REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY AGEING, DISABILITY AND HOME CARE

At Sydney on Thursday 30 September 2010

The Committee met at 9.10 a.m.

PRESENT

The Hon. I. W. West (Chair)

The Hon. G. J. Donnelly
The Hon. M. A. Ficarra
Dr J. Kaye
The Hon. T. J. Khan
The Hon. H. M. Westwood

CHAIR: On behalf of the Standing Committee on Social Issues I welcome you to Parliament House and to the public forum today. Thank you for contributing to this inquiry, whether through the written submissions we have received or through speaking to the forum. It is great to see members of the public coming to Parliament and speaking their minds about issues that are important to all of us and having their say before a parliamentary committee about the issues of funding by the Department of Ageing, Disability and Home Care.

Our Committee has six members from the upper House and we represent a range of political parties and perspectives. My colleagues come from the Greens, the Labor Party The Nationals and the Liberal Party. The inquiry's terms of reference require the Committee to examine the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care. This inquiry is an opportunity for service users, carers, families, organisations and others to provide input into how disability services can best meet the needs of people in New South Wales. You will find more detailed terms of reference on the table by the door.

At the end of our inquiry we will make a report to Parliament that sets out our findings and makes recommendations for the Government to take action. The Government must respond to our recommendations within six months on what action it will take on each of the recommendations we make. Everyone who participates in the inquiry will be sent a copy of the Government's response and will be put on the Committee's website. This forum today is an important part of our inquiry. The Committee has received over 110 submissions and has held five public hearings to hear from witnesses with a diverse range of views. Clearly, there is a high level of interest in disability services in New South Wales and today is about hearing directly from individuals about their experience of these important services.

I remind all speakers of the gravity of today's proceedings. What you say today will go onto the public record and we will consider your views as we consider our report. Although the Committee will not be asking you to take an oath or affirmation to tell the truth, we expect that you will be speaking truthfully and I remind you of the responsibilities that accompany the opportunity to speak on the public record. We understand from the submissions received that many people are angry or upset about their experiences of the disability services system and with some individuals in the sector. While the Committee is keen to hear of your experiences, I remind speakers that this forum is not an opportunity to make adverse reflections upon specific individuals. The Committee is required to examine issues at a systemic level and I ask that you avoid naming people and instead talk about their position—if you have to talk about them at all—rather than using any names.

Today's proceedings are being recorded by Hansard and will be made publicly available on the Committee's website. Names of individuals adversely mentioned will be removed from the record before any publishing takes place. In addition, it is important to note that while what you say to the Committee is protected by parliamentary privilege, this does not apply to what speakers may say once you leave this room. Therefore, you should be cautious about any comments you make to anybody—the media or anyone else—after you finish addressing the Committee, even if it is within the confines of this parliamentary building.

I stress that although this is a public forum, it does not allow for comments from the floor. Obviously we warmly welcome audience members at today's proceedings but we ask you to not in any way disrupt the proceedings. Each speaker will have eight minutes to address the Committee. In order to ensure everyone has a fair opportunity, the time limit will be strictly adhered to and you will hear at the end of seven minutes a bell advising that you have one minute to go, and, unfortunately, we will need to be strict in enforcing that time limit. Prior to today's forum speakers were advised they could bring a copy of their statements so if they run out of time we can arrange for it to be inserted into the Hansard transcript of proceedings.

As you can see from the program, we have a number of speakers—11 or 12—between now and 1.00 p.m. I will invite three speakers at a time to come to the table, and there will be an opportunity for a light lunch with the Committee at the end of the forum. Committee members normally ask questions of participants but I will be asking my colleagues to refrain from asking questions today other than for quick, specific clarification—and I probably should not have even said that—so that each speaker is free to make his or her statement and take full advantage of the eight minutes. It will not be the Committee's wish in any way to interfere with your ability to maximise your time. I remind everyone to please turn off their mobile phones. Finally, the Committee secretariat is here to assist people in any way necessary with any questions about today's forum and the inquiry process.

VALERIE NOONE: Mr Chair and other Committee members, I would like to give you a brief overview of my dealings with the Department of Ageing, Disability and Home Care. These have been in regard to my younger sister, a 51-year-old Down syndrome lady. She has been in the care of the current service provider for nine years and we have always been very happy with the service she has received from them. The service provider is funded by ADHC. The death of one of the female household members created a vacancy in the home. The remaining household members included my sister, and two males in their 40s and 50s, both of whom have Down syndrome and are quiet and gentle.

ADHC has some wonderful policies and guidelines regarding the placement of a new resident into a group, which would include the involvement of the existing residents in the choice of the replacement as the resident has the right to feel safe and have their privacy and dignity respected. My sister requested a female resident. ADHC decided to ignore all its policies and practices and act upon a provision that allowed it to direct the placement as it sees fit. What it saw fit was the placement of a 28-year-old fully autistic male, who is nearly half the age of the other household members and with an extremely different disability.

A long transitioning process of a directed placement began. It was late in this process that my family and I became involved with ADHC. Over the transitioning period of the new resident into the home, our sister, who was quite small, became fearful of the new resident and some of his obsessive behaviours. These behaviours included sock checking, where he would lunge at my sister's fleet to observe her socks. He also entered the bathroom where she was preparing for her bath and had to be assisted out, and her bedroom, even though the doors were closed, and he was clearly unwelcome. By this time we were becoming quite alarmed for our sister's safety. We requested ADHC to reconsider its choice of resident as we thought it was unsuitable. The other residents objected to him and the service provider also raised a number of concerns, all of which were ignored. So, insisting that the placement go ahead, the needs of the other three residents were completely disregarded.

Last December the transitioning of the new resident was completed and he moved in permanently. After this, over a period of months, the unacceptable incidents between my sister and the new resident escalated. These included my sister being pinned against the wall to have her socks checked and him laughing when he saw that she was frightened; also forcing his way into her bedroom. At this point, even ADHC agreed that it could no longer guarantee my sister's safety. We then requested a temporary transfer to another household until the situation could be resolved. We have been having discussions with ADHC over this unsatisfactory situation for almost 12 months now. My sister would like to return to her household in Windsor, and the two remaining residents are still suffering abuse and intimidation.

Over this time it has become very apparent to us that the complaint-handling process in ADHC is badly flawed and ADHC uses this to its advantage. The first major flaw is the culture of blame-shifting that exists throughout the department. It is difficult to get a complaint looked at when all it wants to do is shift the blame onto someone else and does not want to look at the situation objectively. An example of this is when ADHC would tell us that it was its job to support the service provider and that it was the service provider's job to manage the situation. It was suggested that maybe the service provider was not doing its job properly. Another proposal was that my sister could receive counselling for fear. It did not seem to matter that she had good reason to be afraid. Also, ADHC was the one who created the situation by insisting on the placement of an unsuitable resident despite strenuous objections, especially from the service provider.

Another flaw is the way the process has dragged on for weeks and months with what is euphemistically referred to as ongoing discussions. This became particularly distressing while all the time we felt our sister was in danger of being harmed when she remained in the house. This dragging out of the complaint process was achieved in a number of ways. Firstly, we were called to meetings but then told at the meetings that those present from ADHC did not have the authority to make decisions; that they would report the content of the discussions to their boss. This then resulted in more meetings and ongoing discussions with no resolution of the complaint.

Secondly, we have been told that a particular matter that we wanted to discuss would have to be taken up with someone else from another section of ADHC and not the section we were currently dealing with. Finally, we were told the only way to have the resident removed would be to make a formal request from the service provider that the resident be exited. The service provider would then request from ADHC that the resident be exited on the basis that the situation was unmanageable. However, ADHC would have had to agree that it was unmanageable. Unfortunately, ADHC had a different view on what constituted an unmanageable situation and insisted that it continue to implement various strategies to make the situation work. To date, none of these strategies has worked and is not likely to.

It is a sad fact that we never made any real progress with our complaint with ADHC until we introduced external pressures, which included the following: A detailed letter of complaint to the office of the Ombudsman outlining ADHC's failure to follow its own policies. This process has also taken several months and has resulted in the ongoing interest of the Ombudsman, but still without a resolution. The second thing was an apprehended violence order which was taken out on my sister's behalf against the new resident. This proved to be quite effective in gaining their attention and we did get to meet with some people who could make decisions. We also wrote to various members of Parliament and made a submission to this inquiry. What I would like to know is: why is it needed to go to such extreme lengths to get a complaint taken seriously?

I want to state again that the complaint handling mechanism is seriously flawed. One of the major reasons for this is that there is no means by which ADHC can be held accountable for their actions or decisions. ADHC needs to be held accountable for their own policies and practices without loophole clauses. I believe there needs to be an independent tribunal set up to deal with the complaints. A great deal of time, money and resources have been wasted over this matter, which should have been very simply a matter of common sense. We have been involved in this dispute for 12 months and it would seem that the likely result was that it was a mistake.

If they had followed their own codes of practice in the first place, the situation would never have occurred. ADHC is responsible for the wellbeing of some of the most vulnerable members of our society; many of them have no voice to defend them. It has been a long and frustrating journey for me and my family, but I do fear for those who have no-one to defend them. I hope as a result of this forum that there will be an independent body created to arbitrate complaints without the fear of negative repercussions.

CHAIR: Thank you very much. Ms Judy Brosas.

JUDY BROSAS: This deals with the same situation. I am just going to read a letter from my father and I will put my own personal ideas in as well. The letter states:

> As the parent of a Down Syndrome, selective mute child, I was concerned for the welfare of my daughter after the death of her mother in 1991. After one failed placement, where she was bullied and retreated within herself she was fortunately accepted in 2001 as a resident of the group home she currently belongs to. The home is very caring and until late 2009 she lived very happily with the other residents. Unfortunately, in 2008 one of the residents died but my daughter continued to live happily with the two other residents both of whom are small, gentle, middle aged men with mild down syndrome disabilities. However, in October 2009, a fourth resident was placed in the home. This person is a very large [non-verbal] autistic male with aggressive behavioural tendencies. His obsession with other people's socks has caused great anxiety with my daughter as he has forced his way into her bedroom, cornering her in her walk-in robe and forced his way into her bathroom, pushed her up against walls to check her socks and pushed staff out of the way to check her socks. The result of this behaviour is that my daughter became so distressed that she, the victim, had to be temporarily removed from her home and moved to a safe group home. This has added to her anxiety as she does not understand why she is the one that was removed. In spite of frequent submissions to ADHC by the families of the three original residents, stating that the residents could be in danger of injury and they now live under constant tension and intimidation, ADHC have brushed aside all complaints and refuse to find more suitable accommodation for the newest resident. My hope is that ADHC will be persuaded to admit their mistake and rectify the matter urgently and have accountability in the future.

