



## **Mental Health Carers Australia**

National Mental Health Carer Voice

### **Joint Standing Committee On The National Disability Insurance Scheme**

The provision of services under the NDIS for people with psychosocial disabilities  
related to a mental health condition

A submission by Mental Health Carers Australia

February 2017



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For further information please visit [www.mentalhealthcarersaustralia.org.au](http://www.mentalhealthcarersaustralia.org.au) or contact Jenny Branton, Executive Officer, Mental Health Carers Australia

[jenny.branton@mentalhealthcarersaustralia.org.au](mailto:jenny.branton@mentalhealthcarersaustralia.org.au)



## Introduction:

Thank you for the opportunity to submit to the inquiry into the provision of services under the NDIS for people with psychosocial disabilities. Mental Health Carers Australia would welcome the opportunity to address the Joint Committee when hearings are held as a part of the inquiry process.

Mental Health Carers Australia (MHCA) is a member based national organisation representing people who support and/or care for a person with a mental illness. The state based member organisations have extensive connections with and understanding of families and carers of people with a mental illness. We wish to acknowledge our gratitude to those individuals and family members who have shared their personal experiences with us for the purpose of strengthening this submission. Please note that examples used have been de-identified.

MHCA supports the overarching objective of the National Disability Insurance Scheme (NDIS), however has concerns regarding the availability of supports to particular groups of people living with mental ill health and to their family, friends and others in a caring role who provide the majority of support

MHCA and its member organisations are confident that by working with mental health carers, service providers and government, the experience of carers can be improved. Improving the capacity of carers in turn improves the experience and outcomes for people with mental illness and reduces demand on the public and private mental health system and the costs to the public purse associated with that increased demand. MHCA is grateful for the opportunity to provide this submission and is keen to support the process in any way possible.

## Mental Health Carers:

### Carer role

MHCA experience of NDIS operations in trial sites is that often the needs of the family member/s supporting an individual with severe mental ill health are not fully recognised or understood. The NDIS legislation rightfully acknowledges the important role a person's support network plays in their recovery<sup>1</sup>. However, in practice, although carers are eligible for assistance, it is often difficult to identify who the carers are and adequately assess their needs. As a consequence, carers are less likely to receive the support they require to sustain their caring role. This places the carer, the family and the person with mental ill health at risk<sup>2</sup>.

Carers are less visible in the NDIS where the focus is, understandably, on the person with disability. A person experiencing acute mental ill health may not identify that their family member or friend is providing care. A family-centred approach is required by the assessor

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<sup>1</sup> Supports funded by the Scheme (NDIS) <https://myplace.ndis.gov.au/ndisstorefront/families-carers/family-supports.html>

<sup>2</sup> O'Halloran, P. 2014. Psychosocial Disability and the NDIS.



to ensure that family or friend carers are identified. Children in a caring role are particularly vulnerable to being overlooked yet their needs are considerable and they respond very positively to receiving support<sup>3</sup>.

While people who support or care for a person with a mental illness share common issues and experiences with other carers they also experience a range of factors unique to caring for someone with a mental illness. Some of these factors are outlined in appendix 1.

### **A family's experience of PHaMS, NDIS and Mental Health Respite: Carer Support**

Joanne, a 32 year old mother of three children, is an NDIS participant who has transferred from PHaMS, retaining her PHaMS service provider for one cluster of NDIS supports. Over many years, Joanne has been suicidal and has found parenting overwhelming at particular low points. Her eldest daughter, aged 14, was identified by the PHaMS case worker as being in a caring role for Joanne. With Joanne's permission, her daughter was referred to a carer service provider and received young carer counselling and participated in a young carer peer support program funded through Mental Health Carer Respite. Joanne, with the assistance of the PHaMS case worker, enrolled the children in a school holiday program funded through Mental Health Carer Respite. However, Joanne's eldest daughter became disengaged from school, and, due to a number of concerns, was formally placed in the care of Joanne's Mother. This distressed Joanne and created a level of conflict between Joanne and her Mother. Joanne's Mother was recognised as a carer by the PHaMS case worker and was also referred to carer counselling. Currently, under Joanne's NDIS plan, there are no items relating to the support of the children in their caring role, nor for Joanne's Mother. Joanne no longer has access to a case worker and has not received funding for coordination under her NDIS plan. The previous PHaMS service provider continues to advocate on Joanne's behalf, arguing that Joanne and the family require additional support, particularly around coordination of access to various supports for the children and in-home parenting support for Joanne. However, it is uncertain what supports will be available for young carers in the absence of Mental Health Respite: Carer Support funding. It is also unclear whether, in the absence of a case worker (previously funded through PHaMS) whether Joanne will be well enough to source supports for herself and her children or to re-establish a more positive relationship with her Mother and her daughter, both of whom are important to Joanne's long term wellbeing.

