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Official Committee Hansard

**HOUSE OF
REPRESENTATIVES**

STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING
AND YOUTH

Reference: Better support for carers

WEDNESDAY, 15 OCTOBER 2008

CANBERRA

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HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON FAMILY, COMMUNITY, HOUSING AND YOUTH
Wednesday, 15 October 2008

Members: Ms Annette Ellis (*Chair*), Mrs Moylan (*Deputy Chair*), Mr Abbott, Ms Campbell, Ms Collins, Ms Ley, Ms Livermore, Mr Morrison, Mr Raguse and Mr Trevor

Members in attendance: Ms Campbell, Ms Annette Ellis, Mrs Moylan, Mr Raguse

Terms of reference for the inquiry:

To inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

WITNESSES

GOW, Mr Robert, Queensland Member, National Carers Coalition 1
MADDISON, Ms Felicity D, Queensland Liaison, National Carers Coalition 1
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Committee met at 10.09 am**GOW, Mr Robert, Queensland Member, National Carers Coalition****MADDISON, Ms Felicity D, Queensland Liaison, National Carers Coalition****TOPS, Mrs Jean L, Victorian Liaison, National Carers Coalition**

Evidence was taken via teleconference—

CHAIR (Ms Annette Ellis)—Welcome. There is no response yet on Robert's phone, so, if you do not mind, we will get going. Although the committee does not require you to speak under oath, you should understand that these hearings are formal proceedings of the Commonwealth parliament and the giving of any false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. Jean, you are on the line from Victoria, and, Felicity, you are in Queensland. The committee wants to thank you for the submission that we have received from you, which we all have. If you do not mind, there is just one very quick point that I want to make for the *Hansard* record, although I know you two realise this already. In your submission you make reference at the very beginning to the term 'carer' and who we might be referring to. I want to point out that in our terms of reference for this inquiry it actually says:

For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.

I know that you understand that is in the terms of reference, but I just wanted to clarify that because you make some very pertinent and relevant points at the beginning of your submission in relation to who is in fact a carer out there. But that is what we are looking at within our inquiry. We have your submission. Would either or both of you like to make a brief introductory statement additional to the submission before we proceed to questions and discussion?

Mrs Tops—I think we would both like to make a quick introductory statement. I am a full-time single-parent carer for my 39-year-old deaf, blind and profoundly disabled daughter, who lives with me at home. I have raised two sons with phenylketonuria to be fully contributing members of our adult society. I now play a key role in supporting my eldest son and his wife to raise his developmentally disabled eight-year-old child. So therefore my caring role spans over 45 years.

I would like to discuss briefly four of the points that we have made in our submission as key to making life better for carers. These are: legislated recognition, rights and entitlements; funded disability family advocacy networks; realistic payments for carers; and population based benchmarking of services.

We are very passionate about ensuring that family carers of our nation are given the legislated recognition, rights and entitlements that they should have but which they do not have. Families are far and away the most significant providers of accommodation and support, both in percentage terms and in financial contribution. Yet recent research, which reflects our own experience, shows that family carers are amongst the most stressed and unwell people in our community. Finding the resources to replace family carers will cost tens of billions of dollars.

This being so, we are clearly at a loss to understand why legislated recognition, rights and entitlements are not a first order issue for government. We believe that these rights and recognition will go a long way toward ensuring the continuation of family care.

A critical omission from the support offered to family carers is the funding of a disability family advocacy network. We have long sought equality with disability self-advocacy and service provider peak organisations, which are funded at regional, state and federal levels by both tiers of government. We draw the committee's attention to comments made in submission 845 to this inquiry by the Australian Federation of Disability Organisations. In particular, we quote:

AFDO would like to see carers acknowledged for their contribution to society, but that acknowledgement should also include an understanding that the work of carers should actually be the work of paid professionals.

This is a backhanded way of saying, 'We want family carers out of the way and paid professionals in the job.' This is a clear demonstration of an unacceptable anti-family culture, where carers are pitted against those we love and care for. We ask for a regionally based network to be established in order that family carers may have the advocacy support they clearly desire, the voice they desperately need and a place at the policy and planning table that they have clearly earned.

