Submission to the Productivity Commission Inquiry into Disability Care and Support

An experience in Germany

Dr Paul Petrie-Repar

Introduction

I am writing to the Commission because I think my family's story clearly highlights the inadequacies of disability and health services in Australia. I am an Australian citizen and my family was living in Germany when our son Michael was born in 2000. Sadly, Michael was born with a severe muscle disorder. We initially planned only to stay in Germany for three years, but after we investigated the quality of the care that Michael would receive if we returned to Australia, we decided to stay in Germany indefinitely. This was an easy decision to make because in Australia, it would have been impossible for us to provide Michael with the same quality of care that he received in Germany.

I think that Australia can learn a lot from how the health care system operates in Germany and other European countries and that the Productivity Commission should consider the German system and many of its positives. I note that consideration of models from other jurisdictions is within the Terms of Reference which provide at page vi that:

> *In undertaking the inquiry, the Commission is to:*
>
> *1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.*

We found that the German system assists people who suffer from disabilities and their families by providing support which is simple and straight forward to access, thereby allowing families to concentrate on being a family instead of fighting for every piece of equipment and care needed for their loved ones to live a life with dignity.

I am relieved that the Productivity Commission in its Draft Report has clearly identified the poor, underfunded and unfair situation that currently exists in Australia for those who have a significant disability and their families. I support in general the recommendations made in the Draft Report, in particular the establishment of a National Disability Insurance Scheme which is neither income nor assets tested, to ensure that any Australian who has a significant disability receives vital support and care. For example, I hope that a practical outcome of any new scheme would be that a person who is ventilator dependent 24 hours a day is entitled to home nursing support for up to 24 hours a day.

I hope that the Commission's work is the foundation for the reform that is desperately needed in Australia to care for those who need it most because of significant disability.

Our son Michael

Both my wife and I are Australian citizens, born and bred in Australia. We moved to Germany after I was offered a job there. We planned to stay for only three years, but ended up staying for five years because of the care and support provided to our disabled child, compared with the lack of support in Australia.

After living in Germany for one year, our first child, Michael was born on 24 November 2000. Michael was also an Australian citizen by descent. The night after he was born, Michael struggled with his breathing and was moved to the main pediatric intensive care unit at the University hospital in the town where we lived. The doctors told us that Michael was what is called a “floppy infant” and was best described as appearing to have very low muscle tone and being like a little rag doll. After numerous tests for a multitude of diseases and disorders, his condition gradually deteriorated and at the age of two months, on Australia Day 2001, he was ventilated. Shortly after he was ventilated we found out that he had nemaline myopathy, an extremely rare muscular disease. Michael's prognosis was that he was unlikely to improve and that he would probably die before his first birthday.

Michael was mentally normal, incredibly bright in fact, but could not move. He could not breathe on his own or eat on his own. He had a PEG for feeding and was ventilator dependent 24 hours a day. He spent the first 17 months of his life in intensive care and had a number of close calls when we nearly lost him. Eventually, his condition stabilized and we were able to plan to bring Michael to our home in Germany. After spending so long in hospital, we were happy to at last be able to bring Michael home on 15 April 2002. He lived with us in our home until he was nearly four years old. He died on the 8th of October 2004 after a bout of pneumonia.

Plans to bring our son to our home in Germany – How the system worked

While Michael was in intensive care, he received regular physiotherapy and later occupational therapy and speech therapy (three to four visits each week for each therapy). Once a portable ventilator was found, the staff at the hospital worked out a plan for us to be able to care for Michael at home. This included training us in all aspects of his care and arranging a nursing company to provide home nursing support 22 hours a day, 7 days a week. The hospital staff also organized for a company to provide all of Michael's medical equipment and supplies for his life at home. Regular physiotherapy, occupational therapy and speech therapy was also organized for him at home. These were all home visits as it was a major logistical operation to take Michael out. It was easier for the therapists to come to our home rather than for us to visit their practices with Michael.

All of these plans to arrange for Michael to live at home with us were made in consultation with us of course, but primarily by the hospital staff. All costs were covered by our health insurance which was compulsory in Germany. There is a statutory scheme of health insurance in Germany. As I was employed there, I had paid for my health insurance directly out of my pay packet (12% of my gross salary was deducted for health insurance which included disability services) and therefore, all Michael's medical expenses, including all his home care costs, nursing, therapies, equipment, supplies were all covered by our German health insurance. Our out of pocket expenses for all of these services and equipment during Michael's life time was only a few hundred Euros.

Plans to bring our son home to Australia – How the system did not work

My wife and I visited Australia about one year after Michael moved to our home in Germany. Michael was doing really well at home with all the care he received, and we wanted to find out what process would be involved in bringing him to Australia to our home, as we had only planned to stay in Germany for three years and then return home to Australia. We were missing our families and our families were missing out on knowing Michael. We wanted to investigate the logistics of flying him home and the support he would receive if he were to live in Australia in terms of therapies, equipment and home nursing support.

We met and spoke with a number of individuals, including those who work with disabled children in Brisbane, as well as Health department representatives. We also made inquiries with our private health insurer, with whom we were still members. We were eventually told that we should write to the Director General of Queensland Health to clarify the level of support that Michael would receive if we returned to Queensland. Attached is the response we received. The news was not good. The bottom line was that if we were able to get Michael home to Brisbane in the first place, (no financial assistance would be provided from any quarter for this) he would receive very little in the way of home care support.

