Seeking the Cure.
Providing the Care.

Submission to the Senate Inquiry into the Funding and Operation of the Commonwealth State Territory Disability Agreement (CSTDA)

from

The Multiple Sclerosis Society of South Australia and Northern Territory

August 2006

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The SA and NT MS Society supports people in SA & NT living with Multiple Sclerosis, and other neurological conditions which are primarily progressive degenerative and demyelinating conditions of the Central Nervous System.

Summary of our concerns

South Australia

The SA model of service delivery for state services for people living with MS (and other adults with any significant disabilities) is unique. Our Society is expected to support and advocate for the majority of our members from the time of diagnosis, through the early years of their disease, with little or no funding from the SA State Government.

Last financial year we raised just over 96% of what we spent on client services such as counselling, social work, physiotherapy, hydrotherapy, OT support and nursing assistance. State Government support amounted to $208,000 of some $1.3 million we spent assisting our clients.

If our members Multiple Sclerosis progresses to the stage where they are assessed as having 'significant and permanent disabilities' we are required to then pass them on to State Funded services. These have been organised as follows: -
"Options Coordination is a state-wide network of five agencies working together to assist people with significant and permanent disabilities to get access to assistance, information and community services.
These five agencies are:

APN Options coordination - auspiced by Julia Farr Services (JFS)
Adult Physical and Neurological Options Coordination - for adults with a physical or neurological disability.
BIOC- auspiced by JFS
Brain Injury Options Coordination (BIOC) - for adults with an acquired brain injury.
Novita Children's Services
Novita Children's Services - for children under 18 years of age with a physical or neurological disability or an acquired brain injury
IDSC
Intellectual Disability Services Council Options Coordination - for people with an intellectual disability
Sensory Directions - Guide Dog SA & NT
Sensory Directions is a program of Guide Dog SA & NT, for people who are deaf, hearing impaired, blind, vision impaired or deaf-blind "[1]

Our clients are covered by the first agency "APN Options Coordination".

This agency has very extensive waiting lists for most of their services, particularly in-home support services. There are virtually no away-from-home respite services that are suitable for our clients, particularly our young adults.

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[1] Family and Community Services web page, as at May 31st 2006
http://www.dfc.sa.gov.au/disability-services/Options.asp

There are very substantial levels of unmet need in the Options APN System which have been documented and reported to, but not funded by, the state government.

Therefore our clients often come back to us seeking additional services, usually initially obtaining support from our Social Workers, OT’s and Nurses. We receive no funding at all for this and frequently end up case managing people who are also eligible for support and being managed by APN Options. Despite our regular meetings with APN Options staff to try and resolve some of these issues it would actually save time, effort and money if we were adequately funded to maintain continuity of care and be able to meet all our members needs without another agency being involved.

If our member’s needs cannot be met while they are living at home and they are placed in Aged Care then they generally no longer qualify for APN Options support. Again we try and step into the gap with the support of our Social Workers and a Support Worker. And again we receive no financial support for any services provided to our members in Aged Care or in Julia Farr (at this point there are 30 of them under 59).

We have no official access to the Unmet Needs List that has been kept by APN Options, and which they pass to the Minister for Disability Services, however we can put together information from various sources, including our own files (see Attachment A and B).

Waiting lists and records of unmet need tell us that our members are the majority of APN’s caseload, and have the largest level of unmet needs. Of the 586 members of the MS Society who are active clients of APN we have evidence from the APN Option Unmet Needs lists and our own data collected by our staff that at least 100 to 150 are in crisis at any point in time, and several hundred have substantial unmet needs.

As from July this year structural changes have been made to this model of service delivery and services now provided by APN Options, the Intellectual Disability Services Council, Julia Farr Services and the Independent Living Centre will be delivered by the same staff through “Disability Services SA”.

