Submission to the Australian Productivity Commission

Disability Care and Support

My name is Sharon Lane and I am the Coordinator of the South West Carer and Respite Services Network. We are a network of federal govt, local govt, not for profit, respite and carer support service provider agencies and also a range of independent carer support and advocacy groups and individuals operating through Neighbourhood Houses, Parent Support Groups, Carer Support Groups and parent advocates located throughout the South West of Victoria. Our unusual membership can lead to many differing and competing viewpoints but does enable us to identify areas of potential conflict and to work in partnership to address such issues.
This submission focuses strongly on the needs of people with a disability from a family perspective.

About Us

The South West Carer and Respite Services Network Strategic Plan focuses on four main directions:

CONCEPTUAL DIRECTION: A level of conceptual rigour that evolves from conversations and projects that push the boundaries of respite and carer support. By considering the role and history of respite, The South West Carer and Respite Services Network poses and addresses key questions that will, over time, improve the accessibility, diversity and quality of respite and other carer support services.

ATTITUDINAL DIRECTION: Respite is a human service activity that has been reviewed repeatedly over the last decades. Unfortunately, many of these reviews result in outcomes that do not improve the coordination and provision of respite and carer support services. In most cases this has been due to an emphasis on planning, at the expense of planning for implementation. The South West Carer and Respite Services Network is based on an assumption that a vigilant focus on the “achievable” creates an attitude of achievement.

PROCESS DIRECTION: The South West Carer and Respite Services Network have a clearly documented process. There are established guidelines for Membership, Terms of Reference, Project Plans, and access to the resources of a Coordinator to maintain momentum and complete projects. Networks benefit from the experience of each other and maintain close links.

PROJECT FOCUSED DIRECTION: Projects are selected on the basis of making significant improvements in the co-ordination and provision of respite. The projects are a mix of activities, focussing on information sharing between agencies, identification of gaps in the sector, fresh approaches to service design, links with other sectors and the creation of opportunities for agencies to collaborate.

The objectives of the South West Carer and Respite Services Network are:

- To provide a focal point for interagency collaboration around the development of inclusive and unique ways of providing respite.

- To plan for and develop respite services equitably across the aged care, mental health and disability sectors.
- To maintain a flow of information regarding the progress of all projects and broad developments in the respite sector.
- To conduct activities and develop projects that will improve the quality, accessibility and availability of respite.

Our Response to key questions

Who Should Be Eligible?

The South West Carer and Respite Services Network strongly support the introduction of a federally managed no-fault disability insurance scheme. Preferably the scheme would be funded through a tax payer levy system.

Although we cannot say who would be the most appropriate managers of such a system, on a federal level we currently have Centrelink, and we have the Commonwealth Carer and Respite Services either of whom may partially redesign or it may be an entirely new department that emerges. We feel that whichever option eventuates that the management agency/department/structure must be removed from the direct provision of services in order to ensure that conflict of interest does not develop.

We believe it is the duty of every able bodied citizen to support the wellbeing of those less fortunate in our community. While we do agree that the new system should make a difference between those who were born with or acquired a disability, as opposed to a disability acquired through the natural aging process it is very important that there is a seamless transition from one to the other for a person with an intellectual or physical disability when they reach retirement age. We also believe that the official retirement age for a person with a disability should be 50- 55 years of age because of a lower than average life expectancy and quality of life.

We strongly disagree that the scheme should be designed in such a way that it is not available to **all** people with a disability. By excluding people with a mild to moderate disability we are again creating a tiered system of support which encourages the family or person with a disability to view the disability in the most negative ways possible in order to achieve greater support outcomes. The severity of disability itself is not always the most powerful factor in ensuring quality of life for the person and their family circle. It is the ability of the family unit to cope with the disability that is at question.

Our fear is that by excluding those who are deemed ‘not severe enough’ the system will leave those with more moderate disabilities without adequate support and services which may in turn lead to the break up of the family unit, the progression of co-morbid disorders, e.g. drug and alcohol abuse, emotional and physical abuse and depression. The human ability to cope is highly subjective and does not relate directly to the level of disability. If a person is a carer for three family members with moderate autism does the collective level of disability become recognized? There are too many variables. A disability is a disability and needs to be addressed in an individualized proactive manner to achieve real outcomes for the person.