We do agree with AFDO that all carers should be paid. That is why we have strongly recommended in our submission that carers are remunerated for caring. We have further detailed this through the FaHCSIA pensioner and carer payment inquiry, and we trust that this committee will access our submission to the secretary of FaHCSIA. We stress at this point to this committee that the tax-free and means-test-free criteria as proposed are indeed the province of the Australian government.

We acknowledge the Rudd government for making benchmark funding a commitment of their pre-election policies, and we thank them for that. The NCC has been in the vanguard of those calling for population based benchmarking to underpin the planning and provision of services. This was a significant part of our submission to the 1996 Senate inquiry into the funding and operations of the CSTDA. However, the current implementation of such a policy is being undertaken behind closed doors with no input from family carers, who are doing the lion's share of all the work. This, for us, is unacceptable.

Disability and family caring are not a first order issue for the Rudd government, it would seem. First order priority means that disability family advocacy networks so that carers can support each other and take their place at the planning table are essential. We want to be able to speak for ourselves. Family caring will have to be made more attractive to family members in the future, particularly women who expect to be in the paid workforce, or there will be no family carers, and AFDO and other service providers will have their wishes granted.

Society and government have to make a vital choice—support family carers to eliminate the stresses they currently endure or make alternative arrangements to care for those we alone care for today. This means hearing what we, the family carers, have to say and then acting to make caring a first order priority for government. I thank you for the opportunity to speak with you today.

CHAIR—Thank you very much, Jean. Felicity, do you have anything you want to add at this point?

Ms Maddison—I would like to add something. I have just been on the phone to Robert. He said that they have changed the last digit of the phone number he gave from 5 to 6. So maybe you could try that number again. We actually planned to have him come on as the second speaker.

CHAIR—We will try that. Do you want to speak in the meantime?

Ms Maddison—If you are happy with that.

CHAIR—Absolutely. Please go ahead.

Ms Maddison—I am a sole parent and carer for my three adult children aged 33, 32 and 30, who live with disability. My daughter and younger son were born with multiple disabilities and require ongoing and constant support, supervision and care. They both live with me. My older son's requirements of care and support are episodic, unpredictable, intense and acutely stressful. I completed my hospital based nursing training in 1968 and have been a registered nurse for over 40 years. I also hold a Bachelor of Nursing degree and a master's degree in social planning and development. Both prior to and throughout my marriage I was able to participate in the paid workforce mainly in a part-time capacity. As there were two adults I worked shifts around family needs. At the time of my marriage breakdown I was working full-time and had been for three years. The loss of the back-up support of another parent and the lack of formal substitute supports available resulted in my being forced into a position of leaving the paid workforce to meet the support needs of my children. As the only potential breadwinner in our family this was devastating, personally, emotionally and financially. Our family home was the first casualty.

Over the last 17 years I have been, in the main, dependent on the carer payment for income support. I have been able to re-enter the paid workforce for short periods when hard fought for and sufficient and appropriate substitute supports were available. However I have found that substitute support can and has been withdrawn at the whim of the service provider, usually following my challenging an aspect of their service delivery. Carers should not be intimidated or bullied into accepting a substandard service for themselves or for the people they support, nor should they be subjected to retributive actions and withdrawal of services when they complain. Governments and their bureaucracies perpetuate this behaviour when, despite having been informed of such actions by service providers, prefer to bury their heads in the sand and distance themselves from the actions of the organisation they contract and fund to run their program.

As a result of my challenging the status quo over the years, sufficiency of substitute supports has fluctuated. Presently there are sufficient supports in place to allow me to be in paid work for 22.6 hours per week. However this could change through the decision of a person who does not walk in my shoes. I find it particularly affronting that judgements can be made about me and mine by someone who has not lived my life and makes little or no effort to understand the complexity and intensity of our lives. I am fortunate in that the employer I work for operates a carer friendly workplace and as a consequence, when issues arise at home, I can work from home. I was recently doing a big clear out of all the paperwork in my office, which I might add is an Amazon rainforest and I came across something that I wrote in 2001, which is pertinent. I

had been challenged as to why I was involved in disability debate when I was just a carer. It is fairly strong but I was peeved, to say the least, at the time. My response was:

