CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Ms S. Tait, president, Intellectual Disability Review Panel.

The CHAIR — I declare open this subcommittee hearing on the Auditor-General's report no. 53 on services for people with an intellectual disability. I welcome Ms Sue Tate, president of the Intellectual Disability Review Panel, to the public hearing. All evidence taken by this subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected from judicial review. However, any comments made outside the precinct of this hearing are not protected by parliamentary privilege. All evidence given today is being recorded, and witnesses will be provided with a copy of the transcript later this week. In accordance with guidelines on public hearings, I remind members of the public that they cannot participate in the committee's proceedings; nevertheless, they are warmly welcomed at this open hearing. Could mobile phones be turned off, please. Ms Tait, if you would like to make a brief opening statement for the subcommittee on developments that have occurred in your precinct since the Auditor-General's report, we would appreciate it.

Ms TAIT — Thanks very much. I have given you all a package, and just in case any of you have insomnia, you may be able to find this a treatment aid for that. It is intended to be a resource that hopefully demonstrates some of the panel's commitment to implementing the recommendations of the Auditor-General. Perhaps if I say by way of overview that I have been in my position for four and a half years, being appointed on 1 January 2000. I commenced the position in a time of change — a new government and a new minister, in the context of the Auditor-General's report and with the history of the Intellectual Disability Review Panel, which was then about 13 years old. During that 13 years my predecessors had consistently and persistently criticised some of the powers of the Intellectual Disability Review Panel and said that there were structural defects in the legislation which meant in effect that it was a toothless tiger. The panel is intended to be the watchdog or an ombudsman on the delivery of disability services. As I say I started six months into a financial year, and to give you some statistics, the population of Victoria is about 4 million which means by definition there are 80 000 people with intellectual disability in the state of Victoria.

The department provides services to just over 10 per cent of this group of about 9 000 people from my memory of the department's latest statistics. Of that the department identifies that nearly half of the people who receive intellectual disability services are considered by the providers to have no effective communication. So if people cannot communicate it is very difficult for them to complain, and we are the only mechanism through which people with an intellectual disability or their families can complain. Half way through the financial year from 1 January 2000 I can say that the Intellectual Disability Review Panel had conducted zero hearings. I can say that we had a 300 per cent growth in productivity in my first six months — that meant that there were three hearings for nearly 9000 service users. The Auditor-General in the report commented upon the fact that the panel seemed to be poorly understood, that people did not know their rights and there were concerns about people being informed of their right to complain. As part of our response to the Auditor-General's inquiry, we had an extensive education campaign; we had our mugs advertised on *The Panel* television program. I have stress balls as well as fridge magnets in my bag for you later. In the first annual report I probably spoke to about 1000 people personally at conferences in relation to hearings and the key function of the panel which is to hear complaints, and the other key function is to monitor seclusion and restraint.

I have talked about the complaints function: we do not do it very well, and there are very good reasons, after talking to people over the years, why family members do not complain. One understandable one — though maybe not necessarily a true concern — is backlash, because people are going to have to leave their adult son or daughter in the service after they have complained. It is a legitimate and understandable fear; that there will be backlash. The other concern — and I have heard it on more than one occasion — is that people are told that they are very lucky to have the service they have, that if they do not like it they can leave because it is voluntary and there are significant numbers of people who by the time they have had an adult with an intellectual disability for 18 years of trying to get support, numbers of ageing parents will say, 'I am too tired to complain'. The problem with those who know the system well is when they come to us, all we can do is make recommendations as well. So if the department chooses to ignore our recommendations, they have had the trauma, expense and, if you like, time effectively wasted. I should say that the great majority of our recommendations are accepted by the department but when you are talking about 5 to 12 hearings a year — we have done 12 hearings this financial year; a huge increase in productivity from 3 but still, frankly, a joke. That is the hearing function.

The restraint and seclusion function is even more vexed. There are inconsistencies within the legislation, inconsistencies in relation to the department's policies and, I think, inconsistencies in relation to some fundamental rights issues. There is no clarity about what should be reported or who should report it and when. We have a system which is still, in 2004, paper based. We were criticised by the Auditor-General for having a largely paper-based system. The costs associated with investing in a computer-based system are not insignificant. For the four and a half years and more I have been in the position the legislation has been under review and changes have been coming. Why invest in an electronic database which may change? Frankly, I have significant criticisms of the way we receive reports. Some people are on drugs properly and appropriately and why we get bits of paper about them every month is a flight of fancy; there is no logic to that. On the other hand, there are restrictive practices happening within services that we have no ability to monitor and no ability to audit. The department will not be able to tell you how many people live in locked houses. The department will be lucky to be able to tell you how many authorised program officers it has and who they are. The regions will not be able to tell you who the authorised program officers of their non-government agencies are. We know in terms of our annual report of the number of services which provide reports to us but probably significant numbers of agencies do not report to us. We cannot tell you who because we do not know who they are.

We have no authority to go and inspect or audit services. We have done some trials in relation to that, mainly as an evidence-gathering exercise in the hope of being able to inform legislation, but that is by invitation. We do not have much work to do, because we have little demand on our hearing process so recently my executive officer emailed the adult training services asking if they would like me to come and talk to the service users about what their rights are; in your package is a kit developed to work with people with intellectual disability themselves. We got responses from four agencies, quickly but clearly they are the four agencies you have no worries about if people are wanting you to come and visit. I guess that is the overview of the intellectual disability review panel. You will see from our submission to the Auditor-General that we said the structural defects could not be changed without an urgent legislative change. That is still the position four and a half years later — urgent legislative amendment is necessary. I do not want to say anymore about the intellectual disability review panel unless you have some comments or questions about that.

However, I would like to make one comment in relation to the department's response to the recommendations about individual planning, and I will do it by way of an example. The Intellectually Disabled Persons' Services Act was really groundbreaking, innovative, world-leading legislation in 1986. This Parliament is to be congratulated because it really led the world. This is one of very few jurisdictions internationally which has a separate piece of legislation for people with intellectual disability. The key mark of that was instituting statutory plans for people. The way they have been implemented is another issue. We find in the few reviews we do conduct that the plans are pieces of paper — they are not living and breathing plans. I think the Auditor-General recognised that, and in its attempt to respond to that area the department has a program it is calling Support and Choice. It is about planning for individuals with intellectual disability who may need more than one sort of service.

I am not up to date with how each of the regions is implementing this. I know each of the regions is able to implement it separately and apart, but because we have departmental members on our panel I know how one region is implementing Support and Choice. They have identified planners. Those planners go out and meet with the person and the people around that person and develop a plan about what should be happening to develop that person intellectually, emotionally, socially and with a skills base. They develop a comprehensive plan. That plan then goes to a second employee whose job is to cost the plan. Once the plan has been costed there are three more people who sit as a panel. Their job is to look at the way the plan has been costed and to approve the funding in relation to the cost of the plan. There is then a sixth person whose job is to broker the service if the plan has been approved. There are six people who have looked at an individual's plan, five of whom may never have met the person about whom they are making decisions and none of whom except the planner has done anything yet — the person has not received any services yet. Frankly, it does not matter whether you are talking about a $5000-a-year plan or a $250 000-a-year plan.

My concern is that if it is happening in one region, then it is not achieving the desired outcomes in relation to what was intended. The notion of being able to have probity and appropriate responsible money management is a clear thing, but if we are talking about having value for public money, should we not be talking about having one person who has a budget and is able to develop a plan, is able to, if you like, own the plan with the person who is affected by the decision and their family and their associates, who knows the area, who can broker it and do the whole job in one, and then that notion of there being corporate or collective responsibility for what has been decided?

I guess I can give you another example of my concern about the way the Support and Choice plans are being implemented and that is in relation to a hearing I conducted where an individual was moving from a restricted service — in fact, the statewide forensic service — to another service. We were recommending this person leave. The beginning of the hearing involved me working with the person about what they liked doing, where they wanted to live, what sorts of activities they wanted to do during the day, what footy team they barracked for, what music they liked and developing a comprehensive picture of the person. In the hearing there were existing staff and new staff — new case managers. I spent half an hour finding out about the person. I then went to the case manager at Northern region — and I do not want to identify any person — and said, 'Well, now, Case Manager, what are you going to do next, after this hearing, given that we all agree this person should leave?'. He said, 'We think we are going to use some of the Support and Choice money, and we are going to employ a planner to work out what this person wants to do'.

I think there has been an enormous amount of well-written documentation in the time that I have been in this job, and the state plan is visionary, but I think it reinforces the vision that was established in 1986 which is that citizens with intellectual disability have the rights to reasonable quality services, the right to be part of the community and to have access to mainstream services, not to be discriminated against but to get the specialist services they need when they need them. That is what the act says and that is what the state plan says. But I am not sure whether people with intellectual disability — I should not say that, I know that significant numbers of people with intellectual disability have had enormous quality of life enhancement experiences over the last 15 years — but I am not sure that that has changed very much over the last four to five since I have been in the position.

The CHAIR — We normally allow people about 10 minutes for their presentation. Yours went quite a bit longer, but it was extremely informative. So thank you for that. We therefore will necessarily have to curtail our questions in order to keep the process running on time today. What we are able to do and have been doing is following up with written questions so that if people wish to put on the record a couple of questions and you have not had time to answer them today, that can be done. Is that acceptable?

Ms TAIT — Yes.

The CHAIR — Can I go to the implementation of Support and Choice that you spoke about in detail, particularly on value for money. What would be your key recommendation, other than the person who is the broker basically identifying the plan that is required and brokering it? Is there anything else that you would recommend that would enable a person with an intellectual disability to have a roads-based framework and also meet the objectives of the act and value for money?

Ms TAIT — I am by no means an expert about this, but I would be saying that my experience is that there are two issues. People with intellectual disability are not a homogenous part of the population. All they have in common might be that they have an intellectual disability, so the ability to which individuals might be able to assert their individuality may depend on their family and their environment and the sort of network they have around them, the sorts of people in their lives who are interested in wanting to, if you like, tap the potential of the person or help the person to tap their potential. There needs to be a mechanism in place that enables people with impaired communication — 4600, the service provider, says no effective communication. That means the person is not able to use words, probably; it does not mean they cannot communicate, but it is lengthy and time consuming to understand what the person is saying. In our submission to the legislation we introduced the notion of an assistant decision-maker, not a substitute decision-maker; not somebody whose job is to take over like a guardian or a parent, but somebody whose job is to bring, if you like, as much as possible a conflict-of-interest-free background.