The cost benefit from an organizational perspective would certainly be comparable. Comparing the cost of point of entry assessment and analysis on whether a person is eligible for the scheme to the cost of proactively supporting those with milder needs would be minimal. It seems that an assumption is being made that people with lesser support needs will *want* to access services any more than is reasonably necessary? From experience it costs a lot less in the long run to proactively address smaller issues and needs. Also, the need for long term care will be directly related to quality of care at the point of entry for the client.

Respite services for a carer should not be included in the scheme as it affords a potential conflict of interest. Carers that we have spoken to would not be willing to access respite services if they thought they were using funding that could provide aids, equipment or social opportunities to their family member. They would then run the risk of burn out and compassion fatigue which leaves the care recipient vulnerable to the breakdown of care provision. Carer support funding needs to be channeled from and through other avenues. This may continue to be the role of State Government.

Who Gets The Power vs. Who Makes The Decisions

Perhaps it is not so much an issue of who gets ‘the power’ but rather who is no longer disempowered.

The decision making process needs to be firmly placed with the individual and their family in the first instance. If this is not possible an independent advocate should assist on the families’ behalf. Far too often we hear hysterical comments about families who will abuse the financial power and spend the money on drugs and alcohol. This is a smokescreen. It would be difficult for any competent assessor not to be able to identify families/carer’s who do not have the capacity to undertake sound financial decision making in a very short period of time if they are doing their job properly. In such cases the opportunity to learn such skills in a supported environment must be offered. Families must be empowered to reach their own decision making potential with independent support. Broader family support must also be provided through family centered practices, parent education and family capacity building.

There may indeed be cases where the capacity to undertake financial management and service choice is not possible e.g. where a person with a severe intellectual disability has no family support structure or where there are parents with an ID themselves. Case management for some families will always need to be an option, but only after all other avenues have been explored.

The majority of people with a disability and their families will not have issues with accountability and it is presented as a reason for caution far too often. What is the difference between a family who uses a portion of their funding to buy a new family car for outings to an agency that takes 30% from funding packages as ‘overhead costs’ to buy fleet cars? Are they not still vehicles being used to support the person with a disability?

Agency viability should be subject to free market supply and demand. That way, those who respond best to the needs of their clients will not experience any detrimental effects. In rural areas there will always be an issue for client choice and the viability of rural agencies will probably be less compromised from free market competition but perhaps more from loss of infrastructure funding for transport and physical resources etc., This is an area that does warrant further support as there are already very few service options available. Perhaps a specific funding stream for innovative rural projects needs to be developed and certainly independent funding for the support of infrastructure is very necessary to rural service providers.

If a person is funded through the scheme they should be in a position to decide what portion of their funding they wish to pay for aids and equipment. For items that are very expensive .e.g. a pool with a hoist, the NILS (No interest Loan Scheme could be adapted to support such expenditure) after all the client will have a secure income for the rest of their lives so repayment contracts can be set up. It will not be difficult. The decision as to whether primary carer's should pay themselves for undertaking their caring role is an intensely individual and personal issue. Many Carers would not wish to, but some, due to the intensity of their caring role may not have many other financial options. It is not something that should be viewed as a negative option, but may again be an option that sustains the family unit. Individualized funding may be monitored through the funding body or may be through an accountant in a similar way to a self-employed person with the fees being claimable in the next financial year. A yearly or six monthly certificate of compliance could be issued that would then allow the next tier of funding to be released.

People with a disability are as entitled as anyone else to choose the type of service that they access as opposed to following any current theories of what is the most appropriate intervention. I have attended many conferences where the experts themselves cannot agree on what the best interventions are, so why should a person with a disability or their family be expected to?

