COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Aged Care

TUESDAY, 26 APRIL 2005

MELBOURNE

BY AUTHORITY OF THE SENATE

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COMMUNITY AFFAIRS REFERENCES COMMITTEE

Tuesday, 26 April 2005

Members: Senator Marshall *(Chair)*, Senator Knowles *(Deputy Chair)*, Senators Humphries, Hutchins, Lees and Moore

Substitute members: Senator Allison to replace Senator Lees for the committee’s inquiry into aged care

Participating members: Senators Abetz, Allison, Barnett, Bishop, George Campbell, Carr, Chapman, Colbeck, Coonan, Crossin, Denman, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Forshaw, Greig, Harradine, Lightfoot, Ludwig, Mackay, Mason, McGauran, McLucas, Murray, Nettle, O’Brien, Payne, Tierney, Watson and Webber

Senators in attendance: Senators Allison, Forshaw, Humphries, Hutchins, Knowles, McLucas, Marshall and Moore

Terms of reference for the inquiry:

To inquire into and report on:

the adequacy of current proposals, including those in the 2004 Budget, in overcoming aged care workforce shortages and training;

the performance and effectiveness of the Aged Care Standards and Accreditation Agency in:

(i) assessing and monitoring care, health and safety,

(ii) identifying best practice and providing information, education and training to aged care facilities, and

(iii) implementing and monitoring accreditation in a manner which reduces the administrative and paperwork demands on staff;

the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

the adequacy of Home and Community Care programs in meeting the current and projected needs of the elderly; and

the effectiveness of current arrangements for the transition of the elderly from acute hospital settings to aged care settings or back to the community.

WITNESSES

Committee met at 9.00 a.m.

HILLS, Ms Sandra Rae, Board Member, Victorian Association of Health and Extended Care (VAHEC)

MUNDY, Mr Gregory Philip, Chief Executive Officer, Aged and Community Services Australia

STANLEY, Ms Martina, Senior Policy Officer, Victorian Healthcare Association

CHAIR—I declare the hearing open and welcome representatives from Aged and Community Services Australia, the Victorian Association of Health and Extended Care and the Victorian Healthcare Association. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Mundy—The first of the terms of reference relates to the adequacy of the proposals centring on last year’s budget in aged care. I would like to make a couple of observations. The first is that the National Aged Care Work Force Strategy, which we advocated for in our submission, was in fact released last Thursday, which is a welcome development. We have also suggested that its scope should be extended to include community care. I have had a number of discussions with officials from the Department of Health and Ageing and that is something that they now support, perhaps for the next iteration of the strategy, which is a welcome development from our point of view. I think the most central element in the range of the budget measures last year was the provision of what is known as the conditional adjustment payment of 1.75 per cent to boost the funding to residential aged care services. There was no similar provision for community care. This is worthy of one comment by way of an update, and that relates to the recent decision in the New South Wales Industrial Relations Commission which awarded a further six per cent wage increase to nurses in New South Wales. That is very welcome from their point of view, but I would simply make the observation that the wage rise enjoyed by nurses alone in New South Wales—and they comprise a little bit over 30 per cent of the care work force—accounts for all of last year’s indexation, including the additional 1.75 per cent, and an additional $4 million on top of that. I make that observation because some people have had very ambitious and in our view unrealistic expectations of just how far that 1.75 per cent can stretch in terms of the ability of our members to pay competitive wages. You can only spend it once, and in New South Wales they have already spent more than that in the year to date.

On the second of the terms of reference, we have articulated our position around accreditation. We think accreditation for residential aged care represented a significant step forward when it was introduced in 2000-01, but we do think a more universal system which contains service standards that are specific to particular types of services—residential aged care, community care and other service streams—should be maintained but we should have a common or universal process for measuring the application of those standards. Really there are three reasons we would cite in support of that. One is that it is more efficient. The second is that it would reduce the paperwork burden that is placed on care staff. The third is that it would support what everyone I think would agree is a desirable policy goal, and that is continuity of care. If you have got several different services all providing care to the same cohort of people, it actually does not make a huge amount of sense that each one has its own unique processes as well as its own distinctive standards for assessing quality. We think moving to a more universal system would be a step forward for everybody.

We have stated a view on the question that was in the terms of reference about the role of the agency in providing education and training. I think there is a very clear role for the agency to explain its role and how it goes about conducting that role within Australia. It also has access to good information about practices in the industry. In that latter field it is of course in competition with the whole marketplace of training providers and I think it needs to be careful not to overuse its distinctive position in the system to overdominate the market in the provision of training around quality. I have got no objection to it being a participant in that marketplace for the provision of quality training but I think it needs to be careful not to overuse its strong position in that regard and to avoid, for example, creating the impression that, because they are the Aged Care Standards and Accreditation Agency, their views about how quality should be achieved have a distinctively privileged position in the marketplace of ideas about what constitutes good quality management. They are a legitimate player but by no means the only one.

In terms of the issue of younger people in nursing homes, we agree with many of the submissions that it is inappropriate for younger people to be accommodated in nursing homes. As long as there are no other alternatives available systematically across Australia, our members will continue to welcome them as residents in their facilities, but I do not think anyone regards that as anything other than a compromise between the needs of those people and what it is possible to do under current policy settings. It is an issue that has been around for a very long time, several decades, and really the solution would seem to necessitate a specific service stream designed to deal with those people, recognising that providing age-appropriate accommodation for younger people is going to cost more money. I think that if governments—I use the term collectively because clearly there is both an Australian government and a state role—want to solve that particular problem, they need to grasp that nettle.

The other comment I would like to make about the adequacy of current funding for meeting the needs of people with specialist needs, and it picks up a particular point we made in our submission, is that the funding system used for residential aged care has been reviewed and a new system or several variants of a new system are about to be piloted in a major exercise across Australia. One element that we are a little concerned about in terms of the trials is that all of the reviews of the funding system, and that includes the one that was conducted by Aged Care Evaluation and Management Advisers back in 2001 and the observations that Professor Hogan made on the funding system in his major report on residential aged care funding, identified a group of people in residential care whose needs were not covered by the existing funding system because they were much higher than was ever envisaged. Professor Hogan recommended as a solution to that the provision of supplements over and above the existing funding to pick up that substantial minority with very high care needs. Currently the proposal is to meet those very high needs by the redistribution of the existing pool of resources, and that is a source of some concern to us and our members, that if you do that then there are necessarily going to be people who are currently receiving services or who would have received such services into the future who will miss out. In other words, it could be seen as a form of rationing residential aged care as well as a form of targeting residential aged care. The latter point we certainly support.

In terms of community care, we have been broadly supportive of the government’s reform program in community care. We would make the point that community care services are spread very thinly in Australia and that more resources would certainly be welcomed by service recipients. We would also look for a good deal more subtlety in the implementation of the reform process, some aspects of which recently have been problematic for our members.

Lastly, in terms of the transition of older people between health services as they are conventionally regarded and aged care services, I think what we need to do in this area is to take the excellent pilots of services around Australia, the extra learnings we have had from particular projects, and set as our goal making them a universal part of the service system that cares for older people so that we do not just have half a dozen really excellent services in particular parts of Australia but we set out to achieve a universal part of the service system that bridges the gap between acute health, residential aged care, community based aged care and indeed primary care in the community. I think that would be a very worthwhile goal for us to set as a nation.

CHAIR—Thank you, Mr Mundy.

Ms Hills—The paper that VAHEC prepared was fairly lengthy. Mary, the CEO, is overseas but, in consultation with her, I have summarised it for you. Many of the things I say will support what Greg has said already. In relation to the first term of reference, what we do know is that the need for a skilled, flexible and available work force is crucial to the future of a quality aged care system. The current and predicted shortage of aged care staff has been documented quite widely. Professor Hogan’s recommendations, in the review of the pricing arrangements in residential aged care addressing work force issues, have been met in part by the Australian government, which is most welcome. However, they do fall short of the number of places proposed by Hogan in his report. VAHEC urges the Australian government to give serious consideration to implementing the measures outlined in the Hogan report.

We would like to emphasise that work force issues, the attracting and retention of staff, need to focus on a range of staff to provide services in an aged care environment—we are talking about division 1 and 2 nurses as well as personal care workers. To date, not much attention has been paid to the community care area. This is a particular concern because of the future direction of services—that is, the future of where aged care services will be provided in the community, not necessarily in residential care. The issue of pay and conditions for nurses in the aged care sector is a huge one. The difference in salary levels experienced by aged care nurses and the way in which subsidies are calculated are significant barriers to addressing the current work force issues.

In regards to models of care, we need to continue to focus on developing practices that ensure specialist skills of nurses are used at all times, not wasted on paperwork that might be unnecessary. Plans need to be put in place to ensure that there is a flexible and growing work force able to deliver residential and community care services. Who knows what models may be around in 2025? VAHEC acknowledges and congratulates the government on the recent release of the National Aged Care Workforce Strategy. Whilst I have not had time to look at it in detail, because it was released late last week, there are a couple of things I would like to say. Once again, there appears to be little mention of community care work force issues, which is of concern. There are also issues, once again, about who will pay for this. It also emphasises the cooperation that will be needed between both levels of government, particularly with regard to the state government addressing some of the barriers we currently experience in recruiting and retaining staff.

In regards to the second term of reference, the VAHEC submission identified three key areas in which we believe improvements can be made. I reiterate the advantage of adopting an accreditation system that provides an overarching and active quality control framework. The benefits of such a framework, JAS-ANZ, have been outlined in the VAHEC submission, so I will not go into that. While it is generally acknowledged in the aged care industry that the accreditation process has represented a step forward, it is VAHEC's view that better outcomes would be achieved if a competitive service provision and quality control under the JAS-ANZ framework was introduced.

With regard to the third term of reference concerning young people who have a disability in residential aged care facilities, I know that you will be hearing from people from Melbourne Citymission tomorrow and that they will be able to speak with great passion. We have a case study in our submission about some people with motor neurone disease. That is quite a sad story but I think it highlights some of the needs of our clients who are serviced by our members. Funding the needs of younger people who have a disability does not fit neatly into either Commonwealth or state government funding structures. VAHEC encourages both Commonwealth and state governments to work together to address this situation and to ensure the needs of younger people with a disability are met in a more appropriate and humane way in a more suitable environment.

There was also a comment made about other special needs groups in the May 2004 budget, the government's response to the Hogan report. The recommendations picked up on two of the special needs groups but it did not address the needs of people who come from disadvantaged backgrounds. VAHEC believes that the government should acknowledge this group and, accordingly, provide appropriate supplements for that.

With regard to the area of community care, the fourth term of reference, community care services are a way of the future, as Greg said. I certainly support Greg's comment that the services are spread far too thinly. We know, from recent reports, that we are looking at sometimes one hour a week of HACC services. This approach to community care is the preferred choice of a vast majority of older people and people with a disability and their carers. In addition, it is also the most economical, preventative and social effective model of care.

The increased amounts of government funding over the past are acknowledged. However, the current community care system is not meeting all needs of those who currently require it and the requests are increasing. I have just given some examples of the hours. These issues have been documented in detail in VAHEC's submissions. Once again it is crucial that, with the ageing of the population, both state and federal governments work together towards finding a solution.

There are three areas I would like to highlight. The first is that of informal carers. My other job is working at the Brotherhood of St Laurence as the general manager. About 18 months ago the Brotherhood, NATSEM, Carers Australia and the Myer Foundation actually funded a report looking at informal carers, and what we do know is that the available carers will actually drop by 40 per cent in the next 30 years. That is significant. I am talking about unpaid carers, informal carers. That is mainly due to the ageing of the population.

The second area is the issue of affordable housing. The issue of low cost housing for older people who do not own their own home or are on a low income also needs to be addressed. If community care is the way of the future, if people do not have secure, affordable housing, how will that service be provided?

The third area is the issue of tendering. Recently the national respite for carers tenders were announced and closed some time ago. We suggest that government needs to give serious consideration to benefits versus risks it hopes to gain out of tendering.

The Department of Health and Ageing’s *The way forward* report has identified five key areas that need to be addressed if Australia is to be serviced by an effective community care service system in the future. It is pleasing to note that some of the work arising from this report has already commenced. The work of the Community Care Coalition in bringing about a more effective care system at both state and national levels should also be acknowledged. I know that you have got Pat Sparrow talking to you later on.

On the final terms of reference, quality health and aged care need to be strongly linked and there is plenty of room for improvement here. If the goal is to keep people in the community out of residential and acute care, we need policies and strategies to integrate primary care, community care, health promotion, illness prevention, rehabilitation, acute and subacute care and residential care. As we have seen with community care and young people in nursing homes, this does once again involve cooperation in planning and funding between state and federal governments.

Ms Stanley—We have approached our submission a little bit differently and we have called our submission ‘Fragments of care’, because we believe that the current system that we have in Australia, as highlighted in the questions being asked of the Senate inquiry, is a very fragmented system. While it provides good care, a lot of that could be provided much better if the system was less fragmented. In particular, we are concerned about the fragmentation of funding streams and the multiple funding streams; the accreditation and quality control systems which mean that often it is difficult to navigate the various accreditation systems; the lack of work force planning and development; and of course the delivery of care both in terms of managing complex needs and integrating acute residential and community care needs. In particular, we are concerned about the difficulty in caring for the needs of those with complex care needs.

As a result of system that we currently have to deal with, our industry and our members find that they have great difficulties attracting enough staff, particularly in rural areas. Many of our members are functioning in small rural communities and they find it difficult to attract staff to aged care settings. This is due in many cases to the terms of pay, to the lack of career planning and to the planning for other workplace issues. We also feel that we struggle because we cannot get the balance between people and paper right. The administrative systems in place at the moment are very paper based and very resource intensive. Our members say that they spend more time caring for the paperwork than caring for the people. We also have increasingly complex needs that are not are not being compensated through the current funding system. Systems such as those recommended by Professor Hogan which would see us getting supplements for people with complex care needs would be welcomed by our members.

We also believe that the current training funding is not adequate because the complexity of the administrative systems are such that people are currently spending more of their training time in training people how to manage paperwork rather than how to manage patients. We are concerned also because of the impact that the current systems have on clients and on those people who need the care provided by our system. The system, because of its complexity, administrative difficulties and fragmentation, does not provide easy and freer access for clients who are trying to find their way to receive care. Our clients are subjected to duplicate assessments. This often means they have to discuss difficult personal, embarrassing and distressing issues to fulfil the administrative need to respond to paperwork rather than providing them with better care to the system.

In summary, we believe that by introducing more appropriate systems of care and funding, the community, together with providers and the government, should work to develop more appropriate models of care that account for the changing needs of our community and that also account for the complex care needs, particularly given the growing number of people with dementia and other psychogeriatric problems. We would also welcome more work being done on work force needs. Like my colleagues, I acknowledge that last week we saw some good progress in this direction, but this is still only one part of what was recommended by Professor Hogan, for example. We also see the need to work closely to ensure there is a continuum of care by making it easier to move funding and information between acute, subacute, residential and home based care settings. This would mean that clients are better looked after, that the care is more accessible and that their needs are addressed in a more holistic manner.

We also recommend that the government give some more serious thought to the problem of younger people in aged care settings. Like the private providers that have spoken before, we find that we have to take younger people into aged care settings because we have no other options. We welcome the work that VAHEC are doing at the moment on this topic and would support their recommendations. We would support further work being done to supplement what they have done. Finally, the current system needs a greater degree of trust between funders and providers in order to enable us to reduce the burden of administrative work that stands in the way of providing better care and achieving more innovative and successful approaches to providing care. We thank you for this opportunity.

Senator KNOWLES—One of the things you said about work force issues is that the state created barriers in trying to recruit staff. Would you mind expanding on that a bit?

Ms Hills—Probably the most relevant example I can give is that there have been incidences where we have looked at traineeships for people. I believe that is a state issue. People would not be eligible for traineeships if they already had an existing qualification. So even though that qualification might be 25 years old and one that they do not want to pursue anymore, they would not be able to be funded; therefore they could potentially be seen as less attractive by an organisation. In my job at the Brotherhood of St Laurence, we have employed a lot of people in traineeships. They have undertaken the certificate III or IV in aged care but all of those people had no previous qualifications. There were a number of people that we had to turn away because they were not eligible as they had a prior qualification.

Senator KNOWLES—Are there any other barriers?

Ms Hills—That is the main one that I am aware of.

Mr Mundy—Two very brief comments. One is that that is a nationwide phenomenon. There is a rule that you cannot get two traineeships, which I think must therefore emanate from DEST rather than being administered by the state. The other thing that we have heard recently, which I actually tried to track down before I came here today, is a rumour that mature age traineeships are to have further restrictions placed on them. I could not substantiate that between the time I heard it last Wednesday and this morning. That would be very unfortunate should it turn out to be the case, because we have a mature age work force and aged care in particular has a mature age work force. It is not a terrible thing, given that it is providing care to mature age people, and it would be very unfortunate if the valid targeting of traineeships to young people was at the expense of the people we are actually most likely to recruit. But I have not been able to substantiate that that is in fact the case.

Senator KNOWLES—I want to move on to the accreditation process and the agency itself. You will recall that some years ago the government was placed under incredible societal pressure and political pressure to have spot checks and to have a tighter accreditation system. Since accreditation began there have been 18,000 visits to aged care homes and 4,000 spot checks. Between 2003 and 2004 there were 862 spot checks. The committee has received a fair amount of criticism of the agency and its processes. This has been demanded of us by, as I say, the community and also politically, yet there is now criticism of the agency. How best do we deal with that—by maintaining standards and ensuring there is confidence in the sector while trying to appease the industry, who feel as though they are now being overburdened by the agency? I would like all of you to give us a comment on that, if you would not mind.

Mr Mundy—There is a micro answer and a macro answer I would offer to that. One is that there is scope to improve the way in which the agency conducts its spot check process. We certainly have talked to them about developing more refined approaches to spot checking, to targeting, to being clear about which visits are about providing support and training and which are in response to urgent issues that really cannot wait. That is about clarifying the purpose that is to be served by follow-up visits. Follow-up visits are a feature of all forms of accreditation. Certainly our advocacy of a more universal system of applying accreditation would not be at the expense of follow-up visits of all sorts of classes. The agency itself is accredited under Standards Australia’s international procedures and they do a regular follow-up with the people that they accredit to make sure that things have not slipped. So all systems of accreditation must have follow-up mechanisms. In aged care, because we also have very vulnerable clients and we have a complaints system, there does need to be a capacity in the system to respond to short-term and ostensibly urgent matters to make sure that if they are genuinely urgent something is done about them expeditiously. So we recognise the necessity of having that capacity in the system, but both we and, for that matter, the standards agency think it can be done better than it has been over the last couple of years.

The remarkable thing about the statistics that the agency produces on its accreditation program is really how successful it is. There is a very small number of negative findings and things that require urgent action. You do need a system in place to make sure that that is the case but it does represent a bit of a success story rather than, as it is sometimes presented in the media, a set of failures. The failures are few and far between—unfortunately sometimes there are spectacular failures, but they are very much a tiny minority of what goes on in residential aged care.

Senator KNOWLES—Ninety per cent actually receive their full three-year accreditation, don’t they, which says something about the system.

Mr Mundy—It does. It is working but it can be improved upon.

Ms Stanley—Picking up on what Greg says, I think it is important to recognise that the system is working and has to a certain extent achieved a raising of the standards overall over the last five to eight years. It is important to recognise that we are now entering into a phase where we can recognise that the industry has got its house in order a lot better and we can perhaps move on to a more mature approach to the industry. As Professor Hogan mentions, the industry is increasingly mature and more of the decision-making could now be left to the actual managers within the organisations, within the agencies, rather than being controlled and monitored so tightly and so closely by the accreditation agency.

At a more practical level, the concern of many of our members is that they have to report for multiple accreditation processes and that many of the questions they answer for each of those processes are the same. Many of those are nationally based, Australian government based accreditation processes, and we believe that a lot of paperwork could be cut out by trying to streamline those and avoiding the duplication that currently exists.

Ms Hills—I certainly support the comments of my colleagues. With regard to Martina’s comment and the future development of services, as part of the way forward strategy for community care in fact some thought is being given to how you look at accreditation across community care programs as well as residential aged care. That is the reality. A lot of providers actually provide a range of state and federal programs and they have to report. Some of them have 10 or 20 ways of reporting. It is extraordinary. Yet many of the actual standards are very similar.

I think we have reached a new phase. We certainly have moved forward and we are moving forward. It has been a positive thing. The pain that was there three or four years ago has certainly gone for most organisations. But we need to really focus on the future. Do we want just one system? Does one size fit all? I am certainly not saying that, but we need to look at some way of coordinating the community care and residential aged care accreditation systems.

Senator KNOWLES—Ms Stanley, you talked about duplication. I think it is an established fact that quality homes that are already accredited and continue to meet the needs of their residents will have the documented procedures in place to meet the accreditation requirements. Is that working? Also, I think we need to understand that the government subsidises the process to ensure that no undue burden is placed on the industry. With that step forward, once they are established as quality homes, is there a problem with that? Are you saying there is still duplication even though that has been refined by the agency to ensure there is less duplication?

Ms Stanley—I understand it is still the case that there is a lot of duplication and that they have not actually felt the impact of those improvements to a very large extent at this stage.

Senator KNOWLES—Are you able to give us examples? Maybe you could do that on notice if it would be easier for you.

Ms Stanley—Specific examples of how the system has not yet improved and how they still have multiple systems?

Senator KNOWLES—That would be very helpful.

Senator McLUCAS—I want to pick up on the question of duplication. Ms Stanley, is the issue compliance with an accreditation process or is it an accountability process? And is there an opportunity to streamline both of those processes so that reporting in both those streams can be made simpler?

Ms Stanley—Absolutely. There are so many reporting systems, both for quality systems and for the funding streams, that when you add the two together that is where the mountain of paperwork arises so, yes, we would agree it is both.

Senator McLUCAS—I understand there is a Commonwealth committee at the moment looking at streamlining that process. Are you aware of that?

Ms Stanley—We have not been invited to participate.

Mr Mundy—There are two that I am aware of. One is an 18-month project looking at the effectiveness of the accreditation system that was one of the recommendations of the Joint Committee of Public Accounts and Audit. They identified that that had not been done and that process is now in train. I think that has just started and that they are due to do consultations this month and next.

The other process that is relevant is the government’s review of red tape as it applies to small business. The threshold they have set for small business would only include some aged care providers, but it would be a very relevant thing for them to look at because I think they have set their threshold at a turnover of $10 million, which would certainly include a large proportion of the industry but by no means all of it. I guess there is the issue of what is good for the goose should also apply universally.

There are organisations in our membership that do use internationally recognised accreditation systems as part of their own quality management approach, and no doubt some of them have made submissions to this inquiry. ISO 9000 is a common one. They do test the compliance of those organisations against all of the standards to which they are subject from external sources. It is not that the standards go away; it is just there is a single process for measuring them all rather than a separate one for each particular set of standards. That has the promise to be both more efficient and economical, and more effective because the skills of the people doing the audits are improved by the fact that they are looking at all of these things in the one organisational context rather than looking at them as vertical streams within the one organisation.

The majority of our membership do more than one thing. Very few of our members are stand-alone nursing home providers. There are some—and some big ones—but the majority of them provide residential aged care, both high and low; community care, particularly packages; and also independent living units. So they are providing an integrated range of services that flexibly meet the needs of older people. But the funding streams, and particularly the reporting streams, are an inhibitor to achieving that. They manage it, but it would be a lot easier if they had a single process. It would also make the integration of those services with what we conventionally call health services more straightforward if there were some common yardsticks and common processes for assessing quality.

In fact, there are things we in aged care can learn from the approach to quality that has been taken in the health care sector. They have been forced through some spectacular failures to look very carefully at questions of safety and quality in acute hospitals. They ended up developing the concept of no-fault incident reporting as really the only robust way of moving forward to eliminate catastrophic errors from medical procedures. The concept of no-fault incident reporting has some applicability also in aged care so it ceases to be a question of finding and blaming the person responsible and it becomes an issue of finding the root cause of the problem so that you can eliminate it. I think there is a sophistication in that approach that we could learn from in the aged care sector.

Senator McLUCAS—Which goes to Ms Stanley's point about trust.

Mr Mundy—Indeed.

Senator McLUCAS—The other issue that has been put to us on a number of occasions is that, instead of reporting every event that happens to a resident in a residential aged care facility, reporting by exception would be a more appropriate and more efficient way to go. That is, you basically take it as given that the person will be bathed daily and on the day that that person does not get bathed that is the report that is made. Do you have any comments about reporting by exception?

Ms Hills—One of the problems with that, as we know, is the high turnover of staff in many aged care homes. One of the issues is trying to make sure there is some record of what has been done and what has not been done. Many organisations rely heavily on agency staff or staff that work in a temporary or a casual capacity, so the systems would have to be fairly foolproof because of the turnover of staff. Where you have a staffing structure with a more regular staff, that is something that probably could be achievable. But I think there would be some risks. It is not something that I have given a lot of thought to, I have to say, for my organisation, for my residential aged care facilities. Certainly staff turnover and the skills set of staff would be very important in doing that.

Senator McLUCAS—Mr Mundy and Ms Stanley, do either of you have any comments on the question of reporting?

Mr Mundy—I am not quite sure whether the context of the question was about internal reporting—where I would entirely support what Sandra has said; if you do not keep records of these things, the hierarchy will never know whether things have been done—or external reporting, which I think should be done more on a by-exception basis. People should be audited to make sure they have the systems in place to record things internally rather than people looking at excessive numbers of individual transactions trying to find the one that was missed. If someone does not have a bath or a shower, there may be a reason for it. Aged care facilities should have a system so that the management in those facilities can identify that there was a reason, and it was not just that someone forgot. That really should be the focus of audit. People should have the capacity for self-correction because that way you have a much greater chance of there not being further errors in the future than if you transfer responsibility for finding the errors to an external third party. I think that would be the wrong way to go.

Ms Hills—Just to clarify, I was referring to internal checks, because when the assessor came around they would have to have some evidence of what had actually happened. If that was not happening, there would need to be some system put in place. So I was referring to internal checks.

Senator McLUCAS—And that was the intent of my question as well. The other issue in terms of reporting that we have talked about as a committee is the fact that, in residential aged care in particular, the use of IT is very limited. It has been put to us on a number of occasions that an increase in use of IT—palm pilots and a whole range of systems that could be used—would make the work less onerous and leave more time for staff, particularly trained staff such as registered nurses, to spend more time with the resident. Do you have a view about why we have not taken up IT in the way that, for example, the hospital sector has?

Ms Stanley—I think one big issue is cost. Our members are already operating at a loss in most cases. There is an average loss of $22 per bed day throughout our membership. So adding expensive systems like that is almost impossible, but, even if you have a system that is electronic rather than paper based, unless the systems underlying that are streamlined it is not going to make it any easier. Just because you happen to be able to do it at the bedside or in an electronic fashion does not actually make it easier. So, while there may be some gains in that, there has to be some underlying work to the reporting systems.

Mr Mundy—To add a comment to that, I think one of the reasons why it has been slow in aged and community care, and it is not the only reason, is that there has not been any explicit investment in IT by any of the funding levels of government, which is in contrast to what has occurred both in the acute health sector, where there have been scores of millions of dollars invested in IT, and more recently in the case of general practitioners, who also had a significant amount of money spent on equipping them with IT. Opinions may be divided about who should pay for what, but I think that does explain why both of those sectors are much further advanced than the aged care sector. Advancing the take-up of IT in aged care is a project that both of the national associations take quite seriously. We have been organising events to get people’s level of interest up; we have been showcasing the successful examples, such as the one that you mentioned. But in other areas of the care of older people, what has really given things a boost along is that the governments have said, ‘Yes, we want this to happen,’ and have invested substantial amounts to make it happen—and it has happened. That has not yet occurred in aged or community care.

Senator McLUCAS—I think Ms Stanley’s point, though, is well made—that, unless the underlying system is right, adding IT on the top is not going to solve the real problem. Moving on, we have done exactly what all your submissions have said and talked a lot about residential aged care and not the real issue, and that is community care. Mr Mundy, you talked about COPO not being a sufficient measure of inflationary needs in the sector. Do you have any advice for the committee about what would be an alternative method of looking at the change in the real cost and the lack of response by government funding streams?

Mr Mundy—Yes, indeed. I think it is appropriate to have an index that measures the costs that apply in the sector that you are using the index for. The difficulty that we have in aged care and certainly in Commonwealth funded community aged care is that the measure they use for wages is the safety net adjustment. That drives 75 per cent of the indexation factor and, because of the supply and demand issues that Sandra alluded to before, our staff have done considerately better than the safety net over a sustained period of time. What I think would be a more appropriate solution would be to use an index that measures the costs in the labour market that we in fact are forced to draw from. So we would use the health and community services index rather than the safety net adjustment figure. That would measure the way costs for wages are moving in the group of people that we employ, whereas the other one simply does not.

