



Mental Health
Coordinating Council

**Developing a National Disability Strategy for Australia:
Access Inclusion Participation**

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Discussion Paper **Developing a National Disability Strategy for Australia:** **Access Inclusion Participation**

The Mental Health Coordinating Council (MHCC) is the state peak body for non-government organisations (NGOs) working for mental health throughout NSW representing the views and interests of over 200 NGOs. Our member organisations specialise in the provision of services and support for people with a disability due to mental illness. MHCC provides leadership and representation to its membership and seeks to improve, promote and develop quality mental health services to the community. Facilitating effective linkages between government, non-government and private sectors, MHCC participate extensively in public policy development.

The organisation consults broadly across all sectors in order to respond to legislative reform, and sits on numerous National, State (NSW) and State Government Department (NSW) committees and boards in order to affect systemic change. MHCC manages and conducts research projects, develops collaborative programs on behalf of the sector, and is an accredited training and professional development provider for the sector.

MHCC thank the Commonwealth Government for inviting them to provide input into discussions for the development of a National Disability Strategy.

Focus

MHCC have consulted our members for the purposes of this submission in which we focus specifically on the design and implementation of a national strategy to address barriers faced by people with disability, emphasising the importance of the work of the non-government sector in developing a framework that supports people with diversity of impairment including psychiatric disability in the community.

This focus is underpinned by a **social model of disability**, a philosophy embracing the lived experience of people with disability to eradicate discrimination, and the stigma that is a barrier to their engagement in all aspects of life.

The term 'social model of disability' emerged from the United Kingdom in the 1980s, originally coined by disabled British academic, author, and disability rights activist Mike Oliver (1983), Emeritus Professor of Disability Studies at the University of Greenwich. The origins of the approach can be traced to the 1960s and the civil rights and human rights movements.ⁱ

Oliver wanted to draw a distinction between the prevailing individual model of disability *underpinned by the personal tragedy theory of disability*ⁱⁱ and the concept of social disability. This was expanded and developed by activists in the UK, Europe and the USA included people with psychiatric disability.ⁱⁱⁱ

*The **social model of disability** proposes that barriers, prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognizes that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal.'*^{iv}

Our core objective is that the National Disability Strategy commit to agreed targets for eradicating social exclusion for people with disability in Australia, enabling them to access a broad range of services; participate in the workforce, and address the consequential impact of social exclusion on the potential for recovery and maintenance of good mental health. The strategy must acknowledge and foster the contribution people with disability give to society and provide opportunities for people to maximise their contribution.

Defining Disability

What is disability? In the first instance, MHCC propose that a National Disability Strategy must discuss and define what is meant by disability from a philosophical perspective, since this significantly affects the lens through which strategic policy is developed. The discussion paper for consultation does not clearly articulate this discussion.

Defining disability is complex and controversial. Though arising from a broad spectrum of physical, psychiatric or intellectual impairment, disability has social as well as health implications. A thorough understanding of disability recognises that it has a powerful human rights dimension frequently associated with social exclusion, and increased exposure and vulnerability to poverty. A definition within a social model of disability characterises that *'Disability is the outcome of complex interactions between the functional limitations arising from a person's physical, intellectual, or mental condition and the social and physical environment'*.^v

Disability is multi-dimensional, and whilst the lived experience of a person with disability is unique to each individual, it is far broader than an individual health or medical problem. On this basis, the working definition of disability adopted in a National Disability Strategy must clearly state for example, that disability is *'long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community'*.^{vi}

The needs of people with disabilities differ widely. People with psychiatric disability; children; older people; women; indigenous people; refugees and displaced persons; and minorities may all experience disability differently. Some may suffer multiple disadvantage as a result of their wider social or economic status. The consequences are particularly severe for women with disabilities who may also be subject to social, cultural and economic disadvantages due to gender discrimination. Similarly people with co-morbid disabilities as a consequence of their HIV or Hepatitis status may experience particularly acute discrimination and isolation in the community.

