

Corrected

REPORT OF PROCEEDINGS BEFORE

STANDING COMMITTEE ON SOCIAL ISSUES

INQUIRY INTO DISABILITY SERVICES

At Sydney on Wednesday, 12 December 2001

The Committee met at 9 a.m.

PRESENT

The Hon. Jan Burnswoods (Chair)

The Hon. Dr A. Chesterfield-Evans
The Hon. Amanda Fazio
The Hon. D. F. Moppett
The Hon. I. W. West

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ANNE ELYSEE, ANNE WHAITE, BRIDGET RAMSAY, JANE THOMSON, "DAVID SMITH,"* "LOUISE DIXON"*, "MARY ALLEN"*, "JACK BENNETT"* and "MARIA FINNANE"* before the Committee:

CHAIR: I gather we are going to start with an opening statement from you, Anne?

Ms ELYSEE: Yes.

CHAIR: Do you prefer us to not interrupt to ask questions as we go and wait until the end, or does it matter?

Ms ELYSEE: I think each of the families, aware that the time might be short, have actually put thought into preparing a written summary of what has been happening for you, but questions are very welcome.

CHAIR: Obviously some questions are across the board and others relate to individual circumstances.

Ms WHAITE: Yes, and we are very aware, I think, that obviously you want the information also to focus on the issues that you need to address, so you will need to ask questions to clarify that.

CHAIR: Yes.

Ms ELYSEE: Thank you very much for meeting with us. A couple of weeks ago we sent to the Committee the document called "Endless Words ... Endless Waiting", the story of six families who gave evidence to you in May 2000. You met with these six families and they, at that time, gave you the history of their difficulties in obtaining services. Eighteen months later none of those families, at this point, have permanent accommodation for their family member and that, I think, is the bottom line.

Four of those families are present today and two families were unable to attend. In your papers there is some information about the reasons why those two families could not attend. Just to draw attention to them briefly, the family that is known in the book as the Gordons, a submission from them has gone into the SAS system, but they are still being questioned as to whether they are eligible to be accepted and so they are right back at the beginning of the system. The family written in the book as the Chapmans are at the moment receiving some supportive services as a three day a week part-day placement and some respite, and they are experiencing a great deal of difficulty in that they have to keep putting in repeated applications on a three monthly basis for renewal of this crisis service. They have asked the department why this is necessary and the quote that I have to give you is that they say the department says that it is not possible for them to keep checking their files in order to make decisions about applications or funding, so this family has to keep putting in new applications all the time, so that is one of the stresses that they are under.

Of the six families altogether, four are seeking permanent accommodation through the Service Access System (SAS). The other two families are through what is known as the 197 Program. We also have with us today a family member who is not one of the six original family members, but he has a fairly horrendous history and would like the opportunity to bring that to you.

We suspect that the overwhelming majority of families who put in an application to SAS have not received permanent accommodation and we believe that the main reason for this lies with huge bottlenecks at every step of the Service Access System through to the Community Living and Development Unit process and suggest that the existence of these bottlenecks raises serious questions about the capacity and commitment of the department to actually do what they are supposed to be doing.

We do acknowledge that the SAS system is a positive step forward and a good idea in principle, but we have to say to you that it is not working in practice. Just for the record, the process we are talking about

* These names have been changed, including names of children referred to in evidence, by resolution of the Committee.

has three levels: There is the Service Access System; there is the Community Living and Development Unit stage and, finally, most importantly, there is the availability of organisations to be able to actually provide the services, so even if you get through all the bureaucratic process, what happens at the end?

As I said, there are significant bottlenecks at every stage of the process. People are putting in application forms and then have to wait. They then have to go on a waiting list to be assessed by an eligibility committee. If they make it through the eligibility committee they then go on a waiting list for a support planner to be assigned to them. They then have to wait for the plan to be developed and go to the minister for approval, and that just gets them through the SAS part. Then, if their application has been approved, it goes to the CLDU for implementation.

At the top of the second page of the notes we have some figures that we believe, to the best of our knowledge, are accurate. We believe that up until now there have been approximately 2,000 SAS applications received.

CHAIR: That is across the State?

Ms ELYSEE: I would say, yes, in approximately a 14 month period. That is an estimate. We believe at this stage that approximately 1,400 of them have been assessed and, of those that have been assessed, approximately 140 have actually got through as far as the Community Living and Development Unit. They are the figures that demonstrate the bottleneck and that has been taking place over at least 14 months.

The Hon. DOUG MOPPETT: And the 140 does not imply that they have actually had it completed?

Ms ELYSEE: No.

The Hon. DOUG MOPPETT: It is in their hands.

Ms ELYSEE: They are just on to the second stage. To our personal knowledge, we actually only know of one person down in the south of the State who has actually got out into supported accommodation. There may be more, but we only know of one.

CHAIR: Just to clarify, when you say 1,400 applications have been assessed, going back to the bottom of the first page where you have dot points, are they in dot 3 or dot 4?

Ms ELYSEE: If they have been assessed they are now waiting for a support planner to be assigned and for the actual plan of what services they require to be developed.

If you look at those figures it means that in approximately 14 months 1,400 applications have been assessed. That is at a rate of about 100 a month or 25 a week. If we look at the backlog of the 600 that they have not got yet, the likelihood is that it is going to take until June 2002 for them to get all that they have here at present assessed. I would just refer you to a statement that was in your report on page 2: "The Committee has been assured by the department that substantial service growth will take place by June 2001." We are now talking about going to June 2002 simply to get everything assessed, so that gives you the scope, and that is to assume that they have all the applications that they are going to get. We understand that, from September until now, 400 came through the door and there is no reason to understand that there are not going to be more coming in.

Why do these bottlenecks occur? Whilst it is very obvious that the bottlenecks are there, this organisation does not have the resources to definitively answer why. We have some suggestions which we will put to you. However, we are quite clear that if those bottlenecks are not cleared your major recommendation, which is for a growth target of 200 additional supported places per year for the next five years, will not be met. It cannot possibly be met at this current rate of progress.

Our main recommendation to you today is that there has to be an analysis of why these bottlenecks are occurring. What is the underlying reason that it has all been so slow? We believe that an organisation such as the Community Services Commission or maybe the Audit Office should conduct a speedy - it has to be speedy - audit of the process so far and analyse the reasons why these bottlenecks are occurring and recommend how they could be removed. At the same time we are at a loss to understand why the department is unable to do this analysis for itself.

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We have attached in your papers a list of some of the more detailed problems which the support group has identified about the process and maybe, if there is time, we could talk about that, but we really want to hand over to the families so that you can see the real living effect of the inability of this system to deliver on real-life people who are experiencing it.

Another reason why the bottlenecks have got to be cleared, of course, is that your recommendations concerning devolution and the 197 Program also involve the Community Living and Development Unit. They are supposed to be doing all of this, not just processing the system, which is an additional reason for getting the bottlenecks cleared.

As outside observers, people sitting watching this bureaucratic process, some of the systemic reasons for the bottlenecks seem to us to be as follows: There is no clear strategic planning, by which I mean a plan which is flexible and which you are able to modify in light of changing circumstances. We cannot see that. There is a lack of systemic focus which is looking at the big picture and people cannot see the wood for the trees, they are mired in the detail.

