you because if you do have a copy you might be able to give it to your local radio, your local provincial paper, whoever. I won't labour the point but it explained schizophrenia, it showed examples of bad reporting and it also included, what I think is the best way to describe someone with schizophrenia provided it is relevant to the piece, it is just that, a man, a woman, a teacher, a Donegal man with schizophrenia and this sort of people first language has to come about to make the changes. I am not comfortable when colleagues say he is a schizophrenic I think it is nasty, it is daft, and it doesn't actually help me to understand anything about what that person needs.

More than anything I often think that if myself and Pat and Melvyn and Paddy went around the world and we gave a talk a week about schizophrenia, we would not achieve as much as this one single film has achieved. The image that that portrayed of an intelligent person with difficulties, the strain it put on his wife, the way he really believed that delusion I think was a powerful de-stigmatizing tool. If people are saying well what is good for stigma, this is terrific for stigma, this has been a great year for good movies about mental illness. We have had 'A beautiful mind', we started the year with 'Iris' about Alzheimer's a terrific film if you have ever been a carer with someone who has Alzheimer's, we have also had 'Kaypacks'. So the media is not terrible.

So come back to my definition that stigma is a prejudice based on a stereotypes causing discrimination. This morning we heard about discrimination about using the law and Tom Cooney I felt was very pessimistic. I still believe there is a Disability Discrimination Act on the statute books, mental health is included and test cases are absolutely essential to see is that legislation any good. Don't ever lose sight of that and when someone asks the very important question 'how do we get access to a lawyer', and I am hoping that is one of the few things that the Mental Health Commission will do in a positive way, to empower people to challenge a system that I think is loaded against them. With stereotypes, of course we use the media, contact the media, advise the media, and engage with media. At some point, and I have been lucky, I have had very good opportunities to do a lot radio broadcasting and I have even made a short film, you can actually beat the media at their own game and you can actually start to determine the agenda. The film I made was called 'One in four' and it is interesting this year the Department of Health were issuing information on disability and they started using the phrase 'One in four' and 'one in four' has become part of the language of disability and mental health disability and the people who were involved in that, two different ad agencies Warner Brothers, we have a lot to be proud of the affect of that film. In terms of prejudice this is the hardest thing and I am going to address this last that with prejudice we have to look at target groups and you will have sat in on the Kent Police Awareness Project and the police are very clearly one target group. But the target group I am going to refer to are the target group in the next slide that I think are even more important than the police. In terms of beating prejudice I think we should learn a lot from other countries. There are terrific examples of good practice from Australia and New Zealand. I haven't been to either countries but I have met the Mental Health Commissioner from New Zealand Julie Libridge who is a consumer/service user and her story was so powerful that she was appointed Mental Health Commissioner in New Zealand, which is John Owen's job, a

service user taking over a job that big I think, is an outstanding achievement for a country and ditto in Australia.

The two biggest names in the literature, academically with incredibly readable articles are Pat Corrigan's here on my left and Bruce Link. They have written incredible amounts, very very interesting and very direct ways on how to beat prejudice, how to reduce stigma, Pat will tell his own story. Use your own resources, use what you have got. This conference I think should be about forming alliances with individuals, just one or two and that should be carers to users, other disability groups, adopt a journalist, get in touch with a lawyer, get in touch with the professionals. I am always blown over by the number of psychiatric nurses who come to Schizophrenia Ireland conferences. There are very few psychiatrists here which I think reflects very badly on my profession but psychiatric nurses are great allies and sometimes even psychiatrists will actually do things that are novel and that move out of the comfort zone for them.

I suppose in everything you have general action and you have specific action. There was a lot of talk about changing the term schizophrenia that would be a general action. The important thing in terms of any campaign is that it exists everywhere, it is in your local neighborhood, it is educating your neighbors, it is going to the local school, it is getting your local press involved. But there is also the national agenda. Occasionally you might have an item on the Late Late Show, or something might come up, a new movie, where you could bounce something from that.

