The MS Society of Victoria

Australian Home Care Services

Seeking the Cure.
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SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO AGED CARE

Submission on term of reference 3 of the Inquiry

The appropriateness of young people with disabilities being accommodated in residential aged care facilities

This submission is a joint submission of the MS Society of Victoria and Australian Home Care Services.

Multiple Sclerosis Society of Victoria

The MS Society of Victoria is the peak service provider for people living with MS in Victoria. The MS Society work to reduce the impact of MS in the community through service delivery, awareness programs, collaboration and per support.

The MS Society provides a range of specialist services to people living with MS and their families including:

- Allied health services
- shared supported accommodation
- case management
- education and information, employment support
- respite care
- peer support
- comprehensive lifestyle planning
- promotion and participation in research
- service development
- advocacy

Australian Home Care Services

Australian Home Care is a wholly owned not for profit subsidiary of the MS Society of Victoria.

Australian Home Care Services is a leading provider of quality in home services to people with a disability and the aged, operating in a number of States. Australian Home Care Services has been working with people with a disability and the frail aged for nearly twenty years.

AHCS has developed expertise in residential service development and individual service planning that is the mechanism to move people out of nursing homes and other institutional settings.

Introduction

This submission focuses on the Inquiry's term of reference concerning the appropriateness of younger people with disabilities living in aged care facilities.

The work undertaken by the Multiple Sclerosis Society of Victoria (MSV) and Australian Home Care Services (AHCS) in the development of community based accommodation options for young people living in residential aged care is briefly described. It illustrates the need for collaborative action for in on the Young people in nursing homes issue (YPINH) in the domains of policy, legislation and service development.

Some short form case studies are included to outline how some young people have moved out of nursing homes and made remarkable gains in their quality of life as a result, and the pathway into nursing homes for others.

The gains made by those young people who have moved are the result of significant degrees of planning and collaborative work by both organisations, by families, case managers and others, including some nursing home staff.

To expand and entrench the move of young people in nursing homes, some changes are required to the Commonwealth State/Territory Disability Agreement (CSTDA) and its connection with the Aged Care sector.

The Commonwealth Innovative Pool is a program of the Department of Health and Ageing that is, in a limited way crossing the jurisdictions. This is a model that is worthy of review and expansion in the context of a dedicated national YPINH project.

The addition of nursing services to the CSTDA is an imperative to allow younger people with disabilities with complex needs to be appropriately serviced under the Disability Services legislation, and not forced to live in aged care simply to access a nursing service.

New Service Development

The MS Society and AHCS have developed services that have enabled 10 people to move out from residential aged care into shared community settings in the past 3 years. The settings are all shared services and have involved the designing of new services for both people with MS and acquired brain injury.

This work has been undertaken in 3 main contexts:

- In response to housing projects funded by the Victorian Department of Human Services (DHS)
- Service development for individuals
- A Department of Health and Ageing Innovative Pool Project

The particular services that have been developed in Melbourne include:

- A share house for 3 women with MS coming from nursing homes as part of the MS Society's Innovative Pool program (in development)
- A multi unit site with active 24 hour support for people with acquired brain injury and MS in Beaumaris, called St Martin's Court (4 people moving from nursing homes)
- A 6 person triplex site for people with acquired Brain Injury (3 people coming from nursing homes) in Glenroy

In addition to these services, AHCS operates a 10 bed facility for young people with acquired brain injury in Frankston (Wattletree House). All these young people are compensable through the Transport Accident Commission scheme, so have their complex needs met comprehensively through insurance funding.

A number of them had been living in nursing homes on the Mornington Peninsula before the creation of this service, and moved to the service when it became available.

All these individuals would have ended up permanently in nursing homes if not for their compensable status. The entitlement based individualised funding available through the TAC makes it much more possible to create tailored services than in the Government sector, however the individual planning and service development principles used to create the service applies across the board.

The MS Society operates 2 disability accommodation services, providing beds for 28 individuals with MS with complex care needs. They are funded by the Department of Human Services, and are part of a Commonwealth Innovative Pool Pilots, from the Department of Health and Ageing.

Australian Home Care Services has developed an expertise, shared with the MS Society in individualised planning and care design for people with complex needs moving from aged care into community settings. This methodology has been presented at a number of national conferences, and has been independently evaluated.

This work has created a methodology that is instructive for more work to move young people out of nursing homes. It centres on the fact that, as long as both their needs and life choices are included in service planning, young people can move into a less restrictive service model and funding can be made available for new service development.

Cyril Jewell House

In addition to these recent developments, MS Victoria was also closely involved in developing the younger person's annexe at Cyril Jewell House, a nursing home developed in Keilor in 1996. This service is the only one of its kind in Australia, in that it is a dedicated MS service for people under 65, that has core aged care funding from the Department of Health and Ageing, and top up disability funding from the Department of Human Services.

This combined funding model works well in providing additional care resources and a community access service that assist residents to get out in the community. It is a model that shows that a cross jurisdictional funding arrangement can work without threatening the integrity of the each sector and actually work in the interests of the young residents.

It is a promising development, and is the only effective way forward to resolve the issue, since the YPINH group have dual eligibility for both disability and aged care, so both jurisdictions must work to design the solution.

Joint funding of care

The Cyril Jewell model has received little attention in both sectors since its establishment, and not until the inception of the Commonwealth Innovative Pool, disability focus, has joint funding in this area been on the table.

This model has definite merit where there is a need for people with high support needs to continue to receive care in an aged care facility, and would not get their needs met without the addition of the State services.

It is even possible to take the simple funding model and apply it to individual young people in aged care. This would result in the much needed availability of disability services being available to people with disabilities who are unfortunately living in nursing homes.