We believe also that in a very large bureaucracy it is extremely difficult for one central unit to manage the scale of change that is required. In practice we see that central unit actually doing hands-on case work and trying to deal individually with too many people instead of being a central strategic unit. Because of that they are not delegating the operational processes down to the regional level, they are not making use of other resources in the department. We are very concerned about the ability of the disability services system to actually provide all the services needed. There are not all that many disability organisations on the ground. Some are more experienced than others, some are less experienced, and they need help. They certainly need help with how to address the complex needs of the people that they will have to provide a service for and there also needs to be more flexibility in the range of service models provided.

In conclusion to this part, on page 94 of your report you said this: "There is little point allocating additional funding for direct service delivery if the department does not have sufficient resources to roll out funding."

CHAIR: I think we agree with ourselves.

Ms ELYSEE: Yes, it says it all in a nutshell. The \$20 million that was announced as being available to provide services at the beginning of the year is, I believe, still sitting there pretty much intact and we are now all talking about \$20 million slippage, you know, is it going to move into next year or what is going to happen to that money?

We have to ask: What commitment has the department to making this an effective system? What is its staff commitment on a permanent basis? My understanding is that all the people in the SAS unit or section are temporary people and there has been a lot of roll-over and change of people, and that applies to what is their current staff commitment. We just do not believe that sufficient resources are being put into the system. That is assuming that in its present incarnation it actually could, if sufficiently resourced, do the job, and there is a big question there anyway.

That is my opening statement.

CHAIR: I gather from what you are saying that you think the system is a good system in principle and could, with these matters being addressed, be made to work for the families?

Ms ELYSEE: The idea of having a rational, so to speak, system of bringing together the applications of all of those people who have needs so that we can see the size of the need is a good thing, and that is fine, but it is as though the department embarked on that without fully thinking through the consequences.

Ms WHAITE: Without realising how many people. They were looking for 200 or 300 applications.

Ms ELYSEE: Yes, they have stated they were expecting 200 or 300 applications, but I have to point out that in this report you have figures from all sorts of sources, including DOCS itself, which in 1997 indicated something like 2,000 people, so on what basis they reckoned they were only going to get 200 to 300 - we suspect it is because they try to narrow the focus of the SAS system by saying it is only for people in

crisis, thinking that of those 2,000 none of them were really in crisis, but crisis is in the eyes of the beholder. Every family here believes that it is in a crisis and every family that has put in an application believes it is in a crisis, so the way that they approached it in the first place was wrong. We do not want a new system, but we need a system that works properly, particularly to try and undo these bottlenecks which we have tried to identify for you. It is a resourcing, it is a commitment and it is a capacity situation that has to be addressed.

Ms WHAITE: Could I just add that we are a little concerned about significant changes to the system because that is what has been happening over a long period of time and I guess one of our issues is that all that really does is give the mountain of words that has already been written and the waiting lists different names. There is a crisis response to situations which will also be demonstrated here today, but this has been going on under a different label for a very long time, so we think that a whole new system is probably not going to be as effective as a revamp of the current system which, as Anne says, has a lot going for it because there is no doubt that the Service Access System has identified and quantified, to some extent, the unmet need in the community.

Ms ELYSEE: Otherwise we end up playing snakes and ladders: We keep going back to the beginning and starting again and we never get anywhere.

Maria is from the Finnane family in the book and would like to talk about her experiences.

Ms FINNANE: I have chosen to read you the update on our situation since May of last year.

A submission for accommodation was drafted by a case worker at DOCS Blacktown and finalised by the family. On 19 January 2000 it was received at Acting Director-General and given the data number 186. A letter dated 1 September 2000 was received from the acting director general of ADD. It stated that John had been assessed as having a high priority to receive assistance and a nominated support planner would be meeting with our family. A service need assessment profile was done on 5 October 2000 and a key support issues report was filled in with our allocated support planner on 21 December 2000.

We received a list of housing and support services, eligible service providers from ADD, along with a letter dated 21 March saying, in part: "You are now able to discuss with service providers the support plans for your relative and development proposals for future living arrangements." This list contains 67 service providers State-wide. My husband and I agonised over that list. We knew this was the most important decision we would ever make for our son. We finally narrowed the list down to approximately six to eight providers we wished to learn more about. We contacted them by phone and visited some. A couple of organisations said that they were not interested in being on the list and did not even know they were. We finally made our choice on 8 August verbally and advised Wesley Mission we wished them to be our service provider. On 13 August I phoned the CLDU unit and advised them. Later we were verbally advised by an officer at the CLDU that the house would be up and running with John on his own and then, as more people came through the system who appeared to be compatible, they would be moved in.

On 15 October I rang the CLDU requesting an update on the accommodation. I was advised that they were meeting with Wesley Mission on 16 October and when I questioned how long it would take before moving in I was told about six months. That support officer left the CLDU at the end of October. He was only seconded for six months.

Upon being advised by Wesley Mission that DADHC had decided not to put John in a house by himself but to wait until more people were made available who were compatible, I commenced trying to phone the current officer of the CLDU as they had not advised us of this. I tried unsuccessfully to contact him by phone and was told that he was away sick, away for the day, not at his desk or at a meeting. On one occasion I asked to speak to the officer who was doing his job while he was away. The person who answered the phone reluctantly asked if she could help, as there were only two people in the office. She said normally there are eight and they were advertising for more, but on that particular day, for one reason or another, only two were there.

When Western Sydney Intellectual Disability Support Group contacted me regarding the Standing Committee review I decided to fax Wesley Mission on 6 December for an update report on John's accommodation, which I duly received and I have it here along with a copy of this to be tabled.

I also faxed the same request through to the officer at the CLDU. He telephoned me the next morning and stated that they have John's service development plan, but at this stage there are no people for

John to move in with. I said I had been told that he would move in on his own and others would move in when identified. He replied that they were not doing that any more as it costs too much money. It costs a quarter of a million dollars, which was taxpayers' money; other people's funding packages were being affected; the funding comes from the pool of resources. He also stated that I had requested, via a case worker in DOCS Blacktown, interim funding for respite. I said I had forgotten about it as it was so long ago, July 2001. I had requested that interim funding as an organisation that I get respite from was not meeting the family's needs by insisting on not allowing the support worker to transport John, and I am now deviating a bit because I have had to cut down on what I had originally put in my report here.

Regarding the accommodation, he suggested we consider using another service provider who had a placement that might be suitable for John. I explained that my husband and I had taken a long time in making up our minds which service provider to go with. We had visited, spoken with various service providers and, for various reasons, decided on Wesley Mission. I also insisted that we had been told John would move in on his own to start with until others were found to be compatible and move in with him. He said he would talk with his manager, Pamela Riddiford, and get back to me.

That afternoon he phoned back and offered a placement in Inala where there were two boys awaiting someone to move in with them. I said, "I am not being listened to. Our family has chosen Wesley Mission". He also said they had just identified a man who could possibly be compatible with John and is currently living in another organisation in a temporary setting. He also offered interim funding so that John could be out of the house seven days. I stated we are already receiving that and the main need for John is accommodation. I asked him what is the criteria for compatibility. He said, amongst other things: They need not be bosom buddies, live in tolerance of one another, be safe, not at risk, have coping skills with one another, have the same interests. There is a formal assessment tool which is used after they have been living together for six months. Perhaps we can negotiate interim funding for a period of three to six months for them to live together and then use the assessment tool.

On Monday, the 10th, I received a phone call from the officer from DADHC. He said he had made a phone call to Wesley Mission and was unable to contact them regarding this man who currently lives temporarily with another service provider in the Bankstown area. He is also asking a case worker in Laurel House to look at the profiles in more detail to see if he and John are compatible and, if so, then maybe they can live together for a three to six months trial period. Wesley would need to put in a submission for this interim funding. He also emphasised that the final decision for compatibility would rest with the service provider and the family.