Mental Illness and Psychiatric Disability

There is much misunderstanding surrounding the use of the terms 'mental illness' and 'psychiatric disability'. It is necessary to define the language in order to inform the debate for and against the separation of clinical and disability support services.^{vii}

*The inclusion of psychiatric disability in the **Commonwealth Disability Services Act 1986**, the **Commonwealth State Disability Agreement** and the **Disability Discrimination Act 1992** adds an extra dimension to these discussions. Acceptance of the existence of such a distinction gains even greater weight with the relatively recent recognition of 'psychiatric disability' in the spectrum of disabilities mentioned in recent reviews other Commonwealth programs (HACC, SAAP) and policies. (VICSERV, 2008).^{viii}*

Examination of the relevant legislation including the Mental Health Acts concerning disability and Minimum Standards clearly identifies two differing approaches to client rights and entitlements to service delivery.

Perceptions that people with disabilities have regarding their rights to services in the community; their rights to dignity and integrity; and the right to control all aspects of their lives are integral to the way in which disability is understood and policy developed. However, people with psychiatric disability are faced with a number of conflicting messages about their 'rights'.

Even the so-called 'right' to treatment for a person with a mental illness may be transformed into a 'right' to be imposed by the treating agency under statutory powers. This makes no sense unless there is some attempt to differentiate 'mental illness' from resultant 'psychiatric disability'. A person with a psychiatric disability, then, has exactly the same rights to community services, dignity and integrity as any other. This is enhanced if disability support is separate and autonomous from clinical support.^{ix}

Psychiatric disabilities are significantly different from many other disabilities in that they may fluctuate and be episodic. It is also necessary to recognise that there are distinctions between the 'disease' process and the resultant disabilities that may be less clear or obvious than for other disabilities. This has resulted in an interchangeable use of the terms 'mental illness' and 'psychiatric disability'. This has frequently resulted in policy makers and clinicians defining the area of practice as 'mental illness' to include almost every aspect of a person's life. People with a diagnosis of some form of 'mental illness', may become locked into a *clinical services system which dictates that all aspects of their life require intervention by this system. These people discover their world is defined and controlled in terms of psychiatric diagnosis and treatment.^x*

It is precisely for this reason that the debates about the separation between 'mental illness' and 'psychiatric disability' arose. It was perceived that, if community integration and active participation in community life was a desired outcome for people given a diagnosis of a serious mental illness, then providing community support in an environment which facilitated their identify as other than 'mentally ill' was also desirable. NGO psychiatric disability support services were envisaged as providing these supportive environments from which participants could venture back into community life or which could maintain their existing community connections and enhance them. Many psychiatric disability support services have, in fact, been at the forefront of the movement towards consumer-directed and responsive service delivery.^{xi}

Good Practice

There has been a long debate within the disability movement and among practitioners about what constitutes good practice. The worldwide shift to a broader framework for action has occurred, with a widespread recognition of the social and human rights dimensions of disability – **a social model of disability**. Within that approach, prevention must be a top priority. Prevention in this context implies the ability for people with disability

to have access to a broad spectrum of services, the absence of which may be further disabling from both a social and clinical perspective.

This needs to be accompanied by actions which seek to ensure that people with disabilities are supported in their efforts to develop their full potential, and to lead productive and fulfilling lives. *As a broad principle, good practice suggests that this means that change must occur within society and in the way it views disability. Rather than people with disabilities having to change to fit society, society must make room for them and uphold their rights.*^{xii}

Burden of Cost

In 2006–07, services funded under the Commonwealth State/Territory Disability Agreement (CSTDA) delivered assistance to over 232,000 people with a disability, accounting for \$4.42 billion of government expenditure.^{xiii}

Specialist disability services funded under the Agreement include accommodation support, community support, community access, respite, and employment services. A report recently released by the Australian Institute of Health and Welfare (AIHW) entitled *Disability Support Services 2006-07*, outlines the characteristics of people who used specialist disability services in 2006–07 and the services they received.^{xiv}

The report identified that the number of people using disability support services in Australia increased by 24% over the past four years. The data showed that 232,000 people used disability support services in 2006-07, up from 188,000 in 2003-04.^{xv} AIHW's Functioning and Disability Unit identified this as an average annual growth rate of 7%. The largest increases over the past four years were seen in respite care (46%), community support (25%) and employment services (25%).

