

Survey results are in

Although finances, physical health and loneliness remain an issue, the survey has revealed several areas of improvement in the past 12 years.

Every person with schizophrenia, everyone who is affected by schizophrenia has a personal story to tell but now a broader, new picture has emerged of how Australians with severe mental disorders face the challenges of living with psychosis.

It's revealed in the second National Survey of High Impact Psychosis (SHIP), carried out to provide important information to help develop policies and plan services for people with severe mental illness.

The Schizophrenia Research Institute, through the Australian Schizophrenia Research Bank, collaborated with the survey which involved screening people in five states and conducting structured clinical interviews. "This is the largest and most comprehensive national survey of psychosis ever undertaken in Australia," says one of the authors, Professor Vaughan Carr, CEO of the Schizophrenia Research Institute. "It provides uniquely valuable information for policy and service development to help improve the lives of people with schizophrenia and related disorders."

The survey found "encouraging signs of changes for the better on several fronts" in the past 14 years. These are: an increase in community-based health services, a drop in hospital admissions from 59 percent to 39 percent, including involuntary admissions down from 31 percent to 21 percent and improvements in the pattern of accommodation. There are also signs that outcome has improved since the previous survey over 12 years ago.

People defy simple characterisation

However, the survey reports a "striking feature": the wide variation in illness profiles that defies simple characterisation. As an example, in the majority of cases age at onset of psychosis is less than 25 years of age but as many as a third report onset after this age. Another example is that while disability pensions are received by a

majority, almost a third had some form of employment during the previous year.

People in the survey identified a number of leading challenges they face, with financial matters the number one concern (named by 43 percent).

The challenge of financial security is real, with three-quarters of people with psychosis earning less than half the national average disposable income, and for most the main source of income is the Disability Support Pension. "Thus, many live in poverty and are at risk of all of the adverse consequences of belonging to an underclass", according to a paper on the policy implications of the study.

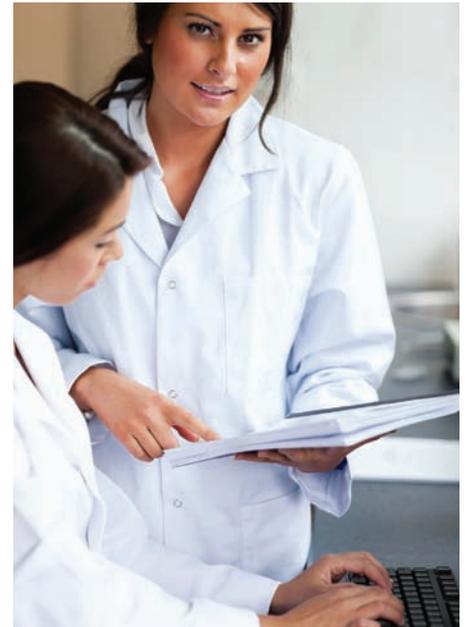
The second biggest challenge is social exclusion: 37 percent of people in the survey name loneliness and social isolation as a common worry while almost half have never been in an enduring intimate relationship and 13 percent have no friends at all.

Lack of employment is high on the list of challenges. Only one-third of people with psychosis report having had some employment in the past year, which ties into the major problem of dealing with financial security. Paid employment not only helps deal with financial matters but it's also "an important form of community engagement that brings with it a degree of self-esteem."

Stigma or discrimination was experienced by 38 percent of study participants and women reported the problem more often than men. For some people, just the fear of being discriminated against or the stigma of having a severe mental illness stopped them from doing the things they wanted to do.

The burden of poor mental health

The survey canvassed the difficulties of coping with poor mental health, the high rate of suicidal thinking, widespread substance abuse (66 percent smoke



tobacco) including alcohol and other drug abuse. Not only are these proportions much higher than the general population, but they've increased since the psychosis survey of 1997-98.

The survey found that 56 percent of women and 26 percent of men were parents and a substantial proportion, particularly women, had dependent children living with them. While programs have been established in some places for children of parents with a mental disorder, there is clearly scope for expanding them and further evaluating initiatives aimed to benefit both parents and children.

The outlook for treatment of psychosis has improved in several areas but new problems have emerged. For example, psychosocial interventions don't appear to have been as widely used as they could be, and there are plenty of areas where new policies and services could be developed.

To read the full SHIP report visit www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-p-psych10

CEO's Report

Why is the SHIP study so important? First, it was very large, involving 1,825 participants across five Australian states, accurately representing the population of people with psychosis receiving care from mental health services or non-government organisations. This means that its findings are reliable and can be regarded as a correct reflection of the true state of affairs for people with psychotic disorders.

Second, to some extent it told us what we already suspected was the case – that psychosis is associated with poverty, loneliness and social disadvantage; that it begins in youth and is lifelong. It is always useful for research to confirm what is generally known.

