

Submission No. 807
(Inq into better support for carers)

From: lesley
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To: Committee, FCHY (REPS)
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Submission to Inquiry into Better Support for Carers

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Committee Secretary,
Inquiry into Better Support for Carers,
House of Representatives Standing Committee on Family,
Community, Housing and Youth
P.O.Box 6021
Parliament House,
CANBERRA ACT 2600

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee into Better Support for Carers.

I am submitting this to the Inquiry because I am now 64 years of age and have been the sole carer for my 30 year old intellectually and physically disabled son for 29 of those years. My son also suffers from Chronic Sleep Apnea – a potentially fatal disease, and a mild form of epilepsy.

I have, until six months ago, also had the care of my now 98 year mother. I feel I am well qualified to discuss the matter, to give insights into the tasks, heartaches and joys of caring – and I want to do my best to ensure those just beginning their tasks have more support, understanding and acceptance than have my peers and I.

I would like to include as part of my submission a speech I was asked to give at the NACS Conference in March 2005. This is attached. Most of what I had to say then is still valid and needs to be heard.. You may find the “Job Description” at the end interesting.

I have been trying to work on this submission for some weeks, and I apologise at the outset if some things are repeated and others a little rambling. Unfortunately – although not unexpectedly – carers cancelled shifts at the last minute, and the time I had set aside to edit and produce this disappeared.

ROLE OF THE CARER

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My role as Carer has been to give both my son and my mother a life style as close as possible to that enjoyed by most people. They have had family, visitors, constant stimulation – in other words, they have enjoyed a “life” – not just an existence.

I have kept both in good physical condition and as mentally acute as they can be. I have kept them in contact with the outside community – and especially with my son – have educated many people about disability.

In doing this I have saved the government many millions of dollars over the years – receiving only a pension out of which I have housed and fed them, taken them to doctors, and worked 24 hours a day.

We have long been a ‘forgotten subculture’ – doing whatever it is we have to do for those we love – existing on a pension no greater than those given to the aged, the unemployed, school leavers and the like – despite the fact that we have to work constantly for what we receive. We do not simply have to reach a certain age or apply for a certain number of jobs a week to receive our payment – we have to put in hours of work with the people we care for, and many hours over that attending meetings with service providers, therapists, attending medical and other appointments, educating ourselves as to the best way to assist our charges, filling in forms and more forms, liasoning with agencies of all kinds and having to consistently explain ourselves and almost apologise for asking for assistance. We cannot please ourselves what we do each day – our lives are controlled by the necessities of caring – being there 24 hours a day in some case

The community in general tell me how “wonderful” I am, but do not recognize that I, as a person, just exist. Without support and an income I have been unable to take holidays until recently, have been unable to undertake any continuing employment which would spread my social network, or even create a social network apart from others in my situation.

I believe the work of carers should be recognized as valuable and skilled. We contribute to our communities every day. I was a member of some of the earliest self-help groups – including the steering committee for Interchange – Southern. I made and edited the original commercials for interchange in the region. My contribution, in partnership with other parents, has been considerable to promotion of disability issues – and, in some instances, to the discovery and promotion of alternative and effective treatments for some conditions.

For all this, I am dressed in clothes that are some 20 years old. I have a very nice house – as my mother paid to have some changes made when we built on for her – but that is all. I have no assistance, emotional support or money to assuage the worries I have constantly about how to repair things, how to run a car which is needed for my son, how to exist.....

I would love to be able to say proudly: “I am a Carer” – and to have the community genuinely acknowledge my role and contribution. However, many have the same attitude as my own brother (who is a highly placed University lecturer) that I should ‘place my son in care and get a job and stop wasting the tax payer’s money’!!!

I think the only way to recognition of our role and importance to the community is for Government to lead the way. To recognize that we, in fact, have employment – looking after those who cannot care for themselves. If paid carers were undertaking the task they would be paid at least \$20*, where my salary is approximately \$1 per hour.

The inclusion of “Carer” on forms which contain boxes to tick to state one’s profession would be a start. We now just tick “other”. A title would be something.