The Nature Of Services

There are so many gap areas in the provision of services, particularly early intervention that it is hard to know where to start. I see this issue as one of the greatest downfalls of our current service system and one of the clearest indicators of why such a system cannot work. The system as it exists is almost entirely reactive and any innovative ideas or 'outside the box' thinking is viewed very cautiously to the extent that creativity is stifled and good people leave the sector. Innovative projects that are funded are almost always 'pilots' and funding is short-term and non-recurrent. Given the amount of paperwork that goes with such funding submissions and the tiny amounts of funding available it is not surprising that we have agencies that will just maintain the status quo.

The areas that we have identified through high levels of community and agency consultation can be listed in the following sequence:

- Access to information
- Access to flexible support options
- Access to specialized support at times of critical need

- Capacity Building of the entire family Unit through family education, advocacy and personal development.

Support at times of transition:
- Moving from Kinder to school.
- Moving from Primary to Secondary School.
- Moving to supported employment and/or accommodation.
- Moving into retirement.

Again it is too subjective to attempt to quantify the most important services and costs as they will be so variable across areas of need. They can perhaps be classified into different streams.
- Aids and equipment, home modifications, transport and infrastructure costs can be put into one stream.
- Medical, Psychological, and Allied health costs into another.
- Social and Emotional support and development into another. This would include counseling, education, training, supported employment, social activities, capacity building etc.,

As with all individuals, our needs for certain services and supports will differ at different stages of our lives. It is the ability to *access* these services that is the most important issue.

In a free market environment the onus to provide a quality, value for money service will be become integral to the success of the service. Monitoring at present is ad-hoc, over-reliant on 'data reports' that often bear little or no correlation to the actual client outcomes and are often ticked off without proper evaluation because it is too difficult for DHS to withdraw funding. It is that simple.

A number of questions in section 8 are very worrying as they still imply a hugely service provider decision making attitude. If the capacity for full decision making is given to the funding recipient, the majority of these questions are obsolete. The question *To what extent, if any, should people be able to cash-out the benefits from a basic service/appliance/aid (for example, a wheelchair that met assessed need) and use it as a part payment in purchasing a premium service (a more advanced wheelchair)?* What does it matter how a person decides to fund or refund aids and equipment? It is a choice that many of us make on a regular basis, for example changing our car, or washing machine. Does it matter if my car was paid for when I was a recipient of Centrelink benefits? Does that make my car the property of Centrelink? These are decision making processes that every individual has to make on their own level and to assume that a person does not have the right to make such a decision is arrogant and disempowering.

From working in the sector for a considerable time, it is quite clear that the majority of carers will have their goals substantially met when the care recipient is happy, well cared for and achieving to the best of their potential. The pendulum has swung too far on the side of encouraging families to consider their caring role and the person they care for as an onerous task. Carers want respectful, empathetic service delivery. There is a very high level of distrust of 'case managers and disability workers who think they know what is best for us'.

Case Study: A middle aged couple, one of whom is a paraplegic wanted to install a pool and hoist in their home. This was at the recommendation of the care recipients

OT, doctor and specialist. There was no funding available to support this goal because the care recipients case manager (DHS) said it was not achievable under the guidelines to spend such a huge chunk of their package money on a pool. They would have to be content with other services such as gardener, cleaner etc. (which they did not need or want). The couple managed to save for a few years and with support from family and friends have now installed the pool. The pool hoist will cost them around $6,000. Again, they have been told they cannot use any of the package money. They can access $1,000 from CCRC and $1,000 from another agency that support carers aged over 65. It will take about two years to save the $4,000 needed as the primary caregiver has recently undergone treatment for cancer and is unable to resume full-time work. In the meantime the caregiver is pulling her partner out of the pool by hand every day. Where is the logic? If this funding had been provided 6 years ago when first requested, what would the quality of life, sense of goal achievement and reduced stress have been like for this couple? There would have been a greater extension of time where respite and other medical services were not needed or sought. Now we have a couple who are stressed, guilty (for being a burden), ill, and who need significant periods of respite to maintain the caring relationship. I have spoken to this couple about direct payments and self-directed funding but they are so disempowered at this stage that it will take a considerable effort to explore this possibility further, and who is going to facilitate them in this process?

