NCOSS Conference Paper

Working Together for Mental Health

Poverty and Social Exclusion

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The impact and experiences from a consumer perspective

Abstract

People with mental illness, and particularly those with chronic mental illness, are more likely to have low incomes, fewer social, economic and cultural resources, and experience marginalisation and exclusion in everyday life. They are less likely to access the available disability support services that aim to enhance the social participation of people with disability. Problems exist in the mental health services (MHS) that allow people to fall between the gaps within them (e.g. between inpatient and community rehabilitation services) and between these services and other government and non-government disability support services. Social movements of people with mental illness rely heavily on MHS consultative arrangements and internal consumer advocacy strategies to address service delivery, integration and access problems and wider issues such as stigma and discrimination.

Introduction

I thank NCOSS for this opportunity to speak to you. I'm here with several of my hats, as consumer, service provider and researcher. Unfortunately or fortunately depending on your taste, the hats are completely metaphorical today (the revised 'multiple others hat parade' is making another appearance at the Mad Pride Concert tomorrow night at the Ryde Civic Centre). I've been asked to talk to you today about poverty and exclusion from a consumer's point of view. I'll be drawing indirectly on several research projects that I've worked on over the last couple of years.

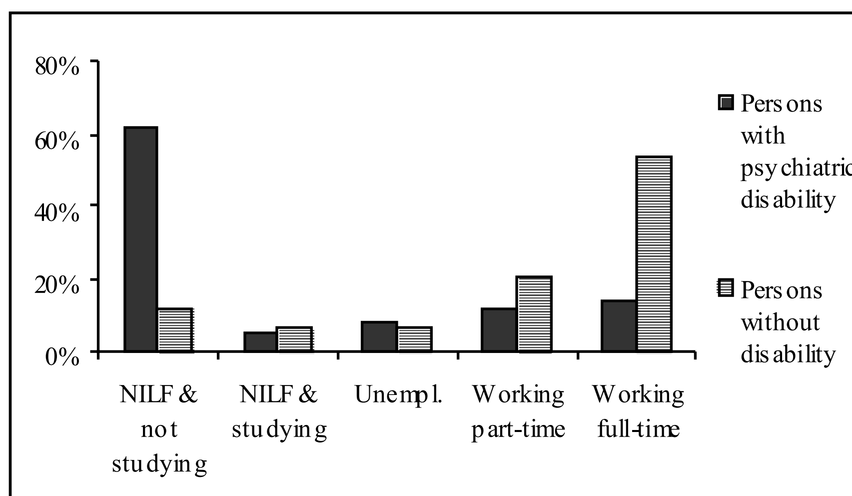
Background

No keynote address is complete without some graphs and data, and these are a bit sobering. They're from the 1998 ABS Survey of Disablity and Carers. Though they're five years old they still give a clear picture of the socioeconomic relativities. The first snapshot is about labour force participation. Income from work is one of the few ways out, and some people with psychiatric disabilities work.

As the chart below illustrates, in 1998 people with psychiatric disabilities were:

- More likely to be out of the labour force or study (61.6% compared with 11.9%);
- Less likely to be studying (4.9% compared with 6.8%);
- More likely to be unemployed (8.1% compared with 6.4%);
- Less likely to be in employment (11.8% compared with 21% for part-time work; 13.6% compared with 53.8% for full-time work).

Table 1: Labour force status of people with psychiatric disability compared with others



Source: ABS Disability and Carers Survey 1998
Adapted from Chalmers J. and Siminski P. (2003)

They were also almost as likely to be in full-time or part-time work (compared with non-disabled workers who are two and a half times more likely to be in full-time work than part-time). Women with psychiatric disabilities were twice as likely as men with psychiatric disabilities to be in part-time employment.

The next graph shows the weekly income in households with a member or members with a psychotic illness[1] .

Just under a quarter live in households where the income is in the range of one pension payment. A fifth live in households where the income is in the range of two pension payments. Over half of households with a person with a psychotic condition had a weekly household income below $480 in 1998.

