Submission No. 849
(Inq into better support for carers)

Recd 17/7/08

Thank you for the opportunity to contribute to the inquiry.

I also write from the perspective of my qualifications (MPH) in which I interviewed numerous fathers who were carers.

This submission covers three points

1. Diagnosis support
2. Physical care support
3. Carer breaks
4. Carer recognition
5. getting back to work

Please note it is written hurriedly and within the demands of my caring role

Thank You.
Michiko BHsc MPH

Phone:

1: Poor psychological care after diagnosis:

Process: We were told of our child's diagnosis and left the paediatrician's office to face the unknown and the grief on our own. It would have been very helpful for the paediatrician to give us a number to call, that we could get a home visit or just have another parent WHO HAS BEEN THROUGH THIS, to act as a bit of a 'peer support' role. Even a national support line (like Lifeline) so that I could talk to someone who has lived the experience, would have been enormously helpful. Looking back, five years later, what would have helped my mental health more than anything is the HOPE that we would enjoy our lives after the catastrophe of the diagnosis and in spite of the workload of the care and barriers we face in everyday life. I know that agencies provide psychological care, but that is more 'listening' and not that helpful. I'm talking about specific after diagnosis support to get through the first few months. A visit to a GP just resulted in antidepressants and was not helpful.

Parent groups are available through our support agency but it's hard to be part of the group while still grieving and coming to terms with the life changing diagnosis and often, lack of sleep and other issues with siblings. The parent groups tend to be more help a few years down the track when one can actually sit there and participate and engage with other parents, and help them with advice and mostly, to have a laugh. The timing needs to be right. My first visit left me feeling worse off as , I was still grieving and unable to function and felt they had it 'all together' and I was a mess, leaving me with low self esteem and feeling inadequate. It's a great support later on, but not suitable as in the immediate aftermath.

Our experience: My husband and I felt very isolated, and our experience is common to other parents. I can't tell you what a horrible period in our lives the first few months was, (not to mention the years that followed), but that initial shock and grief was awful to face alone. It was a nightmare of coming to terms with our reality. I was desperate for someone to talk to who understood. Let me say the ONLY help various GPs have EVER given me over the last five years is a free sample pack of antidepressants. These were given for post diagnosis 'going mad with grief' phase, addressing broken sleep cycles, stress, AND poverty. I was not ever depressed, and that's poor medicine in my opinion. The reason given when asked is that there is 'nothing else'. I needed spiritual support! I didn't wan't someone who hadn't been through this to talk to me, I wanted another parent to listen and tell me my fears and my feelings were normal. It was like falling into a big black hole with no lifeline. There is an enormous pool of resources available in the many wonderful parents who ARE carers, yet who is employed as counselors? Those with no or 'normal' children who don't even know what it is like to have no income, lose a career, suffer from 'invisible' syndrome where you fade from the community as you get locked into the caring role and suffer from the endless tiredness of needing to be resilient.

Psychological support has always been given by a counsellor or psychologist in which everyone is treated the same based on 'evidence based guidelines for treating anxiety and depression' and which consists mostly of filling out forms to 'measure' depression, and measure the benefit of the counseling the product is just listening. The whole process is of measuring, rather than peer support.

Issue: The linkages from the point of diagnosis to any support agencies are poor and it should be something measured at a national level through Carer agencies. Our paediatrician said he would write a letter to our relevant agency. After four weeks we had not heard anything. I had to contact them to get a counsellor to come and see us, but although she was great and listened, <u>she hadn't been through this</u>. I can see now the difference between psychological support (having had it) and how different it is from the 'grief support' and 'diagnosis support'...and peer support.

Recommendation: That research is undertaken to assess interest in carers being trained in support / counseling roles for employment at a local level (relevant agencies) but filtered through a national phone number. It would also create jobs for people who could work part time.

It's not that great having counseling support from people who just see it as a 'job' and haven't experienced it, or who are very young and doing work experience or training. They only listen but can't add anything of value as they haven't BEEN THERE. I rang a help support line at Carers Association once as I was in a down phase about having no income, and my childs high dependency needs, lack of sleep and physical inability to work in my previous professional capacity. I was told to 'get a job in a factory'.. the lady did not understand my grief at losing my career (*she had not been through it*), after working hard at completing my masters degree, and working in a Division of General Practice delivering health programs to being a complete wreck of a human and unable to function at any really useful level! It was simple <u>understanding</u> I wanted, and to be told my feelings were normal, and that there would be light at the end of the tunnel when school started (free childcare!!), not to be told to *do something impossible*. The issue wasn't about getting any old job, it was about the grief and loss.

