

COMMITTEES

Community Affairs Committee Report

Senator HUMPHRIES (Australian Capital Territory) (6.07 p.m.)—I am very pleased to be able to return this afternoon to the subject of the report which the Community Affairs Committee presented earlier today on the Commonwealth State/Territory Disability Agreement. I want to record that, although this is not the only report that has been done into that agreement and Australian disability services in recent decades—nor is it the most authoritative on that subject—it is certainly a report which highlights a present and real need on the part of Australian governments to take seriously an area where, frankly, government performance at all levels has been unacceptable.

The report finds that there has been substantial dysfunctionality in Australian disability service provision. It goes on to strongly recommend that the next iteration of the Commonwealth State/Territory Disability Agreement tackle the underlying problems which leave large numbers of disabled Australians and their families either without proper services or with no services at all.

The CSTDA is essentially a funding agreement purporting to establish key national priorities for service provision for those in this country with disabilities and to coordinate that service provision so as to ensure that all areas of need are adequately addressed. Although the three previous CSTDAs made, I think, huge progress towards meeting those goals, the committee completed this inquiry more aware of the agreements' failings than their successes.

The facts are stark. There are numerous examples within our disability system of inflexible access criteria, siloed services, bureaucratic application and assessment processes, poor linkages with companion services and obscure entry points to programs. Urgent reform is required to lift consumers out of the labyrinth which the system often represents and help Australians already under pressure to find which services are available and the support at hand.

More transparency and better coordination are, however, only peripheral solutions to the central problem in disability services, and that is the fact that need in Australia outstrips capacity by an enormous margin. There are hundreds of thousands of Australians whose quality of life is greatly compromised because of their own or a family member's disability. The committee heard countless stories illustrating this very point: younger disabled people in rural and regional Australia with no access to day programs or employment services; multiple sclerosis sufferers trapped in hospital beds because no suitable accommodation in their community exists—I am not only talking about rural communities but even major cities; people receiving some state support who are unable to move interstate because they would thereby drop to the bottom of the services queue in that new jurisdiction; and ageing carers facing the reality of needing care themselves, with limited prospects of residential options for their children when they reach that stage.

The report draws attention to the most important recommendation arising from this inquiry—that is, recommendation 21—that Commonwealth, state and territory governments jointly commit as part of the fourth CSTDA to substantial additional funding to address identified unmet need for specialist disability services, particularly accommodation services and support. I think it is fair to say that, after Indigenous Australians, those affected by disability rank as the most disadvantaged Australians today. Yet the burden of disability seems to have suppressed the capacity of this group of our country men and women to bring their concerns to national attention to the extent that their numbers and the severity of these issues would suggest.

The fact remains that it is extremely distressing, as the committee discovered, to see so many Australians with a severely compromised quality of life by virtue of the fact that they either have a disability or have made the decision as Australians to shoulder the responsibility of caring for a

family member with a disability because they believe that the importance of that responsibility transcends anything else.

The committee recommends in its report a number of other changes to the operation of the CSTDA. Those are important and they are warmly commended to all of the governments concerned. Particularly, we believe that the next CSTDA should attempt to focus on services from the perspective of those who consume them. There should be, for example, a whole-of-government, whole-of-life approach to services for people with disabilities; there should be a partnership between governments at all levels, service providers and the disability community to set priorities and improve outcomes for people with disabilities; and it should be clear to the people who approach those services where they need to go to obtain a service if it is available. So much valuable and precious time and effort on the part of people under great pressure is expended in seeking services which are either not available in the form that they require or not there at all. The report makes a number of other recommendations which I commend to the Senate and particularly to the Commonwealth, state and territory governments.

Let me say just a couple of things before I sit down and allow others to speak in this debate. I draw attention to the fact that this is again a unanimous report of the Community Affairs Committee. We have certainly tried in recent years to make reports which reflect the unanimous view of its members, and we hope that that carries some weight in the eyes of the government and the community when examining these issues. I also commend the committee for having worked so very hard to produce this report after an extremely busy year as a committee. I draw attention to the fact that, according to figures published yesterday, the community affairs committee of the Senate is the committee with, at the least, the greatest number of working hours—and, I would suggest, it also has a record in terms of the production of reports which other committees in the Senate would be hard-pressed to match. I want to close by commending the committee secretariat, which has borne so much of the hard work in making this report possible after a year in which many other reports and matters were dealt with by the committee.