BARRIERS TO SOCIAL AND ECONOMIC PARTICIPATION

1. Lack of substitute carers

Undoubtedly the primary obstacle I must overcome to participate in the wider community or paid employment is the lack of substitute carers – be they professional or volunteer.

I cannot leave my son unattended at any time, and the only time available is during the hours he attends a day centre – except, of course, when they are on holidays.

There is an appalling lack of paid carers available – and the majority of those are part time carers who are studying or need weekend work to top up their incomes. Sadly, caring also attracts a great many social misfits and often people with personality problems who feel they have some power in working with those less able. I have personally had a carer who had recently left hospital after a total nervous breakdown and became a carer to build up a clientele for himself of people who may like small

group day trips. He took my son for a shift from 10 am to 4 pm, had verbal and written instructions on toileting, places to possibly go, his lunch, my phone number etc. He returned one hour late – which was frightening for me – having not had my son out of the car all day. He had not toileted or fed him – claiming he had lost the written instructions and could not remember what to do. This had a disastrous effect on my son emotionally, to say nothing of the state of his nappy!! There have been many oddities through the years with the result that I will not allow anyone to take my son without my observation and personal training for at least three visits.

Professional care workers are the life blood of we Carers. Without them we have no freedom to do anything, but the current ad hoc system is totally inadequate and not designed to attract quality people who would like a career – not just a very underpaid job. There are some wonderful carers but most are filling in on the way to somewhere else.

My life is constantly being thrown into turmoil but Carers canceling jobs at the last minute. I cannot plan anything with the surety that I will in fact get to do whatever it might be. A never-ending round of itinerant people does not assist my son in any way to further his skills, and I lose at least three respite periods training each new carer. I note that the agencies providing the staff get paid for training – I don't and yet I do their job for them.

Personal situations vary, and some receive assistance from family. When my mother was younger and able to assist, I managed to continue on a casual basis with my acting career when offers came. Once she was no longer able to assist my career is effectively ended. I have not received, nor am I likely to receive, support from my extended family. My brother (who has a Doctorate in English and is in a senior position at Melbourne University) has *informed me that I should "stop being "self piteous", put Ben in care and get a job and stop wasting the tax payer's money. After all I had nothing to do while Ben was at school but sit and drink coffee with my friends"*. He was also banned from attending his youngest son's wedding for fear he would make an inappropriate noise and 'spoil things' There is certainly no help from that quarter – so that leaves me solely responsible for absolutely everything. I have no volunteers or friendly people to call on. (Interestingly enough, I have several who will look after my dogs in an emergency – but will not visit my son)

I have long pleaded for a politician to come and be part of this – or any other household for a couple of days. To see at first hand what this is about.

Employment is not something to be considered without someone to replace me at home. I have applied and failed to get casual employment on the basis that I would not always be available etc., or the hours required are impossible. Even in my profession as an actress the salaries are not sufficient to employ the assistance I would need.

I would, at this point, like to state that we Carers are EMPLOYED! We work for the Government and work incredibly long hours for the pittance that we receive. We are in lieu of paid carers from agencies who receive salaries – and what is more we feed and cloth our children as well as transporting them. We entertain them and attend to all their needs. No other pensioners are asked to work full time! We are a highly productive band of employees who never resign – we can't, there is nowhere for our charges to go, and there is no one else to do the care. A SALARY commensurate with our commitment, hours, etc. plus holidays and superannuation might be a start.

2. Lack of time and respite hours

My time is taken up with liasoning with professionals, running the household, doing accounts for 3 adults, maintenance, keeping up with research world wide on my son's condition. I also headed Parent's Groups at 2 of my son's day centres.

But that is nothing in comparison with the constant pressure of being there, being well, being able to cope when you have been up for 48 hours, of constantly teaching your child, supervising and training carers, filling in forms and the greatest of all the fear that never leaves of what the future holds for my son.

There is no relief – I have absolutely no one to turn to, to discuss things with, to comfort or take over from me. I deal daily with looks from strangers, explaining to curious children and their parents what he is doing. Trying to fill in holiday periods when he has no 'friends' to invite round or to go out with.