We—and, I think, some of the other submissions—have noted that the Department of Veterans' Affairs, for its Veterans' Home Care program, had consultants who came in and looked at the costs and said, 'No, for measuring your cost increases you need a better measure than that,' and, because they could do that, they did so. They used the health and community services wage index as the driver of the indexation for that program. Something like that, which is a better and more accurate measure of wage movement in our sector, would stop the continual cycle we have of always falling behind. Every time there is a one-off increase there is a short-term improvement, usually for less than 12 months, and then we fall behind again because the underlying cost drivers are moving much more quickly. Perhaps the most extreme but very common example is the cost of health care in the privately insured sector, where over the last five years the government endorsed increase in health insurance premiums has been seven or eight per cent—more than double the rate of inflation as measured by the CPI. We are employing the same people. We employ nurses, personal carers and ancillary staff. They are exactly the same people, yet we are supposed to do it on three per cent plus COPO. Last year's net increase in the residential care subsidy was 3.8 per cent. We have to manage on 3.8 per cent but private health insurance premiums went up by eight per cent. We are employing the same people, yet we are handicapped in competing in that employment market.

It is worse in the case of community care because they did not get a 1.75 per cent supplement courtesy of Professor Hogan's review. In terms of staffing they are subject to the same cost pressures as the residential care sector, but they have only had COPO for the Commonwealth-only program since 1996 when it was first adopted. So it is not surprising that the value of a Community Aged Care Package has been eroded over that period of time. Costs have risen more than the value of the subsidies—they have gone up—so the value of the content in a Community Aged Care Package has been correspondingly reduced. There is no reason to think that the wage movements that apply to community care are qualitatively different from those in residential aged care but there has been no budget attention in that area, whereas there was at least some in residential aged care. Some of the responsibility for cost increases in the community care sector is, of course, shared with state governments. The Home and Community Care program is the largest community care program by an order of magnitude of between four and five. The state governments do a have a role in indexing the payments they make to those services, but within constraints and parameters that are set by the Department of Health and Ageing.

Senator McLUCAS—Mr Mundy, you talked about a need for subtlety in the implementation of *The way forward*. I think you are suggesting that competitive tendering is not very subtle. Ms Stanley talked about it as well. What is wrong with competitive tendering? I have my view but, for the record, can you explain why the competitive tendering for programs, which happened a couple of weeks ago, is not an appropriate way to go?

Mr Mundy—I think competitive tendering is a rather dated and blunt instrument which probably reached the peak of its applicability in the 1990s. I have tried these things myself, in previous iterations, and have learnt from the experience. We have a particular issue with the tenders which have recently closed. Three services were tendered: information services for carers—that is probably the least problematic; the carer respite centres—that is slightly more problematic; and national respite for carers—which I simply cannot see advancing any worthwhile cause. When national respite for carers money came in in the mid-1990s, all of our members used it to top up their existing services. They have a little bit of HACC money and a little bit of day therapy centre money, and they use the national respite carers money to expand the provision of their service. I cannot see how any good purpose can be served by taking all those little blocks of service away from provision that is already integrated on the ground and retendering it, other than maybe lining up the world better on paper. It certainly cannot in principle lead to better integrated services on the ground. They are already integrated. This is disintegrating them—or it at least carries that risk. It is an expensive process.

If people are not happy with the pattern of service provision in a particular region, a better approach—it might take slightly longer but would not necessarily be more expensive—would be to get all the players in a particular area, sit them around a table and say: ‘We need to sort out these particular problems in this particular region. We’ve got this duplicated and that’s a gap. Can’t we negotiate a solution that would remove the duplication and fill the gap?’ That is what we used to do before the nineties made us do competitive tendering, and that is where a lot of people who have been through that phase are moving on to a more sophisticated approach between funders and providers that is not based on treating the services as commodities, which is a limited metaphor. It is based on treating them as valued services that have many dimensions and looking towards negotiated outcomes in the directions of reform that we support, rather than simply putting them out to tender to the lowest bidder, one presumes.

We have yet to see the outcomes of the tender process. I have certainly had discussions with the officials in the Department of Health and Ageing about what might need to be done to minimise the disruption to the service system. Discussions will occur once we know who has been successful in the tender process. But my overall point would be that it is hard to see how, going into it, you could have imagined anything other than disruption coming out of such a process. I really do not understand why they thought that was a good idea, to be honest.

Ms Stanley—Just to add to what Mr Mundy has said, I think the other problem with the tendering process is that it does not get us any closer to a system that is actually focused on providing better care for an individual. If we ever want to have a more integrated system, it is more likely that we will get that by focusing on the needs of an individual and how they navigate their way through the various tiers or the various parts of the service system. Tendering, as you say, distracts from that.

Ms Hills—And, as I said in the submission, the government needs to be very clear about why it is doing it. If it is about accountability, there are other ways of doing that. If it is about providing quality services, there are other ways of doing that. What actually happens at a local level—as our members have told us—is that normally the national respite for carers services are very localised. So when the tenders were announced, even though people were told, ‘You’ve known this for six weeks,’ or whatever, there were certain organisations that went off and did their own thing. Some organisations work together as a team anyhow—they have their planning meetings and things like that, and they actually work together. And you have large organisations that perhaps give consideration to whether or not they will come in and swallow up everyone. These are very locally based services. It is very interesting that many of our members tell us that they actually own the buildings that the services are provided in. I am not sure what the government thought they were going to do if in fact those people were not successful, because there are not spare buildings lying around that organisations have got to offer up.

I think that there was quite a bit of disruption in terms of the connectedness and the actual relationships between agencies, which has been well documented in the 1990s in Victoria. The sense of cooperation, trust and camaraderie between agencies was not destroyed but certainly came under some question, and also there were a number of larger agencies wandering around wanting to get into partnerships quickly with other organisations, trying to do what they thought would fit the bill of the federal government. Who knows, if they are successful, whether or not they will be able to form those partnerships and provide quality services?

Senator McLUCAS—When you say ‘larger agencies’, do you mean privately based agencies?

Ms Hills—No, not always. Some are the large not-for-profit organisations.

Mr Mundy—Can I make one further observation on that point—that is, while there was advance notice of these particular tenders from February, they actually only had an open period of about 15 working days because of Easter and various state based public holidays. It is not a long period of time for people to put together arrangements to provide for the integration of services at a local level, particularly since the tender documents also contained warnings against collaborative behaviour in terms of offences under the Trade Practices Act. It was at best a bit of a mixed message. The short time frame and those generalised warnings about collaboration may in fact have inhibited people from coming up with the integrated solutions for particular areas on the ground. I think the whole process would have benefited from a little bit more clear thinking, much more sensible time lines and, I would argue, a different approach to achieving the realignment of services on the ground.

Ms Hills—It was also very hard to explain to families, service users, carers and staff why this was happening. If they thought they were providing a quality service and if they were meeting the need, why were we going through this? If they thought that they were meeting all the requirements—and many of these organisations were accredited anyhow, even though they did not have to be—why was it happening? Many organisations I am aware of did not let the families and the service users know, and some of the staff did not know. It was the senior management that dealt with it because they were concerned about some of the issues that might cause anxiety amongst service users and the staff.

Senator McLUCAS—I also understand that current providers have been advised that they must tell people who are using their service that there will be a continuing service. I am not sure how a service provider can actually do that. It is a very difficult thing to say, ‘We mightn’t be here but there will be one there.’ On what basis can you make that statement? I find that very hard to come to grips with. Mr Mundy, you partly answered my question about the time line, in that there were in some states only 15 days to comply with a very large tender document. It has been put to me that there are many current providers of national respite services who just did not have the capacity to tender. Was that your experience as well?

Mr Mundy—I think that is likely. I have only got anecdotal information—some of it quite touching, actually. I had one from a woman who was going to do the tender but she could not get child care over Easter—and I do not think I could either—and was going to have to work with children in the background over five of the critical days. That would be additional to the 15. If you have a multimillion dollar tender for serious government services that are needed by vulnerable older people and that are a good deal more complicated than tendering for beer cans for CUB, trying to do that in a 15-day time frame strikes me as being bad business. I know that CUB tender their beer cans every two weeks, but they are the same every two weeks. This we are doing to a very complicated set of services, with a wide variety of players and with a limited capacity to fill out tender forms—because they do not do it every two weeks. I think 15 days is too short a period of time to guarantee a quality outcome.

It is frankly a bit rude. It is an insult to those people to say: ‘Here you are. You’ve been providing this service for decades. Now you’ve got two weeks to stake your claim to continue to provide it.’ Certainly there was a degree of anger from people who thought they had been treated with contempt. I stood in a room full of people in Mount Gambier and anger was the dominant emotion in the room. They said, ‘Why are they doing this to us? You show us where we’ve been doing a bad job.’ I said, ‘Hang on—this is not necessarily me doing this.’ I think more attention to due process and even to fair and reasonable tendering and contracting processes, which I do not happen to support, was missing from this particular instance. I hope that all of the people responsible have learned and will learn the lessons from that and do not do it again.

Senator McLUCAS—Do you know the date that successful tenderers will be advised of their status?

Mr Mundy—I do not know. I know that the implementation date is supposed to be 1 July this year, which may or may not have something to do with the time line issue that I talked about before, but I do not know when the successful tenderers will be advised. There was a date specified—I think it was late April or early May—but I am not aware of anything specific.

Senator ALLISON—A statistic that frightened me when I saw it in this submission, Ms Stanley, was that there were ‘4,500 vacant shifts in residential care homes per fortnight in Victoria’. Can you tell the committee what happens in those circumstances, if there is nobody there in that shift? What are the implications of that situation?

Ms Stanley—Actually, I was quoting Mr Mundy’s organisation in those figures and maybe he would be better to answer that, but I could also get you some specific examples on notice if you wanted me to.

Mr Mundy—I would need notice to provide specific examples but basically people do the best they can. They combine units and they have people covering more than one unit. They will of course try to engage agency staff but in many areas extra staff are simply not available. It is harder in rural areas than it is in metropolitan areas. If people are sick you cannot replace them.

There have been no catastrophic consequences as a result of these instances. They are short-lived. What tends to happen though is that the technical care that is needed to stop people getting sick or adverse events from happening is maintained but the human side of care—having time to talk to people and address issues of loneliness and social support—gets cut out. You should do those things every day but you can get by for one day without doing them. That is an unfortunate thing to have to say but that is generally how it would happen. People would always give priority to the technical care and the human side of care is what would be cut first. If you are living in an institution, which of course all of our residents do, that is actually very important. Our members are responsible for both the technical, clinical care and the quality of life of residents, and having to compromise one for the other is not a desirable thing to have to do.

Senator ALLISON—I invite anyone who wants to to respond to the idea that we have something less than an optimum continuum of care as clients move between acute, subacute, residential and home based care.

Ms Stanley—At present our members tell us that the funding systems are such that it is very difficult. The fragmentation of the funding systems means that it is very hard to track the care for somebody through the different stages of their care needs. In particular, if they have an acute episode in a hospital and have to move into community based care, there is no clear transitioning of that care. Often the funding moves to a different funding provider, and so it has to be reported differently. In addition to that, you get fragmentation that happens when a person is living at home in the community and receiving care. Some of the care may come through HACC funding but some of the care may come through a different funding source. Our members tell us of cases where different care workers visit the same home but are not able to look at anything beyond the small part of the care that they are being funded for. They cannot even assess needs beyond the particular care parcel that they have to provide. There are people who as a result of that go without adequate care because each little segment is only looking at a particular focus and has to exclude anything else. I think that is a direct result of the way that the funding happens.

Ms Hills—Our members see people being discharged from an acute health area. When they have been there for too long, the message is they want them to move on and they return to their residential care facility. Quite often they require additional care that would perhaps require more than the state registered nurse might be able to provide. That does create problems, particularly if they are returning from hospital to a low-care or hostel care facility where there may not be a div 1 nurse. I am talking about wound management, the administration of certain medications and those sorts of things.

If they are discharged from the hospital to the community, many of the hospitals in Victoria participate in a discharge planning or post acute care scheme. I am not sure if that is available in other states. If you are lucky enough to be selected to be part of that—and you have to fit certain criteria—you will get a risk assessment and you will receive certain levels of care for up to about six weeks. But what happens after six weeks? If you slip through the net for whatever reason and are not assessed as needing to get that care, then you are discharged and you are in the home. If you are living by yourself, there are issues about who provides the care.

There are other programs which the Victorian state government have funded which have proved quite useful. I have been involved in one looking at older people who are at risk of being readmitted to hospital. That is in partnership with St Vincent’s hospital and a whole range of community care providers. That has been quite successful because it very much targets those people who are likely to present back to hospital. It looks at all the support that they might need to stay in the community. It involves a lot of community care providers as well as the hospital and has been quite successful.

Senator ALLISON—Can the model you have just been speaking about be applied more generally to provide this more holistic approach? What would you recommend the committee recommend in this instance?

Ms Hills—I really could not see why not. One of the core things is that the hospital is pivotal in this model. They have a significant involvement. They certainly have to provide some major education for their staff, and it has been my observation over many years that significant attitude, skill and knowledge changes are required from the hospital staff and management as well as the community care providers. These pilots are certainly worth while expanding on. A number of them have been taken up in Victoria and I am sure they exist in other states. Many of them are being evaluated. I think that needs to be looked and, where practical, it should be expanded. There is still a great divide between acute health providers and community care providers. They have different cultures, and my colleague here will probably have a lot more to say about that. It definitely needs to be worked on. Why does it work in some areas and not in other areas? It is not just about systems, structures and processes; it is also about people’s attitudes and beliefs and about the power structure, where the funding sits and the incentives.

Ms Stanley—I support what Ms Hills just said. I think she is referring to the HARP, hospital admission risk program.

Ms Hills—Yes.

Ms Stanley—It is operating now in a number of different settings. Our members have had very positive experiences with that system because it acknowledges the different cultures as much as it can and tries to explicitly deal with the divides that occur among the various parts of health service provision.

Senator HUMPHRIES—I am a bit concerned about the comments that you have made about the need to pull back on accreditation agency vigilance or supervision of what is going on in nursing homes. These submissions today, and many others that we have received, are replete with descriptions of the pressures on providers at the moment: acuity of residents, rising demands, problems with the training of staff and so on. Yet you say, to paraphrase Ms Stanley in particular, that it is time to let the agency step back a bit and let managers take a greater role in maintaining standards. Is it realistic for us to accept that? Is it realistic for us to be saying, ‘This is the time to step away from agency supervision and let the temptation to cut corners rear its head in respect of standards in homes’?

Ms Stanley—My first response would be that it is a matter of degree. It does not mean stepping back altogether but it means acknowledging that there has been a maturation in the industry in recent years and that particular providers, if they have a good track record, need to be recognised for that rather than being policed in the same way that you would police a provider that perhaps did not have the same track record. The other issue, of course, is the availability of funding to deal with all of the accreditation standards. In the system currently there is not enough room for overheads that make it possible to do that beyond what is actually necessary. Thirdly, Professor Hogan makes the point very eloquently that in a more mature industry, if you want innovation and better models of care being trialled, you have to show trust in providers and there needs to be the opportunity for them to make some decisions, otherwise they will be forced to do things the way they have always done them. That is perhaps the biggest area where we are losing out.

Senator HUMPHRIES—I am suggesting that you could not guarantee to the committee, though, that, if we recommended and government accepted that there should be a pulling back of the accreditation agency overview, we would not see the sorts of headlines we saw a few years ago about low standards and incidents in nursing homes that in the first place generated this reaction by putting the agency in place and lifting and enforcing those standards.

Ms Stanley—I believe we would not revert to that, because overall our members have learnt to work within better risk management frameworks in all of the aspects of their business. I think there is a different consciousness of the importance of good business practice and good risk management which now is part and parcel of running any organisation. You cannot actually do without it, whether it is being controlled or not.

Mr Mundy—Could I come in on that question too. We had quality-monitoring processes in place before the standards agency was developed in 1997—I guess it was in the Aged Care Act—in the form of the standards monitors, and it was recognised at the time of the 1997 reforms that there was a need to transfer some of the responsibility for quality from an external body, the standards monitors, to the management of the industry through the accreditation process. So we have been moving in that direction over the period of those reforms.

I think there is capacity to take that a step further. We should continue that mission of building up the responsibility of the managers and providers of the services and not have them rely on external agencies to impose quality standards. But I guess, as a step along the way, what we have advocated would be a more efficient way of monitoring the quality and effectiveness of services, not a less efficient or less active means of monitoring. If we could reduce the overhead costs that result from having one agency that only monitors the quality in one thing and other agencies that monitor the quality in a slightly different but essentially the same way in other things, we would actually have more quality management capacity in the system rather than less—notwithstanding the fact that I do actually support Martina’s comments that we should be looking to try and transfer as much as possible of the responsibility for getting it right to the people who are in the position to get it right.

There will always be reports of adverse incidents in any aspect of human service delivery. It is an unfortunate fact that humans make errors and sometimes those errors have consequences. But we should be always looking to improve the systems that we use to monitor quality, rather than saying, ‘This has served us well; let’s stick with it.’ In that way you do fall behind. The thrust of our submission is about what should be the next step and how we take that process forward. We made a step forward in 1997, implemented in 2000, but we cannot say that the solution that was the best thing available in 2000 is going to be the best thing possible ever and that in 2005 we should not be looking to take the next steps so that we can make a similar level of improvements into the future. It is about not being complacent and saying that, just because we did this and it was a good thing then, it is still the best we can do now. That is not a good attitude to take, particularly in a quality improvement scenario.

So, yes, I think there is a need to monitor quality. We are dealing with vulnerable people, and we are dealing with an area which is prone to human error. We need to have the best possible ways of managing those risks and making sure that adverse events do not occur. I fully support the thrust of your question.

Senator HUMPHRIES—Could I ask you, Mr Mundy, particularly, to respond to allegations that have been made to the committee that there is a culture in some providers at least, in Australia, at management level, to intimidate and victimise residents and their families who choose to use complaints mechanisms against particular providers. These allegations emanate from a particular jurisdiction, but it was alleged that they were in fact evident in other parts of Australia as well. Have you had complaints of that nature made to your organisation and, if so, is there evidence that this is a problem that is significant or widespread?

Mr Mundy—I have had no representations to me of that issue—none whatsoever. I have had some made—from the other side, if you like—by providers who feel they have been the subject of vexatious complaints by disgruntled staff, which have made their way through the complaints system, which they have spent a lot of time and effort to deal with, and which have in the end proved to be groundless. But I have heard no instance of bullying or intimidation by providers of residents or their families. None have been brought to my attention. I meet quite regularly with the residents' rights association. We sit on the same committees and so on. No-one has raised that issue with me.

Senator HUMPHRIES—Could you respond, Ms Hills, to that question as well? Is there any evidence from your organisation?

Ms Hills—No. I was concerned when you said that. It is something that could possibly happen; I am not saying that it has not happened. But I am not aware of anything that has been raised with VAHEC. As Greg has said, I am aware of members raising issues regarding what they see as being unduly harassed by families and clients. We have done some work with the Complaints Resolution Scheme and a number of other advocacy groups. I am not aware. That is a very interesting comment. No, I am sorry, I cannot shed any light on that at all.

Senator HUTCHINS—How at the moment are aged care staffing levels set at your facilities? Could you explain how that is done currently?

Mr Mundy—The Aged Care Standards and Accreditation Agency actually have a very good policy—I will be even-handed in my comments about them—on setting the staffing level. It identifies a range of the issues that have to be taken into account, which would include the numbers of residents, the mix, the levels of need and the physical configuration of the building, such as walking times and so on. Those are the sorts of considerations that we would expect our members to take into account in developing rosters for particular units. They are in fact the things the standards agency look at when they do either an accreditation visit or a short-term spot check or support visit. There are probably a dozen variables that need to be taken into account in determining what are appropriate staffing levels for a particular configuration of residents in a particular physical location.

Senator HUTCHINS—Are those staffing levels minimum? Do they say that from 11 p.m. to 7 a.m. there should be three people in this facility because of the types of difficulties these people in the facility have?

Mr Mundy—They would tell you that. If you have a large number of residents who are up and about during the night, which would not be that common, then that would need be to be factored into the rosters so that you have staff there to deal with them. The only minimum levels that are specified would be to do with evacuation. Whether the people are awake or asleep, you do actually need a minimum level of staffing so that in the event of a fire or other emergency you could evacuate. Those levels are actually specified, generally in state law.

Senator HUTCHINS—So the other levels are not specified?

Mr Mundy—No.

Senator HUTCHINS—Are they recommended? Are they expected?

Mr Mundy—The difficulty is coming up with a number that you can set from Canberra as opposed to saying, ‘You must cover off all of these considerations in determining your staffing level.’ I think that is what has led people away from setting specific numbers.

Senator HUTCHINS—Most of my colleagues here, except for Senator Humphries, do not come from Canberra at all. We come from other parts of the country.

Mr Mundy—Very fortunate.

Senator HUTCHINS—We have always thought so.

Senator HUMPHRIES—I did not hear that!

Senator HUTCHINS—It was a compliment.

Mr Mundy—Do not worry, I used to live there, too. The other downside in specifying minimum levels is that what you do first is fill up the shifts that you do not need to—all the ones where the residents are asleep at night, when leaving them alone is actually quite a sensible thing to do. If you set a minimum, across-the-board staffing level then you spend your first X million dollars on putting staff where you do not need them.

Senator HUTCHINS—In the submissions there are a number of statements by employees of facilities who feel that the staff levels that are set are inadequate, particularly in the evening. Are these aged care facilities given the opportunity to essentially set their own levels? You said the only minimum requirement is for evacuations—is that it?

Mr Mundy—The only statutory minimum would be for that. Facilities do set their own levels. I want to make two comments about this. One is that, in terms of the quality of aged care as measured by the standards agency, we already heard just this morning that 90-plus per cent of services across Australia have full three-year accreditation, so from that point of view the standards are being met. On the other hand, I think it is true—and there is data which will show this—that the ratio of staff to residents across the board in residential aged care has in fact declined over the last seven or eight years. There are a couple of private benchmarking surveys that are done every year. They track the data over a number of years and you can see that the staffing levels have in fact declined over that period.

Senator HUTCHINS—Why do you think that has happened? Is that because people are not available to work in the industry?

Mr Mundy—It is a number of factors. I refer to my opening comments this morning about the New South Wales industrial decision that affects nurses. What else are people supposed to do? They have an increase in wages just for nurses that is more than the total increase in government funding for 2005. There is no scope to increase the user charges when 90 per cent of residents are pensioners who do not have the income to pay. So what else are people supposed to do but rationalise and make their staffing structures more efficient? Some of those do not involve reducing the absolute number. Sandra and Martina both referred to looking at optimising the mix of staff, making sure you are not using your most scarce resources on routine tasks such as pushing the medication trolley around for two hours a day. There is scope to develop more sophisticated models of care, and the work force strategy picks up on that.

There has been pressure over the last eight years between the need to provide a quality service to people with more and more complex needs and the levels of funding that have gone up more slowly than the demand that care imposes. So, yes, people working in aged care facilities would experience having fewer staff now to do the work than they had five years ago. That is true. It has not reached the point of being unsafe, otherwise the aged care standards agency could be accused of massively falling down on its task, which I do not think is the case. In our view what has suffered is the attention to people’s quality of life—the ability of staff to sit down and read the paper for 20 minutes to a resident, which used to be quite common. You will not see it happen these days. They do not have the time. So the experience of staff working in aged care facilities is that they do not have staff to do the job the way they used to do it, which they thought was better. They could well be right, but it has not reached the point of placing people at risk, if you like, but it possibly has gradually eroded their quality of life living in what is after all an institution.

One of our members said that their staff said to them that years ago they used to have the time to stop and sew a button back on someone’s shirt. They cannot do that anymore. They just do not have the time, because of the pressures I have outlined. I think that is unfortunate. I think we have lost something without ever having made a deliberate conscious public policy decision that that was what we were going to give up, but I do not think it has reached the point of being dangerous or unsafe, and let us hope it never does.

Ms Hills—Clearly, if an organisation when setting their budget every year say to their management staff, ‘We will tolerate no deficit,’ that sort of sets in train how they develop their staff rosters and those sorts of things. Just thinking about the responses that the commission received, when staff are saying they are under-resourced, short staffed or whatever the term was, clearly the relationship between management and the nursing staff is very important in terms of why is it that you can get X out of some staff and X-plus out of other staff. Clearly there are some relationship issues and there are some efficiency issues.

Greg referred to benchmarking. Certainly many organisations do benchmark within their own organisation and externally. Greg described a whole range of issues that an organisation has to look at when they develop their rosters, their staffing mix and their levels of staff. But I understand one of the biggest issues is that the population is not static. You have residents moving in and out, going to hospital, and you have people with higher levels of care. The senior management team requires real skill to monitor the care levels going up or down and those sorts of things. That is when sometimes people get caught out in terms of trying to manage their budgets, manage the care and meet the accreditation requirements. I am aware of some of our members who have found that quite challenging.

Senator FORSHAW—Just following up that issue from Senator Hutchins, Mr Mundy, you said that there is some data that has been tracked over the last seven or eight years. Could you supply that to the committee or direct us to where it may be available?

Mr Mundy—It is a commercially produced report. I do not think I can give it to you. I can give the secretariat all the details.

Senator FORSHAW—If you could take it on notice and follow that up, that would be good.

Mr Mundy—I can certainly do that.

Senator FORSHAW—One of the responsibilities of the agency, besides the accreditation of standards, is its involvement in promoting and providing training. It has been put to the committee and argued that the agency should not be trying to carry out multiple roles and that it does not do the training side of it effectively. I am interested in any comments about that observation and whether there should be a different body or some other means whereby training issues—both training needs and training standards—are monitored and promoted.

Ms Hills—What I thought about straightaway was: ‘What is the definition of training?’ That is the key thing.

Senator FORSHAW—That issue has also been raised in the context of what the responsibility of the agency is. People say, ‘What does that really mean?’

Ms Hills—The agency have had a couple of what I think they call ‘best practice continuous improvement forums’, and they have been travelling around the states. My understanding is that they have opened those up to involve all members so they can present as well as attend. They have been seen in a very positive light. The way I have looked at those has been that they are actually looking at best practice continuous improvement things that sit quite neatly with accreditation. That is why I asked the question about the training, because continuous improvement encompasses training in a whole range of ways. I think that there are a whole range of training opportunities that residential care providers avail themselves of which the agency do not provide. If their focus is upon continuous improvement, best practice and trying to promote that, it is probably quite appropriate, but if it goes further than that then there probably would be some questions.

Mr Mundy—In the interests of transparency, one of the issues that we have with the agency provided training is that they are in competition with our state associations, which are also providers of training. In fact, in three states—Queensland, New South Wales and Victoria—they are registered training organisations. I do not mind competition. I think competition is healthy in the provision of a service like training. However, I would be concerned if the agency got too much of a free kick as a result of its government funding. I do not mind competing on merit, and we have tended to offer training in different areas. There is a huge need for training in the sector. The more the merrier is a good thing. As long as there is no unfair advantage to the agency in terms of that provision, I think that is fine. Our New South Wales association, for example, is currently seeking to get reaccredited for the certificate course in quality management, which I see as complementary to what the agency is doing—

Senator FORSHAW—The argument is that really the agency could just get out of any involvement in providing training or trying to be some sort of body that promotes and provides training. Sure, it can assess training levels in the context of accreditation, but it should confine itself to that role and do that properly rather than trying to have some sort of multifunctional—

Mr Mundy—There is virtue in sticking to the knitting and not trying to spread your available resources too widely, but actually I am not opposed to the agency offering training courses and am quite happy to let the marketplace decide whether they want to do them or not. For the first round of seminars that Sandra referred to people felt they had to go and find out the agency way of doing things, but in fact after the very early ones people said, ‘No, it is just training like any other. You can take it or leave it in terms of how good you think it is.’ It is not intrinsically different from the sorts of activities that we provide as an organisation and I am happy for there to be a diversity of resources out there, provided that they are not getting huge government subsidies to compete unfairly. Training is a commercial marketplace—possibly overly so, but that is the fact of the matter. I am happy to have them participate in it. I think diversity of input in that sector is quite a healthy thing. I am not opposed to it. I would not say they should be banned from providing training. It is in their charter and if they are good bring them on.

CHAIR—We are going to have to leave it there as we are out of time. Thank you for your submissions and your presentation today.

Proceedings suspended from 10.30 a.m. to 10.47 a.m.

FEAR, Mrs Vanda Rosalie, Private capacity

ATKINS, Ms Megan Jane, Secretary, Inability Possability

McCORMACK, Ms Eileen, President, Inability Possability

DONOVAN, Dr Brian, Director, Karingal

LARKINS, Mr Kevin, Executive Director, Palliative Care Victoria

HARDING, Mrs Bronwyn Lee, Disability Services Programs Manager, Southern Health

YOUNG, Mr Gregory John, Executive Director, Southern Health

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions. I now invite you to make an opening statement, to be followed by questions from the committee. Who is going to start?

Mr Young—We are quite happy to start. Thank you for the opportunity to speak with you today. I would like to hand over to Bronwyn Harding to give some feedback around this issue on behalf of Southern Health.