There is also specific action and what I want to address is the group that I think most needs education here and that is Doctors and I have used my time in the UK to look at the issues facing UK doctors. We actually identified the problems within each specialty starting with our own and the work we did was called 'putting our own house in order'. We have also published the studies such as I have shown, to look at bad practice and just like we spoke about going into schools, we need to start with medical students. There is now an agreed general medical council, the British Medical Association, Dept. of Health and all the Royal Colleges endorsed report about stigmatization by our own profession and changing psychiatric practice is all about that. My own professional organization the Royal College of Psychiatrists has just joined the Mental Health Alliance and for years it was a crusty, old fashioned, we know what is best for you organization. They have joined with all the service user groups so we get to go on all the street demonstrations now and it is such an exciting time to be a psychiatrist in the UK, we can relive the 60s we never saw. We also go out on roadshows, which I think is very important, you need to take your message out to conferences like this but take it out to the doctors who are part of the problem here.

This is my last slide to finish up, reducing stigma is paralleled with increasing empowerment, there is no doubt about that, we don't try to improve bad prejudices in doctors or journalists and then say oh that schizophrenic guy, I wish he would just take his tablets, that is just nonsense we need to shift the balance. The person who has schizophrenia is the person who needs the care and as I have just said it isn't just a medical label it has a social, economic, political relationship, it has all those

consequences and empowerment is about addressing those. I think this conference has been brilliantly designed, because it started with the media, looking from the outside in and the workshops identified the nuts and bolts of what stigma is and where the solutions might be. Stigma isn't one thing and remember that when you put good laws on the books, the nature of discrimination will change. Look how publicans get around not serving travelers, that is what happens when the out group gets a law to back them up. The three big issues, and this is something I have picked up from yesterday and today, do seem to be secrecy and that's an enormous problem here because if we are going to walk on eggshells and if we are going to say everything to somebody except the word schizophrenia or except the word psychosis, we are not going to make any progress and everyone leaves with that secret and keeping that secret in, I think is an enormous distraction from the work that really needs to be done. The second issue is funding we are the 7% people, we get 7% of the health funding and that is a political issue. I am quite sure that when Government ministers have relatives with mental health problems, they do not see public psychiatric services and that is part of the problem and I think we need to be in their face with that. I think we really need to push this point home, that we haven't by any international standards, got proper services here in this country and you can't reduce stigma without improving the services where people attend. My own point which regularly comes up, this is about equality or parity, we just want the same as everybody else, this isn't special rights, this isn't as I say the get out of jail free card, this is a severe disabling mental illness and we want the same treatment as anyone who has heart problems, asthma, diabetes etc. but more because the illness of schizophrenia is much more disabling than any of those, probably more than all of them put together. I don't think any of us need pity and as I say locally and generally you have to fight discrimination. Everywhere there is prejudice you have to highlight it. The best way I have of saying that is, every time you highlight prejudice, okay you may get somebody's back up but every time you do that, even chip away, you are removing another obstacle to somebody getting better, and that is an obstacle that adds up to exclusion and I very much believe in that. The antidotes, I think, are this idea about education and contact.

I want to close with just one thing, I was very conscious in Paddy and Mervyn's workshop this morning 'what is the solution' and sometimes you can draw back and look at parallels in history and it always occurs to me that during my mother's lifetime, people were exterminated in Nazi death camps and by the way mental illness, they lined them up first and you will be pleased to know that psychiatrists shortly afterwards. Having said that in my lifetime the civil rights movement in America, effectively had a system of apartheid, where they were discriminated against day by day and what things did they do to actually change that. It occurred to me the enduring message that I have is of one black woman sitting on the bus for whites only, and in trying to be imaginative about this I think that is what it takes. I think it takes a lot of courage turning your back on the secrecy that is already there and going up to the Government Minister, going on to the television news shows and saying I am a citizen of this country and this is how I am treated. Thank you for your attention.