There are many other things I have to comply with apart from simply caring. Filling in forms eternally, complying with rules which keep changing, dealing with the Pension Department – a department created, I am sure, to add to the numbers of people in mental institutions – making sure that one complies on the date set down to do certain things – regardless of whether you are in the Casualty Department of a hospital with your son and cannot contact. Regardless you get fined.

We DO NOT have after school/day centre care to give us the hours needed to work full time. We DO NOT have holiday programs suitable for all disabilities to cover those periods – as do other workers in the community.

We DO NOT have sufficient respite care for all those who may wish to use it.

In short, we lack any assistance to facilitate returning to work, or to have any time to ourselves.

Lack of time, respite and money also badly affect our health. We cannot participate in exercise programmes, join a gym and I am too tired to race to a swimming pool and home in the time I have available.

As a carer of 30 years, I find now, at the age of 64, I am isolated. I cannot participate in the wider community – or establish friendships that would continue when inevitably my son goes into his own home.

Over the years old friendships have lapsed as I have been unavailable in my caring role to attend parties, dinners, sporting occasions etc.

I do not have the funds to do so – nor do I have the freedom. At no time can I exit the house without having to be back at a particular time without fail! My life is ruled by time restraints. I must be here when my son is here – to meet buses etc.

I cannot go out unless he is at his day centre – which means between 8.30 and 3.00 pm – or unless I have a paid carer. My son's meal times, bed times are not the usual, making it impossible to have any but the closest of friends to my home for a meal or the evening. Most people are not available during the day for visits and gradually it has become my son and I. In short - I have been unable to participate in the 'outside' world.

My 'free time' is when my son attends his Day Centre – giving me approximately 6 – 7 hours per 5 day week (with the exception of school holidays) During that time I have to take care of everything else – house work, preparing meals, maintenance of the house, finances for my son and for my mother, phone calls to agencies, arranging carers, filling in forms etc.

My 'respite hours' when paid carers care for my son, are occupied in the main by catching up with cooking, housework that has had to wait or correspondence. Keeping my son's financial records up to date to satisfy the requirements of VCAT annually is a large and constant task.

My continued care to my mother – visiting, maintaining her clothes, taking her on outings and to doctors – take approximately 2 hours out of my 6-7 hours on 4 days a week

I can, occasionally, meet some other parents for a coffee or quick lunch – if finances allow. I do not have sufficient funds to attend many things – even if I have the carers to relieve me. We are offered "Carers Pampering Days", but I nearly killed myself cramming everything into one hour in order to attend in the time my son was away – that I have not attended one since. (I must also confess, that I really don't want to play games or share experiences with people I don't know so that the day is spent talking about disabilities and caring. A 'pampering day' to me would be to sit in the

sun and have someone bring me a magazine, watch a movie and have a meal cooked and a laugh)

I managed to get my first holiday in 26 years three years ago, thanks to funding I had accumulated over time and hard work by a case manager to ensure I had rotating carers for the hours needed to care for my son in his home.

We have difficulties taking holidays – if we can afford them – due to the lack of choice in having our children/adults cared for in our absence. Respite houses are few, and not always suitable for the individual – my son being one of those. We cannot get people to live in and so we do not go – and yet most of us desperately need a break. We need choices and care.

My pension is less than my son's and I am restricted to the amount of his income I can use to care for him. I have to run a car as he cannot walk distances and wheelchair travel is not always possible on foot for me. Petrol costs are rising; food prices are rising. I have to pay tradespeople to maintain my home when necessary – although much goes unattended due to lack of funds. I do much of the work myself, but am time limited as well. I have no one to call on at all.

I receive no concession from the banks as do “age pensioners” They pay no monthly fees and are allowed over the counter transactions for which I get charged.

I face daily barriers that I should not have to. I am unable to work – which would give me a sense of belonging in the community and an outlet for other facets of my personality, and help establish other friendships. This is due to lack of relief care and rulings on the pension I receive. I cannot attend many social events – and the longer it goes the less I feel I fit in. I see few people on a daily basis – most of my friendships being conducted on the telephone when I have the time. I receive some 20 hours of respite, in home care – which is not a great deal and certainly not designed to give me a sense of being an individual and not simply my son's care
I find I am losing contact with simple things such as what clothes are in fashion!