Ms DIXON: I understand that we were asked to inform the Committee as to what has happened to us since our last appearance in May 2000. Our family struggled to keep looking after Terry up until about August 2000 when we could not cope any longer. Terry went into the respite care house on a Friday evening and I packed my bags and I walked out of the family home. The family could not cope any longer and we did not pick him up from the respite care house. Yes, I am guilty, I blocked a respite care bed, but I do not apologise for that.

The respite care house had one on one care, 14 hours a day, to look after Terry. After five days of respite care, the respite care staff called the police and had Terry admitted to the Cumberland Psychiatric Centre where he remained for about four weeks. The social injustice here is that I could not get one half hour a day help. The professionals could not manage Terry, but I was expected to. They were getting one on one, 14 hours a day.

After about four weeks the hospital called a meeting with DOCS and I agreed to take him home with the one on one care which was provided by ADD the very next day. We also had some domestic assistance, for which I am very grateful. We have had this one on one care since October 2000, that is 15 months. While I am forever grateful for this assistance and extremely aware of the dollar cost of this service, I cannot help but feel if we had well-planned practical assistance with managing Terry over the past 11 years since Terry left school the family breakdown may never have occurred.

Also in October 2000 after Terry returned to his day placement at 4 pm on a Friday afternoon there was a Post-It note in his communication book telling us that Terry was not to return to the day centre until his behaviours were addressed, even though he had a full-time carer with him, and Terry did not have a day placement for the following six months. So we now have strangers in our house. For the past 15 months we have been prisoners in our own home: There is no privacy; the carers are exhausting; we have to be home by 9 pm so that the carers can go home. We did, however, manage to get some Friday, Saturday and Sunday

night sleep-overs during May and June this year when my husband and I went overseas to get away, recoup, relationship damage control perhaps someone could say. Terry is now not welcome in any respite care house. We have accessed three weekends away for Terry in the last 15 months. The first one the carer did not turn up, so now I book a hotel room and I arrange for the carers to stay over.

In the meantime, in September 2000, I requested support for Terry through the new Service Access System. On 14 September I received confirmation that we had been approved as being eligible for assistance and that our support request ID number is number 3. I have a letter, if anyone wishes to see it. I found myself in a bureaucratic maze of an unplanned, ineffective, ad hoc, full of delaying tactics Service Access System. It has taken 15 months to progress through this ad hoc service system.

On Thursday, 6 December 2001, which was last week, I rang ADD to ask for an update on the progress as I was appearing before this Committee. To my surprise, on Friday afternoon, 7 December, at 4.45 pm I had a call from ADD telling me that they were going to put an offer on a house that I had found in early November.

In conclusion, I would like to ask the Committee that if I am number 3 on the Service Access System list and given that the key recommendation by the Standing Committee on Social Justice in December 2000 was that a target rate of 200 additional permanent supported accommodation placements be provided each year for the next five years from the date of tabling that report, what is a matter of priority? That is all I have to say.

Ms ELYSEE: David Smith is not one of the six families, but he wishes to speak to you about the situation of him and his family.

Mr SMITH: I am probably one of the hundreds.

CHAIR: So we do not have any background information on your situation?

Mr SMITH: No.

Ms ELYSEE: He has papers he would like to table.

Mr SMITH: In five minutes it is not going to be easy--

CHAIR: We might give you a bit longer.

Mr SMITH: --to explain all that we have been going through for almost half our life, but what I have done is I have put together a few documents, since I got advice of this meeting only a few days ago, that summarise more or less the things that I have to say. I did make a submission to the Standing Committee originally in November or December 2000, I think it was, and my name is on the submission, so I have a copy of the submission that I made there together with odd bits and pieces.

CHAIR: Would you like to give us that now so that we can refer to it or do you want to hold on to it?

Mr SMITH: No, I have it all here.

(Documents tabled)

My wife and I are 76 years young and we have a girl who is 40 years old with a dual diagnosis. She is mentally and intellectually ill. She broke down about 20 years ago and we have been looking after her ever since full-time at home.

In my original submission to the Standing Committee on Social Issues I had listed our main concerns as follows, and I think I will just leave those out. In view of our age and failing health, we would like at least eight to ten weeks of respite in our home or preferably in a suitable centre; the setting up of high support accommodation services that would cater for her complex needs, and gradual transition into such a set-up. This needs to happen while we are still able to assist her during the transition and feel confident and secure that she will be well placed before we are either too frail or pass away.

I do appreciate that I am addressing only my specific needs and I am aware of many families and individuals who are faced with similar problems and are unable to access the meagre facilities that are now available. For instance, we have been getting mid-week or weekend respite in two homes. In one home there is a total blockage of people who have gone there and stayed permanently and there is only one respite bed which we get once a year on a mid-week basis, so that is the only time we can get away or sit at home and charge or recharge our batteries. The other one - apparently there have been some problems - is likely to close down because Mission Australia is unable to cope with the funding that they have and they have about five beds. We have had a bit of respite once a year or twice a year there and that is about all. In addition to that we get four hours a fortnight of someone coming into the home and looking after her. Our daughter is a full-time job, 24 hours a day. She cannot do anything. She cannot transport herself; she cannot cook; she cannot wash; she cannot do a thing, apart from basic toiletry.

Over the years we have been assessed and interviewed by I do not know how many dozens of agencies. It has now become painful, distressing and totally frustrating because invariably the results are inconsequential. I do not think there is very much I can say. Some of it is here. She was assessed in 1998 by a team of psychologists and what have you from Laurel House and they made certain recommendations at that time of our great need, that we were in crisis in 1998 and she needed some kind of group home, high support type or something about it. That is also in one of the papers there. A SAS submission was made in December. A case worker was finally assigned to us and she made a very elaborate submission some time in August 2000, I think it was. Since then we have had two acknowledgments from ADD, which again are there. Two acknowledgments from ADD in November 2000 and June 2001.

CHAIR: When you say "acknowledgment", is that all it is?

Mr SMITH: Acknowledgment in two letters. The first one was just an acknowledgment saying that we are looking at it. The second one was saying we have looked at it, you are eligible and someone will come to assess again. That assessment has never taken place.

In desperation we again rang the case worker and someone from advocacy also came to see us and wrote two very strong letters to ADD. Copies of those are also attached there. As a result of that, the case worker put in a case for interim emergency funding so that we could get away for at least two weeks somewhere. That apparently has been lost. That was in June. That has not been found and when I rang the case worker the other day to remind her she said, well, somehow or other, or the advocacy said that it had been misplaced, ADD had not received it, so they are making a second submission.

The last we heard was that the case worker that was assigned to us has resigned and we no longer have a case worker. The last I heard from the person who handled this earlier, because she has risen in the hierarchy, was that she said: Very sorry, David, but this is what has been happening and we have had two or three other resignations, we are very short-staffed and as and when it is possible we will give you another case worker.

After all these years and all the information that has been given to dozens of people, as I say, we are still at square one where we started off. We just do not know what is happening and our concern is that we are getting on. I mean that is our main concern. We do not want to let go of our girl, she is the only child, but on the other hand we want to know what is going to happen when we are no longer there. It is a terrible strain on my wife and myself.

CHAIR: So you are still where you were in 1998 or before 1998?