2. Physical care of carers.
The model of physical care of carers can be summed up as:
Medical model and antidepressents!

I would like carer's physical health 'maintenance' and care to be properly examined within a model that is holistic and excludes GP's so that wellness is a focus, not treatment. There is adequate research indicating carer's physical health declines in the caring role. There is enough research showing how health suffers, but none undertaken to show the best solutions to self care.

We should be able to access services without wasting time going to a GP. The truth is GP's can only offer antidepressants for carers in distress or anti-inflammatories for bad backs etc. Prevention, and holistic body and mind care excludes GP's at the centre and sees them as just a resource. GP's are being paid under the medicare care plan inititative for doing NO work, and this money could be generated into more services from allied health that could help.

- For carers like myself, who do not qualify for carer allowance, and who did not work, bulk billing should be mandatory so family health issues can be treated.

- One of the biggest barriers to participating in personal health care is lack of child care. Gyms and exercise classes which offer creche's do not take children with special needs. However, the organisations that do have crèches and the experience to care for the children, do not have the programs!

The dilemma is, prior to school, accessing exercise is difficult. When school starts and time is available (child free) we go back to work!

The only exercise I could get in the five years previous was walking, however walking doesn't help back strength or build and maintain muscle. I take my daughter to her therapy and her swimming, but my body is ignored!!! It doesn't make any logical sense. Heart health, back health, weight gain, diabetes, depression, all affect carers at higher levels than the general population BECAUSE of the barriers to accessing care. Stress leads to depression and both contribute to disease.

The work involved with lifting a child (she is nearly 6), and her equipment means a strong back is essential, and without resistance training, muscles waste away. This is a very important issue that is overlooked when there is so much financial and human resource support for our mental health.

I have recently started work, and on the weeks my husband works away, I am limited to a daily walk IF my daughter wants to participate as I have no childcare. If it's cold, raining (daylight saving boiling hot), or my daughter is demanding or sick and doesn't want to go, I miss out. I have absolutely no place to put her, while I swim or go to the gym. *I take her swimming*, but then the stress on my back and neck leave me in pain and with functional difficulties for days and then there is no care for me, but the expectation is that I do her therapy!

I want to swim for my cardiovascular health, and work out with resistance training for my bones and my back muscles, but no childcare is available. The benefits of social interaction of group exercise applies just as much to carers as it does to the over 55's for mental wellbeing.

Recommendation: Fund some trials of NGO placed gym programs and exercise activities where a crèche is already supplied that can cater to special needs.
A trial at least would provide some evidence of the benefits for carers and their health of a program like the over 55's gym program. It would also provide a way of ensuring screening activities and other health issues be incorporated into programs that are more holistic than just providing gym equipment.

3. Carer breaks. These are funded through disability services to provide a break for carers. HOWEVER I know of many besides myself who have no one to leave their special child with to take advantage of these breaks or who do not wish to be apart from their children. (In one case a mum who's child has a breathing disorder). My own daughter is at high risk of choking of she vomits and needs to be held upside down and have vomit scooped from her mouth...her muscles are too weak to project the vomit out of her mouth and she risks inhalation. She may not vomit for a year, but if it happens... it's a serious issue. One can't entrust these things to someone else who has no experience but people shouldn't miss out on some much needed self care because we have to throw the baby out with the bathwater by not going at all.

Carer breaks are something that benefits the same group of people all the time.. those who can have childcare and who can trust that childcare, or those who want to get away from their children. One gentleman I know is a single dad of a very severely affected child, who has no family (his wife left him on the birth of their child and went back to indonesia) and his mother is elderly. He cannot work. He needs a break, yet he can't leave his child. Many carers I have talked about have said they want a break with their children, and need care so they can have some self care activities and some fun, but want to be with their children, not leave them for the weekend. They want a carer break with childcare provided while they enjoy 'me' time. Not every carer wants to 'get away' from their children completely, just to have some time out, however time is essential for good health of carers. They should not excluded because they can't find childcare, or choose not to leave their child for a weekend. In many cases, particularly for young children with sleep issues and feeding issues, and in my case communication issues, I was the only person who really understood what various facial expression meant, and how to sooth her when she was upset and various other subtleties of communication. I needed self care too, but could never take advanatage of it. There is a group of Carers who are not reached by these initiatives, yet are most needy. Those who have partners around to care for their children, get the breaks!

I was recently given a holiday for four people by the ocean. We can't go as there is no point going on holiday with our daughter as she can't particpate in the beach, and we can't take her equipment and fit our family in the car at the same time. In addition, it isn't really a break without taking a carer. We can't afford to pay someone for week's holiday, and we don't' wish to leave her with anyone for that time as my 70 year old mother can't even lift her.