<sup>3</sup> Cooklin, A. 'Living upside down': being a young carer of a parent with mental illness'. *Advances in Psychiatric Treatment*, vol. 16, 141-146.



## NDIS Eligibility

*a. the eligibility criteria for the NDIS for people with a psychosocial disability;*

### Consumers:

The draft Fifth National Mental Health Plan estimates that there are over 690,000 Australians who experience severe mental illness each year. The vast majority of these people receive assistance from their family and friends who provide support in cognitive and emotional tasks, personal and health care, mobility, household tasks, transport, and reading and writing tasks<sup>4</sup>. The National Mental Health Consumer and Carer Forum (NMHCCF) anticipate that there are likely to be between 149,000-206,000 people who have severe or profound core activity limitations associated with mental illness. This represents a significantly larger number than the accepted figure of 64,000 used by the NDIA and will result in many people with severe mental ill health and their carers being unable to access support through the NDIS. It is estimated that only 12% of people with severe and persistent mental illness will be eligible for the NDIS<sup>5</sup>.

To be eligible for an NDIS individually funded package of support a person needs to have a 'permanent impairment' or an impairment that is likely to be permanent. Unlike many disabilities, where support needs are consistent and predictable, mental illness and the associated psychosocial disability is often episodic with the health and support needs of the individual varying enormously over a lifetime. The current assessment process for eligibility draws heavily on medical and diagnostic information, rather than assessment of functional impairment. If eligibility were tested on the basis of someone's functional impairment, then it is likely that more people with psychosocial disability would be deemed eligible, and would therefore get the support they need to participate in social and economic activities. However, people with mental ill health have not necessarily had assessments of their functional impairment.

### Young people and functional assessment

Young people with significant mental health issues may have a long history of mental ill health and have received ongoing support from their family but not have a diagnosis. Their current clinician may be unable to assess the extent of the young person's functional limitations. This has led to protracted assessment processes with Local Coordinators directing repeated requests for information to the applicant. While functional impact is a more important factor than a diagnosis, in the absence of a diagnosis that Local Coordinators understand as 'severe' for example, schizophrenia, they request additional information which the young person and/or their family may not be able to afford financially or not have the ability to organise. Many people with mental health issues are not in contact with occupational therapists, for example. Hence, while the young person may actually be eligible for NDIS support, neither they nor their family, are necessarily in the best position, financially or functionally, to fully comply with ongoing requests for information.

<sup>4</sup> Australian Bureau of Statistics. 2015. Survey of Disability, Ageing and Carers: Psychological Disability, 2012 - Australia. Tables 3 and 8.

<sup>5</sup> Productivity Commission, 2011, Inquiry into Disability Care and Support Report No 54



It is not uncommon for people experiencing mental ill health to have limited comprehension that they are ill or that they need support. In this circumstance they might be eligible for a package but are unlikely to seek it out. The mental health sector also operates on a recovery model. Recovery is not synonymous with cure but rather refers to both internal conditions experienced by persons who describe themselves as being in recovery - hope, healing, empowerment and connection - and external conditions that facilitate recovery - implementation of human rights, a positive culture of healing, and recovery-oriented services<sup>6</sup>.