Mr SMITH: 1998, and there are three recommendations made on a two page submission that the psychologist made: She needs a group home, she needs to be put in a group home with high support needs.

CHAIR: Has anything been said about, as in the other case, the need to wait until compatible or suitable people are found?

Mr SMITH: The thing is, as and when the SAS thing does come through, if it does, from what I have heard of what has been going around and comparing notes, it is going to be a hurdle where the compatibility problem will arise and the availability of a suitable home, so if this thing comes down in, let's say, three months or so, how many more months is it going to take before a home is going to be set up? Anne spoke about the system that has been set up so far. My question is: What planning, strategic

planning, has there been for the moneys that are there, the budgets formed? What is the infrastructure? What is the point in having money which is probably going to be sitting there and there is no place for them to go? If that is not in the plan then the whole purpose of funding is absolutely nullified.

Ms ELYSEE: In fact I believe that could be the subject of a separate inquiry: How many announcements we have had of money available over the years and how much of it has actually been spent. On the political level, announcements of money allocations is a wonderful thing and it is a great success, but what happens to the money? It is never actually spent, we suspect.

Mr SMITH: If it is invested maybe it would get enough interest to set up something.

CHAIR: Certainly some of that has been rolled over to the next year, but we are still waiting to see what ends up coming out.

The Hon. DOUG MOPPETT: Certainly after we have dealt with each of the individual cases I would be very happy to hear from the organisation as to how you see it in numerical terms. We identified you when we came out as representing a group of people in the classical crisis situation, not the sort of people moving towards crisis but clearly in a crisis situation, and how many from that time have actually arrived at a solution - I mean we do not want to interrupt, but at the end we would like to say what is the final outcome of all this.

Mr SMITH: When we talk about crisis - pardon me for coming in, but you mentioned crisis - we have been in crisis since the time she broke down. She has been in and out of hospital. We have a crisis every day. For instance, last night she suddenly threw a fit and she smashed something. She has broken television sets and things like that. What do we do? Do we ring up a crisis centre or an ambulance or something and say take her away? We cannot do that. She is under medication and fortunately she has stabilised to a certain extent, but there are odd moments when she just throws a fit and being home-bound constantly she also exploits the situation--

Ms ELYSEE: She is frustrated.

Mr SMITH: Yes, she is frustrated.

CHAIR: We will come back, as I said, and compare the stories.

Ms ALLEN: We are in the position, and have been for the last 12 years, of having a service provider that is very keen to take our son, but we have not been able to get any funding. Twelve years.

My focus today really must highlight again the effect of neglect by DOCS and their inexcusable failure to support and help my family in our struggle to survive. Just to recap, our son is profoundly intellectually disabled, cannot even butter a slice of bread, get a glass of water from the tap, let alone shower or dress himself. He cannot speak, has no communication skills, all due to the severity of the condition he has which is an insidious multi-system condition. In the last 18 months since the inquiry his health has deteriorated alarmingly. He has been almost living in Westmead Hospital. His father and I alternately stay with him in the hospital, night and day, attending to his needs, as the staffing shortage is critical and if he is not observed 24 hours a day he pulls out cannulas and catheters and anything else that is essential to his treatment.

My distress has been exacerbated by the many promises by the case worker to obtain crisis funding as our only funding was \$70 a week, a meagre three hours which we used for in-house respite once a week. The case worker told me there were many delays, excuses, et cetera, and I remember a comment from her clearly saying it is no use applying now for this crisis funding, we will have to wait until after the GST is introduced. I obtained the funding myself after numerous phone calls to ADD, the last of which reduced me to breaking down over the phone whilst begging for help.

During this time I also must draw attention to the fact that our local NGO, through their assessment and process, deemed us not in need of help. We had been allocated \$1,200 and that was provided for six months for in-home respite. We used that to have two weekends respite away during the six months. The funding was not reallocated to us and that is why we were left with the \$70 a week and that is all we had. Our son was not able to access his day program regularly and his father and I continued to care for him 24 hours a day. Many sleepless nights were had by all.

I believe this organisation needs a thorough investigation as they have been primarily responsible for much of our emotional distress resulting in the cause of me having a severe breakdown a couple of years ago. Complaints to the Community Services Commission fail at the initial stage to discover the truth. After I discovered the missing 21 submissions were still at the area office of DOCS a couple of years ago, I made a complaint to the Community Services Commission in May 2000. I was the only one that would do it because no one else would support me. They decided to investigate it and called for our son's file from DOCS. I decided to view it before it went to the commission. During that viewing it was suggested by the case worker that a letter from my husband's psychiatrist be removed as she was sure we would not want the commission to see it. I was absolutely disgusted at that suggestion and the next day my husband phoned her to say that it was vitally important that that information be left there. At that time she also removed a couple of other letters that had been there for 28 years and asked did I want them because, you know, it was not needed to be put in there. It did not hit me at the time, the relevance of those letters, but just in the last week I decided to look at them and way back in 1974 that letter was written to DOCS stating that we would need an accommodation service. That was 28 years ago.

The more disgusting part of the whole thing was that some weeks later - the file was obviously sent off to the Community Services Commission - I had a call from the case worker, and she has been our case worker for probably eight years now, "Could you please tell me when you were first in crisis because we do not have much information here". They were obviously preparing a brief for the commission and that is when I noticed that this particular letter was identifying our needs 28 years ago.

I am sorry, I have so many notations in my files, I cannot cover it all in five minutes.

I would like to stress that I believe that there is a need for accurate crisis identification. I do not know how they do it, but we have been in crisis for at least 15 years and well-known to the department. Many letters to the department and ADD have been written. With the Service Access System there is no clear communication or process and also I would like an investigation of the Community Services Commission complaint lodged in May 2000 which, when I inquired in May 2001 as to where it was at, the person responsible at the Community Services Commission advised that the supervisor was on holidays, a preliminary investigation report had been completed, but they are not sure of protocol and who to send it to as DOCS is now DADHC. Where is the accountability? The person responsible stated she will ask the supervisor to phone me. I am still waiting for that phone call. It has been eight months. I question the unusual delay of this lengthy period.

Where are we at now? We are a vulnerable, disempowered family, in a mess, totally shattered, looking forward to our future when we need our superannuation funds to support us. We are going to be totally dependent on the pension - how degrading - as our funds have been depleted over the last nine years caring for our son and his brothers. Will we have to sell our own home to survive? All those years of hard work by my husband to accumulate his superannuation, an essential psychological need for a husband and father to provide for his family. I believe we need to be compensated for that. Precious lives tampered with, fragile emotions shaken violently, wounded nervous systems, our spirits completely exhausted, our very essence, our heart and soul bereft.

We have been encountering the same problems within the SAS. I have been having to go out and ring up real estate agents and find the house myself. The company involved in looking for houses needs to be investigated, I believe. Because of the receipt, I firmly believe, of these six stories by DADHC, I have had in the last three weeks so many phone calls from them it has been unbelievable and last Monday night at 6 o'clock we were given a time frame that our son would move in in February. Now I have not had the problems that the other people have had simply because I have had the service provider waiting for 15 years to provide a service and the house is for him. That has been my experience.