COMMUNITY attitudes are not conducive to our inclusion in society., although with the recent publicity carers have received on television there has been a swing to understanding a great deal more.

The majority of people – and I daresay Parliamentarians could be included in this, are totally ignorant of what being a Carer entails. They see the obvious physical assistance required in those requiring that care, but generally the attitude is that the 'normal' family is much harder worked than Carers.

They do not see, or perhaps are unaware of, the hours we put in, the emotional anguish that is constantly there – especially when many, as I do, have absolutely no idea what will happen to my son when I can no longer care for him. We have no plan for his future, no residential places that we know he will be placed in – no choices. We are constantly on guard.

The more the years pass the less I feel part of the community. My career as a successful actress effectively ceased years ago – with only a few opportunities that fitted ‘guidelines’ and when I was able to access carers to practice my craft over the years. My confidence is at low ebb and I am in isolation.

Gradually people who once were friends have a tendency to slip away. They stop inviting you when your constant reply is “I can’t – I don’t have a carer”. Many are not comfortable around disability and as your child grows older and more intrusive into social occasions, less people come to visit. While my neighbours are supportive to a degree, none would even take my son for a walk in his wheelchair, let alone baby-sit

LACK OF MEANINGFUL *EMERGENCY CARE*

We have all been provided with a refrigerator magnet with the CARER CRISIS CENTRE phone number emblazoned on it.

We were told this was our emergency port of call if help was needed that you could not access elsewhere. I have had 3 occasions to call that number. The first when I was suffering from total lack of sleep because I was up with my son most of the night was successful and I was given assistance.

The second call was made when a Carer walked out in the middle of a shift, leaving me unable to care for my son due to a foot operation. I was on crutches and totally useless to assist him. Have tried all other sources I called the Emergency line to be told that they could only call 4 agencies, they had found no-one at the ones they contacted and I would have to wait until the day staff came on at 9 am the next morning! This was disastrous as he often needed assistance during the night, and would be up at 7.30 in the morning without anyone to assist. **NO EMERGENCY HELP.**

In recent weeks, due to some physical problems he is being tested for currently, my son has been up most of the night – and I was up with him. I averaged 20 hours sleep in a period of six weeks, and finally had to call for help. I received help instantly and a carer arrived to sit up with my son for the night. I was told not to hesitate to call if I needed more help. My son’s problems continued and the following week I knew I was in trouble and called to see if I could get another relief worker for the night. This

time I was informed that there was a \$600 limit per carer per annum and that I used that the previous week. They did offer 4 hours assistance from 8 pm to midnight, but I was unable to use that time as I had to attend to other things for the next day. They had no suggestions for where I could get assistance and I am in no position to pay privately for carers.

I simply had to abandon the behaviours I had been working on and put a bed in my son's room to get any sleep at all. There I remain until I can get help. I simply cannot be awake and alert 24 hours a day!

I doubt if every carer had called on emergency help last year, but rules are rules. They need to be broken at times

2. LACK OF INCOME

The Carer pension is the same as that paid to the aged, disabled, school leavers etc.

Qualification for the 'age' pension is simply to attain a certain age and have less than a set amount of assets, income etc. The unemployed have to seek a certain number of jobs a week in order to receive a payment – as do other recipients.

However **Carers have to work for their pension**. We spend hours, without holidays, time off, superannuation or any other compensation to care for those others have passed into Government care. In my case, I am often up 24 hours as my son suffers chronic sleep apnea on top of his other disabilities. Not only do we undertake the physical care required, most are involved with research, therapy programmes, transport, medical supervision etc. We cannot sit down and watch TV, go away for the weekend at no notice – or simply 'take it easy'. We are constantly on duty and on standby. We save the government millions of dollars each year, and yet we are expected to maintain ourselves – and to a greater or lesser degree – those for whom we care. I need to own, run and maintain a car to transport my son and my mother – and pay the same amount of registration etc. as those who earn money and complain. Care in a residential unit for my son would cost the government in the vicinity of \$70,000 per annum. Little wonder then the task is left to me with my pension of some \$13,000 per annum – a job from which I cannot walk out, resign, or join a militant union – because there is no where for my son to go.

