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Schizophrenia – The Costs

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Abstract

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Schizophrenia – The Costs

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ABSTRACT

By looking at a particular subset of mental illness in Australia, (schizophrenia), this article reflects on the way in which direct costs falling within the parametres of the health budget are privileged (inscribed) above indirect costs which fall outside this boundary (and thus fail to be appropriately inscribed). This article concludes that, from a social accounting point of view, this boundary is arbitrary and an example of poor accounting.

INTRODUCTION

Schizophrenia is expensive. No one doubts that. What this article argues is that some of the costs of schizophrenia, the direct costs, are far more visible than other costs, the indirect costs. Accounting serves to make some costs visible (or "inscribed") whereas other costs are silenced. Sometimes they are silenced by being outside accounting's entity assumption. Sometimes they are silenced by being difficult to quantify. In either case, it is the contention of this article that accounting, by inscribing some costs and ignoring others, accounting privileges direct, quantifiable costs above other costs. From the viewpoint of social accounting (Ball & Seal, 2005) this failure to balance and consider all stakeholders is flawed accounting.

What costs are associated with schizophrenia?

Table 1 (below) is sourced from Access Economics (2002, p.31) Schizophrenia: Costs Report for SANE Austrlia in 2002.

Of the total costs included by Access Economics, only about $661 million are direct health costs. Considering that the total direct and indirect financial cost of schizophrenia was found to be $1 847 million, direct helath costs represented less than 36% of financial costs relating to schizophrenia in Australia in 2001.

However, decisions that affect the level of help, support and and treatment provided for people with schizophrenia are largely made by institutions whose accounting boundaries (budgets) only encompass that direct, health related 36% of costs. Perhaps this silencing of the indirect costs associated with schizophrenia goes some way to explain why Australia is on the low end of the international spectrum when it comes to spending on Schizophrenia. (Access Economics, 2002, p. 1) notes that Australia spends only 1.2% of health spending on schizophrnia compared to between 1.6% and 2.6% spending in comparable countries.

How are the Direct Costs of Schizophrenia made up?

Table 2 below (Access Economics, 2002, p. 18) shows how the bulk of direct costs of $661 million for schizophrenia was derived. Of this $661 million, $653 million was from direct health system costs. The majority of these direct health sytem costs ($395 million) was from hospital expenses, with another $152 million from other health services expenses which included spending on community mental health services.

The balance of the direct costs of schizophrenia ($8 million) was made up of the direct costs associated with the suicide of people with schizophrenia and the costs spent on suicide prevention and management associated with people with schizophrenia (Access Economics, 2002, p.20).

How are these direct costs inscribed?

Following LaTour, the idea of accounting numbers as inscription (Robson, 1992) is that numbers are the dominant metaphor of accounting (Morgan, 1988) and assist in enabling action at a distance (Robson, 1992, p. 686).

These direct, quantified, inscribed numbers that are known and acknowledged costs of schizophrenia in Australia, are then in a position to influence public policy and health spending. They are caught and quantified and find their way into our budgets. This is not true of the indirect costs of schizophrenia. Whilst some of the indirect costs do appear spread across a variety of government budgets (such as welfare or correctional services budgets) they are hidden amongst other budget items for these government sectors and so lose impact.

Table 1: Summary of Direct and Indirect Costs of Schizophrenia Australia 2001. (Adapted from Access Economics 2002 p.31)