Not all services should be free and the options for co-payment should be available. Again it depends hugely on what the service is, where it is being provided, (rural services may have a much higher transport component), and the capacity of the individual to contribute towards the cost of the service. Hopefully over time services will become less service provider agency structured and will be more integrated into mainstream services.

In order to promote individual choice and self-direction families need to be informed and educated in regards to their rights and responsibilities. Rural areas are lagging very far behind their metro counterparts in this regard because of the limited choices that are available in regional Victoria. In many cases there is only one choice available. That is not to say that the service being offered is not of a good quality. All of our survey data reports that clients are very satisfied with the *quality* of residential, day stay, holiday service provision in this region (facilities are clean, staff are nice, cost is generally reasonable), but the flexibility, suitability, and personal satisfaction for the care recipient are less than satisfactory in most cases. Activity programs for young people are very few and far between in the region and families have to travel for up to three hours each way to access programs. So, when we speak about ensuring that supports are directed by the individual, it will be predominantly through capacity building within the family unit. Following on from this, ensuring individual choice will be more reliant on services available, flexibility and suitability. It is particularly important in rural areas to concentrate on the capacity of non-disability service providers to become part of the choice. This work is happening in the Neighborhood House sector in our region at the moment but is very disjointed at present and relies heavily on the goodwill of the organization. Government funding for community, health and welfare should be scored and allocated with a greater emphasis on access for people with disabilities. A more consistent and communicated effort needs to be made.

Under the present system the information, resources and decision making referral systems that individuals would need to make informed choices are held by service providers. This is a direct conflict of interest. Very often information is not given, or given and interpreted incorrectly. I recently met a lady caring for her autistic 15 year old son who had never applied for a carer allowance or health care card for him, thereby excluding her from a range of services and supports, because she had been informed many years ago that she would loose her parenting payment if she received the Carers allowance. She was very distraught when she realized what she had been coping with financially that need not have been if she had received the correct information. Another lady was informed that she would have to include her drive to work as part of her 25 hours that she can work before her carer's pension is affected. This is not correct. Both of these ladies were given this information by Centrelink staff and both only found out that their information was incorrect after I had chance discussions with them. How many more people are being misinformed? We need a single point of entry for this information. The system that I prefer is to normalize referral pathways and family education through a structure like the Neighbourhood House Network. When I worked in the sector in Ireland we used the Family Resource Centre model based on providing a non-partisan family centered approach to support the local community. That is what we are missing in the current system. The Neighbourhood House structure is government funded, locally based, non-partisan, family focused and is aimed at providing support, referral and low cost services to the community.

Residential Respite for people aged between 20 –55 is non existent in our region (and in many others). It is heartbreaking to see a 35 year old woman with MS consigned to an aged care facility. This mother has forbidden her young children from visiting her as they get so upset. Another gentleman who has an ABI following an accident is also residing in one of our aged care facilities, his family are very distressed by this, and very recently a young mother who has an 18 year old son with a severe physical disability was also told that an aged care facility was her sons only care option while she underwent surgery herself. Needless to say she has not had her surgery yet. Again, these gaps are widely known but the funding to tackle them is not being provided.

Physical access to facilities is an issue. An audit of our local area shows that there are a large number of social clubs and community groups that a person with a disability cannot access or has very limited access to. Access to the beach is limited for a large number of people. Grants need to be made available on a wider scale to encourage renovations to be made. Inclusion of people with a disability may come in a number of forms from the community. Our survey of the region showed that most carers do not belong to a support group. Why? The main reasons are varied. Support groups are held during the day, lots of carers work, support groups are not funded to develop their own activities but are facilitated by organisations (where is the empowerment?). Carers are too stressed and busy to join a support group. Again using a family resource centre structure would be the best option to strengthen and support the needs of carers and people with a disability, it would normalise the situation a lot more. Education and advocacy need to be supported to a much greater degree. The South West Sports Assembly has a great facilitated sports integration program and this can be duplicated in a number of other interest areas. Carers and people with a disability want to achieve and contribute in a manner that they feel is worthwhile, not just go on trips to the movies, or shopping all the time. Respite Services need to develop more active personal development programs for their clients and to refer clients to non-disability services as a form of active engagement. Partnerships need to be developed with the community sector where there are gaps at the moment. A number of years ago I worked on a project with the DHS Office of Housing. A high number of their tenants and their families have disabilities of some sort, yet there was no training provided to staff in how to identify such issues who to refer to etc., We were successful in identifying this gap and in gaining funding for the appointment of a part-time social worker within the Office of Housing whose job was specifically to support such tenancies. This worked very well for both staff and tenants. I don't think that the position is still being funded, but it certainly did support the sustainability of housing for people with a disability whilst it was in operation. To ensure meaningful responses, this will have to take a whole of government approach and I do advocate for a distinct Office of Disability Services within **all** departments of Government.