That is from Ivor Russell Nyman, my father. I would like to say that ADHC's slogan should clearly be, "We say yes to domestic violence" because they knew this resident's background of dealing with frustration with aggression and of his obsessive compulsive disorders and still they placed him in this house with the three Down syndrome adults. The agency stated that it was not a suitable home because of the differences in the disabilities, ages, the level of personal care required, the independence of the other three residents and the social skills. This resident is not compatible in any area of assessment. The agency offered to set up a purpose-built home with trained staff so this resident and other autistic people could have their own needs met. This was refused by ADHC. The agency was told they had to accept the resident in their current home.

As you have heard, my family became alarmed when incidents occurred during the transitioning of this person joining the house. ADHC refused to listen; even when my brother became involved as my sister's solicitor and said he would hold them accountable for anything that would happen to her, they did not care because, it seems, they are accountable to no-one. I sent many emails to the Minister for Disabilities asking for an interview so our situation could be heard but the replies came back from ADHC telling us what a great job they were doing and that maybe it was the agency at fault. This agency has implemented every strategy, every suggestion that ADHC have given them, but still the situation remains the same.

As Linda's legal guardian and out of sheer frustration with ADHC, I applied for an apprehended violence order against the resident—something I hated doing, but ADHC had left me no choice. It was only then that they paid any attention to our complaints. We have had three visits to court over this and prior to our last visit to court, I spoke to one of the resident's brothers to ask if the behavioural management plans were working and if it was safe for my sister to return to her home. He advised me that, from his observations and from the summary of incidents caused by this resident against his brother, things were deteriorating. There had been over 100 incidents since January this year that have been documented and they had escalated since my sister left the home at the end of April. This resident has a pacemaker and his brother is very concerned for his health and safety.

Where is ADHC's humanity? I do not understand how ADHC, knowing this abuse occurs daily, can continue with this placement. Their offer to help the three original residents is counselling. What about safety? Behavioural plans have been set up only addressing the interests of the newest resident and expecting the other three to comply. Throughout the process they have trivialised the incidents and referred to them simply as "he checks her socks". They do not mention the force or invasion of privacy that has led to fear, a fear I witnessed on my sister's face that gave me the determination to keep fighting for her.

ADHC has contravened the Human Rights Convention on the Rights of Persons with Disabilities ratified by Australia in 2008 in Articles 4, 6, 10, 13, 16 and 19. I have a copy here that I will leave. ADHC have acted in the most discriminatory way, sacrificing the safety and wellbeing of the original three residents for the convenience of housing one. The money thrown into this situation is obscene, especially when you know so many are waiting for accommodation. The stress ADHC has imposed on the residents and staff of this group home is criminal, not only for the original three members but for the autistic man as well. This situation will never work, despite the revolving door of staff and assessment teams that have turned a lovely family home into a public thoroughfare that has just added to the anxiety of all the residents.

My request is that an independent tribunal be set up, one free of hidden agendas or discrimination, one that has the power to act. This would give a voice to the voiceless and protection for the vulnerable in ADHC's care. An independent tribunal would treat all cases fairly and equitably, a concept ADHC appears not to understand. The original residents have lived together for seven years—my sister and one of the residents for nine years—without any incidents of abuse or invasion of privacy. The latest resident has been in the home for less than a year—the quality of three lives sacrificed for the convenience of one. Where is ADHC's policy of equity and fairness? Where is their concern for all people in their care? Thank you.

CHAIR: Thank you. Mr Tony Varrall.

ANTONY VARRALL: Good morning, Chairperson, Committee members, ladies and gentlemen. My name is Antony Varrall. I broke my back 32 years ago, leaving me completely paralysed from the armpits down. In the last three years the muscles in my right shoulder joint have become detached and I have had septic arthritis in my joint. I am very fortunate to be married and I have three almost adult children. I am fortunate to receive Home Care once a fortnight for two hours of general assistance and I also have personal assistance a couple of mornings a week when my wife goes to work.

Today I would like to share with you some thoughts and opinions I have about my home care. Firstly, I am acutely aware of the fact that I am unable to help my wife like any normal husband and that I am somewhat of a burden to her, which does create a strain on the marriage. To preserve our happy marriage I have to be very careful to spread the workload between my friends, my wife, the family, Home Care and other people I pay for assistance. When I do not get that help, obviously I get very frustrated waiting and repeatedly asking, and the people who are helping me get fed up attending to my never-ending needs, et cetera.

I firmly believe that the general help I receive from Home Care is paramount in relieving some of the workload on my wife so that we can maintain our happy marriage, which has now lasted 27 years. I particularly wanted to point out this because, although my needs are trivial in comparison to these other people who are suffering a lot more than me, if this little amount of assistance we get is not maintained, it will end up costing the Government a lot more if I lose my wife because then I would need help seven days a week instead of a couple of mornings, and a lot more general assistance to be able to stay in my own home. There is also the possibility that I might not even be able to stay in my own home. It is so important that the Government appreciates that even people who need so little help as me and pale into insignificance—I can understand the enormous amount of suffering by other people—I think that they must make sure they assist people so that you can keep your happy marriage.

Moving on, I would like now to talk about the complaint procedure. I would like to know how I can complain in the event that I am not happy with my Home Care provider. I have always had a big confusion in my mind concerning who is funding all of the different Home Care providers and whether I can change my Home Care provider if I feel, after some consultation, that they have just not been able to supply the helper that will satisfy my needs. The correct avenue of complaint needs to be communicated to all Home Care recipients once a year, along with a short survey giving them the opportunity to give feedback to their Home Care provider in an anonymous manner. It would not be hard to do this and it would keep them informed as to who you can pass on your complaints to.

Two years ago I rang my Home Care provider four months prior to my wife going overseas, asking for personal assistance each morning while she was away. I was distressed to be told there were no funds available to provide a subsidised carer at this time. This was very worrying because you have to book your overseas trip and once again I tried to let my wife do what she wants so I can keep a wife. I was not given any further directions to seek alternatives, just told to tell my wife to cancel her plans in order for her to stay at home and care for me. Fortunately, after making several more calls over the next few days, I found out that I could call the Commonwealth Carer Respite Centre. They had no problem providing emergency respite funds to a provider, who went out of their way to be most helpful, organising a carer every day at the time needed and capable of helping me with all my required needs.

I was very fortunate to have the ability to push my case higher in order to obtain the respite help that we needed. The information needed to source emergency respite help should be readily available to every disabled client. This could be provided easily by home care suppliers once a year at the same time as they ask their clients to complete a short feedback survey. Again, that is easily done. If you could organise something like that it would be wonderful. There have been a number of times that, for some reason or another, my home care provider has not been able to provide a carer at the last moment. It might have been because of a car accident, or because the home care provider was sick.

Only the other day the home care provider forgot to come to me. Fortunately for me my wife has been able to postpone going to work in order to help me on those occasions. We are lucky that my wife's employer has tolerated her arriving late on those days. It is not good for her or for her work comrades. When it happens too often obviously they do not think well of her and they might think she is putting it on, or whatever. Many employers would not be able to tolerate that. The point I am making is that there should be some arrangement between home care providers, or through an emergency provider agency, for replacement carers to be organised quickly when carers are unable to come at the last moment due to a mishap or whatever.

As a matter of interest, I am aware also that the carers of some speakers who are coming today did not turn up as they should have. I am not sure whether they were able to make it at all, or whether they are running late for that reason. A while back I needed to change the scheduled day for my carer's help, only to find that that was not possible, despite giving three days notice. It should be possible to get an unscheduled personal carer in the morning or on special or rare occasions, provided that two days notice is given, as that would avoid unnecessary strain on family arrangements. That should not be too hard. On the positive side, we have been most appreciative of our home care provider, which has always done its best to provide high-quality carers on the days and at the times that we requested. There has never been a problem on the rare occasions we have requested that it provide a different carer due to our unhappiness, for some reason or another, with the carer that it has provided. Home care is a wonderful and extremely important service, without which many disabled people like me could not survive in a home situation.

CHAIR: The remainder of your statement will be incorporated in *Hansard*.

It is quite obvious that funding is always a problem affecting the provision, amount of care and quality of carers on some occasions. The solution will not be found by squeezing more money from the disabled recipients for the service that they receive. Their life is already enormously financially burdened by their need to pay so many people to help them with their never-ending list of tasks so easily completed by others without a disability. With a little more funding and a few minor improvements the disabled in our community will be able to stay living at home in a much happier environment, which is more stress and strain free, resulting in better health, productivity and psychological well being.

Thank you for the opportunity to address this forum today.

(**Short adjournment**)

BERNADETTE MOLONEY: Thank you for giving me a chance to speak. A lot of what previous speakers said resonated with my observations over the years. My complaint basically is that, for the past 17 years in which we have been involved with Ageing, Disability and Home Care [ADHC], I have not seen any progress or forward planning, or proactive or preventive planning. That terrifies the living daylights out of me because when Charley turns 18 we will be left with no service option other than the ADHC services. We first started dealing with ADHC about 15 years ago when Charley was diagnosed. When Charley was about two or three years old he needed no more than two or three hours of sleep a day so we were exhausted. Even though he was a baby we needed some respite.

We had a caseworker who referred us to one of the ADHC respite houses for children. I think I left Charley there two or three times and I felt guilty each time I left him. I never saw the same person twice. I dropped him off with complete strangers and I picked him up from complete strangers. I think the last time I took him my older child, who must have been seven at the time, looked at me and said, "Don't leave Char there, Mum. Don't leave him. Go back and get him." I cannot remember a lot from those years and I cannot remember whether I did go back and get him. However, I know that we did not use that service again.

After that we discovered St Anthony's Family Care, which was run by St Anthony's Church in Croydon. That was a totally different thing. We would drop Charley off at the weekend with Joy, who I will never forget. When we picked him up we would pick him up from Joy. She would communicate how his weekend had been. It was a personal service. I knew he was in good care and we enjoyed the respite. Once again we had to learn to use respite. St Anthony's operated on the same sort of timescale as the ADHC service—about two days or two nights every six weeks. In the beginning we would finish the two days of respite feeling hollow, depressed and usually fighting. What we were trying to do was to cram six weeks of normal family fun and relaxation into two days, and obviously that cannot be done.