As of writing this submission we have no confidence that this new structure will be of any real advantage to our members. It appears that many will continue to struggle at home with inadequate support or be pushed into crisis and into Aged Care facilities. We have been informed by Departmental Officials while meeting with them to seek extra support for the MS Society and our clients that if any money is available (and at the moment it is not), that money will go to the APN Options or “Disability SA” system and not to us.

Northern Territory

We provide ongoing services for our members in the Northern Territory. We currently receive no recurrent funding for any of the services we provide to them. We have however been able to access some ‘once off’ Territory funding to provide an MS education seminar to health professionals by our allied health professionals last financial year.

We provide a paid staff person in the role of Therapy Services Coordinator who is based in Darwin for three days a week. We also co-ordinate volunteers who support our office in Darwin. The MS Society services provided include:

- Case management for People with Multiple Sclerosis (PwMS) and allied neurological conditions;
- MS education for PwMS and allied health professionals;
- Psychological support for PwMS, their families and carers;
- Advocacy;
- Referrals to appropriate community services.
- Immunotherapy support is also provided.

Our Therapy Services Coordinator will visit to Alice Springs once a year.

Currently there are 41 active clients that we provide support to in the Territory. Four have co-morbidities and 17 use a mobility aid of some type.

Specific Terms of Reference

a. an examination of the intent and effect of the three STDA's to date:

These agreements between the States and Territories and the Commonwealth have been set up with the clear intention of ensuring essential services are available for people in our community who have a disability.

We quote from the Annual Public Report 2003-04 on the current agreement "The Commonwealth State/Territory Disability Agreement (CSTDA) is the national framework under which the Australian State and Territory Governments work together to provide support and make a positive difference in the lives of people with disabilities their families and carers." [2]

While this intent is very positive the outcome for many people in SA living with Multiple Sclerosis is often a mix of frustration and distress. Our clients, in particular those with Progressive Multiple Sclerosis, frequently wait on long queues for the support they need, or receive a few of the hours they have been assessed as needing and accept that there is no real chance that more hours will become available.

The effect is that the long wait for in-home support can put a person's physical and mental health at risk. In some cases our clients are at risk from falls and increased fatigue as they struggle to shower or prepare meals without support. In other cases people are at risk of suffering poor nutrition and dehydration due to their inability to prepare quality meals on a regular basis. A lack of support can also lead to social isolation as PwMS are confined to their home, and in some cases to bed, for extended periods as they can not get the carer hours they need to assist with dressing and access to their wheelchair. Depression is very common.

An example is Client 11 (Attachment A page)

> "Client 11- has Multiple Sclerosis. She lives on her own and does not have family or other informal support nearby. She requires assistance with all personal care tasks including transfers, showering, dressing, using the toilet and grooming. Assistance is also needed with meal preparation, shopping, cleaning and attending appointments. She does not currently have funded support in the mornings and stays in bed until lunchtime when the support worker arrives. As her transfers are very difficult for her now and she is unable to access the toilet safely until lunchtime. She is at risk of ill health, dehydration and imminent institutionalisation without additional support."

The effect of inadequate levels of support, both in home and out of home respite, can be early institutionalisation.

An example is Client 2 from the APN Options Unmet Needs list (attachment A)

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> “Client 2 – lives alone and has advanced MS. She spends over 16 hours per day in bed, as she is unable to complete daily tasks without assistance. She also requires assistance with feeding. Client 2’s support worker does many more hours then what she is being paid for. Her worker is not covered by insurance when she is working outside her contract. The worker cannot continue to do this, and when she stops the client will need to apply for institutionalised care. It is urgent that the support worker be paid and additional 14 hours per week for the hours she is working, as she is stating that she cannot continue to work voluntarily.

Another effect of the current CSTDA in South Australia, and the APN Options process for distributing the funding, is the cumbersome process of assessing client need and securing services. The MS Society OT’s may assess a PwMS as being in need of services, but APN Options may not accept this assessment, only partly accept it, or can simply not find the funding to support it.