Mr BENNETT: Thank you for this invitation and possibly, as a result of your request for me to attend this session, it might have expedited a little quicker the eventual accommodation process for my daughter. I am not going to open old wounds about the crisis that we have been through. The Committee has my submission, the confidential submission, it has the Bennett story. I do not want to add to that, but since May last year when we met there have been 21 items of correspondence between myself and DADHC or ADD, so on receiving your request to appear as a witness today I faxed Pamela Riddiford, who is the manager of the Community Living and Development Unit, DADHC, on Wednesday, 5/12. I will read this fax and I will also submit it accordingly to the Committee. Excluding the salutations:

Dear Ms Riddiford,

Request to Report to Standing Committee for Social Issues - Deborah Bennett's Accommodation Submission.

I have not told Pamela that I had already met you, I was trying to be a bit cunning.

I understand that there exists a Legislative Council inquiry into the residential and support services being provided for people with disability. I have been directly approached to appear as a witness before this Committee on Wednesday, 12 December 2001, with the aim to advise them what has transpired and what progress your department has made towards the implementation of my daughter's accommodation strategy and submission. I have written to your office on several occasions, including discussions with your staff, with correspondence dated as late as 19 November 2001 still unanswered. The simple aim of such communication has been to clarify for us our daughter's situation, particularly in our predicament ...

I do not want to tell you again of the problems I have. I have a disabled wife, a disabled daughter, I had three showers between 5 o'clock and 6 o'clock this morning, and the story goes on, breakfast, et cetera. The simple aim of this communication has been to clarify for us this situation, particularly under our predicament,

... and the expected timing of her placement.

As you would understand, I have a dilemma due to the above invitation. I still do not have any clarity from your office as to the expected final resolution since the initial approval and submission. In order for me to provide an effective response to the Committee I require from your office an up to date status of the progress of my daughter's submission by Inala."

Inala is our selected service provider.

We understand that the submission has been accepted in total.

That is the submission by Inala for the costs and so forth, through the department, has been accepted in total.

But no clarity exists as to when final approval will be provided to enable Inala to commence the accommodation facility process. Simply advise me of your anticipated date your office will provide final approval which will allow me to provide an accurate response to the Committee.

Yours faithfully.

Also, "Naturally a response by 11 December 2001 at the latest is required". I thought that my English has not been very good. I will submit this later.

Incidentally, I have another two letters. I want these to be part of my initial submission and I would like to keep them in a confidential manner like my original submission, if you do not mind.

Last Friday, 7/12, two days after my fax to Pamela Riddiford, I had a call from a lady called Karen Thompson and after a lot of talk on the phone it resulted in a meeting being held on Monday, the 10th, at 2 p.m. at DADHC between myself, this lady, Karen Thompson, who happened to be a SAS program officer, and Paul Hawes, who is the team leader, 197 Program, SAS.

I have always dealt with people at DOCS and ADD, then you go and talk to them on the phone or meet them and they are not the same people. I am aware of the dilemma here that they do not know who they are talking to, they do not understand my daughter's problem, my family's problem, so I made sure that minutes were to be taken and advised that the minutes would be discussed at the day's meeting. Karen agreed and obliged with the minutes.

I also said to Anne before we went for the meeting I wanted a review of my daughter's needs with these two officers as I was concerned, they being in a decision and/or recommending position to facilitate my daughter's accommodation process, they must be fully aware and conscious of Deborah's needs in their entirety. I do not think that is too much to ask. I also indicated that the Bennetts are not going to hand over their 38 year old daughter of diligent and loving care to any organisation, i.e. service provider, that is Inala. I am not going to hand her over to Inala without knowing whether or not they are going to care for her properly, or for that matter to a funded organisation by a government agency. We are not going to do it that easily because, after all, we have experienced these difficulties over the last 38 years; there might be a few

years, as long as I am still alive and healthy, I am not going to give up because if you do not identify my daughter's considerations and they are not strategically placed properly in the first place they will never be placed afterwards. An example of this: If they say that my daughter needs this and there will be the funds available for it and then the service provider, after they have experience with our daughter, needs certain things, when they apply for funds there is a blank cheque, but who suffers from this? It is my daughter's life that would suffer, so I wanted to make sure that they understand because, after all, up until this point, none of the officers have, in both DOCS and also ADD, sought my daughter's medical expertise or results. They are only working from bits and pieces of paper that people write. They never talked to the activity centres that she attended for 18 years to see what her real needs are and what her problems are so that when they are in a decision making process they will know the appropriate things that they have to give her.

So in a dignified manner in this meeting we discussed, in earnest, Deborah's needs and as a result of this meeting the department made certain commitments. The meeting was held for an hour and three-quarters. I will read you some of the items, I will not go into all of the details because I do not think people will be interested and I do not want to waste your time, but the minutes: Mr Bennett reviewed Miss Bennett's support needs. He outlined the following issues: Accommodation needs, respite services, day activities, medication, long-term accommodation, behaviour issues, physical support. I raised this matter and I said to these two people, "You must be aware fully of them if you are going to negotiate accommodation for my daughter". The action that they intend to do, and it is in writing:

DADHC will request Inala review of the family respite situation and develop a plan to increase respite services to Miss Bennett.

The service that we were having for respite was next to nothing. We had respite once every three or four months. So Inala, because it is a whole unit, possibly can do that for us.

DADHC will request Inala to review Miss Bennett's day program service with a view to increasing it to five days a week.

Deborah went through a transition period. She attended Dunrossil activity centre and then, because she has gone to another activity centre, she has been doing a transition, she goes three days to Inala and two days at Dunrossil. Now Dunrossil has finished because Deborah is quite happy where she is, so we want to increase it to five days and they have said to me that they will do that in the new year. Well, that is fair enough.

DADHC has requested Inala to develop a plan over the Christmas period to ensure Miss Bennett continues to receive services.

One of the dilemmas we always had was those five weeks during Christmas when they had nothing to go to and we had to face our daughter and she says, "I'm bored". We would put her in the car, go down to the airport - she loves to look at the planes - go to the river, walk on the beach, and you think how long are you going to do it? Then when we get home she says, "I don't want to eat this rubbish, I want to go to McDonalds", and she says, "I'm bored". Because Inala has already six group homes and they have a system during the holiday period where they integrate their clients and they do day's activities, et cetera, while their workshop is closed, we are trying to get Deborah to spend two days or three days and it will also act as a transition for her.

DADHC is currently negotiating services for Miss Bennett with Inala. Inala is currently considering a model to provide services for a woman in either a duplex or granny flat support option.

This was the first time I had heard of these terminologies, but my ears are open, I am not objecting, I am not objecting to them because I might be an old-fashioned person and think, oh, duplex or granny flat, holy moses, granny flats were something of a no-go, we do not want to put our mothers in a flat in the backyard, it is a terrible way to treat them. There is a note here which says:

DADHC can provide interim funding to rent a home for the provision of supported living arrangements while plans for a long-term arrangement that meet the needs of Miss Bennett and compatible co-residents are developed.

CHAIR: That was the meeting on Monday afternoon?

Mr BENNETT: That was the meeting on Monday.

Ms ELYSEE: This week.

Mr BENNETT: This week. This is what happened in one week. The 5th was the first fax to them.

There have been a lot of things discussed, but I do not want to open wounds because I nearly told this beautiful lady on the phone, who I met, off when I told her, "Is this call that you are giving me on the 7/12 as a result of the fax that I sent to Pamela?" She said, "What fax?" I do not have to tell you what I said to her, but I asked her, I said, "Do yourself a favour. If you are going to have the meeting on the 10th, familiarise yourself with that fax", which she did and, as I said, I was very warmly received by those two people, so I am not complaining.