Indeed the need for this reform was noted by Professor Hogan in the recent Aged Care Pricing Review:

The Review notes that one of the priority areas for action in the third disability agreement is the intersection between the ageing and disability support systems, particularly for people with a disability who have age care–related needs, and younger people with a disability living in, or at risk of living in, residential aged care.

The Review considers that no disabled person should be disadvantaged as a result of his or her residential status in an aged care facility…[1]

This conclusion reinforces the need to integrate the jurisdictions of aged care and disability to be able to fund services to eligible people on the basis of need, not location. In those cases where an aged care facility is a person's only option (most often in regional areas), the availability of the full range of disability services would make a big difference to their quality of life.

Service models and service design

A common question in discussions around young people in nursing homes is 'What kind of services do they want?'

The general answer to this question includes all types of community support models available in disability services, from individual care at home, to group homes, cluster units and congregate settings. Though there is a finite range of service models available in disability services, young people in nursing homes will be able to be supported by services in this range.

The specific answers can only be provided in the context of individuals living in aged care (and those at risk of entering), funding program design, available services and service development initiatives. The other essential ingredient is effective advocacy.

In most cases, young people living in residential aged care do not have the luxury to choose where they want to live. The people that MSV and AHCS have moved have exercised their choice to move but, because of the extremely limited range of options available, have had less choice over the location to which they have moved.

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[1] **Investing in Australia's Aged Care**

Review of Pricing Arrangements in Residential Aged Care, S 13.2.3, Department of Health and Ageing 2004

We have ensured, however, that the support services developed are tailored to meet the individual needs of each person, including their family circumstances, physical care needs and future goals.

Clearly, one size does not fit all, and a successful transition out of a nursing home requires a strong and inclusive planning function.

The transition process out of aged care

Re-establishing a person in the community is a complex task, especially when people have been institutionalised. It is even harder when individuals have lived in an institutionalised setting for long periods of time.

How a person responds and the capacities they demonstrate beyond the confines of a more familiar institutionalised setting, can be very different without that feeling of familiarity. It is not always possible to know what an individual's true capacity can be.

To be effective, the transition process must actively redress the lack of focus on emotional and social factors intrinsic to the nursing home model. Because of the particular transition program used, all the people we have assisted to move into the community have made significant gains in their physical, emotional and social abilities.

Individualised planning

Individual care plans are developed with each resident using a Person Centred Planning approach (PCP). Moving the focus away from systems and pre-determined program, this approach concentrates planning around an individual and his or her needs. By positively identifying each person's needs, wants, aspirations and abilities, PCP also identifies the support needed and designs a personal arrangement for providing that support.

Implementing a PCP approach for each of the residents was the key to developing a better understanding of each resident's

- Life before acquiring a disability
- Journey since the onset of disability including family supports and social networks
- Future life goals including, expectations, needs, wants, dreams, aspirations and social interaction

For each individual and their support team - including their family members PCP creates the opportunity to express and identify concerns, anxieties and hope for their loved one or client. This information then forms the framework for each individual's transition, orientation and support plan, including a pictorial representation of the individual social plan. These individual profiles provide a measurement tool and benchmark from which regular reviews can be conducted for both the resident and service.

This information also contributes to the overall framework of the service and staffing model.

Potential residents are already participating in their personal planning and have expressed some wants of the service and expectations which will help to further shape the service to support a lifestyle they have participated in creating rather than a lifestyle in which is imposed. These wants and expectations can include:

- socialisation opportunities inside and outside the residence
- flexible use of a 'bank' of support hours to be used at the resident's discretion
- a desire to purchase cooked meals or the services of a trained cook in preference to having to cook themselves

This opportunity to buy services using core hours further empowers resident independence and invites greater participation in planning routines suitable to their individual needs and wants.

In planning for transition it is essential that we know about the person, their history and their thoughts for the future. Our transition plan includes attention to the following:

- **Needs, wants, dreams and aspirations of the individual**
- **Their life before acquiring a disability**
- **Their journey since the onset of disability**
- **Expectations for activities of daily living, security and choice**
- **Cognitive challenges for the individual and their carers**
- **Cultural requirements and expectations**
- **Family concerns, anxieties & hopes**
- **The need for specialist health services**
- **Strategies to assist integration in the community**
- **Strategies for personal growth**
- **allied health assessments to ascertain**

- **Skills in respect to services, safety and recreation**
- **skills in all activities of living**
- **client interests**
- **To build client confidence in respect to the change of environment and their supports**
- **To understand each client's current routine and how this may translate to the new environment.**
- **To orientate clients to the new suburb, community and home**

Leadership

Through the experience of developing these new services, it has become clear that leadership is a key part of the process. The services that we have developed have had funding support from Government (from of the Victorian Department of Human Services, and the Department of Health and Ageing) and compensation funding. In each case the technical aspects of service design, individual planning and operationalising concepts belong with the service provider (and in the case of St Martin's Court, involved collaboration with the non profit property developer).

In every case, the various funding program guidelines did not on their own provided the momentum to make these services work, but merely the opportunity. On some occasions during the implementation of these services, the strict adherence to these guidelines created additional barriers, as moving young people from aged care required more attention to transition than regular disability services, and existing processes did not account for this.

The real leadership has come from the service developers/providers and the individuals wanting to move. What has been instructive here is that any serious initiative to relocate young people from aged care will rely on a partnership between Governments, service providers and developers and individuals/families.

Governments will always have policy tensions in areas of joint responsibilities.

