Overview

The Mental Health Coalition of SA Inc is a not for profit association whose mission is to ensure that all South Australians are able to access the quality and quantity of services that they need to recover and live full lives in the community.

There are many people in the community with disabilities of various kinds, however our submission is focused on the needs of people with mental illness. People with mental illness, particularly severe and enduring illness, face significant disabling impacts associated with the illness and in some cases there are significant complexities such as co-morbid conditions. The disabling impacts are not just related to the symptoms of illness but can include poor physical health outcomes, loss of housing, employment, daily living skills, cognitive and social skills and support networks. There is a growing evidence base showing that access to effective and timely treatment and support can significantly reduce the severity and duration of the disabling impacts of mental illness.

Given the short timeline and capacity constraints within our organization, our submission is based on consultation and research that is more limited than we would like. This submission was developed from a workshop that we hosted of our members and interested organizations as well as written and verbal feedback from our members. We encouraged people to provide written examples of people with mental illness that describe support needs and how well (or not well) our services systems have been able to meet their needs. These examples are neither comprehensive nor exhaustive but are provided to start to illustrate some of the complexities, barriers, gaps, successes and possibilities that feature amongst the potential beneficiaries of a national approach to disability support. A national scheme for disability support should complement and enhance the effectiveness of the existing support service systems.

The important role of family carers needs to be acknowledged and we draw the work of organizations such as Carers Australia to the attention of the Productivity Commission.

Writing this submission has been a difficult task as the Productivity Commission issues paper raised many questions that are complex and, in many cases, interrelated. It has been impossible to answer these questions adequately, however we have attempted to provide information, ideas and insights that might assist the Productivity Commission towards the next stage of this work.

Our consultation has confirmed that a move to a rights based approach to service system development is supported. The examples that we present demonstrate some of the gaps and issues that result in insufficient access to effective and timely support.

Our feedback showed strong support for the Productivity Commission to continue to consider the needs of people currently enduring or at future risk of enduring the disabling impacts of mental illness.

The evidence shows that investing in effective supports for people with mental illness to live in the community is not just a cost, but an investment that will lead to significant long term benefits to both the individual and society. The experience of the non-government community mental health support sector is that often a high level of support is required initially, but that the need for support usually reduces substantially after a year or two. Many of the benefits to the individual, the family and the community are difficult to quantify but are long term. More quantifiable benefits include reduced demand for other services including acute mental health care, physical health care and welfare payments. As people with mental illness become employed at similar rates to the rest of the population benefits flow to governments from additional tax revenues.

It is important to note that one of the key elements of a successful approach to mental health is the reduction of stigma and discrimination towards people with mental illness. This will require both a national and local approach. The stigma reduction will also be reinforced as the community sees the evidence that people with mental illness, even with severe and enduring illness, can lead productive lives in the community if the effective supports are in place.

We would be willing to provide more information to assist the Productivity Commission.

Background and context

The purpose of this section is to refer to relevant material that gives context and depth to some of the issues that are important to consider in developing a national approach to disability support for people with mental illness.

A key concept to modern mental health systems is the notion of 'Recovery'[i]. The MHCSA has developed a leaflet on 'Recovery' and this is attached as well as available on our website www.mhcsa.org.au . The concept of recovery has been adopted as the goal of our mental health system in SA by the SA Government. It is important to recognize that this is a significant change from historical goals of mental health systems which were much more focused on ameliorating symptoms. The recovery concept is that people with mental illness should be accessing the full rights of citizenship to the same degree as anyone else in the community. This approach is in line with international treaties that argue for rights based approaches to disability support systems.

It is widely acknowledged that our mental health support system in Australia requires considerable reform. Our policy statement 'Mental Health – Lets Make it Work Better'[ii] is a document that we developed in March 2009 to identify the major priorities for mental health reform in SA. As you can see from the document we have a long way to go to support people with mental illness effectively. Any national disability support scheme would need to recognize and respond to the existing system shortfalls.

A key element of support for many people with mental illness is support to access or maintain safe, affordable and appropriate housing. People with mental illness feature amongst the homeless and populations in vulnerable housing. Even people with access to quite high levels of mental health services support are known to experience homelessness or vulnerable housing to an alarming degree. Our 'Housing for Mental Health'[iii] statement highlights some of the issues relating to this problem. In the state of SA there is a lot of effort being put into programs aiming to deliver housing and support for people with mental illness, however the scale of the problem will need ongoing attention.