In addition to that I have received a fax dated 10/12 from Pamela Riddiford. It is an official one because it is under the heading of the aging department. There are seven paragraphs. I think myself I do not want to go into detail, I will let you in your deliberations look at it. I do not want to bother my friends over here and open their wounds any further. She said in one of the paragraphs:

At your meeting with Ms Karen Thompson and Paul Hawes of this unit earlier today I understand that you clarified the current situation with regards to the planned new living arrangements for your daughter.

So she agrees with what they have done.

The unit has been working with Inala to develop accommodation for your daughter as soon as possible. As discussed at your meeting earlier today, it is important to move forward whenever possible with at least two people with disability sharing accommodation support.

In our submission to Inala we asked that Deborah would live on her own.

Another paragraph, and I agree here wholeheartedly because I can understand the dilemmas:

In establishing a home for one person and then introducing others we have found that the first person may well consider the later inclusion of someone else unwelcome.

I can understand that that could happen.

So for this reason we are trying to ensure that people able to share support are identified before an initial move is made.

She tells me also:

Inala has now identified a person able to share a living arrangement with Deborah. We have spoken to Mr John Wilshire.

Mr John Wilshire is not the secretary, he is--

Ms ELYSEE: He is the manager, isn't he?

Mr BENNETT: No, he is not the manager.

CHAIR: We can check that. He is at Inala, is he?

Mr BENNETT: He is at Inala, he is number one at Inala.

We have spoken to Mr John Wilshire about finding rental property to provide supported accommodation as soon as possible.

So when I got that I picked up the phone and rang John. I said, "John, you have been talking with Karen?" He said, "Yes", and I said, "I do believe also that there is a girl that you think--" and he said, "Yes". I said, "Well, I see you every second day when I bring my daughter over there, you haven't been telling me anything". "Oh well, Jack", he said, "I don't want to raise your hopes and then something goes wrong". I said, "All right, when are we going to talk?" He said, "We will talk this week". That is a light at the end of the tunnel. I do sincerely hope it is not a train coming at us. Also I do hope that the enthusiasm shown by the department will continue because I will make sure that I keep in contact with them.

Ms ELYSEE: Thanks, Jack.

Mr BENNETT: Can I finish up this way, please, if you don't mind - I have to say my peace.

Ms ELYSEE: So does everybody.

Mr BENNETT: May I take this opportunity, Madam Chair, to thank two organisations for their continued support towards our daughter, providing counselling and advocacy all during this time, and I refer to none other than the Western Sydney Intellectual Disability Group and the Statewide Disability Coalition. Thank you.

I will hand you those documents and I would appreciate it if they are confidentially kept.

CHAIR: Yes.

Ms ELYSEE: Madam Chair, what you see demonstrated here is the depth of effort of persistence and perseverance that family advocates have needed over the years to undertake to keep going and Jack has been the most wonderful advocate, as has every other family member here on behalf of their family members. Not every family has been able to achieve advocacy of this level and our concern is about all those other families who are experiencing truly terrible things still silently out in the community and it has been a major role of our organisation to try and bring this to the fore.

Anne has a couple of closing remarks.

Ms WHAITE: I just wanted to add to what Anne Elysee has been saying. The reason for writing these stories was that within our advocacy group about 18 months ago people had come to you and given evidence. In November 2001 when we produced these reports, as it says there, there had been no significant change in terms of permanent accommodation for the six families here. We sent a copy of this to Margaret Alison at DADHC, the new director general, and we sent a copy to each of the Committee. We did that as a first phase because we thought we should do that - it is a very bad time of the year - as a courtesy to you and to them to let them know that, come the beginning of the year, we were really going to act on the lack of any progress, if you like, in these cases. What we have seen so clearly is what that has led to in a period of two to three weeks in terms of really positive and effective changes for at least a couple of the families here. However, we also feel that the experience of the families today and the response to this is a very graphic illustration, if you like, of the problems that we are trying to bring to you that are within the system.

We have also had Mr Smith here who has described to you what it is like to be at the beginning of the system, to have even a request for respite lost, so that for six months, when you are thinking you are about to have a two week break, the submission that has gone in to request that has been lost, it does not even exist. I mean that is just an appalling situation and that shows you some of the problems, the bottlenecks, call them what you will, at the very first stage of the system. You have also seen from the stories the way that continues throughout the process, the real problems. There is a lot of good intent from people within the SAS system to move these things forward, but it is just not working effectively. It has also I think highlighted the crisis response. I guess our first reaction is obviously delight for the people that were involved, but it raises the question: Is that saying that the system can produce this when required and it is just not choosing to do this or is it rather, I guess what we suspect, that when a crisis comes, when a political situation arises such as this, these situations are taken outside of the system. They are now the absolute priority so that there is not a lot of negative feedback to the department. Again, that is wonderful for our families. What we are saying is: What about the other 2,000? The system needs to be working better to address these issues.

We have already said we are not looking for another major change in the system, we are really concerned that yet another change is just more words and more waiting and different labels, but it does not change the situations on the ground. Our main recommendation to the Committee is that if there is anything that you can do to address, by your processes, and identify the inefficiencies in the system and perhaps have it looked at by, we say, an organisation such as the Community Services Commission because of their slight independence but also because of their knowledge of the disability system, and I think one of the major problems is that people come in all the time who really do not have a lot of knowledge of this system and we just simply feel that, if this does not happen, any recommendations that you make, any other issues, any other recommendations that are made, nothing is going to happen and the only way that things

are going to happen is through this crisis management or crisis response, I suppose, that has been illustrated to you here today by the production of these six stories.

I think that is all we wanted to say to you, thank you very much.

CHAIR: What you have shown to us is how long it takes and how difficult it may be and also perhaps the value of a committee. I do not know whether we could do six families a week for however many weeks it takes to provide for 2,000, but it certainly does raise issues about the whole process, so we are very glad we have listened to you because you really have reinforced a number of the points we are thinking about mentioning in our final report.

Ms ELYSEE: We just have to delve deeper into the ability of large bureaucratic structures to deliver community based services. What are the structures and organisations, first of all? That is your first move. It is the structure itself. I often see the large bureaucracies - it is a bit like turning around a battleship, it takes three miles and several hours to turn it around, so how do bureaucracies organise themselves in a flexible manner, first of all, to be able to be responsive? To a certain extent I believe that the terrible stories we have heard about submissions getting lost at regional level, these horror stories that we have heard in the past, this time around they decided they were going to centralise everything, but they did not just centralise the receipt of the applications, they centralised the whole process and so now they have lost the flexibility of the regional level, so the pendulum swings backwards and forwards.

CHAIR: Let us ask a few questions because obviously we do not have too much longer today and you may want to say some of that in answering questions and then maybe someone else in one of the families might want to say something.

The Hon. DOUG MOPPETT: The difficulty even in the course of this inquiry seems to have developed rather than to have been resolved, but the metaphor I was going to use was that at head office they cannot see the trees for the woods, but the case worker cannot see the woods because they are engaged tree by tree, and it seems that as we go through the laudable, shall we say, refinement of the process - I mean we are always being told, oh no, that has been superseded, we do not think the group home is now the be and end all, we think that respite care has to be delivered in a more flexible way. That leaves those delivering the services in a state of flux and those that are seeking the services are just parked again while the whole thing is being resolved and refined and up in the clouds someone is saying at the end of all this process it is going to be better, but no one actually moves.

Ms ELYSEE: That is right.

Ms WHAITE: There is not an outcome.