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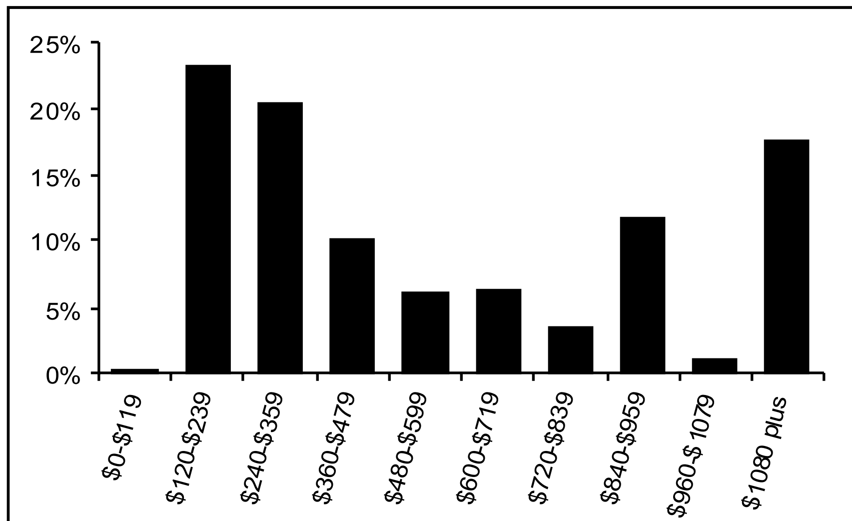
[1] Schizophrenia, Depression and other psychotic mood conditions.

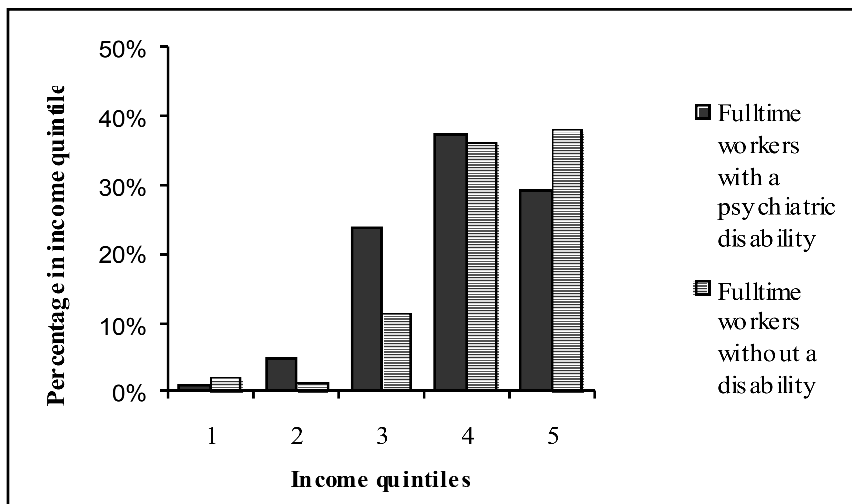
Table 2 - Income of households with a member with a psychotic condition



Source: ABS Disability and Carers Survey 1998
Adapted from Chalmers J. and Siminski P. (2003)

People with psychiatric disabilities were also more likely to receive lower income when they work. The following graph illustrates income distribution (in quintiles) for full-time workers, those with a psychiatic disability[2] and those without.

Table 3 - Income distribution of full-time workers with a psychiatric disability compared with other full-time workers



Source: ABS Disability and Carers Survey 1998
Adapted from Chalmers J. and Siminski P. (2003).

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[2] A psychotic or mood 'disorder' including anxiety conditions

The numbers in the data set are getting fairly low here, but they show people with psychiatric conditions are:

- less likely to be in the lowest quintile (due to the effects of income from social security benefit part-payments),
- more likely to be in the lower (second, third and fourth) quintiles and less likely to be in the highest (fifth) quintile.

So what does all this 'evidence' tell us that people with a pychiatric disability don't already know? That we are more vulnerable to the compounding effects of poverty and illness? What it does tell us is that there are compelling reasons for us as a society to deal with this problem, while the number of people with disability resulting from mental illness continues to climb and the costs escalate.

Poverty is central to social exclusion but exclusion is not just about income. Social, political and cultural resources are also part of this poverty. One discussion in a 'consumer' focus group I conducted recently illustrated this well (four participants are speaking):

> A: Poverty is a risk factor for mental illness. B: Basically you exist, but you don't ever get the chance to do all the other things that everyone else is doing, like go out to restaurants, go to the theatre, all those sorts of things ...C: Yes that's right.A: So it cuts down your options and choices doesn't it.