Senator McLUCAS (Queensland) (6.15 p.m.)—I too commend to the Senate the report of the community affairs committee in its inquiry into the Commonwealth State/Territory Disability Agreement. Likewise, I am very pleased that this is a unanimous report. Virtually the first sentence uttered by one of the first witnesses to our inquiry, Dr Bronwyn Morkham, was that the power of the committee's previous report, into the provision of aged care in Australia, particularly the chapter devoted to young people in nursing homes, was in its unanimity. I think that Dr Morkham's plea to us to come to a unanimous report has been heeded. Hopefully, the governments—all governments—will recognise that this is not a report that reflects the views of any political group in this country; it reflects the views of people with disabilities and their carers as expressed through our committee process.

I initially moved the reference for this inquiry at about this time last year, and unfortunately that was not agreed to—I could make some points about that, but we do not have time. However, I am pleased to say that the Senate did agree to this reference in the middle of last year, for which I thank the Senate. The purpose of moving the reference was to allow all people in the disability community—people with disabilities, their carers and the disability service sector—to participate in and inform the negotiations that are currently underway in the lead-up to the fourth Commonwealth State/Territory Disability Agreement. The timing of this report is helpful to that, I think, along with its unanimity.

During the inquiry, we heard on many occasions that, in searching for support—and I say searching, not looking; scrabbling for support—people with disabilities and their carers were often told by a service provider that they were funded by, let's say, the Commonwealth and so therefore providing a service to that individual was not their responsibility. And that was the same

with the states and territories. If these recommendations are adopted, that blame game—that ‘not my responsibility’ argument—will stop, and that would be a great contribution to assisting people with disabilities.

Part of the reason that service providers have to say, ‘I can’t help you,’ is lack of funding. Our first recommendation is that all governments, Commonwealth, state and territory, increase the level of funding to disability services in Australia. The other thing that is absolutely essential is that the fourth agreement must clarify the responsibilities of each of the parties so that people with disabilities and their carers know who should be funding certain services. The other achievement, if these recommendations are adopted, will be that people will have an understanding of what their expectations should be. People with disabilities know that they are not going to have their every need fulfilled, but they simply need an indication of what could be provided to them, and they also are looking for some sort of equitable access to services.

The recommendation I would like to talk about tonight, though, is recommendation 4:

That in the life of the next CSTDA, signatories agree to develop a National Disability Strategy which would function as a high level strategic policy document, designed to address the complexity of needs of people with disability and their carers in all aspects of their lives.

If governments adopt that recommendation, I believe it is the blueprint for the way forward that will allow people with disabilities to access all types of services that will support them. Too often people with disabilities are only supported with disability funding. A person with a disability has the same right to access transport funding or housing funding or health funding. We know, from undertaking this inquiry, that people with disabilities do not access generic funding to the level that other Australians do. That must change and, if we have a national disability strategy that encompasses all departments right across government at the Commonwealth, state and territory levels, we will have a document that is a blueprint for people with disabilities that recognises their rights as consumers of disability services but also their fundamental human rights.

Just briefly, there are a couple of other recommendations I would like to bring to the attention of the Senate. Recommendations 7 and 8 go to the question of indexation. In some respects indexation for some disability services is seen as growth funding, and that is absolutely inappropriate. Why is it seen as growth funding? There simply is not enough money to go around anyway. Indexation is designed to accommodate the increase in costs that any service will have. I encourage both the states and the Commonwealth to recognise our recommendation to set a realistic indexation level, in line with the actual cost of delivering services. Most of the costs in delivering disability services are human costs—staffing and wage costs. That will not change. It cannot change.

The other recommendation is that the Commonwealth government consider removing the efficiency dividend from the indexation formula for funds allocated through the CSTDA. There are very few efficiencies to be found when most of your costs are human costs. You cannot lift a person out of a bed faster. You cannot bathe a person faster. Those costs are going to be there. They are not going to change. You cannot computerise them. The application of the efficiency dividend to the indexation from the Commonwealth results in a direct cut to overall income.

The other issue I would like to go to is the issue of lifelong planning. It is very important for people with disabilities and the parents of people with disabilities to have an expectation of the sorts of supports that they will be able to have during their lives. Those support levels will change—that is natural—and they may change quite quickly. We have to have in place, though, a commitment from governments to support people with disabilities in their aspiration to be a part of society and to contribute to society.