The Hon. DOUG MOPPETT: No, there is no direct service being delivered or at the rate that we had hoped in our report because I think we have always felt, whilst the public hide their gaze from all this by words like the floodgates and, you know, there is just an inestimable demand out there, we know that there is not, it is a finite amount of people.

Ms ELYSEE: Yes, and it is achievable.

The Hon. DOUG MOPPETT: Yes, and I think the question I wanted to get back to was that I think it is terribly important for us to be familiar with the individual cases, that is looking at each tree, but we do need the assistance of your organisation to have some idea about, at least in your neck of the woods, what are the proportions. Do you feel there are more people being identified who are even further down the track who are not as yet accessing services? That has always been our problem when we talk about devolution, that we are dealing with people who have some form of accommodation and are trying to find something better. There are heaps of people out there who are almost in intolerable situations.

Ms ELYSEE: That is right. I think the SAS, the Service Access System, is tapping in on the unmet need in the community, not in the institutions, so those 2,000 applications that have gone into the SAS are from family members and people in the community who are not getting access to any service.

The Hon. DOUG MOPPETT: And do you think that is a reasonable method by which an administration says, well, look, this is the test. If you claim you have a real problem that you think should be resolved, at least you should be able to put in an application form and pursue it. Is this going to be

ultimately an accurate tool for assessing unmet need?

Ms ELYSEE: We support the concept of SAS in principle. What we have really been discussing today is, at the moment, the very, very long-winded way in which it is being implemented and which we are trying to identify, but at every step of the process there were bottlenecks. People are starting off on a waiting list here; they move to stage two and they go to another waiting list; they move to stage three and they go to another waiting list, and these families spoke to you in May 2000 and just now we have two of them who have actually just about got offers. That is 18 months later.

Mr BENNETT: And it did not come voluntarily from the department. As I said earlier, I keep knocking, to the point that it is almost embarrassing.

Ms ELYSEE: That is right, persistence.

Mr BENNETT: It could be possibly also that that occurred because when I see a crisis I get very angry and that is when I pick up the phone. When everything is quite smooth we just live harmoniously. Plus the fact too you have hundreds of other parents like us who have not got the vocal thing where they will pick up the phone and talk to somebody.

CHAIR: Part of Doug's question I think is do you think, for instance, that the approximate 2,000 applications that have been received represent the majority of the families in or approaching crisis--

Ms ELYSEE: I would like to.

CHAIR: --in which case maybe do we now have some idea of the dimensions of the problem and can we therefore look forward to solutions?

Ms WHAITE: There does seem to be a sense of that. The Service Access System itself replaced something which was called crisis funding which was, in many ways, exactly the same system in that, if you were in crisis, you put in a submission and you would be responded to. From what we can gather, and I think part of the problem is the lack of information about this, organisations such as the Community Services Commission have been trying to get data on this and it is promised and it does not necessarily come very rapidly, but we think that the Service Access System has identified that to some extent, so I think we are getting some sense of the quantity of it. The 197 Program is, of course, in addition to that SAS program, so obviously we are not looking at accurate numbers, but I do not think we are perhaps looking at the difference between, you know, is it more like 2,000 or 3,000 or is it more like 10 or 20? I think we are looking at more like the 2,000 or 3,000. Of course, being called a Service Access System, if I was someone in the community wanting a service, I would try and access it via the Service Access System, so I think just by its very name it encourages people to come to it who might not necessarily be in as much of a state of crisis as anything else, but I guess our feeling is, to answer your question, that we are getting some idea of the order.

Ms ELYSEE: To get to the heart of your problem, though, we have to be looking at the people at the moment, the younger people with disabilities living in the community now who are actually not yet in crisis, who are not yet at the stage where they need to put in a SAS form and we need to try and tap into those figures to get a good idea of what is going to be coming up.

Ms DIXON: Can I just ask a question on that issue: When you say we need to be - who? Who does the research? Who provides the evidence?

CHAIR: We, the community.

Ms ELYSEE: We, the community, and identify it as a responsibility of government.

Ms DIXON: Isn't that being done now?

Ms ELYSEE: No.

Ms DIXON: Aren't people researching the needs and the children that are growing up and coming into this system?

CHAIR: Perhaps I could ask my question because we might get to some of that.

Ms DIXON: I am sorry, but I just think that is very important.

CHAIR: It is, but there are different ways of getting the information. I wanted to ask about respite, for instance. I think one of the ways in which respite services are developing is also giving us information on developing needs as well, but it is all a great jigsaw.

The Hon. AMANDA FAZIO: I wanted to ask Maria, mainly because your son seems to be one of the younger people who are included in the six case studies here today, your son was in a school situation until what age?

Ms FINNANE: Until the age of 18. He has always lived at home. He went to a special school until the age of 18 and is now at a post-school option program. He was in the first year of post-school options.

The Hon. AMANDA FAZIO: When he was getting towards the end of his school years, and maybe some of the other parents can comment on this as well, apart from the offer of post-school options, did anyone from the State Government talk constructively with you about what might happen later on, because it seems a lot of the stresses, particularly for families with older family members when there was no post-school option program - did anyone ever talk to you about what might be done to alleviate that being at school five days a week to being basically cared for by the family for that five days? Did anyone talk to you about anything other than post-school options or was that the only offer?

Ms FINNANE: Well, for a start, post-school options were not offered to us. He was a school leaver of 1993 and we, as parents, had to lobby and through various organisations such as CID we lobbied the Government. We actually had a Tent City in Hyde Park for a couple of nights and we rallied the streets and, through that, we were able to get the post-school options up and running. 1994 was the first post-school options. Prior to that the outlook was he is not able to go into a workshop situation because he has high support needs and would not be accepted. Prior to that he would have had to be sitting at home with us, his parents, and some of my friends whose children had left school one or two years prior, that is actually what was happening with them.

Ms DIXON: And that is what happened to us too.

CHAIR: We are going to have to finish very soon; we are actually not permitted to sit while the House is sitting.

Mr BENNETT: There were the special schools, there were activity centres, sheltered workshops. If you happened to have a child who was not capable of attending a sheltered workshop, his or her only opportunity was to go to an activity centre or stay at home, but there was no guidance in any shape or form from any government body to direct our children, when they finished special school, to where was best suitable. It was up to the parents, as Maria has experienced, I have experienced, that you have to push your own barrow.

The Hon. AMANDA FAZIO: I think that follows on a little bit from your question about whether anybody is looking at needs. You have all the kids now in special schools and apart from post-school options which is subject to review and all the rest of it, it would alleviate, perhaps, a lot of the crisis if there was some discussion--

Ms DIXON: It would, if there was a strategy before they left school for what we did or were going to do, but that never happened until a lot of years down the track.

CHAIR: That is related to some extent to what I was going to ask. I think each of you has given us some detail about your experience of respite services, whether good or bad. There is some evidence that suggests that the injection of funding across the three areas we identified, devolution, respite, accommodation - in the respite area some sort of breakthrough is occurring, that the funding for services there may be moving a little bit faster. I suppose a double-barrelled question: Have you, as a group of families, seen any improvement, development or increase in respite and, secondly, does the association see any across the board with your other families as well; do you see any increase or development in respite?

Ms DIXON: Well, I do know I cannot access a respite care house now because of Terry's

behaviour, and the fact that I left him in the respite care I guess, but I do know that Maunder Avenue still only has one bed available for all the families in our area and that is wrong.

CHAIR: Because of blocked beds or--

Ms DIXON: Yes.