Mrs Harding—Thank you for the opportunity to speak with you today. I will be speaking on behalf of the Acquired Brain Injury: Slow to Recover Program, which is a result of a number of Victorian government initiatives over the past decade. Our submission covers in detail the development of the ABI: Slow to Recover Program. I would like to make it clear that, when I am referring to a young person, in this instance I am referring to anyone under the age of 65. I provided you with a handout this morning that fleshes out the main points which I would like to cover today. I will skip over the background information on the first four pages and commence on page 5. Pages 5 and 6 outline the ABI: Slow to Recover Program eligibility. The program provides slow-stream rehabilitation services to people in Victoria with a catastrophic brain injury who are aged five to 64 and who have no compensation. Priority is given to those under the age of 50.

On page 7 are the ABI: Slow to Recover Program results. These results reflect the last quarter, from 1 January 2005 until 31 March 2005. During that period of time, 135 clients received services. Currently, 134 clients are receiving services—one client has deceased. In addition to this, 24 clients are currently on our waiting list and eight clients are currently having a care plan written up and will be admitted into the program if deemed eligible.

Page 8 has the ABI: Slow to Recover waiting list. Of the 24 clients who are currently on the waiting list, four are deemed priority 1, or under the age of 50; 18 are priority 2, aged 50 to 60; and two are priority 3, aged 60 to 64. Of the 24 clients currently on the waiting list, 12 were referred from a public hospital, nine from a rehabilitation facility, two from a nursing home and one from a community physiotherapist.

Page 9 is about accommodation outcomes. The graph demonstrates the accommodation outcomes for all clients who have received services from the ABI: Slow to Recover Program since its inception. It is worth noting that the majority of clients have been able to return home with ABI: Slow to Recover support. Moving on to page 12—

CHAIR—Just before we do, in terms of the nursing homes the numbers have actually gone up. I thought you indicated earlier that two people had come out of nursing homes into the program. Or was that the waiting list?

Mrs Harding—That was the waiting list.

CHAIR—So all those people on that graph of accommodation outcomes are in the program at the moment?

Mrs Harding—Yes. That is a combination of clients who have received services since the inception of the program. It shows outcomes over the last seven years. So the majority of clients have moved from hospital to home.

CHAIR—Sure, but am I reading that right—that the number of people going into nursing homes has actually increased, from 43 to 53?

Mrs Harding—Yes. Looking at our limitations, the ABI: Slow to Recover Program is a state-wide service. This service is not available to people in other states. Our waiting lists probably do not fully reflect the needs of people over the age of 50. Most referring agencies know that there is a very lengthy wait for services for the over-50s as they are deemed a lower priority. Consequently, they fail to refer.

While most clients would prefer to be at home, this does put enormous strain and responsibilities on families and carers. The support provided to carers in the long term is currently inadequate. Rural clients are often disadvantaged because they do not have access to the same services, such as qualified therapists, as city clients do. Other groups of younger disabled people, such as those with spinal injuries or neurological disorders such as MS and motor neuron disease, and people with terminal diseases such as brain tumours do not have access to like services.

Page 13 are our recommendations. We recommend: an expansion of the target group to include people with spinal injuries, long-term neurological conditions, palliative care needs and major injuries; increased funding to more adequately reflect the need for services so as to be able to provide services to all eligible people in a timely manner; increased funding to cover adequate respite for carers, including plans for end-of-life respite and appropriate long-term accommodation; creation of more appropriate accommodation options for younger people who are currently placed in nursing homes because they cannot be managed at home; and consideration to extending this valuable program to other states throughout Australia.

In conclusion, I would like to illustrate by means of case studies how the ABI: Slow to Recover Program has assisted two of our clients. While both of these clients have quite high needs, their care needs are quite different. Before presenting these two case studies, I would like to take the time to acknowledge the tremendous amount of support that this program receives from the Department of Human Services. The very open communication that we have with the department assists us in delivering a flexible and responsive program.

Case study 1, on page 14, is Mr G. He is a gentleman aged 30-plus who acquired his brain injury in 1995 following complication of an elective resection of a large occipital parietal arteriovenous malformation. Mr G was accepted onto the ABI: Slow to Recover Program in 1996. Mr G has been left with profound cognitive and linguistic impairments and sensory agnosia. He is also visually impaired. With the support of the ABI: Slow to Recover Program, Mr G was placed in a nursing home some months after surgery. He suffered severe behavioural problems, which included uncontrollable outbursts. The behaviour problems could be directly attributed to being placed with elderly, demented patients.

Despite behavioural intervention, his behaviour continued to escalate and he ended up punching an elderly resident. Mr G was charged with assault and placed in the Royal Talbot brain disorders unit. With support from the ABI: Slow to Recover Program and through a long search, accommodation was found at a group home with five other younger residents, all of whom have an ABI. The ABI: Slow to Recover Program has continued to assist with funding this placement since August 2001 by providing an addition 21 hours of attendant care a week for Mr G. Overall, the placement at the group home has been a success, with Mr G having full days of meaningful activities. Any behavioural problems have been minor and are quickly and expertly dealt with.

Case study 2, on page 15, is Mr A. He is a 31-year-old man who sustained a severe hypoxic brain injury in July 1991 after he allegedly attempted to hang himself while in police custody at the age of 17. As a result of his ABI, Mr A has severe limb spasticity and contractures. He has no effective speech and is unable to swallow safely. He is able to make semipurposeful limb movements and he is able to track with his eyes. He is able to respond to yes/no questions.

Mr A was initially treated in another state and was then transferred to a major public hospital, where he remained an in-patient for three years. Mr A was accepted onto the ABI: Slow to Recover Program as its first client in 1995. He was eventually transferred to another hospital for assessment before being admitted in 1995—with assistance from the ABI: Slow to Recover Program—into an aged care nursing home close to family. Mr A requires 24-hour nursing care. He is doubly incontinent and, due to his spasticity, requires two nursing staff to attend to even the simplest of care. He is fed and hydrated via a PEG tube directly into his stomach.

The ABI: Slow to Recover Program provides additional funding to the nursing home so that Mr A is able to receive the level of care that he requires. The ABI: Slow to Recover Program funds regular physiotherapy and massage for Mr A, as well as occupational therapy and speech pathology intervention. The allied health professionals also work with the nursing staff to train staff how to best look after someone with Mr A’s high needs. As a result of the extra services that Mr A receives, he remains reasonably healthy and comfortable. Despite being bedridden since 1991, Mr A has had very few chest infections and no major skin breakdowns, which is a very common problem for people who are confined to bed for such long periods. Thanks for your time today.

Dr Donovan—Thank you for the opportunity to be able to speak to you today. There are lots of links between what Mrs Vanda Fear and I would like to say and what was just said, even down to the last case study, on Mr A, because every day of the year Vanda and her husband, Keith, support a son who has a severe hypoxic brain injury. They get support for 44 hours a week—just over 25 per cent of the time—and the other 75 per cent they make up themselves in order to keep their son out of an institution. Karingal, which supports them, is a community organisation founded 50 years ago in Geelong by parents of people with a disability.

This morning's presentation to you is to give a glimpse into the life of one of our clients, Paul Fear. He has the highest support needs of any of our clients across the south-western part of Victoria, which we serve. There are no facilities there to provide for his needs other than nursing homes. Paul is therefore being cared for in his own home by a dedicated mother and father. They receive trained carer support for about that 25 per cent and the other remaining 75 per cent they do themselves, even though the father works full-time shiftwork. The strain from doing that is enormous. But they are not asking for more funding; they just want to be able to use the federal respite funding that is designated for them—and there are some structural obstacles to doing that. Vanda will talk to you now and I will add a bit on the structural obstacles shortly.

Mrs Fear—Good morning. I am here with my husband, Keith, on behalf of our family. Our family consists of my husband, Keith; me; our daughter, Rachael; and our two sons, Glenn and Paul. Until early 2001 we had what we thought was a great life and that we were truly blessed. Then our whole world fell apart. Paul was diagnosed with severe depression. We still do not really know what went wrong. Paul was just the best son you could ask for—he had a great personality and he loved playing his guitar, playing football, and girls.

We thought we did the right thing once we were aware of how bad things were with Paul. He was feeling suicidal and we were worried sick. We took Paul to the doctor, who prescribed antidepressant tablets that can take up to six weeks to start working. We all agreed that, until the medication started to work, Paul needed watching over in hospital. Paul was only 17 years old when he tried to commit suicide while in the Swanston Centre in Geelong. He went without oxygen, which resulted in a severe hypoxic brain injury. After nine terrible days in intensive care, where Paul was not expected to live, he was transferred to a normal ward. He stayed there for about nine weeks with either Keith or me by his side at all times. At the end of this time we were really pressured to place Paul in a nursing home in Geelong without any rehabilitation as Paul did not qualify for mainstream rehab.

You do not abandon your kids when they are sick, and we were not about that to do that to our son. We decided he was coming home with us. At about this time we heard about Ivanhoe Manor, a private rehabilitation hospital in Melbourne. We did not have any funding such as TAC or WorkCover, but luckily our private health insurance with GMHBA allowed us to take Paul there for three weeks with us paying a copayment. In this time we learned how to take care of Paul at home. It was pretty daunting as we kept getting told that this had never been done in Victoria. Paul was still very much in a comatose state with a tracheotomy. All of Paul's doctors are now our biggest allies and can see that he is doing great at home. Paul has been home with us for four years this June.

Looking after Paul 24 hours a day is a full-time job. My husband Keith is pretty amazing. So that we can afford to care for Paul at home, Keith still works full-time shiftwork, usually two 12-hour day shifts followed by two 12-hour nights. After being away for 14 hours at a time, Keith comes home and helps look after Paul. Twenty-four hours a day with Paul means exactly that. Every night means getting up with Paul between five and 20 times, depending on what sort of a night he has. Paul also suffers from sleep apnoea and needs his oxygen levels monitored all night. On Keith's days off from work he takes over getting up with Paul during the night so that I can catch up on some sleep.

Paul is part of a state funded Home First Program through which we receive 34 hours of support per week. We also receive 10 hours per week from the state's Slow to Recover program. These hours are used for carers to come in daily to help us with Paul. A few months ago some additional funding was made available. This is a great help as it means that, twice a week, carers come in at night and care for Paul so that Keith and I can catch up on some sleep. This funding, though, is once off and only goes to 30 June this year. Paul was also assessed by the aged care assessment team from Grace McKellar Centre in Geelong and he qualified for nine weeks high-level respite per year. The problem with this is that there is nowhere suitable for Paul in Geelong. Our only choice is nursing home accommodation.

One of our options was the dementia ward at Grace McKellar. The day we took Paul there for an interview broke our hearts. Paul loves elderly people, but he is only 21 years old—and he was only 19 at the time. No young person should be subjected to that environment. The only thing the nursing staff could assure us of was that Paul would be got out of bed, washed and fed. They freely admitted that they were not trained to look after somebody with an ABI injury. People with an acquired brain injury need a different type of care to that needed by the elderly. A really important part of their care involves plenty of physio and stimulation such as music, which Paul really loves.

We have all worked really hard with Paul, and placing him in an aged care facility could undo many of the great things that we are still achieving. We still have not had any respite, and we take Paul with us when we go away. While we really love doing this, you could not really call it a break. What Geelong really needs is a purpose-built facility for young people with high needs. In the meantime, we would love to see the nine weeks of federally funded respite care being made available to our service providers. This would be great. We could use the hours for our carers to come in on a regular basis overnight. Also, our carers could look after Paul at home while we went away for a break from time to time. We are really lucky: our carers are brilliant and love to take care of Paul; they are already well trained in Paul's care.

Probably the most important thing that I would like to mention today is our fear for the future. While we love looking after Paul at home, we will not always be here to do this. I am terrified about what will happen to Paul after we have gone. I would never expect my other children to take over this responsibility. They deserve a life of their own. There has to be somewhere in the future for our young people to be accommodated for either respite or long-term care. This problem affects us all: it is our kids that we are talking about, and it could happen to anybody's family. I really hope and pray that things will change for the better in the future. Thank you.

Dr Donovan—This Commonwealth respite funding can only be applied in Geelong to an aged care facility. The demarcation line between state funded carers and federally funded respite leads to the anomaly of a family that desperately needs respite only being able to obtain it in inappropriate and inadequate facilities and not being to apply it to carers who are already known and trained and who can be there in the home. The result of this sort of inflexibility is that the parents do not get respite. In spite of their extraordinary courage and dedication, without respite their situation is unsustainable.

Ms Atkins—We welcome this inquiry and thank you for the opportunity to give evidence today. Inability Possability is a volunteer organisation which seeks to advocate on behalf of young people with an acquired brain injury who require high levels of care and have no form of compensation. We also facilitate and support a family and friends association and have contact with 30 young people with ABI and their families around Victoria. We are here in a voluntary capacity to give voice to this group of young people who cannot speak for themselves, many of whom are non-speaking and require 24-hour care. Incorporated in 2001, Inability Possability is a registered charity, and we rely on donations, grants and fundraising for our operation. We undertake projects to promote the issue, including the publication of a book—a copy of which you all have—the production of a short film, lobbying of politicians, participation in conferences and raising awareness through newspapers and radio. Eileen and I both work full time. Eileen is a social worker and I am an industrial designer.

In our submission we have addressed term of reference (c) about the appropriateness of young people with disabilities being accommodated in residential aged care facilities. We make six points as to why this is not appropriate. The first concerns the design of aged care services and facilities. There are no examples in Victoria of facilities and models of care designed specifically for this group of young people with ABI. These young people are no different from other young people in that they have their own interests and needs, they need their own space and they want to interact with family and friends. This is dependent on them being provided with appropriate nursing care to maintain a level of health that enables them to do such things.

The second point is social environment. The interests of a young person, male or female, are vastly different to those of their parents and grandparents—which is the age of the majority of the people that these young people live with in nursing homes. As a 30-year-old woman, I could not bear the thought of living in such a place for the next 50 years of my life. Friendship groups often disappear not only because of the confronting nature of severe ABI but because of the environment of a nursing home. Also, the pre-injury history of a person is vital. This is not often accommodated when people are transferred to nursing homes. It is necessary to understand their needs and assist in their recovery and enjoyment of life.

The third point is rehabilitation facilities. Rehabilitation is only provided if these people are placed on the ABI: Slow to Recover Program. Often in nursing homes there is no specific exercise or rehabilitation room. Often the only visitors these young people have are their families or paid carers. The fourth point is staff training and medical needs. The requirement of a person with ABI is very different from that of an elderly person. The processing of information, and responding to questions, often takes a lot longer. There is a need to understand the complexities of brain injury and that it is unique for every person.

The fifth point is on funding. As we all know this group of people is up against a number of barriers: state versus Commonwealth, disability versus aged care, and the specific classification of that person’s disability. The sixth point is that a specific assessment tool is needed for young people with ABI as they are currently assessed under the aged care assessment tool. We put, at point 7, the recommendations we are putting forward to address the issues raised. Our knowledge of this comes from interaction with these family and friends and working at the coalface for the past five years and listening to their stories.

Mr Larkins—Thank you for this opportunity. Palliative Care Victoria is an incorporated body that represents the interests of hospice and palliative care services throughout Victoria. It has been involved in these issues for some considerable time. The submission put to the committee represents the collective wisdom in a consolidated way of that group. A lot of the points that have been made here have been made by specialist palliative care services. It is important to realise that palliative care does not necessarily cover the last two or three days of a person's life. In terms of specialist palliative care, it is pushed back beyond that into life-threatening illness and the management of that. It is the management not only of the pain but of the involvement of families in that process. A good engagement of that can improve outcomes for families and for the community generally.

For Palliative Care Victoria the issues for this inquiry are specific in terms of the ability of aged care facilities to deliver those services to people. There are Commonwealth guidelines—the Australian palliative residential aged care guidelines—that were developed over two years. They are about to be implemented, but are not mandated for, as is the case in most guidelines. Most specialist facilities would see a huge advantage in those guidelines being taken up over time by the Commonwealth in the agreements that are reached with aged care facilities, such that all aged care facilities have the capacity to both identify and respond to the palliative needs and to provide a palliative approach to those people within their facilities.

Increasingly, in the experience of palliative care services, the issues that have been raised here at the table are the same issues that palliative care services face—that is, people going into aged care facilities who are under the age of 65 and who are not demented but have severe, complex disorders, and young people with brain injury and brain tumours. The issues are those around the needs of the people, the skills of the staff to meet those needs or their ability to recognise when to call in the specialist services, and how to integrate the specialist services of palliative care with those of the residential aged care services.

There is an increasing dependency of aged care residents. As a result of that, increasing skills are needed in the aged care facilities. As that dependency increases, so does the likelihood that they will be in need of palliative care and palliative responses, and there will be a need to engage the families. There are specialist issues related to PEG feeding, ventilation and other things that are mentioned in the submission. I will leave the rest to questions. I should say that I have only been in this job for five minutes—it is three weeks—so I bring to you the wisdom of those that I have contacted during that time on the executive and from the reading of this report. I can say that it is symbolic of palliative care that I am speaking last. Very often people wait too long to bring in the services of a palliative care specialist and also to understand the palliative approach—that the experience, particularly of families, goes way beyond waiting for the last gasp.

Senator KNOWLES—Dr Donovan and Mrs Fear, I would like to see what you have done in relation to dealing with the state government about them exercising their responsibility for the accommodation needs of young people with disabilities.

Dr Donovan—They have pursued all the funding avenues they are able to pursue. They have had bits and pieces of funding over time. There has been plenty of pursuit of state government and federal government. If someone knows of any other avenues, we would be happy to hear them.

Senator KNOWLES—I asked that question in relation to the fact that the Australian government does not directly fund or plan accommodation needs for people with disabilities.

Dr Donovan—Our focus here, in the presentation to you, was around respite.

Senator KNOWLES—I am coming to that.

Dr Donovan—We are certainly trying to pursue appropriate facilities in our area, the Geelong region, as I believe people are in lots of other areas. To get something happening there is a longer term goal. What is needed is to be able to make it to that point for a family that are trying to keep their son out of a nursing home—not to look for more money but just to be able to access that for which they are eligible and the money has been designated.

Senator KNOWLES—I want to focus first and foremost on the requirements of young people with disabilities to be kept out of nursing homes and put into accommodation of a standard that is suitable for their requirements. This afternoon we are going to visit the multiple sclerosis facility that was opened recently as part of a pilot project. I think the state government needs to be congratulated for accepting that pilot project in conjunction with the Australian government. I am looking for responses from all witnesses today as to what they are doing in relation to ensuring that the money that is allocated to the states under the Commonwealth State/Territory Disability Agreement is being used appropriately to provide those accommodation facilities for young people so that they do not have to be inappropriately placed in nursing homes. Does anyone have a comment on that?

Mrs Fear—That seems to be the whole point—the focus seems to be on aged care facilities, especially where we come from. In Geelong there are no other facilities. There is not even anything that could be modified and made better. There is nothing for young people. All there is is a bed in a dementia ward. We have looked into really good private nursing homes, but their residents are still frail and elderly people. There is nothing available.

Senator KNOWLES—That is the point that I am getting at. Under the Commonwealth State/Territory Disability Agreement, money is provided to all the states and territories to provide accommodation facilities specifically for younger people with disabilities so they do not have to be placed in nursing homes.

Mrs Fear—That is certainly not happening.

Senator KNOWLES—That is what I want to know. What are your organisations doing about ensuring that that money is being spent on providing those accommodation facilities that are so desperately needed?

Dr Donovan—We have got six state government politicians in Geelong. Because they change at different elections, one would think they would listen to what people are saying. We have had people from Karingal visit all of the state politicians to bring their attention to these sorts of issues. It is a longer term issue, though, to get it addressed and to get significant funds for the facilities and the running of them. I can tell you that at a political level we are certainly endeavouring to lever things.

Senator KNOWLES—It should not be a longer term issue. The Australian government has provided nearly $5 billion to the state and territory governments to do exactly what they should be doing. That is why I am asking the question: what is happening now—not in the long term but now—with that money that has been allocated to do exactly what you are asking to be done today?

Mr Young—There are a couple of things. That money has already been committed, but I think it has been committed for the lower level of care that is required. The people that we are talking about today, in particular from ABI, need a higher level of care. There are not those facilities at this stage. One in Mount Waverley provides some of that care. A lot of the money is distributed to work with people with disabilities who are at the lower end of the care, but it is not distributed for people with disabilities at the higher end of the care. The amounts of requirements, needs and funds attached to caring for those people are the difficulty that we fight to overcome.

Senator KNOWLES—What is the answer from the state government as to why they are not addressing the problems of the higher needs people?

Mr Young—One of the programs that we look after in the ABI is at the beginning phase. We are committing close to $6 million to begin to support that process. Again, we would like to think that that would increase. I have to admit that the Department of Human Services at the state level have been very supportive in increasing our funding to support this high-level group. So we have commenced that over the last three years. It has increased every year and we have continued to support that. Again, we are not saying that it actually meets the needs. There is still, as we see it, quite a substantial number of people on the waiting list that we just cannot pick up because of the funds attached. But we have to admit that the state government has been very supportive in providing funds to support this group up to this stage.

Senator KNOWLES—The stories that you are all painting today are pretty drastic. Money has been committed through the agreement from both the state and the Australian governments. I wonder whether Ms Atkins of Ms McCormack would like to add something.

Ms McCormack—One of our members has recently met with a state minister, Minister Pike, and the federal minister, Julie Bishop. On those occasions both put up the old chestnut of it being either a state responsibility or a federal responsibility. While you may make the comment about the state and territory disabilities agreement, that argument is still being put up to people, so it is still a hurdle.

Senator KNOWLES—Let me stop you there. The current agreement does not expire until June 2007. Everyone has signed off on that agreement. This is not an agreement under negotiation at this time, as we speak. This is an agreement that is currently in place until June 2007. So there is no point in people duckshoving one way or the other. It is a case of saying: where are the results? What is happening? What commitments have been given to organisations such as yours to address the problems that you are currently experiencing?

Ms McCormack—There is a reluctance in relation to young people who are in an aged care facility who require a very high level of care and who currently receive about $65,000 per year. Maybe the states fear giving up that amount of money to take responsibility totally for this group of people. While we can say that that agreement is in place and there should not be this nexus, there is.

Senator KNOWLES—I agree there is a nexus.

Ms McCormack—We represent families, and we are not experts in some of these agreements. But this is what families are up against—dealing with those political hurdles and complexities.

Senator KNOWLES—Absolutely. I agree, and that is the problem. We have instances, and I could provide evidence, of state ministers responsible for this agreement writing to the federal minister and asking for permission to place a young person in a nursing home—a person who should be placed in a facility provided by that very minister. That is in complete contradiction to the agreement. Without pressure from organisations such as yours, this agreement will just continue to slip through the stools. That is why I am very keen to find a solution for people like Mrs Fear. Mrs Fear should not have to worry about her son Paul not being adequately accommodated if and when Mr and Mrs Fear cannot look after Paul. That is why I think there is an immediate problem about respite care, but there is the longer term problem, as Mrs Fear explained, when you and your husband are no longer able to look after your children in the way you want them to be looked after. I am interested to know where we are at in terms of this agreement. It seems that it is really falling apart at the moment.

Senator McLUCAS—The Victorian government is seeing us tomorrow. By way of answer to Senator Knowles's question, the Victorian government would, quite rightly, say that they were pressured into signing the Commonwealth State/Territory Disability Agreement at a lower level of funding than they would have wanted.

Senator KNOWLES—I have not asked Senator McLucas a question.

Dr Donovan—From this end of the table, I can tell you that that illustrates that this is a political question. While we can all play a part by raising our voices in relation to it, when one considers issues to do with the Commonwealth State/Territory Disability Agreement, one realises that those issues have gone on and on, for years and years. If you go back to 1992, there are a range of things that have never melded together in ways that, as a consumer of service, you would think, 'Why can't they get their heads right to do it?' This is another one of those things, and it certainly needs addressing at a political level, and people have a voice at that level too.

Senator KNOWLES—I agree. But the fact of the matter is that these agreements were signed and agreed to. If I cannot ask questions of organisations like yours, we may as well not have an inquiry at all to know what is happening and where we are going. We cannot continue to have young people being inappropriately placed. That is the reason for the question. The other question is in relation to palliative care. The palliative care issue is also primarily a state and territory government responsibility, because it is generally provided under their health network. Mr Larkins—and I know you have been in the job for only five minutes, as you said—has your organisation pursued increased palliative care facilities with the state government? Would you like to take that on notice?

Mr Larkins—Yes, I will. The issue in our submission is more around the skill base and the application of palliative care in the aged care setting—an acknowledgement that in the aged care setting, the population of people coming into that setting are ageing anyway and suffering from dementia and complex disorders. There are an increasing number of under 65-year-olds finding their way into aged care services—including young people with brain tumours who have complex needs. The aged care facilities are finding it increasingly hard to meet those needs and to link up the specialist palliative care facilities with aged care facilities. Palliative Care Victoria and Palliative Care Australia have done a good job in the past 10 years in integrating their care with the generalist health system. So you have continuity of care from tertiary care through to primary care, with the availability of specialist care and with general practitioners providing that support in the home.

The APRAC guidelines that the Commonwealth has developed provide the basis upon which aged care facilities can move towards providing better care for those people in those facilities. That is where our submission comes from. I am not sure that it is a matter of providing more specialist palliative care services, but of being able to provide the palliative approach in an aged care setting. That requires resources and skilling, which presumably is a Commonwealth-state issue, in terms of being able to complement the directions of facilities at the state level and the agreements reached between the Commonwealth and the aged care facilities about how they deliver their services. That is the best spin I could get on it this time. I would be more than happy to take that question on notice and explore it a bit more for the committee to see if I have answered it properly.

Senator McLUCAS—The key message that we have learnt out of all of your submissions today is that, from your perspective, you do not care about the level of government with responsibility; you would prefer the funding and services to be delivered on the basis of need by whomever. That is a message we have received at every hearing we have had, especially from representatives of people who are working for young people in nursing homes. Can I go, though, to the question of where the money comes from. Mrs Harding, on page 9 of your submission, you talk about from whence the person came and where they ended up. Without the Slow to Recover Program, where would you predict that the 144 people who came from hospital might have ended up?

Mrs Harding—A large proportion of the 86 that have been able to go home would have ended up in aged care facilities, because without that additional support there is no way that families would have been able to care for those people. Many more would have ended up in nursing homes.

Senator McLUCAS—That goes to the question of who should pay. With $5 million of investment from the Victorian government, you have been able to more appropriately accommodate quite a large number of people. The other part of the question is that I dare say a lot of those people would have stayed in hospital.

Mrs Harding—That is correct too.

Senator McLUCAS—So getting 86 people out of hospital and out of nursing homes means there is a saving to both the Commonwealth and the state. Many people have submitted to us that historically the Commonwealth has supported especially young people with acquired brain injury or people with multiple sclerosis in residential aged care, however inappropriate that might be. Historically there has been a commitment from the Commonwealth to that group of people. If that support is withdrawn, it then pushes them onto the Commonwealth State/Territory Disability Agreement, which everyone agrees is an underfunded program given the current and growing level of need out there. Has there been any cost analysis of the savings in a global sense of the history of that group of people? Have you done any work on the costing and benefits?

Mrs Harding—Like my colleague, I have only been in the position for 4½ months, so I am fairly new to the job. I know that those sorts of figures have been looked at but I cannot draw them off the top of my head for you today.

Senator McLUCAS—It would be really useful to the committee if you could give them to us. I think you know what I am getting at. What are the savings to the Commonwealth for this investment of $5 million? What are the savings to the state? That real data could be very useful to our committee.

Ms McCormack—A lot of people would not survive if they were not placed on the Slow to Recover Program. I think that comes into play.

Senator McLUCAS—That is a real fact as well.

Mrs Harding—That is right. I think there is an issue too in that, for some of the clients we do have in nursing homes, the slow to recover program is actually topping up the Commonwealth in assisting those people to be cared for. Without that assistance those people would be at real risk because nursing homes are not able to provide the level of care that is required for some of these people.

Senator McLUCAS—In your case study you talked about someone who was being topped up, if I can use that terminology. What is the cost of that to the Slow to Recover Program?

Mrs Harding—We pay about $53,000 a year.

Senator McLUCAS—You talked about the fact that one of your clients came from another state.

Mrs Harding—He is actually a Victorian resident who was travelling interstate when he was held in police custody.

Senator McLUCAS—But he was a Victorian resident?

Mrs Harding—Yes.

Senator McLUCAS—Have you had requests to come from people from other states?

Mrs Harding—Yes, we have.

Senator McLUCAS—Actually, I know of one. One of my constituents has tried to get on your program, and I come from Cairns. What level of interest do you have from people from other states?

Mrs Harding—These days parents have access to a lot of information and are quite proactive in seeking out the best for their children. For the particular client that you are talking about in Cairns, the mum found the Slow to Recover Program on the web site through a search. So it does happen occasionally that there will be inquiries from interstate people.