*Thank you very much Dr. Peter Byrne. What I am going to do now is to explain the arrangements for the afternoon. I am now going to introduce the next speaker to come on and he will be talking until 4pm or shortly after that and then we will have half a hour because this seems to be an important session to give people the opportunity to raise any particular points or ask any particular questions and we would hope to wrap up the afternoon about 4.30pm*

*Our next speaker needs very little introduction, he is world famous, Professor Patrick Corrigan, Professor of Psychiatry at the University of Chicago. Now as you would expect with a name like Patrick Corrigan his family background is from Ireland. He tells me that he comes from Wexford like a lot of famous American people, President Kennedy came from Wexford so there you are following in a fine tradition. So then let me introduce Professor Patrick Corrigan. Professor Corrigan has been very much involved in the area of stigma and research, published a lot on stigma eradication. He has been involved in rehabilitation psychiatry which is a branch of psychiatry which very much relates to the needs of people with schizophrenic type illnesses. He is very learned, very well researched, very well published and it is a great privilege to have him here this afternoon.*

### **Professor Patrick Corrigan, Professor of Psychiatry, University of Chicago – “Don’t call me Nuts! – Coping with the Public Stigma of Mental Illness”.**

Well I have just learned two things since I have been in the country the Corrigan's are part of the Kennedys, so I can't wait to get home and tell my Mom and Dad that we are part of the Kennedy's fortune, and the other is that people keep telling me that Corrigan's are from Northern Ireland so there is a bit of coming home here and learning about our roots as such.

Let me tell you, I am a social scientist by trade, my goal is to go out and get information and give it to people, so they can use it powerfully. I give it to doctors so they can determine what meds work or not, I give it to policy makers to determine what services work or not, and I give it to advocates so they can go and let the rest of the world know what works right and what does not, in terms of stigma. I am also a person of the sixties, I am old enough to be mostly a voyeur of the sixties, in fact my whole goal in college in the seventies was to protest and drive my Jesuit fathers nuts.

But I think it is important to start my conversation with you about stigma by a quote by Booker T. Washington. Booker Washington was known as a free man, which is actually an embarrassing time in American history, where black people had to be freed of their slave background and they were called free men and he said just after our civil war ‘then all things that are purely social, we can be as separate as the fingers yet one as the hand and all things essential to mutual progress’. I keep Dr. Washington's messages like this and other peoples close to me because I think my work on stigma is fundamentally an issue of social justice. My goal, and what I can do partnering with you and Peter and

other people partnering with you, is to give you the data, give you the facts so you can go out and clean up this mess in the world.

Let me give you an example, actually this is an example I tend to use with psychiatrists, it'll probably be much more common to you folks and you would probably understand the stigma in it but it is the story of Franklin Goodman. Franklin was what we would call in America, consumers, and you would call service users, and I was providing rehab services to Franklin. He was fully employed in a hardware store, 30 years old, lived in his own apartment, had hobbies, played softball, had a very concerned mother, was struggling with schizophrenia, was hospitalized several times for schizophrenia. The first time I met him he was coming out of an emergency room, where he had had an acute flare-up, he was actually quite delusional, he was punching at the residents, ended up in the hospital for several weeks, needed significant time to recover. Here was a man Franklin Goodman with schizophrenia, compared to Harriet Oglesby who also had a long chronic disorder. In her case she was also working full time, lived in her own apartment, had hobbies, had concerned relatives and believe it or not, she came in the emergency room the same night as Franklin did, in her case in a diabetic coma, because she wasn't able to manipulate her sugar intake. She had an acute flare up of her disease and she had to go into hospital for a couple of weeks and needed the time to recover. The interesting difference is, what became of the two of them. Harriet had to convalesce for a month or two, move back in with her Dad, had to meet with doctors and nurses about how to take care of this insulin problem but eventually went back to work, went back to living in her apartment, went back to her hobbies and her social life. Franklin Goodman, you know a lot of doctors I was with said you know Franklin has schizophrenia, now we are going to do latin, schizophrenia is dementia praecox. 'Dementia' means Alzheimer's disease, 'praecox' means precocious or at a young age. He is eventually going to end up demented and unable to take care of himself, so we might as well face that now, we might as well take him away from his job, it is only stressing him out, have him move back in with his mother which is across town, so he is going to end up losing his hobbies and end up giving up his friends. Now there is an interesting point about stigma here, it is that his mother who is the big booster behind this, anyone would agree with this, she cared for him deeply so it was not an issue of a hateful prejudice behind what she was doing, there was an issue of misinformation and myth and misunderstanding.