These policy dilemmas are best able to be resolved in addressing particular issues around individuals and projects as they arise, rather than through endless intellectual debate on joint working parties. We are faced with significant incompatibility between aged care and disability jurisdictions, and as the Innovative Pool program has demonstrated, nothing will happen until real individuals in a real project present themselves for funding.

The jurisdictions need to be open to promoting jointly funded projects as a way of aligning their guidelines, rather than waiting for the policy work to be complete before beginning work. The latter is the natural inclination of policy makers, but given the increasing number of young people in nursing homes, we do not have the luxury of time to wait for a pure policy outcome.

The protracted negotiations around the Carnegie house in MSV's Innovative pool project (over 18 months) delivered some significant understandings about managing Aged care and disability jurisdictions. Now that it has become a reality, future projects surely will have a smoother path.

Leadership is required at every level. Governments support the aspirations of people with a disability, and have endorsed community living and choice as core principles of disability services, however in the case of young people in nursing homes, practical delivery of this rhetoric through the CSTDA has been miserable.

Policy makers need the mandate from Governments to create programs that will deliver real outcomes, and in turn the service developers/providers need to be innovative and not be put off by the policy challenges.

Case Studies: A snapshot of the improvements to the lives of those that have moved

Susie

Susie is a 32 year old who had a cardiac arrest while swimming 5 years ago. She suffered a hypoxic brain injury resulting in global impairment, including cognition & behaviour challenges, decreased motor skills and mobility. Prior to her injury, she had a professional career, had several interests and strong family ties. She lived in a nursing home for 3 years. She lacked consistency of care & opportunity for independence. It was a noisy and confusing sensory environment that provoked negative responses and depression in Susie.

Through her involvement in the Slow to Recover rehabilitation program, a program of the Victorian Government, she as identified for a place in a shared accommodation setting in 2002, and her transition began.

Susie wanted

- To live in a home of her own that was quiet and predictable
- More control over small things
- to have increased contact with her family
- to be more independent and involved in doing things around the house
- To be given opportunities for trying new things

The transition:

- established a personal hygiene routine, including practices in the nursing home
- provided regular faces in Susie's life, build rapport with carers and co residents
- established a regular eating program to teach her to feed herself
- established a walking program to get her on her feet
- establish a routine, offering consistency, opportunities for participation and choice
- supported her in familiarising herself in a new environment with new people
- recruited and trained of carers to support Susie's choices and to minimise unnecessary triggers for anxiety related behaviour

The Outcome so far

Susie has been in her new home for 18 months, and she has made great gains. Many of the barriers she faced in the nursing home have now been shown to have been situational. No one there had the time to teach her to eat, so she needed to be fed.

There was little opportunity for self direction and independence, and external noise made her depressed and exhibit behaviour that put staff and other residents at risk. In particular her fear of water created havoc in the nursing home. Susie now:

- contributes to personal hygiene routine- can almost shower herself
- is now eating independently
- exercises choices about food, activity, visitors, staff movement
- initiates requests for things
- experiences less frustration, aggressive behaviour from being over stimulated
- Participates in all activities of daily living

Susie is now is back swimming and is going out more and is involved with a number of community activities.

Steve

Steve is a man who lived with a mild intellectual disability, and was severely physically assaulted on a railway platform, and sustained a brain injury. He had lived a sheltered lifestyle, with limited schooling, community access, recreation and work experience. He lived in a nursing home for 6 years after his assault. He now lives with some physical constraints and speech difficulties There he had little opportunity to develop personal or domestic skills. He managed to get a small community access program that served to get him out and develop friendships through his carer. He came to the notice of the DHS through the advocacy of his aunt.

Steve wanted

- freedom from the elderly, sick and dying
- to make and have friends
- to go out lots, more freedom and opportunity
- to have a reason to make a choice
- to be more independent
- to have fun
- to have money to spend

The Transition

- To introduce Steve to new activities and people
- Involve his family in his care planning
- Design and implement a program to make him independent with managing money
- Support him in learning to incorporate all the daily living tasks like shopping, cooking, working with carers, planning activities
- Involving him in staff selection of carers

Outcomes so far

Steve has managed to establish himself in his new shared unit, and has developed a range of skills and interests he was not able to pursue in the nursing home. Steve is now

- managing own personal spending
- planning social and daily tasks
- independent in personal hygiene and grooming
- independent in some domestic tasks
- working two half days a week
- part of a widened social network
- initiating conversation
- beginning to self advocate with support, making own choices and decisions
- is becoming more comfortable with his own company

Summary

Our work in this area has proven that better lives are possible for people, and that the effort is worthwhile on many individual, organisational and systemic levels.

The activity to create these services has required leadership. In come cases, the efforts made have operated in a policy vacuum and much effort was expended in 'bending' the system around the individuals and their needs.

The tools utilised, the requisite experience and the support models needed to successfully achieve these outcomes, all exist in the disability system. What is lacking is a policy and funding framework to pursue this process in a more systematic and coordinated way.

This work is continuing with the implementation of the St Martins Court project (see appendix 1) and the Commonwealth Innovative Pool service in Carnegie (see appendix 2).

Policy and Funding Conundrums

The Commonwealth Innovative Pool

The Innovative Pool is a Commonwealth Department of Health and Ageing (DHA) program that offers two years of transitional funding to enable providers in Commonwealth State/Territory Disability Agreement (CSTDA) jurisdictions to move young people out of aged care. Service Providers need to have the endorsement and funding support of their State jurisdictions for projects to be eligible for Commonwealth funding.

This is a worthy initiative in approaching the Disability/Aged Care interface with a dedicated funding program, and the Department of Health and Ageing are to be lauded for recognising this as a critical issue. Clearly this is a beginning to Commonwealth taking responsibility for younger people with disabilities, and as the first wave of Pilots are evaluated, further work will need to be much wider, and embedded in the CSTDA.