Eventually we learned that respite was just breathing space and that we could not expect anything to change. At the end of it everything would go back to normal and it was only a bit of breathing space. We also started to access Sunnyfield, a non-government organisation funded by ADHC. It operated on the same sort of roster system as ADHC so I never saw the same person twice. I guess I had a little more confidence in this service because I had a lot of confidence in the coordinator. I knew that she was overseeing the service, so at least that was a face that I trusted and with which I felt comfortable, even though I knew she was not always present. That service allowed us to save up the two days every six weeks so that we got four days every school holidays, which was a lot more useful. We were then able to have some normal family holiday time with our other children.

Once again, the rotation of staff meant that nobody really knew Charley. On one occasion when I picked him up he was not wearing a nappy. Obviously, whoever was caring for Charley knew him so little that he or she did not even realise Charley was incontinent. What else did they not know about him? When Charley turned 10 he went to Kingsdene special school where he boards from Monday to Friday. I think that was lifesaving for our family because it was real respite time that we could use to plan and to get ahead. Charley loved it. The carer system that they have there is one carer per family group of three or four, and that person knows the children inside out. Obviously she is not on duty 24 hours a day, but she is the one who is spoken to about Charley. When there is any concern with Charley she is the one to go to.

Charley is coming up to the age of 18, which means we will be back in the ADHC system. We already have a caseworker. In fact, in the past three months we have already had three caseworkers, and that is fairly typical. The caseworkers seem to play musical chairs there. There seems to be low morale within the system. My concern for the long term is that there does not seem to be any forward planning or any idea of seeing a need and trying to prevent a crisis. I have heard that most of ADHC's money is pooled in the Crisis Response Fund, which I think says a lot. In the future we will require supported accommodation. I have not bothered putting Charley's name on the list because I know that the list is never referred to.

Referring to the case we heard about earlier, I would not be surprised if the newcomer to the house was what parents call a Department of Community Services dump. We all know that the only way to get a supported accommodation place is to keep going until you cannot possibly go any longer and then to leave your child—they are all children, no matter how old they are—at respite. ADHC is responding to this. It is building policy and procedure around it. It now offers parents counselling because they know it is traumatic to leave your most vulnerable child at respite.

Until just recently leaving your child on respite meant declaring them homeless. ADHC have changed that now because they realise that it is actually easier for them to have the parents on side so that the parents are still the ones mainly responsible for their child. They offer the parents counselling. You no longer have to declare your child homeless. Is this now the official way in? Policy and procedure is being built around it. My concern is that the need for supported accommodation is only going to get worse and while ADHC continue to just resist any sort of forward planning, pooling all their money into crisis response rather than crisis prevention I cannot see the situation getting any better.

JOSEPH HARRISON: Thank you for seeing me today. I have provided a personal submission as a person with disability who has had the good fortune to work in the disability sector since 1980, after years in rehabilitation due to my disability. That included 11 years with ADHC, only nine months of which was served in head office. I currently work for NSW Health. I would like to raise the following matters that may inform this review. Possibly my complaints are far more academic than the very emotive complaints of a lot of people you will be hearing from today.

My major concern is ADHC's definition of disability. While it is consistent with a lot of definitions in State and Commonwealth legislation, it is seen by many in the disability sector as an anachronism. It defines people in terms of impairment. From my view, that has had a negative impact on its policy direction and outlook of ADHC. Before I go further I should clarify my distinction between impairment and disability. I developed idiopathic epilepsy and asthma following a traumatic birth. I see epilepsy and asthma as impairments. I cannot run and I cannot drive both of which I see as handicaps. I often apply for clerical jobs. The advertisement requires a driver's licence even though no driving is involved in the role. I remember interview when a panellist told me that I could not meet the criteria because I could not write or think clearly because I have epilepsy. I see the assumptions underpinning the advertisement and the panellist's assertion disabling.

Some maintain that disability is a form of social apartheid—a set of barriers restricting equal access to participation. Nelson Mandela once stated that he was disabled by apartheid. It is therefore not surprising that South Africa was among the first nations of the world to adopt a social model of disability for all its disability policy—New Zealand has followed as well as a number of other countries—with the main focus on the elimination of barriers. It is not by chance that the logo of International Year of Disable Persons in 1981 was Break Down the Barriers. Yet, even then, when the term people with disabilities was still acceptable and in vogue, New South Wales addressed the United Nations year with a lead agency called the Handicapped Persons Bureau and funded its first State disability peak which was The Union of Handicapped Persons.

The union has metamorphosed to become People with Disability Australia. The new National Disability Strategy FaHCSIA has decided to celebrate International Day of People with Disability. Everybody is acknowledging that disability is a matter of social economic barriers, but ADHC has failed to keep up with the change, failed to address barriers to equal participation being instead focused on impairments. At the beginning of 1981 I was a policy officer with the Handicapped Persons Bureau. At that time it was argued that issues related to people with acquired brain injury were the responsibility of NSW Health. Last year ADHC took up the reins as the lead agency addressing people with acquired brain injury. For ADHC it is seen as a new client group. It has not yet accepted responsibility for issues relating to people with psychiatric disability as it fails to distinguish between mental illness and psychiatric disability. It is necessary to make that distinction if one government department is to be given the role of addressing disability—the creation of economic and social barriers to full community participation.

I think that attitude has some internal impact on ADHC. The failure to change its focus has an impact on ADHC staff and their capacity to determine clearly the direction the department should be looking. I noted in my earlier submission to the inquiry that I know of one ADHC staff in a senior position who still refers to people with intellectual disability as "morons", arguing this is an acceptable medical diagnosis . That person was originally from a rural agency but was working in head office in a senior role when we met in 2000. None within ADHC thought to address the matters as "she is entitled to her private beliefs" is the argument that I often heard. However, as a representative of ADHC addressing people with disability and their families and carers, and the non-government sector, her attitude has caused some disquiet and concern.

The issue is broader than the peculiarities of a single staff member. I have known five ADHC staff with disability and I count them among my friends. It is significant as that each of those at some time has complained about some for discriminatory treatment by ADHC or ADHC's failure to address the special needs of their disability. It is interesting too that those five people equate with the majority of staff with disability ever employed by ADHC. So for the organisation that is aiming at addressing issues of people with disability, there are very few staff that actually identify as people with disability. It is almost arguable that if you have got a disability you can apply for jobs in other government departments but do not try ADHC.

One of my friends with disability applied for a position in an ADHC regional office some years ago and was called for an interview. As far as I know ADHC no longer uses the premises of that regional office. It was accessible via a large staircase at the front with level access at the rear. My friend could not walk for more than 100 metres without a rest. She was not asked about the need for level access when she showed up for a job interview. She climbed the stairs to her detriment. She could not breathe during the interview. There was no indication at the front of the building that there was access from the rear. The question arises as to why no-one thought that the premises were inappropriate to house the department which is supposed to be addressing the needs of people with disability.

It also has an impact on services. ADHC claims it has a client-centred focus in the provision of services. From what the Committee has heard today from very emotive things that is clearly not the case. The claim is not always matched by a review of services provision. Services are still determined by the provider. I can report many difficulties with ADHC services from speaking to ADHC clients socially or, from the past, as a professional advocate or rehabilitation manager as its counsellor. From my own experience I can report the following: When asked to supply a ramp to my partner's house, the Home Modifications Service provided a lift and said a ramp was inappropriate. It has meant we pay for annual maintenance and continue to call for assistance when the lift breaks down; Most of our friends use wheelchairs and those in larger electric chairs cannot use the lift as it is not accessible. The house remains inaccessible to them. Luckily my partner is in a very small chair. The Home Modifications Service provided a portable ramp for my partner to get from the house to the backyard because there was a step. She cannot use the ramp unassisted and a ramp I do not need to help her down a step. Our bathroom has been modified to suit my partner's disability. However, I have to bend to see in the mirror to have a shave. It has been modified for her and not for us. [*Time expired.*]

CHAIR: We will have to close here. Your full statement can be recorded in *Hansard.* Obviously we will scrutinise it for any adverse comments, which we do not expect to find.

We paid additional money to have the bathroom modified the way we wanted it - yet a smaller mirror and the decision to tile only part of the floor were done to save costs - not meet our needs; My partner and two of our friends needed specific modifications to addressed their individual needs which were different to modifications suggested under Australian Standards. An OT was called in each case to verify their need rather than obey the standard although, in each case, meeting the standard would have meant the modified equipment was of no use to them. When needing assistance to get to and from bed my close friend was at the mercy of the timetable imposed by the availability of HACC staff, even when it meant rising at noon or being in bed before 4.30pm.

It is my contention that ADHC sees its role as addressing the tragedy of disability. People needing assistance are seen as a burden on the public purse, not people denied the same right as other citizens to participate. Its service delivery suggests this as does the attitude of many of its staff. ADHC's new responsibility, for services to Carers, reflects this view. From my view it has abrogated its responsibility to ensure participation and reinforced the view that people with disability are a burden on family.
Thank you for listening to ·me. I hope it has been worthwhile.

JANICE MARSHALL: My name is Janice Marshall and I am the mother of Daniel, my 22-year-old son, who has autism, suffers from extreme anxiety, has bizarre behaviours, is very destructive and has an intellectual disability. He lives at home with us. I would like to address one of the most critical problems facing ADHC, that is, the acute shortage of supported accommodation for our adult children with disabilities. Access continues to be by crisis only. ADHC has no future planning process or transition strategy to help relieve the pressure from families hanging on by their finger tips. Parents have to die, be seriously ill or abandon their loved one to even get into the system. This crisis driven scheme causes widespread mental and physical illness within the families and often leads to family breakdowns, which ends up costing the State and ADHC even more money than if they actually funded the accommodation in the first place.

If a large number of families abandoned their loved ones simultaneously, which is pending, it would be catastrophic for families and services and ADHC would be swamped. We have already had so many inquiries, reports, service provider, conferences, et cetera, into disability services that I am sure that you really do not need to hear anymore. But in summary, the "Shut Out" Report 2009 summed it up by saying that the disability industry is "irretrievably broken, chronically underfunded and under resourced, crisis driven and struggling against a vast tide of unmet need". For a first world country like Australia, this is a disgrace. We do not need more inquiries, we need the money spent on services.