	Real Costs	Transfer Payments	Total
Direct health costs			
Hospital	399.5		
Other	261.0		
Direct costs ($m)	**660.5**	**-**	**660.5**
Direct cost per person with illness			*$17 740*
Indirect costs			
Loss of earnings	459.8		
Absenteeism	27.8		
Mortality burden NPV	94.3		
Tax foregone patients		165.7	
Subtotal patient earnings	*581.9*	*165.7*	*747.5*
Carer costs	88.1		
Tax foregone carers		23.4	
Subtotal carers	*88.1*	*23.4*	*111.5*
Disability support		249.9	
Sickness allowance		15.2	
Newstart etc		8.8	
Subtotal welfare	-	*273.9*	*273.9*
Prison costs	30.4		
Police and legal costs	21.5		
Subtotal criminality	*51.8*		*51.8*
Indirect financial costs ($m)	**721.8**	**464.4**	**1 186.1**
Indirect cost per person with illness	*$19 385*	*$12 472*	*$31 857*
TOTAL FINANCIAL COSTS ($m)	**1 382.3**	**464.4**	**1 846.7**
% of GDP	0.21%	0.07%	0.29%
Cost per person with disease	$37 125	$12 472	$49 597
Cost per capita	$71	$24	$95
Burden of disease	**Schizophrenia**	**Related Suicides**	**Total**
YLL -Years of life lost through premature death	298	3 296	3 594
YLD – Years of healthy life lost due to disability	18 996	27	19 023
DALYs (YLL + YLD)	**19 293**	**3 323**	**22 616**
Deaths	24	129	153

Table 2: Components of Direct Health Costs for Schizophrenia 2001 (Access Economics 2002 p.19)

Direct Health Cost	$m	% of Total
Psychiatric hospitals	299.3	45.8%
Other ambulatory services	144.9	22.2%
Public hospitals	82.8	12.7%
Nursing homes	28.2	4.3%
Specialists	26.2	4.0%
Private hospitals	12.8	2.0%
Pharmaceuticals	11.7	1.8%
GPs	10.6	1.6%
Out-patients	7.1	1.1%
Research	6.1	0.9%
Other	23.4	4.0%
Total	***653.1***	***100.0%***

What are the indirect costs of schizophrenia?

According to Access Economics (2002, p. 31) the indirect costs of scizophrenia make up about 61% of the total, quantifiable costs of schizophrenia. Without entering the debate as to the strenths and weaknesses of quantification, the central point here is that, at a minimum, most of the costs of schizophrenia are "externalities" to the budgets of the institutions making the decisions that most impact the provision of treatment and support for people with schizophrenia. These indirect figures do not find their ways directly into the Health Budgets of Australia. To an extent, they fail to be inscribed in a mobile, combinable way (robson, 1992, p.697) and so fail to be "inscribed".

In the language of inscription (Robson, 1992, p.701)the most powerful (and thus influential) elements in action at a distance are those that are mobile, stable and combinable. These are the inscriptions that will influence decision makers (including funding decisions) made by those removed from the direct context of mental health (government policy makers). So, in the case of indirect costs, these would not be inscribed in a mobile, stable, combinable way to decidion makers where they can influence policy and spending. As "externalities" or items that do not directly fall within the Australian health budgets, and fail to be meaninfully inscribed, they are silenced.

Table 1 shows that the indirect costs that Access Economics has included four categories of indirect costs. These are patient earning costs; carer costs; welfare costs; and criminality costs. These categories would, of course, exclude those costs that could not in any way be quantified. But even given this limitation, social accounting (which this article returns to in more detail in section 3) requires that stakeholders such as people with mental illness; their carers; and the welfare and forensic sector costs be taken into account in thinking about just policy outcomes (Ball & Seal, 2005, p.460).

Giving voice and form to these silenced costs of schizophrenia

Following the categories chosen by Access Economics (2002), this article will consider the indirect costs associated with schizophrenia in the following categories: People with Schizophrenia; Carers of people with schizophrenia; Welfare sector costs ; and Forensic costs. The sources from which the following evaluation of indirect costs are drawn are: The Burdekin Report (1993); The National Mental Health Report (2000); and various reports put out by mental health support groups, charitable organisations, and newspapers.

People with Schizophrenia

Access Economics (2002, p.31) includes in its calculation of the indirect costs of schizophrenia the quantifiable costs involved in loss of earnings, absenteeism Net Present Value of mortality burden and tax forgone from people with schizophrenia. These quantifiable costs have been calculated as standing at $748 million in 2001 (See Table 1).

To flesh out (or make visible) the lived experience that go with these numbers, it is necessary to explain that (perhaps because of the small proportion of costs of schizophrenia that get inscribed and thus appropriately acted upon) there is a dearth of appropriate treatment and supported housing for people with Schizophrenia in Australia.