As a defensive strategy for DHA, the Innovative Pool seeks to reduce the admission of younger people and to facilitate the moving of current young residents. It creates a joint funding relationship between the DHA and State Community Services departments around innovative proposals from service providers. Proposals must meet both the provisions of the Aged Care Act 1997, and the imperatives of local disability policy under the various States' Disability Services Acts.

The pool projects are being evaluated by the Australian Institute of Health and Welfare. The evaluation model is rigorous and detailed, and will deliver some good data for future policy analysis, although decisions about cross jurisdictional work can not be allowed to be delayed by the existence of this evaluation.

The Innovative Pool program first included the Aged Care/Disability interface in their priority areas in 2002/03. The initial priorities were:

- People with disabilities in disability funded accommodation services at risk of permanent aged care placement
- Young people living in aged care facilities who could move out of aged care.

While most States supported proposals in the first round, most approved projects were in the first category, that essentially meant the DHA topping up disability accommodation services to delay or prevent premature entry of residents into aged care facilities.

Since disability was included in the Pool priorities in 2002, the DHA has provided 225 flexible care places in 9 projects nationally to people with disabilities currently in disability accommodation.

At the time of writing, only three places have been approved in the second category: to get young people out of aged care facilities. In the current year's guidelines, this is the only eligible category.

In the 2003/04 funding round, the MS Society was successful in gaining approval for two Innovative Pool projects from the Department of Health and Ageing (DHA). The projects are aimed at reducing the number of people with MS going into nursing homes, and establishing a jointly funded project to rehouse some young people currently living in nursing homes.

The 'Changing Needs' project for young people with MS was first submitted in October 2002, was finally approved in late May 2004, and has only recently commenced.

In agreeing to fund this project to move these three individuals out of residential aged care, Victoria is the only State to take part in this part of the Pool, provide new money to support such a project. This project has received significant media coverage. (an example in appendix 4)

Is the Innovative Pool effective?

The Innovative Pool has provided new funding outside the CSTDA to target young people with disabilities either in aged care facilities or at risk of entering the aged care system. It is a most welcome imitative because it offers a targeted joint funding opportunity outside the strictures of the CSTDA.

The Innovative Pool is a good concept and demonstrates that the Commonwealth has recognised its role in resolving the YPINH issue. For many years the Commonwealth has insisted that it is solely the problem of the States. The fact that the Pool prioritises the Aged Care/Disability interface and makes funding available to people with disabilities is significant and, in the case of Victoria, was certainly an incentive to create the Carnegie service.

The Innovative Pool has been a program that has carried much expectation from the Australian Government with regard to their commitment to solving the YPINH problem.

Senator Vanstone highlighted the Innovative Pool and the inclusion of it in CSTDA agreements in answer to a Question on Notice from Senator Allison in March 2003:

> *FACS has undertaken to continue to encourage States and Territories to address the needs of young people in nursing homes via their bilateral agreements, including participating in the innovative pool.*[2]

[2] Senator Amanda Vanstone, Answer to Senate Question 1357

In year following Senator Allison's question, the Innovative Pool delivered 3 places to young people to move out of aged care. In the same period (March 2003 - March 2004), there was a net increase of 196 people under 65 going into residential aged care.

The Innovative Pool provides welcome access to Commonwealth dollars to fund services to people with disabilities However with only 3 out of 225 participating young people actually coming out of nursing homes, it is not yet achieving what is possible.

This is disappointing, since there is significant goodwill from the Department of Health and Ageing and its Minister towards this program. The Pool is but a component of the wider YPINH solution, not the entire solution, although at present it is out there on its own attempting to bridge a huge jurisdictional gap.

In our case, the need to comply with both the precsriptiveness of the Aged Care Act 1997 and the policy and funding imperatives of State disability services made designing and getting approval for projects difficult. The MSV project took over 18 months to negotiate. Both the DHA and DHS were supportive of the project, but each was constrained in their own ability to be flexible enough to make it work.

The Innovative Pool forces the DHS to bend its processes and policy to fit the Aged Care Act 1997, something that the DHS initially had great difficulty in reconciling. The Aged Care Act is not flexible, and attempts by the DHS to influence the workings of the Act with its own policy imperatives did not (and will never) succeed.

It appears that the incentives for States to participate in the Pool are not adequate, although we understand that some of the bilateral agreements in the CSTDA may be addressing this.

Another comment by Senator Vanstone perhaps describes this incentive problem in the context of competing interests within the CSTDA:

> *That has 550 new flexible aged care places to pilot alternative strategies for particular target groups. Not one state has put in an application to use the innovative funding pool to find a better way to house younger people who should not be in nursing homes—not one state. So the first place to go, Senator, is to each of the states to say, 'Hey, there's Commonwealth money for innovation: why haven't you done something about it?*[3]

[3] Senate Hansard Wednesday 20 August 2003 p 14128

Without resolving the overall tensions in Commonwealth/State relations in aged care and disability, the Pool cannot be as effective as it is expected.

Some States reportedly refused to take part out in the Pool due to the rigidity of the guidelines, and the lack of incentive. But with some states expressing an unwillingness to participate, providers in those states saw no future in putting resources into service development given the projects would not be supported.

This closed off any opportunity for young people to benefit from the program.

In the current environment of increasing demand and growing numbers of young people going into nursing homes, the Innovative Pool cannot be the only program initiative at the Commonwealth level focused on moving young people in residential aged care into community based living arrangements.

While we would support its continuation, and look forward to participating in the program and the evaluation, we would recommend a separate and larger targeted initiative linked to the CSTDA, with a more ambitious scope.