Senator McLUCAS—And how do you have to respond?

Mrs Harding—If people have been Victorian residents and can clearly demonstrate that and are moving back here, then that is not an issue and we can put them on the program. But we would be very hesitant to recommend that somebody move interstate just to receive adequate services. That is clearly not appropriate.

Senator McLUCAS—It is very difficult for you to say no, I am sure.

Mrs Harding—It is very difficult to then find or recommend suitable services for somebody who is interstate.

Senator McLUCAS—Mr Larkins, you talked in your submission about younger people with brain tumours, MS or motor neurone disease. Let us talk about the group of people who are currently housed in residential aged care and then require palliative services. Is it your advice to the committee that they stay in that facility, rather than relocate to a purpose-built palliative care facility?

Mr Larkins—My reading of our submission and discussions with others would suggest that the latter would probably be the case. It would depend, I guess, and it would be a clinical and a family decision based on the level of care that is currently being provided. Throughout all of the discussion there is a theme that says there is a requirement for a specialist facility. The difficulty with all specialist facilities is that they cannot always meet the global needs within the state, and they need to be located within proximity of families so they can have access. Ideally most of those people would be better placed in a facility that was age specific or at least within their age range. Someone with a brain tumour who is young, in their 30s and with a young family, has specific needs associated with that yet can be in a facility dealing with aged people suffering dementia. It is clearly not a great mix, but sometimes necessity requires that. So in answer to your question I would suggest that, yes, that would be the preference.

Senator McLUCAS—I was meaning those older people who are currently in a residential aged care facility—they may have been there for 10 years, for example—and then require palliative services. Is your group suggesting that the most appropriate response to that event—

Mr Larkins—You mean an older person?

Senator McLUCAS—Yes, an older person—for example, somebody who is 70 or 80.

Mr Larkins—No, I do not think so. I think the response would be that what they need is the appropriate care in the facility that they are currently residing in. I do not think it is necessarily a difficult ask for that to happen. You could link up with a specialist service located within the facility or you could develop the skills of the staff to meet those needs. Sometimes it is fear that prevents that from happening, and lack of knowledge and understanding; that is all.

Senator McLUCAS—There would be a cost to delivering that extra service, a palliative service.

Mr Larkins—Yes, there is. Those guidelines that have been developed have all of the requirements detailed in them. Like all guidelines, they now need to be implemented. Dissemination and implementation is always at a cost—that is, the training.

Senator McLUCAS—So it is a training cost rather than an ongoing service cost?

Mr Larkins—Yes. Globally a greater reach would be had by that training cost and linkages with specialist services to provide the palliative care needs of residents.

Senator ALLISON—Mrs Harding, looking at some of the statistics you have provided the committee with I see that you have 193 clients and yet you say there are 4,700 people with acquired brain injury in nursing homes alone. How is it that you have a waiting list of just 24 when there are obviously so many people in this category in nursing homes? You also recommend that we extend the eligibility to a whole range of other groups with spinal injuries and the like. Can you comment on the waiting list approach.

Mrs Harding—Clients are only accepted into the program if they are referred within two years of their acquired brain injury—so within two years of the event happening. Given that this program has only been up and running for seven years, there would be a number of people who were deemed ineligible when the program began because they would have acquired their brain injury some time before the program was established. The other point to make is that often the over-50s are not referred because they are not given as high a priority as people under the age of 50. So when you start talking to your referring agencies, many of them will say, ‘I don’t bother to refer anyone over the age of 50 because I know they’ll sit on the waiting list for too long and I might as well look at other options.’ So I think there are a number of people out there over the age of 50 who are never actually referred to the program.

Senator ALLISON—Is this part of the tender that you accepted that people are not eligible to apply if the event took place more than two years prior?

Mrs Harding—That was the guideline that was established in the beginning of the program.

Senator ALLISON—Do you have any understanding as to the justification for the two-year limit?

Mrs Harding—The idea behind that is that the best rehab happens in the first two years after somebody has suffered a brain injury. So most advances will be made in that first two years.

Ms McCormack—Even though that assumption is questioned now.

Mrs Harding—That is questioned now, but when the program was established seven or eight years ago that was the thinking behind it.

Senator ALLISON—Can we explore that two-year cut-off further. Ms McCormack, maybe you have some views about that. I understand that there has been some research in recent times which challenges that notion.

Ms McCormack—There is more current research that indicates that brain recovery can take place for up to 10 years or more. When the Acquired Brain Injury Slow to Recover Program was established they were using statistics from that time that were indicating a two-year period of best recovery post injury. I suppose expediency means that it is convenient to keep using that statistic of two years because if we look at potentially 10 years then that is going to include a whole other group of people—and of course that means money.

Senator ALLISON—I just did a back-of-an-envelope calculation on that 4,700 people currently in nursing homes with ABI. If they receive the average that is being received by people in your program, we would be talking about $178 million just for Victoria. Does that sound out of the ballpark to you?

Mrs Harding—It is about right.

Senator ALLISON—So the level of unmet need is gigantic, to say the least. Mrs Harding, can you indicate how this works? I noticed that the vast majority of your clients are sent back home. Perhaps you could take Mrs Fear’s son as an example, but typically what would be provided by your program to the families providing 24-hour care?

Mrs Harding—We would provide 10 hours of attendant care per week.

Senator ALLISON—Is that where a person comes into the home and is there for 10 hours a week?

Mrs Harding—Yes, for 10 hours a week.

Senator ALLISON—Would that be in one lot, or two hours a day?

Mrs Harding—It can be worked out according to the needs of the family and the client. Normally we would space that out over the week, because that 10 hours is for rehabilitation and to try and assist the client to reach their rehabilitation goals. We will also fund 34 hours of attendant care whilst somebody is on the waiting list waiting for a home first package. Sometimes it can take some time for somebody to be accepted to get the home first package.

Senator ALLISON—I am just wondering about the ones that are on the program. Could you spell that out for the committee.

Mrs Harding—We will pay for the 34 hours of attendant care, plus the 10 hours—so up to 44 hours of attendant care. In the initial stages we will provide up to three hours of each allied health professional—that is, physiotherapy, occupational therapy, speech pathology—per week. That is tailored down according to how a person is rehabilitating, so according to their needs.

Senator ALLISON—There is a period of intense support and then that tails off. Over what period of time?

Mrs Harding—It depends on the individual client. In the past that was specifically around the two year mark and then there would be a dramatic reduction to maintenance. As I said, I have only been in the program for 4½ months, and one of the things I am very aware of is that often people do have needs after that two-year period. They are rehabilitating quite nicely, but they may still have needs beyond a maintenance level and so we will fund according to what their care plan has been written up as. Therapists will write to me stating, ‘We need X amount of hours to carry out these goals,’ and we would fund that accordingly.

Mr Young—There is also brokerage-based money, which helps to buy equipment to support the person in the home too. This will include a wheelchair, or a change to the car or a change to ramps within the home.

Senator ALLISON—The Chair has drawn attention to the increased number of clients who are in nursing homes, which would appear to be contrary to one of your key objectives. Can you comment on that? What sorts of services are provided when people are in nursing homes?

Mr Young—The people who end up in nursing homes are really the most profoundly disabled people, or people who have no family who can support them at home. Often we will top up the nursing homes to assist them to care for that person. We will provide up to 15 hours of attendant care. We will also sometimes negotiate with additional nursing care if that is required, so it is done on a needs-by-needs basis. Some of these clients have very high needs. They might require weekly physiotherapy, for example, to minimise their risk of contractures.

Senator ALLISON—What sorts of skills do the attendant carers have in physiotherapy and rehabilitation?

Mrs Harding—They are trained by the therapists that will go in to treat that client.

Senator ALLISON—But they are not physiotherapists themselves?

Mrs Harding—They are not physiotherapists, no; they are attendant carers. They are trained by the attendant care agency in basic care and then the therapists that are employed by the Slow to Recover Program will train them in the specific skills that they require to work with that particular client.

Senator ALLISON—Can you tell us a bit more about that training? It is hard to imagine that someone would acquire the skills necessary for speech therapy or physiotherapy or other kinds of therapy required for rehabilitation.

Mrs Harding—Sure. They are just trained to carry out very specific tasks within those rehabilitation goals. For example, they might be trained to assist somebody with their walking. They will be trained to look at how they can appropriately assist that person to walk. Or they might be trained to carry out a set of very specific speech pathology exercises with a client.

Senator ALLISON—It is my understanding that, if rehabilitation is to be successful, people with brain injury need a very intensive and long period of care and attention. Is the program that you are running a token gesture, or can you demonstrate that the outcomes are as good as they might be should someone have that intensive rehab service?

Mrs Harding—I think we have a number of clients who rehabilitate to the point where they are able to be discharged from the program, so that is testimony in itself that the service we offer is adequate for some people. I think there will always be a group of people on our program, though, who will have long-term high needs, who will never be effectively rehabilitated, but we really need to look at supporting those people with their long-term needs.

Senator ALLISON—Just to clarify: this is not the pilot program that the Commonwealth agreed upon with Victoria—I think it was midway through last year. This is another kind of program, isn't it?

Mrs Harding—Yes.

Senator ALLISON—It is entirely the state's initiative. Is that right?

Mrs Harding—That is right.

Senator ALLISON—Do you have any knowledge at all about the pilot program that Senator Knowles referred to earlier?

Mr Young—No.

Mrs Harding—No.

Senator HUMPHRIES—It is good to see these groups gathered at the table today to make these points about the need for better services. I am wondering how often groups like yours come together on a coordinated basis to mount campaigns to raise the profile of young people with disabilities in nursing homes in Victoria. Another submission has made the point that this is a largely hidden problem—that most people would not realise, unless they were familiar with the area, that there are young people in our nursing homes—and that the only way of putting that on the political agenda for state governments like the one here to react to is by mounting campaigns and getting a profile for this issue. Do you people come together to raise the profile of the issues, apart from on occasions like this?

Mrs Harding—There are disability forums as well as acquired brain injury forums in all of the regions throughout Victoria, and then we have VCASP, the Victorian Coalition of ABI Service Providers, that meets I think four times a year. Younger people in nursing homes are certainly a frequent subject on their agenda.

Senator HUMPHRIES—Is that a case of people with similar outlooks talking to each other, or is it a case of the sector generally—if I can call it that—coming together to project this issue onto the consciousness of Victorian voters, if you like, to get some action on this? What pressure is there on the Victorian state government from bodies like yours to get some action in this area?

Ms Atkins—I have a comment. We provide information to the National Alliance of Young People in Nursing Homes and have participated in two conferences on young people in nursing homes in the past three years. So there are groups, and the MS Society is a part of that. Under that umbrella, there are a number of organisations which do talk with each other, participate in conferences and lobby politicians on both the state and federal levels. We are a part of that alliance as well.

Mr Larkins—Palliative Care Victoria has a strategic alliance with the aged care sector and has invited a member of VAHEC onto the board. Also, Palliative Care Australia links with Carers Australia, and we link with Carers Australia. We are also a member of the VCOSS advocacy group—the peak bodies group which pulls together peak bodies to look at these sorts of strategic issues at Commonwealth and state levels. I guess others are the networking that is done within the various industries that really pulls together some of these issues. We link very strongly with the Motor Neurone Disease Association—I think they are presenting later on today—because they represent a lot of the views that we hold.

Senator HUMPHRIES—I do not want to teach you how to suck eggs, and networking with each other is great, but networking with the electorate, the community, is also pretty important in order to advance the issues you have been talking about today. Could I just clarify something you said before, Mrs Fear? You were talking about the Commonwealth respite funding and saying that, if you wanted to access that kind of respite care, it was only accessible through aged care providers. Are you saying Paul was not able to access that because he could not go through an aged care provider? How does that work? Are you saying that you would not want Paul to be getting respite in an aged care facility?

Mrs Fear—Yes. They are just totally inappropriate for a 21-year-old. Because of Paul’s very high level of care, one of our options was a dementia ward for people that were pretty bad, because they need a high level of care too. We have plenty of places in Geelong for aged care accommodation, but nothing at all for young people to be accommodated in. So we, by choice, have not had any respite. We could have had him in any number of those kinds of places, but, by choice, we have not.

Senator HUMPHRIES—I certainly think that a permanent setting for a young person in an aged care facility, say with people with dementia, is obviously pretty inappropriate, but for relatively short periods for respite would you see that many people would regard that as a suitable alternative for the sake of taking some pressure off families?

Mrs Fear—It is totally unsuitable. You have got to work really hard with somebody with an ABI injury and the physio is constant. My husband and I do daily physio with Paul. We motivate and stimulate him daily. You could do so much damage in just two weeks by placing somebody in an aged care facility, putting them in bed and just leaving them. All the hard work that we have done in four years could be undone in that short a time. That is how important it is that they have the right staff in these facilities to look after the people. It can just undo all the hard work.

Dr Donovan—But then the issue is that there are people who are trained and the home has been made suitable, so why can’t that sort of funding support then be applied to an area that he knows, to people that he knows? It is not extra funding. What about funding flexibility that will mean that that family is able to care for him longer? Otherwise he will be in a nursing home.

Senator FORSHAW—Given that you say that an aged care facility is inappropriate—and we all understand the argument there—what sort of facility would be appropriate to provide respite care? Are we talking about a purpose-built facility? This really goes to the nub of this issue. There are thousands of young people with ABI or whatever in nursing homes. Generally people say that is inappropriate. It presumably is also not appropriate, or there is no capacity—putting aside the arguments about state and federal responsibilities—within what we might call children’s facilities, where I understand there may be availability of some sort of respite care for parents who may have an autistic young child. So we then have this sort of middle, if you like. How do we solve that problem? What do you think we should be providing, putting aside who provides it? What type of facility should we be providing?

Mrs Fear—From my point of view, as a mum looking after a 21-year-old with acquired brain injury, it does not take that much. Have a facility where you have got trained nursing staff, where young guys can have more life going on. They are 21 years old. Have people go in and offer them stimulation by going in and playing the guitar for them—just something more suitable.

Senator FORSHAW—That is what I expected you to say. Taking it to the next position—and this is the cold face of reality—in the Geelong region, for instance, what would be the demand for that facility?

Mrs Fear—There is a lot of demand, from what we have been told. There are not just people with an acquired brain injury; there are so many parents. I have heard a story of a lady who is looking after a child in Geelong with cystic fibrosis. The only respite this lady can get is to place her daughter in a hospital in Melbourne. She is worried sick about her daughter, so it is not any respite for her. She has to travel to Melbourne and back daily.

There are all sorts of different people. I do not mean young just in terms of a 21-year-old; I mean young in terms of state of mind. A 60-year-old who has had a stroke and who is recovering does not belong in a dementia ward. Their quality of life is different. They need different things around them. There are so many people it could be used by at any age—up to, say, 65 years old. I heard a story from the carer respite association in Geelong on Friday. They have just had to place a 25-year-old lady in the permanent nursing home. It has just devastated her whole family. It devastated the workers who had to do it. It would be really, really well-used in Geelong if we had one.

Senator FORSHAW—Dr Donovan, did you want to add to that?

Dr Donovan—I do not have the data that I think you are asking for in actual numbers.

Senator FORSHAW—At the end of the day this is what the bureaucrats are going to look at in terms of where they can allocate the dollars.

Dr Donovan—I suspect they already have it. I do not believe that that is unknown.

CHAIR—Thank you for your submissions and your presentation today.

[12.08 p.m.]

ANSET, Ms Alicia, Member, Health Services Union of Australia

JACOB, Mr William Patrick, Member, Health Services Union of Australia

THOMSON, Mr Craig, National Secretary, Health Services Union of Australia

WILKEN, Mrs Iva Maria, Member, Health Services Union of Australia

WILLIAMS, Mrs Debra, Member, Health Services Union of Australia

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission, and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Thomson—I thank the committee for the opportunity to appear today. There are four key areas that we want to address this morning. These areas are in relation to staffing levels, training, the budget and aged care accreditation standards. What we would like to ask the inquiry first of all is: by what measure can anyone ever say that an aged care facility that has 73 residents, 41 of whom are high care, with only one person looking after them at night is adequate? Armitage Manor has 60 residents and only one person looking after them overnight. Under what system can that ever be said to be appropriate? Alroy House at Singleton has 49 residents at night, 12 of whom are high care, and only one person is looking after them. Under what system can that ever be said to be adequate?

That goes to the nub of our submission and the nub of the problem that we have in aged care: no minimum staffing levels apply anywhere. We find situations where the quality of care that is delivered to the resident is affected by the level of staffing. Pages 2 and 3 of our submission go to some of the research that has been undertaken both in Australia and internationally in relation to this issue. The National Institute of Labour Studies was commissioned by the federal government to conduct a report, and 6,000 care staff were interviewed in relation to it. Of them, 13 per cent of nurses and 19 per cent of staff overall said that they had enough time to adequately do their work. Therefore, over 80 per cent of staff believed that they did not have enough time to perform their basic duties at work.

That study had a very similar result to that of a survey done by our union back in 2002. In that study we interviewed over 3,000 aged care staff. Over 50 per cent said that they were unable to do their work in the time allocated and 21 per cent believed that residents were in physical danger because of the lack of staffing in those aged care facilities. That is on top of the US Department of Health and Human Services survey and report to congress in 2001, which was conducted over four years. In its conclusion that report found strong and compelling evidence of a relationship between staffing ratios and the quality of nursing home care. We believe that there is evidence that cannot be brought into question at all in relation to the effect that the level of staffing has on the quality of care that is delivered in aged care facilities.

We also say that by and large our position is supported by the employers in the industry, although they have concerns about the costs that come with it. In submissions that were made to this committee on 11 February, both the Uniting Church and the Catholics supported the concept of there being some minimum staffing levels. On page 13 of our submission we set out a paragraph in which we say that all participants in the National Aged Care Alliance agree that there needs to be some level of minimum staffing and a discussion on staffing mix. We say that there is overwhelming industry support for minimum staffing levels.

Today we bring some new evidence. Last weekend we conducted a Newspoll survey of over 1,200 people across the country. We asked, ‘Should the federal government have a set of minimum staffing levels for each facility in Australia?’ The response was overwhelming: over 82 per cent believed that the federal government should have some minimum staffing levels that apply in aged care facilities across Australia. The evidence from our submission, from the workers, from the employers and from the general public is overwhelming: minimum staffing levels are required in aged care to make sure that proper quality care is delivered to aged care residents.

The second issue that I would like to touch on briefly is training. Training in aged care is abysmal. There is no mandatory training. Those of us who have not worked in aged care could get a job there tomorrow, looking after high-care patients without any training whatsoever. On page 15 of our submission, the evidence from Shantell Barry from Kanella Aged Care Facility is compelling because of the lack of training that applied there. A recent report from the Aged Care Accreditation Agency said that staff at a hostel in Redfern were given an inadequate 15- to 20-minute briefing before they started work. Performance appraisals were the only way management knew what staff training requirements had been undertaken. Those staff appraisals had not happened in years at that facility. Again, unless and until there is mandatory training in aged care facilities the quality of the staff cannot be guaranteed. We are taking potluck, and we believe that we cannot take potluck with the future of elderly Australians. That issue needs to be addressed.

The third area that I want to briefly spend some time on is the budget and finances of aged care facilities. We think that it is time that the veil of secrecy over what happens and how much money providers earn is raised. It is time for a reality check on the capacity of employers to pay higher wages and have decent staffing levels. Providers received an extra $877.8 million in the last budget, which unfortunately was not tied to any outcomes in terms of staffing or higher wages. They also received $3,500 per bed, which was not meant to be spent on capital and which did not need to be spent on capital works. None of this has had any improvement in relation to either the level of staffing or the wages of people working in this industry.

We know that you have heard evidence from nurses already about the wage gap between registered nurses and the public hospitals, but the wage gap for carers is about $60 to $70 a week between the public sector and the aged care sector. But what is important is that in the aged care sector carers actually do a lot more than they would in the public hospitals. I know the argument in relation to nurses is that they may do less and it may be less stressful. That is something that we would dispute. Aged care carers perform far broader roles than any comparable classification that could exist in the public hospital system, yet they earn $60 to $70 a week less, are on $13.50 an hour and, for their survival, need movements in the minimum wage. Without that, they do not receive pay increases.

We say that employers have consistently refused to open their books to show how much they are earning and how much they are able to pay. There was evidence in the recent New South Wales nurses case in the IRC which showed that employers were deliberately trying to withhold information. After the Hogan report there was the opportunity for employers to open up their books. This was the one time where they had the chance to say: ‘Here are our financial records. We’re not being paid enough.’ Less than a third of the aged care industry were able to provide their records to the Hogan report. The conclusion of the Hogan report was that aged care providers are making enough money, if they operate in right and sensible ways, to have adequate staffing levels and pay their people the right amount of money. It is a no-brainer, when you see organisations such as Ramsay Health Care buying into aged care in a big way and you see Macquarie Bank partnering another organisation to take over the Salvation Army homes in Victoria, Tasmania and South Australia, that big business sees big profits now coming out of aged care. We believe that the time has come for that veil of secrecy over these issues to be raised.

We also would like to put on the record that our members have faced intimidation in relation coming forward today and giving evidence. We have a member, Bella Millar, at Isomer Retirement Home, who gave evidence. Her statement is attached to our submission. Bella was rung up by the proprietor and threatened that she would be sued for $2 million worth of damages for giving evidence to the Senate inquiry. The proprietor then went on and made a similar threat to staff working at that particular facility, trying to stop them from giving evidence about their working conditions and what the system held for them. We think that the government needs to make sure that there is proper scrutiny of public records, that it should go beyond residents and prospective residents, which is the commitment that was given in the last budget by the aged care minister. The financial records of aged care facilities need to be made publicly available.

We also say that the Aged Care Standards and Accreditation Agency has continued with a veil of secrecy over information. We frequently seek to FOI information from the agency to see if we can get to the bottom of particular reports, and we get the following sorts of responses back: ‘The request to get documents in relation to a particular facility was refused’—get this—‘because the agency is wholly owned by the Australian government and subject to the Corporations Act 2001.’ So, an agency that was set up to look at, monitor and investigate aged care facilities—to give the public confidence in terms of what happens in aged care facilities—hides behind the fact that it is a corporation, even though that corporation was set up expressly for that purpose, to stop documents going to the public. That requires the government to act. At this stage, FOI does not apply to the agency, because it has not been declared a prescribed authority for the purposes of the act. That is something that needs to happen.

The Aged Care Standards and Accreditation Agency itself has serious flaws, and since we gave our submission to the committee there have been further examples of that. Viewhills Manor in Endeavour Hills in Victoria passed 44 out of 44 accreditation standards in April last year and was granted three years accreditation. Six months later, it was said to be so bad that there was a serious risk to the health and safety of residents. Sanctions were imposed; they had passed just 31 of the 44 accreditation standards. Staffing levels were found to be so low at this facility that one nursing assistant was left for nine hours overnight to look after the 60 residents, 35 of whom were high care. The inspectors who found such terrible conditions recommended that it lose accreditation. It did not, but, again, it shows a problem with the accreditation agency: six months earlier it was fined; six months later it was a major problem and there was a recommendation that it should be closed down. Emerald Glades in Dandenong: same thing. It was given three years accreditation in 2003, passing all standards; conditions nine months later were found to be so bad that it failed 16 standards. Two personal-care staff were left to look after 54 residents during the day and evening, and on the weekends and at night, only the director of nursing's son was available on duty at the facility. These are not isolated examples—they are further examples of what we have set out in our submission.

I could go on, but I will try to keep my discussion of this matter relatively brief. There is clear evidence from Alicia Anset on page 20 of our statement of what actually happens at accreditation time: the place gets a lick of paint, casuals are called in and extra staff and further activities are put on until the agency has been through the process, and then things suddenly go back to 'normal,' because the expectation is that they will not be seeing someone from the accreditation agency for another three years. A recommendation from this committee needs to be made that there need to be more spot checks. Every facility should expect at least one spot check during its three years of accreditation.

The last area, which I would like to touch on briefly, is in relation to the foreshadowed changes in industrial relations and the effect that that is going to have on the aged care industry. The majority of our members in aged care are employed under state awards. They have general conditions of employment that go well beyond the existing 20 allowable matters or the foreshadowed 16 allowable matters that are going to come in as part of the IR system changes. Our members are on minimum wages, so whatever happens to the minimum wage case directly affects some of the lowest-paid and most vulnerable workers in Australia. The changes to the IR system also mean that we will no longer be able to bargain on an industry basis. We will have to bargain workplace by workplace, with thousands of different employers, for workers who will immediately upon these laws coming in lose many of their conditions and who rely on the minimum wage, which may no longer move. The foreshadowed changes also mean that many of our members will be working in facilities where they will no longer be able to get redundancy, and unfair dismissal laws may no longer apply to many of them as well. These are additional burdens that are being placed on workers in an industry where they are highly stressed and overworked trying to care for our most vulnerable and elderly. It is something that we think this committee should take into account in relation to the recommendations that it makes. Thank you.

CHAIR—Before I hand over to my colleagues, you raised a very serious matter of privilege. Information on parliamentary privilege and the protection of witnesses and evidence was provided to you. The committee secretary will contact you after this hearing and discuss how to progress those matters.

Senator McLUCAS—Thank you, Mr Thomson, for your submission and thank you to the other people for coming along. When I ask some questions and others, especially workers, would like to contribute, I would very much appreciate that. You raised two issues that I want to go to. One was staff training and you also wanted more exposure of the financial statements. My understanding is that for the conditional adjustment payment that the government has just brought down there was a requirement for both a training element and audited financial statements to be provided. You are obviously saying that that is not good enough. Can you explain to the committee what the limitations are with those conditions?

Mr Thomson—In relation to the adjustment that was meant to be tied to training, it was not actually tied to training. There was an intent stated that it should be spent on training but, again, it was not specifically tied to that in any mandatory sense. What that means is that it leaves the industry open to those providers who choose to use it for other purposes. In relation to the financial records of institutions being available publicly, we have had a meeting with the minister for aged care and have written to the department to clarify whether we are able to get access to that under the initiative announced by the minister earlier this year. We have received no satisfaction on that. We are told that it is available to residents and potential residents and we are to make of that what we will. We do not think that that is good enough. We think that it should be publicly available. Professor Hogan in his report talked about having a star rating system for aged care facilities. One of the things that was to be looked at with respect to that was their financial records. That is a recommendation that has not been taken up and it is one that we would urge this committee to make.

Senator McLUCAS—My understanding was that the condition was that the residential aged care owner simply had to provide advice to staff of the availability of training.

Mr Thomson—Yes.

Senator McLUCAS—Earlier today we had evidence from Aged and Community Services to say that the conditional adjustment payment in New South Wales, the 1.75 per cent, along with the indexation, will not quite cover the increase in nurses' wages that has just been through the industrial commission in that state. His evidence to us was that the government is saying this money has been provided and is then suggesting that it needs to be spent in a whole range of ways and that certainly in the case of New South Wales that money has been spent on just the nurses' component of staffing. Would you agree with Mr Mundy's evidence?

Mr Thomson—We make three points in relation to Mr Mundy's evidence. The first is that there is no evidence to support what he has said. That is the point we were trying to make today: the evidence has not been forthcoming from the employers in relation to their financial records. The second is that, with respect to the case that was run in the New South Wales jurisdiction, at some stage of that case the employers were going to argue incapacity to pay. They chose not to, and the evidence that came out in relation to their financial records was that they could pay the sorts of increases that were granted in that particular increase. So we do not see that as being anything more than the provider grandstanding for more funds.

Of course, we support that there be more funds spent in aged care, but we need to look at and open up what is there at the moment and make sure that it is being spent on things that directly affect the quality of care, like making sure you have enough staff, your staff are adequately paid so that you can attract them and that the proper training is there. We would also like to make the point that needs to be made: 80 per cent of people who directly look after residents in aged care are not nurses; they are direct carers, who are our members. I think sometimes the arguments and the focus get a little shifted to the registered nurses area. We need to keep in perspective what the industry actually looks like in terms of its work force.

Senator McLUCAS—Finally, I want to go to the question of accreditation and paperwork. I think that, uniformly, the providers, workers, nurses and care providers have said that the paperwork that is required both for accreditation and under the RCS system is onerous, time consuming and really does not change outcomes in the quality of care for residents. Would the HSU make some comments—not only, I am sure, to support that but we are also interested in finding out how we can actually make the accountability regime more effective so that governments and the community are confident that quality of care is being delivered without making you spend enormous amounts of time behind a desk rather than working with residents of residential aged care.

Mr Thomson—I will try and answer that in a general sense and then some of my colleagues can talk about their personal experiences. We do not necessarily support the idea that there is too much paperwork; what we say is there are not enough staff to actually do the paperwork and look after the residents at the same time. One of the reasons why there is the requirement for that paperwork is that you do not have any other guarantees as to the quality of care that is going to be delivered to residents in an aged care facility. There are no minimum staffing levels, so you need to make sure that there are properly filled-out care plans for each resident and that they are followed through. Certainly, we are not saying that paperwork should be done away with; it could be simplified to some extent if you had minimum staffing levels, because you would know what sorts of staffing levels are going to be there and they would match up with care plans, which could then be simpler.