The seminal Richmond Report (1983) suggested that in order for "community care" of people with mental illness to be just and fair, it was necessary for the government to fund an "integrated community network" allowing people with mental illness a "normal community environment" and providing them with "adequate follow–up". Burdekin (1993, p.341) noted the bureaucratic shuffling between the Departments of Housing and the Departments of Health in Australia – each claiming that housing for people with mental illness was the other's problem. The result of each department denying responsibility was that people with mental illness wound up with very little by way of help in housing and (with that vital stability absent) often fell through the bureaucratic cracks into homelessness and marginal accommodation such as boarding houses.

The precise extent of homeless people in Australia who suffer from schizophrenia is difficult to pinpoint as it is such a transitory and ignored population. St. Vincent de Paul (2001, p.6) gave as their "guestimate" that between 25 per cent and 50 per cent of homeless people presenting themselves at the Matthew Talbot Hostel in Sydney had some form of mental illness. The Down and Out in Sydney Report (St. Vincent de Paul et al, 1998, p.2) suggested that 75 per cent of homeless people had at least one mental disorder. Perhaps those with the organisational skills to actually present at a hostel are less likely to suffer severe mental illness. Other alarming statistics from Down and Out in Sydney (1998, p.7) are that 58 per cent of homeless people in or contacting inner Sydney hostels and refuges run by St Vincent de Paul, Sydney City Mission, the Salvation Army, Wesley Mission and the Haymarket Foundation had been physically attacked or assaulted; 55 per cent had witnessed someone being badly injured or killed; 68 per cent of women admitted to having been indecently assaulted and 50 per cent raped.

Carers of people with schizophrenia

Access Economics (2002, p.31) included in it's calculation of the indirect costs of schizophrenia the quantifiable costs involved in Carer costs and tax forgone by carers being less able to work outside the home as causing a total of $112 million in indirect financial loss. (See Table 1).

Amongst the categories of costs that carers have to bear, the following less tangible cost categories have been gleaned (Burdekin Report, 1993):

Exhaustion

Donelly (as cited in Burdekin, 1993, p.455) of the National Carers' Association explained the sheer weariness involved in being a carer. Carers could be called upon at any time, around the clock and around the calendar. Crises were frequent and generally extremely stressful. There was no time off and no respite for carers. They had huge responsibilities but often very little control over circumstances, which served to make the job even more tiring. They had served to save the government a huge sum of money. They got very little in return.

Uncertainty and lack of information

ARAFMI (Association of Relatives and Friends of the Mentally Ill) made a submission to the Burdekin Report (1993, p.462) noting that when people were discharged from hospital (often still quite ill) carers were "left in the dark, expected to pick up the pieces" whilst often not being properly informed of the medication and treatment regime that the person discharged should be on. This lack of information made their job exceptionally difficult.

Lack of coordination and follow-up

A variety of carers (for example, Lanson, as cited in Burdekin, 1993, p.462) commented on the dearth of follow up and discharge planning after an episode of hospitalisation for severe mental illness.

Stress

The stress and strain on the mental health carers and on anyone else living in the household was commented on by many carers. For example: Bacon (as cited in Burdekin, 1993, p.471); Ormorod (as cited in Burdekin, 1993, p.472) both reported the edginess and overwhelming stress and responsibility that came to a household caring for someone with a mental illness.

Spokespeople for a variety of carer support organisations also highlighted issues which increased stress to carers and their families. The Alliance for the Mentally Ill Australia (as cited in Burdekin, 1993, p.471) noted the unreasonableness and dangers inherent in expecting frail, elderly parents (generally mothers) to care for large (sometimes psychotic) adult children with no help. Lococo (as cited in Burdekin, 1993, p. 471) representing the Support Group for Relatives of People with a Psychiatric Disability and Carberry (as cited in Burdekin, 1993, p.471) representing the Association of Relatives and Friends of the Mentally Ill, made submissions to the Burdekin Enquiry which spoke of the severe stress that becoming carers meant for the other children, marriages and mental health of carers. (Burdekin, 1993, p.471). It was pointed out that the cost of family and other relationship breakdown and mental stress would (indirectly) cause an increase of costs to the government via health, social and legal services in the long run.