Community support services, such as therapy, early intervention and case management, were the most commonly used services over the last four years. AIHW reported that most of the growth in employment services occurred in open employment services, which are most commonly used by people with less severe disability than those who use supported employment services.^{xvi}

Accommodation support services accounted for 16% of all service users in 2006-07, almost half of which reflect people with disability who have continued to receive services for four years, making this a very stable user group. Likewise the proportion of disability service users who need ongoing assistance with basic activities such as mobility, self-care and communication has remained stable over four years.^{xvii}

Intellectual disability was the most common primary disability (accounting for around 1 in 3 service users), followed by psychiatric disability then physical disability. According to the AIHW, *'there are now more people who need help in areas such as learning, household chores, and fostering social interactions'*. In 2006-07, about 68% of service users report needing help with activities of independent living, 63% with work, education and community living and almost 60% with daily living activities.^{xviii}

Frequently, the direct cost of disability is unequally shared, the burden of care most often falling upon family members, usually mothers or other female relatives. The burden of care also often falls on children and adolescents who may become 'parentalised' and miss out on their own education and employment opportunities in order to care for a family member.

The benefits of reduced disability and morbidity to the economy are numerous and include increased productivity, greater opportunities to obtain better-paying jobs, longer working lives, and inestimable in terms of the benefits to the individual and their carers.^{xix}

Agency sector

In 2006–07, 29% (3,118) of outlets providing CSTDA-funded ^{xx} services were classified as government outlets, most (2,858 or 92%) were operated by state/territory governments; whilst local government operated 260 outlets (8.3%). Non-Government agencies represented 71% (7,504), the majority of which were income tax exempt charities (6,104 outlets or 81% of non-government outlets) and the remainder (1,400 or 19%) were non-income tax exempt. Whilst the Australian Government did not operate these services, they provided funding. ^{xxi}

The international framework

Australia ratified the United Nations Convention on the Rights of Persons with Disabilities Convention on 17 July 2008. Australia was one of the first Western countries to do so. By ratifying the Convention, Australia has joined other countries around the world in a global effort to promote the equal and active participation of all people with disability.

The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity. The treaty asserts the rights of people with disabilities to education; health; employment; living conditions; freedom of movement; freedom of exploitation and equal recognition before the law for people with disabilities. It also asserts the right to transport, access to buildings and facilities, and recognises the capacity of people with disabilities to make decisions.

The Optional Protocol which is also binding, permits individuals to petition an international expert body with grievances. By ratifying the Convention, States commit themselves to enact laws and abolish discriminatory laws and practices. ^{xxii} The Australian Government has now commenced a process to enable it to make an informed decision on whether or not to become party to the Optional Protocol to the Convention.

MHCC support the position stated by the Australian Human Rights Law Centre that ratification of the Optional Protocol would be symbolically significant, and would play an important role in mainstreaming the human rights of people living with disability. It would:

- *complement and strengthen existing domestic mechanisms designed to promote disability rights;*
- *foster and promote analysis and change;*
- *strengthen Australia's role within the international community;*
- *be consistent with the Australian Government's commitment to constructive engagement with the UN human rights system and to the harmonisation of domestic laws, policies and practices with international human rights standards; and*
- *enhance public awareness and understanding of the rights of people living with disabilities.* ^{xxiii}

International standards for upholding the rights of people with disabilities are set out in the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (see Appendix 1). However, the rules are not compulsory, but they imply a strong moral and political commitment to take action for the equalisation of opportunities for persons with disabilities. The 22 rules set out important principles for responsibility, action and co-operation. They point to areas of decisive importance for the quality of life and for the achievement of full participation and equality. ^{xxiv}

Without embedding these 'Rules' into the framework of a National Disability Strategy, a commitment to meaningful targets will be as weak as the **Outcomes** identified in the *Developing a National Disability Strategy for Australia: Access Inclusion Participation* consultation discussion paper, which were:

People with disability and their carers have an enhanced quality of life and participate as valued members of society. Core outcome areas are:

- *People with disability achieve economic participation and social inclusion*
- *People with disability enjoy choice, wellbeing and the opportunity to live as independently as possible*
- *Families and carers are well supported.*

The Standard Rules offer an instrument for policy making and action for persons with disabilities, and the organisations that support them. Their purpose is to ensure that all people with disabilities may exercise the same rights and responsibilities as other members of society. They draw from other international agreements which constitute the moral and political foundation for them.^{xxv}

A Special Rapporteur has been appointed by the UN to monitor implementation of the Standard Rules. Regular progress reports are submitted to meetings of the UN Economic and Social Commission. These show that progress is being made, but also suggest that more effort is clearly required by states and the international community to give more prominence to the rights and needs of people with disabilities. The Standard Rules provide a good strategic framework, but need to be delivered with energy and commitment.^{xxvi}

The National Disability Reform Agenda

The discussion paper suggests that the development of the National Disability Strategy '*presents an opportunity to influence government policies and initiatives that will follow over the coming years*'. To that end MHCC propose that the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, be embedded in the framework at the outset. The 22 Standard Rules set out the critical principles for *responsibility, action and co-operation*.^{xxvii}

MHCC suggest that in order to '*drive a reform agenda*'^{xxviii} some fundamental areas of decisive importance relating to quality of life, full participation and equality must be identified for action such as:

1. Preconditions for equal participation

Awareness raising, access to psychiatric and medical care, rehabilitation and support services delivered in both main-stream and community settings

2. Target areas for equal participation

Accessibility; education; employment; income maintenance and social security; accommodation choices; personal integrity; culture; recreation and sports; religion and policy participation

3. Implementation measures

Information and research, policy-making and planning, legislation, economic policies, co-ordination of work, organisations of persons with disabilities, workforce training national monitoring and evaluation of disability programmes in the implementation of the Standard Rules, technical and economic co-operation, and international co-operation.

Key areas

The Discussion Paper for Consultation identifies that it will drive the reform agenda in a number of key areas. Listed as follows:

1. Service benchmarks
2. Disability services' quality standards
3. Service planning
4. Building people centred service delivery
5. Early intervention and prevention
6. Workforce capacity
7. National consistency
8. Ageing carers

MHCC support the above key areas, and also suggest additional key areas for consideration:

9. Consumer participation & advocacy
10. Family and carers of people with psychiatric disability including young carers
11. Culturally and linguistically diverse communities & ATSI
12. HIV
13. Advocacy services
14. Research
15. Sustainability

In particular response to key areas:

4. Building people centred service delivery

In order to achieve this key area, good practice principles in service delivery must embrace the social model of disability. Good practice is most likely to be ensured through a collaborative approach, using best practice in both social and clinical terms.

The key to ensure the best use of resources is to empower people with disabilities to be heard in all aspects of policy development and service implementation, in addition to embarking upon a major strategy to eradicate negative attitudes in society as a whole. Community based services best meet the holistic needs of most people with disability, empowering them through choice and participation in service development.

In order to facilitate 'Good Practice' in NGO and government policy it is necessary promote a rights-based approach to sustainable development for persons with disabilities through an emphasis on satisfying five basic principles:

1. **Social Protection:** People with disabilities should have access to basic social protection, defined as housing, health care, rehabilitation services and access devices
2. **Accessibility:** People with disabilities should have access to education, financial, legal and service information, and income earning opportunities
3. **Consciousness:** People with disabilities are conscious of their own needs and rights. They are aware of the consequences of neglecting and discriminating attitudes in the society

4. **Influence:** People with disabilities are entitled to have equal opportunities to influence decision and policy making through processes of participation

5. **Control:** People with disabilities are entitled to take initiatives to assert their influence, and promote awareness of their rights. This enables increased control over the distribution of resources and benefits. ^{xxix}