The CHAIR — Why would that be different to what you have, in your capacity, with the IDRP?

Ms TAIT — We should be, if you like, an independent check and balance. At the coalface there needs to be someone in people's lives to assist decision making, and their key job must be to know the person, to know their environment, to work with the person to enhance their communication, enhance their experience of working out what they like and what they do not like, what risks to take and what not to do. I think some family members can do that really well, and some advocates can do that really well, but some people have neither of those. There needs to be a check and balance in relation to people's lives so that that is, if you like, in-built as part of the service system. We say that if someone is receiving special services, then the service provider should have a responsibility to make sure that the person is assisted in decision making by someone who will bring, if you like, the right framework and not a conflict of interest in relation to that. That is at that level in relation to them being, if you like, a negotiating partner with the person with the disability.

The CHAIR — So you are bringing one more person into that. You were critical of the numbers that are involved, unnecessarily, but this is one you see as essential.

Ms TAIT — I guess it is, yes.

Mr FORWOOD — I have four issues I would like to briefly raise. The first issue is that you said that you had provided recommendations to the department. Are they recommendations about individuals in the system or other recommendations?

Ms TAIT — In our hearing process we do a bit of both. We will make recommendations about individuals, but we may have some systemic recommendations as well.

Mr FORWOOD — I would like your opinion on the department's reaction and response to the Auditor-General's report.

Ms TAIT — I re-read it four years later, recently. I think the department was hoping and was inspired to improve the service system. I think it put a lot of investment and reliance on the Disability Advisory Council to assist that — the recognition that there was going to be some independent support for that. The department, without a clarity of vision about what it was going to do, did go some way to embracing it in its response. I do not think that that impetus, even though it was not necessarily wildly enthusiastic, has been maintained.

Mr FORWOOD — I must say my own view is that it was well intentioned but ineffective.

Ms TAIT — Yes, much more articulate and shorter.

Mr FORWOOD — Yesterday I put to the department that I was suspicious that the intention behind the legislative change was because it could not meet the statutory obligations that currently exist in the act and that it would do away with them in the review. I wonder if you would care to express a view.

Ms TAIT — I am finding it very difficult to express a view on the review, because there is very little information coming out of the department. I think there may be some impetus within the department for there to be a broad wish-list framework which will assist it to do some cost shifting in relation to resources, so a funding framework. I think there is still some impetus for that, just to assist them to achieve, if you like, a resource redistribution. My answer to them in relation to that is that there is nothing in the legislation that stops them doing what they want anyway. The current legislation is not a prohibitor to that.

Mr FORWOOD — I have one last question — very brief. The act says that you hold office for a period of five years and you are four and a half years in. Are you going to be reappointed?

Ms TAIT — No, I am not seeking reappointment.

Mr BAXTER — That was a very illuminating presentation, thank you. But it made it clear that the practice is not meeting the theory, as glorious as the theory might be. Could I just go to a couple of details? You mentioned that when you circulated to the adult training centres offering some sort of presentation you only had responses from four. Roughly how many are there anyway, and do you have any idea why the response was so low? Is it because they perceive the panel to be some sort of checking policeman that they do not want to get involved with, or simply some other reason? And you made another comment, I think it was to do with seclusion. You said the panel does not know who they are? Why does the panel not know who they are? Because the department does not have a full list, or what? Could you just expand on those two aspects, please?

Ms TAIT — Just with the number of adult training services, at page 44 I can tell you the number of adult training service providers — there are 81 — that report to us statewide. In relation to the locked units the department cannot tell you, and I cannot tell you. I do not know how many CRUs have a locked-door policy; there is no record. The definition of seclusion under the act is the sole confinement of a person in a room that they are not able to open the doors or windows of. But there is nothing stopping two people being confined in that room. That is not seclusion according to the act; that is an example of the real problem I have with the language of the act. The way around seclusion is to lock two people in a room together.

Mr BAXTER — So it is statistics and damn lies and all that wrapped up in this?

Ms TAIT — Yes. And for four years now there has been a critique in our report, under restraint and seclusion, about the unreliability of the figures and what they mean. The other thing about seclusion is that you do not have to lock a door for some people with an intellectual disability. You just have to be bigger than them and say, ‘Do not come out’. You do not even have to be bigger; you just have to have some keys and say, ‘You are not allowed out now’.

Mr MERLINO — Just following on from Mr Baxter’s question about seclusion, could you inform the committee what kind of changes you would like to see within the legislation in regard to both restraint and seclusion?

Ms TAIT — Some of those details are in our submission which you have. I would like to see a licensing of services. Services that are able to lock people up need to be licensed, and they need to be audited in relation to that. Some restrictive decisions need to be independently reviewed automatically by a body that has got determinative powers — for example, it should not be possible for a person to be admitted to an institution without prior permission from an independent body. That does not happen now.

There needs to be some flexibility around, if you like, proclaiming drugs that are reported. One of the real problems I have is that if a person with an intellectual disability is receiving drugs under the auspices of a psychiatrist, they are not reported to us. So if you look at our stats at Kew Cottages we have — this is last year, so there are not so many people there — at page 44, Eastern Region, 449 residents of an institution. That is all Kew. Three of them were reported to us as being on restraint and/or seclusion. Now we are reviewing them we know that an unknown number of them are receiving services from a psychiatrist but none of them is being reviewed by the Mental Health Review Board. So none of them has their mental health monitored. If they are receiving treatment for a mental illness and they are not able to give informed consent, they need to be either protected by the Mental Health Act or by this act. Currently they are not protected by any.

The CHAIR — Thank you very much for your report. Personally I think it has been a very informative session. I am glad you are about to hand us a stress ball in Demons colours. I am very impressed, even if they are not yellow and brown for Mr Merlino. Thank you for that. Should there be any other follow-up, that will be distributed by our research officer. Thank you very much.

Witness withdrew.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Ms A. Lyon, director, home and community services, MECWA.

The CHAIR — I now welcome Ms Anne Lyon, director, home and community services, MECWA, to the public hearing. All evidence taken by the subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected from judicial review. However, any comments made outside the precincts of this hearing are not protected by parliamentary privilege. All evidence given today is being recorded and you will be provided with a proof version of the transcript for your comment and verification. In accordance with the guidelines of public hearings I remind members of the public that they are very welcome, but they cannot participate in the committee proceedings. I ask anyone who has just joined us with a mobile phone to please turn it off. Ms Lyon, would you like to make a brief presentation in relation to the Auditor-General's report and your experience post that Auditor-General's report?

Ms LYON — It is some time since I was familiar with the Auditor-General's report, but I did take the opportunity of rereading it apropos of being invited to appear before this committee. I think there were some valid observations within the report. I would suggest that there has been some movement, but I would probably make one other comment that there are things happening out there in the community that are not reflected in the Auditor-General's report, and they are some positive things for people with an intellectual disability. I have a background of having worked in government, so I am familiar with the workings of how these reviews are undertaken. More recently I have worked in an agency that provides services for people with an intellectual disability. I am also a board member of an organisation that provides a support service to people with a disability, so that gives me some background about what is currently happening in the broader community. Having been part of the process to develop the state plan, I was very pleased to join an agency where services for people with a disability were being delivered well ahead of the policy direction. That, to me, was very encouraging. That is about access and participation as members of the broader community and this is a vision that can be realised and in fact is happening now.

With regard to some of the points made in the Auditor-General's report, one of them is resource allocation and individualised planning. I feel there are some significant flaws in the present system. However, I think the policy direction will seek to address many of those issues. The clarity coming out of the department on how that will work is a work in progress. That has to be stated up front. There is a degree of lack of clarity about how individual planning and support will take place. We as service providers and I certainly feel families and people with intellectual disabilities await that direction and clarity around it. The notion of individualised funding should be well supported as a mechanism by which people can exercise a degree of choice and autonomy over what happens to them and how they live their lives. Some of the current funding mechanisms do not allow for that. I think some of the models which have been developed provide very good templates for the progression of individualised planning and support and I feel there are great opportunities to build on that. I think the department is in fact doing that. The mechanisms by which that is going to be achieved lack a bit of clarity and that obviously needs further work, but I would congratulate the department on the efforts and resources it is putting into refining and developing that process.

The CHAIR — Thank you. The first question I would like to take you to is you talked about the clarity of the individual plans being a work in progress. Does MECWA cover more than one area within the department or is it just in the east?

Ms LYON — It is predominantly an aged care provider, but it does have what might be described as a bit of a niche disability service. We have 47 people who access that service. Some are in the futures for young adults program and others are older people from the adult training support services. The age range is 18 to 87, so we have quite a spread.

The CHAIR — Not age range but departmental regions — I probably was not clear.

Ms LYON — The eastern and southern regions.

The CHAIR — Could you give the committee a little more information on what you have picked up in terms of the clarity of individual plans and work in progress and whether there are any good templates which you have found particularly helpful and you could direct our attention to?

Ms LYON — The existing mechanisms around individualised plans, certainly in our agency, are being enacted according to the legislation. I think the move forward is how you use the design of individualised funding for those plans. That will be the challenge. Individual Support and Choice is about packaged resources applied to those plans. I think people are still grappling with how that will occur.

The CHAIR — If you could provide us with one example that worked particularly well and why and one that could be improved and how, that would be helpful. It does not have to be done right now; you might like to think about it.

Ms LYON — Yes, I would like to take some time to think about that.

The CHAIR — Thank you.

Mr FORWOOD — It is nearly four years since the Auditor-General reported and I wonder if you would care to characterise the department's response in those four years.

Ms LYON — Specifically?

Mr FORWOOD — The Auditor-General made a number of recommendations, particularly in relation to things like whether the act was being followed, services that individual clients were receiving and the method, and particularly made recommendations about individual rights. It is four years on and this committee is looking at how the department has responded to what the Auditor-General said. I was interested in your views of how well you think it has or has not, both from a system-wide point of view and I guess in the delivery of services, and from the point of view of an individual in the system.