The services we are offering in our projects, particularly the Carnegie House, will demonstrate the simplicity and value of the joint funding arrangements, and the positive difference this will make in the lives of the 16 individuals.

Entry into Aged Care

One of the critical elements of the YPINH problem is the pattern of people with acquired disability entering residential aged care. Until recently the community understanding was that people with disabilities could enter residential aged care on 'compassionate grounds', where no other option was available.

Current Department of Health and Ageing guidelines have strengthened this language to give young people with disabilities an 'entitlement' to enter aged care facilities.

Younger people with disabilities are entitled to enter aged care facilities. This entitlement should however only be exercised if, and only if, they need the intensity, type and model of care provided in such facilities and no other more appropriate service is available[4]

[4] Assessment and Entry to Nursing Homes and Hostels of Young People with Disabilities: Aged and Community Care Division, Commonwealth Department of Health and Ageing. http://www.ageing.health.gov.au/standard/stmts/ypwd.htm

The same young person has no such entitlement to more appropriately targeted disability services. The MS Society is aware that the rigour required by this guideline is rarely used, and that many younger people with MS and other neurological conditions enter aged care not because of the intensity of their condition, but the lack of availability of more appropriate home support or disability accommodation.

The difficulty in matching the needs of younger people to the *intensity, type and model of care provided in such facilities,* means that there is inevitably either under servicing or over servicing of a persons care needs, that generally results in a misdirection of care.

Over-servicing young people

While there are people with a range of disabilities with very high needs in aged care facilities, there are many instances of people with MS and other neurological conditions being over serviced by being in residential aged care. This is particularly evident upon admission to nursing homes.

For these people, the danger is that they will lose independent living skills and physical and cognitive function because the nursing home environment does not encourage independence. This can then increase the process of decline. In many cases depression also exacerbates symptoms of disability.

Under-servicing young people

In addition, there are numerous individuals who are grossly under serviced in nursing homes. Young people are often referred into aged care because they have high needs that cannot be met by the disability services system, but can be met in aged care.

Given that they receive approximately half the per-head funding in aged care than they would receive if they were fully funded in disability services, this is a particularly perverse practice. It also means that the basic safety net of nursing supervision is available to the individual, but there is no guarantee of a comprehensive service.

Due to the CSTDA/Aged care divide, essential CSTDA services such as equipment, therapy, social engagement and case management needed to assist in finding alternative services, are unavailable to people in aged care, so their needs go unmet.

Inappropriate entry into aged care

The example below showing the interaction of a number of Aged Care provisions that contribute to the distress to younger people going into aged care. Brian's case is unfortunately, relatively common. The fact that the State Disability Services will not provide equipment, therapy or community access because he is in a nursing home has also contributed to his isolation:

Brian

Brian is a 42-year-old man with MS who was living with his wife and 14 year old son and attending a HACC funded disability social day program. He is an articulate man who was always philosophical about his situation. He was forced to go into a nursing home when his MS had progressed beyond the limits of his State funded attendant care package.

He had to be admitted to his local nursing home to receive the care he needed. Centrelink was obliged to assess the assets and family income that was supporting his wife and son at home. Hi daily fee was set over $60 per day, a sum that was totally unaffordable for the family, as the family living costs were still at home, and did not reduce substantially when Brian moved out.

Following Centrelink and other advice, he formally separated from his wife so he could then receive the full Disability support pension to reduce his fees. This forced separation was a double blow, when combined with the nursing home admission itself. Brian became severely depressed.

On top of this he was unable to continue in the HACC day program, as the HACC guidelines see this as 'double dipping' and do not permit nursing home residents to attend their programs.

In a period of 3 months Bruce lost his home, his marriage and his social contact because no better option, or combination of options, could be found.

Three jurisdictions conspired against Brian to take away his place in the community. This is the 'entitlement' given to him by the Aged Care Act 1997.

He is still hopeful of finding something better sometime soon.

The MS Society has attempted to secure services and flexible funding for Brian, but so far without success.

Disability or Aged Care? The need Nursing services

The defining issue here is the fact that people need a level of nursing care as part of their care regime, and disability services seem to be unwilling or unable to consider the provision of nursing as a part of disability services. This is a legacy of historical models of disability services, but not carries cost and workforce considerations.

In many cases, the trigger for people with MS or other neurological conditions to enter aged care is the presence of a need for nursing care, even if it is moderate.

The almost total lack of availability of nursing care in disability services is something that must be addressed by the CSTDA administrators, not only for those people with chronic illness and disability, but also for people with disabilities who are ageing.

If nursing could be included in the CSTDA suite, it would service to significantly reduce the transfer of people from the CSTDA to aged care. If they were able to stay in place, additional accommodation services will still need to be developed for those people with disabilities currently on the extensive CSTDA waiting lists.

Some people with MS do not fit neatly into the disability category and the progression of MS means that people can leapfrog disability services and go straight from home with no formal care, to residential aged care following an exacerbation of their condition. Once they are there, there is virtually no formal means to return to the community.

Edwina

Edwina is a woman in her early 50's who was living alone in a specially adapted unit in Melbourne's East. She was relatively independent and was receiving 3 hours per week of council help. She served on a number of community boards.

Following an MS exacerbation, Edwina was admitted to hospital and it was determined she could not be discharged home to her home help program.

No attempt was made to locate attendant care in her home and she was discharged to interim care, then onto a nursing home, where she remains. Hospital staff and her community case manager did not even make inquiries for care from disability services as they were confident nothing would come from their efforts.

Edwina has now lost her unit and has had to use her own limited funds to buy an electric wheelchair to use inside the nursing home.