Another participant in the same focus group linked low income and fewer resources:

> I'd like a decent meal at night, you know, I'd like to be able to dish 'em out every night of the week, like I used to. I used to be married, I'm single now. I used to be a mother, I had children. Now I've lost the lot. And I used to have a meal every night, cook a meal every night, and serve three meals a day, and cook my cakes in between time, and I had enough money to do it. I find I haven't got it any more. Plus I used to have a car, I haven't got it no more. I got to walk everywhere I go, and you try that. I have to walk about four mile to the shops, otherwise I have to go to the corner shop and get charged extortionate prices.

In an interview another 'consumer' linked employment and self-image:

> We'd like to be paid a bit more money. We do get a little bit for some of the work we do here, but not much, but we'd like some sort of wage, some sort of income. And some way for the younger people to get out of here and maybe get a job, you know, a bit of respect for themselves. Create respect. Social exclusion also

suggests rejection from some mainstream 'other', and this is often equated with the widespread mental illness stigma in our communities.

I want to talk briefly now about the social model of disability, and to illustrate some aspects of that with some observations of my own, about our capacity to accommodate people with mental illness or psychiatric disability in our society.

The social Model of Disability

One feature of modern social movements is the importance of producing new kinds of knowledges about our personal and collective identities. Consistent with new social movement theory, social movements can be seen as social laboratories where identity and the ends and means of action are contested. One of the significant activist groups in these processes since the 1970s has been the academics and intellectuals of the disability movement, and one new way of thinking about disability owes its genesis to these groups: the social model of disability.

> *Disability is a socially imposed state of exclusion that arises from the specific material organisation of society.*

The social model of disability thinkers have focussed on the historical-political development of factors such as exclusive spaces in the built environment, exclusive transport systems, exclusive political structures, exclusive communication systems, limited or segmented access to the labour market, community life and so on.

The importance of the social model is that it enables a conceptual break between the notions of impairment and disability. Impairment is a phenomenon at the individual level, while the historical and contemporary structuring of societies' exclusionary practices is social. I suggest that many of these practices are absolutely invisible to most people — impenetrable 'truth' effects of certain discourses.

This is not to suggest that mental health service policy ignores the real world in which people with mental illness live. The 'population mental health' approach articulates some of these concerns. The consultation paper for the third national mental health plan states:

> The population health approach acknowledges the complex and multi-factorial nature of the causal pathways to mental health problems and mental illness. It recognises that health and illness result from the complex interplay of biological, psychological, social environmental and economic factors at all levels – individual, family, community, national and global. *(The National Mental Health Plan Steering Committee: 2003)*

The population health approach cannot, however, make sense of the historical developments and contemporary politics and purposes of social exclusion in the relationships between the above factors that it identifies. It cannot articulate, for example, the relationship between mental illness stigma and capitalist economic relations. It cannot therefore deal with the underlying social determinants of the abuse of and discrimination against 'mad' people.

The nexus between the social model of disability and disability movements

There is a nexus between the social model of disability and the capacity of social movements to structurally 'remodel' disability, by introducing new ways of being in the social world and being together. 'Cross-disability' awareness and solidarity are relatively new phenomenon and still very shaky. (Re)sexualising ourselves is firmly on the agenda, but only recently so (in Sydney, over the last five years or so). Our artists and performers, our gatherings and events, 'rewrite' what we are, as well. We

can model non-discriminatory behaviour, make knowing 'adjustments' to accommodate each other. There's nothing new in these processes. They are exactly what would be villified in past social movements by the neo-liberals as 'political correctness'. There's a great irony in that. Social movements demand socio-political advancement, while neo-liberal governments pursue policies producing fragmentation and regression.

The constructions of 'disability' have historical, economic, social, cultural and political dimensions. The social world is not fixed and changes in our society have influenced our capacity to incorporate people with mental illness. I want to make some observations now as a person living with mental illness about the social world in which my own disability is inscribed.