Funding: Since the decision to close large institutions some 15-20 years ago, funding for supported accommodation has been very small and fallen well short of demand for places. Minister Della Bosca had the courage and vision to put $1.3 billion into Stronger Together one in 2006. He was able to admit there was a crisis in disability services. Despite this, Stronger Together one failed to address the issue of lack of future planning for supported accommodation and the total crisis and misery of families. On 25 September 2010 on the Quentin Dempster's television program Premier Keneally said "I don't shirk from doing tough things" yet we are still waiting for her—a former Minister for disabilities— to fund Stronger Together two which will go from 2011-2016. Kevin Rudd pledged $100 million for accommodation in 2007, thanks to an emotional plea by Catherine Murray, but the States seem to have "lost" it somewhere!

ADHC has kept no waiting list to gauge unmet need, although a register of future need has recently been introduced after much lobbying. This is, however, not well publicised hence the data is probably not very useful. The Sutherland Shire Disability Accommodation Action Group has offered to help ADHC do a study of unmet need in the Sutherland shire as a proxy for the rest of the State. The group's data suggests that the number requiring accommodation right now may not be as great as ADHC fears. So far ADHC has not responded. However the backlog grows each and every year.

Compliance with standards: Our crisis driven system clearly does not comply with the Disability Services Act 1993 and the standards, which require government to make sure the rights of people who have a disability are upheld. This includes "to reach their potential" and "to choose the way they want to live their lives". Nor does the system comply with the United Nations Convention on the Rights of Persons with Disabilities, ratified by Australia in 2008.

Solutions: For years, families and organisations have been suggesting solutions to the problem, so far to no avail. It is not all about money, although that would be helpful. It is also about thinking smarter and partnering with families, community groups and organisations to take full advantage of informal supports which are available, not just paid services. But this does mean there is no one-size-fits-all solution, but a plethora of options, tailor made to each person and family. Traditionally this has not been popular in bureaucratic government departments, despite the recent trend of using the term "person-centred" planning. Clearly the traditional model of the group home costing $150,000 per annum, for each person is not a solution to the growing problem, nor is it a desirable option for many families. Although ADHC has issued literature with a range of innovative options for supported accommodation, these options are not a reality as there is no funding or planning available for them.

Solution 1—Future Planning: Families should have the right to future planning for an organised and timely transition for their loved one into an appropriate accommodation setting, with quality services and a degree of family control, at a time when family still has the health and energy to do this. This will relieve families of a burden of stress, improve their mental and physical health, encourage them to be greater partners in the process, and reduce total costs.

Solution 2: Individualised funding packages would allow families to be involved in deciding on how their loved one will be best accommodated. They are the people who best know and understand the person with a disability and should help choose appropriate service providers, or change providers if the service quality is not good enough. This will act to improve the overall quality of the whole industry, which is certainly required. Families have extreme concerns currently over the quality and training of many care staff. A suggestion would be to have an independent, non-ADHC funded organisation to oversee the quality of the care services—that is, not someone who is funded by ADHC.

In the event of a planned, timely transition to accommodation, families would also be able to play a role in the ongoing care at least initially, thereby reducing costs to government. Individualise funding packages also should make clear organisations, as well as ADHC itself, more accountable, force them to review their administration and bureaucracy costs and, hopefully, sharpen their pencils. The maximum possible funding should be spent on on-the-ground care services, not tier after tier of administration.

Solution 3: Shared equity—following from the previous two solutions of individualised funding and planning, the issue of shared equity between families and ADHC needs to be addressed. Many families may be prepared to provide equity in some form to their loved one's accommodation solution, either in the form of a physical home, funding contribution or informal supports to help in the day-to-day care by means of friends, family or community members, if ADHC would be more flexible and allow families more control over the type and quality of care. This would all reduce cost to ADHC and spread funding over more families.

Once the shared equity dilemma is solved, some of ADHC's innovative solutions to accommodation could be introduced, such as villa or townhouse complexes for up to, say, 10 people. This could be more cost effective. This and many other models have been proposed but have not been accepted by ADHC. In closing, I beseech the members of the Committee to push the crisis in supported accommodation to the top of ADHC's and government's agendas. Unless you have walked in the shoes of our families you cannot possibly know the anguish and stress under which we all live every day, where there is no hope and no planning for the future.

I come from a privileged background of having had a university education and a successful business career in the investment industry but nothing—nothing—prepares you for the stress and trauma of living with autism every day for 22 years. It has taken a mighty toll on our family. My husband was diagnosed with Parkinson's disease four years ago at the age of 51—an illness which, if not caused by stress, certainly is made much worse by ongoing stress. Our 20-year-old daughter suffers from an anxiety disorder, which has certainly been made worse by our son and which has almost claimed her life.

After years and years of therapy with us, our son, Daniel, also would like to live away from us. He has had enough of us. There are families worse than us, and one family in our group has relinquished care only this week, with all the emotional trauma and guilt which comes with it.

CHAIR: Thank you. Your whole statement will be transcribed into *Hansard*.

Ms MARSHALL: That is good.

It is heart breaking. At the very least there needs to be a future planning process to support families to cope and one day maybe even get a life back

In summary—what is required:

- long term planning individual funding
- quality services which need to be monitored by external organizations
- genuine "person centred planning"
- access to supported accommodation by other means than via CRISIS

Janice Marshall.

CHAIR: You have given us a lot of food for thought.

Ms MARSHALL: Good.

CHAIR: There are some interesting ideas therefore recommendations, which may well be taken up. We will pause to make transitional arrangements and change over. Thank you, Ms Deb Robertson and Ms Jacki Duffy, for being with us.

DEBBIE ROBERTSON: Good morning. My name is Debbie Robertson. I live with my husband, Brent, and three sons. Our son, Brett, has fragile legs and a severe intellectual disability. I am probably going to be a little bit more brief than everybody else because I do not want to rehash. It is pretty obvious that we have all got the same issues. There seem to be deep-rooted cultural and systemic issues, and there does not seem to be any accountability by ADHC.

Anyway, our son Brett: We have had several attempts over the years to access ADHC respite. However, there was never a suitable place for him where he would be kept safe. No service met Brett's needs in terms of him absconding. At one stage Brett absconded and was found at 3.00 a.m. wandering the streets. He has no concept of safety, or indeed road safety, so it was decided that we would, in Brett's best interests, forgo respite. One of the facilities was akin to a Dickensian institution and I felt enormous guilt sending Brett there anyway. This has meant that we have been unable to have much-needed breaks away from the caring role, and this has taken an enormous toll on our health as individuals and as a family. At present, we receive five hours a month in home respite, and that is as far as the respite goes.

At the moment we are in the process: it seems after 20-odd years—Brett is now 29 years old—that we might hopefully have found a respite unit, which is in Blacktown, that is suitable for Brett. But we are in the process now of just going through getting him eased into being away from home. He is now 29 and, because of unsuitable respite, he is not accustomed to being away from home. In relation to the day program, Brett finished school in the year that the State Government reduced the age of leaving from 21 to 18. Brett was offered three hours per week at a day program. Already struggling without respite, we were concerned about our ability to continue caring for our son, Brett, without any break at all. After much exhausting battling for increased hours, Brett was finally given a day program five days a week. I objected to the fact that I had to more or less say that, if we did not get any more than the three hours, we would have to relinquish caring for our son. Why should any parent have to do that? Anyway, these services should be available to all school leavers with a severe disability, or to anyone.

As far as transport issues go, at one stage I was transporting another young woman with a disability to and from her respite and day program, as her mother did not own a vehicle. Because no transport was provided, she would not have able to get to and from respite and to the program, so she would have had nothing. She would have missed out on her program. The lack of transport creates increased hardship for many families, particularly those who do not have, and cannot afford, a vehicle.

In relation to paperwork and constant repetitive questions that need to be answered in order to access ADHC's services, that has caused us and, I am sure, many others great frustration and stress. I spoke to another mother recently who said that she felt traumatised by having to relive difficult experiences over and over again. There absolutely needs to be an acknowledgement of how much burden is placed onto already exhausted carers by asking them to repeat the same processes over and over. Is this not what caseworkers are supposed to be for?

The caseworker service has been fraught with stress and frustration—it is more trouble than it is worth. Over the years we have had constant problems trying to contact our caseworker. We leave messages. It is probably a week or two later they get back to you, if they do at all. Why are they there? Why are caseworkers there? They are there, supposedly, to help us and to be in constant contact and to let us know what is going on, yet none of this seems to have happened—or, it has not happened for us. We have better contact with the respite unit that Brett is now accessing than we have to our caseworker. We have seen her once or twice. With the respite unit, we speak on the phone all the time. If there is any problems, I do not go to the caseworker anymore because we just never get any feedback, or they never come or ring us back. I just ring straight through to the respite unit. The caseworker service needs close examination and important questions need to be asked, such as: Do caseworkers cause more harm than good?

I think there should be full support for the National Disability Insurance Scheme [NDIS]. I think ADHC needs to abide by the United Nations Commission on Human Rights. As parents, if we treated our loved ones in the same manner—because in some cases it is abuse—we would be sent to jail, and rightly so. Why does it keep happening and nothing is done? Is today going to be just another talkfest? Are we just going to bare everything and lay it on the table, and nothing will be done again? Our son is 29. This has happened for the last 26 years, and it is not just myself as a carer; it is our family, our sons, all our relatives, everyone, friends. It just cannot go on. Are there any ADHC representatives here today, I would like to ask? If not, why not? Is that how little they think of our circumstances?

CHAIR: The Department of Ageing, Disability and Home Care has given evidence to the Committee. We are taking your statement today.

Ms ROBERTSON: I just hope today that something does improve. As a parent and a carer I do not feel that I should want my son to pass away before I do because of lack of services. Why should I? I know there are a lot of other parents and carers who feel the same way. Why should we?

CHAIR: Thank you very much. We appreciate your statement.

Ms JACKI DUFFY: Thank you for giving me the opportunity to speak with regards to services provided and funded by New South Wales Ageing, Disability and Home Care. I am here today because I am the partner of a person with a spinal cord injury at C5 level which renders him a quadriplegic. I would like to talk about the issues that my partner and I have experienced setting up home care recently. We have moved back to Australia from Canada on July 4 of this year. Before moving, with the assistance of Dan's parents who are living in Australia, we attempted to contact and set up home care. It was unclear as to which department ran what agency. We found this process initially very difficult. Through many phone calls we were directed to and contacted ADHC with regards to setting up care for when we arrived. We were told that they would not send out any paperwork until we were in the country and we needed to meet with them to assess the specific needs. This requirement is unacceptable because the paperwork and assessment take time, leaving my partner without care when we initially arrived in this country.