Ms LYON — I would say yes, there is progress being made. I think the mechanism of that is the policy direction outlined in the state plan. It picks up on many of the issues which have been identified in this. Its actual implementation is a relatively slow process and I think I alluded in my statement to the fact that service providers and families and people with an intellectual disability are looking for clarity on how the individualised planning and support translates for them as individuals and how the mechanism will be brought together.

Mr FORWOOD — How long do you think it will take?

Ms LYON — I think it is probably — —

Mr FORWOOD — How long is a piece of string?

Ms LYON — Five years before you start to get a flow. It is looking at how current resources are allocated and making that shift. There is a lot of block funding that occurs and it is moving to more individualised approaches. That is an incremental process and I do not think you can hope for anything more.

Mr MERLINO — I have a couple of questions about training for you as a service provider. Could you inform the committee what proportion of your budget is allocated to training, who provides the training for your staff and just a comment about the quality of that training and how it is received by the staff?

Ms LYON — Probably approximately 10 per cent of the staffing budget goes to training. That occurs in many forms. We develop internal training for some of our staff and external training is provided by a range of organisations including some peak bodies and some specialist providers in training. We set a minimum qualification for our workers — they have to have some qualification in disability services.

Mr FORWOOD — Certificate 4?

Ms LYON — Yes. I think the challenge for us is to get a match of where you want to head with your service and the needs of the population or people accessing the service. It is really a tailoring thing.

Mr MERLINO — How is it received by the staff?

Ms LYON — Very positively. The challenge for providers is identifying adequate resources for training. You will always see that you can do more in the area of training than what your resources allow you. I would make one other comment and that is that the regulatory and compliance framework that currently exists places a significant burden on service providers. When you are trying to skill your staff to meet those requirements it is a drain on your resources.

The CHAIR — Does your service have self-assessment?

Ms LYON — Yes.

The CHAIR — How big an impact is the training of your staff on your self-assessment analysis?

Ms LYON — I do not think it is a major impact. I would not say it is major.

Mr FORWOOD — Just to finish that topic, are you suggesting that the burden is so onerous that it should be relieved?

Ms LYON — I think it needs to be refined. The disability service self-assessment tool is being looked at — that whole quality area in disability services is being reviewed. I just think if you are a multipurpose agency the range of compliance and regulatory frameworks that you need to comply with is onerous. In addition they are multiple and they do not interface. From a departmental perspective there need to be moves towards looking at how you can integrate some of the reporting and compliance requirements, particularly around quality because the indicators are very similar across the domains.

Mr BAXTER — Does MECWA have a specific contract then with the department to provide intellectually disabled services?

Ms LYON — Yes.

Mr BAXTER — And in drawing up that contract of specifying it, does DHS say to you as a service provider, ‘This is what we expect of you’? Do they say, ‘Here are the two pieces of legislation that you have to comply with’, or is it much more, ‘We are engaging you as our service provider; it is up to you to work out how you do it and to comply with the law’? In other words, are service providers really alert to the fact that there are two pieces of legislation that deal with disability, intellectual disability in particular?

Ms LYON — Absolutely. The requirements are explicit in terms of legislation and other compliance frameworks, articulated in a new service agreement with the department and also in the policy and funding plan issued by the disability services division. From my perspective there should be no doubt as to what the requirements are as a service provider to deliver your service in accordance with the law and also with departmental requirements.

Mr BAXTER — And, for example, drawing the attention of the clients and their families to the fact that there is an Intellectual Disability Review Panel; is that specified? I know this is asking for recollection of what might in a contract, but we heard from the previous witness that this panel has been doing almost nothing because no-one comes to see it now. Is that because it is not known?

Ms LYON — My view would be that the requirement for reporting to the IDRP — if you are referring to restraint and seclusion — is probably not as explicit as it should be and I think that is an area where service providers need to take it on board in terms of training requirements. However, I would say — I speak from the perspective of the service that I am involved in — a respect for individual rights which underpins our approach to service delivery should be cognisant of the requirements around that from a general perspective. But in terms of whether service providers are generally well aware of restraint and seclusion, I would say probably not.

The CHAIR — Where you have risk of neglect or abuse of individuals, that can have very serious ramifications. Within your organisation, what process is in place for reporting instances of abuse or neglect of people with an intellectual disability? I need to put on the record that I am not suggesting that that necessarily occurs in MECWA.

Ms LYON — We have developed internally our own quality monitoring system whereby any incident is reported up through the program manager to the director and to the CEO directly and we respond to those within 24 hours. That is an internal mechanism. The department requires that we follow its incident reporting system and that is quite explicit. In fact very recently we received a revised version of that. No service provider should be in any doubt as to the requirements to report to the department within specified time frames on a whole range of incidents involving people with an intellectual disability. I think that is quite explicit.

The CHAIR — Given the success of that, what mechanisms would you recommend would be put in place for adequate reporting of restraint and seclusion, given what we have heard from our first witness and from you that that could be an area for improvement? What would you be recommending to achieve that?

Ms LYON — I would recommend better education, particularly for service providers. I cannot speak too broadly about this because we have a small service, but I think it is an educational process and a matter of drawing people’s attention to the requirements of the act. I did say before that they should be aware of those, but that depends on your strength of management and how you take on those responsibilities.

The CHAIR — It could also have something to do, I presume, with what has historically been the practice over a considerable period of time?

Ms LYON — Yes, and I think that we are a community-based program so our activities are occurring in a community setting, which is very different from a residential setting, and a range of practices can occur in those that have the potential to remain hidden.

Mr FORWOOD — I am interested in your relationship with the department. I take it that you have a series of service and funding agreements with the department and one deals with the disability component of the work that you do.

Ms LYON — The way the service agreement is constructed is that it is one service agreement and it has component parts. For us, probably 85 per cent is for HACC and the rest would be disability.

Mr FORWOOD — What relationship do you have with the department in relation to the intellectual disability part of the service agreement? How does that, for example, ensure that you meet your obligations, measure the quality? Do you have reviews or audits? Do they visit you regularly or do you see them once a year, or how does it work?

Ms LYON — There is a range of mechanisms. We have reporting requirements around our quality system which is submitted annually.

Mr FORWOOD — On your authority or imposed by them?

Ms LYON — Imposed by them. However, we have the opportunity to talk about quality and issues we may be instigating within our own agency. We have fairly regular meetings with a range of departmental staff. We engage in forums. I think the department has been very proactive in delivering a number of provider forums to keep abreast of the move forward with individualised planning and support, and also broader development of the service system apropos of the policy direction. So I think the department has been very proactive, certainly in the southern region, in progressing those initiatives. We have that less formal engagement: we meet when we want to explore issues of service development with individual officers of the department.

Mr FORWOOD — So it is general rather than specific around clients?

Ms LYON — We would meet with the department when we had specific issues on people with a disability who — —

Mr FORWOOD — Access your services?

Ms LYON — Yes. The other component of our service is the Home First program, which is quite intensive personal and individual support in the home setting to enable them to continue to live at home. In instances like that you may meet with a case manager for case review or you may also meet to discuss issues around resource allocation.

Mr FORWOOD — How many Home First suppliers do you have?

Ms LYON — All up, around 10. There is a bit of movement because they have a choice to move from providers.

Mr MERLINO — Could you expand on the issue of movement outside of the service system since the Attorney-General's report — plans, resources?

Ms LYON — Specifically, I am not sure what your question is.

The CHAIR — I think perhaps what Mr Merlino is referring to is your opening comment that since the Attorney-General's report there has been quite a deal of movement outside of the service system that existed at the time that that report was done.

Ms LYON — Yes. I think the move is in place to make a shift from block funding to individualised funding. So that puts resources with people, and I think that is a very positive move in terms of ensuring that individual goals and aspirations can be realised.

The CHAIR — Could you expand upon how you identify the individual's goals and plans?

Ms LYON — The current system is individualised IPPs, which are a requirement of the act. I think they are being refined.

The CHAIR — How do you ascertain what a person wishes to occur out of state government and commonwealth government funding?

Ms LYON — By sitting down with them and going through what they wish to do. That is certainly our process.

Mr FORWOOD — Are most of your clients high care, low care, middle care?

Ms LYON — Middle.

Mr FORWOOD — So they can communicate themselves?

Ms LYON — Yes, and that is also done in consultation with their family, and they are reviewed on a regular basis within our agency.

Mr FORWOOD — So you are confident that all of your clients — and I presume some of them are at home, some are in CRUs and some might be in training centres — have IPPs that have been managed properly, appropriately and meaningfully rather than just being a bit of paper?

Ms LYON — Yes, I would speak absolutely confidently about that. I just have to go out and view some of their activities on a daily basis and I feel very satisfied with that. I think the challenge with that move is identifying what the individual wants, and sometimes that can be clouded by what the family wants, but that is the skill of a good case manager or facilitator.

The CHAIR — MECWA is considered to be outstanding in that regard, but what distinguishes it from others?

Ms LYON — It is well practised. It has had this service running on that basis for eight years. As I said before, it is policy being enacted ahead of its time, and a firm commitment and belief that people with an intellectual disability should be able to participate and access the facilities of the general community.

The CHAIR — Do peers from the others services come to see how yours is done?

Ms LYON — Yes. It is a quiet little service, but for me it was remarkable to see that a lot of these things that were articulated in the state plan were happening and were well practised.

The CHAIR — Would your service mind providing to the committee what you consider to be outstanding resources that your peers may care to peruse? If that would be in order, we would appreciate it.

Ms LYON — Yes.

The CHAIR — Thank you very much, Ms Lyon. I appreciate the fact that you have juggled your schedule and that you do have to be somewhere else in a very short period of time, so thank you.

Witness withdrew.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Ms H. Forsyth, member, Disability Advisory Council of Victoria.

The CHAIR — I welcome Ms Heather Forsyth to the public hearing. All evidence taken by this subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected from judicial review. However, any comments made outside the precincts of this hearing are not protected by parliamentary privilege. All evidence given today is being recorded and you will be provided with a proof version of the transcript later this week. In accordance with the guidelines for public hearings, I remind members of the public that they are very welcome here, but they cannot participate in the committee proceedings. If anyone has recently joined with us a mobile phone, could they please turn it off. I will pass to you, Ms Forsyth, for a brief comment in relation to intellectual disability in the Auditor-General's report. I failed to say that you have been invited here because you are a member of the State Disability Advisory Council.

Ms FORSYTH — I have just been re-elected, as you know. I was on it for three years and I have been re-elected to be on it again for 18 months.