I realise of course that it is entirely selfish of me to want to resume the ordinary parental role that my peers without disabled offspring enjoy and for my daughter and son to enjoy the benefits of individual choice in lifestyle, that it is selfish of me to want to resume my career, earn a decent wage in order to provide some sort of financial security for myself and my son and daughter, afford the extra costs associated with disability and, heavens above, perhaps even be indulgent enough to take a day off or a holiday, be spontaneous or be a sexual being. After all as a carer you are doing so much for society. You are an enabler—you enable government to abrogate its responsibility to its citizenry. You are a saver—you lessen the taxpayers' burden. You are a contributor—the care role you do saves governments and taxpayers hundreds of thousands of dollars each year. You are a facilitator—the savings you generate facilitate growth in the human service sector. You are a role model for industry—it is the work you do that others seek to emulate in paid career opportunities. You are fortunate that you cannot afford alcohol—think of cirrhosis. You are fortunate to be celibate—think AIDS and STDs. You are fortunate that your bills exceed your income—a day of fasting per week is good for body and soul. You are fortunate to feel numb, depressed and have no hope—so you will never be disappointed.

I went on further to say:

The family home in the community is becoming the replacement institution, complete with all the life opportunity limitations, isolation and oppression identified as so undesirable in large institution, differing only in that this time around families are institutionalised too.

I believe that if I wrote that today it would be as relevant to carers today as it was seven years ago. I have been politically active and challenging the status quo my entire life. When I was awarded an AM my old school rang me to ask me what I received the AM for. They did not think that it was funny, but I did when I told them that I actually got it for the same thing that they gave me Saturday morning detention for. So it has been an innate part of my personality to challenge. But I am getting old and I am getting tired. I am very concerned about the future for my son and daughter and I am very sick of being looked down upon, treated as a burden on society and a welfare recipient when in fact I am contributing a great deal to Australia and to Australia's economy. Thank you for the opportunity today.

CHAIR—Thank you very much, Felicity. We are very grateful. I now welcome Robert Gow. Sorry for the confusion in getting you on the line. Do you wish to add anything about the capacity in which you are appearing before us this morning?

Mr Gow—I live in Bunya in Queensland, just outside of Brisbane. My wife is the primary carer for my 25-year-old daughter.

CHAIR—Thank you. We have had both Jean and Felicity give us a very short additional comment to the submission that we have received. Do you want to say anything at this point?

Mr Gow—Yes. Firstly, I would like to congratulate the minister and the government for yesterday's announcement. That will help. I would also like to thank the committee for this opportunity to discuss support for carers. I would also like to reiterate the point that we are carer advocates—real ones. There is a multitude of topics on which I could speak, but it is on the subject of the carer advocacy network that I would like to expand on. Jean has possibly made the point that we have sought and continue to seek quality of representation with disability self

advocacy and service provider peaks. I would like to inform the committee of some of the compelling reasons that underpin the National Carer Coalition's proposal for a national carer's advocacy network. Our proposal for a funded national carer's advocacy network was the subject of a detailed and costed submission to the Treasurer for the federal 2008 budget. I will not go into the details of that submission but I will bring it to the committee's attention. It is one of the attachments to our submission to this inquiry and also one of our recommendations in the submission to this inquiry.

From the outset, it is important that I do two things: firstly, to make a statement and secondly to dispel a myth. First the statement: I in no way deny disability advocates the right to act for their constituents. I believe that they do this very well and should continue with their best efforts. This applies equally to service provider organisation peaks. Having said that, I would now like to dispel a myth. It is a fact that disability advocates and service provider organisation peaks represent themselves and their constituents—that is, people with disabilities and service providers respectively. It is a fact that their role is not to represent the interests of carers. It is a fact that carer's advocates and disability advocates do not necessarily share the same concerns. Certainly there are some crossovers, that is true, but it is a fact that the two are not mutually inclusive. Please do not assume that because advocates and peaks raise issues that involve carers that they represent carers. That is the myth—because they do not, and that is a fact.

I wrote to the inquiry's secretary, Mr James Catchpole, stating my reservations about the list of witnesses appearing at the public hearings. It seemed to me that disability advocates had a very substantial representation with this inquiry and that the public hearings included a dominant representation of organisations which were anything but carer advocates. Some of the organisations that have appeared have pre-stated conflicts with the interests of carers, so my concern was that the inquiry would be led to see carers' interests and issues as synonymous with the issues of people with disabilities. This would clearly be a serious skewing of the central tenet of this inquiry.