### **Carers:**

We recognise that NDIS potentially offers eligible people with psychosocial disability and their carers/family great benefits. An assessment of some of our member organisations clients over the past three years indicates that only about 14 per cent of the services provided were to people caring for a family member with a diagnosis that would make them eligible for the NDIS. In a survey conducted by Carers NSW in 2012 they found that 60 per cent of mental health carers reported needing support in comparison with about 30 per cent of other carers who responded. Mental health carers also rated their health and mental health significantly lower than other respondents in different caring roles. When put together these figures suggest that channelling significant state government funding into the NDIS will leave many families caring for someone with a severe mental illness without access to any supports.

Given the NDIS will be the primary avenue for people with severe mental illness and psychosocial disability it must have the flexibility to cater for the unique needs and circumstances of consumers and their families/carers.

MHCA supports the recommendation of the National Mental Health Commission (NMHC) Review of Programs and Services recommendation to 'urgently clarify the eligibility criteria for access to the National Disability Insurance Scheme (NDIS) for people with disability arising from mental illness and ensure the provision of current funding allows for a significant Tier 2 system of community supports.

## **Transition of Commonwealth funded services**

- b. the transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular

### **Personal Helpers and Mentors**

MHCA is concerned about the potential impacts on community mental health should *Personal Helpers and Mentors* funding be transitioned into the NDIS. This outreach based program has enabled high levels of engagement in the community by adopting a community centred approach. Some of MHCA member organisations have achieved significant success with this approach, particularly with Aboriginal people in regional and remote communities with suicide prevention and family support services. By first gaining trust and engagement in a community and then a family based level, individuals can be

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<sup>6</sup> Jacobson and Greenley, 2001



assessed and referred to appropriate formal services. Unfortunately, the NDIS approach requires that individuals be firstly identified and diagnosed as mentally ill and only then will their family carers be eligible for supports as carers. The level of stigma around mental ill health and different cultural ideas about ‘caring’ are likely to deter both consumers and carers from identifying themselves to service providers. As a result, it is likely that both will miss out on supports.

The case worker model supported by PHAMS has proved particularly important to assisting parents with mental health issues who require support in parenting their children and re-establishing connections with family members who have become estranged but who are potentially able to provide support if they themselves were supported. Hence we have witnessed PHAMS case workers assisting parents to enrol their children in school holiday programs and young carer peer support programs funded through Mental Health Respite: Carer Supports. PHAMHS case workers are able to assist with the referral of family members to carer supports with the goal of providing the psycho-education that assists family members to re-engage and offer support to the individual who is living with mental ill health. We have not witnessed a similar level of case worker support in WA NDIS plans.

## Transition of State and Territory funded services

- a. *the transition to the NDIS of all current long and short term mental health state and territory government funded services, and in particular;*
  - i. *whether these services will continue to be provided for people deemed ineligible for the NDIS;*

The lack of clarity regarding the extent to which State and Territory governments will engage with and fund carer services, during and following the transition to the NDIS to support consumers and carers who are either not eligible for or not engaged with the NDIS needs to be resolved. Without support services demand for acute and crisis services will inevitably rise, as will the demand on informal carers and families at great social and economic cost to governments, communities, families and consumers.

## Services Funded under ILC

- d. *the scope and level of funding for mental health services under the Information, Linkages and Capacity building framework*

MHCA does not believe Information, Linkages and Capacity (ILC) has the capacity to provide for what existing services deliver or respond to the needs of people who won't be eligible for the NDIS due to the limited amount of funding and the fact that there are no ILC funds earmarked for people with psychosocial disability and/or mental ill health.

## Planning process

- e. *the planning process for people with a psychosocial disability, and the role of primary health networks in that process;*

Of particular concern for MHCA is the lack of engagement by planners with mental health carers in the planning process. Despite this strong policy framework<sup>7</sup> the common

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<sup>7</sup> Carer Recognition Act 2010  
National Mental Health Standards 2010



experience of mental health cares is that they are not included in the planning process. The consequence of this can be reduced carer well being, care-consumer relationship damage and ultimately poorer outcomes for the consumer.

When service providers work in partnership with consumers and carers there will be improved outcomes for consumers, reduction in family and carer anxiety, improved ability and desire of family and other carers to continue in their caring role and improved satisfaction for staff.

MHCA recommends that planners be trained in family centred practice and further recommends using *A Practical Guide to Working with Carers of People with a mental Illness* to guide their practice.