Service Delivery and Inclusion

Service delivery must expand from traditional disability service provider models to a more inclusive community models. This can only happen with time and financial capacity. We will see greater social change over the next decade as more young people with disabilities who have been educated in mainstream schools age and progress to more socially diverse activities with their peer groups. We have a lot of anecdotal evidence of young children in primary schools acting as the educators of their parents and other family members because they have a classmate with a disability. This was not an opportunity that many of their parents and grandparents were exposed to over the last number of decades unless they had a family member or neighbour with a disability. Service providers need to be aware of shifting social dynamics that are already in force. To make a broad generalisation: older carers of a person with a disability are traditionally more passive and very often accept services from a welfare perspective. Younger carers are more information savvy, they explore options, opinions and services to a much greater degree and they are stronger advocates. Our older carers tend to use comments like "We are very grateful for what we have received" or "We don't want to bother anyone by asking for too much" Younger carers, although they are very wary of being labelled a 'trouble maker' by service providers are very aware of their rights and will challenge 'authorities' to a much greater degree. Service providers need to understand the changing dynamics of carers and to meet these challenges by becoming more inclusive and working in greater partnerships from a family-centred perspective rather than by viewing it as direct confrontation. Research from the University of Sydney and other reports clearly shows the high level of family breakdown when there is a child with a severe disability in the family. Most families interviewed in that study reported that they did not want to break up the family and therefore chose to seek full-time residential care for their child with a disability *by the age of 5* in order to protect the family unit and quality of life of other siblings. What would the cost of early intervention and support have been compared to a life of residential care for a child and the human cost for the rest of their family?

Disability service delivery will also be impacted upon by our aging workforce and the reduction in the traditional caring role as more women become higher educated and seek well paid professional positions. This sector is very over-represented in female employees, although mostly at the lower to mid-management levels. While there are currently a number of projects at different stages of development that are aimed at addressing the current employment shortages, it is unlikely that enough people will choose a low-paid career with few advancement opportunities as a first choice. This leads us to a range of people being employed who (a) do not have any other employability skills (b) who are older and do not intend to work in the sector for a long-time (c) those who view it as a temporary stepping stone to further education/employment with better outcomes. Probably the worst case scenarios are the small minority of people who enter the sector in order to “rescue” people with a disability. People with disabilities need to be exposed to a wide range of opportunities for personal development. The term inclusion is one that I am not comfortable with. Firstly it assumes that everyone wants to be included. This is not the case. Many people with a disability do not want conscious inclusion, they want acceptance and companionship. Others, such as adults with autism spectrum, do not particularly want to socialise to a great degree with others at all, but isn’t this the same as the wider community. How stressful would it be if we all felt pressurised to become included? One of the greatest gifts we have is the ability to go unnoticed at times. This is so much more difficult for a person with a disability. The only way to achieve real and meaningful relationships is to allow them to develop over time. This is the same for all people. It is only by knowing and understanding each other that we really develop relationships. That is why opportunities to integrate socially must be of the highest priority for people with disabilities. We are lucky in our region that we have a very high level of cooperation between service providers, however this does not always translate into meaningful choices for the clients. As with all rural areas there is a constant struggle to provide quality and choice across a huge geographic range with limited resources.

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