Disability advocates do represent people with disabilities. However, Jean has probably informed you that family carers provide over 93 per cent of all supported accommodation required by children and adults with severe or profound disabilities, so the question the inquiry needs to consider is: do disability advocates represent a majority of people with disabilities? I believe the answer is quite clearly no, and I will explain why.

'Discrimination' is a word that is often associated with minority groups. Disability advocates represent the vocal minority. They are very vocal about discrimination, and quite rightly so. But carers actually represent the silent majority. Who are the silent majority? It is hardly a mystery that there is no group that represents people with severe physical and intellectual disabilities. It is easily and readily understood. They are a disparate group of people who range from people who have Down syndrome, to people with the autism spectrum of disorders, to the profoundly physically and intellectually disabled and all degrees in between. They are all individuals and are a vastly diverse demographic with little in common except the label that they have, which is disability. Even if these people wanted to advocate for themselves—and I am sure many do—their bodies and their minds do not give them the tools that they need in order to do so. They are adult Australian citizens, yet they do not have suffrage. They do not enjoy representation, and yet every decision of government has some bearing on their lives.

Carers understand the concept of 'all about us, without us'. Decisions have been made about us and for us forever, in our absence. One thing that profoundly physically and intellectually disabled people do have in common is that they have carers. Carers are the one common denominator. In the absence of the ability to represent themselves, their parents and/or their relatives who are their carers have to be their voice, because carers are the only ones with half a chance of being able to do so. Anyone else who makes claims to be their advocate really is starting from a long way behind the game.

We have love for our sons and daughters. We care for their wellbeing. We ensure they are fed, housed, comfortable, clean, safe and ultimately provided with the best quality of life our family's money can buy. Self-advocates and peaks cannot make these claims. They have their own agendas and they do not represent our sons and daughters. They do not live with our sons and daughters 24/7. They do not live our sons' and daughters' lives. They cannot possibly know, because they have never walked a mile in our shoes nor the shoes of our dependent loved ones.

The inquiry should heed our voice on carer issues, but equally it should not disregard our voice on the issues that affect our sons and daughters. We are the only ones truly equipped to advocate for our sons and daughters. We, through our care role, have become joined for life. We are married to our disabled loved ones through our need to ensure that they have as good a life as we wished for them when they were born. They are married to us through their need. In the absence of any alternatives—that is, alternatives that would suit their needs better than what we provide—they are married to us for life, because statistics show that in 93 per cent of cases there are no alternatives. The plain fact is that carers represent far more disabled persons than do disability advocates, yet disability advocacy is funded. Why is it that carer advocacy is not?

In my letter to the committee secretary, I urged the committee to spend more time speaking to real carers' representatives and less time with those that represent that they do. I am pleased that you have chosen to speak with us today and I thank you. It is interesting to note that, of the 1,282 submissions received by the inquiry, approximately 140 were from interest groups, advocate support groups, peak bodies, service providers, disability support organisations, government departments and various other foundations, associations and non-government organisations, including some carer advocate organisations.

I would bring to your attention that approximately one per cent of the total submissions were from carer advocate organisations and over a thousand more were from individual carers. What does that tell us? Simple—that carers are forced to be their own advocates. That is the reason why you received over a thousand individual submissions and it is why the National Carers Coalition exists. It is the reason why the Carer Support Network of South Australia, Gippsland Carers Association, the Bright, Kiewa and Myrtleford carers groups, Bathurst District Carers Voice, the Vietnamese carers group, Newcastle and Lake Macquarie area Carers Action Network, the carer support group of Benalla, Frankston/Peninsula Carers Inc. and a handful of other carer advocate groups made submissions. We are our own advocates. Our stakeholders are ourselves. We do not have a funded organisation that advocates for us first and foremost.

All tiers of government fund disability self-advocacy and service provider peaks. Why is it that they discriminate against carers by continuing to deny carers equal status with these other providers? Peak bodies and disability advocates have a real and important place in society, and I do not question that. This inquiry is about carers, so I question the significant level of

representation the advocates and peaks have been afforded at the public hearings. This is our inquiry. It says so in the title—'Better support for carers' inquiry.