9. Consumer participation and advocacy

A rights-based approach to disability and development implies a right to self-representation. Such rights are best promoted by people with disabilities themselves. The growth of a democratic, representative disability movement is the critical to ensuring that government provision is appropriate to the needs and rights of people with disabilities. In this way target groups can be actively involved in the planning, implementation and monitoring of all disability and development work, and to take measures to remove barriers to participation and to combat discriminatory behaviour, practices, policies and environments. ^{xxx}

10. Families and carers of people with psychiatric disability including young carers.

Recent research has identified distinctive characteristics and needs of families and carers of people with mental illness for respite and support services. In particular, consultations conducted nationally by FaHCSIA in 2007, and the consultancy group HMA for Community Mental Health Australia (CMHA) in 2008, raised concerns that existing frameworks and services for respite derived from the aged care and disability sectors do not adequately meet the needs of carers and consumers supported by the mental health sector. CMHA through the National Building Capacity in Community Mental Health Family Support and Carer Respite Project has identified these concerns (attached in more detail in Appendix 11). The priorities for action were identified as follows:

Priorities for Action

- Increased provision of community based psychosocial rehabilitation and recovery services for consumers
- Provision of respite services that enhance and facilitate consumer recovery
- Development of support and respite services to meet the needs of the whole family, not just the primary carer. This is particularly the case in indigenous and CALD communities
- Provision of Coordinated Care within a 'whole of family approach'. Where the carer and care recipient require a range of services, cross referral and coordinated case management are required
- Development of support and respite services responsive to the needs of young carers
- Development of service delivery models that are flexible and responsive to the changing needs of the consumer and the carer and facilitate access into the service delivery system
- Development of service delivery systems that promote and enhance relationships between the mental health respite and support system, other components of mental health system and primary health and community care systems
- Workforce development of generic respite and support system to better respond to the needs of consumers and families and carers of people with mental health issues.

14. Research

Most research into disability tends to focus predominantly on health or social welfare aspects. There is little coordination or integration between research on disability and research on associated issues in gender, social development, and human sciences. Specific attention needs to be given to both quantitative and participatory components in research methods to ensure that the different dimensions of disability are appreciated. Research also provides opportunities for the international community to share experiences and seek a better understanding of disability.^{xxx1}

MHCC propose that in developing a National Disability Strategy that research be integrated into a service delivery framework on an ongoing basis to measure outcomes. It is critical that longitudinal research also seeks to explore collaborative service delivery, investigating seamless pathways to accessing services and identifying gaps and barriers to providing co-ordinated services.

The policy framework

MHCC propose that the Government state a target through a Vision:

In Australia by 2028, all people with disability will be included and respected as equal members of society, enjoying equal opportunities and choices to improve their quality of life.

The National Disability Strategy must provide a framework to deliver this vision, together with the goals, policy objectives and strategy to deliver.

To ensure effective delivery of reform agenda programme, MHCC propose the following recommendations:

1. That government commit to a vision for a strategy for improving the life chances of disabled people, developed fully and timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2028.
2. That coherent and explicit standards be developed bringing legislation and other rights into a coherent framework.
3. To provide a broad range of government and community services that are sustainably funded.
4. That review of service provision should address ways of encouraging effective delivery of services that meet the needs of disabled people and build workforce capacity.
5. That a strong focus is maintained within government to make sure that priority is given to disability issues over time by provide oversight of a process to reform delivery in line with the public service reform agenda.
6. That arrangements should be established for securing participation of disabled people in policy design and delivery at all levels.

MHCC are acutely aware of the current global financial environment which may impact of State and Commonwealth Governments' ability to meet its reform agenda promised during the election. However, we view with concern reports indicating that the Commonwealth is 'talking down' state expectations that it would deliver more than \$20 billion additional funding to secure deals in health, disability services, housing, and education under COAG (The Australian, 21 Nov.08). We urge governments not to waver from the commitment made in 2007 to implement one of the key recommendations of the Senate Inquiry into the Commonwealth State and Territory Disability Agreement underpinning the principles of the *UN Convention on the Rights of People with Disabilities*, in order to fulfil its promises to provide socially inclusive strategies to all Australians.