Also, some of the changes to the RCS classifications that have been foreshadowed will certainly make some things slightly simpler. We do not think it is as simple as saying, ‘Let’s make the paperwork slightly easier and the problem will go away.’ We say that there are not enough staff to both do the paperwork and deliver the quality of care that is there. The simple answer is: if you have enough staff, you are able to do both. Some of my colleagues might like to add their personal experiences.

Mr Jacob—On doing RCSs, I spoke to the DON at a meeting one day. I said: ‘With the RCSs, sometimes you have seven people on RCS, two staff and 20 residents. If we have four or five residents in soiled beds, do I leave the residents and attend to the paperwork or do I see to the residents and let the paperwork go?’ All she said was, ‘The RCSs pay 95 per cent of your wages.’ So I said, ‘Okay, you’re saying to leave the residents and do the paperwork.’ She said, ‘The RCSs pay 95 per cent of your wages.’ That is all I could get out of her.

Senator McLUCAS—The message was pretty clear.

Mr Jacob—Yes: leave the residents—and how can you do that?

Ms Anset—I am finding the same thing at the place where I work. A lot of the staff are rushing to get their residents done in the amount of time that they are allocated per shift, and a lot of them stay back in their own time and do their documentation—firstly, because they do feel threatened because it has been stated in staff meetings how important this RCS documentation is. If we do not do the paperwork, we do not get the funding and, if we do not get the funding, the place will close down. That sort of threat is hanging over our heads all the time, so you try and do the paperwork either in your meal breaks or after work, and they will not pay overtime for you to stay back. It is a catch-22 situation: you do not have enough time to do both, so you have to do it in your own time.

Senator HUMPHRIES—Can I go first of all to this question about what you referred to, Mr Thomson, as a culture of secrecy. Wouldn't you concede that the first step that needs to be taken in order to break that culture down is for there to be much greater scrutiny and exposure of what is happening in nursing homes and other facilities with the spending of taxpayer money and that the Commonwealth decision to link those conditional adjustment payments to the opening of their accounts and to the disclosure of audited financial statements is a very important first step in getting that additional information on the table so we know what is going on with those sorts of expenditures?

Mr Thomson—We welcomed that initiative, but it did not go far enough. As I tried to outline, probably not terribly eloquently, we made inquiries directly to the minister at a meeting and to the department to see whether that included us and to see what the restriction was—where the line was drawn for those accounts. We were told that they would be available to residents and prospective residents only, and we were to draw our own conclusions from that. While it was an important initiative, to take it further than where it is at the moment, where those accounts are totally concealed from public scrutiny, is necessary. The information needs to be available so that outside organisations with an interest can go through and examine exactly how the money is being spent. An example of why that needs to happen came up in a case in New South Wales where there was direct evidence of money that was meant for training being spent on the university degree of the provider's son. Clearly, if those financial statements are open, available and accountable, those sorts of dodgy practices will be weeded out of the industry. We think that it was a good initiative, but it needs to go further.

Senator HUMPHRIES—You mentioned that standards of minimum staffing should be set in the accreditation standards that providers work under. Given the enormous variety of client needs within any given system, the huge variety of categories of people—even putting aside young disabled people in nursing homes—isn't it going to be administratively extremely difficult to set and monitor minimum staffing levels when no two nursing homes are the same in terms of their staffing requirements?

Mr Thomson—That is not the experience overseas. For example, the majority of states in the United States—and I do not think anyone holds that up as being a model for health care or aged care—now have minimum staffing levels through the legislative process. Those minimum staffing levels need to be flexible so that they can be adjusted for the particular care plans and circumstances of each facility. But underlying that there has to be a stage when government says: 'One person looking after 73 residents at night when 43 of them are high care is not something that as taxpayers we are going to fund. We are going to ensure that people who are in those aged care facilities at least have this level of staffing so they are looked after. On top of that is a process to look at what the correct and appropriate staffing levels are at each particular facility.' There needs to be a mix of both, but you need to provide that basis of minimum staffing levels across the board, otherwise it is totally open to people to provide whatever level of care they want to their residents.

Senator HUMPHRIES—You say the United States is a good model.

Mr Thomson—I said it is not a good model.

Senator HUMPHRIES—But of course the United States is 50 different states and presumably there are different models in every state. Do you have a particular state that you would recommend as a model that we should adopt in Australia?

Mr Thomson—No, but in the years subsequent to the four-year congressional inquiry that ended in 2001, the states have been adopting particular standards in terms of that. Most frequently the way in which they have done that is by attaching hours of staffing care to a particular resident, depending on the particular condition of that resident at the time. We would be happy to provide the committee with further documentation in relation to that. For the congressional inquiry, though, there were many volumes of evidence. Its conclusions were that staffing levels are indelibly tied to the quality of care. For that reason, they made those recommendations and the various states have started to adopt those progressively as time has gone by.

Senator HUMPHRIES—You raise in your submission a large number of issues about work force management, developing a better work force and training and so forth. Presumably, you have seen the document that was recently released on the National Aged Care Workforce Strategy. What is your view about the direction this lays down? To what extent do you think that it sets the pattern of future development of an aged care work force that we need to pursue in this country?

Mr Thomson—Without trying to be too critical, having read through that document I could not understand one thing that it was actually proposing in a concrete sense. It appeared to me to be incredibly general. It did not address any of the issues that we have tried to bring to the Senate’s attention today and in our submissions. We ask: how can you ever have some sort of work force planning document that does not come to terms with the very basic question of how many staff you need to adequately look after people in an aged care facility? That document certainly did not do that at all. We think it was a lost opportunity. We do not even see it as a good step in the first direction, because we do not see that it has set any direction at all in that particular document. We are very critical of the lost opportunity that could have been taken by the committee in that particular document.

Senator HUMPHRIES—You say that you have seen no improvement in standards in nursing homes, particularly as far as staffing issues are concerned, arising out of extra Commonwealth spending in recent years—in particular, through the budget last year, which put a record amount of extra money into aged care. How would you account for the fact that, since 2002, there has been a decline in the number of complaints that have been received about Australian nursing homes to the complaint resolution service over each of those years?

Mr Thomson—It depends how you read those complaints and the levels of the complaints. We would make the point that it is very difficult to complain to the complaints tribunal in the first place. You need to go through three or four stages before it is actually recorded as a complaint. We see the number of aged care facilities that are now approved for three years as a much better measure of the way in which the industry has declined in recent years. That number has declined. The aged care accreditation agency has reduced that number. From 95 per cent in 2001-02 it has dropped back to 89.7 per cent in 2003-04. Even in terms of the numbers in the agency's own measurements of homes that they were prepared to accredit for three years, there has been a drop-off. So, on that measure—and we think that is a better measure than going through the convoluted mechanisms of getting a complaint registered by the ombudsman—there has been a decline in the standard of nursing homes across Australia. That is the experience of our members.

Senator HUMPHRIES—You have raised an issue here about the spending of Commonwealth money and Commonwealth responsibility for maintaining standards in nursing homes. Fair enough—this is a Commonwealth issue. But you also, in your submission, talk about the inappropriateness of younger disabled people being in nursing homes. That is clearly a state government responsibility. What has your union done to drive home the point to, for example, the Victorian state government that it needs to do something about getting those young disabled people out of nursing homes and into facilities that it builds and funds to care for them appropriately?

Mr Thomson—Unfortunately, we have been as successful with the state governments in that area as we have been with the Commonwealth—and that is we have not. The problem that faces young people in nursing homes is that they fall between the cracks in terms of whose responsibility it is. They are in a far better position to make submissions in relation to that. We have raised the issues with state governments, as we have asked state governments whether they could consider looking at legislation in terms of nursing homes because in many states there still are nursing home acts which predate the aged care reforms of 1996. So we have had discussions with them in relation to that but we have been no more successful in that than in convincing the Commonwealth that there should be minimum staffing levels.

Senator HUMPHRIES—You mentioned an FOI problem that you had in getting documents from the accreditation agency. Would you be prepared to table the documents of the request you made and the response you had to the FOI request?

Mr Thomson—Absolutely. It would be a concern for the governments when the agency actually writes in its letter that it does not have a statutory obligation to invite a departmental officer to attend board meetings as a representative of the minister, because it is concerned about the flow of information between the government and the agency, as well as our concern about the fact that the agency which is meant to police and monitor these issues is hiding behind the cloak of FOI when it should be there to expose the bad providers in this industry. We are more than happy to provide you with examples of our requests and the refusals that have come back.

Senator ALLISON—You cite the Hogan report in talking about the fact that in 2001 there were 11 per cent fewer enrolled nurses and the other sort of nurse in aged care. What was the movement of personal carers in that time?

Mr Thomson—Certainly there has been a change in terms of the staffing mix. Carers are becoming more frequent than registered and enrolled nurses, and that is a trend that is happening across the board. We believe that part of that change is because the type of care that is required is different to that that a registered nurse will provide on all occasions, but we also think that part of that is cost cutting as well. Registered nurses are far more expensive, there is a worldwide shortage of registered nurses and employers are looking at other options. I note that Mr Young's evidence—about wanting to start again in relation to the way in which the classifications are set out—is something that is driven at that—

Senator ALLISON—You have not given us overall figures of the total level of staffing or any figures that, if I may say so, are useful to us in determining whether we are getting fewer staff in aged care as a percentage of the number of people being cared for than we were previously. I know it is a complex situation but, while you are putting to this committee that there should be a regulation for the number of staff per client or per resident, I suggest to you we are only getting half of the picture in your submission.

Mr Thomson—There are very few figures in relation to overall staffing numbers in the industry. There has been some work done by the National Aged Care Alliance, which is trying to break down the actual numbers of staff across the industry, and we are happy to try to provide you with that material, but again it is not something that we would say is definitive. Our position is based on the experience of our members, the surveys that have been done by both the federal government and ourselves and the reports from the accreditation agency which continually show that staffing is an issue.

Senator ALLISON—Would it be one of your recommendations to the committee that, as part of the monitoring and reporting process, we understand the level of staff in particular aged care facilities? Would that help us to understand whether we have reached the appropriate level or not?

Mr Thomson—We are not suggesting that the solution to staffing is saying, ‘You need X number of people across the industry.’ If that was the solution then some of the criticisms that employers raise as to inflexibility and how that would work in a particular place would clearly be valid. What we are saying is that, looking at the level of care that is required for residents across the board, there can be a minimum standard and above that the provider, the staff and the union can sit down and work out, on the basis of the care plan that is required for the particular residents who are there, an appropriate mix—and staffing levels—for that particular facility. We do not say that you can have one size that fits all. We also do not say that you should not have a floor in terms of the staffing numbers. There needs to be flexibility to look at the particular circumstances of the aged care facility, but you also must provide some basic safeguards for the elderly when they go to aged care facilities.

Senator ALLISON—How easy would that be to do, given that this morning we heard that where previously nursing homes might have been able to have personal carers or nurses read the paper to residents and have conversations with them now they cannot do that because of the pressures of time and the reduction in funding—or rather the inadequacy of the funding? Where do you draw the line? It seems to me that these negotiations might be endless. Does it include reading the paper or is it something else? What sorts of guidelines could you possibly develop that would do this?

Mr Thomson—Let us have a look at what we have at the moment. At the moment we have the federal government funding aged care providers on the basis that they are going to be providing some sort of quality care for residents, but the only guidelines they have is the accreditation agency going in there with a measure and saying, ‘Are their appropriate staff numbers?’. What does ‘appropriate staff numbers’ mean? Appropriate staff numbers means that someone is fed on time and that they get their basic level of care. There are a range of things that are beyond contradiction as to what is required to ensure that someone has quality care when they are in an aged care facility. All of those things could be put into the mix in terms of coming up with a minimum staffing number.

In relation to whether you want someone to read the paper or a book to residents or provide additional services, that is a matter for the facility—above the basic level of ensuring that there is a quality of care. It is something that may distinguish them from the facility down the road and may attract particular clients to that particular facility. We are not saying that it needs to be done to that level of detail at all, but we do say that without having a minimum staffing level somewhere at a nursing home you run the risk of one person looking after 73 people at night. I ask the senators here: do any of you think that having one person looking after 73 residents at night is adequate? I challenge anyone to say that it is when 43 of them are high-care residents.

Senator ALLISON—So you are saying that the accreditation system does not pick that up?

Mr Thomson—No, quite often it does not.

Senator ALLISON—But if there was an inspection done and it was found that there were 73 residents and no nurse on duty or whatever you think might be the minimum overnight then that provider would not continue to be accredited?

Mr Thomson—Not while the accreditation standards are as they are at the moment. That particular facility passed in relation to staffing levels.

Senator ALLISON—Even though the accreditation agency understood that that was the level of staffing at the time?

Mr Thomson—Yes, that is right.

Senator ALLISON—The Hogan report made no recommendations about minimum staffing levels. Were you surprised at that?

Mr Thomson—It did not surprise us because of the terms of reference of the particular inquiry. We were disappointed. We sat on one of the review committees and constantly said that this is an issue and that if you are looking at the funding of an aged care provider then you need to look at the major funding cost, which is staffing. Staffing accounts for 70 to 80 per cent—which is what Hogan said—so you need to look at the levels of staffing. So from that point of view we were disappointed but we were not surprised.

Senator HUTCHINS—Ms Anset, in your submission you talk about training. Do you have any regular schedule of training where you work?

Ms Anset—Recently—I would say within the last couple of months—basic training has improved. We do fire training, and they are putting forward a course for CPR and first aid. But that has been only recently.

Senator HUTCHINS—What do you mean by ‘recently’? Since this inquiry started?

Ms Anset—I do not know the reasoning. I do not know whether it was because of the inquiry or what it was. I know head office has had a few management changes. From the head office they are bringing it around to the other facilities. We are now having this basic training that we have to sign for. Whether that has made a change to it I do not know.

My point about training referred to the actual training of people who enter this industry. At the moment our facility has division 2 nurses who come and do their placements at our facility. We have got to not only do our own work but also oversee these people while they are there. I am a PCA and yet I am overseeing division 2s. I cannot see the sense in that. They need to have better training outside before they come into aged care. Personal carers come in and I cannot understand how on earth they got their certificate. Their basic English is not very good and nor is their understanding of looking after somebody. When you orientate them, although they have just got their PC 3 certificate they do not even know how to shower a person, how to wash them properly, how to toilet them properly or how to transfer them properly. Yet these people are being put into aged care to look after elderly people. There needs to be some sort of training outside before you enter them into aged care.

Senator HUTCHINS—Can I ask a question about accreditation. Both you and Mr Jacob talk about the time when the inspectors are on their way. It seems that a bit of attention is given to the place and then I get the impression that after the inspectors go it reverts to normal, a bit like going from Savile Row to skid row.

Ms Anset—Definitely.

Senator HUTCHINS—You talk about relatives feeling that they could be victimised.

Ms Anset—Relatives are very reluctant to speak up. They will complain to the staff on the floor, but they will not go and complain to management. Their reasoning is that they do not want their mother or father to be victimised in any way. They are afraid that they will be asked to leave the facility or find an alternative place to go. As I said, they talk to the actual carers but they are afraid to go to management and complain.

Senator HUTCHINS—In your opinion is that to a large degree due to staffing levels, in your experience in the industry?

Ms Anset—I would say so.

Senator HUTCHINS—With your knowledge of the industry, would you suggest that some sort of outside determinant of staffing levels would take away that threat—that sense of intimidation—for families and residents?

Ms Anset—I would say it would. I think it would make a big difference if there was enough time allocated to carers to provide the time. I watch residents buzz for me or call for me and I have to turn around and tell them, ‘I’ll be with you in a minute.’ Then what registers in their head is, ‘That’s what you always say.’ But that is all I can say to them. I cannot care for so many people when there is only one of me or a few of us to care for all these residents. We definitely need more staff to accommodate their needs—basic needs like toileting. Try hanging on to go to the toilet when you are being told to wait because the staff member is busy.

Senator FORSHAW—In regard to the proposal for minimum staffing levels, funding is essentially tied to the RCS, where residents are classified or graded according to their level of need and care. Surely that concept could be then linked to minimum staffing arrangements. In other words, as you have half the equation being regulated in terms of levels of care, couldn't there just be an extension of that to relate that to staffing levels?

Mr Thomson—I think that is a very astute observation in relation to it. We have regulations as to what care should be given, but they are not related to any staffing levels that can actually provide the care. There is an obvious link there that, if this is the funding that you are going to get to provide for someone at that RCS level, then you will tie that to their care plan, which is tied to a staffing level that is mandated. In some respects that is what happened in the United States. Before we finish, in relation to a question that Senator Allison raised earlier in terms of staffing numbers I have been reminded that the national institute's last survey was the first time that work force figures were actually asked for in terms of aged care for the whole work force. The only figures that we can go on are from the ABS census, and they saw a drop of 14 per cent from 1996 to 2001 in terms of the aged care work force. They are the best overall figures that we have, but that is certainly consistent with what we put in our submission.

CHAIR—Thank you for your submission and your contribution today.

Proceedings suspended from 1.03 p.m. to 1.53 p.m.

SMITH, Ms Vicky Marie, Private capacity

FARRELL, Mrs Deborah Jean, Residential Services Manager, Australian Home Care Services

McMILLAN, Mr Lindsay, Chief Executive, Multiple Sclerosis Society Australia

BLACKWOOD, Mr Alan, Manager, Policy and Community Partnerships, Multiple Sclerosis Society Australia

MORKHAM, Dr Bronwyn Elizabeth, National Director, Young People in Nursing Homes National Alliance

CHAIR—Welcome. The committee will be visiting the MS Society house in Carnegie later today. I would like to thank the society for that opportunity, as I am sure it will greatly assist the committee in its understanding of the special accommodation needs of younger people with disabilities. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions, and I now invite you to make an opening statement, to be followed by questions from the committee.

Dr Morkham—Thank you to all members of the committee for the opportunity to appear before you today and to discuss what I think is one of the most vital issues on the social and political agenda around the country. I am going to be making an opening statement on behalf of my colleagues here, and then we would like to engage in a discussion with you around the issues that affect this particular question of young people living in aged care facilities. The first thing I would like to say about this issue is that it is above politics. I have yet to meet a politician of any political persuasion who is not completely concerned about this issue and who would not like to see something done. I think the problems for all of us are: where do we go to fix it, what do we need to do, where do the funds come from, and how do we move beyond the impasse between the Commonwealth and the states that has seen this issue exist for well over 40 years without any resolution?

The need for this issue to be dealt with has never been greater. If nothing is done, we will look at 10,000 young people being in aged care facilities by 2007. The current rate of entry for young people at the moment is a young person entering an aged care facility somewhere in Australia every day of the week. Not only does this prevent the frail aged population of nursing homes from getting the care meant for them—indeed, $372 million is spent every year around the country supporting 2½ thousand frail aged individuals in acute-care hospital beds because they cannot access the nursing home beds meant for them—but the young people who live in aged care facilities are largely individuals with acquired disabilities. Most of the state based systems that exist have been developed to deal with people with congenital disabilities. Congenital disabilities by and large have a much more predictable path, with outcomes that are easier to plan for and to make allowance for. Young people with acquired disabilities are a quite different group, and they present with a more complex level of need that state systems are ill-equipped to handle.

One of the things that we really want to make clear at the outset is that the states, probably within the current CSTDA arrangements, are doing what they need to do for the population their systems were meant to address. We are dealing with young people in nursing homes—a group of people who were never meant to be in that state system, which was largely developed around congenital disabilities.

One of the things we have put into our supplementary submission to you was the need for a dedicated young people in nursing homes commission. Looking at the transcripts of hearings that you have already held around the country, we felt that you are more than aware of the issue and the need for change. What does not seem to have been addressed quite so well are the solutions that we all need to take notice of. It is very clear how young people enter nursing homes. The pathways in are quite obvious to everybody. What is not so clear—and what I think the committee has an opportunity to really address—are the pathways out and how best these might be developed, as soon as possible.

We have called for a young people in nursing homes commission that would have the mandate to act as a bridge between existing Commonwealth and state jurisdictions. It would also be a stand-alone commission that would stand outside existing state bureaucracies that have their own difficulties in conversing with one another and working in partnership. The way forward for young people in nursing homes is this partnership between the Commonwealth and the states. I think we need to be very clear that if nothing is done the Commonwealth will continue to deal with increasing numbers of young people. We need to do something now.

The solutions that we have proposed in our submission are simple and straightforward, and I think that addresses one of the most predominant misconceptions about this issue—that we need to go out and do more studies, have more discussions et cetera to find an answer. The answers are already out there. They exist in every state of the Commonwealth. There are small things happening that are very good. I believe you have already visited some of these facilities in Western Australia and other states. I know you are coming to see the house in Carnegie this evening, and we have another couple of facilities in Victoria that are also doing some tremendous things. So it is not a matter of going out and trying to figure out what we have to do; the solutions are already out there.

I cannot emphasise strongly enough that this issue is about young lives—and lives are on the line. We have evidence about young people, and it is certainly not the nursing homes that we have to be pointing the finger at here. Nursing homes are developed, they are funded and they have procedures developed to deal with frail aged Australians, not these young people. I have already mentioned how they have to devote a lot of additional funding to coping with the different needs a young person has. I believe the nursing homes need to be supported to go back to the resident population they were always meant to address, and that is certainly not younger people with disabilities.

As Vicky Smith can testify, she went into a nursing home at the age of 16, after a car accident in which she was injured, and has lived there for the last 17 years. She is now 34. Vicky has fought her own battles in her local community to raise awareness of the issue and try to get something done. Vicky exemplifies one of the problems young people in aged care facilities have: they fall off the disability radar. They are not considered in any new moves that come along.

The commission that we have talked about would have that as part of its mandate: to go and find these young people, discuss with them what they want, where they want to live and how they would like to be supported—and give them a voice that they have not yet had. I think that is most remiss. Deb Farrell will be talking a little bit later about the sorts of things we need to consider in terms of transition, but I might stop there and just say, lastly, that I think the committee probably has a historic opportunity to make the decisions that young people need to bring them out of nursing homes. I think it has been the great hope of all 6,300-plus of these young people around the country that you will be able to make the difference they so desperately want. They want their lives back, they want to be productive people again, they want to have futures worth having. I think one of the saddest things for all of us—because any one of us could find ourselves facing this situation at any point in time—is that a lot of funding, resources and energy go into saving lives where once they may not have been saved but, when families and young people look to find the resources they need to live the lives that they then have, there is nothing there for them.

It is no oddity that family members have said to me that if this is what their family members are condemned to—and they use the word ‘condemned’ advisedly—they would rather their child was not saved, and that this is not a life for them. To live in these situations is not good enough. I doubt that any one of us would think that to do so is an okay thing. I will close there and look forward to talking with you more about the sorts of policy issues that we believe need to be addressed and some of the ways that we believe the young people in the nursing homes commission can deliver those lives worth living to young people. Thank you.

CHAIR—I thought you indicated there is another presentation. Mrs Farrell?

Dr Morkham—I was making an overarching statement on behalf of all of us. We thought it would be easier if we could just speak with you about the various issues that you make have questions about.

Senator KNOWLES—Thank you for that presentation and also for your two submissions. They are certainly comprehensive—but also they are innovative, from the point of view that you are recommending a commission and you are also recommending a national no-fault insurance scheme. Your supplementary submission goes through some of your thoughts about this no-fault insurance scheme, but how do you think this would work? Who would pay the premiums, what would premiums be based upon, who would be able to claim? There is much that needs to go into the formulation of an insurance policy as to where you will actually draw the funds, what the payouts will be, what the reserves will be, and all of those aspects of formulation of insurance.

Mr Blackwood—You are correct in saying it is a very complex area. There is some work going on at the moment: the national insurance ministers have been looking at this for some years and, I think, in the last 12 months it has been sped up by a couple of events. The recent Guy Swain case—the man who dived into the sandbar at Bondi Beach and collected $4.2 million—has forced the New South Wales government to speed up their plans to introduce a catastrophic insurance scheme. The Attorney-General in Victoria has just received a report on how Victoria could move to incorporate a no-fault catastrophic scheme on the back of its no-fault motor vehicle and workers comp insurance schemes.

The Australian Institute of Actuaries have been doing a lot of work with the insurance ministers about where that would come from. There are a number of different financial models, but it would probably involve looking at which insurance pools are already out there with money for these sorts of injuries or looking at how they could be paid for through contributions. So there is some debate at the moment about whether we will in fact end up with one national scheme or with eight state based schemes. For citizens, it probably does not matter that much, as long as there is a decent revenue stream to cover the lifetime care costs of catastrophic injury.

Senator KNOWLES—The point I am making is: if you piggyback it onto third party insurance or workers compensation then, as you say, we are going to have a different range of payouts if we are going to take no fault all the way along the line, whether it be for suicide, catastrophic medical events or whatever. How is that pool of money going to sustain that sort of demand on it?

Mr Blackwood—That is an issue around the design of the scheme or schemes—where they get their money from and how they calculate their benefits. The Transport Accident Commission in Victoria is probably a model scheme. It has been around for about 17 years and it is still fully funded. It has a very broad base for collecting its premiums and it provides pretty comprehensive cover. In the context of this inquiry, it is not the whole answer, because there are a lot of disabilities and progressive illnesses like MS that will not be captured in the scheme. But in a lot of states there are young people living in nursing homes as a result of non-compensable motor vehicle accidents, assaults and things that could well be captured by such a scheme.

The New Zealand Accident Compensation Commission is another model whereby any kind of injury can be supported over a lifetime by the scheme. It is part of what we see as the solution to take the pressure off having younger people going into nursing homes because there is no other option. Part of the reason why there is no other option is because there is no money. At least if you had a national scheme there would be a revenue stream that would be funded and set aside for people. Again, there is a lot of politics in how that is actually funded. I know that in some states any attempt to turn a fault based third party scheme into a no fault one with an increase in registration fees would probably threaten to bring down governments—it is a very sensitive issue—but I guess it is part of some of the structural changes that we really have to get across.

Senator KNOWLES—Who have you been talking to in Victoria about his?

Mr Blackwood—We were part of the consultation for the report that has just gone to the Attorney-General. It is an issue that has been on the backburner for a long time. We have seen it as a solution to disability funding for more than just young people in nursing homes, mainly because the Transport Accident Commission Scheme works so well for people with catastrophic injury. We see a lot of inequity. With people who do have compensation, the compensation does not take away the burden of their disability but it does create a lot of extra options. You heard today from the Slow to Recover Program in Southern Health. That is an attempt to model a compensation scheme for people without compensation. Where you have adequate compensation you do not get young people going into nursing homes. It just seems that we are too small a country to have so many schemes and so many different outcomes where cause is more of an issue than the effect. Clearly, what we are dealing with in the nature of this inquiry is the effect of disability.

Dr Morkham—The family members that we have spoken to have often mentioned that this is an additional impost in terms of whether people are going to be willing to pay for it. I have yet to find somebody who is not supportive of paying more money if that is going to give the coverage. I guess at the moment we all already pay for a lot of personal injury insurance and yet we are still not covered finally if we fall outside the gaps of those insurances, despite the money we have paid out. So I guess it is a way of bringing that together and trying to manage the funds that are already being paid out by people into a system that would allow a better outcome for those instances where there is a catastrophic injury or health event.

Senator KNOWLES—I am just trying to think through this. I have been brought up in an insurance household and I always remember my father saying to me when I was a child, ‘There are lots of people who don’t think anything will ever happen to them—their properties will never burn down, their car will never be damaged or anything else.’ For this to work, it would almost have to be a compulsory system, wouldn’t it?

Dr Morkham—Yes.

Senator KNOWLES—Therefore, the cost of premiums per se would have to be taken on. Where would it be put?

Mr Blackwood—Think back to the medical indemnity crisis of 12 months ago. Medical indemnity is all about insuring the practitioner against legal exposure. We are proposing that, rather than insuring the practitioner, you insure the patient. Again, that is how third-party insurance works: every citizen has insurance cover. As patients of doctors who have massive insurance premiums, we are paying for those premiums and the poor design of them. If we redesign the system there will be plenty of money to cover the unforeseen events. There will not be more unforeseen events by changing the design of the insurance scheme; it just shifts the money to a better use.

Senator KNOWLES—You are talking about a proposal for a commission, with state and Commonwealth governments taking on joint responsibility. I am a little unsure why we would need a commission when, as you state in your own submission, there are examples of the system working well. Why do we have to set up another bureaucracy to invent what is already working well, instead of transposing that model to other jurisdictions?

Dr Morkham—Again it comes back to the inability of the states to deal with this issue. Then there is the fact that many of the other good examples that exist out there are like spot fires: they develop in response to acute need; family members become desperate and try to agitate for something to be done; something will happen. There is no systematic way—no service delivery—that is an organised procedure to do this. Where these instances have happened, they have often happened very well but it has taken enormous energy, time and money to make them happen. For example, the Blackwood Street house has taken nearly three years to bring three women out. That is simply untenable. There is no managed process to develop these answers—these pathways out—and that is why we feel a commission is important.