You have over a thousand submissions from ordinary, real carers. In most cases it is just their story and little more, telling it like it is. They do not propose solutions. They do not even complain. They are not used to anyone actually listening, so they do not complain. What this committee needs to do is read their submissions and understand what they are not saying, understand that they are frustrated and alone. They are existing, but they are spent from a lifetime of work and they fear for the future of their dependent relative when they pass on. They do not get out. They have little or no social life. They did not get to 50-something and do the world trip. Even if they could take the time off, they could never afford it. You do not save much when your full-time job has been 30 years of unpaid work. They never became empty-nesters like the rest of their friends and family. They do not get superannuation. Superannuation is for people who retire. When you are 80 and your dependent son or daughter is 50, when did you retire?

What this committee needs to understand when they read these submissions is what these carers, these real carers, are trying to say is: we need better support. One way to offer that support is to recognise carers and give them the voice that they need to represent themselves and their loved ones. I would urge the members of the committee to examine our submission and give significant attention to our proposal for a funded carer advocacy network. The value of this network would be that not only would it provide a long-overdue platform for carers to have a voice but it would have the added benefit of providing a mechanism for people who have no voice to be heard, through those who are the only ones equipped to give them that voice. In simple commercial terms, it is exceptional value for money. But, with estimated savings over \$30 billion, carers have a track record of providing value for money, so it should come as no surprise.

I would like to thank the committee for their time. I wish to assure them that we will provide the most insightful and compelling information that this inquiry will get about the real issues that affect real carers. Thank you for your time.

CHAIR—Thank you very much, Robert, and thank you to the three of you. We are a little bit limited in time, as we are at all of these public hearings, and we do want to have some questions and discussion with you. Before I start, do any other committee members want to come in?

Mrs MOYLAN—I just have one question to ask.

CHAIR—Please do.

Mrs MOYLAN—Robert, Jean and Felicity, thank you very much for your submission. It is very detailed. You talk about the severe financial difficulties facing carers and their families. I think Felicity's experience highlights the difficulties for many women, sometimes in disproportionate numbers. I formerly had a ministry which was responsible for disability services and I am also part of the Politician Adoption Scheme in Western Australia, so I have seen some of this first hand. In your submission you talk about that, but can you comment further on how current mechanisms for income support and tax influence the capacity for carers to combine work with their caring responsibility. In addition to the provision of extended hours

of care for people with dependent disability, what do you think can be done further now to assist carers who wish to work?

Mr Gow—I can probably comment on that. As I said earlier, my wife and I are still married, which, as you alluded to, is—most carers are single women. We are a minority within a minority, I suppose. I believe the number of dual parent families with disabilities is very low, below 25 per cent. I am not able to aggressively pursue a full career, because I need to be available at times to assist my wife and my daughter, who has had an ongoing health condition throughout her life. I possess a master's degree and yet I am the most junior paid person in the unit I work for. The reason for that is that I actually have to jump about three levels, which is not easy, to break even. If my wage goes above what I am currently on then my wife risks losing the caring payment, the healthcare card and other benefits. I cannot risk going up a level, because we would be financially disadvantaged; our household income would actually go down. It is frustrating. I did postgraduate study to get ahead, but I have found that the constrictions caused by being a carer place so many things in the way that it is disadvantageous for me to pursue a higher position with my employer.

Mrs MOYLAN—Thanks for that, but—

Mrs Tops—I will jump in on that and say that our very strong recommendation, in relation to this particular issue that Robert has raised, is that the carer payment should be completely reformed; it should truly reflect the fact that an individual is actually working to receive their carer pension benefit. They should therefore be treated the same way that foster carers are treated. They should be allowed to have their payments for services rendered means test free and tax exempt. If this were the case, Robert's wife and everybody else's spouse who is denied access to this payment or has their amount cut because they have a partner working, would no longer face those measures. Only 116,000 of our full-time primary carers actually have access to the carer pension payment simply because it is means tested; that is pretty telling. We have over half a million full-time carers without counting those who do 30 or 35 hours a week. Each and every one of them has a right to receive a payment from the government that reflects the work they do. Each of them needs to receive those pavements means test free and tax-exempt.

