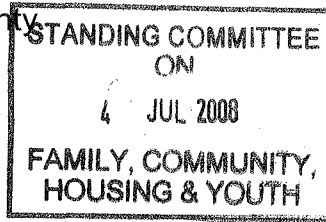


From: Karen McCann & Kerry Geraghty  
Sent: 1<sup>st</sup> July 2008  
To: Standing Committee FCHY  
Subject: Better Support for Carers



The Secretary  
House Standing Committee on  
Family, Community, Housing & Youth  
Inquiry into Better Support for Carers  
House of Representatives  
PO Box 6021  
Parliament House  
Canberra ACT 2600

ROC 17/7/08

Submission No. 884  
(Inq into better support for carers)

We hereby wish to make a submission to the Inquiry into Better Support for Carers.

Thank you for the opportunity for us to comment on the needs of parents and carers of children and young people with mental health problems, as this is a group of carers which is often overshadowed by the needs of adult mental health consumers. Statistically, outcomes improve for families when problems are addressed with early intervention and we see any extra support for carers of children with mental health problems as a very positive step. Although we have highlighted a range of issues relating to the support of carers, we have only touched the 'tip of the iceberg'. Our submission by no means captures the severity and wide ranging needs of this particular group of carers.

In our role as Consumer Consultants<sup>1</sup> for a Child & Youth Mental Health Service in Queensland, we meet with many parents and/or carers who have a child or young person<sup>2</sup> with a mental illness or psychiatric disability. This submission is to highlight the needs of this particular group, which is often not given sufficient consideration. Many of these families are struggling to come to terms with the deterioration in the health of their child, the diagnosis, grief and loss, change in family circumstances this illness often brings and sometimes, loss of income of a parent due to their caring role.

The information we will present in this submission is collected from conversations with families and clinicians, our attendance at conferences, forums and state-wide meetings, our own surveys and feedback forms as well as drawing on our own 'lived experience'.

## Summary

In summary, we have commented on the role and contribution of carers in society and on the practical measures required to better support carers as listed in the committee's Terms of Reference. The key points are

- Without the role and contribution of carers, particularly parents, the financial burden on government resources would be enormous.
- Parents and carers are often left to be the ones struggling to find a reason behind their child's mental illness
- Parents and carers struggle to find suitable services

1 - For the information of the committee, a Consumer Consultant is a staff member who has experience of living with a child or young person with mental health problems or a mental illness and who listens to and supports consumers, carers and their families.

2 - When we refer to children and young people, they are between 0-18 years of age.

- Navigating inconsistent government departments including Centrelink, is complex and frustrating
- Parents and carers are required to coordinate and case manage their child's care
- Parents and carers assist their child to find suitable recreational activities and employment
- For many families where a child has a mental illness, the emotional, financial and physical burden is immense
- Respite options need to be considered
- Consider a review of the criteria around eligibility for Carer's Payment and Allowance

## **The role and contribution of carers in society**

Historically, people with mental illness were removed from their families and placed in institutional care. Since the Burdekin Report initiated the release from the institutions back to the family and community, the responsibility of looking after the mentally ill has fallen heavily on the shoulders of families. The situation was compounded by the lack of planning and resources to effectively manage their integration back into society. Without the role and contribution of carers, particularly parents, the financial burden on government resources would be enormous.

Some of the things parents and carers are required to do are:

- Source information – Parents and carers are often left to be the ones struggling to find a reason behind their child's deterioration in health and behaviour. It is common for these parents to feel guilty, confused and frightened about their family's future. GP's do not always validate the parent's concerns, or have the most current knowledge of treating these issues and can therefore be dismissive of the parent's cry for help. They are often told, *'Don't worry, it is only a stage they are going through'* or *'You are a first time mum! This is not unusual'* or *'Let's just keep an eye on things for the next few months'*. This leaves parents feeling unsupported and floundering in their efforts to navigate 'the system' in order to find answers.
- Finding a suitable service – Again, some GP's do not always know where to direct worried parents to the most appropriate service. In rural and remote areas, the problem is exacerbated through lack of specialised mental health services. Treating children and young people in an Adult Mental Health Service is totally inappropriate. The longer they are not linked into a service can lead to lengthy delays, prevention of early intervention into the problem, and consequently, increased stress for the family.
- Complete a range of complex forms – For many parents, Centrelink can be their worst nightmare. Insensitive and judgemental staff, rigid policies, lengthy waiting times etc do not fit with the daily routine of someone caring for an unwell family member. It can even be an expensive exercise to arrange for a doctor to complete the Treating Doctor's Report or to arrange a referral to the Treating Psychiatrist. In many cases, a Psychologist has been working with the child and family for some time and is better informed about the case, but is prevented from completing the form, simply by their profession. (Even navigating the Centrelink website searching for a Treating Doctor's Report in English was difficult for us.)
- Navigate inconsistent government departments – Not all diagnoses are recognised across government departments, eg Centrelink will acknowledge a Psychiatric Disability but Education Queensland will not and therefore not provide support and

assistance to the student under this criteria. Children are mis-diagnosed or labelled inaccurately to fit particular criteria in order to receive benefits with educational assistance. Some children are then over-prescribed medication and other children who do have a specific and accurate diagnosis, suffer stigma because they take medication. These situations can lead to confusion for families and they are left to struggle with each department giving them contradictory information.