We look forward to the results of the Government's deliberations and express our willingness to be consulted further on the matters contained in this submission. For further information please contact Corinne Henderson, Senior Policy Officer at corinne@mhcc.org.au or telephone: (02) 9555 8388 ext 101.

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Appendix 1: United Nations Standard Rules on the equalisation of opportunities for persons with disabilities

1. Preconditions for equal participation

Rule 1. Awareness-raising

'States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution'

Rule 2. Medical care

'States should ensure the provision of effective medical care to persons with disabilities'

Rule 3. Rehabilitation

'States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning'

Rule 4. Support services

'States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights'

2. Target areas for equal participation

Rule 5. Accessibility

'States should recognise the overall importance of accessibility in the process of the equalisation of opportunities in all spheres of society. For persons with disabilities of any kind, States should:

- (a) introduce programmes of action to make the physical environment accessible; and
- (b) undertake measures to provide access to information and communication'

Rule 6. Education

'States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system'

Rule 7. Employment

'States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market'

Rule 8. Income maintenance and social security

'States are responsible for the provision of social security and income maintenance for persons with disabilities'

Rule 9. Family life and personal integrity

'States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity, and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood'

Rule 10. Culture

'States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis'

Rule 11. Recreation and sports

'States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports'

Rule 12. Religion

'States will encourage measures for equal participation by persons with disabilities in the religious life of their communities'

3. Implementation measures**Rule 13. Information and research**

'States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles which affect the lives of persons with disabilities.'

Rule 14. Policy-making and planning

'States will ensure that disability aspects are included in all relevant policy-making and national planning'

Rule 15. Legislation

'States have a responsibility to create the legal bases for measures to achieve the objectives of full participation and equality for persons with disabilities'

Rule 16. Economic policies

'States have the financial responsibility for national programmes and measures to create equal opportunities for persons with disabilities'

Rule 17. Co-ordination of work

'States are responsible for the establishment and strengthening of national co-ordinating committees, or similar bodies, to serve as a national focal point on disability matters'

Rule 18. Organisations of persons with disabilities

'States should recognise the right of organisations of persons with disabilities to represent persons with disabilities at national, regional and local levels. States should also recognise the advisory role of organisations of persons with disabilities in decision-making on disability matters'

Rule 19. Personnel training

'States are responsible for ensuring the adequate training of personnel, at all levels, involved in the planning and provision of programmes and services concerning persons with disabilities'

Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Standard Rules

'States are responsible for the continuous monitoring and evaluation of the implementation of national programmes and services concerning the equalisation of opportunities for persons with disabilities.'

Rule 21. Technical and economic co-operation

'States, both industrialised and developing, have the responsibility to co-operate in and undertake measures for the improvement of the living conditions of persons with disabilities in developing countries'

Rule 22. International co-operation

'States will participate actively in international co-operation concerning policies for the equalisation of opportunities for persons with disabilities '

Appendix 11: Families and Carers of People with Mental Health Issues

Research indicates that models for mental health family and carer support and respite service need to make provision for episodic nature of mental illness and the resulting changes in levels of functional independence of the care recipient. Support and respite service delivery must be inclusive of the needs of the whole family and not just the primary carer. This is particularly applicable to indigenous and CALD communities.

Service delivery needs to be flexible and responsive to the changing needs of the consumer and the carer. These needs will vary according to the nature and course of a person's illness and recovery journey, their age, and the particular situation and experiences of family members. Opportunities for assessment at critical points are a vital component of respite and support. The well-being of carers improves, and stress reduces, as the consumer progresses on their recovery journey.

CMHA through the National Building Capacity in Community Mental Health Family Support and Carer Respite Project has identified the distinctive characteristics and needs of families and carers of people with mental illness accessing support and respite services to include:

- **Stigma**

Families, carers and people experiencing mental illness might shun respite and support because of stigma still associated with mental illness in parts of the community. Personal factors that may reduce access to respite and support include the carer and family's own values of privacy and self-reliance and their limited understanding and knowledge of mental illness. This may result in failure to identify symptoms or seek help as they feel they are to blame and must face the situation alone. Furthermore many families and carers who want support do not know where to start to get help. Most families are not familiar with support services, some workers do not discuss such services or the information provided may not be useful or relevant to their needs.