This is what we are trying to struggle with stigma, and so it has been my privilege for the last five years to partner with several advocacy groups around the Chicago area. First we start out with what we seemed to know, and you know we don't have to do a lot of research to find out what we know about stigma, all we have to do is to sit down with groups like this and they can tell us. They can also tell us what we need to know in terms of the researchers questions, but the big question advocates have is, how do you fix it, how do you change it and what I want to talk about today is some of the research we've looked at, about what is the best way of changing the stigma of mental illness.

What we seem to know, and Peter talked about this in some of his research, what we seem to know is, that there is clear evidence that stigma is a major hurdle against housing, do you all know the acronym 'nimbi', it's a big one in Chicago, not in my back

yard which means housing is okay in your back yard but don't bring it into my neighborhood. Work, the United States has the America with Disabilities Act that makes it illegal for an employer to discriminate against anybody because of their mental illness. Despite that we, and other groups, show it is very easy to get around. All you have to do is to find a big gap in somebody's work history and they say they were in a psychiatric hospital and you just breathe in and you never interview them anymore. Criminal justice healthcare, another study Peter talked about that is done in the United States, is that if you have a cardiac illness and you are diagnosed with a major mental illness, you are 2-3 times less likely to be referred on to the cardiologist. Finally a big stigmatizing group is policy makers. They are not providing the necessary resources and the appropriate laws to protect people with mental illness. So the lesson is the problems with mental illness are not due to the disease alone, they are also due to the world people live in.

So what I have done for the last few years is set up a Chicago consortium for stigma research. As I said there is power in knowledge, so what we have gotten together is researchers from eight different institutions to put together what knowledge we have, and what different disciplines we have, to put together a National Institute for Mental Health Stigma research center. The very important partners to the center are the public partners, there are six in our center and these would be equivalent to Schizophrenia Ireland, and perhaps the 500 lb canary in the United States in the consumer movement, is NAMI, the National Alliance for the Mentally Ill. There is also a National Mental Health Association, a totally consumer run group called the Mental Consumer Education Consortium and three other groups. They are there because they have strong opinions about how to fix this and they guide our research quite directly.

Our goals are to first come up with some explanatory models of what stigma is. Secondly to try and define its impact. Thirdly and most important to try and find out how to fix it. Finally the message I want to give you as a social scientist is, that I really believe that science first generates knowledge but second generates power, because a lot of people look to me for answers to questions, policy makers say which intervention should you do, doctors say which med should you do, so I want to provide you with some information, you can go out and use in the battle you are doing. If you're interested in more information about this, this is our website [www.stigmaresearch.org](http://www.stigmaresearch.org) We have listed about fifty papers, we have had the opportunity of writing in the last few years and you can order them on line.

What is stigma? Let me be an academic a bit and see if I can take this big amorphous thing called stigma, and break it into something that is much more tangible. As I have gotten to know over the past five years, I think stigma impacts individuals, so it impacts everyone in this room as individual human beings and it also impacts the societies in which we live in. In terms of individuals, as Peter alluded to, our group tends to distinguish stereotypes, prejudice and discrimination. I used to illustrate this example by showing how it would play out in African Americans but believe it or not the issue of colour is still so raw in the United States that we feel guilty sharing with you disrespectful images of African Americans. So then I used to do it by going after my own heritage which is Irish American, which in this crowd should really go over well, but in

the United States the stereotypes of Irish is that we are all drunken sots who make terrible mates and blindly follow the Pope. That is a stereotype. You cannot live in America without learning about stereotypes, so stereotypes cannot be erased. They are something that just occur, there are stereotypes about blacks, there are stereotypes about women, there are stereotypes about gays, they are just out there.

Prejudice is agreeing with the stereotype, yea that's right all Irish Americans are drunken sots, and having an emotional reaction to it. I am either afraid of them, they might hurt me or I am angry with them because I can't afford to get drunk and stay up until 4 in the morning and I really enjoyed learning about my Irish roots since I got here but I have had a hard time keeping up.