Recommendation: investigate the need for special breaks which include childcare, so a blend of parenting and time out can be accessed for that group of parents who have no access to 'respite' or can't access it, or choose not to.

Investigate holiday option for families who need to take a carer so they can access the beach and spend time alone to maintain relationships.

4. Carer recognition:

During the first five years post birth, my whole life has been dedicated to my daughter, my own health needs have had to take a back seat.

Recognition of my role as carer would have been nice and gone a long way to my sense of purpose. I was literally left to cope alone with no social support (friends are hard to maintain when ones life is about getting some sleep). It takes effort to go out' and it's hard work to go out with a child in a wheelchair, so its easier to not do it. However that's a choice which I don't expect is anything to do with this submission. However, to be recognised at $50 a week is a bit insulting (the carer allowance). When I worked as a carer, the agency was being given $50 an HOUR to do what I do all day. Their workers also get superannuation, leave, sick leave, carer leave, manual handling training. We don't' enjoy any of those benefits. It would have been nice to have some payment that recognises that caring is a BARRIER to normal life for some people (not all). The first thing we had to give up when I left work was our private health insurance, and of course, my superannuation.

The problem with the carer allowance is that it doesn't come with a health care card. I have not had dental care for five years as we don't qualify for government dental services and could not afford health cover, I now have gum disease and need teeth extracted. We have only recently (six months) received the income needed to cover the cost of private health cover.

In addition, carers health is something that declines..yet it is only seen as something fixed by medicine when self care activities like exercise would go a long way (and there's ample evidence to prove it).

While the medical model is great for immunizations and antibiotics and screening, its' not doctors that keep us *well*, it's access to things like massage and physiotherapy and exercise classes like pilates which can't be accessed or are prohibited in their cost if you don't have a health care card or private health insurance or child care appropriate.

This wellness approach is important and I want to illustrate why through a snapshot of ONE day in my life.

Tuesday: I lift my daughter (16kilo's) into the car, carried from her wheelchair in the house, as we are going to drop off my 16 year old for school, who catches the train at 7.15. No point putting the wheelchair in the car. We drop him and come home. I lift her out of the car and into the house back into her wheelchair.

Give her breakfast, lift her manually onto her potty chair. Then lift her onto her bed, to dress her. Then lift her back to her wheelchair to do her hair and teeth. Once she is 'done' she is lifted into her walker, to get her upright exercise, or her standing frame, for 1/2hour while I get ready for work.

Then I pack her walker into the car then I put her in the car, then put her wheelchair in the car. Drive to school. Take out her wheelchair, lift her out of the car and into her wheelchair take her to her class. Lift her from her wheelchair into her chair in class. Go back to the car to get the walker and wheel that to class.

Then go to work, and work through without a lunch break as I only do 'school hours' five hours a day and lunchbreak costs money.

After work, go to school, get her walker, load that, go back to get my daughter in her wheelchair, load her, load the chair, come home, unload the walker, go back unload the chair, then unload her, take her into the house, and put her in her standing frame for her half an hour... then the time comes to drive to the train to get my son who has finished school. So we load her into the car (get him, come home) unload her back into her wheelchair.

In half an hour, it's time for basketball training, so I carry her to the car, drop him off, come home, carry her back into the house.
Then in one hour, do it again, to pick him up, come home, lift her into the house, in her chair for dinner, then into her shower chair and potty, and then lift her to her bed to put pyjamas on, then back into her walker for exercise before bed.

Then she sleeps, but needs to be turned over two to three times a night (sometimes none and that's the best nights ever).

Repeat every single school day, if it's not basketball its shopping, or her therapy or other things that require lifting her chair out of the car, lifting her out of the car and doing the same thing again (four lifts for every in and out of the car), plus the walker AND sometimes her special bike that goes to school.

We can't afford a wheelchair modified car and have no hoists or tracking at the moment. So I undertake at 12 lifts a day.

This illustrates the need for a healthy back which walking doesn't give one.

If after school we have dental visit, physiotherapy visit or any other activity, even shopping, add another two lifts and transfers.

I only share this so that you understand that <u>caring for a child with equipment is working</u>... it's just unpaid, relentless and extremely taxing on the body. My experience may be different to someone caring for a child with autism, or a child who has

reduced mental function and doesn't express a need to participate in dancing, playing, jumping etc, all done through different equipment. My physical workload is <u>increased</u> because my daughter has normal mental function yet physically is unable to engage in the activities she want to do, so I have to do them for her (with her).

6. Getting back to work

My experience: professional in the health field, maternity leave, back to work, unable to work on no sleep, resigned, five years later returned to work school hours currently contemplating reducing hours.