So, we must go back and lobby APN Options for our clients and hope that at least our clients are put on the waiting lists. Often by the time they reach the top their need has increased and more hours, or different equipment, is needed. Or, the family unit or support system the person has been relying on collapses under the strain and a whole new set of needs arise. We do not believe this was the intent of the current CSTDA’s.

b. the appropriateness or otherwise of current Commonwealth/state/ territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;

The current joint funding arrangements are not appropriate for people with a progressive illness. Our clients cannot get adequate support in a system where basically there is a set pool of funds, and very small pool considering the substantial needs, and people with chronic progressive illness must effectively line up to get access.

We also have great difficulty working effectively with, and advocating for our clients in the current system in South Australia. Our system basically insists that our clients who have a ‘significant’ level of need work with a sole provider (formerly the government’s APN Options and now ‘Disability SA’) and they have no choice as to who their Service Broker is or who their case manager is.

Below we detail eight specific service types and detail the unmet need in, and issues affecting, each.

In-home care

This includes support for basic household tasks such as cooking and cleaning, laundry and shopping. There is a constant need for extra support for our clients, particularly those who are diagnosed with Primary Progressive or Secondary Progressive Multiple Sclerosis. As I have outlined above, there can be significant negative consequences if this basic level of home help is not available.

Some clients who live alone can fund a small amount of cleaning themselves, particularly on a short term basis, but as most clients in need of APN Options support are on a DSP it may mean other items or services (such as taxi fares or food) cannot be afforded.

If family members who are also primary care givers providing personal care have extensive cleaning, cooking, shopping and child rearing responsibilities as well it can put unbearable pressure on relationships that are already stressed.

An example of these difficulties is this client from our current SA unmet needs list:

> **CLIENT M12**
> This client has formally complained through the Disability Advocacy and Complaints Service of South Australia about the lack of services from Options. He is in his 40’s and has just secured 3mths funding through Wesley Uniting Care for 2hrs per week. The funding is to help his wife who is currently caring for him, looking after two small children, managing the household and pruning in the vineyards (their business).

> They complain that their Options coordinator is frequently changing. Currently our client is only getting showered once a week because his wife just doesn’t have time to do it more regularly. They would prefer that the client’s wife assist with his showering and that they have some other sort of assistance to reduce the stress and time pressures on her.

Sometimes a very small amount of money can make the difference between a family being able to cope, and not staying together. An example of where just 2 hours of home support could make a substantial difference is:

> Client 24- is a 45 year old woman who has a progressive form of Multiple Sclerosis. Fatigue is also a major issue. Her husband is her major support. He works full time in a manual job and must provide assistance to client 24 and take care of all the household tasks. This client requires 2 hours per fortnight of household assistance so that her husband can continue in his caring role.

In other cases just a few hours of respite and/or a few hours help with domestic duties can make all the difference.

> Client 43- is a 62-year-old man with MS, COAD, stroke, Polio and Aestheme. He requires 24 hr supervision and 3 hrs per day assistance with personal care including; showering, dressing, grooming, feeding and transfers. He has an indwelling catheter and a history of pressure areas. This client lives with his wife and one of their teenage sons who works night shift. He is not receiving any assistance from APN; his wife is providing all the care. His wife also has MS and experiences extreme fatigue and weakness, therefore 3 hrs per week respite are needed to try and decrease stress related to the level of care provided. Also 3 hrs per week are needed to assist with household management.

Personal Care
This critical area is where the greatest number of our clients can be found with substantial needs. Ongoing high level of needs in this area is leading to family breakdown and/or institutionalisation.

Personal care may include support for getting out of bed, showering, dressing and/ or meal preparation - and possible assistance at mealtime. It can include some nursing duties such as changing a catheter or assisting with medication (including injections).