- Coordinate and Case manage the care – Many hours are spent arranging family routine and the needs of each family member to accommodate travelling to and from many appointments. Parents are required to remain up-to-date with information on treatments, medication, side effects etc, as well as learn to understand the mental health jargon often used by health professionals.
- Liaise with the education system – Where a child has a diagnosis of a behavioural problem, education staff often use suspension as a form of discipline. This places further stress and strain on the family and usually results in little change in the child's behaviour. Teachers need to participate in training on challenging behaviours to adopt more appropriate responses. Because the child's behaviour is not understood, the parent's feel they are being judged as bad parents and the children lose more of their already fragile self-esteem. This can all lead to the child and their family becoming disengaged from their school community and future educational opportunities.
- Assist their child to find suitable recreational activities – Even children and young people with mental health problems need to feel accepted and part of their community. They too, wish to pursue interests and develop their personal self, but they will require some extra support to achieve this. Some non-government organisations fulfil this role but often close their doors once funding for special projects has ended. This leaves a gap in the lives of these children and their families. Once again, the parents can spend many hours searching for appropriate clubs and activities where their child will feel accepted.
- Assist their child to find suitable employment – As we have already outlined, mental illness often results in young people being disconnected from their school environment and fail to complete their education. Consequently, employment opportunities are limited. Many mental health services recognise this gap but for many reasons are unable to provide this service. In addition to this, the changed criteria for the Disability Support Pension puts some young people at a disadvantage when seeking support from Disability Supported Employment Agencies. In cases where a young person is able to secure employment for 15 hours per week, it does not automatically transfer that the same young person is capable of working full time, competing for jobs alongside people without a disability.
- Burden of work/family commitments – For many families where a child has a mental illness, the emotional, financial and physical burden is immense. This often leads to marriage and family breakdown. In the case of single parent families, when a child's condition deteriorates the parent may be forced to resign from paid employment in order to take on the responsibilities that caring entails. This then leads to social isolation, financial stress and a lower standard of living for the family. In other families where the father is required to work long hours, this leaves the mother as the primary carer, the father feeling guilty for not being there for his wife and family, and health problems are often the result of such stress.

Special mention should be made to the increasing number of grandparents who provide full-time care to their grandchildren as a result of family breakdown. This is often attributed to

drug and alcohol problems and mental illness of their adult children. Child and Adolescent Mental Health Services are providing treatment and support to these needy grandparents and their new families. The grandparents now find themselves challenged by parenting a new generation in a changed and modern society. This group of carers also face the prospect of relinquishing their plans of retirement as well as their savings to provide a better life for their grandchildren, who are also at risk of developing some serious mental health problems.

### **Practical measures to better support carers**

In our role as Consumer Consultants, we have heard many families speak of the financial, emotional and physical burden that they shoulder. We have listed some areas that are commonly raised.

- Respite – Mental health carers find it very difficult to access good quality respite for their loved ones. Often they are considered to be not eligible because organisations are not funded to cater to the needs of under 18's, or mental health is not one of their criteria. Even when they are eligible, the care available is not appropriate to a young person. Also, training of respite workers does not always include mental health issues, especially for young people. This leaves many families not feeling comfortable about leaving their children with untrained staff in an inappropriate setting. Too often we hear of situations where a child with a mental health diagnosis has to be placed into a hospital ward in order for the family to receive any respite. In these cases, the child is not necessarily unwell, but does require supervision. It is inappropriate for these young people to be placed in an environment with unwell children and no place to 'have fun'. Often these children return home and their behaviour deteriorates because of their unhappy respite experience. We see a huge need for formal respite services that are able to provide age appropriate respite and recreational activities in a supervised and safe environment.
- Increase carers payment – The majority of carers are in a fragile financial situation. With the increase cost of living, particularly petrol, groceries and rent, Carers Payments are not kept in line with these rises. Even a small increase could make a difference to the quality of life for these families.
- Continuation of carer bonuses – Many carers have come to rely on this annual payment to replace large household items, eg refrigerators, washing machines, repairs to the family car etc. Other families use this bonus for an annual holiday in order to experience some happy times for the family, particularly for the siblings. The recent confusion around the payment of these bonuses caused much unnecessary anxiety amongst families.
- Transition from Carers payment to paid employment – When carers begin to receive income from employment, they are required to advise Centrelink as soon as possible. When this occurs, the concession card is immediately cancelled and any benefits associated with it are withdrawn. Perhaps a transitioning scale could be invoked, similar to those with the DSP, so as to avoid unnecessary hardship. These carers have lived on the poverty line for so long, that they do not have any savings to draw on.
- Transport bonus – With the rising cost of petrol reaching record levels, there is no light at the end of the tunnel. Carers of young people with mental health problems are