Thank you for inviting me here. I have noticed that I am the only person with an intellectual disability here, so I have asked two of my co-workers to come along with me to be my moral support. We went through the book, and we have to say it is very hard for us to understand the book, but I did have a person to help me yesterday go through the book and I have just done a few points. On case management outreach, some people with a disability need case managers for a long time, especially if they have children and are living in the community. The other one I really thought was very interesting was the legislation review. It was very poorly received in Frankston. There were 30 clients with an intellectual disability. The Department of Human Services did not have anyone to support those people with an intellectual disability. They decided on the day, 'We've got 30 people with a disability here. We'll do something for them'. They did not have it in plain English for people with an intellectual disability. I was one of the people on a panel and I asked if they were going to have people with an intellectual disability, to give us plenty of notice; and they did not do that. My two colleagues and I were on the standards review. We went out with two colleagues from the department and we did the hotline and the roster review. With the roster review, the clients did not know what we were there for. They came to a session, but they did not want to talk to us because they did not know what we were there for.

Last, advocacy and self-advocacy. I am a member of a few organisations, but I am here on behalf of the DACV. Reinforce, one of the organisations that I am involved with, has been asked many times to come to functions like this, but it has no funding. We are running on the smell of an oily rag. The Department of Human Services says, 'We will give you the money', but we do not get it. We would really like to see some more money for self-advocacy organisations because Reinforce is the only self-advocacy organisation that is run by self-advocates alone. I am going to have to ask my colleague to help me read it: protecting the rights of people with an intellectual disability — first of all I think that a group like Reinforce, in conjunction with Human Services, should be going out to places, houses like CRUs, to run training sessions on rights and responsibilities, explaining what their rights are and that they have rights, and get people with an intellectual disability used to having a say, knowing what they are and also to understand that respect comes with responsibilities and to understand that sometimes when they see you have rights you do not get it and may not get what you ask for.

The CHAIR — Thank you, Heather. You have reminded me of something that we need to be mindful of when we do our report — that is, that we make sure that as well as our report to Parliament, and as part of it we have a component that explains in plain English what we are actually saying. I undertake to do that as Chair of this subcommittee. You covered a number of really important issues: case managers, the legislation review, standards review, roster review and self-advocacy. Would you like to pick one of those and give me a little bit more detail. One that I am personally very interested in is training sessions on rights and responsibilities. I know there was a group of people — I cannot remember if you were one of them — that did a training session on — —

Ms FORSYTH — On the standards?

The CHAIR — On the standards.

Ms FORSYTH — Yes, the three of us sitting at the table today — —

The CHAIR — I am glad that the results of that are before a parliamentary committee.

Ms FORSYTH — The three of us sitting at the table today have done the standards review. You came and gave us the certificates. That was interesting.

The CHAIR — Can you explain what is important for people with an intellectual disability in terms of ensuring the standards and the act are living?

Ms FORSYTH — People with a disability, if they are working for one organisation or going into another service, thought the standards were just the rules of where they worked. They did not understand that they have got rights where they are working. They thought they have got to stick by — if the staff said, 'You have coffee', you have to have coffee, you do not have a right to say, 'No, I don't want coffee, I want tea'. Or they say, You can't go to the toilet,' and things like that. People with a disability do not feel they are being heard.

The CHAIR — After the Auditor-General's report — and we are following that up — how would you recommend they be heard?

Ms FORSYTH — Get people with an intellectual disability more involved in things that you are going to do, and put it in plain English for people with a disability. As I said, I had to get one of the co-workers that we were with yesterday to go over the book with me because I did not understand the book even. She has picked out a lot more than I read out, but I knew I only had a certain amount of time. I have gone through what I thought was the guts of it and I did listen to what Sue Tait had to say and I agree with what Sue Tait had to say today as well.

Mr FORWOOD — Ms Forsyth, you said that you had been on the disability advisory council for three years and you had just been reappointed. Do you think it is an effective body for ensuring that the views of disabled people are heard by the government.

Ms FORSYTH — Yes, I do think so because the last DAC that I was on was service providers as well as people with an intellectual disability. The new DAC is all people with an intellectual disability. Of the 19 members on the DAC, there are I think five of us still on it who were on it last time and we have other new members on it, but they are on a three-year terms whereas I am only on for 18 months to show them what is going on.

Mr FORWOOD — You meet and you discuss issues and then you make recommendations to the department?

Ms FORSYTH — We meet with the minister, Sherryl Garbutt. Really it is the minister's advisory committee for Victoria. My friend here, Janice, is on the National Disability Advisory Council. I am on the Victorian one. We put ideas up for the minister, we just talk to the minister and she comes along. Minister Christine Campbell was a minister on the DAC. She came to a couple of our meetings and had tea with us as well. So yes, I have just been — —

Reinforce has just done two sessions on finding out what people with a disability want and need — most people give you the answers that they think you want to hear — and the report is coming. Nobody with intellectual disabilities who were interviewed knew what their rights were. Colin at the moment is having a break from work, but Colin was doing the interviews. He was employed and, as he said, no-one knew what the rights were.

The CHAIR — I must admit that we nearly fell into that trap ourselves of not having a witness with an intellectual disability and I am pleased that we did not fall into it completely.

Mr BAXTER — Could you just tell me again about this meeting in Frankston you referred to. Was it designed to give an opportunity for people to put their views on what should be in the new legislation, and were you not forewarned beforehand — —

Ms FORSYTH — No.

Mr BAXTER — So it was presented to you without any warning so you could think about it.

Ms FORSYTH — I went to a meeting at the Department of Human Services. They said they were going to be having these sessions and they were going to have one in Frankston. I said, ‘That is good. Is there going to be a session for people with a disability?’. They said, ‘There are no people with a disability going to be coming’. When I got there I found that there were people with a disability there, so I went up to one of the members from the department and I said, ‘We have got people with a disability’. They said, ‘Well we will just do a session for them now’. But the people with a disability, the 30 who were there, did not understand what it was about because they did not get the paper in plain English because it was not put in plain English.

Mr BAXTER — Thank you for confirming that.

Mr MERLINO — You talked about the lack of funding for self-advocacy organisations.

Ms FORSYTH — Yes.

Mr MERLINO — Could you explain to the committee what funding, if any, you receive from the department and if there are other resources or support that you are provided with, not money but maybe other types of support?

Ms FORSYTH — Reinforce gets money — $500-plus a month. Their rate is $600, but they only get $500. But from that $500 they have to pay rent, electricity, phone and insurance, and they are all volunteers. They do not get paid to be at Reinforce. They all volunteer their time to come to Reinforce and work. I feel it is not fair for a self-advocacy organisation that has been going as long as Reinforce to be not funded. We are getting about $40 000 from the department, but we do not know when. We have two organisations — Bear in Mind and Reinforce — that are getting it, but we do not know when we are getting that — —

The CHAIR — We might be able to find that out for you.

Ms FORSYTH — For the resource unit.

Ms ROMANES — Ms Forsyth, on the state disability advisory council, are there also DHS representatives who work with you?

Ms FORSYTH — I work with Miriam McDonough, Simon Anderson and we did have Patsie Frawley, but last year she resigned from her position. We have someone in that position, but I cannot say who it is yet because we officially have not been told as a DAC member who is going to be doing it. I know who it is, but I cannot officially say here.

Ms ROMANES — Who follows up the decisions of the council?

Ms FORSYTH — We have a chairperson that has a disability. What happens is she follows up with what is going on. I think the chair is a paid position. We all get paid sitting fees to be on the disability advisory council, but the chair gets paid a little bit more than we do because she is doing a lot more running around.

The CHAIR — The chair is Rhonda Galbally?

Ms FORSYTH — Yes.

Ms ROMANES — Are there any agreements between disability groups or the council and DHS about how consultations should be conducted?

Ms FORSYTH — Last year when we had the disability advisory council, no self-advocacy organisations knew about the advisory council. I went to do a talk for Having a Say for another organisation and no-one knew about the disability advisory council because when we first started the disability advisory council up we said we were going to go over the country too and that did not happen because we changed our chair in the first 12 months of the first DAC. We changed our minister three times in the first three years of our DAC. We have still got the same minister, but we changed our ministers.

Ms ROMANES — I have one further question, if I could. In your own experience have you experienced a situation where you have seen consultation and good participation?

Ms FORSYTH — No.

Ms ROMANES — You have not seen any instances of that happening?

Ms FORSYTH — No.

The CHAIR — Thank you very much to Ms Forsyth and her support workers.

Witness withdrew.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Mrs W. Urch, secretary, Parent Carers Support Network.

The CHAIR — I welcome Mrs Win Urch, secretary of the Parent Carers Support Network Inc. to this public hearing. All evidence taken by this subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected from judicial review. However, any comments made outside the precincts of the hearing are not protected by parliamentary privilege. All evidence given today is being recorded and witnesses will be provided with a proof version of the transcript later this week. In accordance with guidelines for public hearings I remind members of the public they are warmly welcome here, but they cannot participate in the proceedings of the committee. Please turn any mobile phones off, for those who have just joined us. Mrs Urch, it is over to you to make a brief opening statement before questions.

Mrs URCH — I would like to read it because you might get the feel more if I read it. I will not take long. I am Winifred Urch, I am the parent of a person with high needs for 44 years. I have over 25 years of fundraising for a day centre; 2 years committee of management at a day centre; committee of management for North West Residential Association from the beginning, and office-bearer or treasurer for about 8 years, and secretary ongoing. I was in that organisation from the time it began to the time it was taken over by the government. I was on the western incorporating northern disability services committee of management for four or five years, and I was on VICRAID as a representative of North West RAID for all those years that North West RAID was a part. I am secretary of the Parent Carers Support Network, and as well I have aided a person at a centre for 10 years for three days a week — and that is 40 years ongoing. As a parent I became a participator in the reform and development of services. I rang other members of the Parent Carers Support Network who do not attend our meetings for their personal comments so I could add this to the résumé of services. I do it this way mainly because it is a different language that parents talk. My first contact was the new day services centre, which was originally started by the parents to help meet the needs of their children. The task was too great for parents in the community re fundraising personally and financially for them so parents and teachers took the funding issue up with the state government.