### Supports required by the carer

The shift of funding of carer supports to NDIS will mean the eligibility of carers to receive supports will no longer be linked to an assessment of the carer and their needs. Instead it will be entirely dependent on the NDIS eligibility of the person with mental ill health. The supports then available to carers will largely be based on enabling the carer to “have a break” by engaging the person with mental illness in an activity which frees the carer to do something else<sup>8</sup>. Whilst this is a relevant way to enable respite it does not cater for the broad range of carer support needs. Consistent with the Statement for Australia’s Carers<sup>9</sup>, carers have a right to participate in activities outside of caring. There is no guarantee of a coincidence in timing of activities available for the person with psychosocial disability with the needs of a carer to participate in employment, education or other activities, or to attend, for example, to their own medical appointments.

What this means in practice, for example, is that a young person caring for their parent a mental illness may no longer be eligible to participate in a school holiday program that introduces them to other young carers who offer peer support, as well as providing them with communication, coping skills, and resilience tools.

The majority of carers of NDIS participants consulted as part of the Carers Australia’s NDIS Carer Capacity Building Project reported that NDIA staff had not made them aware of the option to have a separate conversation with the planner or of the ability to submit a Carer Statement.

MHCA strongly recommend referring to the National Carer Strategy and the Carer Recognition Act (in particular the Statement for Australia’s Carers<sup>10</sup>), to drive actions to improve carer identification and recognition. Carers should be acknowledged as individuals with needs beyond the caring role. Carer support services should extend to facilitate a carer’s need or desire to discontinue their caring role due, for example, due to concerns about the carer’s own health, wellbeing and safety.

Further to that it is recommended that carers be assessed based on their own needs as well as the needs of the person they care for.

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National Safety and Quality Health Service Standards 2011

<sup>8</sup> Anglicare, Carers doing it tough, doing it well, 2016

<sup>9</sup> Carer Recognition Act 2010

<sup>10</sup> Carer Recognition Act 2010



MHCA opposes the NDIA's move away from face-to-face assessment and planning as it will have a significant impact on all people applying for the NDIS as it creates significant difficulties for communication and diminishes the capacity to build a trusting relationship between the person and the planner. Further for mental health, which is typically episodic, having non-face-to-face assessment and planning creates difficulties in adequately assessing need and the person's circumstances.

## Spending on psychosocial disability services

- f. *whether spending on services for people with a psychosocial disability is in line with projections;*

MHCA has concerns with the overall transparency and uncertainty about how funding is being provided by governments at the federal, state and territory level to both the NDIS and state and territory community managed mental health services. This is creating difficulties in determining if spending for people with psychosocial disability is keeping in line with projections.

## Outreach services:

- g. *the role and extent of outreach services to identify potential NDIS participants with a psychosocial disability*

MHCA is concerned about the potential impacts on community mental health should Personal Helpers and Mentors, Partners in Recovery and other outreach service funding be transitioned into the NDIS. Outreach programs such as these have shown significant results in reaching and engaging the most difficult to reach clients<sup>11</sup> Some of MHCA member organisations have achieved significant success with this approach, particularly with Aboriginal people in regional and remote communities with suicide prevention and family support services. By first gaining trust and engagement in a community and then a family based level, individuals can be assessed and referred to appropriate formal services. Unfortunately, the NDIS approach requires that individuals be firstly identified and diagnosed as mentally ill and only then will their family carers be eligible for supports as carers. The level of stigma around mental ill health and different cultural ideas about 'caring' are likely to deter both consumers and carers from identifying themselves to service providers. As a result, it is likely that both will miss out on supports.

## Forensic disability services

- h. *the provision, and continuation of services for NDIS participants in receipt of forensic disability services;*

Our understanding is that people experiencing mental illness pose no higher risk of perpetrating family violence than the rest of the community unless they are not receiving adequate treatment or support.

Where a person is resistant to treatment, lacks insight into their condition or actively seeks to undermine the treatment regime, they have a strong chance of being inadequately treated. Overstretched public mental health services generally do not seek

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<sup>11</sup> Partners in Recovery Annual Report 2014-2015



to find these people. In such cases it will be the family, friends and carers who will try to support the person and reconnect them with the clinical services they require, with the result that should the individual be violent the family member or carer is most likely to be the victim.