- **Perceptions of Carer Role**

The terms '*carer*' and '*respite*' are difficult terms in the mental health area as many people in relationships and families where there is mental illness do not identify or view themselves as '*carers*' nor do they readily perceive the relevance of '*respite services*'. A more flexible approach to respite is required in order to best to meet the needs of a carer for '*a break*' and to sustain their ongoing role.

- **Service relevance**

Families, carers and consumers will not use respite services if they are perceived to be unsuitable or irrelevant, or more suited to the needs of elderly frail aged people or people with intellectual or physical disability. A key element in the uptake of services is that the services provided must contribute to the recovery of the care recipient. A lack of staff skills and appropriateness of design and flexibility in delivery of generic programs can also reduce their relevance or usefulness to carers of people with mental illness. Generic services often do not have the skills to engage with people with mental illness and to inspire confidence by the consumer and carer that relevant services will be provided.

- **Systemic and programmatic barriers**

Barriers of a systemic or programmatic nature can arise from a range of factors including eligibility criteria, program priorities and related assessment measures that discriminate against people with mental illness, their families and carers. Family and carers encounter difficulties in accessing in-home and outreach support programs, such as Home and Community Care and disability services funded under the Commonwealth State and Territory Disability Agreement, and Centrelink benefits.

- **Indirect vs. direct respite**

Many of the services that are helpful to families and carers of people with mental health issues are classified as indirect funding and as such, according are often not a priority for funding. This presents a barrier to service delivery.

- **Complex Issues**

Some respite and support services either cater for or are perceived to target a specific illness group and to exclude others. Families, carers and consumers experiencing a range of complex problems such as mental illness and intellectual disability of mental illness and substance abuse often fare poorly.

- **CALD and Aboriginal Groups**

In common with other groups of people with disabilities and their carers there is a lack of adequate respite service provision to CALD groups, Aboriginal groups, remote communities and young carers, and there is a need to develop more flexible service delivery models for these groups.

ⁱ Oliver, M. (1996). *Understanding disability: From theory to practice*. New York: St. Martin's Press.

ⁱⁱ Oliver, M. (1990). *The Individual and Social Models of Disability*. Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians UK, p.1.

ⁱⁱⁱ Oliver, M. (1996). *Op. cit.*

^{iv} Unknown author. Wikipedia. 2008. Available: http://en.wikipedia.org/wiki/Social_model_of_disability

^v DFID. (2000). *Disability, poverty and development*. Department for International Development, UK.

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- ^{vi} DFID. (2000). Op. cit.
- ^{vii} Psychiatric Disability Services of Victoria Inc.(VICSERV). Available:
<http://www.vicserv.org.au/library/papers/mentalillness.htm>Mental Illness and Psychiatric Disability [Accessed: 28.11.08].
- ^{viii} Ibid.
- ^{ix} Ibid.
- ^x Ibid.
- ^{xi} Ibid.
- ^{xii} DFID. (2000). Op. cit.
- ^{xiii} Australian Institute of Health and Welfare (AIHW) 2008. Disability support services 2006–07: national data on services provided under the Commonwealth State/Territory Disability Agreement. Cat. no. DIS 52. Disability series. Canberra: AIHW.
- ^{xiv} The information from the CSTDA National Minimum Data Set (NMDS) used in the report was collected from around 10,000 service outlets around Australia. The 2006–07 NMDS is the fourth collection of full-year data on disability services and coincides with the official end of the third CSTDA.
- ^{xv} AIHW. (2008). Op. cit.
- ^{xvi} AIHW. (2008). Op. cit.
- ^{xvii} AIHW. (2008). Op. cit.
- ^{xviii} AIHW. (2008). Op. cit.
- ^{xix} DFID. (2000). Op.cit.
- ^{xx} Commonwealth State/Territory Disability Agreement of 2002–07.
- ^{xxi} AIHW. (2008). Op. cit.
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