The day service system was established. The government established the framework and the legislation to safeguard the rights of people. This system changed over the years and many children were denied access because of their special needs. Children did not have a right to a place and parents kept children at home. The day service was split in two. Children came under the education department, giving them the same rights as other children to an education. Extra training was added to the education diploma (special education). In late 1970 it was the beginning of the development of the CRU program, with houses for children and adults to live in the local community rather than big training centres. The residential accommodation service was established in all regions, metropolitan and rural Victoria. This slowly developed, and bit by bit the large institutions have closed and people are being supported by department or non-government agencies. Later on the government took control of all the CRUs and since then has slowly been contracting the services out to the non-government sector. As well there is a mix of services supporting the needs of people with intellectual disabilities. The problem is implementation, monitoring and accountability. They are not funded adequately by government budgets.

The knowledge of the legal rights of people are not obtained or are ignored. The rationing of services creates a crisis in the service delivery. There have been state plans, updates of legislation and proposed legislation, standards set and new reviews of those standards. There are quality assurance programs within the department. As well there are accredited services if you can and continue to meet the audit. Very slowly the community has been educated to the needs of disability because of the above services, not that the community wants to be educated to disability, but with the ageing of the population it is a fact of life. I understand the workings of the Behaviour Intervention Support Team Services program, the Making a Difference program, the assessment and registration procedure, the intake response worker, the case manager services, the quality assurance program, and respite, transition and permanent accommodation services. Unfortunately many of the above services are geared to crisis needs. Those providing medical services at public hospitals need additional training to adequately support people with intellectual disabilities who access those services. This lack of training results in parent carers needing to stay in hospital with their adult children during procedures. A parent has told me that these problems occur in the mental health system as well.

As a member and honorary secretary of the Parent Carers Support Network we require and need planning for services, and we want to help and support the department and the non-government sector. In administration our association has initiated a financial management system and kit to meet the requirements of people living away from home — for example, administration skills and financial management for parent carers. It has circulated the medical records kit of Dr Mary Burbridge of the disability health unit for the benefit of all clients who have medical records of our children. These initiatives may make less work for all at a later date.

In recreation we initiated a small recreation and social development activities program designed to meet the social needs of people 16-plus years of age living at home or in CRUs et cetera. They meet regularly once a month on the same evening at the same time in the same venue. The program is funded by local government. People need to get themselves there, and the council provides a bus, or other transport is arranged to ensure a safe return journey. All these things need to occur if you want to provide a good service for people with a disability.

Dealing with respite, we are most concerned about the homeless person being placed for too long in respite, as it stops the true service of respite happening for families. We are trying to educate our child that he or she will not always live at home — in the context that we all make other homes. Estate planning is an ongoing agenda item, with consultants brought in to plan for our disabled child and our other children so that support is still around for our disabled child when we have died.

To all authorities, I have read out the report. Please use the Behaviour Intervention Support Services correctly; do the incident report correctly; access the general service plan — at the moment this is not encouraged at all; do the individual personal programs and carry them out; allocate funding for parent education, firstly, for behaviour management of their children, and secondly, for the role of the Intellectual Disability Review Panel which monitors medication, restraint, seclusion, abuse and other frameworks that may affect people with an intellectual disability; and make recommendations to government.

In conclusion, parents in their 50s and 60s need plans to guard against crises in the future so they can enjoy their retirement. We would still like to be able to support the government or agencies by supporting our children when they are in accommodation services. This is viable financially, it is beneficial, it is great for the staff, the relatives and the residents. Accommodation services need to be located close to where parents live so that the parents can still be close to and involved with their children. We must continue to provide centres for students who move on from special development schools at 18-plus years and whose needs are different from those of children who are leaving secondary or special schools and who can access the Futures 18-plus program and who may stay at home or live independently elsewhere. Without these centres parents are faced with having to leave work at 40 years of age to be at home to care for their child on leaving special developmental schools. Accommodation services and centres need to be placed in the local community for accessibility and transport. It would be much cheaper in the long run. Transport is the one service that is never mentioned, but it is the one service which makes it all happen — be it by public transport fixed lines or vehicles. The budget allocation for transport needs to be in keeping with the community standards for all members of the community who access disability services.

The CHAIR — Thank you very much, Mrs Urch. I would like to take you to one of the points that you have made where you say that parents in their 50s and 60s need plans to guard against crises in the future so they can enjoy their retirement. In the coffee break I talked about one of our ministers who mentioned the need for businesses to have certainty in terms of regulations — the electricity industry, as it so happened — and he was saying that if you know what the rules are and where the future may be leading in terms of regulations, you can plan. Going to the parents' perspective, the Attorney-General referred to long-term planning for individuals. Would you like to comment on parents who have cared for their sons and daughters in the family home and are nearing or have reached retirement age and their requirements for long-term plans?

Mrs URCH — It needs to be planned earlier than say, myself at 70, because it is very sad when you cannot be part of that placement of your child in accommodation services. At 60 it would have been great but at 70 it is much more difficult, and you would have loved to have had those 10 years of retirement that you could enjoy. So you need to consider permanent placement. It does not have to be seven days a week. It could be like transition at the present moment — two days in the middle of the week, which is great. It needs to be planned so that parents can feel that they have the right to do the things that most other people do; and as well that you are there to see that the service can actually accommodate their children's needs adequately. We need to be part of that make-up because that is still our child, and we still want to bring them home to parties et cetera.

When I said that this is financially viable and beneficial, it just means that it takes the stress off the house if you take a couple of children out or you take one out and you have the same staff member who can give more time to or do more activities with the person who is in the house. With the shutting down of all the residentials, the only thing about CRUs that you must be aware of is the isolation. You do not want to have people isolated in units. Isolation can happen even if you have a member with intellectual disability or any physical disability, because it still takes a great deal of time and effort to provide care. I might say that in my 40 years I have had to plan my time every minute of the day to get out and keep from just going willy-nilly. Because I do like to be involved in the community, each time I go out I have to make certain that there are two support people — not one. When a person goes to a centre that person has one aide plus the support of the agency, so that is not one to one, that is two to one for some people. Some people do not realise that that needs to happen. They think it is one to one.

The CHAIR — Can I get back to long-term planning for the eventual movement of the son or daughter out of the family home? Could you be a bit more specific on the Attorney-General's reference, which was long-term planning for individuals?

Mrs URCH — Well, you have to have the house first, and then you have to have the money to support the services, because as soon as I got into the association for accommodation — it is not the accommodation but the support services that you have to have the money for. The capital outlay is one thing; the support services is the other, so you have to have a budget to meet the needs. You have to get the statistics right; you have to look at how many are on the waiting lists and then you have to — —

The CHAIR — That is you worrying about the government and the department, but what about you personally?

Mrs URCH — The government has to meet us in providing the houses. It is no good me worrying about it. I can worry all my life but if there are no options for the houses, you cannot plan.

The CHAIR — Do you have any comment in terms of what parents would, in an ideal world, require in terms of long-term planning?

Mrs URCH — It is very hard to say that because some parents do not want to use the service, and they leave it too late. What we are saying as a carers group is we like to actually plan so we go side by side with our child so they learn to be independent. We want to be there because at the end of the day they are going to go into accommodation services. Some start early, some start at 30 — it depends on the needs of that family and the availability of the housing.

Mr FORWOOD — At the bottom of page 2 of your submission you ask authorities to use behaviour intervention support services correctly, do incident reports correctly, access general service plans and do the IPPs. Do I take it from this that you do not think they are being done correctly at the moment?

Mrs URCH — I think in the report Mr Cameron did say that incident reports were not being written up, and sometimes the parents do not even know about the incident reports, which is very interesting. Incident reports often stay in-house so that you might not know what your child is doing — no-one tells you until it gets to a crisis, and then they say, 'Oh, they did that'. To my way of thinking, it would be much better if we actually knew. What it is in some way, when you start looking at incident reporting, some of the service providers start to feel guilty that they have not done something. I would say no, not really. We want to look at the incident report to see if we can change it and stop it from happening. That is what I say about incident reports.

Mr FORWOOD — I guess the point I am trying to get to is that in November 2000 the Auditor-General made some findings in relation to these issues, and we are now four years on — —

Mrs URCH — I know. I realise that.

Mr FORWOOD — What I want to know is whether the department has responded adequately to the recommendations of the audit office in 2000 and whether the system is now operating better. I take it from your four points there that you do not believe it is.

Mrs URCH — No, the parents are not always aware of the incident reporting and where their child is. Sometimes it might not be necessary. Concerning Behaviour Intervention Support Team services, not all government agencies want to call in BIST. I find that really interesting because it happened to me personally. I actually had to call in BIST myself from my home and from the centre to get what I call updated services. I think that is a duty of care.

The CHAIR — Is that in the last four years?

Mrs URCH — There is still a very long waiting list. There is a six-month waiting list for BIST so while you are waiting for that service to happen and you have the person doing what he may be doing or at risk you do not get the service.

Mr FORWOOD — I do not know whether you have a son or a daughter — —

Mrs URCH — I have a son.

Mr FORWOOD — Does your son have an IPP which has been regularly — —

Mrs URCH — He had an IPP last year, and I reviewed it. I think this year the centre he attends is now in a pilot study for another program so the IPPs have not been done this year. I think they are doing a pilot study for another program which might take the place of IPPs under the legislation. I have not been told, but I think this may be what has happened.

Mr FORWOOD — Do you think the IPP has been done properly? Do they follow it? Is it adequate?

Mrs URCH — Mine is, and it has been followed, but I know in some cases that IPPs are the service itself — it does not mean that you get it. General service plans are something I access. It takes a while to access. I have done the general service plan — that is how I can talk about it. I have had it done twice, but now to go and access it you have to ring the department, and they will say you can do this area — health, education and so on. I said to my case manager, 'Please access it. I want to put the health and communication in because that is a legal document which, as far as I am concerned, overrides the services you will run the IPPs through'. If I do not put that there, when I am not here who is going to know what my son needs?

Mr MERLINO — You talked about the need for funding for parent education. Could you inform the committee what currently occurs in regard to parent education and what role the carers network plays?