Three examples of this need are clients 44, 47 and 52 from the APN Options waiting list:

> Client 44- Is a sole parent of adolescent boys. Her MS has deteriorated significantly and she immediately requires assistance with personal care and meal preparation. In attempting to carry out these tasks she is experiencing falls and extremely high fatigue levels, which are putting her health and safety at risk. She requires assistance with showering, dressing/undressing, transfers and is having to rely increasingly on emergency services due to urinary and bowel accidents. Client 44

currently receives 13.5hrs per week for assistance with personal care and 7.5hrs for household tasks. She requires an additional 1.5 hrs per day with personal care in the evening, 2 hrs per week assistance with meal preparations and 2 hrs per week with household management. Client 44 has reported incidences of verbal abuse from her sons, which she attributes to their inability to come to terms with her condition and its deterioration. This client is at immediate risk of family breakdown and institutionalisation if the above supports are not put in place.

and

Client 47- has MS and lives with his wife who is primary carer. Following episodes of exacerbations of his condition, he has deteriorated and requires personal care assistance for toileting and showering. His spouse finds it increasingly difficult to deal with continuing demands of this level of support. Without the personal care assistance, there is an immediate high risk to the heath and safety of this client and his spouse, which may result in hospitalisation, and breakdown of the family unit.

and

Client 52- Has Multiple Sclerosis and cerebellar degeneration with poor balance. She is now living alone and has had several falls. This client requires personal care as her condition deteriorates. Husband who was the clients' main carer has left the marriage so now the client has no support.

Clients are frequently assessed by an ACAT team as being in need of hours, but all this entitles them to is a place on a waiting list. An example from our current SA list of unmet need is:

CLIENT M15 has formally complained through the Disability Advocacy and Complaints Service of South Australia about the lack of services from APN Options. This client is totally dependent on his wife. Nine months ago this client had an ACAT assessment done and he was approved for 20hrs per week, he has been allocated some time but is now only receiving 4 ½ hrs from Domiciliary Care to fund showers 3 times per week; and 4hrs per week respite for his wife who is the sole carer.
His wife prefers to take it in an 8hr block every fortnight as it allows her to do more (shopping etc.) The client used to have some physio that he no longer has, his wife believes that he would really benefit from this.

- **Unmet need:** The other 11.5 hours support he is approved for. More respite for his wife. Physiotherapy on a regular basis.

In-home respite

This involves a paid care worker residing at the home of our client for perhaps just one night, or perhaps more, so the usual carer (generally a family member) can have a short break.

An example of when this type of support may be needed is this client, who is currently on the list of those with unmet needs.

CLIENT M6 is a non-English speaking client in her mid forties. She lives at home with her husband and teenage child. The client's husband is her primary carer and receives support for care from their older children

> and also some paid carer hours. The client has developed significant mental health problems and is frequently hospitalized, and at one time became resident of a Nursing Home. The family experience enormous distress when the client enters hospital, and her health tends to deteriorate greatly in these circumstances so the family takes her home. This increases the stress on this family as the illness and mental health issues exacerbate one another. In-home respite is the only reasonable option for this client and her family, but this has so far not been available.

In home respite can be combined with household support and these tasks, such as cooking, cleaning and laundry can be done while caring for the client.

Equipment

Also long are the lists of those waiting for equipment, and for our clients there are problems with access to what equipment is going to be needed as opposed to what is the cheapest immediate alternative. This leads to the need for rapid replacement, and consequent waste of money. In those cases where MS is progressive (rather than remitting relapsing) people are most at risk of not being able to access services or equipment when they need them.

An example of the issues that arise when people are kept waiting month after month for the appropriate support is client M4 from our SA unmet needs list.

> **CLIENT M4** is a single man aged 42 years living alone in cluster style accommodation. This Client describes his living experience as being ‘solitary confinement’. The client reports carer attendance to his needs morning and evening and his mother helping with his meal in the middle of the day. Client says he spends his day watching TV as he cannot independently get around his home and cannot access his computer/music etc independently. This is due to the client no longer being able to manage a manual wheelchair. Client asks that he be allocated an electric wheelchair as this will allow him to move around his flat. He indicated he had been on the waiting list for this equipment for at least 18 months. The client says he does not see anyone else day after day and does not have the opportunity for any meaningful activity. He has little or no contact with the young people in the other flats that make up the complex of 7 units.