Success factors for getting back to work.
a) child sleeping <u>normally</u> all night (no thanks to doctors who only gave ME antidepressants). The answer to her sleep problem was melatonin which we got through a friend, AND sleep postural support which came very late in life through the support agency (two years too late).

b) school providing free childcare every day (except for pupil free days and strikes) making reduced working hours viable.

c) work available school hours at hourly rate reflecting personal worth.

Failure factors: lack of personal care time means I am currently contemplating working three days a week so I can get exercise on the days between. My back and neck are seriously suffering from sitting all day at a desk job, and physical care requirements including lifting before and after work. My daughter needs to be taken into the pool on weekends, and one day a week. This puts added strain on my back and neck as the pool is not equipped for changing her so I have to do more physical holding and lifting while drying her and dressing her (there is no change table in the disabled toilets).

Success factor for retaining five days a week work: HELP to <u>access</u> massage, physio, exercise, strengthbuilding, when husband is away. I don't have a solution. I am trying to make our garage into a gym so my daughter can play in her walker while I do exercise but its $$$'s.

Considerations for returning to work: Access to a short course focusing on personal presentation, self esteem, work skills (how to use outlook for example) like the old New Opportunities for Women, but at a higher level, delivered in consideration of childcare or school hours, and payment to help with work clothes (after no income for five years, personal presentation suffers).

Note: I did not know that if one did not access a centrelink job seeker payment one could still access job placement agencies!!!!!! Why the services are 'reduced' for those not on a payment, I don't' know, it makes no sense. I wanted to get back to work, but didn't feel I qualified any more for professional level but wasn't qualified in administration. Carers should be considered just as needy for job search help and placement and training help as those with disabilities as being a carer is a disability.

Luckily I managed to go back to the health industry but prior to that worked as a paid carer for a few weeks till my back gave out, (getting $14 an HOUR, compared to $50 a week as a parent carer!).

I can only comment on my experience caring for a young child with equipment and physical care needs. I would like the federal government to support women who choose not to work in paid work before their children join mainstream school just as we support any parent who puts their child's needs before financial needs. There does seem to be more emphasis on children being raised in childcare than by a parent prior to school, because of the financial benefits to the government, rather than the boding, social benefits to the child of being parented. I feel better support to parent children in the early years will lead to a healthier more enthusiastic workforce. The mothers I know who work full time with little kids are unwell, tired, and have poor personal relationships. Health underpins marriages and personal capacity. Money should not HAVE to be the primary focus on parents of young children.

In my case, I have only now been able to work as my daughter was settled into preschool and she was able to sleep most of the night, only needing to be turned once or twice. It was physically impossible to cope during the day without sleeping, as her needs were ongoing throughout the night as well as the day.

Sleep issues are something that all women face, but carers of children like my daughter, who had sensitivities and postural problems and pain, mean that normal life wasn't even something on the radar. I enjoy working now, but the first four years was about surviving, there was no quality of life, and absolutely no physical or mental capability of working. During the three years prior to work that she was in daycare two days a week, those days were my respite. My husband and I had to pay for mainstream childcare in order to get the 'me' time, other parents take for granted and for me to sleep. Things like shopping, washing, housework, were only able to be done on these days when my husband was working away. My daughter cannot hold anything or reach out to grasp things, so I am her hands. Putting pressure on carers to work only adds to the sense of being undervalued. We are not 'cash cows!'. Work needs to be something carers can undertake without it adding to mental or physical stress.

There is no financial benefit working part time if one has to pay for childcare. It's much better to wait till a child starts school and support parents better to care for under school age children. It's only four years and what goes on during those four years leads to the state of the carer when the child starts school!!! It's also a chance to do as much therapy as possible without pressure of doing it all around work.

Recommendation: Don't try and force women (the majority of carers) back to work in the pre school years, but support them to be a in healthy place when they are ready to go to work without childcare costs. Its MORE beneficial for all.

In my masters thesis, which I attach, one of the themes that came through was that men have better mental health and coping ability because they work. But is it the work itself that contributes to their better health? It is actually RESPITE afforded by the work, escape from stress, recognition for their efforts, reward in the form of pay, and value in the form of holiday pay, superannuation and sick leave. This is a model we as a nation should think about to help full time carers of pre school children, and adults who are full time at home.

Superannuation for carers
Sick leave
Respite (sourced by the carer with funds, not 'applied for and managed' by external agencies who may have 'no places left'.
Rewards – payments to reflect non access to holiday pay, sick pay, superannuation as a non choice!