Mrs URCH — We get a community grant, and we do personal advocacy with our parents. It is very private — that is why there are not many names or anything in this. I say to people, 'Come to our meetings and get used to us. We make it very general and then we pair off. If you want personal advocacy, it will be done this way, and it will be strictly confidential'. We might have one parent who will go with a person they know and trust. If there is any reason to be concerned about the service delivery at any agency I might go with another parent to health and community services to sort out a minor detail or support that person. That is as far as it goes. It does not get written up, but we do have an ongoing feel for what people need. There are lots of little things like that which if you are mindful of you can tell people how to use the service rather than saying, 'You need to get in there and '. You can help the service in lots of ways, even in a community residential unit.

The CHAIR — So you help the service and you help the family?

Mrs URCH — You help the service, you help yourself and you help the child.

Mr MERLINO — Where are the gaps in education for parents?

Mrs URCH — Because I have two relatives at director level in day centres and because I have had that general education. There is not enough education in the way people can understand and control. Therefore, as you train your staff, they learn that, but the parents do not get the opportunity to do the same training at that level. It might help the staff, it might help the family life and it might help people out in the community if training were provided.

The CHAIR — If I could follow that up, my understanding was the BIST teams or behaviour intervention support services were required to speak not only to the day programs but to the family, community residential unit or the accommodation providers so people knew what the others were doing. I understood that was a requirement.

Mrs URCH — It is, but it is very personal. Remember BIST is not the same as it was originally — now they call in consultants. You could have concerns about what they are saying; they are not always right. I have professional proof at a medical level that they are not right about some behaviour, but that is because they were not aware of my son's very special disorder. Restraint is very interesting because as a parent I have had to restrain him, and so I found it very difficult to accommodate restraint from my point of view. At the same time I had a duty of care that that person did not get hurt. My younger relative helped me to do that because she was qualified, but at the centres they did not want to do it first so they did not even want to call BIST in. What I am saying is that it does not always happen at the centres. I am not saying overall, but it does not always happen that this service comes in as a matter of course.

Mr BAXTER — Mrs Urch, in your long experience what has been the circumstance of staff turnover, particularly of case managers? Is there a rapid turnover, particularly in the last five or six years, and what sort of problem does that cause, if it is the case?

Mrs URCH — I cannot talk about the turnover in case management; I can only talk on my own personal level. The case manager from the department through our group, it takes a while to get them, but you eventually get them. You might have a wait, but they come. At the non-government sector I have only had two case managers and that was only in the last 10 years and I find that case management is a very involved and complex service delivery because it can actually, how shall I say, give prickles to parents if they actually step over the line, so you have to be able to talk about what you consider should happen. Their main priority is the client, and secondly, the family. So as a primary carer I have to be aware of that and then remember that as a primary carer I have the full responsibility of protection and privacy of our own personal family life. In the first stage plan I said, ‘Never have so many looked at so few’. You feel a little bit looked at, as though you are not doing the right thing, and for years I thought I was not doing the right thing until someone pointed out to me, ‘No, you have to tell your son that he has to do it’. You put it as his responsibility and then it is up to him to see that he can make some of those choices. It was not actually my fault or my guilt, and it was much better to know that. I dealt with that about 15 years ago. A psychologist in the training centre helped me learn a lot by saying, ‘Hands off, Mother!’ so that the child actually did develop.

Ms ROMANES — Win, just a question regarding your comment about the need to continue to provide centres for students who move on from special development schools at 18 plus years — and you make reference to the fact that some children can access the Futures 18-plus program — or stay at home, or live independently elsewhere. Can you tell us a bit more about what you have in mind for those other centres?

Mrs URCH — Those day centres are already established, so with the population in special development schools, which are quite different from special schools, they need somewhere to go and you cannot run them round the community or go to somewhere like TAFE. They need a permanent place to go like most people go to work.

Ms ROMANES — Daily?

Mrs URCH — Yes, daily, like the centres are now. We have a policy that the day centres should stay because you need them for that activity for the child that leaves the special development school. You cannot expect a mother — and some homes run on one or two incomes — to realise all of a sudden at 18½ years, ‘Oh, they are back home, now I have to do the job that I did before. The education system takes them at five years, and education is great because it means those parents can work if they want to, or be at home. It was wonderful because a lot of children were not accessed into centres. They were at home and some people kept the children at home, so it is good now that the child goes out. The early intervention program is great because the learning possibilities of the young child are enormous at the beginning of life, and so to go to school when they are five years is great. If you do not have that right to go to a school, like you now have with the education system, you can go to the development schools. I think you do — I hope that is so. I am always concerned that if the education system took over the child of five years, it would be a right for each child to go, and it would go into the special development school or to the special school, or have an aide at primary level — whichever — so that the intellect of the child does develop appropriately like it does for most people. So that is why I put them down as two different sets.

The CHAIR — Thank you very much, Mrs Urch, for being extremely helpful. We will forward you a copy of the transcript when it becomes available. Thank you for your attendance this morning.

Mrs URCH — Thank you for the opportunity to put forward suggestions so that life will not be harder for parents.

Witness withdrew.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Ms J. Tops, president, Gippsland Carers Association.

The CHAIR — I welcome Ms Jean Tops, president, Gippsland Carers Association, to this public hearing. All evidence taken by the subcommittee is taken under the provisions of the Parliamentary Committees Act 1968 and is protected from judicial review. However, any comments made outside the precincts of the hearing are not protected by parliamentary privilege. All evidence given today is being reported and witnesses will be provided with proof versions of the transcript later this week. In accordance with the guidelines for public hearings I remind members of the public that they cannot participate in the committee's proceedings. I ask that mobile phones be turned off. Ms Tops, would you like to make a brief presentation if you have prepared one?

Ms TOPS — Thank you very much to the committee for the opportunity to speak to our submission in relation to the Auditor-General's review of the department's efforts in providing services to people with intellectual disabilities. In doing that I would first of all like to say that I want to introduce to you the 36-year-old daughter of mine of whom you now have a picture in front of you, because she is profoundly deaf and legally blind as well as intellectually impaired and profoundly disabled, and is therefore unable to be here to speak for herself. As the mother of Moya and as president of the carers association, I am here to speak on behalf of the vast majority of people with intellectual disabilities who are living at home with their families with very limited support services, and for whom very little concern is being expressed at this point in time in relation to planning and support for them.

In relation to the concerns we have under the act, we essentially believe that the responsibility of the department to plan for people with intellectual disabilities who are living at home with their families is not being upheld in the manner in which it should, and that the department has failed in its responsibility to the families who are actually providing 91 per cent of the accommodation and support services which people with intellectual disabilities who are dependent are receiving in the state of Victoria. Evidence of that is quite clear in the fact that there are only some 5000 people with intellectual disabilities in receipt of shared accommodation support services out of a possible 40 000.

It is fairly clear that a majority of those people are in fact living at home supported by their families, and supported by families who are living in circumstances of complete stress without the support services they need and who are providing support services even unto death because the department has failed in its responsibility to plan for the transition of adult people with intellectual disabilities into the community according to first of all the requirements of the act, and secondly, the department's own 10-year plan which says that people with disabilities have the same rights as other members of the community to live in and be supported in their own accommodation within the community. We maintain that living in your home — the home of the family — for the rest of your life simply because you have an intellectual disability is not providing you with the support to live in the community that as an adult with an intellectual disability you have the right to expect.

We believe planning for families to be able to retire from that responsibility is not happening. It is still not happening today. Our concern about general service plans is they may say that a person with a disability needs to be provided with support to live in the community, and that is where the whole thing ends. People get put on to an urgent accommodation waiting list, and my daughter joins the ranks of about 4500 other people waiting for an accommodation and support service. At 36 my daughter is classified high need. There is a whole raft of people classified urgent need who are waiting 140 weeks for an accommodation and support service, so I think I can expect a service for my daughter when the cows come home. The same thing applies to all of the families which are out there providing those support services.

Our concern is that the government has failed to plan for individuals and that it has not safeguarded their rights in the services they are currently in. It is not providing the resources in the manner that will make a difference. We note that the government has increased spending on disability services by 63 per cent. We go, 'Wow, this should be great. That means that a whole bunch more people will be getting support services'. We look around and ask, 'How many of you guys have now got an accommodation service for your son or daughter because of this 63 per cent increase?'. Nobody is getting extra accommodation services — 281 places since 1999 does not seem to be a lot of places when you consider that there has been an increase in spending of 63 per cent. We are most concerned about the fact that the department only spends $40 million a year on respite services for families who are providing 91 per cent of the support needs of people with disabilities who are living in the community.

We are appalled that the Department of Human Services has consistently denied our requests for dedicated facilities to provide respite for us, those very weary families who are working 365 days a year, 7 days a week, 24 hours a day, without a break, without time off, sick leave, pay or anything. We say we have a right to expect annual leave. Why can't we have four weeks off like everybody else? Could you please provide us with dedicated respite care facilities so we can have what everybody else takes for granted — a holiday break from this arduous job that we take on? The department consistently, blatantly, without any excuses whatsoever labels our request institutional, says it does not meet standards — which I would very much like to argue about because the standards that are currently in place are not being upheld by the department. I think we have alluded to that in the submission we have made to you in terms of the way people are being treated in a group home in our own area, and the way people are being treated in respite services in our own area. We believe the department is not being responsible in meeting the individual needs of any of those people. We believe there is a long way to go if the department is to pick up its game sufficiently to say we are meeting the individual needs of the people who currently receive service and those who are waiting for service.

I guess our plea to the committee would be there is an urgent need for you to recommend that the department fund sufficient support services to shore up the families who are willingly carrying the burden of providing accommodation and support to people with disabilities as the most urgent criteria. The second most urgent criteria is that the department be made to ensure that the rhetoric of the 10-year plan, the individual planning and the individual funding and Support and Choice is actually put into practice on the ground because clearly that is not happening either, in our experience. We sit here today having been told by the department, 'You cannot have holiday respite'. We sit here today having been told by the department, 'You cannot have a choice in the support you want to have in looking after your family', and we sit here today saying we believe the department is being totally bloody-minded about all of this. We believe the department is not listening to its own rhetoric. It is not saying, 'You have a choice here. If you want facilities to provide you with respite, then we have to look at giving them to you'.

We were actually offered a 12-bed building up and running, en suites, completely refurbished, ready to go and the bloody-minded department — excuse me but that is how I feel — said, 'Institution because it has 12 beds, you cannot possibly have it'. I contend that my daughter is already in an institution, and so am I. I contend that we are prisoners in our own homes. I contend that we have no choice in what we are doing, because my only choice and the choice of families who are doing this job is to abandon our adult sons and daughters to the system. We can abandon them to an accommodation waiting list which is in excess of 4000 and say we are not going to do this anymore. We care about the people we look after, and we are being punished because we care.