We heard, as Senator Humphries has said, some horrifying stories of people being kept in their homes almost as prisoners. We heard stories many times of people living in nursing homes because the support simply could not be provided outside. But we also heard some very positive stories, and we should learn from those positive stories and make sure that the positive experiences, where people are supported and are encouraged to be participants in our society, are the model that we adopt and ensure is applicable to all people.

Finally, there is a chapter on the ageing-disability interface. In the years to come, the number of people with disabilities who are ageing will grow quite considerably. That provides a challenge to governments, and our recommendation is that people who are ageing who have disabilities need to be able to access services from whichever stream of funding is most applicable.

I thank all witnesses who came before the inquiry and all people who provided submissions, but I particularly want to thank Christine McDonald and Owen Griffiths and all the staff of the secretariat for their exemplary work and for their enormous patience in some trying times, even up to yesterday. I place on record my thanks.

Senator PATTERSON (Victoria) (6.26 p.m.)—I rise to support my colleagues in commending the Senate Standing Committee on Community Affairs report on the funding and operation of the Commonwealth State/Territory Disability Agreement. The Commonwealth State/Territory Disability Agreement is to be completed by June this year, and this inquiry was a perfect opportunity for the committee to go to nearly all the states taking evidence from carers and organisations about the way they see the functioning of the previous Commonwealth State/Territory Disability Agreements.

When I resigned from the ministry, I said that one of my greatest sadnesses was that I would not have the same clout in fighting for people with disabilities. I made a commitment that during the rest of my time in parliament I would continue to fight for them. I hope being a member of this committee has been part of fulfilling that commitment. As we moved around hearing the various stories, I felt embarrassment that, in a country with the wealth and resources we have, we were subjected to stories—and I think it would have been beneficial for other colleagues to have heard them too—that were tragic, of people who had been caring for their children for years, year in and year out, who had given up hope of even thinking that they might be on a list for accommodation, who were at their wits' end to know where they should go and to whom they should speak to actually have someone listen to them. This was an opportunity for them to be heard.

We heard from a young man in Tasmania, 31 years old, with cerebral palsy—an articulate, bright young man who said that what he wanted to do was leave home, like any young person. He felt that he was a burden to his mother and stepfather, but there was nowhere for him to go. Today we met a young man with three children who has spent the last three years in Canberra Hospital. We met another young man today who had had a skateboard accident and been sent out of hospital in a parlous state because he was 'blocking' a bed—that was the word that was used. That young man read a statement at the press conference about his situation. He was considered virtually gone at one point.

We could go on with story after story. I commend the recommendations of the committee. I know it is not popular with treasurers, finance ministers, shadow treasurers or shadow finance ministers to be told that more money is needed for a program. But, if anything needs more money spent on it, it is the area of disability. There are people who are at their wits' end, who have cared for their son or daughter or niece or nephew or partner to breaking point. That is the only way I can describe it.

One of the things that I wanted to point out in the recommendations—and I will not go through them all for some of my colleagues have covered them—was recommendation 3, the last dot point: that the CSTDA should include a transparent and clear mechanism to enable people with a disability and their carers to identify and understand which level of government is responsible for the provision and funding of services. When it is not clear it is easy to buck-pass. When it is not clear who is responsible for a 24-year-old with multiple sclerosis, it is very easy to pass the buck. What has happened when we have had young people in nursing homes is that once they were in the nursing home the Commonwealth was paying for them and there was no moral suasion on the states to do anything because the young people were off the waiting list. I am not criticising the states but that was what happened. There are some arrows that could be shot at the Commonwealth as well, but unless you have a clear definition it is easy to pass the buck.

We could not come to an agreement in the committee on a definition. My view is that you should specify an age and if the person is under that age the state is responsible for them and if they are over that set age the Commonwealth is responsible for them. With regard to accommodation in particular I am not saying that they should move, but they should be able to remain in place but with somebody to take responsibility for them. At the moment when you are on the cusp—if you are not young and you are not old and you have not got an absolutely clearly age related condition that is not related to your disability—it can be fudged about who is responsible. The fudging has to stop. There is no more excuse for fudging. The CSTDA should make sure that fudging from either side cannot continue.

I think that one of the most important things about this report is that it has been a unanimous report. As Senator McLucas has said, it reflects as much as it can, through the committee, the views of those carers and those people with disabilities who spoke for themselves as well. I want to commend this report to all the ministers. I know some of them and I hope that we have assisted them in jogging their treasurers and finance ministers into recognising that this is something that needs addressing. We cannot use excuses any longer.