Lack of funds also precludes me and many of my peers from undertaking any activities to maintain ourselves either emotionally or physically. I cannot join a gym, or even embark on a really good diet – those things cost money I do not have. I have to go on public waiting lists for health issues – waiting as I did for 4 years to have a serious problem with my foot operated on, and a further 2 years for the other

foot to be corrected. The problems were caused by having to carry and piggyback my son a great deal of the time – especially when he was younger. I was to have a recovery period of 6 weeks with a pin in my foot and on crutches to achieve proper correction. Following the second operation a carer walked out in the middle of a shift leaving me alone to cope....and the emergency Carer Respite agency informed me they were unable to access enough agencies to find someone to come in a hurry!!!The result was that I had to have the pin removed 2 weeks early and the foot has reverted to pre-operative status and can no longer be corrected. I am simply used to being in pain.

I am not impressed that the carer suffered no reprimand and is still employed! The only people to be affected were my son and I.

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A FUTURE FOR OUR CHILDREN

The anxiety level of carers increases with the age of the child. The closer we move to old age and our children into adulthood, the more we fear for their future. There are no residential places available for our children. Lists are long for those requiring eventual care. We have no choice of where they would be best place to have a good quality of life when we are no longer able to care – or no longer here. I and others have often seriously contemplated taking our children with us when we go, rather than leave them to an uncertain – and quite possibly – inappropriate future.

I fear constantly that the scenario often acted out does not happen to him. So often parents are taken ill, or die suddenly, and weeks later their child who is having enough difficulty comprehending why they are not at home, and where their parent/s are – are still on a merry-go-round of temporary care going from respite bed to respite bed on often a nightly basis while waiting for a permanent placement. I personally have witnessed a parent collapsing and her daughter being housed in 11 different houses on 11 nights – the consequence being she commenced fits and is now little more than a vegetable. Another lost his mother and six months later is still going from respite house to respite house. In his case, he is higher functioning and has sisters and brothers to assist him. For my son that would not occur. I consider this cruelty in the extreme and if this occurred to ‘normal’ children society would be up in arms. Why is it good enough for the disabled???

Why are parents/carers placed in the position of hopelessness?

SINGLE PARENTS

As a single parent, I would be unable to undertake employment as my time is almost totally filled with the care of my son, maintenance of the house we live in, meetings

with service providers, visits to my mother and her extended care. I have no one to call on to undertake repairs of any kind, no one to ring to ask them to bring home a pint of milk or anything else I may have forgotten.

I have the sole responsibility for everything – including accounts for my son and my mother.

MEASURES REQUIRED TO ASSIST CARERS

A LIVEABLE PENSION

Enough to enable us to exercise our own choices, enjoy a little of the free time we may have, accumulate superannuation etc. Alternatively – a Full wage, plus superannuation

PROFESSIONAL CARE WORKERS. (see ‘Strategies’)

Dismantle the current ad hoc system and make Caring a Profession. There are too many agencies, not enough care workers and too great a variation in pay rates. Make this something people would aspire to undertake as a profession – not just a part-time job.

IN HOME PROFESSIONAL ASSISTANCE for Behavioural and other issues.

Disability takes many different forms – and some adopt difficult or challenging behaviours which parents find difficult to deal with in the home situation. I readily recognize that some behaviours have been exacerbated due to my inability to deal effectively with it. While many times I know what needs to be done, and what my attitude should be, but time restrains, exhaustion etc. play a part in denigrating my effectiveness. Often parents are too close to their children to be totally effective and this is particularly true in the single parent situation where there is no-one to toss the ball to. My son has suddenly started head banging – and I think I know why and what should be done. However as a sole carer I cannot stay up all night and all day to handle it.

There are many instances where we need professional in-home assistance. We need someone there to give us confidence and to guide us. There is no such thing.

TIME OUT and HOLIDAYS

While short term respite (3 – 4 hours) is available through some agencies, Carers need really meaningful time out. Time to recharge, time to be themselves. We need holiday time – at least one week per year. Time to read a book, have a meal cooked for them./

Over the years the Carer Respite centres have offered “Pampering Days” – however, in order to be pampered, we have to find someone to do the caring, do whatever else is necessary before leaving which can be exhausting, and then participate in ‘fun games’ and lunch with other carers. So often when carers unknown to each other are put together the conversation turns to the person for whom they care, the difficulties etc. and you are thrust right back into the anxiety of it all again.