We were able, however, to get respite organised for a three-week interim period. Respite said that they could promise us an hour a day. My partner's care involves close to five hours per day seven days a week. Three of these hours are involved with bowel care, which when we attempted to try to get more hours we were told that we would have to suck it up and do it ourselves. As the man who spoke earlier regarding the relationship with his spouse, that does not constitute a very good marriage when you are dealing with faecal issues with your spouse. Due to guidelines set up by respite, I feel this is a big service gap with regards to people relocating from overseas or even from another State. I know that we are probably a very small number of people in this situation. However, I feel that this issue needs to be addressed so that people with special circumstances can be allotted an appropriate amount of care time that best suits their individual needs.

I feel that government agencies, ADHC included, lack interdepartmental communication and cooperation to provide an integrated approach to providing client care. Dan had to go into hospital. When he was ready to be discharged we learnt that respite care was no longer available. The hospital discharge planners, nurses and social work department said that he would have to go into a long-term aged care facility until the money was allocated from ADHC to set up home care. Dan has been out of hospital mentally well. Putting him into a long-term aged facility would not constitute a proper mental wellbeing. It would actually regress the situation, since he has been out of hospital since 1 April 2009. At that point we were told that we should have filled out the paperwork before returning to Australia. It is just a kind of nasty circle. We were left once again frustrated and with this unacceptable, inadequate access to alternative care arrangements, with inaccurate information, lack of funding and cooperation between agencies. I feel that with more funding and an integrated approach, the respite and other government health agencies involved would be able to provide relief support for a number of people that need it in the community, as well as for special circumstances that may arise.

On a home care front, I feel government-funded home care agencies suffer from a lack of adequate funding and integration of services, affecting the quality of care they are able to provide. It is apparent to me that the quality of care that is being provided by home care agencies is lacking because there is not enough money being allocated to care agencies to provide the service. For example, one night we received a phone call from our home care agency informing us that Dan would not be receiving care the next day because 80 per cent of their staff had called in saying they would not be showing up for work. This unreliability is a major problem for the service, which is necessary for people who are unable to help themselves.

It was stated many times by different home care workers that they did not feel comfortable with the level of training on the job. We had a home care agent perform a bowel routine who was not trained in the procedure and tore my partner's bowel wall. I believe that due to lack of funding these agencies are unable to train and send out qualified people to do a successful job. They then cause further complications. It seems the duty of care in some of these home care agencies is also inadequate. We had an RN administering pre-poured medication for the incorrect day. If it was not for my partner's interjection to the RN's actions, he would have been given the wrong day's pills. When he addressed her on this issue, she replied that it did not matter and that she was not supposed to be there anyway. If more money is allocated to these agencies I feel that situations like this could be avoided due to properly trained staff who are not overworked and who are happy and willing to perform this very important job. Appropriate funding would prevent overworking of an entire agency and offer better care to clients.

As a side note on transportation, we live in a population pocket on the Central Coast which leaves us relatively isolated due to a lack of public transportation. There are very few accessible buses. The train stations are not fully accessible, as at some stations there is a ramp only on one side. So we can get on but we are unable to get off. We have to travel 20 minutes more down the line, then get back on the train to come back to where we live. As a young couple we like to go out and do things. That has put a little rift in us getting out and being a normal couple. In conclusion, it is our hope that this Committee can make recommendations to improve the quality of services available to citizens in home care, transportation and other accessibility requirements. Thank you.

CHAIR: Thank you.

Mr BARRIE STYLES: Firstly, I would like to convey my thanks and appreciation to the inquiry for giving me the opportunity to have my say about the impact of DADHC on home and community services in New South Wales. I will focus mainly on social support streams services, as this is the area where I have most direct experience. My general theme is that against a background of increasing need with a rapidly ageing population and people with disabilities surviving to adulthood, the Department of Ageing, Disability and Home Care have missed the opportunity of consulting widely with services on the ground to see what works and what does not. They have implemented a reporting system that is time-consuming and does not allow services to indicate the specific services they deliver and they have not developed a process whereby service outcomes can be gauged. They have also implemented a funded process, competitive tendering, which favours regional funding and, hence, large organisations to the detriment of small, stand-alone services, like the one I manage.

The first issue and concern, the Neighbour Aid and Social Support Association of New South Wales Inc. [NASSA] is the unfunded peak body for neighbour aid and social support services in New South Wales. I became a member in 1999. They are an excellent peak body and I learnt a lot through attending their annual State conferences. In 2007 I was elected onto the NASSA State executive committee, a position I held until my resignation last year. While on the committee I drafted a position paper on the social support stream, which made many recommendations to DADHC regarding the way forward for social support services. This paper was presented to the department during their triennial planning consultations, signed by all the then NASSA State executive members. Apart from an acknowledgement that they had received the document, we received no further communication or follow-up, which I believe was a missed opportunity for the department to consult more fully and to form a stronger partnership with this statewide peak body.

Two, because NASSA is self-funding, State executive members run their own social support services and volunteer their time on the committee. This makes maintaining the peak body extremely difficult. DADHC does provide piecemeal support for this body. But considering that NASSA represents over 100 services around New South Wales, the support has been paltry. They have virtually left the peak body to flounder and, once again, have missed an opportunity to strengthen the New South Wales social support peak body and subsequent flow-on benefits to individuals social support services.

Three, DADHC have placed a huge administration impost on HACC service providers over the last 10 years, that is, minimum data set [MDS], OH&S requirements, validation, self-assessment, et cetera. This load has fallen most heavily on part-time stand-alone services with one paid worker, like myself, and has resulted in allocation of time away from direct service provision to meet these requirements, which means that the clients lose out. Conversely, the larger non-government organisations and the multiservice outlets, et cetera, have sufficient staff to meet funding requirements without impacting on direct service delivery. This is an inequitable situation.

Four, the Home and Community Care [HACC] reform agenda, the minimum data set [MDS] is outputs focused and the HACC service streams have been siloed. This means that services can only report service hours and these must be reported under their service stream, that is, mere social support. As social support is defined as "accompanied activity", it can include a myriad of different supports, that is, transport support, shopping support, et cetera. However, this information is lost, as everything must be reported as social support. Currently, there is no mechanism that allows HACC services to inform the funding body of the variety of services they may provide or qualitative benefits that may accrue to the services they provide. If an outcomes focus could be included in the MDS this would allow the department more opportunity to better assess the benefits and cost savings generated by the service provided.

Five, basing funding on outputs implemented by DADHC as part of their reform agenda has forced social support services to focus on group activities to basically make up their outputs and maintain their funding. That is all well and good and it shows there is a definite need for group activities. However, it has also led to a decrease in one-on-one volunteer-based social support. This adversely affects those clients either not interested in group activities or too frail to participate in group activities. It also means that there is a growing service gap for those clients desiring one-on-one social support from a fellow community member, that is, volunteer.

Six, I am extremely critical of the current funding process, as it appears to disadvantage small stand-alone and often part-time services. In my case, I inherited, I got into the job of a small part-time social support/neighbour aid service funded for 28 hours a week. I had 21 clients and 19 volunteers when I started in 1999 and I generated 2,000 outputs per annum. My funding in 1999 was approximately $53,000. After managing the service for 11 years, I now have 40 clients and 40 volunteers delivering 4,000 outputs per annum, and the program now receives approximately $63,000 funding. After 11 years in the job, my wage component represents 78 per cent of the total funding, which, if you include on-costs, which account for 16 per cent of my funding, leaves only 6 per cent of funding to run the program. As a result, I am desperately cutting my program costs in order to continue to reimburse my volunteer expenses.

This is not satisfactory, especially if you consider that $1 million of social support funding has gone into my region—that is the Sydney inner west—in the last two years and that my catchment area in the region, which is the Leichhardt local government area, represents a seventh of the region's population. I believe that DADHC's adherence to the competitive tendering model and focus on regional service provision has disadvantaged small stand-alone, part-time services that do not have the resources to tender for regional funding.

To sum up, DADHC has been too busy covering their own liability and growing themselves to provide support to the small players in the system. They have not genuinely consulted with existing services and their peaks before implementing their reform agenda. By ignoring the work of the unique volunteer-based social support stream in New South Wales, delivered by countless small neighbour aid services, already operating a client-centred approach, they have thrown the baby out with the bath water and lost a lot of flexibility in service delivery. Social support funding is now thrown at large charity-based organisations, where it is swallowed up and delivered by paid workers who love the opportunity to have a chat and gossip with their existing clients.

Real community-based social support delivered by a volunteer one-on-one with a client is a very different service. It is enduring, providing service continuity, and links are maintained with the volunteer even when the client moves out of area or into a residential setting, and vice versa. It represents the community giving back to the less able members, which means building stronger communities. Finally, it links the client to the local community directly and uses social solidarity to deliver the service at minimal cost. While I have a few seconds I will mention problems with Commonwealth-funded packages.

Recently, a 98-year-old client of mine was assessed to receive an EACH package to assist her to remain in the home. That is a high-needs package. When she informed them that she had a private cleaner and a social support volunteer, they told her that she would have to get rid of these people before her service could commence. As, firstly, she has had those cleaners for the past 12 years and they provide additional assistance like making the bed and, secondly, she has had the volunteer for five years and he took her to the shops weekly, watered her plants, helped her purchase a new microwave, et cetera, she told them that she did not want the package.

As her service manager, I referred her to community transport for eye appointments and placed two additional volunteers with her, one to take her to the hairdressers fortnightly and the other to visit weekly, make a sandwich and help her make her bed fortnightly. The client continues to maintain her independence living alone in the community setting and is very happy with the services she is currently receiving.

CAROLYN MASON: First, I thank the Committee for affording me this opportunity to speak to you today. The experiences and treatment of my daughter, Amy, and our family have been outlined in an extensive submission to the Committee. I believe it highlights how the disabilities system in this State is totally failing to protect the rights of people with disabilities. It fails to properly protect the rights of freedom from abuse and from the incompetent and poorly managed service providers who do not fully comply with New South Wales disability service standards. It also fails to protect their rights by removing families from being the most continuing, enduring decision-maker for the person with a disability.