Over the years I have also been in the paid workforce, and carers do extraordinary things. For example, I worked six years of permanent nightshift because there is no way that I would be away from taking care of my family during the day. I then spent another 13 years in nursing where I took all the weekend shifts, all the afternoon shifts and all the night so that we could juggle caring, as a family, with my husband and the children's father. At the end of the day, when our marriage was destroyed by all of this caring I ended up having to give up work altogether and become a full-time carer. As an aged pensioner now, I am not eligible for any carer payment because I have an aged pension. How wrong is that? The work that I do in caring is just as hard and just as valuable as the work a 40 year old does who gets carer payment because they do not have a partner. But I am classed as not needing that money because I get an aged pension. So there is an absolute necessity for carer payment structures to be completely reformed. We do recommend really strongly that this committee obtains a copy of our submission through the pension and carer inquiry.

Mrs MOYLAN—We have the submission, but I guess the nub of the question was specifically about what kind of income support and tax system would better support you. Have

you actually had any detailed work done on how that could better be done? For example, would it be better if the income attached to the person requiring support in terms of not interfering with the parent-carer income stream? Have you look at any of that? I am just thinking out loud; I am not making any suggestions. I am just trying to explore ways with you that we can make sensible recommendations to government as to how we can better approach this.

Mrs Tops—To do something like being able to access the workforce. We have got the sort of comparison there with the ‘working family’ where the working family gets a 50 per cent rebate on family day care so that mums or dads, or whoever is the primary carer, is able to go to work, albeit part-time or full-time and have access to family day care that is subsidised by 50 per cent. People caring for older children with dependent disability, young adults with dependent disability and indeed older adults with dependent disability have no access to any such service.

Mrs MOYLAN—Is there no day care facilities available?

Mrs Tops—No.

Mrs MOYLAN—None at all?

Mrs Tops—No. Definitely not.

Mrs MOYLAN—None anywhere in the country?

Mrs Tops—In fact, my 39-year-old daughter does attend an adult day program but that adult day program operates from 9 am to 3 pm. There is absolutely no way that a family member who has a young adult attending a day program could possibly access paid work with those hours of alternative care available to them. So those services definitely need to have the ability to extend their level of care to adults with dependent disabilities so that there is long day care available for families to actually have access to paid work.

Mrs MOYLAN—Is there any allowance for families to get in an individual carer.

Mrs Tops—No. As I said, most carers get, if they are lucky, \$50 a week as a carer’s allowance. Well, I do not reckon that \$50 a week would buy in very much care.

Mrs MOYLAN—No, you are right. Okay, thank you very much Jean. Thanks Robert.

Ms Maddison—As I am in work at the moment, it is on me. Obviously with the qualifications I have and the years in the profession it is fairly obvious that I cannot work to the level that I could be working. I am constrained in two ways: firstly, I have become so dependent on the welfare system from the point of view that I am in public housing and secondly, the healthcare card is an enormous influence in maintaining part carer payment. There is obviously a discrepancy between carers who work and self-funded retirees who get a healthcare card. That healthcare card is a major issue for a family who, because they have had to live on income support, have been unable to maintain private health insurance.

I have done full-time work, and that was really good fun when it came to taxation time. I was earning too much to be able to get the tax offset for over-58-year-olds. I was also hit with the

Medicare surcharge because I did not have private health insurance. The other factor is being in public housing and knowing that, no matter how hard I work or what I do, I will never be able to afford to purchase my own home. I am now dependent on public housing forever. So I am mindful of that too. There have been changes to public housing tenancy which limit you from being in public housing if you earn over \$80,000 a year. They include my son and daughter's pension in that income, which makes it more difficult. The more money I earn, the more rent I pay. Certainly when I was working full time I was paying full market rent for the public housing. I am not complaining—I am more fortunate than others—but every time there is a pension increase or you earn any extra money you are penalised quite severely through pension cuts and through increased costs associated with accommodation.