Discrimination is the behavioral result of that, those damn Irish Americans are all drunken sots so I am not going to hire them, I am not going to rent to them, as a matter of fact our group is particularly interested in discrimination in key power groups. Let me just say now, it would be nice to erase stigma altogether in the public but as consumers who work with me say, what is more important are these people in power doing things to us, like employers who won't give me a job, or landlords who won't rent to me, or legislators who won't give me the appropriate legislation or policemen who over react, or primary care physicians who won't give me the proper medical care. So I am interested in discrimination in these key power groups. I am also interested in this last group called potential consumers. You know it is interesting that we hear a lot of concern about how screwed up the mental health system is and you know you are right, it has got a lot of problems, but it has some benefits to it. I mean most people in the room perhaps can tell stories that despite the bad side to it, the medications had benefits, the counseling you've got from counselors and psychiatrist and the like, the case management, the peer support all of it had benefits. There is research done in the United States that suggest two out of every three, 66% of the people with serious mental illness never go and get it. Now it would make a lot of sense for you to come out of the closet to get the kind of treatment that we have all known here, but people who are potentially consumers do not pursue it, so we have to reach out not only in helping ourselves, but to changing the systems who provide better care and to decreasing the stigma so that potential consumers seek it.

So I am interested in what the public does to people with mental illness, the left side of the equation, I am also interested in what people do to themselves, we talked about this a bit yesterday. The point is that people who are born in the world with the message that being mentally ill is bad, and then they turn around and find they have a mental illness themselves, so they end up beating themselves up with it.

Yesterday we talked about how to look at the self-stigma side of the equation, today we want to look at how to fix the public. There is another part about this though, stigma not only exists in the hundred or so people's minds here, but it exists all by itself in society, what sociologists look at. It exists in terms of institutional policies, in other words what happens when a powerful person makes a rule like Dennys, I don't think you guys have Dennys here in UK, Dennys is somewhere between McDonalds and a nicer restaurant. It has a big chain, it used to have a policy that they wouldn't serve blacks after 10 o'clock

as formal policy. They used to also have a policy that if they had the option of hiring a black or a white, they would go for a white. Now you might think this is not a big surprise except this came out two years ago. So there are institutional policies that hamper people with mental illness and I will talk about these a little later.

There are also social structures, what happens over time when historically there is a difference between people with mental illness and other groups. What happens politically or economically? None of the function of any ignorant or angry person sitting at the back of a room making stigmatizing decisions but purely as a function that is the way the system is. For example in the United States we have a big concern about what we call parity, which I think, might be what you call equity. In the United States the quality of care in the physical health system is about 10-12 times better than the quality of care in the mental health system. So people are looking for parity so that you get the same resources in mental health as you would in physical health. The problem here is putting aside the whole stigma issue, if you take all that money and put it into mental health, you perhaps end up taking it from the physical health side, so some of the biggest people fighting it are physical health insurers, not because they necessarily buy into the stigma but because there is already disequity and they don't want to lose their share of the pie.

I talked a bit about structural stigma and the stigma that comes out in institutions and I want to put this up. This is Jim Crow, I am not sure if you know much about American history, after the Civil war and the emancipation proclamation, blacks were supposed to be on equal footing as the whites, in the south in particular but most of the states of the land came up with Jim Crow laws. The purpose of Jim Crow were to maintain the disequity at the legislative level and you have probably seen it in movies or at drinking fountains for blacks and whites, and blacks went to the back of the bus. These are the kind of things that keep us in mind and when we are working in the states, what laws keep people with mental illness at the back of the bus.