Ms FINNANE: There were originally four beds blocked, one by a family and three by the department itself. They discovered these people were inappropriately placed, even though the families were happy with that situation. They took them out of their placements and blocked the beds, so that has been now for at least three years.

Mr BENNETT: You asked whether there had been an improvement and the thing that frustrates me is that it is correct to say that there are three beds blocked. These three clients at Maunder House are part of the 197 Program, they are people that used to be ADD or DOCS and between these two departments, after how many months now, they have not placed those three people so that they can give people like us, with our children at home, a bit of respite. Now this is the inadequacy and inefficiency that it chose for itself. If you use Maunder as a glaring example of the lack of cooperation, that they can place these three people in proper accommodation and they are under their own wing, they know them back to front--

Ms FINNANE: They are assessed as being compatible, so the three of them who are currently blocking are assessed to move out into a home.

Mr BENNETT: That is glaring example.

Ms THOMSON: There are only two respite houses in the western Sydney area that we cover. One of them is Maunder Place, which has three blocked beds and one bed available. The other one is Deed Place which we talked about earlier which is run by Mission Australia. They are pulling out of that. It is going to tender, it is being re-auspiced, so the families are actually in the situation where they do not know what is going to happen with that place, the only other place for respite, apart from Maunder Avenue where there is only one bed, so in fact I think things are worse than they were.

CHAIR: Is there any sign of new services developing?

Ms THOMSON: DADHC is talking about taking that on as well, and other services and Mission Australia - they are pulling out because they cannot afford to run it.

Ms FINNANE: They have not been able to access extra funding.

Ms RAMSAY: They are not funded sufficiently to run it.

The Hon. DOUG MOPPETT: And what about the magic words: Non-centre based respite?

Ms FINNANE: That is what I wanted to say something about. Our particular requirement is that we need respite for seven days a week and I have tabled in my letter - I did not speak about it earlier because I just spoke about the SAS - we are currently using a non-centre based respite service for the weekends. It is so-called flexible respite. It does not meet the need of the family. The first instance is that this organisation, Riverlink, does not allow their support worker to transport the person with a disability in their own car, which means that he can only access the bus or the train and, as I have said here, he has high support needs. It is inappropriate for him to always travel on public transport. For example, the first time he was taken out he refused to get on the bus and they then walked him to the station and he got on the train but he refused to get off at the destination. So there are numerous problems with this particular type of respite, that is if your support worker turns up for the day, and you are having a different support worker nearly each weekend. For a person who has autism, this is inappropriate, and so it has caused problems with my son to the extent where his post-school option program has phoned us and asked us what is happening. It has completely unsettled our son.

CHAIR: Do you have any idea of the qualifications or training of these various support workers who turn up?

Ms FINNANE: None. We have to take everything on trust. We have to meet new people to

take our son out, probably spend about ten minutes to continue to tell the story of what our son's needs are and then we pray that he is kept safe while he is taken out by a stranger.

CHAIR: Getting back to what I was saying before, what about families with children who are younger? Is there any sign with respite services - obviously western Sydney is not looking good. We have had some evidence about other areas where new services seem to be developing. Is there any hopeful news coming out of that?

Ms ELYSEE: Well, I do not think we are really in touch with that sector, you would have to ask other people. I think it is always a problem in following through whether announcements of money actually get on the ground and whether money is actually spent.

The Hon. AMANDA FAZIO: I sometimes describe it as a funnel: You put all the resources and all the money in a funnel and occasionally a drip comes out the bottom.

Ms ELYSEE: Yes, absolutely.

Ms ALLEN: Could I make a comment: There are probably not a lot of families, but I always try to accentuate those families that have people at home with medical problems that cannot access day programs or anything else and there is, I believe, a great need for support for those families and that is where we have had to tap into because our son has not accessed his day program for over a year and it is a real difficulty again to find appropriate workers because they sort of need a little bit of medical background. I have been deeply concerned to the point where I search around myself to try and find people I know and I have been fairly successful with that, but again it is this great dilemma of: Can we trust these people with our children, particularly our children that cannot speak to tell us what goes on when they are taken out to the activity or, in our case, when our son is looked after at home and we have a little bit of respite.

CHAIR: When you say you search for people you know, how do you manage that in terms of the funding that is available, or are you talking about meeting the cost yourself?

Ms ALLEN: Sometimes we have, but it is people that I have made contact with from day programs or you meet, you know, I always go out with an ear open and someone will invariably say, "I don't have a job at the moment" or "I'm in the process of changing jobs" and so on. It is extremely difficult, but one of the carers we have at the moment is in that position, but it has not been for very long.

CHAIR: All right, well, we had better finish I guess. We have a couple of formal things that we have to do. Doug, would you like to move a formal motion to authorise the publication of the transcript of today's proceedings subject to the deletion of any material that identifies family members of people who have a disability?

The Hon. DOUG MOPPETT: I am happy to move that.

CHAIR: The other thing is to say that we would be very pleased to accept any later material from you, particularly written material, which is obviously easier for us. Obviously we are working on our final report, which we hope to table early next year, but we would very much like to be able to continue your stories through, hopefully to excellent conclusions, so we would be grateful if you could keep us updated, so those of you who look as if there might be actually a house--

Ms WHAITE: So a February update?

CHAIR: Well, a February update would be fantastic.

The Hon. DOUG MOPPETT: Just one other thing, and the February update might be the appropriate time, just in these figures of 2,000 applications received, 1,400 assessed and 140 referred, there is no mention of your being aware of any that have been, shall I call it, declined.

Ms ELYSEE: No, I do not know how many have been rejected, but I can find out.

The Hon. DOUG MOPPETT: If you could.

Ms ELYSEE: Yes.

The Hon. DOUG MOPPETT: Because I think there has been some wrestling with what sort of assessment is the 2,000, could you quote the 2,000 as being in extreme crisis and undeniable cases.

Ms ELYSEE: All you can say of the 2,000 is that whoever knows about the SAS system has put a form in.

Ms WHAITE: But you are looking at how many people have actually been deemed to be eligible under that system given those criteria.

Ms ELYSEE: No, how many have been rejected, which is a different thing. They may be still processing.

The Hon. DOUG MOPPETT: There is a gap between the 1,400 assessed and the 140 passed on, so are they just pending or--

Ms ELYSEE: If the 1,400 are assessed as eligible, they have to be passed on. In other words, only 140 have had plans made, the whole 1,400 have got to have plans done.

CHAIR: So we need to find out whether the 600 include some people--

Ms ELYSEE: That is right, who have been rejected or are still to be dealt with, yes.

CHAIR: Our guess is that most of the 2,000 would be families like yourselves who are probably the most experienced and knowledgeable people.

Ms DIXON: Yes.

Ms ELYSEE: That is right. As I said, one of the six is still being questioned by the department as to whether the risk they are experiencing is high enough for them to be eligible.

Ms THOMSON: That is another issue of the reliance on a single form, that you are deemed eligible. People from non-English speaking backgrounds and others may not have the ability to fill the forms out.

Ms RAMSAY: And they do not want to admit that they are in crisis, it is something that they do not want to actually have to tick to say that they are not coping.

CHAIR: We need one final motion, the authorisation to broadcast public proceedings, if someone would like to move that.

The Hon. DOUG MOPPETT: Yes.

CHAIR: Thank you once again for sharing your stories with us. It is incredibly helpful for us and we hope that your stories and what they show about the system might be helpful to other families as well.

(The Committee adjourned at 10.50 a.m.)