Senator KNOWLES—I want to stop you there for a moment. Mr Blackwood, why can’t the Blackwood Street example that you are talking about be put into other jurisdictions? It might have taken three years to come about, but surely it is not beyond the wit of similar organisations right across Australia to say: ‘This is working. Why can’t we do it?’

Mrs Farrell—It is about replicating services. We can do it, but in every situation there are particular leaders who end up doing what it takes to get that service up and going. If we leave it to governments to put these things in place, or leave it in an organised way with no systematic approach or process, I do not think we are going to get the number of places up and happening that we need to to bring young people out of nursing homes or even to prevent young people from going into nursing homes.

Senator KNOWLES—Let us take MS as an example. Why wouldn’t what you are doing here be able to be replicated by the MS Society in each state and territory?

Mr McMillan—It needs commitment. It needs the desire and will to have it happen. It needs a commitment from the decision makers. As Bronwyn said, it takes nearly three years to have a place ready for three women. When you see the house tonight you will say: ‘This is fantastic. Why shouldn’t we do this more often?’ But the commitment comes down to champions. What this industry lacks—if it is an industry, and it is not—is a champion. The best example by which we could illustrate that is the Cyril Jewell House—you have the details of that; it has been written up.

MS is basically a disease of young people aged 20 to 40 years. The average age at present is about 29 years at diagnosis and it is mainly women. Some years ago I went to see Rob Knowles, who was Minister for Health in this state. I put it to him that this was a major issue that he, the state representative, needed to take on. The outcome of that was that he stood up—and this is to show how we need a champion—walked across to his phone, picked up the phone, rang Rosemary Calder, who at that stage was looking after aged care, and said something like, ‘We need to solve this and we need to solve it now.’ The outcome of that is that we have a house that looks like a Californian bungalow in a brand new housing estate out at Keilor, for 15 young people. It has never been officially opened. Why? Because the legislation that was funding it was funding for aged care people, not younger people.

The outcome of that was that we finished up with three champions, including Rosemary Calder and Mary Murnane, who would be known to many of you. It was just a remarkable experience. It actually took less time to get that up and going than the example that has been illustrated here. Why? We had three champions who basically said, ‘We have to solve this problem.’ Our concern about this is that you will come to Carnegie tonight, look at this house and say, ‘This is fantastic—we should do more of that.’ Your question is a valid question. We need somebody who is going to take this challenge and lead it. The house at Keilor has never been officially opened. It is the best example of something that can be done with the three levels of state government. It has never been officially opened. I have never been able to officially open it because it was not something that the aged care legislation was able to achieve.

You ask, ‘Why can’t it?’ but the question needs to be the higher level question of how we can solve it on a national basis. The house you will see tonight will be for three people. You will walk away very excited about it. You will walk away saying, ‘This is wonderful.’ You will hop into your cars and go. But there are 6,000 other people in this country who need something like it, so it needs to be solved on a much wider basis than that.

Senator KNOWLES—I could not agree more that it needs to be on a wider basis, but I suppose I am just honing in for one moment on the MS Society itself. The MS Society is probably a federation of—

Mr McMillan—Basically we are trying to lead an environment of change here. As part of that the MS societies across the country—and I know you have met with many of them; I know Gary has a very keen interest in this field as well, as does Lyn—are trying to marshal an interest and mount a cause. We are trying to be the instruments of change. But, again, we can only do so much, because, as Bronwyn said, it relies much more upon others than it does upon us. Our concern, quite frankly, is that we will run out of puff unless there is something that happens at a higher decision-making level than we can marshal. That is really what we are saying here. We are trying to be solutions based, not problem identifiers. There are problems out there—we know it and you know it. We are saying that there is a range of ways in which we can solve this. Our challenge is not to see it for the one-offs. Let us take the higher calling here and the high moral ground and, across all of our areas of politics and government, say, ‘This needs to be solved.’ We do have some solutions—let us solve it. We can identify the solutions, but again it needs to be taken at a much higher level of decision-making. That is why we believe today is critical. This is a watershed for us.

Mr Blackwood—The other reason why we cannot replicate it in every state is the design of the innovative pool. That again is part of the reason why it took two to three years to get that house going. I think you have heard evidence from other people who have put in innovative pool proposals to their state government and they have not actually made it across the border to Canberra. The innovative pool is a good concept that has been absolutely tortured by the bureaucrats into a scheme that is almost unworkable because it needs to get through the state sausage machine before the Commonwealth can adjudicate on it. If you fail at that step, the Commonwealth does not even see the good idea.

We pursued our project probably harder than a lot of other providers and we were fortunate that the cards fell our way and the Victorian government supported it. But we hear from other states, and you may have heard during the inquiry, that states are reluctant to participate in the innovative pool because of its time limited nature. If the funding conditions were right, if the innovative pool could be restructured—the Commonwealth and states, perhaps through the commission, could structure an agreement whereby they could jointly fund these solutions—you could have 10 or 12 in every state very quickly. The technology, the models and the skills of assessment and service delivery are there. What is not there is the machinery of government—or governments—to get these proposals onto the table.

Senator KNOWLES—The Victorian government was the only government up until early this year—I am not too sure of the current status—that had taken up that offer of the innovative pool.

Mr Blackwood—That is right.

Senator KNOWLES—To me that is remarkable because, if the Victorian government can do it, surely the other governments can do it.

Mr Blackwood—They should.

Dr Morkham—It has been such a tortuous process and I think, were it not for the MS Society's commitment and dedication in staying with it, it would not have got up. But the Victorian government has now said that it has been so difficult for them to do under the current arrangements that they are not interested in doing another one. That again leaves us, as Lindsay said, back at square one. Do we then have to ramp up again, go forward and try and get another thing up? In the meantime, young people are going in faster and faster.

It is a great question, but I really think that, to develop the prescribed pathways out, (a) we need political will and commitment to do it and (b) we need a dedicated funding stream from both the Commonwealth and the states. If we do not have that, no state government is going to step up to the plate at all. As Alan said, Queensland has decided that it is not doing anything. There is no service development happening anywhere now because they are so under the pump. The disability systems that exist are already dealing with the unmet need. That is why we feel a stand-alone commission that was independent of the state based bureaucracies, which have difficulty dealing with one another on a day-to-day basis, and that could act as a bridge between the Commonwealth and the states would stand beyond all of that and work.

Senator McLUCAS—Can I come back to the evidence you have given us about the difficulty of the innovative pool funds. You said that they are time limited and that was essentially the objection from the state. Would you like to explain that a bit more?

Mr Blackwood—The way that the innovative pool works is that the Commonwealth provides two years of funding to assist young people out of nursing homes. To get a proposal up under the guidelines it has to come from a provider and then get to the Commonwealth with endorsement from the state government. So essentially you have to work with the two levels of government and a group of families and individuals and have a project that is fully costed and agreed to by both governments, which is what we did. But another flaw we found in the design of the scheme was that there has been no more than an exchange of letters between the two levels of government around our project, it took the Commonwealth probably most of the first year to approve the project and it has taken most of the second year for the state to get their system organised and to get the house modified and the funding organised for the women. Again, it is new so I guess everyone is feeling their way, but there was no joint accountability through time lines and targets that each government had to meet at the same time to get this project up and running.

It could have been going in six months or less. We had the building, we had the women, we had the service design and technically we had the money. But it took a long time to roll out. The women are moving in today so you will be part of their house-warming party this evening. The two years has not start ticking away, thankfully, because otherwise we would have finished the project before we had started. They are some of the things that we need to sort out in the future. What we have done to bring the women out is easily repeatable, but we need a system whereby governments can align their policies and procedures and learn to talk to each other a lot better rather than meeting at our place, as it were. They really need to form a bridge of their own.

Senator McLUCAS—From your perspective, is there also a reticence from the states because the Commonwealth contribution is short term, for two years? And, as I understand, it is usually capital moneys. Do the states believe they will be left with the operational responsibility from now on? Is that a blockage?

Mr McMillan—That is a blockage, particularly the way the funding works. For example, for the Carnegie house and also for a second innovative pool pilot we have at a shared supported accommodation service that we also run, the Commonwealth funding is used for nursing and therapy and the state funding is used to provide personal-care attendance and community access. It is almost broken up down the lines of clinical services and non-clinical services—personal-care attendants and trained staff. The Victorian government, as well as other governments, has a significant problem with accepting that nursing services are an essential part of a disability service. This is part of what we are saying about their core target group and the mission that they are fulfilling as part of the Commonwealth-State Disability Agreement—that it is for people with congenital disabilities. The models do not include the nursing.

There are very few examples of state governments, off their own bat, funding accommodation services with nursing attached. They are very reluctant to do so, and I think they see, particularly with the ageing of people with disabilities in their care, that nursing will become a greater and greater component as time goes on. It is an issue, again, of uncontrolled growth in demand for a very expensive service. The states see the Commonwealth contribution to a joint agreement as knowing how to fund it. The Commonwealth has systems about how to fund nursing in residential settings and the states do not have that expertise. In fact, in Victoria, those sorts of specialised services for people with acquired brain injury and neurological conditions comprise, as we said in the submission, 1.5 per cent of the total disability accommodation sector in the state. It probably is a measure of their expertise in the area as well that the sorts of conditions and models we need are almost not on the states' radar.

Dr Morkham—I will just add to that. In New South Wales, now, once young people have been defined as having high clinical needs—going back to medical model—they do not even get a look-in on the supported accommodation spectrum. That has been a recent development because that state does not know what to do with this group of young people. Again, people are being progressively weeded out of any system. The people who lose, obviously, are these young people themselves.

Mr McMillan—Furthermore, the risk is that this is only a time limited grant—two years. Organisationally, we then have to say, 'What do we do after two years?' We are already asking those questions and saying that this is a concern—that we have to try and marshal again some other resources to ensure these people do not fall asunder.

Senator McLUCAS—I understand that with Carnegie, where we are going tonight, the Commonwealth committed $124,000, which was used for capital—either construction or modification; I am not sure. That is then the extent of their contribution. In the model that you talk about for the commission, are you suggesting that the Commonwealth provide capital moneys? It does not seem to be that clear in what you are proposing. It is just 50 per cent of the cost rather than trying to delineate between capital and operational costs.

Dr Morkham—In defining those costings, I was trying to provide a win-win for everybody. It is sometimes not possible, but I was trying to indicate that the Commonwealth can make some savings, and the states can too, by both being engaged. I did not just draw a line down the middle, but the Commonwealth will already be committing significant funding to keep a young person in a residential aged care facility. They could commit half the recurrent funding that they already provide to go into the community. The states would provide capital. The states are, under the CSTDA, already accountable for some things.

If the states provide the capital—and, in this case, the house you will see tonight is owned by the department of housing in Victoria—the states would then pick up 50 per cent recurrent of that young person’s care needs as they go out. Again, drawing a line quite so directly is probably not feasible. Each person’s needs would be different, obviously, but it was a way of saying that at least each tier would be 50 per cent better off than if they did nothing.

Young people in remote or rural areas may choose, because the numbers are not as high or the services do not exist, to remain in a nursing home because it keeps them near their family and friends. If that were the case, then the states would be responsible for providing the funding to take the services into the nursing home that these young people do not currently get—services around equipment, physio, rehab, higher staffing ratios and so on. Does that answer the question?

Senator McLUCAS—Yes. I have a final question about the model—and I really thank your group for putting a lot of effort into trying to find a solution; this is very valuable for us. At point 8 you say that funding needs to follow the individual. In Queensland, for example, under the Commonwealth-State Disability Agreement, the model that Queensland use is to develop a disability package. People will get a package if they are non-compensable. Is that the model that you are proposing?

Dr Morkham—Deb might be able to talk a bit more about the pathways out and the assessments that need to be done, but basically we are saying there is no ‘one size fits all’ solution to this. We need a range of options. Young people and their families need to be talked with about what they see as the answer for them. Deb has also got some comment around how you manage expectations and the realism of expectations. We cannot all live as we would like to live. There are limits that obviously will be there. How do we manage that? We have argued that it is vital that young people and their families be involved in this, that the services that they need be developed, so that the commission would exist with the funding and the mandate, people would go to that commission and identify their needs to them and then it would be up to the commission to facilitate a project around the support or the supply of accommodation or whatever it would be.

I think we also mentioned a group in Queensland that is another one of the spot fires I mentioned before—the Shavaune 117 group. Shavaune is 32 years old. Her husband has been looking after her with a limited amount of support. Shavaune has deteriorated. She has MS and her condition has now deteriorated beyond a point at which her husband can look after her. When he went to DSQ, they just said, ‘We don’t have anything more we can offer; look for a nursing home.’ So he did, and he found this an untenable proposition. David has started this group. He has got some tremendous contacts in the business sector. He has already got the land to build something. We liaised with him about how the process might be developed. I see the commission as being the overarching body that would liaise with community based groups like that to provide the managed process that they need that would bring people out or stop them going in. I might stop there and let Deb talk about the sorts of things we think need to happen.

Mrs Farrell—I think it is a very practical approach that we are looking for. It is about actually understanding the range of people that are out there or that are potentially out there waiting to go into a nursing home and be placed. One of the women that you will meet tonight that is moving into Blackwood Street is in a nursing home because there was not an individual package available to her. We have another service that is a fairly new service—13 people in an individual, independent style of living. Each of them has a package attached to them. If they develop the skills and the capacity to live more independently, then they can take their package with them and move and still receive support. Alternatively, they could take a step down into another service that can meet their needs if they deteriorate, having a neurological disease.

Attaching individual funding to people means that we do not have this notion that we put people in a place and they stay there forever. Rather, it means that we have a continual planning process, that we open the systems up and that we can step people up and down and move them to where they will receive the support that they need. It means we can prevent, I guess, the quagmire that we are currently experiencing not just in residential accommodation but also in subacute and acute systems, where we do not have any flexibility to move people around to meet their needs. Picking up on a comment that Bronwyn made earlier: we can use nursing homes. If we could put funding into nursing homes, provide an attendant-care model and use some of the models that we have out there already by putting them into nursing homes, nursing homes could be used to raise individual's capacities in skills that they have lost because they have been in nursing homes for even as short a period as six or eight months. They very quickly lose capacity and skills, and we can start to build their skills to help them in their transition to another setting. But we have got to have all of these different models, and I am sure members of the committee have seen lots and lots of different models as you have travelled around. We should be able to use all those models, but it comes back to individual assessment—to understanding the history and the individual: what their needs, wants and aspirations are—and then managing the expectations and risks of putting them in there, and then having a continual pathway.

Senator McLUCAS—You have written quite extensively about the Western Australian experience in your submission. I think the members of the committee would agree that we were fairly impressed with what we saw happening over there. Do you think it is the fact that the department of housing in Western Australia is a partner in many of the solutions in Western Australia that is the key to the success that they have had in a fairly short period of time?

Mr Blackwood—I think it is important that they are a partner. The success in Western Australia is probably attributable to the fact that there was a project. They got all of the stakeholders together—the Commonwealth, the Disability Services Commission, Housing and perhaps Health. They dedicated money and gave a mandate to this project to complete the job. They were the key success factors. Clearly, you have got to have the housing for people to move into—that is a critical thing. I think that the Western Australian project is part of the thinking behind the model for the commission. Lindsay said earlier that it is about leadership and it is about a mandate. Currently there is no mandate from either level of government to do anything and there is no meeting of the jurisdictions, whereas on that project it was not only the Commonwealth and the state but also a number of the state instrumentalities that got together. Ten years on, it is still seen as a very good piece of work.

Mr McMillan—There is another example: Fern River is a very good example. From the viewpoint of the MS Society in this state, we can identify a number of quite successful supported-accommodation environments where the department of housing has been instrumental and, I have to say, very easy to work with in wanting to find the solution. We had a 24-bed nursing home at St Albans that we downsized to supported accommodation and a range of other accommodation environments. As part of that, the department of housing built, to our specifications, at minimal lease, two five-bed homes in Williamstown—again in a suburban street backing onto the railway line. It was wonderful arrangement. As an organisation, we have added value to that, along with the other examples that are even more current and up to date. We see the department of housing as a great partner in many of the solutions.

Senator ALLISON—I start by congratulating you on your submission. It is one of the best submissions to an inquiry such as ours that I have read. It is hard to find a question, really, because you have not only given us very sound recommendations but you have backed them with good argument. Perhaps you can comment on your table 3, which shows comparative funding for a young person through disability services and for a young person in residential aged care. I think this illustrates very successfully the underfunding of young people in nursing homes. Mr Blackwood, you made a comment about not foreseeing state governments adding nursing to whatever accommodation proposal is put forward. I invite you to expand on that.

Mr Blackwood—It comes from the models that are on the ground that are run by state disability agencies. They are primarily built around intellectual disability. Those models do not have nursing attached. There are some examples where nursing is in place. The MS Society of Victoria runs services with nurses but that is partly at our own cost. It is something that I think the department wants to resist, and I think it is related to where the line is between disability and aged care. If someone has or develops complex health needs associated with their disability, the current practice is that the disability sector will call in the ACAS team when this person needs to go to a higher clinical environment. We see perverse situations where someone will be sitting in a state disability bed worth somewhere between $60,000 and $80,000 a year and then, because they need a higher level of support, they get moved on to a service that is worth $45,000 a year just because there is a registered nurse on the premises. It is a moot point as far as we concerned about where that line is. It is probably more about where you can make it for a particular client than about where it should be. Because of that practice and because there is a pathway into nursing homes, there seems to be a notion that if someone has a need for nursing or clinical services they should be in a nursing home.

Senator ALLISON—Yet when they get to a nursing home they are not entitled to any services which might make them able to live more independently. In fact, the Aged Care Act prohibits such services.

Mr Blackwood—That is right.

Mrs Farrell—In fact, one of the biggest amounts of time spent with these three ladies has been on establishing them back into some sort of health service model, to get them back to seeing neurologists and urologists and just having a GP who actually understands their support needs and the right medications and treatment and all of those sorts of things. Once they move into a nursing home, everything just breaks down. There is no need for medical reviews anymore.

Mr McMillan—A very important point at not only the Commonwealth level but also the state level is that the distinctions between health and disability are so finite that the question is: where do the people we are talking about fit in? As you say, they are in a nursing home for aged people so they have to fit in with the services for aged people—which do not match up with a younger person’s needs and interests, as Deb has been saying. So what happens? They fall between the two good ideas. It is a major issue, particularly for this group. There has to be some greater flexibility and understanding of what is disability and what is health. I know that is not our purview this afternoon, but the reality check is that we can give fact after fact but if I am in an aged care environment in a nursing home I only come under aged care legislation. By its very definition, as a younger person all my needs are not for aged care. You are absolutely spot on. It is a very important question and, again, the commission would hopefully be a bridge builder between those two very strong legislatively driven issues.

Senator ALLISON—It is often said that the reason young people with disabilities end up in nursing homes is that they are too spread, so there are not the numbers to require setting up units that would accommodate them and aged care is a better solution because at least there are lots of aged care places around and they will be close to family. Could you respond to that argument.

Dr Morkham—Let me just restate that: it is about the availability of places for young people to go to—sorry, is that what you are saying?

Senator ALLISON—The argument is that, if we set up accommodation specifically for young people with disabilities, because of the number of people who need that accommodation they would necessarily be a long way from where they would prefer to be—close to family. I think people are talking in terms of 90 beds or the sort of scale that residential accommodation is moving towards.

Dr Morkham—Sorry, I misunderstood you. Deb, would you like to take that one?

Mrs Farrell—I will use St Martins Court as an example, where 13 people were moved into that service. Moving was the individual choice of those people, unlike people being selected from the special needs register or something like that and being told, ‘Here’s a place for you.’ There are some people in that service—three that I can think of—that have actually moved some distance away from family and from the nursing home that they were in. That is preferable over living in a nursing home, if that were the option. I think this is where we can look at different models within a nursing home to be able to provide a lifestyle option for young people, because it is not always necessarily about the bricks and mortar of the facility—maybe we could ask Vicky to comment on this—it is about the fact that they can never get out. They are unable to do anything in a timely fashion and they do not have the opportunities that we do every day to make our own coffee, for instance, or contribute to decision making and choices. So this argument is not always about the actual accommodation; accommodation comes. I think it is about the funding, about the knowledge of who is out there and about assessing people and looking at what their needs and aspirations are—I come back to that point again. On a small scale within nursing homes we can provide an annexe to services that will provide a better service.

Mr McMillan—To illustrate that, the 15-bed nursing home at Cyril Jewell House at Keilor is quite a large design that fits into an ordinary modern housing-scape. Yet on the other court it is attached by a passageway, which would be two metres wide, to a 30-bed nursing home. So effectively the property is a 45-bed nursing home run by Melbourne Health. What happens is that the 15-bed nursing home receives all the services of the aged care facility but is uniquely positioned in its own right. We provided a bus and a funded position for an access worker, who achieves what Deb is talking about in making sure that these people can get out and go to the local swimming pool if they want to do swimming or whatever. They participate with the kids in the street who are able to ride bikes and learn to kick the football or play cricket. They are out there in that kind of environment. Yet behind them—where they would never need to go—are all the facilities for food, catering and laundry. So the economies of scale are achieved, albeit that the scaling now is much higher than 45, I think. Again, that is just another example of a design feature that achieves something that is unique for the individual yet caters for and accommodates the costs involved.

Dr Morkham—Could I just respond to that. I do not know whether this is a bit peripheral, but I do think that part of the answer to your question is in going back to young people and their families and asking them, talking to them and including their voices in the dialogue. That is why we feel that the commission is so vital, because it can stand outside established bureaucracies, which often have great difficulties in speaking to one another or finding ways to work cooperatively together, sad though that may seem sometimes. But I think the commission can offer that facility. It can allow young people a voice. They can comment on what they would like, how they would like to be supported. And, as Deb said, ultimately we hope that there would be flexibility. By tagging the funding to the person and developing a range of options on the spectrum, you would have that ability to move as your needs changed or your life circumstances altered. It might be, for example, the Carnegie house you will see tonight, housing three young women, or St Martins Court, with 13 young people. The range of options is not limitless, but there are many and varied answers to that. I just think that we must go back again to giving young people a voice in any of this.

Senator FORSHAW—Last year I became aware of a facility in New South Wales which was run by Anglicare—I am trying to remember the name of it now, but I cannot. It was essentially a live-in residential facility for young people with disabilities who had had them from birth. It was going to be closed down because there was a shortage of funds. Ultimately it stayed open, and they were able to get another commitment from both state and federal governments.

I mention that because one of the things that I think certainly the not-for-profit sector in aged care accommodation does well is to provide a range of different types of accommodation for the elderly, from retirement villages through to what were called hostels, to nursing homes. That leads me to ask this question: is any interest being shown by, say, those large, not-for-profit, very often religious based groups like Catholic Health or Anglicare or whoever in providing specific facilities for the people that we are talking about here, in the same way as they do in aged care proper and for young children or even for teenagers who may have had autism from birth, where they are providing respite care, for example? I know those groups are under a lot of pressure. As I said, one facility was nearly closed down last year, because it was being cross-subsidised by other operations of Anglicare. Clearly, the funding here is an issue. Do you have any comment?

Dr Morkham—Yes, I think there are a couple of answers to that. I think the organisations and the not-for-profits certainly would be keen to do something, but again they are caught up in this division between aged care and disability. Many of them are aged care providers. To operate within this group, to bring young people out—often you have to have accreditation as an aged care provider to get the funding, yet the disability provisions are very different. So there is that problem too. In the example of Shavaune 117 that I mentioned before, they have already approached a church based organisation, which has donated the land with the proviso that, if anything is developed there, it will be the service provider.

So I think the short answer is yes. I think there is interest. I do not know that the mechanisms are out there yet to allow that commitment and that desire to be involved to come to fruition. I know I seem to be saying it over and over, but I do feel that the commission can provide an answer to that too. It can act as the facilitator to develop a project. For example, if an organisation went to the commission and said: ‘We have some land. We’d like to do something, but what do we do?’ the commission could provide the pathways it would need to follow. The commission could provide the tender process—whatever it would need to be—and maybe provide whatever accreditation it might decide needs to be done to get that project under way.

I was in discussion with an aged care provider recently. You are more than aware, I am sure, of the number of hostels for aged care that are being closed down because they are no longer economically viable. That is starting to pop up everywhere. We get a lot of calls from aged care providers saying: ‘Could you use this facility? Is it of use to you?’ The other thing is that you then run into the state based disability system’s position about not going down the path of congregate care.

Senator FORSHAW—That is another issue I have—the bias against what is called institutionalisation.

Dr Morkham—Indeed, and with good reason. The difficulty, again, is that young people by their very nature are fairly social beings and they do not want to be isolated. It comes back to talking to them and asking what choices they want to have available to them, and the ability to be flexible in response to developing those services.

Senator FORSHAW—It is about the needs of the families and the carers in the context of respite and so on.

Mrs Farrell—It is not always about the building. As Bronwyn said, there is a whole host of these hostels or nursing homes around but the issue is then attaching the funding for support.

Senator HUMPHRIES—Thank you for the submissions. They are both very useful. The information you have given us is actually quite comprehensive with regard to some of the areas we have been looking at. I have a question about table 1 in the Alliance’s submission. Obviously it is inappropriate for younger people to be in nursing homes; I think that is fairly well accepted by everybody who has come to see us. The only exception to that might be people who are severely brain injured or otherwise not aware of their surroundings. I do not quite know how you describe that clinically. Do you have any idea what proportion of those people under, say, 50 would be in that category? Are we talking about too small a number to be significant? Do you have any idea?

Dr Morkham—That is an important question and it raises two things in my mind. The first is that it is very difficult to know what type of disability young people already in aged care facility have because the Department of Health and Ageing does not collect data according to disability type, just according to location and age range. We have enormous difficulty understanding what the nature of the disability spread is. I think we made an estimate at some point that roughly 30 per cent of the residents would have acquired brain injury or some other neurological diseases and 30 per cent would be spinal cord injuries. I have forgotten the exact breakdown but the point is that there is not much data around to deduce that from. I have forgotten the last part of your question.

Senator HUMPHRIES—Do you believe that the number of people in that category of severe brain injury—that is, unaware of their surroundings—would be significant? In a sense, would it not matter where they were located?

Dr Morkham—The comment I would like to make in response to that is that we really know very little about the brain and how it recovers. I think we are on the cusp of understanding a great deal more. For example, five years ago people with severe brain injuries were considered not to be able to recover. We now know that the brain can develop new neuronal pathways, that recovery is possible and that it is possible even up to five years after injury. So we know very little and I think we need to be very careful about making assumptions based around a lack of cognition when we really have no way of understanding or communicating with people who are locked in.

I know you will be talking with Mary Nolan later today, and I am sure that Mary will be able to tell you about that. The model that currently operates for people with disabilities, especially acquired disabilities, is largely a medical model. We now know that, if the brain is to recover, it must have social stimulation. It must have a variety of stimulants around it to give it the chance to develop those new pathways. If those stimulants are not there, the person does not go anywhere. Even if we cannot know whether it is having a direct effect, we need to be positive, to assume that it can do and to provide those pathways—those settings, if you like—that would allow that person to demonstrate some recovery at some point. I am not a medical specialist but, as far as I understand it, that is the situation. We simply do not know yet.

Senator HUMPHRIES—I have one more question. My impression is that the campaign to reform insurance or compensation arrangements has more or less stalled at the moment. There was stimulus a couple of years ago during the insurance crisis, but the many difficulties associated with a no-fault compensation scheme seem to have overwhelmed the momentum for that at the moment. Is that your perception as well? Do you see moves happening in various places that might yet spark that into life?

Dr Morkham—Definitely there are moves. Victoria is about to release a report on its assessment of extending to catastrophic injury the Transport Accident Commission’s no-fault scheme. That report is due out on 30 April. I think the government in New South Wales is about to deliver something too. So the two biggest states in the nation are moving towards no-fault basis. I have heard anecdotally that the other states have started to examine this. I do not know whether it will end up as one national no-fault scheme or a series of state based schemes with a national agreement but, far from stalling, it is gathering some momentum. A comment was made to Alan and me in a meeting with Rob Hull’s people that they expect something to have happened on a national level by about the middle of this year. There is a great deal of concern about the states and their own rights being lost somewhere in this mix, and that is a hurdle that they have to overcome, but the momentum is certainly there. The savings are clearly demonstrable. Alan, you might be able to talk about the actuaries modelling that has informed that.

Mr Blackwood—There are two models that they are looking at. One is to collect all the money that is sitting around in insurance pools and to put it into one pool rather than 30 pools. The work is continuing, but the states currently own their compensation schemes—each state has its own work cover scheme and third party scheme—and they are all different. It is an area that is complicated by a lot of interests, for example the medical defence funds, commercial and industry interests and the legal profession, which would have a view—they certainly had a view about the design of the New Zealand scheme. Obviously we have been coming at it from the injured person’s, the end claimant’s, point of view, and I suppose it is a voice that at the moment does not have much volume in the debate because it has been with government and the industry, but there certainly is some movement. However, we probably do not expect things to happen outside New South Wales and Victoria really quickly.