Segregation, isolation and marginalisation are the three most damning things in the life of a person with a disability, yet DADHC uses this as a stick. DADHC's policy in regard to taking families to the Guardianship Tribunal, particularly if there is conflict between families and service providers, where families are treated as nothing more than a hindrance, in my view is outrageous. DADHC took our family to the Guardianship Tribunal in an effort to discredit me as a fit and responsible person in a legal forum, based mostly on hearsay untruths and unsubstantiated evidence, including the fabricated lies of a group home manager from where my daughter, Amy, once resided. She was employed and poorly managed by a DADHC-funded service provider.

Fortunately, I was in the position where I was able to contest the application and prepare a thorough brief of evidence, which resulted in DADHC's application for guardianship, financial control and restricted access being dismissed by the tribunal. Had I not been successful, our daughter would have been placed into the care of an abuser, and her freedom and personality taken away, restricted practices placed upon her and any real quality of life destroyed. I fear for families in similar situations who are not able to defend themselves against such fabrications or to prove their innocence and contest DADHC's application. The Guardianship Tribunal receives funding from the very department that brings cases before them. This is a legal forum where families can be refused to have legal representation and where evidence of the rule of law does not seem to apply.

I hope that no other families will be treated so inhumanely and put through the same fear, trauma, stress and sleepless nights that I have endured, not knowing whether or not I would be purposely removed from my daughter's life. Why? Because I dared to speak out in an effort to protect my daughter from a system that was failing her. I believe there is an urgent need for greater accountability to be extracted from all service providers, and in particular the non-government sector. Increased regulation and improved monitoring, as well as unified standards, policies and procedures and a comprehensive accreditation system, should be developed for all accommodation and respite services.

It is a real worry when many new entrants into the sector receive the lion's share of tenders, with precious little required proof of past experience in providing services to vulnerable people. DADHC's current policy and procedures and mechanism for complaint handling and grievances are totally flawed. It is of major concern that DADHC does not have the power to directly investigate the very services it chooses to fund. Both DADHC and non-government service providers are allowed to conduct their own internal investigations. Complaints can be directed to the New South Wales Ombudsman, who does not appear to have the legislative power, funding or resources to conduct a thorough police-style investigation into serious issues such as breaches of the New South Wales disability service standards, the use of restricted practices and non-compliance with practices, procedures and guidelines which govern these issues.

There is very little accountability extracted and little action of any real consequence when there are breaches of legislated imperatives. This appears to be the very case with my daughter's former accommodation provider, who failed to properly manage and train staff or conduct any investigation into the reports of inappropriate, unprofessional behaviours of the house manager. Even after two investigations and a review conducted, at my request, by the New South Wales Ombudsman, the house manager was still not investigated by the organisation and the New South Wales Ombudsman—I quote from a review report—"does not have the authority to look at funding services or industrial issues such as which staff the service provider decides to employ or keep at a particular residence". Their role is to review and make recommendations only.

Because no action or investigation was conducted, the house manager was effectively allowed to continue, and in fact went on to abuse other residents. If this lack of investigation is allowed to continue, then I fear that group homes will become a haven for abusers and paedophiles alike. We are a society very concerned about human rights violations in other countries, yet the human rights of our citizens with disabilities and those of their siblings and families, are breached every single day and no-one seems to notice. I find it alarming that it should take two complaints and then a further review, at my request, from the Ombudsman before the service provider admitted that there were even any concerns in the way they supported my daughter, Amy.

Only after these complaints were they finally forced to take such steps as a written consent from the person responsible for all prescribed medication and compulsory training and induction of staff in policies and procedures on a regular basis, et cetera. Surely a service of this size, that is receiving such an immense amount of DADHC funding and is expanding its services in a few short years and at an alarming rate throughout the country, should have these vital imperative policies and procedures in place. Even after reassurance was given, nothing changed at the residence until yet another complaint was made to the Ombudsman, again about the abuse of another resident. The organisation was still allowed to conduct its own internal investigation. I believe as a result of this the house manager's services were terminated.

Who, then, do we turn to for better protection and safeguards from abuse of people living in supported accommodation? Often police checks on staff are only made once at the time the staff first begin employment with a service. I believe this highlights the need for a new system of investigation. Perhaps an independent arbitrator with legislative powers to investigate and conduct a more professional police-style investigation such as interviewing witnesses, staff and residents. At the moment there appears to be no more than a little of he said, she said desktop investigation.

My personal experience in dealing with DADHC staff allows me to formally state I found them to be totally unprofessional in their contact and dealings with me. They were totally biased against me and my family, colluded and conspired together with staff of the service provider, and also in my opinion had a close and too familiar relationship with our advocate from one of this country's leading advocacy groups for people with disabilities who are supposed to act independently. I found this advocacy service to be completely incompetent, lacking transparency and scepticism. This is surely a key attribute to any advocate. They showed little regard to the several national disability advocacy standards, such as decision-making choice and meeting individual needs and seeking to minimise conflicts of interest. I was made to feel an enemy of DADHC staff.

I found their dealings with me at the countless meetings I attended more than not always ended up with no result or yardage being gained, with any benefit to assist my daughter to acquire a better quality of life. There was a feeling of intimidation against me, with little regard for our family's wish to advocate and participate in our daughter's life. I believe there should be a complete review into the service provision of every Lifestyle Solutions house to ensure that they are acting within the Disability Services Act. I trust the Committee will make recommendations to address the issues that I have outlined.

GREG KILLEEN: I have probably got more than eight minutes worth written down so I will table my submission for Hansard and maybe get to the appropriate points.

CHAIR: Consider your statement tabled.

Document tabled.

MR KILLEEN: I would like to thank the Committee for providing another opportunity to raise issues and provide suggestions for the Committee's consideration for this extremely important and timely inquiry. My presentation will include information from a personal perspective that was gained through working in the disability sector for many years and my role as a consumer representative on a number of disability, health and community service committees. Firstly, disability, regardless of whether it be acquired by genetics, a disease or trauma, may be the common link for people with disability. But we are all individuals who would like have a good life which may only be achieved with access to, and support from, a choice of appropriately funded and coordinated disability specific or community services and programs, and the option of individualised funding to enable us to have some autonomy and control over the services we require.

To put my presentation in perspective, I will provide the Committee with some of my background. I acquired a spinal cord injury resulting in quadriplegia many years ago—30 plus years now—when there was no government provided or funded personal care support services to support people with disability to live in the community. There was also no wheelchair accessible public transport and related transport infrastructure, no wheelchair accessible taxis, limited access to local shops and public or commercial buildings and there were not even curb ramps in footpaths to simply cross the road. Without the initial and ongoing dedication and support of my family, I would probably have ended up in a geriatric nursing home, and honestly believe I would not be around today to present to this inquiry.

But since acquiring a disability I have witnessed and experienced the benefits from the increasing number of government provided or funded disability and community support services, non-government organisation services and programs, accessible public transport and related transport infrastructure, wheelchair accessible taxis—although currently there are some vehicle design and access issues—increasing access to buildings, facilities and the built environment, access to education and employment programs as well as equipment and assistive technology services, to name a few.

Around 1987, I gained access to the New South Wales Home Care Personal Care Support Service which had a positive profound impact on my life and that of my family's. I am greatly appreciative of this service and other government-provided or funded services and programs and it is why I have devoted a lot of my time advocating for governments to fund these essential services and programs to meet the needs of people with disability, their families and carers. As the Committee would be aware from the inquiry submissions, gaining access to and using the various services and programs provided by Ageing, Disability and Home Care is not always without problems. There are individual and systemic issues of various degrees associated with service delivery, administration, reporting and accountability, funding, client and employee satisfaction, unmet need and long waiting lists to name a few.

Although a large number of extremely important issues need to be addressed I would like to focus on specific areas including the urgent need for an out-of-hours emergency service provided for the home care service throughout New South Wales; appropriate funding and standards for the Home Modification and Maintenance Scheme; and the need for government-funded services and programs to coordinate with a whole-of-government approach that will improve service delivery and save money. With regard to the out-of-hours service, although ADHC requires the service to fund a 24-hour backup service in case there is a breakdown in the service delivery, ADHC itself, as the largest provider of care, does not have that service. The only area that has that service is the Randwick-Botany area, which is my area and which is not coordinated through the service coordinators, it is done by a person who is a care worker with a mobile phone and a list of care workers names and numbers to try to make the service work.

With regard to the home modification scheme there are situations where people are unable to leave hospital because of lack of access to their homes after a acquiring a disability. It means some people have been transitioned into transitional accommodation while they wait for their homes to be modified, and the need for a whole-of -government approach to services means that sometimes people are relying on multiple services. They might be getting stuff through Health, they might be getting stuff through ADHC and where they are hospital-funded programs, sometimes people cannot leave hospital because they cannot get their equipment so, it is all health-funded budgets so if someone is left in hospital there is $1,000 a day to pay the hospital bed, whereas if they had appropriately funded equipment they would be able to leave the hospital. As I said, I have most of the information provided in my submission here. How are we going for time?

CHAIR: A minute and a half.

Mr KILLEEN: I will give my conclusion. As I said, my information is provided in my document. Although this inquiry is in regard to services and programs provided or funded by the Department of Ageing, Disability and Home Care, all governments need to change their attitude towards people with disability whereby funding of disability services and programs is not considered as welfare and a budget drain but to be considered to be a capital investment supporting disability rights that will enable people with a disability to participate as active citizens, contribute to society, achieve goals and undertake opportunities when they arise. Not investing in services, programs and facilities for people with disability, their families and carers is false economy.

Finally, I would like to say that having a disability is 24/7, not nine-to-five Monday to Friday and we do not get weekends and public holidays off. When considering the issues raised during this inquiry, I anticipate the Committee's report will make appropriate recommendations to address them. As the Government has six months to respond to the report, and in consideration of the pending State election in March 2011, I plead with each individual Committee member to give a commitment to pursue these recommendations with the Government of the day and to keep disability on the political agenda.

CHAIR: Thank you for being with us. I can assure you the recommendations to Parliament transcend the fifty-fourth Parliament.