## Other

### Mental Health Respite: Carer Support

MHCA is very concerned that should, as is proposed, funding for the *Mental Health Respite: Carer Support* continue to be transitioned to the National Disability Insurance Scheme families and carers of people experiencing severe mental ill health or psychosocial disability, may no longer be able to access the services they need to maintain their caring role. This may occur where:

- The person with a mental illness is not eligible for the NDIS
- The person with a mental illness chooses not to engage with the NDIS. Many people with mental health issues do not seek services so it is likely, in the absence of assertive outreach, that many people with severe mental ill health will not engage with NDIS
- The person is eligible but the caring role is not fully acknowledged
- The support required by the carer is not accommodated by the activities funded through the NDIS.

The lack of clarity regarding the extent to which State mental health services will engage with and fund carer services, during and following the transition to the NDIS, risks a nationally inconsistent outcome for carers of people living with mental health issues.

### Integrated Carer Support System:

The Commonwealth government through the Department of Social Services (DSS) is currently developing a model to deliver integrated support services to carers across the nation which will, in theory, cater for the needs of carers not met through the NDIS. MHCA supports this initiative to improve access to carer services, however, has significant concerns including:

- 1) Proposed regional service areas potentially being too large geographically, particularly in rural and remote areas where public transport can be poor.
- 2) The proposition that DSS will "link to but not fund"<sup>12</sup> many elements of the local service delivery system
- 3) Lack of clarity about whether funds will be distributed on assessed need or on a geographic or population formula meaning that one region area may experience a shortfall while another has underspend.
- 4) One regional hub service listed<sup>13</sup> is to assist carers to "*access planned respite and support services through collaboration with the NDIA*". As far as MHCA is aware, carer respite is not a service available through the NDIS.
- 5) Whilst there is some information on level of qualification required for different types of workers in the regional hubs, there is nothing on the broader workforce

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<sup>12</sup> Delivering an integrated carer support service, Department of Social Services, 2016

<sup>13</sup> Delivering an integrated carer support service, Department of Social Services, 2016



development required to competently support people caring for someone with a mental illness.

### **Mental health promotion and early intervention**

The NDIA's pricing structure and the associated transition of funding into the NDIS may result in a range of disability services no longer being available<sup>14</sup>. If early intervention and mental health promotion services are no longer available we will see a greater burden on the service system, not only in health but more broadly for example housing and criminal justice and potentially an increase in the tragic consequences associated with mental illness.

### **Advocacy:**

Is advocacy for mental health carers going to be funded at a national level? Establishing and maintaining strong engagement with the carers and translating that into clear information and advice to inform government decisions and process is important to ensure the Government's objectives are realised. Good public policy does not easily translate to good practice and outcomes out in the field. Strong advocacy is one way to support effective transition and implementation of the model.

### **Conclusion:**

MHCA recognises that the National Disability Insurance Scheme (NDIS) has the potential to offer eligible people with psychosocial disability, their carers and families the supports they require. Also recognised is the enormous task involved in implementing such comprehensive reform and acknowledges the efforts of the people involved in the implementation process. MHCA's goal in making this submission and the recommendations below is to assist the Government to honour the commitment to the principle of no disadvantage by highlighting where disadvantage might occur without intervention.

### **Recommendations:**

- 1) The National Disability Insurance Agency (NDIA) continues with the agreed psychosocial disability NDIS target group as scheduled
- 2) Current plans to 'roll in' programs including, *Mental Health Respite: Carer Support and Personal Helpers and Mentors*, which wholly or partly serve target groups ineligible for the NDIS are immediately put on extended hold, while the full implications for individuals and families both eligible and ineligible for the NDIS are assessed. This is consistent with the recommendations made in the National Mental Health Commission's report, which recommended:
  - Do not cash out existing mental health and other associated programmes (e.g. carer and respite programmes) into the NDIS until there is evidence as to eligibility for people with a psychosocial disability, and clarity about ongoing support for those who are eligible for Tier 2 support.
- 3) Given the NDIS will be the primary avenue for people with severe mental illness and psychosocial disability it must have the flexibility to cater for the unique needs and circumstances of consumers and their families/carers.