I think it is significant that this issue is being talked about in an inquiry into aged care, because it does have an impact on aged care, on public health and on acute hospitals. It is more about where the revenue comes from than about the expenditure. I think governments spend a lot of time agonising over how to spend money. This is more about how to collect it, quarantine it and keep it there for a lifetime’s worth of care.

CHAIR—Dr Morkham, we are just about out of time. Are there any other contributions you want to make?

Dr Morkham—I wonder whether the committee would be willing to hear Vicky Smith’s comments.

CHAIR—Of course.

Ms Smith—I have been in a nursing home for a long time, and I have seen death after death. I do not have the willpower to put up with any more deaths. I lost both my mother and brother in 1999, and I cannot cope with any more deaths.

Mrs Farrell—When you speak to any young people from nursing homes, it is a very common story. They become friends with those people.

Ms Smith—And you love them.

Mrs Farrell—And then, all of a sudden, they are gone. Where is the life for the young people? Vicky, people here acknowledge that it is not right.

Ms Smith—But they do not care a shit about us young, not at all, and it really frustrates me.

CHAIR—Thank you for your submissions and thank you for your contribution to the inquiry today.

Proceedings suspended from 3.06 p.m. to 3.18 p.m.

HARRIS, Mr Rodney Neville, Chief Executive Officer, Motor Neurone Disease Association of Victoria

BRYANT, Ms Helen, General Manager, ParaQuad Victoria

COOPER, Ms Margaret Maxine, OAM, Client, ParaQuad Victoria

MARTIN, Mr Allen, Acting Secretary, Treasurer and Executive Committee Member, Victorian Brain Injury Recovery Association Inc.

RAWICKI, Associate Professor Barry, Past President, Victorian Brain Injury Recovery Association Inc.

TIERNEY, Dr Joan, Executive Committee Member, Victorian Brain Injury Recovery Association Inc.

VINCENT, Ms Susan, Executive Committee Member, Victorian Brain Injury Recovery Association Inc.

CHAIR—Welcome. Do you have any comments to make on the capacity in which you appear?

Ms Cooper—I am a student in the field of ageing, related to people with physical impairment.

Prof. Rawicki—I am the head of rehabilitation for Southern Health.

Dr Tierney—I am a medical practitioner. I have been working in the area of acquired brain injury for close on 20 years.

Ms Vincent—I am a physiotherapist in private practice working with neurological clients.

Mr Martin—I am substituting at the moment—very poorly, I will admit—for our president, Mr Ben Bodna. Some of you would know him as the former Public Advocate of Victoria. He sends his apologies, being interstate.

CHAIR—Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions, and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Martin—The document *Making new connections*, which has been distributed to you, gives more reference material to support our initial submission, No. 205. At Mr Bodna's suggestion, and accepting that comparisons can be odious, we have snuck into that document an excerpt from one of our newsletters about the British parliament's inquiry into ABI rehabilitation. The document reflects the views of health professionals actively engaged in the medical management and rehabilitation of persons with acquired brain injury. Our submission refers to several thousand people with ABI—and I know that you have had that figure established again—living in aged care facilities and, to quote from our submission, ‘presently denied fair and proper treatment, and whose voice to date is being ignored by governments and health authorities’.

VBIRA believes that this committee of the Senate has the opportunity to be the catalyst for the federal government’s Department of Health and Ageing, Department of Family and Community Services and Department of Veterans’ Affairs to sort out their differences and jointly work with the state government so that the objects of the Commonwealth Aged Care Act can embrace persons with severe acquired brain injury. VBIRA realises that persons with severe ABI have been admitted to government supported nursing homes for many years, not because they fit the requirements of being frail and aged but under emergency or compassion provisions of the federal and state agreements, where the state has no other option available. By persisting with this practice CSTDA after CSTDA—and we are now into the third Commonwealth-State/Territory Disability Agreement—the federal government has by default accepted responsibility for funding the accommodation and care of persons who need special care and rehabilitation. Actions speak louder than words.

The bilateral agreement which is now operative, signed on 5 June 2003 by Senator Vanstone, on behalf of the Commonwealth, and by Ms Garbutt, on behalf of the state, is scheduled to run until 30 June 2007. It clearly identifies acquired brain injury as a distinct target group for both levels of government. In part 3 of its terms of reference, it mentions how improvements introduced by the Commonwealth will also focus on an individual’s abilities and recognise the potential of people with a disability to become involved in the community or working life. It goes on to talk about how both governments’ approaches have been developed in a spirit of partnership, inclusion and collaboration across levels of government and across the community. Referring to that agreement, policy priority No. 1 has two activity areas: (1) clarifying the role of both parties in advocacy and (2) people with a dual disability and acquired brain injury. As regards this second area of activity, the agreement states the outcome to be a policy paper. There is a performance option that this policy paper be provided within two years from the signing of the agreement—that is, in 40 days from today we should have a policy paper. We ask that the Senate committee make sure that that is a public policy statement.

The Aged Care Act has 10 objects, including providing funding of care; providing quality of care; the need to ensure access to care that is affordable for, and appropriate to the needs of, people who require it; to ensure services are targeted towards people with the greatest needs; to help recipients enjoy the same rights as other people in Australia—and so it goes on. The aged care principles, at schedule 1, part 3—‘Therapy services’—exclude ‘intensive long-term rehabilitation services required following, for example, serious injury, surgery or trauma’. They are excluded.

Here we have the aged care principles, under which nursing homes and aged care providers have to manage their spending of Commonwealth funds, specifically prohibiting nursing homes and other providers of high-level care from at least trying to meet the objects of the act. The committee already has evidence of the frustration of professionals and families of those with ABI due to differences between the states regarding ABI management, accommodation and rehabilitation. This is compounded by the Commonwealth’s varied positions. What is needed is clarity and uniformity so that access to appropriate accommodation, services and supports is not made available only to the few and/or the wealthy whilst leaving those who are unable, poor and frightened to meekly accept apparent indifference and neglect—their fate being that they are denied the full medical care, rehabilitation and common rights which are specified in the principles.

Some of our medical and health authorities persist with outdated restrictions such as limiting rehab access to within two years of injury. A noted Queensland clinician, Dr Ewing, says—and this is at page 13 of that document—'The idea that nothing more will happen and that there is no point in further treatment after two years is not only wrong but cruel.' Another expert, Professor Galea—at page 22—adds: 'We know that there is a potential for recovery over a long period of time. It's not something that will just happen in 12 months; it happens over years and years and years.'

VBIRA's position with regard to people with severe acquired brain injury being accommodated in supported aged care facilities has been clearly stated in our submission. There is one clarification which I would like to make. It has been drawn to my attention that at page 3, where we talk about private medical services in private hospitals, we do not indicate that private insurance meets all the bills, or any of the bills in that particular case—that refers to 'privately engaged by families' et cetera. The document also accepted that the whole issue of appropriate accommodation for uninsured, non-compensable people with severe ABI is a major deficiency in the health system which needs urgent attention and which we do not expect to be suddenly remedied. We are here today to further pursue discussing with you possible actions which could be initiated in both the short term and the long term. We are here because the ABI injured, their families, the health community and the general population need certainty so that they can plan and act now. We want to help, and we look forward to your questions.

Mr Harris—I represent the Motor Neurone Disease Association. We bring a perspective which, I suppose, is very different to that of most of the people who have spoken to you—particularly the last group, Young People in Nursing Homes. We are really talking about people with long-term disabilities and with lifelong expectations and needs in respect of accommodation and support. Our group has an average life expectancy of about two years. Our group are aged anywhere between 20 and 70 at onset of the disease. In fact, Dr Harry Jenkins, former Speaker of the House of Representatives, died of motor neurone disease, as did the mother of Senator Guy Barnett.

The thing with motor neuron disease is its rapid progression, requiring rapidly changing services to meet rapidly changing needs. One of those needs is supported accommodation. At the moment, many people access aged care services for that support and, as we have outlined in our submission, that is inappropriate. We, like Young People in Nursing Homes, are arguing strongly for much more flexible models of funding to allow people to purchase support that will assist them to live in their own homes for longer, allow their carers to continue to contribute to their care and support and enable them to live fulfilling lives while still being part of their own community—and not, because of lack of capacity in their own homes, be forced into an aged care setting where staff do not have time, where they are in an environment which is becoming more and more dominated by people with dementia, and where their capacity to participate in the broader community is restricted, if not completely wiped out.

The other issue that we confront all the time is the basic one of what services you can gain from the state and what services the Commonwealth funds. Can I say that it is very embarrassing, when we have a person living at home with an electric high-rise bed that bends in the middle and vibrates, that they cannot take that with them when they go into a nursing home, because the electric bed has been provided by the state—and, of course, the Commonwealth does not fund equipment to that level. They also cannot take their electric recliner chair, which improves their comfort during the day. They have difficulty accessing appropriate levels of posture support, particularly mattresses to prevent pressure. They are often left in situations where their inability to communicate means that harried and hurried staff do not deliver the services that they need. Quite often, it is only because of interventions from outside the aged care service that their needs are actually met. I will leave you with that. Our submission speaks for itself, but we are very keen to respond to questions. Thank you.

Ms Bryant—I am here to represent people with physical disabilities, mainly spinal cord injury and polio. A lot of our clients are in nursing homes merely because there are not enough services in the home to accommodate them. After people with these types of disabilities have had their disability for more than 20 years they start getting more and more functional, medical and psychosocial problems—this is not necessarily related to their chronological age—and, as the in-home services do not increase and there is no other service for them, they are therefore forced into nursing homes.

We firmly believe that people with physical disabilities should be admitted to nursing homes on the same basis as the general community. So, if you have dementia or an age related disease and if you are of an appropriate age, a nursing home is probably the appropriate accommodation—but not just because there are not enough in-home services to be able to accommodate you.

Ms Cooper—I had polio in 1947, and I have been dependent on assistance with showering, ‘toileting’ and dressing ever since. I represent a large group of people with physical impairment: there are about 70,000 people who had polio during the thirties, forties and fifties in the southern states. There is probably an equal number of spinal cord injury, muscular dystrophy and various physical impairments that would bolster those numbers.

I went to university and worked full time for 27 years, and much of my time was spent working alongside aged care assessment teams. I hated it whenever we came across a person with a disability. The aged care assessment model is based on picking up and totalling deficits. We are used to looking at our abilities and complementing where an ability does not occur. An aged care assessment worker who would automatically consign people in wheelchairs to nursing homes got into a lot of trouble over that.

I had a second career, unpaid, in national disability advocacy. I found that my colleagues and friends were all starting to complain—around 1988, when we all hit our late 40s—of fatigue and the various physical syndromes that go with long-term spinal cord injury, polio or whatever. There is a lot of research; it is becoming a big problem in the USA, Britain and Australia. According to the AIHW, people in the age group of 45 to 64 with severe core activity restriction—that is, needing assistance with activities of daily living—are expected to number 1.3 million by 2006. I am right there in the middle of that.

I am doing a PhD looking at the experience of people who are ageing and who have a physical impairment, to see what they want. They are extremely independent. We are all extremely independent, and we all fear losing control and going into residential care. I spent 24 years in residential care, and that is my nightmare. The problem is that there are no systems of disability impairment support—all the big organisations closed down, the hospitals closed down, the doctors died—and in our 40s and 50s we are going back to try to find someone who can assess our disability impairment progression plus the onset of ageing related problems.

We probably have osteoporosis, obesity, cardiovascular disease and respiratory decline as part of our ageing syndrome, but there is no specialist with the dual experience in disability maintenance and aged care assessment to give us appropriate advice. So what is happening to my friends, colleagues and research participants is that they present to a service provider in a crisis and, of course, there are no services there. The Home First attendant care has a cap of 34 hours on it, and people cannot get on it if they are over the age of 60. There is no funding for night care services, and as you get older you have to go to the toilet more often. I am scheduled to go to the toilet 14 times a week. It does not always work. There is no provision to go more often than that without biting into your other hours, which are for getting up, showering and dressing. I will stop there, and you can ask me later what I think we need.

Senator HUMPHRIES—Mr Martin, I was interested in your comments about the problems of governments buck-passing. You mentioned that people with acquired brain injury are being classified increasingly by state governments as cases in which—and I think this is the way you put it—the state has no other option but to put them in nursing homes. I accept that is happening but, realistically, there are other options, aren't there? We have heard in this inquiry a lot of talk about the other options that are available where there is a will on the part of state governments to fund alternatives specifically for people with particular conditions. Why is that will not evident in Victoria? Why are organisations like yours not able to raise the awareness of state governments of the need for these sorts of services to ensure that they are provided and that they are not falling into that category of an option that is not available in the state system and therefore has to be shovelled over to the Commonwealth?

Mr Martin—I will ask one of the doctors to answer your question.

Dr Tierney—I think one of the biggest problems with acquired brain injury is that it is usually a catastrophic event. You are fine one day, but something occurs. You could spend a few days in intensive care and within a fortnight find yourself in a nursing home bed because the acute care hospital needs your bed. If you are lucky you might be medically stable by then. I come across a couple of patients a year who, within two to three weeks of their injury, are already in a nursing home bed.

Senator HUMPHRIES—But they should not be there, should they? As you point out, they should be in a facility dedicated—

Prof. Rawicki—I am sorry. Can you clarify the services? You talked about other options being available for these people. I have been working in rehabilitation in severe brain injury for many years and I am not quite sure what other options you are referring to.

Senator HUMPHRIES—No, I am sorry. I am not saying that they are available. I am saying that they should be available and that state governments, which have a responsibility for providing for people with disabilities who are not aged people, should be providing those facilities. They are avoiding those responsibilities by saying, ‘There are no options at the state level; we will therefore put them into the nearest nursing home because that is the only place that is available,’ when there should be facilities for people with these sorts of disabilities in the community.

Prof. Rawicki—We all agree with that. The reason we are here is that we believe that young people with severe brain injury and severe impairment and disability should not be in nursing homes. Whether that is going to be ultimately a state or federal government responsibility is something that is not within our ken or power. The reason that we are presenting here is that we wish to see other services and facilities being made available to those people.

Senator HUMPHRIES—We all want to do that, I suppose. The question is: where do we push the responsibility down to?

Mr Martin—On that question, in the first CSTDA there was a timetable that had to be followed by the states to meet the federal requirements. That has never been followed, and the Commonwealth has continued to accept year after year—we are now into the 13th year. And so the nursing homes are clogging up with people who have been accepted compassionately by the Commonwealth. We are not criticising the Commonwealth for doing it, except to say that, if the Commonwealth is going to continue and persist in allowing, please provide the funds to allow providers to give the care that is necessary.

Senator HUMPHRIES—Apart from that last option, what would you suggest the Commonwealth should do? For example, one suggestion is that it could say to nursing homes, ‘You will not get any funding in future for a young person with disabilities; there will be no Commonwealth money for those people in Commonwealth-funded nursing homes.’ Of course, you can imagine the political outcry when some poor person needs a place and the Commonwealth says, ‘There is a bed here but you’re not having it.’ What in practical terms can the Commonwealth do to fix that problem?

Mr Martin—Our task is not to solve the problem that the Commonwealth has with the states. There are continually tensions and we accept that. We have said that we do not expect it all to happen overnight but, at least, we have to start somewhere. There needs to be constraints put on or funding provided by the Commonwealth or by the states so that proper services can be provided. Underlying all of that, we have stated that nursing homes are the wrong environment for people with acquired brain injury.

Mr Harris—Yesterday, we had a wonderful celebration in Australia, which was all about us being Australians—not Victorian, Western Australian, Novocastrian or wherever else we come from. We are Australians, and this is about how we resolve the problems that Australians are facing. We seem to continually tumble back to this federation problem that we created in 1901, which causes a severe delineation between opinions on whose responsibility it is to pay. I think we have to be quite clear that this is about Australians with unmet needs or inappropriately met needs. That is what we have to resolve; not, ‘Who do we point the finger at?’

Senator HUMPHRIES—I accept that, but the question is: How do we resolve it? That is what this committee is trying to determine.

Mr Harris—In 1989, for example, the Commonwealth invested significant time and energy in the creation of the Commonwealth Attendant Care Scheme, which involved cashing out nursing home beds and providing up to 34 hours of in-home support to get people out of nursing homes. Following that, the Commonwealth invested another significant amount of money into providing attendant care to stop people going into nursing homes. They were the forerunners of what you now have in Victoria and every other state: in-home accommodation support programs, which aim to help people live better for longer and remain at home out of the aged care setting and out of that complex blend of accommodation and health care. I think that is the sort of model of thinking that we need. I am not saying we need more of that style of care particularly, but we need people who can think creatively, because the answer is not just more money. The answer really is more thinking, which might then require more money.

Senator HUMPHRIES—I suppose we are the ones who are trying to do the thinking, with the assistance of witnesses like you.

Mr Harris—I wish you luck.

Ms Bryant—In the last month we have tried and failed to get an aged care assessment done on three people. The aged care assessment teams are now refusing to do aged care assessments on anyone who is under 65. That means these people are at home and at risk because there are not enough services. The only thing we can do is to admit them into the acute sector and refuse to have them taken out again. There are no other options; there are no appropriate residential options for them. It is almost a crisis situation. You are just trying to find someone else to dump them on because they have such needs and are at such risk.

Senator HUMPHRIES—That is very true. The question is how we solve that problem and where we sheet responsibility home in this system. As I said, I would argue that the pressure here should be on state governments, which are not meeting their responsibilities in this area. But that is not the debate. I will move on to a different question. We have heard that there are a range of conditions and diseases that will at present put people into nursing homes—things like motor neurone disease, acquired brain injury, MS and all sorts of other things. We have also heard very often that social stimulation is important and therefore being close to where a person has social networks is important so that they have contact with family and people can come in and talk to them and provide them with assistance and so forth.

Obviously, with the potentially relatively small number of people in each of those categories, with the best will in the world even a very generous state government would not be able to provide a dedicated facility for motor neurone disease sufferers, for instance, in Geelong, Ballarat, Melbourne, Eastern Victoria and so on. If you have to compromise somewhere to provide those sorts of facilities, is it more important to have facilities which are close to places where people live or is it more important to have facilities which are specific to the condition or illness which a person suffers from?

Mr Harris—My view is that the minute you start talking about facilities you immediately stop thinking. Part of the response to many of these disabilities and the needs that they create is about thinking about how you are going to deliver the services. If you are going to bury money and infrastructure in a building, for example, it is locked up for ever. The minute you get three people in there with long-term disabilities that facility is effectively taken out of the available options for other people.

We would argue that one of the keys is to keep people at home. One of the best ways to keep people at home is to invest in case coordination and case management that can help look at the services that are available within a community. Self-care packages can be developed with friends, relatives and neighbours within the local community to help that person remain at home for longer. We have to be looking creatively at how we expend money. If we work on a case coordination and case management basis, we can actually help people stay in their own homes. That means there are no facility costs. They are with their carer. With small amounts of brokerage, we can bring in enough services to help them remain at home and to help the carer keep on caring better for longer.

Senator HUMPHRIES—Would that be cheaper than residential facilities?

Mr Harris—My organisation gets funded about $40 per hour for case management and we supply about 14 or 15 hours a year per client on average. That is much cheaper than residential aged care, even at $125 a day. We have to start thinking creatively about service mechanisms and support mechanisms and not immediately think, as we have done for years, about this facility, that facility and the other facility. Obviously, some people cannot be kept at home. Some people may need a facility based service. But let us look at each person’s unmet needs and address those unmet needs with a wide variety of responses. Be creative.

Senator HUMPHRIES—The wider the variety of responses the more expensive the system becomes, doesn’t it?

Mr Harris—That is not necessarily the case. It can be the case if you have thousands of little agencies that have huge amounts of administration to support. But it is not the case where you have specialist agencies that are working closely with people of similar levels of disability or similar disability causes. In that case, you are able to work very efficiently and effectively. Some MND clients, for example, might only get two hours of case management this year. Some might get 40, 50 or 60. But they will all be getting what they need in terms of that case coordination and case management process. We are better able, then, to identity the resources that are available within the community that can help support them in their homes.

Senator HUMPHRIES—They are not the sort of people who are presently in nursing homes, are they? They are already in the community. You would not be able to move people with this model.

Mr Harris—We are working to keep them out of the nursing homes. We are saying that there are mechanisms to stop them going in.

Senator HUMPHRIES—I accept that. The point is that people would not be moved out of nursing homes but rather their going into them would be avoided. We already have 6,000 or more people who are under 65 in nursing homes across Australia. What you are suggesting is not really a solution to get them into more appropriate settings, is it?

Mr Harris—That is true. When the bucket is full, you do not keep tipping water into it. You have to work out a way to get yourself another bucket. You have to start stopping the water going into the first full bucket and then work on how to empty it. Yes, we have 6,000 people to get out, but we probably have another 15,000 potentially waiting to go in and not liking the look of it. So what we have to be working on is not only how we get 6,000 out but how we stop the next lot queuing up to go in.

Senator McLUCAS—I want to progress that a little further. You have made the case very clearly, I think, that people with motor neurone disease are not best cared for in residential aged care. The disease span is about two years. Can you give the committee an understanding of the progression of the disease? I am sure it is variable, but is there a predictable phase of the disease that would help us understand it?

Mr Harris—With motor neurone disease there is certainly a predictable course of needs, although the time scale can vary. The predictable course of needs usually starts with somebody having mobility problems. This extends to speech and swallowing problems, with more complicated mobility issues, and then it reaches difficulty with feeding and breathing and ultimately death. People are different, as we know, and some people can live for 10 years with motor neurone disease and some live only months. Our aim is to try and keep people out of institutionalised care for as long as possible.

Fortunately, we are quite successful in Victoria. At the moment, we would have about 15 people in nursing homes in Victoria. But it is a hard battle to do that because spaces in disability services that are funded by the state government are increasingly getting filled up by people with long-term disability. For example, we have had to argue extensively to get a first jump at vacancies in the HomeFirst program, which provides up to 34 hours a week of support. We have some regions that do that and some that do not.

Our aim is always to try and optimise the use of already funded and available community services. The problem we are reaching now is that, for example, instead of local government being able to provide two hours a week of home support, as they did previously, they are now offering one hour a week. To get the handyman out can involve a wait of 12 to 18 weeks. To get an assessment—and I support what Helen is saying—we have a region in Victoria in the western suburbs that will not see a person with a disability under the age of 70. We have services funded through Linkages, which is a state funded service, where the waiting list opens for 24 hours to try and get people in.

What we are talking about here is a complicated process that impinges on aged care services and puts pressure on the state funded services. It is getting increasingly difficult to get quality support that keeps people at home for longer. Our organisation, like many organisations, is strong in its use of volunteers and its development of community responses to the disease to build networks of people around the person with the disease and their carer to try and help them live better for longer but stay at home.

Prof. Rawicki—I guess we are talking about different sorts of patients. It is a problem that within this group here we have someone representing motor neurone disease, which is really a bimodal condition where there is a group of patients who will live for a relatively short period of time and where there is a another group of patients who will live for many years. For people with acquired brain injury, the life expectancy of most of the people we deal with is perhaps 20 per cent less than the life expectancy of able-bodied people. They have a long life expectancy, and that is increasing due to improved medical care—although to a lesser extent than for people with motor neurone disease. For most people, MND is a fatal condition, irrespective of medical care. For people with stable acquire brain injury, as long as you look after their pneumonias and their pressure areas and their infections, they will have a life expectancy close to that of the able-bodied population. That number is being added to.

The full bucket is not a bad concept to think about when you are looking at what accommodation needs are and what they are going to be. A large number of the people with severe acquired brain injury require institutional care, but they require appropriate institutional care, which really is the issue that we are struggling with: what sort of institution, what sort of care and what sort of ongoing therapy and services they need, both in the acute stages—which Dr Tierney alluded to in her comments—and in the long-term ongoing provision of services. So it is not only appropriate age accommodation that we are concerned about; it is the provision of ongoing rehabilitation and physical therapy management that concerns us, not only in the long term but also in the acute phase.

One of the problems we have when people have a severe acquired brain injury is that they fall outside the funding guidelines of rehabilitation services and for the most part will often bypass early acute rehabilitation and end up in inappropriate care. We feel we need to be managing all those three things: what happens when they have their acute injury or illness, where they go and what services are provided once they go there. They are the three main issues that are not being addressed at this stage. We are hopeful that something out of this committee will encourage either the federal government or the state government—whichever is going to be responsible—to address those issues.

Senator McLUCAS—Thank you. That is the point that Mr Harris is making, too. Motor neurone disease has more of a medical model for the type of care that is required compared to paraplegia, quadriplegia and other disabilities. Who is your organisation funded by, Mr Harris?

Mr Harris—In Victoria, we get 15 per cent recurrent funding and 15 per cent non-recurrent funding from the state government and 70 per cent funding from the community.

Senator McLUCAS—Ms Bryant and Mr Harris made the same point: ACAT are now not assessing people under 65. Mr Harris said that in one region they are not assessing people under 70. That is a changed policy position that you have picked up?

Ms Bryant—Yes.

Senator McLUCAS—Have you ascertained why that has occurred?

Ms Bryant—I can only surmise that it is because of some of the publicity around young people in nursing homes and the desire—and I do not know whether this is true—of the Commonwealth to try and keep younger people out of nursing homes. That is an assumption on my part. There was no rational explanation given. They just said they were not doing it.

Senator McLUCAS—We might pursue that with the Commonwealth when we see them again, and I am sure we will.

Mr Harris—We are coming up to another HACC agreement. There are a variety of beliefs out there in the field about what people should and should not do. But not doing assessments is actually the easiest way to manage a budget. That is one of the problems that we face: too often, funded agencies determine that the way to manage budgets is to close doors. Rather than having doors embracing people and welcoming them in, their doors are set up to keep them out.

Senator McLUCAS—Some of you were here when the previous witness talked about the establishment of a commission which would try and straddle the two funding streams of Commonwealth and state and get around the falling through the cracks that we have heard about. Would any of you like to make any comments about that being a solution to the issues that we face? Picking up on Senator Knowles's comment, is that another bureaucracy that could be expensive? I am looking for advice; I do not have a view yet.

Mr Harris—I have a great fear of bureaucracy and of it being funds that are not necessarily going to go into improving service delivery, but there needs to be something that improves the coordination between the states and the Commonwealth.

Ms Bryant—As well as that there is a shortage of funds on the ground at a state level, which is pushing people into the Commonwealth. It is one sector trying to push people backwards and forwards across the divide, which is just ridiculous. As I said before, quite often you end up with people in the acute sector because it is the only sector left that has a spare bed. Then people in that sector scream because all their beds are being taken up by people who are inappropriate. I know Margaret can testify to people being admitted into the acute sector because they needed physiotherapy.

Ms Cooper—That happened to four of my friends recently. They had a lovely time—the four of them together in hospital. They all had simple things such as joint pains which could have been treated outside. There is one physiotherapist on the ground for polio in the whole of Victoria, so people are admitted to acute hospital care.

Senator FORSHAW—Was that public or private?

Ms Cooper—It was public under Medicare. That was two weeks each for four people, because there is just no physiotherapy on the ground or no home modifications. If you go into acute hospital care you can then get some modifications made to your house from the acute hospital budget. That is highly expensive and highly unsatisfactory. We need some blending of funding. We need aged care packages on top of disability packages. We need the CSTDA strengthened so that agencies that are funded show some innovation in dealing with the in-between groups of clients. We have carers crossing Victoria—multiple agencies are being funded to administer funds. You might have one agency visiting in the next street to me and my agency visiting me. It is crazy; it is not coordinated.

Senator McLUCAS—You said, Ms Cooper, that you need aged care packages on top of disability packages.

Ms Cooper—For those of us in the mid ground.

Senator McLUCAS—For those people who are elderly but have a disability?

Ms Cooper—Yes, I am 61 and I hope I will stay at home for another 20 years, but I will not unless I get a little bit more funding.

Senator McLUCAS—At the moment you cannot get a CAPS package and a disability package, can you?

Ms Cooper—No, I do not fit the age care assessment model. I do not want to go to a nursing home—I keep away from geriatricians. Apart from that, I do not know of a geriatrician who has disability training.

Mr Harris—I think the issue you are raising there is very interesting. In our organisation we call it ‘service stacking’. You might start with a couple of hours from your local council and then move to, say, a Linkages package which might provide up to five to six hours a week. But you get the five to six hours and you lose the two. So instead of having seven to eight hours, you are back to five to six. You go to the next level up and you might be lucky enough to get onto a Home First package with 34 hours, but you immediately lose the six to seven hours—you have already lost the two. So you are gradually going up and stepping back, going up and stepping back. There needs to be some discussion at least about service stacking. Whether it is good in that people get more service but fewer people get it, or whether it is bad and we actually need to free up the bottom-level, lower intensity services so that more people get access to those—so more people getting something rather than fewer people getting more or everything.

Senator McLUCAS—It is a difficult question.