MARC KAY: My name is Marc Kay. I wish to thank the members for inviting me to speak here today. I have worked in the public service for more than two decades and am a long-serving ADHC residential support worker—some 17 years. I have also worked as a psychiatric. nurse and for a decade in youth and street welfare, here and overseas. At ADHC I worked in to a specialist unit dealing with violent clients or clients who had displayed severe antisocial behaviours. The majority of these clients had come in contact with the criminal justice system. Before I expand upon this I would like to say some brief words about the privilege of being here today as it directly impacts upon the substance of my address. I consider this opportunity truly a privilege because I am guaranteed that regardless of what I say today I will not be shot or imprisoned. My wife, in her native country, is part of an abused ethnic and cultural minority and it is certain she would not be afforded this same privilege of speaking against the system to her elected representatives. Again, I thank the committee for this.

The system within ADHC is flawed and feckless. Despite the unequivocal safeguards inscribed in the Public Service Management Act and Protected Disclosures' legislation, senior managers and executives can punish whomever they wish for speaking out. In fact, people, such as my colleagues and I, have found that in reality there is really nowhere or no-one to turn to when the system turns septic. The system does not like whistle-blowers and cannot, indeed, will not, protect or assist those who uncover clear cases of unethical maladministration and the engendering of criminal and corrupt behaviour.

As an aside, when speaking out became too much and my health was clearly affected I put in a claim to WorkCover. In response, one of the senior executives in ADHC stepped in and ordered the external investigator of my bullying claims to not interview any of my colleagues who witnessed what happened. This executive then appointed the best friend of the senior manager who bullied me to provide the only evidence to the insurance company. These facts were set out in documents provided by the insurance company after it not surprisingly turned my claim down. That was two years ago. I have been on leave since, not working one shift in ADHC since September 2008. The executive in question has been promoted several times since then. In fact, all the participants in this travesty have been promoted.

Between 2005 and 2007 I worked at a forensic unit for young men with mild intellectual disabilities. In June 2006 a senior manager from a metropolitan region ordered me by phone to cancel an earlier call to police in which I had reported a client in the process of bringing stolen property onto government premises. This particular client had a long criminal history and was regularly bringing expensive stolen goods, sometimes procured by assault, to the unit. He would then hide the goods for a time and later sell them on the street or at a nearby pawn shop to purchase drugs, including ice. In a subsequent letter to this manager I set out my legal and ethical objections to her ordering me to never report this to police. Several months later our unit was issued with a protocol dealing with this issue. This document ordered us to never report this client's criminal acts to police and directed us to tell the client to place the stolen goods on the footpath and to leave them there. My colleagues and I were, in effect, told to ignore our clients committing further criminal acts. This policy is still in place as I speak.

In order to appear as though they were taking my objection seriously, senior management arranged for a government agency, so-called behavioural experts, to put on a three-hour workshop for us on resolving this particular ethical dilemma. At the end of this pointless and costly exercise in how not to face up to one's ethical responsibilities, I asked the senior manager in attendance and the facilitator the only question left unanswered: "Do we follow an illegal and unethical direction to not call the police when clients returned with stolen property or do we follow the law and put ourselves in conflict with the department?" The answer the senior manager gave demonstrates the moral vacuum at that level: "We don't know and you certainly don't either!" I rascally replied: "Actually, as part of my undergraduate degree I majored in ethics and I do know what I should do!" You could have heard that proverbial pin drop.

Think about that: Here is a very powerful senior public servant manager ostensibly demonstrating an inability to know what to do: report criminal acts, some of which involved assaults and robbery, or direct staff to ignore them and even request the clients to throwaway their ill-gotten gains. Notwithstanding this, this senior manager is on record—it is in her statement to an insurance investigator—that she fully supported this direction initiated by her then friend and boss to turn a blind eye to criminal activity within that unit.

I will not go into any further detail about the response to my speaking out. I will not discuss the fears of my then pregnant wife, and I will not talk about how it affected my mental health—just to say that I was bullied, lied to, subjected to harassment and long periods of silence, financially penalised, not provided procedural fairness or transparency with regard to unfounded and unexamined accusations, punished without being informed either about the accusations or the subsequent disciplinary punishment, and unfairly treated by the application of standards and expectations that were not demanded of anyone else, all because I objected to unethical and illegal directions and the appalling treatment of the lowest-level workers. I expect you will appreciate how the least powerful person in an organisation can be dealt with by the most powerful. Corrupt systems allow human beings in payback mode to be so creatively cruel.

Rather, I want to draw your attention to two key consequences of facilitating an environment within the welfare side of the public service when criminal acts are ignored and, indeed, allowed to flourish. The first are effects upon the clients themselves: it denies the clients the principle of dignity of risk in as much as it exposes them to situations where dangers outweigh any benefit whatsoever; it creates an institutional mindset as though they are different from the community; it creates a culture in which clients are not integrated according to community standards; it makes people with disabilities stand in a different relationship to the rest of us; and it transforms them into second-class citizens

The second is from the community's perspective: purposely engendering a criminal culture in its clients runs completely contrary to any conception of what the community would expect from its public servants. After my colleagues and I whistle-blew to the media earlier this year, for many months I carried around with me the article from the newspaper. I would strike up conversations everywhere and with everyone—in shops, on public transport, to individual police officers, lawyers, housewives and husbands, you name it. There was universal condemnation of these senior managers and executives. Our story was responded to with a flurry of "What sort of society is this?" "Why isn't someone doing something about this?"

It stands in opposition to any understanding of what constitutes ethical behaviour. The people in charge have clearly demonstrated an appalling dearth of probity. Their ignoring criminal acts committed by clients was a cynical exercise in client welfare. It was also an act of self-promotion: They wanted to extinguish the spotlight before it shone too brightly so they can be seen to be doing their job with excellence. Their strategy was that no police intercession equals clients are doing well on our watch. This was also the philosophy of choice in my friends' unit where a rape was covered up, as reported in the newspaper article I have referred to.

My concerns reached the highest levels of the department, yet no-one did or has done a thing to rid the department of its ability to promote criminal acts by clients or to remove the managers and executives who believed that their actions were right. Indeed, the hubris of these people became documented boasts and a belief that they are untouchable. I am informed in writing by the Committee that my accusations were passed onto the ICAC. I would appreciate if the Committee would keep abreast of developments regarding this action. Thank you for this opportunity to be here today.

SAYDE SARKIS: Good afternoon, my name is Sayde, I am 32 years old, married with two young girls aged five and three. I am my younger daughter's primary carer. Her name is Charlize. I think it is important for me to be very open and honest about what life has been like for me, my husband, our children, relatives, friends—friends who are not friends anymore because they do not understand our life and everything that comes with it. Charlize was diagnosed with several medical conditions and she has been left disabled as a result. We are not quite sure yet, it is still pending.

To give you some background, Charlize was born with floppy airways, laryngomalacia and tracheomalacia as well, so she has been left with a tracheostomy. That, in itself, was really hard for us to deal with because in hospital she was in ICU for four to five months; maybe for the first five months of her life. We did not actually know anything was wrong until she almost passed away in my arms and we carried her into the hospital and pretty much our life just went upside down from there. By nature I always saw that my glass was always half full, no matter how tricky it all got. To this day that is still how I see my world, even though it feels like our house was the only house that the tsunami hit and it feels like everything is tipped upside down.

We do not really recognise our surroundings or our feelings; we just know we feel very challenged in every single way. I do have to pose the question: what does support really mean to families facing disability with a loved one? What does that mean exactly and when did it become normal, especially in our great country of Australia? We are known as "the lucky country". How did it every get to feel that our family got so disconnected from society in terms of equality of rights, the right to a good quality of life or the right for our disabled daughter to receive even the basic therapies needed daily to help condition her whole body, the right to obtain special seating, bedding, transport, never mind her starting school or anything else other children get the chance.

I just found that when they have a disability, there are so many barriers in every single thing. It seriously feels like we live in a Third World country when it comes to disability; that we, shockingly, really have no say, no rights, no voice and no personal preference as to how we would like our family to be supported by the Government and what we would like to see happen for her. Who really has the right but the affected person's family and/or the disabled person if they were able to communicate to decide on what they needed for day-to-day support?

I know I might be sounding ungrateful or even disrespectful of the Department of Ageing, Disability and Home Care but maybe they should be respecting us first. Personally, I have come across many cold-hearted souls from ADHC and I am very sorry but I am actually being very nice when I mention what I am saying. Most of the individuals working there should honestly look around them and remember what their department actually stands for. It really does not feel like they have any connection to humanity. There is no compassion; maybe there are a few but maybe they have their own barriers too and it feels as though you cannot really get any truth out of anybody that I have ever had to deal with. I have been given the run-around for paperwork to obtain funding. For example, her wheelchair took 14 months. My daughter is totally immobile; she does not do anything on her own. She needs 24-hour-seven-day-a-week care.

Pretty much I almost had a breakdown. She was 2½ years old and I have not slept for 2½ years; literally I would sleep for maybe an hour and then her alarm would beep and I was up again. She is very dependent; she cannot feed orally anymore. At one point in her life she was fed through her jejunostomy, which means her small intestine, and that was through a kangaroo pump for 22 hours of every single day, even during the night. I am sorry to go into too much detail about what that means for her bowels, but she was probably opening her bowels 13 to 14 times every single day and because she was continuously being fed, stomach acids were always forming, so she developed reflux as a result. That compromised her airway because obviously that brings it all up. She had to have major surgery in October 2007 to help reduce any aspiration into her lungs, which caused pneumonia about six to seven times every year, and every single time she was in ICU.

I just need to be very honest about some of the things that have been said to me personally, whether they be face-to-face, over the phone or just in passing. Many times I have been left shaken and sobbing after telephone conversations and/or meetings. One sentence that was said to me by my supposedly understanding and compassionate case manager, who was also a mother herself, were the cold words—and honestly to this day it still sends a cold shiver down my spine—"It must be so hard, so difficult for you being her mum, sitting there watching and waiting for Charlize to die". Honestly, they are the exact words; I will never forget. I was so shocked and so angry at the same time that I could not muster up any reply. It took me about two days and I had to ring her back and ask her to reconsider what she does say to a parent who is already very fragile in their heart and very vulnerable; not that I wanted her to feel sorry for me, but it is not nice.

On another occasion the same individual said something along the lines of, "What is this, Sayde? Why is it that you have set up Charlize's room like a hospital?" Seriously, is this women mad? Does she not think that it pains me to see how dependent my baby is on medical equipment, medical supplies and machines just to keep her living and safe? Shame on those who choose to be ignorant, especially given their role in the disability field! This and many other useless comments said by the aforementioned person make me believe that they do not read their clients' medical history and prognosis, as that has been questioned also. I find that terribly upsetting and irritating.