- The urban Left, progressive and countercultural movements of the 1970s and 1980s provided a social continuum that could be characterised by mutual aid, collective living, resource sharing, an ever-more complex understanding of cultural difference and a more 'forgiving' attitude to the 'damaged' or 'broken'. Some were even reading anti-psychiatrists such as R.D. Laing. 'You could usually get a feed or a sympathetic ear.' Compare this with the increasing trend to single person households, and the implications of this for social support.
- The rationalisation and systemisation of public services have involved a shift to cheaper forms of service delivery, for example, congregating and segregating forms of crisis mental health services are generally accepted while they are no longer fashionable in other disability service delivery.
- Another part of this process has been that government benefits and services are increasingly directed to those who accept interventions which are increasingly invasive and moralistic. One example is the transformation of living skills and drop-in centres to vocational psycho-social rehabilitation programs. Changes to the income support system and the various waves of 'welfare reforms' entailing greater obligation (but only on the part of recipients) are other examples.
- The gentrification of poor inner-urban areas (which once provided cheap 'slum' accommodation and greater opportunities for homelessness and sleeping rough) means that social attitudes to the use of public space are increasingly contested, and public spaces are subject to increasing surveillance and law enforcement – a new kind of cultural cleansing. To illustrate this I'll recount a story from one of my past lives as a bureaucrat, during the implementation of the Disability Reform Package by the then Commonwealth Department of Employment, Education and Training, in the early 1990s. You may remember that as a consequence of the reforms Sickness Benefit was abolished and a Sickness Allowance was introduced. The allowance was limited in most cases to two years. The then Department of Social Security produced figures about long-term Sickness Beneficiaries. Seventeen percent of the national total received their benefits through one social security office, Haymarket DSS.
- The non-Government service sector has been increasingly effected by the privatisation/marketisation of public services – forcing them, in some sectors, to move away from 'welfare' approaches, adopt competitive business practices, and become less discretionary in how they provide services and to whom. Case-based funding in disability employment services is one example. The move from

politically undesirable block grants to an individual consumer, outcome based payment system has had consequences for consumers with a psychiatric disability. Despite good intentions and sound philosophical underpinnings, providers find themselves considering the 'profitability' (or potential loss making) of assisting individual consumers. Within the trials of the system they have had lower commencements and higher exit rates from assistance.

- The restructuring of higher education has meant that poor and mature age students are being increasingly discouraged from further education. It is commonly the early adult years which are disrupted by the onset of severe mental illness and can delay a 'further education career' (I'm one of these). There's plenty of evidence to show that higher education reduces the level of disability associated with impairment.
- Increasingly the culture revolves around new technological axes: internet, TV, cable, major spectacle (sport and cinema) and news media. The meaning of being part of a neighbourhood, a community, a town, a country or a region becomes more impoverished as we have less and less in common in our cultural consumption.

This issue (of the changing capacity or will to accommodate people with psychiatric disability in society) deserves more attention in the policy realm. One of the suggested actions of the Consultation Paper on the National Mental Health Plan 2003-2008 is to 'ensure that all public policies have a positive or benign effect on mental health.' Perhaps a retrospective look at the effects of past policies is too embarrassing for governments. I recommend a bit less joined up thinking and more linked back thinking. Neo-liberal ideologues talk now about making social capital and building community capacity without acknowledging the destruction wrought by their own past and current policies.

Reforms to the Mental Health Services and allied sectors

I don't propose to go into these very far. You'll hear many speakers talk about these today. This is a brief outline of the policy reform process. The first National Mental Health Strategy was endorsed by Australian governments in 1992. It acknowledged that mental health had been long neglected at the policy level, and established a framework for governments to work together towards a process of broad change and reform and mental health services. The strategy came out of four documents:

- The National Mental Health Policy – outlined the new approach and promoted the move from institutional to community oriented services
- The National Mental Health Plan 1993-98 – set a course of action for the implementation of the policy
- The Mental Health Statement of Rights and Responsibilities – which had been agreed to by Health Ministers in 1991
- Supporting Medicare Agreements – that set out Commonwealth, State and Territory roles and funding arrangements

The strategy identified twelve policy areas for reform, with specific objectives and implementation strategies:

- Consumer rights
- The relationship between the mental health services and the general health sector
- Linking mental health services with other sectors
- Service mix
- Promotion and prevention
- Primary care services
- Carers and non-government organisations
- Mental Health workforce
- Legislation
- Research and evaluation
- Standards, and
- Monitoring and accountability

The participation of consumers and carers in the design, implementation and evaluation of mental health services and any particularly reforms or strategic processes, was central to the strategy - from National and State consumer and carer peaks, to Area-based consumer and carer committees and working groups.