Dr Tierney—I am really pleased to hear this afternoon that other organisations are having trouble getting ACAS assessments for people. From an ABI perspective I think that is really great. The last time that happened in Victoria was the early nineties and we got our first ABI-specific house funded through the state once people started clogging up acute hospital beds and not going anywhere. So I am heartened to hear that—I am sorry for other people.

In 1996 a document came out from the Commonwealth allowing younger people entry into age care facilities, because a lot of ACAS teams were not assessing younger people. We recently had great trouble getting that document from the department. No-one could find it. We were told on the web site that it was available from the state offices, but it took us ages to get hold of it.

That document said that, if there really was this great need and if there was no state funded facility where this person could go, they could go to an aged care facility as a stopgap emergency exercise and that that would be reviewed every six months to see whether there was then a facility or service other than an aged care facility that could manage this person. I look after lots and lots of young people in nursing homes and I do not know that I have ever had anybody come back six months later. They stay there for the rest of their lives. No-one comes back to check whether service systems have changed.

Once you are in your aged care bed, you cannot access any of the state services: you cannot get a case manager unless you were already on a funded scheme when you went in and you cannot get access to any day programs. You cannot get access to any of the resources that are going to allow you to get out. I would think that when they come back after your six-month stay there should be somebody from your regional disability services office there with you when the ACAS team is assessing the person and saying, 'Yes, okay, we could refer them here for case management and get them on.' Who is going to put them on the SNR in Victoria so that it is ever going to be known that they need accommodation? The nursing home is not going to do it. The person cannot do it for themselves. There has to be some coordination at that level so that the state disability regional office know that there is person here who is going to need their services.

Senator McLUCAS—They are just not on the books anymore.

Dr Tierney—They are not on the books. Sometimes, if you can get the regional office in—it takes a lot of work—and get a few things happening, people can get out, but unless they have somebody there to advocate for them it is just never going to happen through the system.

Senator McLUCAS—Doctor, could you point us in the direction of that document that you were referring to?

Dr Tierney—I have a copy.

Senator McLUCAS—Thank you.

Ms Bryant—Just to add to Dr Tierney's comments, if you are to get people out there, there is no service system to pick them up, even if you can get them out the door. We have people with newly acquired quadriplegia who may wait two years to get any in-home funding at all. They are just put back on their families to cope with, and that is an enormous strain on the family of the person with a newly acquired disability. Often the families just crack up and people have to go into nursing homes. There is no other option out there, when they could be accommodated quite well in the community if there were sufficient funding for attendant care.

Senator McLUCAS—And transition funding as well.

Ms Bryant—Yes.

Senator ALLISON—Mr Martin, you talked about the Commonwealth-state disability agreement, which has obviously failed young people in nursing homes, and you talked about the initial Commonwealth-state disability agreement making greater provision for this group of people than the current one. Can you spell out the differences a little more for the committee? Do you think the Commonwealth actually has a vested interest for some reason in not requiring the states to deliver on this issue?

Mr Martin—Mystery is something which I am not terribly good at solving. As to what the Commonwealth's intention is, I read the context of the initial CSTDA as the Commonwealth wanting to encourage states by being kind and allowing Commonwealth facilities to be used for short period of time and also wanting to say that there has to be a system in place for reassessment and that there would be activity to try and make sure that, if that assessment said that continued high-level care was needed, there would be an appropriate placement. That seemed to be the reading and the context of the way in which the CSTDA was drawn up.

The re-signing of the CSTDA and then the bilateral agreement just perpetuates the situation, but perpetuates it in a different way. It is very clear that acquired brain injury is a distinct category, but no money is provided for it. Rehabilitation is a word used once in that bilateral agreement, and that bilateral takes precedence when it is in conflict with the CSTDA. That word, rehabilitation, is mentioned once. ABI is a distinct category in the first 5½ pages; in the balance of the 11-page document there is no mention of it. It is lumped in with everything else and lost.

What is the Commonwealth’s intention? I do not want to get into the political argy-bargy on this, but every now and again we hear that the Commonwealth is going to take over the hospitals and the Commonwealth is going to take over this and that. ABI is falling between the cracks because no-one wants to take this responsibility. What we are after is what I said at the start, that this committee might be a catalyst to get something going—some pilot programs, possibly, or insisting that the states start to do something. We are going to get a policy document after two years of talking, and then two further years to look at that policy. There has been no action apart from talk at the state level, and the talking is being done by two parties: the Commonwealth and the states. The Commonwealth is allowing this to drag on. And every year that it drags on those people are still in the nursing homes, and there are more every day being added with acquired brain injury. It is one of the growth areas.

Medical advances are keeping so many of the patients alive now that 20 years ago would not have had a future; more and more now are surviving. Surviving for what? With rehabilitation commenced as early as possible and maintained—maybe intensively at the start—then, as the patient is able, they can be discharged into the community, to their homes and back to their families. The families are breaking up; it is heart rending. When the husband, or the mother or the child is admitted to a nursing home—this home might be 60 kilometres away or it might be 160 kilometres away from someone in the country—the only contact their families have is by travelling backwards and forwards. This person is there getting some care, at least more than they can give in the family situation, but not rehabilitation which is going to be productive.

Senator ALLISON—On that point, we heard this morning that the Victorian government has a program—roads to slow recovery or slow roads to recovery or something of that sort—but it precludes anyone whose brain injury may have occurred two years prior. Perhaps, Dr Tierney, you can comment on the opportunities for rehabilitation for people who had their catastrophic injury two or three or 10 years ago.

Dr Tierney—For people with a catastrophic injury, their recovery can continue over many years. I have, and Professor Rawicki probably has too, a lot of people that I see five, 10, and 15 years later and who are still making slow improvements. In fact, late last year I caught up with a patient I had not seen for a long time. His wife asked me to see him up in the country. He was 11 years post injury and he had not had any therapy whatsoever. He was being managed in a nursing home, but he had never had a thing. With a bit of creative work I managed to get a package from his regional DHS office, and within a couple of speech therapy sessions this man was communicating with his family for the very first time. He was a man who was 11 years post injury.

How many times has this been replicated, where people are just being left in this situation? This man’s kids had grown up not knowing that their dad could communicate with them. His wife has now taken this man home without any resources. She got sick of his situation because the therapy was coming into the nursing home, but the nursing home staff resented therapists coming in and they resented the physio coming in and showing them how to settle this man so he could be comfortable in bed. They assessed that he had no pain, whereas we were going in and saying: ‘This man’s stuck up in his bed like this. This man is clearly distressed.’ The physio would show them how to have him as relaxed as can be and how he could communicate. The nursing home did not want anything to do with that. They said their nurses knew how to do it and they did not want the therapists there. So his wife has taken this man home. For all those years his kids could not go to the nursing home and see their father. They could not go into that atmosphere and see their father. They were primary school age kids when his injury happened. And that is just one story. I could give you hundreds of similar stories from people.

Recovery can happen for a very long period of time. If you give people circumstances that will not enable their recovery they will have maximal needs forever, whereas if you give people with ABI the right resources in the early years they might have a lot of ongoing care needs but these needs will be a lot less in the long term than if you are trying to manage someone with nasty contractures whom you cannot position anywhere and whom you cannot transfer—

Ms Vincent—You are starting from behind where you would have been in the first place and therefore you obviously have to do a lot more work to get them back to a starting position, and then you have to go again. It is very difficult for families to sustain the effort that is required. It is very difficult for a practitioner on the ground to get all the powers that be onside about doing this sort of work. When you go into nursing homes you have to win the staff over, otherwise it is an hour a week. What difference does that make to someone who has so many hours in their day doing nothing?

I have been involved in the Slow to Recover program. One patient who springs to mind was a bloke who had ‘failed rehabilitation’, as they put it, and therefore went to a nursing home. It was a very difficult placement in a nursing home because he was only in his 40s and had some behavioural difficulties. He would argue with staff, which they understandably resented—that is not what they are there for; that is not what they are trained for—so they would take things away from him. He had some therapy and was able to do a standing transfer but, if he was difficult—he had an electric wheelchair—and came back to the nursing home later than they expected, they would stop doing standing transfers and make him do hoist lifts. He was in that nursing home for 10 years, and eventually a house to which he could move came up. By that time he had lost the ability to do a standing transfer.

Senator ALLISON—Do you mean by ‘standing transfer’ able to get out of a wheelchair and into a seat?

Ms Vincent—With some assistance—but he could use his feet to stand on the ground. It is obviously much faster. Most people with a disability would prefer to do it, if they could. This man had to have rehab to get out of the nursing home, when he could do this years and years before that. It is about the provision of the necessary resources at the time the person needs them.

Prof. Rawicki—Slow to Recover has been a fantastic program. It was initially funded at $1 million a year and then went up to $5 million a year. It reached that ceiling about five or six years ago but unfortunately has now been cut back to $4 million per year. As we talked about earlier, the problem we are having with provision of services is that the number of people who require the services is increasing. So the STR program has had to limit its clientele and it is now basically for younger, family-oriented clients, which means an awful lot of people miss out, and more and more people are missing out.

Senator ALLISON—Would part of the answer be for Medicare to cover those speech therapists and physiotherapists who were in residential care?

Prof. Rawicki—I guess the new government initiative which provides four occasions of service per year will be a drop in the bucket for some of the people we are looking at. It is a non-competitive rate, so it is going to be hard to find therapists who are willing to work for the new level of funding Medicare has offered, and the number of services is extremely limited. On the other hand, as a concept I think it is terrific. If it can be expanded and funded adequately, I think it would make a difference. Ms Vincent, as a provider you would agree that somebody has to take the money.

CHAIR—Unfortunately we are out of time. Thank you for your submissions and your presentation today.

[4.21 p.m.]

NOLAN, Mrs Mary, Private capacity

REILLY, Mr Richard Francis, Private capacity

SMITH, Mr Jeremy Linus, Private capacity

CHAIR—Welcome. Do you have any comments on the capacity in which you appear?

Mr Reilly—I am appearing on behalf of myself and also Chris Nolan.

Mrs Nolan—I am Chris's mother. I am also a founding member of Inability Possability, which presented earlier, and of the Young People in Nursing Homes consortium.

Mr Smith—I am a friend of Christopher Nolan, who has lived in a nursing home for nine years.

CHAIR—Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submissions. I now invite you to make an opening statement, to be followed by questions from the committee.

Mrs Nolan—The three of us will contribute here. I would like to begin by making an apology for Chris, my son, who is not here today. He is in his nursing home, because it is difficult to get him here. Chris is driving this, really. He is a survivor. He had a brain injury—a catastrophic illness in Hanoi in 1996. He was airlifted to Singapore. He spent three weeks in Singapore and then we airlifted him home to St Vincent's, where he spent six months in a coma. He woke up, six months after the injury, laughing at a joke his cousin had made in his room, when all the medical prognosis was that he would be vegetative.

His friends today are witnesses of Christopher and his ability to continue to drive us. He hears and understands. He is not able to speak, to move or to see. Looking at him, some people would declare him vegetative. I think that is a point we need to make very forcefully—that his friends have enabled that vision of him. He is RCS category 1++. He has the highest needs, probably, of anyone in the nursing home. He gets out and about. We had him home to the farm at the weekend.

Chris went into a nursing home because he was refused by rehab facilities and there was nowhere else for him to go. We chose to keep him in Melbourne. He was the first young person in the nursing home with ABI, and we had the Slow to Recover funding. The challenge was to integrate that in the nursing home. We work together. The former director of nursing of the nursing home, Dr Rosalie Hudson, is here today and she has made a submission. We work together with allied health and with medical, gradually getting skilled therapists.

We have developed a core of expertise and skilled, trained people over those eight years in what we call an approach. It has been adapted for four others in the nursing home with an acquired brain injury, who are a special subgroup. It is close to Christopher's social grouping. This is one way forward for Christopher and others like him with an ABI. We have not lived in idle dependency. New brain research confirms all we have done—it has found that the brain is capable of making new connections and that environment is the single most critical factor in this happening. It has been a huge task to provide a suitable environment for him amid the increasing frailness of elderly people admitted to nursing homes. The average age is now 82 and I understand that the average stay is six months.

The people appearing here today and a couple of people in the audience are members of a group of family and friends we formed last year in June. There are about 20 people. The question we asked was: what does Chris want and what solution do we see to this? We campaign for that because Chris does not intend to go away. It really is life or death for him. Another young man who was in the nursing home with him went out to another facility and, as a result of alleged inappropriate care over a period of four years, lived a miserable life and died just on a year ago.

You have in my submission details of media we have used and at the end of it there are pictures of Christopher, one of which is with Jeremy during TV news filming. I think it is pretty obvious from the expression on his face that he understands what Smithy is saying to him. Since January, when I put my update in, we have been informed that the nursing home he is in is closing. This is having quite an effect on Chris, on friends and on core staff. We have an urgent situation. The only option that is being offered is aged care. I know you are going to see the Carnegie house. I would love you to come and have a site visit at a nursing home and experience for yourselves what it is like. As somebody said before, we need a champion in government to take this forward. Chris could be in aged care for the next 40 years.

Regarding advocacy, in the last few months we have been working overtime. You have that information about the radio and the *Herald Sun* article. In the last two months we have met with Minister Bronwyn Pike at the state level and with Minister Julie Bishop at the federal level—that was just last Friday night. We have also met with people from the Department of Human Services in Victoria who say there is no option for Christopher to have disability nursing in Victoria. There is no disability nursing. Both Bronwyn and Julie are sort of saying that it is the other's responsibility, but Minister Bishop is arranging a meeting with Bronwyn Pike to look at the innovations pool for Christopher, which the Carnegie house is funded under. The innovations pool has been going for three years, and there is one project from MS Victoria. We question its appropriateness for Christopher, particularly in the area of long-term care and support, but we are prepared to give Minister Bishop a go. We know there are precedents for long-term state-federal projects. One is the Western Australia nursing home project, which some of you spoke about, and the other one is the MS unit at Cyril Jewell House in Keilor.

To sum up, there seem to be three main blockages as we see them, and we have a solution for us. I have been involved in this area for almost nine years. I have gone on reference groups, I have watched studies being done and, at the bottom line, we are still in the same position as we were at St Vincent's eight years ago. There is nowhere for Chris to go.

The federal must leave. From a historical point of view, I have a news cutting from 1968, two months before Christopher was born, called 'No place for Michael'. It was given to me by a woman in the nursing home who knows Christopher and who had saved the cutting all those years. It is a political issue. Imagine, on a federal level, trying to get through two ministers and the accompanying bureaucracies. On the Victorian level you have got three ministers and three departments. It is a nightmare for family and friends. So the first deadlock, as I call them, is the federal-state issue. The second one is the social-medical model, and that has been touched on. There are no disability models with full nursing care. There are lots of details here. This requires a sort of attitude or style of nursing which I will not go into. The Department of Human Services in Victoria have told us that there is no option for Chris other than an aged care nursing home. There is no nursing care for his needs in the disability system. Why should people who acquire a disability and who are under 65 not have something available? The third deadlock, and it has been spoken about, is acquired brain injury as a disability. There is little known about this group, who are non-speaking and often regarded as not there. There is no dedicated organisation such as the MS Society. Victoria, I think, is leading the field in this area.

We want to do something. I am a country woman and have lived away from my home for the past nine years, since Chris went to Singapore. If we have a problem in the country we usually get together and try to solve it. I think that is what is needed. We need bipartisan support, really, for someone to be given power to push through the solution—which I have outlined on another sheet of paper—which we are proposing for Chris and which we have given to both ministers. We want implementation in the course of a year. This could inform the next stage federally and state wide. I am happy to answer questions on what we want.

Mr Reilly—Mary has covered some of the points that I wanted to make, but there are a few that I will go through. Thanks for the opportunity. I am here to speak on behalf of my friend Chris Nolan, a mate of mine for 25 years, since I met him as a precocious 12-year-old at year 7 at St Pat’s in Ballarat, a school that he would lead as school captain six years later. Chris was your stereotypical leader. He was school captain, a Monash University law graduate with honours, a gun golfer, a gun cricketer and the co-founder of the Meredith Music Festival. At 28 he got sick, as we know, and he has been there nine years. For nine years in the prime of his life, from 28 to 36, he has been in a nursing home in a severely disabled body.

Despite his limitations he is still actively engaged in life. Chris continues to challenge and inspire us with his zest and his capacity for life. He gets out and about whenever friends and family can take him. He goes to rock concerts. He goes to the footy. He is leading the nursing home’s footy tipping competition. He was recently asked to be the godfather of a friend’s baby. He is with us in mind if not in body, and he wants to live life to the fullest. He has full life expectancy, and so we need to do better for him so that he does not spend the next 40 years in an old people’s nursing home.

Just to reinforce what Mary said, we are confronting the scourge of Federation: the inability of both federal and state governments to acknowledge and accept their respective responsibilities for people like Chris. But we want them to be part of the solution. It is not good enough for both governments to say that the other is more culpable and that they should provide more funds, which we have heard from both sides. As a group of family and friends, we are sick of that response because it is lazy and it is thoughtless. Yes, it is hard, but that does not mean there is no solution.

We urge you, as a committee, to champion the issue of getting young people out of nursing homes. I know you are sitting there thinking, ‘Thank Christ that’s not my child,’ because I have thought exactly the same thing. There is a better way. I urge the committee to demonstrate a joint federal-state commitment to bring about change for young people in nursing homes; to put aside any partisan differences, if there are any; to show leadership on this matter and acknowledge that the issues need serious policy attention; and to ensure the federal government maintains its current funding levels but breaks the nexus between the Commonwealth funds and nursing home care. I also urge the government to liaise with their state government colleagues to fund capital development for a small home model, to increase the level of recurrent funding to cover currently unmet care needs and to assist in the development of policy for young people in nursing homes.

Mr Smith—Like Richard, I am a mate of Christopher. The last time I saw him in good health he was 27 and so was I. Since that time I have fallen in love, married, travelled the world, had two children and established a fulfilling and rewarding career. For every moment of that time Chris has been in a nursing home. In the first room he was in 13 men died on beds around him. While I wake to the sounds of my two children at night gurgling and crying, he wakes to the echoes of the frail, the elderly and sometimes the demented. That is the situation which my friend is in and that is why I am here today. I assume the very starting point for each of the senators today is: that is the wrong place for him—how do we find the right place?

I visited him there for nine years and I would not wish it upon my worst enemy. I, like Richard, certainly would not want it for my children, and sometimes I do not know how Mary copes with Chris’s situation. I have read two books about people in the same situation. Both of them have been written by those people by communicating through blinks and movements of their eyes. To the untrained observer and to many trained observers they were vegetables, and they were treated as vegetables. They were locked into their bodies but they were also locked up in nursing homes and forgotten. We are determined that that not happen to Christopher.

We desperately want to get him out of there and find something better for him. We reckon we have found a way of doing that, more or less. I will put it in these terms. At the moment, the Commonwealth chips in a fair bit of money, about $60,000, to keep Chris in a nursing home. If Chris stays where he is, the Commonwealth will be paying that amount of money for the next 40 years, because in all likelihood he will live till his late seventies. Chris is in the wrong place and the Commonwealth will fund him to stay there. If we move him to the right place, the Commonwealth will not fund him. That is Chris’s situation, and it is absurd.

Senator KNOWLES—I do not have any questions, but when I say that I do not want you to misunderstand the fact that we are not asking you questions as a lack of interest. I have already been made aware by Minister Bishop’s office that she had a conversation with you last week and her office is trying to deal with some of those matters as we speak. Thank you for all three contributions. I certainly think you drive the issue home very well.

Senator McLUCAS—Thank you for your submission. I think we all agree, irrespective of political position, that housing Christopher, along with a whole range of other people in Australia, in residential aged care is highly inappropriate. This committee is very much looking at trying to find solutions. Mrs Nolan, you said that Chris did get some Slow to Recover funding. Can you tell us how much that is and what you are able to purchase with that?

Mrs Nolan—Initially it was similar to what Bronwyn Harding said to begin with. I think it was 15 hours of attendant care and probably one hour per therapist per week. It also funded his wheelchair and various bits of equipment. We were never funded for longer than three or six months in the first five or six years of that funding. So every time we would just get going on something we would have to go back for funding. I cannot tell you how exhausting that is.

We had several cuts to our funding. In 2002, Christopher was taken to Caulfield hospital for an independent review. Caulfield recommended what we had decided was his base level of funding, 24 hours per therapist per year and 15 hours of attendant care a week, and they recommended an extra 10 hours of nursing care because they could not handle him at Caulfield. Caulfield is rehab, but not his kind. He is not that difficult but he does require trained carers and time. Our funding was cut after 2002 and at the end of 2003. We got a year's funding. We have spent almost two years appealing. The appeal was upheld in January this year; we have funding through to August at 24 hours per therapist per year. It has been proven that Christopher's health has suffered—he has had chest infections and pneumonias without this level of funding. I hope I have answered your question.

Senator McLUCAS—You have. When you say 24 hours per therapist per year, what therapies are you referring to?

Mrs Nolan—Physiotherapy, occupational therapy and speech therapy. Chris enjoys eating. He is fed mainly through a tube into his stomach. For him, the whole swallow mechanism is very difficult. The speech therapist spends a lot of time trying to train carers to give him something to eat.

Senator McLUCAS—Going to your solution: you are suggesting that a small purpose built community based home in the inner city in Melbourne is appropriate. In your vision, would that be like a group home where a number of people with ABI would live together?

Mrs Nolan—We are developing that but, yes, pretty much—people with similar needs to Christopher. We know that this approach works.

Senator McLUCAS—Have you seen other models where that has been successful?

Mrs Nolan—I have seen other models, in Western Australia and in Canberra, but I think we are looking at a much more social, person centred planning model. It is very difficult for the nursing component to marry with disability—and we have heard about that, that the two seem to be like that. That is one of the advantages of what we have done. We have a core group who know how to work together, basically. It sounds pretty simple, but that is what it is.

Senator McLUCAS—When you say a core group, do you mean of parents of young people with disabilities?

Mrs Nolan—No, a core group of staff, allied health people, a GP—Barry Rawicki is Christopher's rehab specialist—friends, family and the local neighbourhood.

Senator McLUCAS—Even though you live in the country.

Mrs Nolan—I am now living in Melbourne. I have not been home for longer than 10 days since Christopher’s brain injury.

Senator McLUCAS—Mrs Nolan, I do not know whether you were here earlier when other witnesses were talking about the difficulty of accessing innovative pool moneys. Do you have any comments or advice about that? I think you might be at the beginning of coming across innovative pool.

Mrs Nolan—No. We have known that innovative pool has been there. We felt it was not appropriate for Christopher. I think the women are getting $20,000 per year. He gets $60,000 and the state is not going to take him on. He is one of the highest needs people. To try to access innovative pool—you heard about the complexity of it from the others—was almost impossible for a group that did not have a dedicated service provider or somebody to drive it. We are still uncertain about it, but Minister Bishop is looking into it.

Mr Smith—It is also short term. It is for no more than two years and then the Commonwealth will vacate the field, if you like, and leave it to the state, as we understand it.

Mrs Nolan—It is precisely as Jeremy said. The Commonwealth will fund Christopher to stay in aged care, but they will not fund him to go into something else. That is precisely what we are saying.

Senator McLUCAS—Thank you very much for you evidence.

CHAIR—Unfortunately, we are out of time. I want to thank you for making your submission. The close personal experiences being relayed to the committee are very valuable to us in our deliberations.

[4.45 p.m.]

COX, Mr Ian Percival, Private capacity

CHAIR—Welcome. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public, but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission, and I now invite you to make an opening statement to be followed by questions from the committee.

Mr Cox—I am going to read to you; I think you have a copy. I will give you an outline first. We have cared for our daughter for 22 years plus. I am nearly 80, my wife is 77, and it is getting harder every day. We are not so concerned about accommodation as we are with human resources—with the red tape to try to get something in the home. If we want somebody to come early in the morning—you will read about this in the submission; I will perhaps read it to you—they say, ‘We can’t come before half past eight.’ There was an incident where we needed help at half past five one morning, and we rang the emergency number. We live in Bairnsdale and they said, ‘Yes, we’ll get a lady. She’ll ring you and you tell her where to come to’ because we live 15 kays out of Bairnsdale. We have not got the finances to shift. It is a matter of selling our property, which has reduced from 120 to 10 acres.

We have financed all the stuff for Helen except the pension and perhaps a bit of finance from CoCare with odd jobs, and so it is just a personal whinge about the situation. I keep saying to people that we need human resources. One of previous speakers spoke about the need for home care, but you just cannot get it. There is so much red tape and there is the expense factor and the litigation factor. It is out of this world, and we keep plodding along day by day. If something happens to us the only alternative is a nursing home, and our friends have said, ‘Don’t let Helen go into a nursing home because it is a tragedy.’

I do not know that I can say much more. We have been through 10 or 15 years of going to meetings, getting reports, people passing the buck to somebody else and so it goes on. That is about all I have got to say. I will say that Helen wrote a book after eight or 10 years. I will leave them here. My other daughter is there. We have got to get back to catch a train. I was up at half past four this morning, caught a train down and have listened with interest but much of it is rhetorical. We have heard it all before. That is about all I can say. We do not see any light at the end of the tunnel. I blame the bureaucrats and the politicians. The federal government blames the state. The state blames the federal government. When you front them they say, ‘That’s not our department; it is somebody else’s’ and so it goes on. You go around and around in a circle, and there is no way out.

Senator FORSHAW—Mr Cox, you said that you have been helping your daughter for over 22 years. Did you have to make a lot of modifications to your home?

Mr Cox—Yes, but we did it all ourselves.

Senator FORSHAW—I hate to talk about money, but this would have been a huge financial cost to you and to your family personally. Do you have any idea of what you think it has cost you over the years?

Mr Cox—While I was sitting here listening to others, I reckoned we have saved the powers that be—and it does not matter which government—$1 million. We had 120 acres. We mortgaged a bit. I had an outside business, and it went bust. We just got into a situation where we sold a bit, mortgaged a bit and then mortgaged a bit more and sold a bit more. We finished up with 10 acres. If we wanted to go into Bairnsdale, we would need to sell what we have to start again, and I cannot bear the thought of that. Our set-up and environment suit our daughter, but it is not ideal to live out of town. I often say to people when we are discussing these things: if the bureaucrats had any commonsense, I could say to them, 'You build us a place the way we want it as a family and then when we sell our place you can take the money.' But apparently that is not the thinking, so we are just in a bind.

The other part is that we do not get any funding, except a pension and a little bit from CoCare. Just recently, Helen was able to get respite for eight hours a week. She could still get on a horse then. She cannot now, because she has chronic fatigue as well, but she is not a nursing home candidate. She can still do a fair amount of work. You will read about that in my submission. It has cost us our lifetime savings. We have saved a bit now, but we are only saving that in case we have to dip into it to keep Helen going.

Senator FORSHAW—That leads me to one other question. It is a difficult one and I am sorry I have to ask it, but it concerns something that has been raised with me when I have spoken to families who are in a similar situation. When parents who have been caring for a child suffering from a disability or a mental illness become older themselves, they have the burden of trying to plan for their child's later life when they themselves have passed on. Have you had any support or is there any facility available to you to actually discuss with departments or agencies about what will happen down the track as to how your daughter will be cared for—or is it just an assumption that she will go into a nursing home, no matter what age she was?

Mr Cox—I do not suppose there is an assumption. There is a chap who wants to come to see her to reassess the situation and see if they can do anything—I think he is from the Office of Housing—but we do not see that an answer. We see it more as human resources and the cost factor of the human resources. I cannot keep track of all the departments; I do not even bother trying to.

They built six units in Bairnsdale for ABI people and they invited Helen to inspect them but they were only built for ABI people who can look after themselves. There is no attendant carer, there is no telephone and there is no access unless you can get out yourself. It was built by a private company but it was built with funding from DHS or whatever they are. I just cannot work out the mentality. I have a lot to do with Bronwyn Morkham. She said, 'I'd like to get'—and I would too—'all the politicians and bureaucrats to spend three weeks in nursing homes with brain injured people and those with other disabilities'. Until some of you politicians have somebody like Mary's son or our daughter and countless others, it just will not happen as far as we are concerned. It is just going through the motions. I know they are pretty rough words but that is the truth.

That is as much as I wanted to say. I am thankful that I could even get here. We only say about one thing, and our daughter says the same. She says, ‘If it doesn’t achieve anything for me it might benefit somebody else.’ That is the only reason I came here to have a say about things. You do need to listen to the grassroots because the big problem is that when it comes to accommodation or alternative housing the ones who are building it say, ‘We’ll build it; you fit into what we build.’ But it should be the other way around. The person should say, ‘This is what I need.’ They should listen to them. That was the problem with these units in Bairnsdale. As soon as our daughter saw them she said, ‘They’re no good.’ They only had one bedroom with no room for a helper. With the facilities—the shower, toilet and basin—one was at one side of the room and one at the other, so it just does not add up. Thank you very much for listening.

CHAIR—Thank you very much for coming, Mr Cox. The committee will now adjourn.

Committee adjourned at 4.58 p.m.