Where does the stigma come from? A lot of people talk about the media, I would like to put these set of slides here because they get my blood riling, because again this is fundamentally an issue of social justice, but it also helps us to understand what the stigma are and what they come from. One place is from the media, it is important to realise that as people with mental illness were disrespected in the media, so have lots of other groups through the ages. Sam Keane wrote a wonderful book called 'Faces of the enemy' where he puts into perspective, what you folks who are struggling with mental illness stigma, in terms of disrespect other groups have experienced. This is from an American textbook from about the 1890s, science is saying *Negroes still at ape stage, races positively not equal*. I have to admit again, having grown up in America, having grown up in the sixties and seventies and Dr. King and people were struggling with the indifferences, I still cringe showing this. I think this is important not only in showing how we disrespected people of colour, but more importantly how we did this from a scientific viewpoint, and how often do we justify mistreating people with mental illness because there is scientific evidence that fills in the blank, in how they are inferior. You see disrespect in religious groups. This is the front of a polish book showing a Jewish man as a rat, it is also interesting how we tend to disrespect people by framing them as animals, you will see

that issue come up again. Woman's proper place, also the idea that stigma comes out in terms of moral victims, a woman's proper place of course is in the home, blacks proper place is of course in subservient jobs, people with mental illnesses proper place is the hospital.

So how is mental illness disrespected in the media, Peter alluded to some of this yesterday, one is in slasher films, the most popular cinematic maniacs as Darth Vader. I mean it is interesting because I was once at a conference actually with Peter, while my fourteen year old son was at Disneyland and as I was sitting and lecturing about stigma he was coming home from Disneyland with a psycho hat on, splattered with blood. So he learns, as most thirteen and fourteen year olds do, that mental illness is equal to maniacal homicidal behavior, as is also shown in Friday 13<sup>th</sup>. But you know movies are supposed to do that, right, I mean they are meant to titillate us and supposed to go over the edge. Newspapers are supposed to be unbiased. The New York post 'Freed mental patient kills Mom', okay that is tabloid, so they are supposed to do that. This is the Reader, the Reader is one of our most esteemed newspapers equivalent to the village voice in New York City, 'is this man a monster'. Now this is a story about the poor fellow in the center, who in a psychotic fit kills his wife, spent thirteen years in a forensic institute, was trying to be released back to Chicago and the neighbors were in an uproar. You see magazines like the New Yorker magazine again a very serious conservative magazine says 'United schizophrenics of America annual convention'. You see in advertising, the problem with advertising is, how it's so omnipresent also how it slips in under our radar. It says 'this offer could get you committed, Crazy Eddie's record asylum maniac out of control to offer these deals, we would have to be committed', 'lobster lunacy' or this one, this actually won the Cleo award, the Cleo award is the American Oscars for advertising, this is selling pecans in straightjackets, which one black colleague of mine compared to trying to sell rope by showing a lynching. You see in the comics, you don't suppose this guy is really FBI do you, it came out after September 11<sup>th</sup> 'just plain nuts'. This is particularly of concern because it suggests that it is not only okay for public to laugh at people with mental illness, but so do we professionals, so everyone might as well be in on the joke. You see it in kids books, this actually came off my daughter's shelf, Shelley Silverstein is a very well known author in the States, this is from his dictionary *S is for Stanley, Stanley is a crazy murderer who likes to murder little girls and boys early Sunday morning* so Elizabeth, since she was four, was learning that what Daddy did was work with murderers, who were crazy. Remember the rat and the Jewish person, here we have I am not sure what kind of animals they are, animaniacs which is a kids show on Saturday morning showing that mental illness is sort of equivalent with this maniacal silia animal behaviour. You see people with mental illness in part referred to and shown as dangerous, the other big way you see them is what is called the benevolence stigma. It is called the benevolence stigma because it is nicer than looking at everybody's maniacs but it still has a lot of problems to it and particularly look at people as lovable buffoons like this, from a movie called 'The Dream Team', these four people are patients at a Manhattan State psychiatric hospital who got out, and had this zany, whacky, silly day bouncing around doing stupid things in New York. 'Me, myself and Irene' which just came out in the last couple of years, if you haven't seen it, it will get your blood boiling, this is probably one of the best ways of doing it, for disrespectful image of people with mental illness. The