Third, it told us a lot of new things as well. Let me give some examples.

Because physical health was measured for the first time on such a large scale, we now have good information on the extent of physical ill-health and its risk factors in this population. This can guide us in developing strategies to tackle this problem so as to improve quality of life and life expectancy.

Unfortunately, alcohol and drug abuse have increased considerably since the last survey in 1997/98. This is a worrying trend because it is not only associated with poor outcome, but current means for treating or preventing substance abuse in this group are not particularly successful. So, much more work needs to be done in this area.

In spite of this, there are some indications that the outcome of psychosis has improved over recent years. There is a suggestion that the course of illness may have shifted from chronic and continuous to more of an episodic pattern. Hospitalisation rates appear to have declined and people are accessing services at a higher rate than before. On the other hand, we need to do better with what we already know and that is to deploy more widely those psychosocial treatments and work rehabilitation programs that we know are effective but are not reaching people to the extent that is required.

So it is a mixed report card. Some things are better, some things are worse, and some have remained the same. There



Professor Vaughan Carr, CEO, Scientific Director

“There is a suggestion that the course of illness may have shifted from chronic and continuous to more of an episodic pattern.”

is much to do, not only to improve services, but to continue research to find better means for relieving the suffering of people with psychosis and their families.

Challenges over the next year as identified by people with psychotic disorders:



Report gets tick of approval

For Simon Swinson, who's had schizophrenia for 30 years, the SHIP report is appropriately named, because like any good ship, the findings have brought home many of the issues that have concerned him.

“I have long thought that people with psychotic illness form an underclass,” he says in reaction to the report's findings on the high rates of physical health problems.

Simon, a supported worker at a restaurant in Newcastle, says financial and employment issues are indeed the key issues. “But the lack of low skill, entry level positions means that many people seeking work, irrespective of whether they could go the distance, are automatically excluded from the process.”

Simon would like to see government and private enterprise provide specialised jobs for the severely mentally ill, many of whom he says, have excellent skills, perhaps for as little as eight hours a week.

The stigma associated with a severe mental disorder is ever present for people with schizophrenia and Simon believes stigma is an inadequate word to explain the prejudices they face. “I suggest a term like psycho phobia instead.”

Another problem highlighted in the report that connected with Simon was weight gain. “As a side-effect of second generation antipsychotics, weight gain is very debilitating. Not only does it drive people to stop taking their meds, but affects life expectancy,” he said.

Different treatments for his and her brain?

Down the years, poets and writers have written about the differences between men and women.

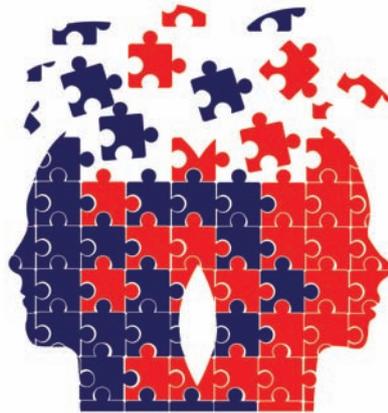
Comedians have joked about the gender gap. Singers have sung about what makes the sexes different. Intrigued by the human brain, scientists have discovered that the brains of males and females have structural, chemical and functional differences.

It comes as no surprise that investigators should take their research further and study the differences in the brains of men and women who have schizophrenia. Discovering the extent of the differences underlying schizophrenia in the male and female brains will not only assist medical knowledge, but it could raise the possibility of the need to develop sex-specific treatments or medications.

It was against this background that Dr Mei Han, an Australian Schizophrenia Research Institute researcher based at the University of Wollongong led a team of researchers in China to study the cognitive functioning of 471 men and women, 200 of whom had schizophrenia

The project involved participants taking a range of memory, language, reading, attention and visual-spatial (perception of objects) tests.

The researchers found there were significant differences between the cognitive function of men and women with schizophrenia, with the women



outperforming men in verbal learning and memory. However, there were no differences between the sexes in language skills or visual-spatial abilities.

“This study means doctors and health carers need to pay more attention to cognitive deficits of immediate and delayed memory in men with chronic schizophrenia,” said Dr Han.

On the question of whether treatments should be targeted specifically at men, Dr Han said, “Yes, the exact pathophysiological mechanisms (changes associated with disease) of these gender differences in cognitive function of people with chronic schizophrenia should continue to be investigated.”

To intervene early or not?

The question of early detection for severe disorders such as schizophrenia has been the subject of much debate and it comes in for mention in the SHIP report.

Just over 8 percent of the people in the survey reported the use of early intervention psychosis programmes. While there are different shades of meaning of the term ‘early intervention’, broadly it refers to detection and best practice treatment of the first stages of psychosis.