From the foregoing, it can be seen that the stress placed on carers and other family members are extreme. As in other areas of mental health, the lack of support services makes the task even more difficult.

Added Responsibilities

Kinnear and Graycar (1983, p.81-83) reinforce that the burden of care falls disproportionately on women, and that the personal costs to these women was often very high. Many had to give up work to become carers and so often became dependent (either on a man or on the state) themselves. Such a decision was deemed in women to be no less than their duty. Men were seldom expected to make such sacrifices.

Kinnear and Graycar (1983, p.85) also drew several conclusions about the outcomes of the onus of care in Australia moving to the families of dependent relatives:

> The picture that emerges is of a caring situation which involves disruption and adjustment, often resulting in the isolation of the caring family from almost all other informal and formal networks. In turn, this isolation increases the pressures that result in cumulative social, emotional and financial costs. It is notable that family care entails these heavy costs because embodied in the current rhetoric is the belief that community care is a less costly form of care.

Once again, as with most of the costs that fall on mentally ill people themselves, costs that fall on carers as a result of the policy of deinstitutionalisation were not directly accounted for in mental health budgets. They might show up indirectly in increased health care costs, in taxes lost because carers were unable to work outside the home, in the costs of divorce and counseling as the strain told on families. But the direct costs were "externalities" and would not be found accounted for in any State Government mental health budget.

Welfare Sector

Access Economics (2002, p.31) has included the follwing costs under the heading of welfare:

disability support; sickness allowance; and newstart payments. These indirect costs were estimated to total $274 million in the 2001 year. As these are relatively reasonable costs to quantify and are inscribed at least to the point where they are noted in welfare budgets, even if they are indirect as far as Austrlian health budgets are concerned, no further comment needs to be made on these costs here.

Criminality

Access Economics (2002, p.31) includes in this categories the costs of people with schizophrenia being imprisoned and police and legal costs as totalling $52 million in 2001. To place the less quantifiable aspects of criminality in context it is important to understand how poorly Australian jails (in general) deal with schizophrenia.

Because of the lack of psychiatric assessment of prisoners in New South Wales (Burdekin, 1993, p.753-754) it was difficult for the Burdekin Report (1993) to estimate the number of prisoners with schizophrenia with any certainty. Professor Brent Waters (of the Prince of Wales Hospital estimated that between 30 per cent and 50 per cent of young people in Sydney's detention centres had a mental health problem. Whether the same percentage applied to adult facilities was not known. According to Burdekin, (1993, p.754): "A startlingly high proportion of prisoners (82 per cent) had suffered at least one "mental disorder" at some point in their lives. However, in this case the term "mental disorder" included alcohol and drug abuse. Whilst drug abuse is positively correlated with mental illness (either as a causative factor or in an attempt to self-medicate) most people would not consider drug abuse to be a mental disorder.

The Sydney Morning Herald (2001, p.12) put the criminalisation of mental illness bluntly:

> Several recent studies show the State's prisons are, in part, last stop, old-style lunatic asylums. But politicians, in the senseless battle to outbid each other in law-and-order auctions, ignore these inescapable and shameful findings.

What was clear to Burdekin (1993) was that conditions in jails were not therapeutic for people with mental illness. Singling out New South Wales prisons for "especially severe condemnation", Burdekin (1993, p.761) cited a number of aspects of prison life as being particularly detrimental to inmates with mental illness. Conditions for both male and female prisoners with mental illness were extremely difficult. Jolly (as cited in Burdekin, 1993, p.771) consultant psychiatrist to the New South Wales Prison Medical Service commented that the system of segregating people having a psychotic episode would "almost inevitably predict a worsening of the psychotic condition".

What is Accounting's role in this?

It would seem incongruent that a State would choose to pursue a policy which imposes far greater costs than it saves. That is, it would seem bizarre to any discipline other than accountancy. Only in accountancy-related thinking does such a decision make sense. Accountancy takes a very narrow perspective. If told to account for a policy change from the perspective of a state government, it will tend to do so only accounting for items directly impacting on that particular, narrow entity. "Externalities" (those costs falling elsewhere than on the narrow entity being accounted for) are ignored. This is the outcome of the entity assumption.