caption here is where crazy glue comes from, again the sort of subtle message as being mentally ill is kind of a silly thing. You see in advertising how to avoid hiring lemons, nuts and flakes. I like to put this in because your culture, as mine, firstly really esteems the fourth state, freedom of press is a huge thing. Second there is a sort of political correctness and concern about that, going around the States, shouldn't we just lighten up a little bit. I have to admit I have been preaching for about 15 years, preaching well there's my catholic background, I have been lecturing now for about 15 years and I used to use Garry Larson cartoons to sort of lighten up this sort of thing, here is a Gary Larson cartoon it says at the bottom things from Eponema and the lower left hand corner is the homicidal maniac. A friend of ours named Otto Wall says you know this kind of satire humour has a really legitimate purpose in society like ours, for lampooning the powerful and as several of us have done, we have no problem in lampooning doctors or politicians or lawyers, because they got a lot of the clout, but right now people with mental illness tend to be at the lower end of the power range, so as long as we allow this kind of humour to go on the longer we are keeping people at the lower power range. But you know an easier way to get at it is, when I grew up jokes were the in word, and jokes about Jews, and jokes about people of Polish extraction, were huge where I came from whereas now they feel like fingernails on a chalk board. You will probably know that your anti stigma programmes are going well when you can turn on talk radio and somebody doesn't say whacko, nut or cook.

The question then is, how do you fix this issue of stigma? Bob Londine who is a friend and colleague of mine, is also an individual who suffers with a schizo effective disorder for the last 20 years. He and I wrote a book called 'Don't call me nuts' that came out about a year and a half ago. What we wanted to focus on mostly, was not the problem because we think there is a lot to issues of problem there, but more how to fix it. So what I want to talk to you about today are models of mental illness and how do we fix them. Since we are going through time quickly, let me just go to how to fix it. Actually Peter sort of alluded to this earlier, is in a review we did, we sort of thought of all the different ways of changing public opinion and it can be broken down into three, education, protest and contact. Education, okay public here's the facts, protest shame on you stop thinking that way and contact meet my colleague Bob Londine and he will tell you about his history. So is a lot of people running out and doing this real fast, but not a lot of evidence of what works and what doesn't work. So we have done a bunch of studies on the public, trying to find out whether education, contact or protest works best.

Education is a review of the myth about mental illness and the facts that counter them. What I want to do is focus on one myth in particular and run through the other examples. This myth according to research in the States is probably the most harmful. It is that people with mental illness are only one step away from being homicidal maniacs and that is a highly endorsed view. Peter talked about the general social survey work that was done in the States, that suggests from 1950 to now, about seven times the number of people agree with that, it is a bad view, because if you view any group as dangerous you want to avoid them, you don't want them working next to you, you don't want them living next to you, so what are the facts. One thing I would suggest is if you are going to deal with the education approach you have to provide information that is based on

## **CONFERENCE CLOSE**

By Mairead O'Sullivan, President of Schizophrenia Ireland

It gives me great pleasure to have this opportunity to bring to a close our 13th Biennial Conference. I am sure everybody who has attended the conference today and yesterday will agree that it has been informative, educational and thought provoking.

On behalf of the Council of Schizophrenia Ireland and all the membership I would like to thank each and every one of you for your presence here. The turnout at this year's conference indicates the degree of interest that there is about schizophrenia and mental illness and specifically about the issue of stigma.

I sincerely hope that everybody who has attended here can leave having learned something new and that they can take with them some hope for the future. Since 1975 Schizophrenia Ireland has been playing its part in bringing hope to people who have a diagnosis and their caring relatives and friends. In many instances it is this hope that energises and helps people to cope with the demands of such a severe illness and which gives them the strength to pursue recovery.

Before we close I would like to thank a number of people. First a big thank you to everybody who was involved in the presentations over the last couple of days. I include here the Chairpersons of the various sessions, the guest speakers particularly Minister O'Malley T. D. Minister of State at the Department of Health and Children and Mr. Pat McLoughlin, Chief Executive Officer of the South Eastern Health Board. I would also like to thank the presenters, from Ireland, England and the United States, who gave their time, energy and expertise to make this conference a fulfilling and enjoyable occasion.

Finally, I would like to thank the sponsors of the conference this year who were the Irish Medical Organisation, South Eastern Health Board and Lilly. Without them it would not have been possible to host this two-day conference.

A final word of thanks to those people in SI who were responsible for the organisation of this conference. Lastly I wish you all well and a safe journey home and look forward to seeing you in the future.