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<sup>14</sup> Evaluation of the NDIS: Intermediate Report, Flinders University 2016



NDIA use the National Carer Strategy and the Carer Recognition Act to inform the continuing implementation and improvement of the NDIS and that carers be assessed based on their own needs as well as those of the person they care for.

- 4) NDIS assessors and planners
  - receiving training in family-centric assessment approaches
  - understand the unique issues faces by mental health carers
  - have experience working with psychosocial disability and mental ill health
  - understand their obligations under the Carers Recognition Act 2004 and the Carer Recognition Act 2010.
- 5) MHCA recommends *A Practical Guide for Working with Carers of people with a Mental Illness*, 2016 to facilitate this and has the expertise and capacity to assist with this if this is considered helpful.
- 6) NDIA collaborate with DSS to
  - a) assess the likely impact of the transition of respite and other funding to the NDIS
  - b) assess the likely impact of the design and implementation of proposed integrated carer support system.
  - c) jointly implement a system to ensure people who care for someone with a psychosocial disability or mental illness are able to access the services they need to maintain their own health and ensure their on-going wellbeing to allow continuation of their caring role.



## Appendix 1: Mental Health Carers:

While people who support or care for a person with a mental illness share common issues and experiences with other carers they also experience a range of factors unique to caring for someone with a mental illness, including:

- The stigma, guilt and isolation experienced are greater than for most other carers and create significant barriers to people asking for or receiving help from both formal and informal sources. Cultural factors may intensify these experiences. Carers are often deeply affected by adverse responses by neighbours, friends, school communities and extended family members<sup>15</sup>. The stigma experienced by carers and consumers in the mental health sector is also exhibited by mental health and other health professionals<sup>16</sup>.
- It is not uncommon for a person with a mental illness to have limited comprehension that they are ill and to resent attempts by family members to encourage them to seek treatment or support. It is also not uncommon for symptomology of mental illness to manifest as paranoia at acute stages with the person turning against the people who have been supporting them most.
- Families have always occupied an ambiguous space in mental health research and practice. They are seen either as burdened carers, as causing the mental illness in a family member, as acting to sustain the mental illness, or as contributing to relapse<sup>17</sup>. However, utilising a person's natural support network has also been shown to promote recovery and reduce acute episodes requiring hospitalisation<sup>18</sup>.
- The experience and nature of a mental illness is obscure and difficult to understand. The state of mind of a person with a mental illness is hidden. Carers and family members see behaviour and personality changes and emotional swings but cannot necessarily comprehend the internal experience which drives these changes. Unlike other carers who can more readily interpret and understand the experience of their family member, carers and families of people with mental illness experience great stress and confusion because they cannot see what is happening, don't know what to do or how to help. When difficult behaviour occurs, family functioning may be significantly disrupted and become crisis-oriented, sometimes resulting in conflict and breakdown. In some circumstances the behaviour can be frightening and bewildering for the carer and can impact on the carer's physical, emotional and financial wellbeing<sup>19</sup>.
- The unpredictable and episodic nature of some mental illness, often with sudden onset accompanied by abusive behaviour, variability of treatment compliance, and potential involvement with the police and judicial system all contribute to the stress experienced by mental health carers.
- The high prevalence of substance misuse among people with mental illness compounds the grief and difficulties families face.

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<sup>15</sup> The Network for carers of people with mental illness, Differences and similarities, 2001

<sup>16</sup> Mental Health Council of Australia. 2011. Consumer and Carer experiences of stigma from mental health and other health professionals. MHCA, Canberra

<sup>17</sup> Wydera and Bland, The recovery framework as a way of understanding families' responses to mental illness: Balancing different needs and recovery journeys, 2014

<sup>18</sup> Amir, N, Freshman, M, and Foa, E. B. (2000). 'Family distress and involvement in relatives of obsessive-compulsive disorder patients'. Journal of Anxiety Disorder., 14, pp209-217

<sup>19</sup> The Network for carers of people with mental illness, Differences and similarities, 2001