Although she is competent, she is not allowed to use the chair outside the home, and has had to resign from the boards she was on.

Her only avenue to return to the community is through advocacy.

The MS Society is working with Edwina to look for alternatives, to educate the nursing home workforce and to source funding for equipment.

Hospitals and nursing homes are the only places in our community where 24 hour nursing care/supervision is available. As there are a growing number of people with disabilities who require regular nursing intervention, other service models that cater to their needs must be developed.

People are forced to go to live in either of these options if they need nursing care. Many YPINH do need some nursing supervision, or the provision of specific nursing procedures (catheter care etc) but rarely need active 24 hour active nursing. Hospitals and ACAS are obliged to place people in aged care on duty of care grounds because the nursing need cannot be ignored. However placement of people (with MS and similar neurological conditions in particular) can be overkill, and a life sentence.

Rather than trying to fit a person into a generic service model, work on a new integrated model is required that provides a quantum of nursing that is somewhere between zero and 24 hours per day.

In an age where moves towards coordinated care for older people and people with disabilities is becoming common, it is telling that we maintain such unhelpful administrative divisions between levels of government and departments within government.

Recommendations

1.Establishment of a multilateral national YPINH project aimed at developing new services for people under 65 currently living in aged care.

We support the call by the National Alliance of Young People in Nursing Homes for a targeted national YPINH exit project.

The National Disability Administrators need to be mandated to deliver a target number of accommodation services through this project in conjunction with the Department of Health and Ageing.

The expansion of the Innovative Pool program, and its location in this project may ground it with the Department of Health and Ageing.

2.Immediate steps be taken at the Commonwealth level to adopt Professor Hogan's recommendation to integrate the aged care and disability sectors.

As a first step, and as matter of urgency the National Disability Administrators agree to extend the reach of CSTDA services into nursing homes to ensure that people with complex care needs get the necessary therapy, equipment, case management and recreation services that are available to other people with disabilities.

3. The CSTDA administrators include nursing as a core CSTDA service type, and make it available to people who need it in the community and in shared supported accommodation services.

The need for nursing care is a threshold issue for disability services, and it is currently a rare exception for it to be available through the CSTDA. It is important that it does become available to people with disabilities to allow people to remain in the CSTDA arena- nursing workforce concerns notwithstanding.

Further Information

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Appendices:

Appendix 1	Description of St Martin's Court housing development and floorplan
Appendix 2	Copy of MSV's successful Innovative Pool program proposal
Appendix 3	Description of Cyril Jewell House nursing home MS Wing
Appendix 4	'Disabled get new home, Hospital and Healthcare magazine July 2004, p 6

Appendix One

St Martin's Court

The Pellatt St (St Martin's Court) Development is a unique multi unit site that has been established for people with ABI and MS, and has a respite care capacity. Located in a quiet residential street approximately 500 metres from the local shopping strip, the Pellatt St Project consists of 13 one bedroom units, and one staff unit and community room

Each unit has one (separate) bedroom with built in robes, a lounge area, a self contained kitchen and separate bathroom. Each unit has direct access to the shared, open space quadrangle in the centre of the property and most have a separate private courtyard at the rear of each unit or a shared courtyard. Each unit is fitted with an integrated hard wired smoke alarm and sprinkler system, and resident emergency call points are located in the lounge, bathroom and bedroom.

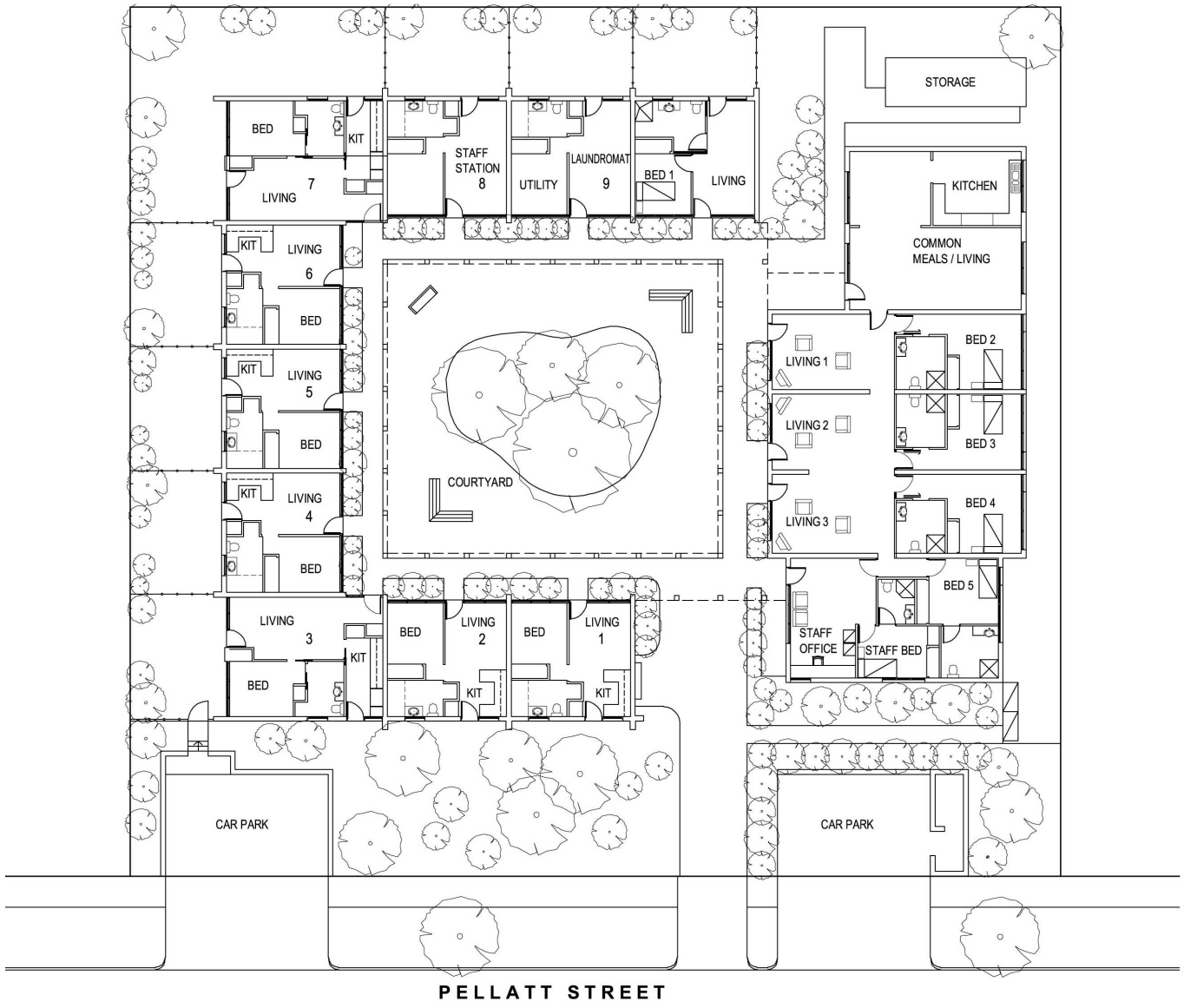
Most units are not modified for disability access; however modifications have been refurbished to the individual need of the resident, tailored to their physical and social needs. The funding for the modification have come from a variety of sources including the resident themselves paying for their modifications. All residents must provide and maintain all household belongings including furniture, equipment, electrical fittings (TV, Washing Machine, and Stereo etc), cooking utensils and furnishings. Residents may be assisted by families and other agencies to acquire these items.