We were advised if we were to return to Australia, that Michael would be admitted to a hospital upon his arrival and assessed. If he were then to move home, he would probably receive a few hours home nursing care per week, and no therapies, nothing in comparison to what he was receiving in Germany. As for his equipment, our private health insurance had a limit of about $600 per year and Michael's ventilator alone cost about $30000. There was at that time we were advised, a high cost home support program that had a capped budget of just over $1million which was supporting six people. We were told that we could apply for this program for some home support, if we were to return to Brisbane, but that other people were already eligible and if we applied, Michael would have to be prioritised. We were told by one official, that the most likely scenario would be that Michael could live in hospital for the rest of his life, rather than having him live at home with us if we were to return to Brisbane.

One doctor told us when we asked whether he thought we should bring Michael back to Brisbane or stay in Germany, that if Michael was his child that it “wouldn't have come to this”. When we asked what he meant by this, he told us that it would have been strongly suggested to us that Michael should not have been ventilated because his long-term prognosis was poor. It appears that unfortunately this is the pragmatic approach taken by Australian doctors because of the limited resources for severely disabled people in Australia.

We were also told that there is a certain amount of money allocated in programs to cater for disabilities and that they need to determine the most efficient use of those funds. Practically speaking, we were advised it was questionable whether our son would be a good use of those funds because it would have been better to spend the money on people who have a better prognosis.

After telling one official of the kind of care and support Michael was receiving in Germany, his comment was that we were lucky to be receiving the care that Michael was in Germany as “non-nationals”. We felt, through comments such as these, that we were being warned off returning to Australia with Michael. Because of the lack of any encouragement or support given to us when we were researching the possibilty of coming home, the officials we spoke to succeeded in warning us to stay away.

If we were to return to Brisbane, we would have to have sold everything we owned, and been reduced to being beggars and rely heavily on charities for each piece of equipment that Michael needed. Neither I nor my wife would have been able to work in paid employment, as we would both have had to have been full time carers for our son because of the lack of home nursing support.

The decision for us after receiving all of this bad news was straightforward. If we were to bring Michael to Australia, he simply would not have received appropriate support for his significant disability. We decided to stay in Germany, even though this meant we and Michael were far away from the family support that we needed because at least over there he was treated with the care and consideration that he deserved, and we were supported with adequate assistance in caring for our son.

Needs based assessment by medical experts

When you are caring for a disabled child, and in particular a child like Michael who was disabled from birth, it is important that parents are provided with support in making the arrangements to bring them home and to care for them at home. This should be made as easy as possible for them, because they are already in a difficult and emotional situation. They should not be forced into seeking out what is available to them as time is at a premium when caring for a disabled person. It is vital that in any new scheme that parents and carers are provided with appropriate guidance to ensure a smooth transition to care at an in home environment from health and disability professionals. Close consultation with family is vital and the focus should always remain on how to support the needs of the person with the disability in an appropriate way.

When we brought Michael home from the hospital in Germany, the health experts were the ones who presented us with the information necessary and they helped to manage his move to a home environment so that it was relatively straight forward from a logistical perspective.

I note that in the Draft Report (page 18 of the Overview and Recommendations) there is reference to the careful use of assessment tools. While I agree with the general sentiment in the Draft Report about careful use of assessment tools, the statement:

> *The people making assessments would need to be independent from the client (unlike treating GPs), be properly trained …*

is in my view, taking the assessment process too far away from experts who have the best view of the needs of the person who is living with the disability. I think it would be wrong to completely remove treating doctors from the assessment process. I would suggest that any assessment should be made taking careful consideration of the expert advice provided by any treating doctors. I would think this is absolutely necessary in order to ensure that a proper assessment is in fact made.

Conclusion

When Michael was born, at first we were devastated that we were far away from our family support network when we needed it most. However, he was able to lead a happy life in a home environment with us in Germany. He even went to kindergarten when he was three years old. This was only possible because of the care and support he received through the German system.

Michael's life, had he been born in Australia, would have been I sincerely believe, much shorter and near impossible in a home environment. It certainly would neither have been a life lead with dignity nor with an appropriate level of care and support. In a civilized society, we should give priority to giving appropriate care to those who most need it. It is clear that those who have a significant disability and their families need it most.

In the end, it turns out that we were in fact lucky that Michael was born in Germany, even though we were far from our family support in Australia. When Michael died, he was nearly four years old. Only then were we finally able to bring him home to rest with us in our home country where he should have been able to live his life. He was after all an Australian citizen born to Australian citizens who happened to be in Germany.

What happened to us could happen to anyone at any time. We are both healthy and could not have predicted that our first child would suffer from such a debilitating disability. This is the inherent and unavoidable risk associated with having children. No one can plan adequately for these kinds of circumstances and private health insurance does not provide any adequate assistance and there are extensive ongoing costs involved in caring for a severely disabled child that most people, even those on a good income, simply cannot meet on their own day after day. It is exactly these kinds of circumstances, which cannot be planned for, that can happen at any time, through no fault of anyone's, that should be subject to an adequate government insurance scheme.

I am deeply concerned about the fate of families who are caring for severely disabled children in Australia. The resources they require to provide the necessary care for their children do not exist. Good caring parents are most at risk because they will try their best to provide good care for their child. These parents are doomed to become financially, physically, and mentally ruined. We should protect these good families from ruin.

I commend the Productivity Commission on its Draft Report and Recommendations. I hope that the Australian Government takes seriously the Productivity Commission's Recommendations, and that the Report does not sit on a shelf after it is finalized, so that other families do not have to suffer the same kind of anguish that we did.

If the Productivity Commission would like any further information about our experience, you are welcome to contact me. Thank you for the opportunity to provide a submission.

Yours sincerely

Dr Paul Petrie-Repar