Another classic was when the case managers and caseworkers who had been working with us personally for the last 2½ years had been going around behind my back without my permission or my knowledge and taking along with them the managers and shift coordinator of the nursing agency who are funded by ADHC and who are paid to place support, in the form of a registered nurse, in my home to care for Charlize overnight. Together both parties went to an organisation. I am not sure if I can mention that but it is from the Commonwealth.

CHAIR: Not unless there is a need to do so.

Ms SARKIS: They have been very helpful anyway, thank God. They have been an incredible support when their funding permits them to. Both those parties made quite a number of demeaning comments about me, my husband and our young family, plus saying to the organisation that they should not be supporting us any longer as Charlize is not as sick as her mother has made her out to be, and that also her epilepsy is not real. I have started videoing my daughter fitting, which is really painful. It has put my barriers up now, because I feel that I am being questioned and I am being set up for DOCS, which they have done numerous times. My door is always open for this department to come in and assess us. They are the ones that got up in countless case meetings and said that we have no place in this family's life. To this day, as we speak I am still being set up.

The same individual who lovingly said all of the above, also went to my eldest child's preschool. They had a meeting with the management there to explore options for Charlize to attend day care as a form of respite because apparently they can access different funding if it is a school kind of set-up. Honestly, I nearly fell over backwards when I heard the words, which were relayed to me innocently by the principal of the preschool, who said, "How sick is Charlize really?" I went into a bit of detail about everything. It is not something I like to share because I always get a bit emotional, but that is okay. Apparently it was said that Charlize can sit up in her chair; she can grasp at objects, play-doh and everything else. Apparently my daughter can do hand movements to "Twinkle, twinkle little star" and "Incy, wincey spider". My daughter does not do any of that, unfortunately.

I have a five-year-old daughter as well who is healthy and she needs me just as much as Charlize does, if not more. She was only 20 months old when Charlize went into hospital. That year I felt like I had honestly lost both my children. My five-year-old just two days ago said to me, "Mummy, my heart is beating really fast. Can you feel my chest?" That, to me, is anxiety. I am not quite sure but I am definitely going to explore that.

CHAIR: You mentioned a Commonwealth organisation that you said was good and that you wanted to name. Please feel free to mention that name.

Ms SARKIS: I think it is the Commonwealth care link, which is an 1800 number for emergency respite.

CHAIR: Is that mentioned in your statement?

Ms SARKIS: No, I did not mention that.

CHAIR: Thank you very much. Do you have more?

Ms SARKIS: Yes, I have more.

CHAIR: The remainder of your statement will be incorporated in *Hansard*.

Who made them the profession Like they've boldly stated that they know better than me and my husband what was best for charlize? By best what do they mean one might wonder?, well how about ADHC trying to pressure or hoax my husband & myself into Fostering out our daughter (who is our life & Joy) out to another family! Oh it's not fostering, they have stated, it's a host family!, why would charlize need a host family when she has her own loving family "Thats the only choice you have!" they have said, when I told them I wasn't coping without any assistance at home. Well lucky for them they didn't have to think about their child being taken to another families home did they? Lucky for them they get to tuck their children into their beds and kiss them goodnight, knowing they were sleeping under their roof! Do these people have no conscience? No consideration? Do they not know that our disabled child was just as important if not more than their healthy child? Or did they think that because that their disabled their life is useless anyway? & so it's a waste of tax-payers money to support them to live at home! Disabled people and their loved ones have a heart too, and they have feelings, needs, rights & wants, Just as much as anyone else walking the face of the earth! We are just as human & Important as the next person!

Did you know I literally had no decent sleep for Charlize's first 2 & a half years of life?

So you get a better picture of our little girl's health, She unfortunately Suffers from a great deal of conditions, so much so, that even her team of Specialist doctors cannot fully diagnose her with a certain syndrome.

Charlize is also Medically challenged as well as physically. She was Born with Laryngo/ Trachea Malacia, in leymans terms (Floppy Airways, therefore she has had extensive surgery to try and repair her airway, but was unsuccessful and so therefore she has literally a plastic, straw-like tube and hole in her throat to breath from Which is called a trachie, She suffers chronic lung disease, she has 2 holes in her heart, she has partial deafness in one ear, She is also currently only one in 2 dozen children treated in NSW alone by her Neurologist specialist, to be on more than 3 drugs 6 hourly, just to mildly control her Epileptic fits, and she has been known to fit up to 18 times in a day.

Charlize cannot speak (& even if she did, we cannot even hear her voice because of the trachie), she cannot walk, stand up alone, roll, crawl, sit-up, grasp at a toy or at our, or her sisters face, she cannot blow raspberries or even kiss us, the only way she knows how to communicate is sometimes with her eyes, but always with her body language. & I live for the moments when her eyes do all the talking, especially when she's telling me she loves me too.

Because she cannot communicate in the natural way, charlize makes it quite difficult even for me sometimes to read her, & understand what she wants, or where it hurts.

At a very young 4 weeks of age she nearly lost her first fight (of many) at the chance of life.

Many times in her first 3 years of life did her life hang in the air, she would catch the common cold and end up with pneumonia in ICU, she basically doesn't have an immune system, & so she would & still does catch anything & everything going around. So to add to her high needs, we need to isolate anybody who is fluey or showing signs of infection, away from charlize, & her environment must be kept as clean, dust-free & sterile as possible, we cannot even own a pet as if the pet hair, or even her own hair, gets inside her trachie, she could possibly die if it reaches her lungs.

So as you can see, it's a pretty awful lot to have to live & deal with everyday, most people are lucky, they can go through this life not having to have to suffer at watching their own child suffering in front of them, and them not being able to do anything more than they've got access to (which isn't much), and most people do not have to throw their own lives away, their own dreams, their careers, their health (mental & physical) , their friends & social lives, let their other ((healthy children" play second fiddle to the disabled child, because the parent or parents have to solely care for their special needs child with no in -home support (which is our only wish) . Statistics have also proven that marriages also end up falling apart, because they end up having to neglect their partner to do it all on their own plus some more! I do not want to become a statistic ,but I tell you the strain is enormous! so the government needs to sit up and listen carefully as what's really going on behind closed doors, & what they can do to help their fellow Australians.

On another note now, Out of home respite or group homes: wow! have I had many experiences there! (most have been good, but we have had our share of horrifying experiences also.)

The situations that my child has been in, and also what has happened to her while she had been accessing respite, leads me to believe that the level of integrity of the employees there who are looking after my child needs to be questioned & checked up on. How closely is my child's care plan followed? Feed regime, medication regime etc. How clean are their hands before they touch my child? , how honest are they being when I've asked them if charlizes trachie ties were changed after her shower? As it had been pretty obvious that my daughter had wet cotton tapes (like a shoelace) had been sitting on her neck for hours, & luckily I'd stopped by to see her, so as I had walked into her room, I find her kicking & thrashing wildly obviously in deep pain from something, then I saw the massive and burst cut open skin, & blood filled welting that had occurred on the back of her poor tiny neck, caused by the wet tape rubbing & cutting her neck horizontally. The registered nurse that was in charge, was assuring me that she had not had a bath that day, & that her tapes had not got wet that day! but busted! I had spoken to the earlier shift's RN, & I was told that she was being bathed as we speak. Plus her tapes were still damp now. Charlize now bears the horrible scarring left from this situation, & it took two rounds of antibiotics to clear up the infection caused. This made me so cross. Looking at her in so much pain felt like a knife was ripping out my heart.

Another incident that happened there also begs me to ask

: "what is the hygiene policy at these respite centres?"

& " are these registered nurses as experienced as we were made to believe?

It was sept 2009, fathers day, charlize had been accessing respite there (the same place), The RN had called me to say that charlize had a high fever, but it was being controlled with panadol. A few hours later, same nurse calls me to say in a panicked voice that charlize was in serious trouble, I recall something like this: " charlize has a high fever, her heart rate has dropped very low, her breathing is compromised, what do you want me to do?" I reply in shock: "Call 000, and at the same time clear her airway, and administer oxygen! ", we were driving down the freeway, about 15 mins away from the centre, when we had gotten the call, my husband was driving, as soon as we had received that call, we thought "that's it, she's going to die", and he stepped on the gas, through my hysterical tears, I thought I'd call paramedics too, I was told I was the 2nd caller, that the 1st caller had rung about 10 mins prior, but that the paramedics were told to go to a different address, which was obviously an honest mistake, but nonetheless a huge critical mistake. We found charlize blue & shaking. Paramedics arrived soon after us.

In hospital charlizes results had come back, she had contracted ROTA-Virus (worst form of gastro for children), which is only contracted via Direct touch, by not washing hands after using the toilet (if you're a carrier of the virus, or between changing pads for children & not washing between patients, she also had contracted Infuenza A Respiratory infection, which again is contracted Via Direct Droplets from an infected person. Or by not washing /sanitising hands before touching her, and /or suctioning her air-way. Charlize once again fought for her life In the Intensive Care Unit for a month. And again that tsunami crashed through our lives once again.

So, can you please check up on how clean the carers are between clients ETC, and could the nurses in charge have refresher courses on how to save a life? & maybe do some integrity testing for telling the truth to the parents of the child that they're paid to look after?

How am I ever supposed to rest my mind, when the whole purpose of respite, is so that I don't need to check up on my daughter, or worry myself sick over her well-being?

(Thank the committee and the audience for their attention, for the honoured chance to openly speak out about all these issues).

CHAIR: On behalf of the Committee, I thank all the speakers this morning for sharing your often difficult experiences, views and recommendations. As I mentioned earlier this morning, your views form an important part of the inquiry process and will be considered as we prepare our report and recommendations. A record of today's proceedings will be made publicly available on the Committee's website next week. If you decide that you prefer the information you have provided to the Committee today not to be put on the website, please talk to the secretariat as soon as possible.

I remind you again that parliamentary privilege does not apply to what speakers may say outside these four walls. This forum concludes the evidence-gathering stage of the inquiry. The Committee will now examine all the evidence and produce the final report by 11 November 2010. Once the report has been tabled in Parliament it will be publicly available on the Committee's website. If you wrote a submission, you will also be sent a hard copy of the Committee's report. I thank each one of you for taking the time to attend today's forum. We look forward to considering your views and making positive recommendations for policy change.

(The Committee adjourned at 12.59 p.m.)