Early intervention has a number of benefits:

- It is good to relieve suffering, where possible, sooner rather than later
- The short-term benefits have been demonstrated
- It usually provides a gentler, less traumatic entry to mental health care than an acute psychotic crisis and involuntary hospitalisation
- Its early benefits might be maintained longer if high-quality treatments and support are sustained over time.

While early intervention ought to be available more widely in clinical services, interventions designed to delay or prevent the development of psychosis must be treated as experimental and not be adopted by mainstream clinical services.

The challenge of poor physical health



One of the new problem areas documented on a large scale for the first time in the National Survey of High Impact Psychosis (SHIP) is the alarmingly high rates of physical health problems. The survey says people with psychosis have poor nutrition and are affected by physical ill health at rates far above those of the general population.

Half of those in the survey had metabolic syndrome, a quarter were at risk of cardiovascular disease in the next five years, 45 percent were obese, a third reported no or very little daily physical activity and two thirds smoked tobacco.

The challenge for health professionals as well as for people with psychosis is that there is not a great deal of evidence about how best to address physical health problems in people with psychosis. We can start with what works in the general population for improving nutrition, reducing weight, lowering blood pressure and treating abnormal blood lipid and sugar levels. But more research is required to determine what works effectively in the psychosis population, given its specific characteristics, including the use of antipsychotic drugs.

Research Profile

Peta Snikeris

Research Assistant, Wollongong University Lecturer for Advanced Topics in Pathophysiology

Research area:

Neuro-immunology

Educated:

University of Wollongong.

Doctorate:

How the schizophrenia susceptibility gene Neuregulin 1 affects the immune response in the brain and body.

Personal Interests:

“Many”. Current interest in cooking and decorating with chocolate. Fascinated by its history and its role in people’s emotions.



Peta Snikeris (right)

As a schoolgirl growing up in Wollongong, Peta Snikeris was always curious about things around her. “I was always asking questions and trying to understand how everything and everyone worked,” she recalls. So it’s no surprise that Peta took up research as the best way to find the answers to all her questions.

Her natural curiosity has become her job. Peta likes working on the unknown; asking research questions for which there are no answers – yet. “I feel like each day I get to work and try to figure out another piece of a great big puzzle,” she says. Her work in helping to put those pieces into place supports her goal to gain a greater understanding

of the brain and schizophrenia.

Peta started her research in the field of immunology but her interest in how the brain works led her to combine the two areas and investigate the role the immune system might play in schizophrenia.

Her current project is looking at whether a mutation in a gene that makes people vulnerable to schizophrenia can also change how their immune system will respond. “I’m specifically looking at whether these immune system changes are evident in the brain as well as in the rest of the body.”

Ultimately Peta wants to work in another area of research that has a

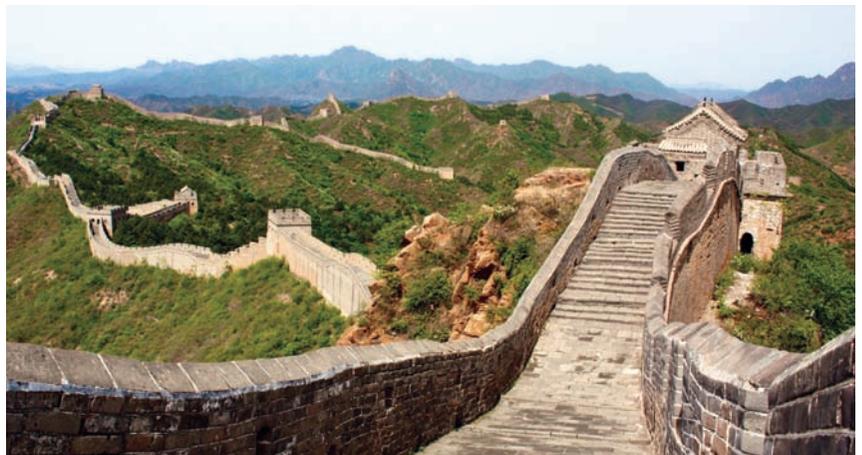
close association with schizophrenia – suicide. She would like to examine the neurobiology and neuroimmunology of suicide.

She believes the topic remains taboo in society and more needs to be done to educate the community that people with psychiatric illness who contemplate suicide are not selfish or simply seeking an ‘easy way out’.

As well as meeting her busy research schedule, Peta is also a tutor at Wollongong University which means she has to plan her routine and balance her life around spending time with family and friends while fulfilling her passion for asking questions and finding answers.

Register now: Trek for Mental Health

Dust off your bucket list, it’s time to tick off an epic adventure and help raise funds at the same time.