The support model developed by AHCS is a combination of shared and individualised support, including provision of 24-hour supervision and assistance to 13 residents within the independent living complex.

The support model is based on a person centred planning approach. A person-centred planning approach, ensures that care is tailored to the needs of the individual. The chief objective of PCP is to empower the individual through the provision of choices and facilitation of decision-making. This approach is modelled at St Martin's Court.

Shared support service

- 24 hr on site supervision and support, including active overnight staff.
- Staff available for assistance/ prompting/ supervision with personal ADLs including hygiene, transfers, meal preparation, and domestic assistance
- Individual support service
- 3 hrs individualised support per week per resident for such tasks as: activity/social planning, assistance for shopping, banking, and diary management etc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BED 1
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2
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BED
LIVING
1
KIT
STAFF
OFFICE
STAFF BED
CAR PARK
CAR PARK
PELLATT STREET

Appendix 2
MSV Commonwealth Innovative Pool Project

Seeking the Cure. Providing the Care.

CHANGING NEEDS

An Innovative Pool Proposal
MS Society of Victoria

1. Introduction

1.1 Background

The MS Society of Victoria (MSV) provides residential services and other support services to accommodation providers for people with MS and similar conditions. MSV operates facilities providing long term accommodation and respite services, and provides support services to a residential service in Keilor provided by Melbourne Health.

The residential services are under heavy demand from across the state, and only meet a fraction of the expressed need for service by clients and families.

The services are aimed to provide a dignified supported living situation for those people who cannot continue to live at their own home due to the breakdown of community and family care arrangements.

In many cases the progression of their disease means residents needs increase over time, effectively resulting in a need for age-related supports to be provided at a younger age. Some of the age related conditions include:

- swallowing problems – diet changes, assistance with feeding, enteral feeding
- bowel incontinence regimes
- bladder incontinence regimes – includes catheterisation,
- high blood pressure treatment
- skin integrity maintenance - wound dressing

These complex needs cannot always be safely met in a typical disability residential service. Although the MSV services have a nursing presence, there is not a 24 hour nursing presence to deal with the many risks and procedures that these types of clients require. The referral of residents on to an aged care facility to provide nursing care is the undesirable result of this situation.

1.2 Purpose of Proposal

MSV proposes to conduct an Innovative Pool pilot, which takes a two pronged approach to targeting two specific disability groups:

1. Individuals who currently reside in disability supported accommodation and are at risk of being inappropriately placed into residential aged care services in the near future due to ageing related needs, (Refer Attachment 1) and
2. Individuals who are currently inappropriately placed in residential aged care (Refer Attachment 2)

Clients will be receiving mainstream DHS disability funding support which on it's own is not enough to meet the needs of these clients. The top-up funding from the Innovative Pool will enable MSV to provide appropriate care and services while evaluating the issues that arise for these clients when transitioning from Residential Aged care to community care and working towards innovative accommodation solutions with DHS.

Delivery of Services

This proposal will provide flexible care to meet the aged care related specific needs of ageing clients with a disability. The service is provided over and above the existing disability service and does not replace that existing disability service. Therefore, the Innovative Pool funding will be used to supplement existing DHS disability services with additional transitional focused assistance such as: nursing, personal care, therapy services, independence skills, and facilitated links to community activity.

The service delivery model is based on identifying the individual client's requirements, developing an Individual Personal Care Plan and assisting that individual to maximise their independence and continue their life-style within their existing community. The aged specific Individual Personal Care Plan will be integrated with the clients existing disability care plan and will be delivered in collaboration with the disability care plan.

As per the Aged Care Act 1997, services will be provided in accordance with the Flexible Care Standards and the Quality of Care Principles.