CHAIR—We are going to run out of time and we have got a million questions we could ask you, but there is one I specifically want to ask whoever—but could we try and keep the answer a little bit brief so that we can maybe have time to get onto a couple of other subjects. Robert brought up the issue of a disability family advocacy network, which is the term used in your submission. You do not all have to answer this, but if someone can: can you elaborate on the need for that network and can you explain why, in your own opinion, you believe the existing carer and family advocacy groups do not actually represent to your satisfaction the needs of carers? How do you see this particular network that you want to establish doing that better?

Mrs Tops—I am the one who spent all of that time and effort and energy on writing about this particular issue, and it is a pet baby of mine, so I will answer. All of the support organisations that actually are definitively representing family carers are support groups without any funding. I know that people from the minister's office and other people have suggested that the carer associations at the federal and state levels act as advocates for families. We want to make it very plain here that the carer associations are in fact service providers. On their own admission, they provide thousands of services to carers every year, and when they do that they do an excellent job. It is inappropriate for service providers to also be advocates for carers.

In order for the carers to have their own self-advocacy, they do need to have a funded network. That funded network needs to mirror the network that is currently available through disability self-advocacy—that is, regionally based so that carers can actually touch the network and be involved with it and be supported by it, and then they themselves will choose their state peak bodies and their federal peak bodies.

Considering making carers associations advocates for families is a bit like saying to disability advocacy centres: 'We're going to take away all your funding because service providers can actually speak and advocate for you.' That is really the position we are in. We think that \$20 million a year for the whole nation to have a family advocacy network is a very small ask for the amount of contribution carers make.

CHAIR—Even though by reading your submission we basically understand this, I just want to ask you on the record here: can one of you tell us more about the Carers Coalition, its structure and its membership? How does it actually operate?

Ms Maddison—At the moment it operates informally. We are obviously not funded and Gippsland Carers actually holds the auspice for the National Carers Coalition. We want to

formalise the coalition. It came out of the walk a mile in my shoes campaign. How many members of the coalition to have at the moment, Jean?

Mrs Tops—It is very difficult to say exactly because we hold different databases in each state, but definitely thousands of members across all of the eastern states in particular. There is a small group from Tasmania and a small group from the western states. Because we are hampered by the fact that we have no resources we cannot actively encourage continued involvement. But if we get the resources we most definitely will incur actively encouraged the formation of specific regionally based carers support networks in the coalition umbrella. If the government will support us to do that we will actively make sure that those networks are established row donation.

Ms Maddison—Can I point out one thing that may give you a greater insight into how many carers and families are interested in carer issues. I am sure that you are aware that the Carer's Alliance was formed as a political arm for carers and they challenged on Senate seats at the last election. Nationally, over 26,000 people voted for the Carer's Alliance. That campaign was largely conducted by email, by word of mouth and by networking. It got very, very little in the way of publicity. I think that it is telling that although we did not get a seat in the Senate 26,000 Australians chose to vote for us.

CHAIR—Understood, Felicity.

Ms Maddison—That may give you an indication of its depth and breadth and that was only in four states.

CHAIR—Thanks Felicity, we understand that implicitly. I am really sorry but we have to draw this meeting to a close because we are nearing 11 o'clock and that is the time by which we need to conclude our business here in parliament house. In doing so I want to say just a couple of things, if I may. Firstly to thank the three of you and to thank the coalition for the submission and to the work you have put into representing your constituency. Can I quickly say to Robert and to the three of you through Robert, that I want to assure you that the amount of effort that the committee has put into, through our public hearings, discussing these issues with individual carers cannot be overstated. We have heard firsthand from individual carers in almost, I think, every possible concept of caring that you could imagine including mental illness and spouse caring for spouse. There is barely a situation that we have not heard from an individual carer about. I just want to make that point, not to argue with the Robert but to assure you that the effort of the committee in speaking with and listening to individual carers is paramount in the conduct of our public hearings. If you do not mind, if the committee through our secretariat have any further questions of information that we would seek to you subsequent to today that we would feel free to contact you through Jean and make that inquiry if we so wish. Is that fine with the three of you?

Mr Gow—Please do.

Mrs Tops—We would be delighted.

CHAIR—Thank you very much for your attendance today, particularly considering the added challenges of a phone hook-up.

Resolved (on motion by **Mrs Moylan**):

That this committee authorises publication, including publication on the parliamentary database, of the transcript of the evidence given before it at public hearing this day.

Committee adjourned at 10.59 am