In the case of pursuing a policy of substantially lower funding for schizophrenia related treatment and support programs than is provided in comparable countries, governments in Australia have made such a decision.

Accounting - type Information and Public Policy

The entity assumption obscures those costs borne by anyone outside the narrow fenced area that is called Health Budget. What effect has this misuse or misunderstanding of the appropriate use of accounting had? Johnson (1990, p.105-106) stated the difficulties from a practitioner's viewpoint:

> The fact is that politically, it is extremely fortunate that so many of the costs of caring for chronically mentally ill people are hidden, because that fact covers up a lot of problems. For one thing, responsibility is diffuse and accountability even more…But as in three card monte, what you see is not necessarily what you get, and nowhere is that principle in operation to greater effect than in obscuring the whereabouts of the mentally ill, not to mention the costs of keeping them there. Strictly from the states' point of view, the mentally ill were and are better off living somewhere "in the community", where they are on somebody else's entitlement rolls and maybe even in someone else's catchment area. (Johnson, 1990, p.105-106).

Boyce (1997, p.14) pointed out the useful mystification accounting causes in other (non-accounting acolytes) as a reason for its defensibility. Accounting brought with it the "aura and social authority of expertise" and could be used to "validate the existing power-based normative order of society". In short, the way in which accounting abets and is implicated in economic rationalism has been widely discussed and elegantly argued by others (for example Rose, 1991; 690; Boyce, 1997, p.10-13; Morgan & Willmott, 1993, p.10-16).

A Role for Social Accounting?

Gray (2001) suggested that social accounting should take into account information about the position and views of those people most directly affected by policy decisions (the stakeholders). In the context of the (lack of) funding for schizophrenia related treatment and support programs, this would allow the indirect costs of not providing adequate support to gain visibility or become "inscribed" (Robson, 1992) and thus to be taken into account.

Schizophrenia in Context

This article has examined only schizophrenia in terms of direct and indirect costs. To place schizophrenia in the broader context of mental health spending, Access Economics (2002, p.18) notes that schizophrenia held only the third largest place in Australian direct spending on Mental Disorders in 2001.

Above Schizophrenia in terms of direct spending came Dementia and Affective Disorders (including Depression). It would make an interesting further study to explore whether these other mental disorders seemed to have the same public policy outcomes as Schizophrenia as a result of their similarly dispersed (and thus not effectively inscribed) indirect costs.

Table 3: Direct Costs of Schizophrenia and Other Mental Disorders Australia 2001 (Access Economics 2002 p.19)

$ million	Hospital	Medical	Pharma-ceuticals	Other Health Services	Other	Total	% of Total
Dementia	158	16	3	13	837	1 027	23.6%
Affective disorders (inc. depression)	321	203	98	101	213	926	21.3%
Schizophrenia and SAD	**395**	**37**	**12**	**152**	**58**	**653**	**15.0%**
Substance abuse disorders	196	66	17	26	196	500	11.5%
Anxiety disorders	35	147	73	36	53	344	7.9%
Behavioural syndromes and other mental disorders	24	76	65	13	72	250	5.8%
Other non-drug psychosis	91	7	1	9	76	184	4.2%
Stress and adjustment disorders	40	39	10	45	27	161	3.7%
Disorders of childhood and adolescence	14	13	1	27	23	79	1.8%
Other mental disorders prevention and screening	88	27	4	60	42	221	5.1%
Total	***1 353***	***631***	***285***	***482***	***1 596***	***4 345***	***100.0%***

Discussion and Conclusion

Australia spends remarkably little (compared to other developed nations) on schizophrenia related treatment and support programs. This article raises the argument that this is because only the direct and quantifiable costs of schizophrenia become inscribed and thus are factored into the policy making calculus.

Indirect costs (or those costs that are not fully open to quantification) are of no account in the language of accounting and are thus ignored. This article explores the suggestion that social accounting (with it's acknowledgement of diverse shareholders) could overcome this silencing of many of the costs relating to schizophrenia and the policy injustice that has come from this obscurity.

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