Workforce development in the non-government community mental health service sector is an area that has lacked attention. Over the last four years the MHCSA has been active in creating a high quality pathway to a Certificate IV relevant to mental health with a particular focus on psychosocial rehabilitation. There has been minimal attention to this issue nationally as the shortages in the 'professions' has occupied the main workforce agenda. The MHCSA has not just delivered training but has also gathered information regarding workforce needs in SA. We would be happy to provide further information on this to the Productivity Commission as required. Our training program is currently being evaluated and early indications are the training is highly regarded by managers of service providers who report that it is having a beneficial impact on service quality.

The presence of stigma and discrimination has a significant negative impact on people with mental illness. With our interstate colleagues we developed an international literature review to identify the elements of successful stigma reduction and social inclusion programs[iv]. Any national disability support program will be more effective if in association with an effective national stigma reduction campaign.

Research in mental health has been identified as an area that would benefit from increased investment [v]. A particular area of benefit would be more research and evaluation into approaches to community based supports and their effectiveness in supporting people to recover in the community.

The disabling impacts of mental illness – who needs disability support and what is the goal of support.

Mental disorders comprise thirteen per cent of the total burden of disease and injury in Australia. This is the third highest - behind only cancers and cardiovascular disease. The disease burden is measured in terms of years of healthy life lost due to death or disability and for cancer and cardiovascular disease most of the disease burden is due to premature death. For people with a mental illness, however, over 90% of the disease burden arises from the disabling impacts of the illness. The disabling impacts are broader than the illness and its symptoms and can include loss of housing, employment, daily living skills, cognitive and social skills and support networks.

People with Mental Illness lose the most years of "healthy" life due to disability compared to those with any other health condition. In 2003, 341,900 years of "healthy life" were lost by Australians who had a mental disorder. Although the disease burden is enormous, the evidence base is clear that effective supports will enable people to live well despite the disabling impacts of mental illness.

Unlike other illnesses, a high proportion of the burden from mental illness impacts on younger segments of the population, however, with recovery-focused supports people can overcome much of the disabling impacts. Increased investment in effective prevention, early intervention and support services will significantly reduce the burden. If this was done then a “30% increase in funding would treat 50% more people and produce a 90% increase in health gain”.[vi]

South Australia has adopted recovery and social inclusion approaches which aim to support people to live well in the community despite the disabling impacts of mental illness. These approaches support people with mental illness to not only manage symptoms of illness but also to gain employment, housing, sustain healthy relationships and live well in their community.

Our consultation highlighted a range of limitations in the current system that leaves many people without effective support to overcome the disabling impacts of their mental illness.

The result of not providing effective and timely support to people in the community is a high burden of the disabling impacts of mental illness.

The definition of psychiatric disability is an issue that was raised in our consultation. This is a contested issue within mental health and disability fields in SA and the examples in our consultation indicated that this ‘contest’ made it difficult for people with complex needs to get the full range of supports needed. As a result our consultation did not seek to define ‘psychiatric disability’ but to urge the Commonwealth is to start by setting the goals of any national scheme of disability support in rights-based terms such as: the goal is to support people with mental illness to access the full rights of citizenship. In this context service development could take a preventative or early intervention approach to minimize the current and/or future disabling impacts of illness by supporting people to achieve their social inclusion/recovery type goals. Services would also need to be flexible enough to respond to the disabling impacts of mental illness which can manifest many forms for an individual, including episodic bouts of illness. The arguments about what is psychiatric disability versus illness would then only be relevant to determining what kind of supports would be most effective.

Flexibility in funding parameters to improve coordination and timeliness of access

The results of our consultation emphasised that a range of psychosocial rehabilitation supports are currently funded in SA and are effective in supporting people with mental illness to overcome the disabling impacts of their mental illness and live well in the community. Psychosocial support services also assist people to engage with a range of mental health and other services that they need, to access and/or maintain appropriate housing, build social and community networks and participate in employment, education, social and recreational activities.

Our consultations identified however that there are some limitations and gaps in service systems that reduce the effectiveness of our service systems in providing timely access to support for people with mental illness and their families.

A national disability support scheme would need to be carefully designed to not duplicate existing supports and also to not repeat the limitations and gaps of the existing systems.

From our consultation examples were given of funded programs where resources are inflexibly tied to specific geographical locations. One service provider gave an example where there were fewer referrals to their southern service whilst the northern service had many more referrals and a waiting list. The funding program however did not allow flexibility to move resources and staff to locations where the demand was greatest. A more flexible approach could have reduced the waiting list and improved coordination and timeliness of access.