Rehabilitation support

This included access to physiotherapy, hydrotherapy and other therapy services. This area is not a focus of APN Options, particularly if clients are deemed ‘low need’. The MS Society must raise the money needed to support our physiotherapists, our gym and equipment, our hydrotherapy pool and those who assist clients there.

Hydrotherapy, used as a specific rehabilitation program, is highly appropriate for people with MS and allied neurological conditions. The properties of water such as buoyancy and turbulence combined with the warmth of the water provide an ideal medium. Certain therapeutic exercises or activities that an individual may not be able to do on land may be achievable in the water with reduced assistance. Benefits such as improved joint movement, muscle flexibility, fitness, strength, mobility and reduced fatigue can be achieved.

Research has shown that exercise and maintaining good fitness levels helps improve quality of life, reduces fatigue, helps lift depression and prevents secondary conditions (such as deconditioning, musculo-skeletal and respiratory problems) in people with MS. Early intervention, ongoing rehabilitation and structured support for families from the time a member is diagnosed with MS are imperative if we wish to reduce the impact on individuals – and the community.

The temperature of our pool is cooler than other pools as heat sensitivity and subsequent fatigue is commonly associated with MS. Other indoor hydrotherapy pools are usually too hot for optimum outcomes and many clients cannot use them. The group situation in the pool fosters a supportive community environment and participants have the opportunity for peer social support. Despite the cost of maintaining the pool the MS Society believes that it is an essential part of our therapy services.

We also raise the money needed to purchase equipment such as Theravital Exercise machines. These machines have an inbuilt motor which provides active and/or passive training while sitting in a chair – or wheelchair. They increase circulation, joint movement and flexibility and can help reduce spasms and spasticity and swelling of upper and lower limbs.

Client after client on both unmet needs lists would benefit greatly from rehabilitation services. Therapy services that help people to maintain a good level of fitness and reduce the impact of MS are vital, and will reduce the need for other services. However the current funding models and priorities under the CSTDA do not support this.

Lifestyle and Community Access support programs

Our clients are frequently faced with managing high levels of fatigue and, as we have detailed above, often have high levels of unmet need.

We also find that many of our clients with ‘substantial’ need also have limited financial capacity to undertake recreational and leisure activities. For many transport (cost and availability) is an issue, as is the availability of the carer support hours that would enable a person to be an active participant in their community.

There seems to be very little funding in the CSTDA’s to address these issues for young adults in SA who are living with a progressive degenerative neurological condition.

Counselling, Mental Health and Financial Planning services

These are a range of services that our clients frequently need.

Recent studies indicate that clinical depression, the most significant form of depression, is more frequent among people with MS than it is in the general population and even more common than among persons with other chronic, disabling conditions. Depression can occur at any point in the progression of MS and one study found that the risk of suicide was 7.5 times higher among persons with MS than the general population.

Despite this prevalence, funding for support services is minimal – and we get no crisis counselling funding at all for our Social Workers and Counselling team.

MS is usually diagnosed when a person is in their mid 20's to mid 30's. At this time a person is usually establishing their career, paying off a mortgage and/or starting a family. To have a progressive degenerative neurological illness diagnosed at this time can place great financial pressures on a family. Again, there is not adequate funding to provide the level of assistance that is necessary for families. Two examples of the complexity of counselling services our clients can require are:

> **CLIENT M16** This client is in his early 30's. He has two young children and was successfully running his own well established business. His partner has recently left their home with their children. He is no longer able to work in his business and has a mortgage which he is paying by the progressive sale of business assets - this is not sustainable. This client believes he will be in a Nursing Home within 5 years and is greatly troubled by the circumstances his children are now living in. This client is wheelchair dependent and requires additional personal care hours now his wife has left. He also urgently needs several hours each week for domestic support. He has received a once off spring clean for parts of his home through APN Options but several rooms received no cleaning and remain greatly cluttered and not usable.
>
> - **Unmet need**: Financial and Personal counselling, care support, support for domestic duties, physiotherapy, occupational therapy, social and recreational activities, legal support

The second example of complex need that requires a range of negotiations across several service providers is :

> **CLIENT M18**
>
> This client is aged in his early 20's and has was diagnosed fairly recently. He lost his job (due to MS symptoms) and for many weeks was entirely without an income. This led to significant debts building up and he was threatened with eviction from SAHT accommodation. The MS Society has assisted with the reconnection of essential services to his home, and also the negotiations regarding rent owed that have ensured he will not be evicted. He had no prior history of not being able to manage his finances.
>
> It is no longer possible for him to work in the area in which he is skilled and he currently has limited employment potential because of non-related health and personal issues and the more difficult symptoms of MS. He now has income support through Centrelink. He is separated from the mother of his daughter and has no contact with the child at present. In addition his partner is unwell and undergoing tests which mean she also cannot work (she had casual/part time employment).

- **Unmet need -** Counselling, financial and employment support, advocacy and networking plus support re contact with his daughter. Again this is a case management task requiring interagency collaboration on behalf of the client. The client is not yet registered with Disability SA and would not receive the services he needs from Disability SA as he is usually mobile.

Away from home respite
Our greatest issue with this type of service for our MS clients is finding appropriate services.

Usually the current options are a Nursing Home or Aged Care Hostel bed, and even these are often not available until a person or their family is in a crisis. Our young adults are generally very reluctant to take either of these options; often don't enjoy the experience if they do go; and Nursing Homes have complained that our clients require a different type of care to what they are accustomed to providing, and/or are too high need for them, and/or can distress their staff.

Generally Aged Care accommodation should NOT be used for respite for people with MS or other chronic illnesses who are under 65 – but this is no reflection on the quality of the Aged Care provided.

There is a new Respite Centre at Strathalbyn – which is proving to be an excellent option for people living with MS. BUT it has only 4 regular beds and is difficult for our clients to access, partly due to the referral process which must be through APN Options. And, it does not cater for long term planned respite.

We are currently conducting a survey of our clients and their carers to determine the need for this type of respite. To date an early summary of needs from the 160 carers who have responded indicates that approximately 80% are seeking this support now or believe they will need to in the future.

Long term Accommodation for young adults.
Appropriate long term accommodation for young adults with a deteriorating neurological condition is very scarce in South Australia. Currently we have some 30 young adults who are living in Aged Care or an institution as of June 2006.

Two examples of clients who are in need of appropriate accommodation are:

CLIENT M2
Client is woman aged 47 years. The client is married and lives with her husband and two teenage children. Both children are experiencing mental health and developmental problems and their father is diagnosed with clinical depression due to the stress of caring for our client. The client is registered with APN Options and has been assigned a case manager. However this family were not receiving any practical support or resources from APN with the exception of one short period of respite care. After much advocacy from the MS Society the best that APN

Options would offer was 1.5 hours two times per week for someone to visit.
The MS Society has negotiated some local government support and this family currently receives 3 hours care per week via the local Government at a cost of $8 per week to the family.
This client has significant cognitive loss and the family cannot continue to care for this client any longer.

- **Request:** The client and her family seek permanent placement in a supported facility with people of her own age.

and also

CLIENT M5 This Client is a woman in her mid 40's with two young adult daughters. This Client is resident in high-level care nursing home (though she uses a walker not a wheelchair for most mobility needs).
The health of the client is greatly improved since she moved to the nursing home. During an interview this client indicated she could not get the care hours she needed at home.
This client is deeply unhappy in the Nursing Home and her quality of life is greatly compromised, she misses her dog. She reports that in the NH friends she has made have died so now she likes to be by herself. The client seeks the opportunity to be with people of her own age.