The devolution of mental health service management to the regionalised area health services was an important beginning to the integration of the mental and general health services. The role of General Practitioners and private psychiatrists emerged as an important strategy for making the best use of health resources available in any area.

Historically psychiatric institutions had operated in isolation from the community. Relatively new service providers and provision had grown in isolation from the mental health services (such as employment services for people with disability, supported accommodation services, welfare services, family services etc). Other government agencies and departments are also providing services to these same populations (e.g. departments of housing, police, ambulance, community services, homecare). The necessary corollary to assisting people with mental illness in the community, with an integrated mental health service system, is to set up protocols, service agreements and other mutual arrangements to enhance people's access to these other essential services.

The strategy advocated a shift away from psychiatric hospitals to a 'single, integrated, service system that emphasised continuity of care'. It was concerned with expanding the range of other services available, reducing psychiatric hospitals and mainstreaming mental health management with general health management.

Within the policy areas of promotion and prevention are issues about the relationship between primary, secondary and tertiary care (ie the relative weight of these and their role in health outcomes, particularly the importance of early intervention and rehabilitation services), and the effects of stigma and discrimination.

The evaluation of the First National Mental Health Plan found that while there had been many developments towards its objectives, that on the whole the Strategy had generally fallen short.

The Second National Mental Health Plan 1998-2003 established additional priority areas:

- Promotion and prevention
- Developments in partnerships in service reform
- Quality and effectiveness of service delivery

The New South Wales Government has responded to the National Mental Health Action Plans with a New South Wales Government Action Plan on Mental Health. This comprises a series of policy frameworks, over the last four years, which have promoted broad changes throughout its Area Health Mental Health Services:

- A Framework for Managing the Quality of Health Services in New South Wales (1999)
- Partners in Health – Sharing information and making decisions together, Report of the Consumer and Community Participation Implementation Group (2001)
- Framework for Rehabilitation for Mental Health (2002)

For consumers and carers the key themes in these are:

- The framework for mental health rehabilitation services focuses on wellness rather than illness, employment as an outcome and consumer empowerment. It promises a greater range of effective and more timely interventions, continuity of care and better mental health promotion and illness prevention strategies;
- The frameworks promote greater integration between goverment and non-government sectors (and Service Agreement-based coordination of clinical, disability support and related interventions), e.g. Area partnerships committees, and commissioning NGOs to provide services.
- Structured and evaluated partnerships and dialogues with consumers and carers are advocated as a basis for planning, implementation and evaluation of mental health services. Service reforms are driven by participatory regional and state implementation groups.
- Evaluations 'need those who are most affected to be involved, in order to really measure "value".' Consumers can also contribute to the 'design of evaluation and the interpretation of information, as part of the evaluation process'. Among the many benefits expected is an opportunity 'for developing an understanding of the social view of health and the health of communities.'

The language is positive, the vision is clear. There have been discernible benefits for individual consumers coming out of these policy changes, and of course, enormous input from consumers and carers in their development and implementation. Yet, on the ground, the troops (and I mean here our advocates and activists) are footsore, confronted by organisational and professional cultures that are both hard and slow to change. Within them are both agents and opponents of change. Mental Health Service partnerships with consumers, carers and non-government organisations and formal

service agreements and understandings bring contrasting organisational philosophies into focus. Integration can be strategically planned but the outcomes are hard to predict. Furthermore a partnerships strategy has to acknowledge the ‘organic’ nature of integration and all of the constraints on other parties in entering into them. In the background to these are over-stretched and under-resourced facilities, programs and workers and continuing unmet consumer need.

There are strong limitations in locating our opposition to current Mental Health Service practices and policies within the system. It seems to me, as I have argued earlier, that the system cannot challenge widespread mental illness stigma, or protect us from the worst effects of poverty. An emerging social movement is beginning to make these demands and remodel the meaning of illness itself. If the neo-liberal ideologues are serious about addressing the problem of mental illness stigma, the first place they should look is in the mirror.

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