Respite needs are totally individual choices – and should be offered.

I, for one, would settle for a movie and a meal and not have to rush home! I am tied to time every day of my life – and to do whatever I want without restriction would be heaven a couple of days a year.

STRATEGIES

1. CREATE A PATHWAY TO RESIDENTIAL CARE

One that contains planning for the individual, a variety of choice in the type of permanent housing each would prefer, so that a gentle introduction is possible for the individual – and a gentle letting go for carers.

Residential care for loved ones is the greatest concern carers have. The lack of

housing generally – particularly the lack of choice in models – is a nightmare to parents. I, and others, have often considered that when I am getting to the end of our ability to care I would find a way to exit gracefully taking my son with me. Having no choice of venue, or of compatible co-tenants, no way to introduce my son to his future – a future he is totally unaware is his and cannot be explained to him, no future ‘home’ or setting I can take him to see and experience before the time comes that he enters it is inhumane and something that ‘normal’ children/adults would not have to undergo.

Housing for our charges in emergency situations – even the unexpected death of a parent/carer – is transient. The thought of my son having to undergo what has happened – and is happening – to others constantly in those situations is anathema to me. Imagine an intellectually and physically disabled person suddenly not being taken to his home from his day placement. Instead being taken to somewhere he has never seen, with people he has never met – imagine the terror he would experience. Imagine someone going to his home and selecting objects they ‘think’ would be favourites and are not. Imagine that same disabled person being taken the following night to yet another different house and different people, and that occurring night after night – very often for months – until a permanent place is found. Is it any wonder then, that in two cases I am aware of the disabled adults died within a short space of time. Another began having constant seizures, and will never recover from her, now, vegetative state.

Is that something that we Carers should have to constantly live with? Is that something that should be done to any human being? My son may be 30 in age, but not emotionally. This is cruelty in the extreme and it is something that I, and my peers, live with and nightmare about every day.

Once again, there are great variations in the ability of people to cope with these situations, just as there are wide differences in what carers see as being the best possible outcome and residential situation for the individual they care for.

Create a variety of options – differing residential models – from individual housing for 3 or 4 high functioning individuals, to villages for those who require more care so that they have the ability to associate freely with more than just their housemates – and can be safe in a wider environment with shared grounds and facilities connecting small units. There are many very wonderful models to look at – and the choices need to be made available.

Create a meaningful waiting list. Create the housing models and then list each individual as waiting for the model of their choice. That can be further narrowed down in time to almost individual places and the future tenant can visit, become familiar with the environment etc. before transition takes place. Currently there is a very long list – my son has been on the list for 10 years or more, and if I threw up my hands for help today he would still have to wait approximately 7 years for a vacancy!

Carers do wear out. I am close to that now – not physically, but the mental pressure is becoming almost unbearable. There are so many things I have to comply with apart from simply caring. Filling in forms eternally, complying with rules which keep changing, dealing with the Pension Department – a department created, I am sure, to add to the numbers of people in mental institutions – making sure that one complies on the date set down to do certain things – regardless of whether you are in the Casualty Department of a hospital with your son and cannot contact. Regardless you get fined.

2. Recognition of the differences in level of disability and the in-home situation.

There are so many variations in the level of assistance required that possibly pensions and allowances may be varied according to need. The basic amount needs to be higher than it is currently – but others need greater assistance. This could come through services or monetary amount. CHOICE is the essential.

Single parents often require more assistance in more varied ways. Depending on the level of care required for the individual, those who have high care dependents need more assistance with the other things such as home maintenance, respite etc.

Horses for courses: examine each family's capacity to care – to give relief to the primary carer. Some have extended families who assist, some have no one. Some have very high care dependents; others care for people who can assist themselves to some degree. Rather than funding going to all in equal amounts, create a 'needs basis' – really examine the options each family has for respite, emotional and financial support. Those who are totally unassisted need more support than those who have others to call on if needed. That does not demean the role they play as carers, but simply enable available funds to be distributed in proportion to genuine need.