Rural and Remote Issues

In rural and remote areas the barrier to accessing services can be considerable and impact on whether or not services are sought. The problem with this is that when early intervention and recovery opportunities are not taken up, the illness progresses untreated and increases the potential for more severe and long term disabling impacts to occur. People with mental illness who access effective support services will have less severe illness and long term disabling impacts than if it is left untreated for longer.

Our consultation highlighted the higher costs faced by rural residents where services are located at a distance from their home. Examples were given where some individuals with a mental illness rely on family members to take them to appointments, particularly when in a phase of illness. This is difficult in the metropolitan area but it is compounded in rural areas where the appointments occur within major regional centres as opposed to the local community areas. If the family member works, the impact on their ability to manage their caring and work role is considerable. There are further costs and implications of this to family carers which have been well documented by Carers Australia.

Our consultation also identified that transport is an issue for many individuals with a mental illness who live in remote areas and who need to travel to regional centres for support and treatment services. If the person is not able to drive then attendance at appointments can be extremely difficult as public transport from many rural, regional and remote areas is infrequent or non-existent and the person either then has to rely on a family member or friend or not attend. Even if the individual is able to drive the associated costs of petrol in driving, at times, lengthy distances can also be prohibitive.

Non-government service providers in our consultation provided examples of psychosocial rehabilitation services that are effective in supporting people in their own homes, but noted that it was expensive to provide supports beyond regional centres. The consultation proposed that for people living in rural and remote areas, access to effective in-home supports could be enhanced by targeted investment in building capacity and flexibility of existing services to support people living in outlying towns, not just in regional centres.

It was also noted that the limited range of services in rural and regional areas (relative to the metropolitan area) results in more obvious service gaps and that increased flexibility of services is needed help to overcome some gaps in service types.

Workforce issues such as access to training and ability to recruit were noted as being more difficult in rural and regional areas than in metropolitan areas.

Gaps and issues in current system design – resource limitations, equity of access, availability of full range of support

Our consultation highlighted many examples of programs that were effective in supporting people with mental illness in a wide range of ways.

The discussion included examples of successful programs which were attracting referrals that were not necessarily appropriate to the program type. The reasons identified for this included the lack of more appropriate programs or, where such a program existed, lack of access to the appropriate program type. A feature of the discussion and examples that were raised was the impact of resource scarcity on the ability of clients with more complex or diverse support needs to access the full range of supports that they needed. Examples were provided where individuals with high and complex support needs were able to access a range of support services but were unable to access one critical support service – such as personal care- to the extent that they needed. The result of this deficiency was to compromise the effectiveness of the other services. A national scheme could learn from this and be designed to overcome such allocation/ access tensions.

The discussion included issues around delivering support for people with very high and complex support needs. One example was an individual with a violent history who was currently in a mental health bed and required support to be discharged. The non-government service providers noted that they have the skills and experience to support people with complex needs, including people from forensic settings, but the impact of having simultaneous referral of a number of high and complex needs clients is to place a considerable strain on funded capacity. The result of this is reduced access for others as that particular service types become ‘blocked’.

In some mental illnesses there is an undeniable and expected deterioration in mental and physical state and requires over time an increase in the type of support services to maintain that person’s quality of life and ability to function within their family. Huntingtons Disease is such an example, where the deterioration over time leads to frailty and inability to care for oneself and the level of services needed increases creating a level of complexity in providing services. One example of this is an individual with Huntingtons Disease provided with package of psychosocial rehabilitation support who over time has become frail. The support need has become more about providing personal care for the person than supporting their rehabilitation and recovery needs. The difficulty arises when there is a lack of funding to increased hours of personal care and support in the home (which requires the agreement of another agency). Limited time is also available for co morbidity issues of alcohol dependence. The situation for the individual is not suitable and places pressure on services to respond where it is not part of their business practice and funding. Resolution can be difficult where different agencies prioritise resource allocation to the same client differently. The lack of a key service types for a client with complex needs can compromise the effectiveness of all the resources contributed to by other agencies.

Our consultation identified that access to support services can be restricted in a range of different ways. The majority of state resources in mental health are allocated to adult mental health services. This presents challenges in program design where under-allocation of services can occur for other population groups such as to young people and older people. Access and allocation is a difficult issue in health and disability.