The CHAIR — Thank you very much. Could I go to the first question in my mind and that is what are the actual services available to your daughter which she is using and to your family? I go particularly to the point you made that families need to plan in terms of retirement. When did you first request a service that would allow full-time care for your daughter?

Ms TOPS — A general service plan back in 1970-something said at the outset that my daughter would at some stage require a long-term accommodation placement service. I note that in the late 1980s general service plans took a dive, and I can understand why — —

The CHAIR — Can I be quite specific if you do not mind? If you do not particularly want to go to specifics in terms of your confidentiality, I accept that.

Ms TOPS — No. I understand that this is what is happening.

The CHAIR — You have made a claim that it is important for people to be able to plan for retirement. My specific question is: have you personally or your family put in a request for full-time care at X period of time for your daughter to enable your family to have the retirement you referred to?

Ms TOPS — We recently demanded a review of the general service plan. The general service plan now says that Moya will require a supported accommodation service and has been placed on the high-need waiting list. The criteria for her need for an accommodation service is this: there needs to be a transition plan so that my daughter can learn to live without me, there need to be services provided that will make that happen, and that at the end of that there needs to be an appropriate alternative accommodation service made available to her with her special needs.

The CHAIR — So that is a fairly recent request that has just been made?

Ms TOPS — Yes.

The CHAIR — And in terms of respite, have you put in a plan?

Ms TOPS — Yes, I have, just very recently, over the last couple of weeks. The new Support and Choices funding package is now being put in place for my daughter, and a part of that package will be that facility-based respite will be provided for her. I need to say, in relation to facility-based respite being provided for her, that the only service that is available is in one house between Sale and Warragul. There is one house in Moe to service the entire area. That one particular house is currently piloting a holiday-length respite service, so four of the beds have been earmarked over there for that. That only leaves another two beds.

In order for Moya to be given respite in that facility, I am not given any choice, or very little choice, in terms of who she actually has to share that house with while she is having respite. So essentially the last time she went in there she went in as a totally defenceless, deaf-blind individual with five guys in the house. The one sleep-over staff person allocated to that house was also a guy. There is my deaf-blind and totally defenceless daughter, and it is, like, ‘Take it or leave it. That’s all there is’. So our request for facilities that actually provide choices in that regard is a very valid one. We think there should be an ability for non-related, mixed-gender facilities to segregate people, so that people with high-support needs are not being plonked into the bedroom right next door to the totally defenceless individual and so that the only person on duty has actually shut the door and gone to sleep, and to hell with what happens overnight. It is not the way I want to see a service for my daughter. I have not given up 40 years of my life providing care for people with disabilities in my family to throw them to the wolves at this point in time.

Mr FORWOOD — Jean, I just want to turn to the Moe CRU story. When the vacancy occurred after the existing resident died, what contact did the department make with either the existing, remaining five members of the CRU or their families before a decision was made to allocate the place?

Ms TOPS — My understanding is that there was none. My understanding is that this was crisis management, that the vacancy was created by one person having the temerity to die, that another person who had hitherto lived with her family no longer had a primary carer available, also because of a death in the family, and that the department placed this person as a crisis managed — —

Mr FORWOOD — So there was to your knowledge no understanding or communication. Did that case go to the intellectual disability review panel?

Ms TOPS — Yes, twice.

Mr FORWOOD — And can you inform the committee what happened in relation to those hearings?

Ms TOPS — Yes, I can, because the families have given me authority to speak on their behalf on that particular matter. I understand that the intellectual disability review panel made a number of recommendations, and these documents can be made available to the committee if you want to have them, because we have the families' permission. Those recommendations included concern that the individual was inappropriately placed and they should consider relocating; concern that the lives of the people who were there for the extended period of time were now compromised and that their individual rights had been compromised in terms of their ability to enjoy their home environment; and concern that a number of other things be put in place, so that if in fact she was to remain there, they should be doing things like building another room, putting on extra staff — a whole raft of stuff which to my understanding has not yet happened. Some of it is in the planning. I understand an independent mediator is now looking at mediating between the families, the staff and the department, because this whole thing has just gone completely to pieces.

My questions about that are: if we have Support and Choice, if we have the capacity to do individual funding, if the department's allegation is that it costs $100 000 per person per year to provide a supported accommodation service, and that is written in their statement on the request to increase fees — they say it costs $100 000 — then for heaven's sake why has individual Support and Choice funding not been applied to this lady, because she is as much a victim as the five people who are there? Why is she not being put into accommodation of her own in the community and being supported to live in the community, so that those five people can go back to enjoying the life that they have enjoyed, some of them for up to 19 years? It all seems like commonsense to me, so why has it not happened? Why are the families still, as late as yesterday, sending me more information which says, 'Nothing's changed, Jean!'?

Mr FORWOOD — Finally, and this is probably an unfair question, do you believe that the process by which this person was added to the house is the usual process, or was that a rare event?

Ms TOPS — I do not believe it is the usual process. As I said earlier, I believe it was crisis management. I believe that the department felt that they did not have very many choices available to them. Maybe they did not even understand, when they first did it, that it would cause such chaos. I understand and accept that too, but what I cannot accept as a parent is thinking that this could be my daughter we are talking about here today and that the ongoing continuation of that arrangement is inexcusable.

Ms ROMANES — As a supplementary to that, Ms Tops, before the events of September 2003, you are suggesting that that CRU for the six people who had lived there for up to 19 years had functioned effectively as their home and that they were very happy there for that long period of time?

Ms TOPS — Yes.

Ms ROMANES — So it had been a very successful unit?

Ms TOPS — Yes, it had been, and now one of the long-term residents has made a specific request to immediately be relocated — they cannot stand living there anymore — after all that time.

Mr BAXTER — Ms Tops, you referred to the increase in the budget allocation, which in anyone's language has been fairly significant in recent years, but you noted that you were not seeing any additional services being provided. Does Gippsland Care have any idea where that extra money is going, if you are not seeing it on the ground?

Ms TOPS — I think, if we look at the department's own budget statements, it is quite clear that about 53 or 54 per cent of the funding, including the increased funding, still goes to the 5000 or so people who are already in a supported accommodation service. We also can see that the cost relating to those accommodation services has escalated exponentially from something like $65 000 to $66 000 per bed per year to the department's allocation at the moment of $100 000 per bed per year. You really have to ask yourself: is this money being spent wisely, and are there better ways to do it? And one of those better ways, I have to say, is: why can the department not provide $2 million for recurrent funding for a respite service to keep families caring as long as possible, because until you are faced with putting them into an accommodation service that you have not got, and with bricks and mortar that are not there, it just does not make sense that families are not being given the support they are asking for. It does not make sense that the Support and Choice funding is not actually translating into that which it is replacing, and that is accommodation services. We do not see very many people being given a supported accommodation service as a result of new funding under Support and Choice.

The CHAIR — Because of the range of choices that are available would be the reply.

Ms TOPS — I guess.

Ms ROMANES — Ms Tops, you have talked about the move from the general services sort of planning to the individualised approach. Do you think that overall has been a positive change?

Ms TOPS — We have yet to see the fruits of individualised planning, I have to say. We have yet to see that individualised funding actually makes life better for people with disabilities and/or the families who are caring for them. I find it fairly innocuous that families are on the one hand accused of holding their disabled people back and not allowing them to be independent but on the other hand being forced into a situation where they have to keep caring whether they like it or not.

The CHAIR — Thank you very much for your evidence before the committee today. A transcript will be provided to you as soon as it becomes available. We also thank you for your written submission to the committee.

Ms TOPS — Thank you very much for that. I would also like to provide you with a supplement to our submission that I talked about today.

Witness withdrew.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Ms M. Ryan.

The CHAIR — I welcome Ms Margaret Ryan to the public hearing on the follow-up of the Auditor-General's report on intellectual disability. All evidence taken by this subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected from judicial review. However, any comments made outside the precincts of the hearing are not protected by parliamentary privilege. All evidence given today is being recorded, and you will be provided with a transcript as soon as it becomes available. Ms Ryan, would you like to make a brief opening comment, or would you like to reinforce the submission you have already circulated to us?

Ms RYAN — I would like to take the opportunity of thanking the committee for the opportunity to be here today. I am here because I have a very strong belief that the rule of law matters, and this is in fact what this committee is doing: reviewing the performance of a department in fulfilling its statutory obligations. I would also like to stress to the committee that it is the performance of the department in fulfilling its statutory duties to people who are assessed and declared eligible according to the criteria of an act of Parliament. There was a 1997 report done by the Australian Institute of Health and Welfare on the definition and prevalence of intellectual disability. That in itself demonstrates that intellectual disability is applied in a wide variety of situations.

What we have in this act of Parliament is a criteria for children aged 0 to 6 years of age, of development delay. We also have what is a very tight criteria for people 6 to — basically they have to have this intellectual disability before the age of 18, and they also have to have the adaptive behaviour part of it in determining that they are people with an intellectual disability. I think this is a very important distinction that the committee must really keep in mind when it is considering the performance of the department. I say this because in fact, in terms of fulfilling its statutory obligations, we have no information in Victoria on services provided to people who meet the criteria of this act. All the information we get — the reports which are provided — are not specific. They might have the criteria of intellectual disability, but they are not specific to people with intellectual disability who meet the criteria of this act.

I do not have the time now to go through all the academic work that is available but it is considerable. This is where you come down to your 1 per cent. It is a very tightly targeted group that we are looking at. I do not understand why the department has such difficulty in providing services and informing on this target group. We have cultural and linguistic diversity target groups, we have female target groups and we have indigenous Australian target groups. In this one we have a target group of people who meet specific criteria for intellectual disability and that is to whom we have this concern that we have a specific act of Parliament to ensure that for this group of people the services are planned and provided for them.