3. ESTABLISH A PROFESSION CARE WORKERS COURSE

Initially “Carers need the government to acknowledge and assist with respite/relief care – to a greater and more effective degree than exists. Paid Carers are the hardest thing to find – and good carers even rarer. There is no formal course – there is no career structure that potential carers can enroll for and be acknowledged as a “Care Worker”. There are short courses, but a great number of those who have come into my home to give respite care are University students working part time. Some have had no formal training in disability or anything else relying on whatever course they are undertaking to gain their knowledge.

The results of this haphazard system is that we families have, in the main, a

revolving chain of people who come and go according to their own needs – exams, holidays etc. I have trained more carers than I care to think of – and each time I get a new carer it takes at least 2, but mainly 3 weeks before I can confidently leave them to look after my son alone.

I had a situation where I had an operation on my foot which required me to keep the foot raised 90% of the time for 2 weeks and then careful moving with the use of crutches. I could do certain tasks for my son, but could not bath him or get meals quickly. I had carers coming to cover those areas – one of whom had been coming for more than a year.

She began to take over the house and demand meals breaks at times that we just not possible – as they were times when my son required help that I could not give. I spoke with her and suggested she ring her agency to check what was and was not possible and did all I could to agency to check what was and was not possible and did all I could to accede to her requests. When I asked her to check how much orange juices was left (she was drinking it all and I was required to have a certain amount for healing) she threw a tantrum in front of my son – who really retreated badly. I spoke loudly to stop the tirade of abuse from her and suggested she go and make herself a cup of tea, that I would settle my son and we could have a chat. I came out to find she was not there. She had left the house – all doors open. There was no-one.

I rang, amongst others, the Emergency Carer Centre – to be told they could only ring 4 agencies – and couldn't find anybody either for that evening or for the next morning – as the carer who walked out would obviously not be doing her scheduled shift. I was told the best they could do would be to wait until 9.00 am and find a carer then – hoping to get someone to care for my son by 10.00. As he gets up at 7.30 and I was in no position to toilet and bath him – this was of no assistance at all. I happened to have a case manager who rang about something else out of hours, who got on line and found a carer for the morning.

The girl who walked out on the shift was not reprimanded. The agency who employed her would not listen to my side of the story and to this day is still employed!!!

These situations will occur with the current ad hoc system.

The answer is a professional course be established, where young people can become qualified carers – in the same way they can choose to do nursing or any other job. The role of Professional Caring needs to be acknowledged as a genuine career choice – with opportunities for career advancement. They need to be paid a wage at least commensurate with that paid to basic nurses. Carers doing 'in home' shifts can be asked to undertake all sorts of tasks and disabilities – for which they have the sole responsibility. They do not have a hospital surrounding them with staff to call on if something occurs. Their responsibilities are sometimes immense. They need to be professional and educated. This should be course young people at school can include in the possibilities for future

employment – and not just a fill in job to earn pocket money.

With properly trained, career carers – families would have the support and relief they need.

Appoint Case Managers – of carer’s choice to support and guide through the maze. Not just for the one occasion. Establish an agency for the purpose. We need to feel a rapport – especially needed for single carers.

ESTABLISHMENT OF VOLUNTEER GROUPS

Possibly establish an “adopt a family scheme”?

I was fortunate enough to visit Perth in my role as an Actress on Prisoner for their ‘Appealathon’. I did not know in advance that the proceeds go to the disabled and their families in various ways. I was very impressed with the way disability was recognized and how the general public was comfortable with all aspects.

They also have a system of local volunteers – men and women in the local community who would help with all sorts of smaller chores from housework to mowing lawns or cooking a meal.

Carers need: RELIEF; EMOTIONAL SUPPORT; CHOICE OF RESPITE OPTIONS; CHOICE OF STAFF; PHYSICAL SUPPORT

Thank you for taking my views into consideration as part of the Committee’s Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Once again I apologise for some repetition that may occur. Preparation of this submission was subjected to all the unknowns one could think of with regard my son and I was unable to properly edit it.

Yours sincerely,

(Ms) Lesley

2nd July, 2008

Attachment: 1