The Schizophrenia Research Institute, in partnership with Inspired Adventures, offers supporters a 10-day trek along the World Heritage listed Great Wall of China that will take you through some of the most breath-taking sites the ancient wall has to offer, including areas not often visited by tourists.

As well as climbing the well-known Stairway to Heaven and walking past the Panlong (Coiling Dragon) and Wuhu

(Crouching Tiger) mountains, you’ll also get to stay in small villages along the wall to experience local culture and perhaps learn how to cook traditional dumplings. Your trip will include between three to six hours of hiking on most days, but there will also be the chance to shop and visit the historic sites of Beijing as well as the Giant Panda Breeding Research Centre where you will see pandas in their natural habitat.

The trek will take place in October 2013 during Mental Health Awareness month, giving you the perfect opportunity to promote awareness of schizophrenia in the community and raise money to fund research. You will be given ideas and support throughout your fundraising journey as well as ways to prepare for the trek in October. Even first-time trekkers will feel confident as they tackle this inspiring part of the world.

To take part in this life-changing event, contact Helen Trussler on: **02 9191 9248** or email helen@inspiredadventures.com.au and she will send out further details, or you can register here: www.inspiredadventures.com.au/SRI/china2013



Betty Kenealy

Hand in hand with charity

Betty Kenealy's fingers are never still, which is a good thing, because her busy hands have raised \$15,780 for schizophrenia research.

It started 27 years ago when her daughter Karen was diagnosed with schizophrenia at the age of 20 and she hasn't stopped. Betty has knitted, crocheted, stitched and sewn thousands of assorted baby's clothes from cardigans and dresses, to booties and bunny rugs, selling them at local markets near her home in the St George area of Sydney's southern suburbs.

Of course she couldn't have done it without husband Bill, who's carried the boxes, loaded the trailer and driven her everywhere.

Recently she lost the markets as an outlet but she's found two retail shops that have agreed to sell her latest line – Christening Booties.

Now in her seventies, Betty's thoughts often turn to retirement but she can't give up a lifetime hobby that's turned into a cause. "I keep saying I'll give it away but I really enjoy working with my hands," she says.

But there's a greater reason why Betty's fingers will never be still. Karen is back in hospital in Toowoomba following a relapse with her schizophrenia. While Betty is unable to help her daughter in person, she knows that by continuing to make and sell baby's clothes, she's making a worthwhile contribution to unlocking the mysteries of schizophrenia.

Losing his hair for a good cause

Greg Boucher was well known in his local Victorian community for his incredible head of hair. He was proud of it but not too proud to lose it for a good cause.

"People always said if I was ever to cut my hair I should do it for charity, and when the time finally came I knew exactly who I wanted to support," Greg said.

He decided that cause should be schizophrenia research.

"As an ambulance officer I regularly deal with the effects of mental illness within my community. And I know that schizophrenia is one of the most devastating for the individuals and their loved ones," he said.

After setting up a simple fundraising webpage through www.everydayhero.com.au people were able to show their support for his brave move. His local TV and newspapers followed his story and he captured a great following.

Greg raised an incredible \$7,000 for the Schizophrenia Research Institute.

If you are interested in fundraising for us then give us a call on (02) 9295 8688 to discuss how.



Greg Boucher before



During



After

Thank you

We had a mighty team of 23 entrants running to raise money for the Institute in this year's 14km City2Surf race, held in August. Their stellar efforts managed to raise more than \$24,000 to go towards schizophrenia research. Jostling with thousands of others on the run to Bondi was Kathleen Smith, who wore a black mask and bright pink sash to raise awareness of what it's like living with schizophrenia, Roberta Elston, whose son has schizophrenia, Jody Graham and son Tazman, Professor Vaughan Carr, CEO of the Schizophrenia Research Institute and Liesl Duffy, the Institute's Director of Operations. Kel Beckett, Director of Development thanked everyone for the



Kathleen Smith raised more than \$1000

training, the commitment and the effort to not only take part in the event, but for successfully raising vital funds for schizophrenia research.



In Memoriam

We offer our condolences and send thanks to the following families who have asked mourners to donate to the Institute in lieu of flowers and in memory of their loved ones. Families and friends who may wish to set up a tribute page for a lost loved one and raise funds for the Institute can do so at www.everydayhero.com.au/event/inmemoriam.

Giuseppina Barrasso
Adam Shaw
Terry Kay
Geoffrey Davis

Carina Angela Fink
Guglielmo Pagliarella
Luke Aarons Robins
Natasha Snow

Our thanks Major Partners and Supporters

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Many thanks to all of our supporters who have renewed their commitment to us and/or donated recently.

For privacy reasons we have chosen not to list all of our individual supporters but would like to take this opportunity to thank and acknowledge their generosity. The commitment of the community is vital to our ongoing success (July 2012 – September 2012).

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