Our consultation discussions included the following observations about access and allocation:

- Allocation processes that are designed for adult populations and inadvertently favor adults above young people (eg an older person with a long history of illness and disabling impacts may be prioritized over a young person with a similar diagnosis for whom providing the supports would avoid the future disabling impacts)
- Mainstream allocation processes can inadvertently exclude minority populations or the actual support type may require modification to be suitable to different population types
- Where programs are perceived to be difficult to obtain access to, this can lead to an attitude of “why bother” and lead to referrals not being made for people who would otherwise be eligible and benefit from the support. This has many implications for example it can give a false impression that the demand is being largely met because there is no long waiting list. If the referral pathway is restricted eg requires a ‘gatekeeper’ rather than self-referral - this can increase the sense of powerlessness for the person with a mental illness.
- Many programs in disability support suffer from resource scarcity in an environment of high need and high demand. Allocation tends towards people who are more in crisis. This generally reduces capacity and focus to provide early intervention practices which are vital in reducing the disabling impact of mental illness. For young people this can be extremely significant where effective support can lead to completing school, retaining/relearning social skills and long term benefits such as workforce participation.

A national disability support scheme needs to ensure that the level of competition around accessing packages does not exclude come populations inequitably. Factors that prevent allocation of effective support to specific populations - such as young people, Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds - need to be identified and addressed to reduce the inequity.

There needs to be greater capacity for disability services to respond holistically where there are comorbid issues. Planning should be possible when issues of physical dependence and frailty are known and can be predicted as the likely outcome of an illness. In situations where the path of the disease/illness is known planning for services should occur in partnership with all relevant and appropriate service providers such that services will be available at the time they are required rather than the current ad hoc system where the levels of unmet demand are high and allocation is based more on crisis or risk factors rather than on need. Carers Australia and Carers SA continually advocate examples of this as a problem where an individual may have complex unmet support needs for many years, however the allocation occurs only when the aging family carer can no longer cope.

A national disability support scheme should take account of some of the shortfalls of the current system and seek to deliver a program that is more rights focused.

Our consultations highlight the diverse and complex nature of individuals' needs and therefore the importance of establishing programs that deliver holistic that effectively support for people with mental illness to 'recover' and access the full rights of citizenship. A national program should focuses on minimizing the disabling impacts of mental illness through a focus on prevention and early intervention that is not compromised by a ragne of potential barriers to access.

Coordination, standardisation and linkages

Alleviating waste and duplication was identified as an issue where funding and programs by Federal and State agencies need to be coordinated. Working together to develop and implement more coordinated, linked and standardized approaches to service design, delivery and reporting is needed.

There are many types of mental health services funded by State and Commonwealth including state mental health services, psychiatrist services, GP services, psychosocial rehabilitation, housing and support, PHaMs, psychologist and allied health providers and more.

Our consultation highlighted benefits of improving coordination and/or standardization around referral processes and paperwork, data collection and reporting, accountability targets and more.

An example was given of the GP chronic conditions and disease care plans where the amount of time available for services is recorded and the person takes it with them as the referral for services they have identified that they want to access. At any point in the system the form can be used to identify current services being accessed and for referral to services and where the person themselves has a copy and can take with them when accessing services.

In a system that is more rights-based and accessible, it is important to improve the navigability of the system for people with illness and families. Sometimes this is termed ‘consumer-centric’. The examples in our consultation indicate that access to some service types is very difficult as resource limitations lead to significant barriers to access. There is also the need to ensure sufficient flexibility to provide effective holistic support for people with complex needs.

Workforce development –‘peer’ workers and non-government workers

Non-government community mental health organizations support individuals through a range of activities and programs to live well in their own community and to remain within their family and home environment. This work reduces the demand on hospital and emergency departments where they would otherwise go to seek treatment, information and support. Positive outcomes are achieved when people can incorporate them into a recovery plan rather than a crisis response. Reducing social isolation by increasing social connectedness through employment, family and community activity can be achieved through the support of non-government mental health service providers.

In our consultation it was noted that currently there is little planning or investment by governments in workforce development issues facing the non-government mental health support services. The non-government workforce has expanded substantially in SA and it was noted that recruitment of qualified staff is getting more difficult, particularly in the country where distance and low population levels increases the cost of service delivery and also the cost to the individual of not receiving effective support services.

Our consultation noted the need for greater investment in peer worker training programs. Peer workers are people with a lived experience of a mental illness who work in mental health support services. Peer workers are a valuable asset to the mental health workforce and can perform a variety of roles – not just in mental health. It is important that any investment in peer worker training has as its core value a commitment to ensuring that the essential criteria for entry into peer worker training is a lived experience of mental illness.