One thing to note: children with equipment and high therapy needs miss out on the level of intervention they get when parents are available to take them to appointments if parents work. Two working parents will affect the access a preschool child has to swimming, playgroup, physiotherapy etc.

Since my daughter has started school, she has gone backwards with her walking sitting and strength. The time prior to school is so important to intervention access. Be mindful of that. Without an available parent, appointments are just not made. (therapy is a whole other issue, it's useless, too little, and not given often enough). You may be aware that parents do the therapy, 'therapists' just show parents what to do. It's added WORKLOAD for us.

Now I am working and it seems to be going well. The reason it is going well is that I have normal levels of sleep, and school is my childcare, otherwise Ashlyn cannot attend after school care as they transport systems they use do not provide for a wheelchair, but I am not concerned as I do not wish to place that amount of stress on her as she is exausted every day just from school and wants a cuddle and to relax after school.

Pupil free days and union strikes and holidays are a problem with getting childcare. I cannot get care for these holidays because a) the out of school care places provided through council are only funded to three places each and they are 'first come first served basis' EACH TERM, so I have missed out, and bookings cannot be made more than three weeks in advance.

I would like to pay someone else to care for her, but can't afford it as my job only pays $25 an hour before tax. I would be working for two weeks for nothing, but it would be costing me petrol and parking every day.

While the local area coordinator at Disability Services told me that they like to encourage carers to 'use church or family members' I think that is insulting. I can't expect my 70 year old mother to lift my child into and out of a car, lift her equipment, etc, for two weeks plus pupil free days etc.

My family members are interstate or work themselves. I am now hoping my husband can use his holiday leave to care for her, but this is not a sustainable solution. I would like to have funds to sort out my own childcare, instead of being reliant on agencies.

It's important to note that working ADDS stress to my life because I am rushing to beat the clock, not something easy to do as in addition to getting myself ready, I have feed my child, she goes to the toilet with difficulty and it involves time, she needs to be dressed by me, she also has to have her therapy and be in her standing frame for half an hour, as well as have her stretching done BEFORE we leave the house. She can't 'rush' or do any tasks herself. I also do not get any personal time that I used to when she was in school and I didn't work, except on the weeks my husband is home. I have already felt the impact of getting no exercise and constant rushing.

Please understand that carers like me who work will face added stress and health issues to do with lack of time and sitting in a desk job all day, in addition to the financial benefits gained by working. We are not machines and while it's nice to have our taxes, remember that it takes more work to get to work, and there is no 'relaxing' after work. Not for me anyway.

I would also like to state that not being able to get carer payment is a bit insulting, particularly when my daughter gets a funded full-time teachers assistant (which of course if for the class not her), because she can't do *anything* for herself. Yet my value was only reflected at *$50 a week?* IF she is disabled to the degree she needs full time assistance, why wouldn't that qualify me for carer payement! I felt very undervalued by not being worth more than that for the work involved. Remember that this is a non chosen non paid career. This feeling of being undervalued contributed to the depression and lack of self esteem and feeling like an outcast, which affected me after years of the caring role. I particularly was distressed about having no superannuation for five years while out of the workforce in addition to having to use my existing superannuation for home renovations to make the wheelchair able to function in the home (and we can't afford to finish them, so our doors are not 'wheelchair friendly), and not being able to access exercise, dental care, and not having a health care card.

Note: the recent carer allowance bonus payment is hugely appreciated given that average equipment costs are
Car seat $3,000
Hoist and tracking $20,000
House renovations $30,000
Flooring for wheelchair ($5,000)
Car $25,000
Car modifications $22,000
(not that we have bought these things).

I believe a better approach is to consider that there are different levels of caring and need. Those who have equipment needs for their children have different needs that those who care for someone who is mobile and can dress themselves etc. Addressing needs should be done within these different categories.

The more care that is provided for carers in the early years, the more the benefits later on. If I was supported MORE through financial help and recognition (not psychological care) I wouldn't have had so many

issues. I would have felt valued. Stress is physical, mental and spiritual and linked to a sense of purpose and value.
I want to work, but I do not want to be pressured to work. I want to feel valued if I can't work, as it makes me appreciate how taxes are used when I do work.

Finally: can we please stop using GP's as the reference point for any paperwork associated with Centrelink, ACROD, etc. It's very draining and expensive and why should medicare pay for this form filling? If we have a letter of diagnosis, shouldn't that be enough! And why should I keep telling Centrelink every year or so, that my daughters Cerebral Palsy hasn't been cured!!

The model to measure carer health?
The definition of positive mental health:

"in which the individual realises his or her own abilities, can cope with normal stresses of life, can work productively and fruitfully, and is able to make a contribution his or her community".
WHO 2001.