Where services are brokered, service agreements will be in place with all external service providers to ensure reliability and accountability of services delivered. MSV will maintain control over the quality of the services delivered by direct monitoring that utilises feedback from the client and the provider. MSV has extensive links with service providers and will utilise these links to ensure continuity of care for the client and the provision of services by staff with whom the client is familiar.

Compliance with the Aged Care Act 1997and commitment to the Disability Service Standards are key objectives of Changing Needs. The organisation applies resources to ensure effective and efficient services that are responsive to clients' needs and safety and industry and government expectations and standards.

Further details for each component of this proposal can be found in Attachments 1 and 2.

Linkages around the Service- Other Services and supports

A number of additional services and linkages exist in and around the MSV residential service. They include direct service from MSV health professionals, as well as community services. MSV supports these residents with the following services:

- Volunteer services
- Pastoral Care and Social work
- Advocacy
- Dietetics and nutrition
- Physiotherapy and OT services (limited-primary and secondary consultancy)
- Neuropsychology (assessment, review and secondary consultancy)

These services will continue with the Commonwealth MSV Changing Needs pilot.

Through the MSV Lifestyle Planning Service, residents are able to get referrals to community professionals in areas such as:

- financial planning and law
- housing and family support
- citizenship
- recreation

While wider demand management and service development strategies need to be worked on across the jurisdictions to secure systemic solutions to the issue of younger people with disabilities taking up aged care beds, the proposed MSV service will secure services for individuals and generate savings to the Australian Government. This will be achieved by reducing the rate of premature placement of this group into the aged care system and permanently removing a percentage of participants from residential aged care.

2. Proposal Structure

2.1 Changing Needs – Williamstown/Watsonia

Summary:

16 flexible places will be utilised to prevent inappropriate placement of people with disabilities into residential aged care. The key outcomes for this part of the pilot will be:

- prevention of premature admission to residential aged care

- provision of aged care specific services to ensure maximum client independence and comfort
- maintenance of the social and living relationships of the client
- investigation and development of other accommodation options within the Disability sector
- provision of skilled and competent staff
- evaluation data

2.2 Changing Needs – Carnegie

Summary:

3 flexible places will be utilised to permanently remove younger people with disabilities from residential aged care, providing funding during the transition to full state government funded disability support. The key outcomes for this part of the pilot will be:

- Removal of Younger People With Disabilities (YPWD) from residential aged care
- On-going provision of aged care services
- Improvement of the social and living relationships of the client to enable placement into more appropriate care after the transition period of the pilot.
- Provision of skilled and competent staff
- evaluation data

3. Duration and commencement

The pilot is expected to commence in two stages.

The sixteen flexible places (stage 1) will begin as soon as practical after approval with the remaining 3 flexible care places (stage 2) likely to commence 4-6 week later due to minor renovations to the second bathroom.

In line with the Australian Government guidelines the duration of the pilot will be 2 years.

4. Approved Provider

MSV is an Approved Provider for Residential, Community and Flexible care under the Aged Care Act 1997.

Watsonia/Williamstown location:

The DHS would continue to provide disability services funding as per the MSV current service agreement.

The additional Australian Government component would be a top up to the existing state funding to ensure an increased service capacity in the areas of nursing, therapy, and independent living skills.

The funding requested from the Australian Government for this component is a total of $704,520 over 2 years. This equates to $60.32 per place per day.

Carnegie location:

The DHS will provide funding to enable three younger people with disabilities to move from aged residential care into more suitable housing and support. This support will be in the range of between $50,000 - $70,000 per place. A letter from the DHS detailing funding support is included with this proposal. (See Attachment)

The Australian Government component will enable transitional services to ensure an increased service capacity in the areas of nursing, therapy and other services which affect the individuals transition from residential aged care into more appropriate State Government supported care. (Additional information in Attachment 2)

The funding requested from the Australian Government for this component is a total of $124,640 over 2 years. This equates to $56.91 per place per day.

Appendix 3
Brief Description of Cyrill Jewell House

In Victoria there is a unique response to the issue that attracts joint funding from Commonwealth and State. Melbourne Health operate a younger persons 'wing' in a larger nursing home complex where 15 people with MS are resident.

This model acknowledges that young people are not well placed with older residents, and has created a distinct residential environment within the larger facility.

The 15 residents are supported with a mix of Commonwealth bed subsidy (currently 2/3 RCS 1 and 1/3 RCS 2) and top up funding from the department of Human Services Disability Services. In 2003/04 this amounted to $236,000. The model acknowledges that for this group, the aged care subsidy alone cannot adequately meet their needs. By creating a critical mass of 15 people, it makes it relatively efficient.

In addition to the top up State funding to Melbourne Health for in house care services, the Department of Human Services also funds the Ms Society of Victoria for providing community access services to residents. The MS Society own a wheelchair capable vehicle that is there for the use of the residents.

This model is successful for those people that would have otherwise ended up isolated in regular aged care facilities, and deals with the problem of cross subsidisation.

As the residents are in fact eligible for both Commonwealth Aged Care and State disability funding, it has made practical sense to get both funding sources to contribute to the care, resulting in efficient use of resources. It has been easily done by managing the joint funding at the provider level without needing complex interjurisdictional agreements to be in place.

This model is innovative in the aged care sector, however other individuals with high level care needs have preferences for other styles of living, including:

- Home with attendant care
- Shared group home
- Cluster units

The models have been successfully implemented by the Disability Services Commission in WA as part of the Young People in Nursing Homes Project 1997. The services that have come out of this project are well regarded by the sector.

The annexe model is a good one for providers in that it makes good use of existing infrastructure, and attracts more realistic funding levels, however other models that can combine funding from a number of funding programs need to be explored.