- **Unmet need:** The client seeks urgent relocation to supported accommodation with people of her own age – a place that will take her dog too!

As we have outlined earlier, the availability of services is frequently inadequate for our clients, and levels of unmet need for in home support services as well as in-home or away-from-home respite services are extensive. The wait for appropriate long term accommodation is longer again.

We are hopeful that the we can tap into the COAG funding that is designed to offer alternatives for those already living in aged care, keep people from being placed in accommodation that is designed for older Australians, and improve the quality of life for those who wish to/have to stay. We have a number of proposals that we will submit through another inquiry.

c. an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency;

One of our key recommendations is that the Aged Care/Disability Interface be more clearly delineated by separating out two key areas; the assessment process (currently done by ACAT's) and service delivery through HACC (see next section for details).

d. an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

Alternative Model:
We believe a new model is urgently needed and that this should include:

1. A separate assessment body.
Rather an Aged Care Assessment Team (ACAT) that does both Aged Care and Disability split the body (and the funding) so there is a second body that specialises in assessment of people under 65 years of age who are living with a disability or progressive illness that results in disability.

This second body could be called a Disability Services Assessment Team (DSAT) and would need among its members at least one person skilled in assessment of chronic progressive neurological illness.

To reduce inefficiencies there would need to be, as part of the CSTDA agreements, either the right for an individual to choose service providers OR the opportunity for service providers to tender for funding so they can provide services (as the Employment Services are now organised by the Federal Government).

2. Separate Home Support Packages
Rather than a HACC package, a package of services designed to support and improve the quality of life of young people would be designed. The range of services potentially provided would include different options from HACC – in particular more (and different) lifestyle support plans and more community access options.

These packages could be called PSP's (Personal Support Packages) and once a person reached the age of 65 they could be moved directly (and hopefully seamlessly) on to a HACC package.

3. Right to access services once assessed.
Once a person is assessed as needing a package/specific service to support them, they then chose a service provider and receive a service.

Currently in SA people are assessed as needing a service, such as someone to help them shower and dress each morning, but they have no right to this. The assessed person must join a queue and wait, for months sometimes, before they eventually get this service or get the level of service they were assessed as needing. By then, many of our clients with Progressive Multiple Sclerosis need a higher level of support, so go off one waiting list and onto another – without ever getting an adequate service.

4. Respite services must be readily accessible

The provision of timely and appropriate respite, within the home or at a separate facility, is the key to keeping many families together. It can also make a very significant positive impact on the physical and mental wellbeing of both our clients and their principle caregiver.

It can delay placement in long term accommodation – and may prevent it altogether.

5. More involvement of non-government agencies.

Productivity Commission studies have shown that not-for-profit services can be delivered more efficiently than government provided services.

We believe we can offer not only a more efficient use of existing resources and services, but that, if able to continue to manage our clients, this service will be more appropriate and would be far more consistent than what they receive now. Our staff are professionals specifically trained and experienced in supporting people with a deteriorating neurological condition.

Conclusion:

Currently the Commonwealth State Territory Disability Agreements have not achieved their stated purpose for most people living with a disability, and in particular for people in South Australia who are living with Multiple Sclerosis.

The money **can** be found. The States have higher than expected revenue from the GST, some $1.9 billion extra this financial year. And, it seems that the Commonwealth has an underlying surplus of over $10 billion.

The key is not only more money but in many cases it is also a change in the system of service delivery and a change in the oversight and monitoring (accreditation) of services. Early support, rehabilitation, services based on need and not on time on a waiting list are but a few of the issues that must be prioritised in future CSTDA's.

We believe that agreements can be reached, must be reached, through future CSTDA's that will make a real and positive difference in the lives of those Australians who live with a chronic, progressive illness.