required to transport their children to a range of appointments, eg Psychiatrist, psychologist, dietician, GP, Pathology, hospital appointments, clinic appointments etc. One solution to ease this burden could be to provide identified carers with a fortnightly payment for fuel expenses, similar to the Mobility Allowance.

- Training for teachers – As mentioned previously, teachers are the people who spend the most amount of time with young people apart from their parents. The impact when teachers are not feeling supported and provided with the necessary skills in managing students with mental health problems, results in poor outcomes for all concerned. Teachers have increased stress levels, take time off work, classes are not managed well with interrupted teaching, students are suspended, parents are required to take time off work to attend meetings with the school and supervise children on suspension...the list goes on. Many teachers, who have children with special needs in their class, find it almost impossible to get leave to attend training workshops and seminars to enhance their teaching skills.
- One-stop-shop - Having a 'one stop shop' approach for families who have a child or young person with mental health problems could be very helpful. Staff at these centres would be well trained in navigating the various government department protocols for receiving assistance and would be able to provide information about the care and support needed for these families e.g. educational assistance, disability services, transport assistance, Centrelink allowances and location of services.
- Stigma and community education – Many parents and carers are on the receiving end of painful comments, hurtful assumptions and community ignorance around mental illness. One solution is to educate the community via television, radio, internet, newspaper and magazines (including young people's magazines) and clarify the misconception that mental health sufferers are violent, frightful people. Increased funding could be provided for Mental Health First Aid programs to be accessed by workplaces, schools and community organisations. In the past, public health campaigns such as 'Slip, Slop, Slap' and 'Life, Be In It' have been successful, why not mental health.
- Carers health care plan – Some success has been reported with regard to the "Increased Access to Psychologist" program and it is widely known that carers' ill health is often related to the caring role they play. Carers could have access to a range of medical services including alternative therapies, eg chiropractic, massage, and dieticians, in an effort to provide better support and care. In the past, the health care needs of carers has been identified as an area for action, but very little in a practical sense has been offered. When carers do not look after themselves, the outlook for the young person they are caring for is also grim.
- Increased access to psychologists – This scheme has been well received for users of mental health services but does need to be expanded to meet the needs of carers. The emotional burden many parents face while coping with their child's mental health problem can be damaging to other relationships in the family unit if some recognition of what they are coping with is not given. By accessing professional care, these issues that friends and family do not necessarily understand, can be given some attention with guidance provided, in order to keep going in the caring role. In addition, the number of visits to a psychologist that is offered should be increased for both the young person and the parent and/or carer.
- Bulk billing for carers in all medical appointments – In order to ease the financial burden of accessing care, Carers should be bulk billed for appointments that involve

their child as well as for appointments for their own health care. Because of the increased cost of living many parents sacrifice their own health needs to balance the family budget. This may result in missing medication, not intervening early enough in the early stages of a problem which may result in escalating complications and subsequent diagnosis of a serious disease.

- Develop workplaces with flexible working hours for identified carers – The need for supportive practices in workplaces has already been recognised by governments and is something which would benefit all families. Carers of children and young people with mental health problems find their work commitment is sometimes spasmodic due to the episodic nature of their child's condition. This can cause disruption because of unplanned leave from work, and specialist appointment times, where you fit in with their time availability not necessarily your work commitment. It would be helpful if workplaces could allow workers to adjust their working hours to accommodate these needs. Examples which have been helpful in some workplaces are the use of TOIL (Time off in lieu) and TIL (Time in lieu), promoting the use of Family Leave Time and working from home.
- More research into medication and its effects on young people – The majority of medications currently used for children and young people who have mental illness, were primarily developed for use in adults. Very few studies have examined the side-effects of long-term use on children and young people. This leaves many parents and carers anxious and reluctant to use medications to better manage their child's illness and behaviours. There is an obvious need for more research funding to investigate this area.

Should the committee wish to seek further input, we are happy to be contacted on the details listed below.

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