Specialized roles for carers are also becoming more important. As with peer workers, the lived experience of the impacts of mental illness can be a powerful influence for improving organizational culture and reducing stigmatizing attitudes, policies and procedures.

Our consultation identified a number of areas where investment in workforce development in the non-government sector would be valuable. These include incentives to employ people with lived experience of a mental illness. Many organizations host students undertaking placements as part of tertiary study or as a way of gaining experience. Through this experience some of the students who may otherwise pursue a career in another field of their profession will be influenced to commence a career working in mental health. Incentives to attract and employ students who show enthusiasm for the area of work may consolidate this.

Promotion, Prevention and Early intervention

A National scheme that is rights based may lead to more interest and economic incentive to invest in effective prevention and early intervention programs.

Violence and abuse, particularly for young people, was cited as an area to target for prevention or early intervention to reduce. As a subset of this broader area, our consultation noted the need for effective strategies to combat the impacts of bullying on young people. Mandatory programs within communities and schools were proposed to address cyber bullying and the social isolation this promotes when the person bullied feels helpless and hopeless to engage with their peers for fear of attack. Bullying generally needs addressing within schools, however another area identified is workplaces. In addition to policies on bullying, there is a need to act on reports of bullying in a consistent and effective manner. Investment in supporting schools and workplaces to develop strategies would enhance the quality and effectiveness of bullying policies.

There are many examples of promotion and early intervention by non-government community mental health service providers. Some of these services are well known in Australia such as BeyondBlue and Lifeline, however there are many services that are less well known. Many of these services are provided by smaller organizations but have been developed by people with lived experience of illness or family members. Often the motivation for these organizations is a significant service gap or need. Services that are provided by these groups include self-help, peer or mutual support groups, education programs, information provision, respite services, counseling support and many other types of service. The effectiveness of a national disability support scheme would be enhanced with strategic investment in some of these service types. One of the examples in our consultation noted that hosting a camp for young people with a diagnosis of mental illness revealed insights that some may find surprising. Many of the young people on the camp stated that they ‘did not really understand their condition and were reluctant to share everything they should with their psychologist or health professional’.

Conclusion

Writing this submission has been a difficult task as the Productivity Commission issues paper raised many questions that are complex and, in many cases, interrelated. The short timeline and capacity constraints within our organization means that our submission is based on consultation and research that is more limited than we would like. Nevertheless we have attempted to provide information, ideas and insights to assist the Productivity Commission towards the next stage of this work.

We encouraged people to provide written examples of people with mental illness that describe support needs and how well (or not well) our services systems are meeting their needs. These examples are neither comprehensive nor exhaustive but are provided to start to illustrate some of the complexities, barriers, gaps, successes and possibilities that feature amongst the potential beneficiaries of a national approach to disability support. A national scheme for disability support should complement and enhance the effectiveness of the existing support service systems.

Our consultation has confirmed that a move to a rights based approach to service system development is supported. The examples that we present demonstrate some of the gaps and issues that result in insufficient access to effective and timely support.

Our feedback indicated strong support for the Productivity Commission to continue to consider the needs of people currently enduring or at future risk of enduring the disabling impacts of mental illness. This support should also consider the needs of families and family carers.

The evidence shows that investing in effective supports for people with mental illness to live in the community is not just a cost, but is an investment that will result in significant long term benefits to both the individual and society.

The importance of the need to reduce stigma and discrimination towards people with mental illness was highlighted in our consultation.

An effective national support scheme for people with mental illness will also lead to stigma reduction benefits as the community sees the evidence that people with mental illness, even with severe and enduring illness, can lead productive lives in the community if adequately supported.

We look forward to participating in the ongoing development of a national disability support scheme that includes the aim of reducing the disabling impacts that arise due to the mental illness burden.

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[i] MHCSA ‘What is Recovery ? A journey of hope.’ www.mhcsa.org.au

[ii] MHCSA. ‘ Mental Health Lets Make it Work Better’ www.mhcsa.org.au

[iii] MHCSA. ‘Housing for mental health’ www.mhcsa.org.au

[iv] Martin, N 2009. From Discrimination to Social Inclusion. A review of the literature on anti stigma initiatives in mental health. www.wldalliance.org.au

[v] Mental Illness Fellowship of Australia. ’40 Thousand people emissing out of mental health services.’ MIFA, Marleston SA.

vi Andrews G (2006). Tolkein II: A Needs-Based, Costed Stepped Care Model for Mental Health Services. Sydney: World Health Organisation Collaborating Centre for Classification in Mental Health. Sydney: WHO