To the committee, I know have they put in 150 per cent. I am concerned about the health of some of them and I would ask the Clerk and the President to make sure that one committee is not overloaded and understaffed, and I think ours has been. I am very concerned about the health of the staff of our committee because of the burden they have had and I would hope that that would be considered. I thank them for what they have done under very difficult circumstances. They have made a major contribution. We often forget them, but without them we would not have these reports. So I thank them and I hope we take consideration of the fact that they have been unduly burdened. Thank you.

Senator SIEWERT (Western Australia) (6.32 p.m.)—I too was a member of this committee and I too am extremely pleased that we had a unanimous report. It seems a bit strange to say that it was a pleasure to work on this committee but it was in terms of working with both committee members and committee staff who were so dedicated to what we were doing. It was also a pleasure to meet and interact with both people with disabilities and with their carers who came to the committee and who told us in many cases very disturbing and tragic stories.

We also heard some positive stories. As Senator McLucas said, there are many very positive stories. But unfortunately those are outweighed by the stories of people struggling, people with disabilities and their carers living in what can be described, I think, as most distressing circumstances. Not only, as Senator Humphries articulated, are some of the most disadvantaged people in our community living with disabilities, so too are their carers, and the carers of those living with disabilities have amongst the lowest rating on the wellbeing index. So I think that we also need to bear that in mind.

The overwhelming sentiment from nearly all people, except two, making submissions to our inquiry was that there should be another agreement, and I also strongly believe that. But as my colleagues have articulated, the overwhelming No. 1 recommendation—even though it is No. 21—is that there needs to be more funding to meet unmet need. The tragedy here is that we do not have a firm understanding of what that unmet need is. In my home state of Western Australia they have a bit of an idea of how many people want accommodation but that is only known from those that are on the waiting list. It works differently in each state but in my home state of Western Australia you just keep applying, and if you do not get accommodation you just keep applying. People get sick of it so they self-select and so we do not have a firm idea of how many people do require accommodation.

As well as endorsing the issues that my colleagues have pointed out, I want to point out that there are issues around portability of services. If you are living with a disability in Western Australia and you want to move to the eastern states, you are not guaranteed access to similar services. In fact, some people told us stories of moving interstate and having to move back to their original state in order to get some sort of support. As we pointed out in the report, although the states and the Commonwealth identified this as an issue before the year 2000 it is still a major issue. There has to be some change in the way we do business to enable people to be able to move between states and have the same level of support services and have their needs met.

Another area that has come up is dual and multiple disabilities. We heard a number of stories where people who have dual disabilities or dual diagnoses were batted between services. It was a matter of: 'No, you do not fit neatly into this service and you should go to the other service,' or 'No, you definitely do not fit into this service so you should go to the other service.' They are falling between gaps because they are a round peg in a square hole. This should not be occurring to the most vulnerable members of our community.

I also strongly endorse the call for whole-of-life planning. Again we heard stories of people having to go back repeatedly for assessments. When people have disabilities, the medical profession and those people living with these disabilities know what is going to happen to them as they age, so they should not need to go

back for repeated assessments. We also need a much more comprehensive assessment of people's disabilities so that we can match services to their needs.

Another area that came out was equipment. Equipment is absolutely essential for those living with disabilities. Again it varies between states; it can be extremely difficult. Different states have different caps on what you can buy. It is also very difficult to transfer your equipment between some states. When you are moving out of a nursing home—we are encouraging young people with disabilities to move out of nursing homes—you cannot take your equipment with you. You cannot take your equipment into nursing homes when you go into one. These things should not be happening to people living with disabilities; we should be looking after them and making their life that much easier.

Ageing in place is also very important and looking after carers as they age. We need to ensure that we are meeting the needs of carers of people with disabilities. We heard stories of people in their late 80s and early 90s still looking after their child who has a disability and not going to hospital and not seeking medical attention because they were worried about their child.

This is an extremely important report, and my plea to the Commonwealth and to the states and territories is to please take on board these recommendations. There are a lot of them; there are 29. They are for things that need to be fixed. Please take it on board. I also make a plea to Minister Scullion, the new minister responsible for families here, to please read this report as soon as he can and start talking to his colleagues and to the states and territories ministers so that we can get this fixed.