What has happened within the department in my assessment — and I have now had 10 years of looking very closely at the department and 10 years of writing articles about them — is that there is a culture which has no problems whatsoever with misleading information, with deceptive information and with straight-out telling lies. These lies have gone to every echelon of the state of Victoria, including the lies which are published and which form the basis of the government's election policy for people with disabilities. I specifically refer — and this policy is on the web site — to the fact that the people of Victoria were told that the Bracks government had increased funding for disability services by 34 per cent, or $195 million. That is quite correct. We have increased shared supported accommodation places by more than 1100 — that is such a lie! An increase of more than 40 per cent. We have increased adult day and support services by more than 1861 places — we do not know how much of a lie that is because the department has changed the criteria for measuring adult day and support places. We have increased Home First by more than 1000 places — that again is just an out and out lie. I cannot believe that members of Parliament can find this acceptable.

I would also suggest to this committee that the review is compromised by the Chair having been the minister responsible from 1999 to 2002. There is a clear conflict of interest in the Chair reviewing the performance of a department for which she had the ultimate responsibility. To ensure that the integrity and credibility of the work of this committee is beyond doubt, the Chair should step down from any participation in the review. Thank you.

The CHAIR — Thank you, Ms Ryan. The first point I would like to take you to is accessing data and information held by the Department of Human Services. You have made reference to that. What in particular would you wish to draw the committee's attention to following through?

Ms RYAN — The committee has no data on the performance of the provision of services to people with intellectual disability who meet the criteria of the IDPS act — none.

Mr FORWOOD — This committee's task is to assess how much progress the department has made since the November 2000 report of the audit office against the recommendations that were made at that time. Perhaps you would care to outline to the committee your views of how well the department has done in addressing the recommendations of the audit report?

Ms RYAN — I made a very detailed submission to the Public Accounts and Estimates Committee, the one dated 20 April, very specifically addressing recommendations in the Auditor-General's report. I was very careful that that was what I addressed and that I provided evidence for every statement I had made. In particular I would point out to this committee that the Auditor-General in his report raised concerns about whether or not the direction being taken in the formulation of the state disability plan would meet the criteria under the IDPS act, there being a three-year plan for intellectual disability services. I would point out in this case that the minister must ensure the preparation of this plan. I have said in my submission of 20 April that it is an absolute farce to even consider that the 10-year plan or the three-year implementation plan could meet any criteria of fulfilling the statutory obligations for a three-year plan for intellectual disability services. I would take it from the top, Mr Forwood, if the department cannot fulfil that statutory obligation they have Buckley's chance of fulfilling the rest.

Mr MERLINO — This is just a point that I think needs to be made for the public record. I notice on Ms Ryan's tag it says, 'Carer and advocate'. In terms of the agenda today, from the material you provided to us, I understand that you are neither a carer nor a parent of a child with a disability. You are just someone with a strong and active interest in disability.*

Ms RYAN — I find that question so insulting, Mr Merlino. I do not know what you are trying to get at. My sister is the mother of a profoundly disabled child.

Mr MERLINO — Thank you.

Ms RYAN — Perhaps you would explain to me what kind of disparagement you were trying to make then.

Mr MERLINO — I find your presentation also insulting, if I can say that.

The CHAIR — Mr Baxter?

Mr BAXTER — Ms Ryan, have you been able to, one way or another, have any input into the review of the legislation that we have been informed is under way and as we heard from previous speakers this morning who indicated it is taking a very long time to actually get anywhere? Have you had any opportunity or discovered any way of making some of your points to that review?

Ms RYAN — I took the opportunity, Mr Baxter, which was offered to the public, the one public consultation process which has been gone through.

Mr BAXTER — About how long ago was that?

Ms RYAN — The discussion paper on the review came out at the end of May 2003. The public consultations took place in June, July and August. I also asked, or I had to make inquiries, as to whether or not others — sorry, I certainly did that; I attended the public consultations. I made a submission myself. I also took the opportunity to ascertain, because the submissions were certainly not up on the web site, to inquire as to their status, and I took the opportunity to go in and read the submissions which have the names of the people blanked out. I have also pursued the matter with my local upper house member and I have met with the parliamentary secretary who is now in charge of this review. But it is the time lag which concerns me greatly.

Mr BAXTER — Apart from that time lag — and I think that is a concern of the committee as well — were you satisfied with the consultation process? Was it open enough and accommodating enough?

Ms RYAN — I was able to make the contrast because the federal Disability Discrimination Act was being reviewed at the same time. There is a significant contrast between the process, the way in which the Victorian legislation is being reviewed within Victoria, and the way the federal government has tackled its review of the disability discrimination legislation. With that review they had two rounds of public hearings. I think they had some focus groups. I took the opportunity there to go along and speak to the committee and answer questions. People were able to make submissions; it was very public. A draft report was finalised in April. It was a process that took about 12 months, and they were doing that Australia wide. It was very public and very open, and as I understand it, the report is now with the federal government waiting on its response.

Mr BAXTER — Would you hope for or want or expect in terms of this process that at some stage there will be a draft bill put out for consultation? Would that be your preferred way of it proceeding, or simply that new legislation were presented to Parliament?

Ms RYAN — There is incredible merit in having a draft bill, but before that there is very much what I call a black hole. There is a very big gap, and at this point in time it looks like there is no final report going to government in terms of the two rounds of consultations that will have been held. I would direct the committee's attention to what is commonly known as the Rimmer report, and I am sure it is in the parliamentary library. It was a report on the legislative framework for people with intellectual disabilities which was done for this particular piece of legislation that we now have. We did not have a similar one for the Disability Services Act in Victoria, because that essentially mirrors the federal Disability Services Act. I would also highlight for the committee that the Disability Services Act was reviewed in, I think, 1995 by the federal government, and many of the recommendations then are relevant today.

Ms ROMANES — Ms Ryan, do you feel the current individualised approach to planning is a positive change from the general service plans?

Ms RYAN — My understanding is that the general service plan and all the thinking underlying and underpinning it is that it be an individualised approach, so it is a change of language rather than a change of intent.

Ms ROMANES — You do not see any positive outcomes from the new direction, from the experiences you have had?

Ms RYAN — My understanding is that there are actually not many people — I am thinking about April of this year when about 600 people had actually had a Support and Choice package in place. I mean in the southern region which has something like 20 per cent of the population of the state, I do not wish to talk about my personal experience, but our family has been allocated one of these Support and Choice packages. We saw a planner maybe about a month ago. It has been a very long process in the southern region.

Could I just say on that, I did provide the committee with a report on Support and Choice. I made reference there to a research report done by the Nucleus Consulting Group and basically it has 42 examples of how what you would call individualised planning and funding can be applied. The main criticism in terms of the direction the department is taking is that if you really want change in disability services in Victoria, let the funds go to the families. We are still in the situation where funds have to be brokered. That is perhaps the most pertinent comment. The conference I attended was very much directed at: how do you get the funds to the families?.

The CHAIR — Thank you very much, Ms Ryan. If there are any follow-up questions we will be circulating those to you and getting you to pop them in with the transcript.

Ms RYAN — Thank you.

Witness withdrew.

---

* Ms Ryan has never claimed, and would not claim, to be a carer and an advocate. Ms Ryan has no knowledge of how or why she was designated as ‘carer and advocate’. Her approval for this designation was neither sought nor given.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Mr M. Gourlay, chief executive officer, Association for Children with a Disability.

The CHAIR — I welcome Mr Michael Gourlay, chief executive officer, Association for Children with a Disability, to this public hearing. All evidence taken by this subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected form judicial review. However, any comments made outside the precincts of this hearing are not protected by parliamentary privilege. All evidence given today is being recorded and witnesses will be provided with proof versions of the transcript later this week. Mr Gourlay, would you like to make a brief opening comment.

Mr GOURLAY — Thanks for having me here today. I wanted to start with a general comment about the overall level of resourcing to our disability service system in Victoria, because I feel that often when we have specific debates and recount specific experiences of families of children and older adults with a disability we are seeing symptoms of a system that tries to provide resources to families and individuals from a very small pie that is not big enough to provide a level of support that families need.

It is useful to put that into perspective from the beginning. I will not quote today's figures, but I just did some figures — because I trust the Attorney-General's figures over those of anybody else — going back to the original report. In that year, 2001-02, the disability services budget was in the order of $668 million according to the Attorney-General's report. It also noted that around 78 per cent of the department's budget of that $668 million is designated for families of people with an intellectual disability, and in turn it stated that there are 40 000 Victorians with an intellectual disability, so very briefly doing the mathematics on that, as I have done, that comes out at $13 026 per person. The figures today would be slightly different, obviously, but I use those figures because they are the ones in the Attorney-General's report at that time.

As you know, for families of people with a disability who are in shared supported accommodation, the unit cost of that accommodation is significantly higher than $13 026. The unit cost of a person who is living in one of our instructional settings is certainly well above $13 026. If you were to take out from those 40 000 people those who are getting unit cost assistance for accommodation in the $80 000 bracket and above, and you then started to do the sums for other people, you would find that the unit cost of provision of service for a person with an intellectual disability is significantly less than $13 026 per person per family. I raise those overarching figures because in the invitation today we were asked to comment on the provision of resources for services, but I do think we still have a debate within the general community about the level of overall taxpayer funding for our disability services system.

It stresses me that so much time and energy are spent and so many families are distressed in trying to access services. In trying to do their best for families even service providers are stuck with a system that is so obviously under-resourced when you take into account the demographics of the population and the money that is there in the system. We often have debates about percentage increases. The Bracks government recently sent me a letter saying that disability services funding had increased by 50 per cent since it came to office. I am not disputing those figures, although we might need to look at how much of that is inflation and how much of that is money that has come via the federal government et cetera. But without quibbling, the real issue is: what was the base? A percentage increase of a base that is inadequate is fairly meaningless.

What I would like us to get back to is the demographics of how many people with intellectual disabilities we have in Victoria, how many people with other sorts of severe and profound disabilities there are and how many families there are where those people are living with them, and then go back to basics and map out our current level of resourcing for the service system against the demographics of who is there — not against historical levels of funding, which I believe are grossly inadequate when you start to look at the figures and the demographics. A lot of the feedback you get from your local electorate offices on families of children with disabilities, and a lot of the feedback you will get through this committee, is, I imagine, a symptom of a system that overall is grossly and inadequately funded. That is the first point I want to make.

The second point is that in representing families of children with a disability our organisation, the Association for Children with a Disability, is essentially a very big self-help group of families of children with a disability, covering all ages and all types of disabilities. I guess I wanted to focus the committee's attention on the system as it begins at age 6 for families of children with a disability, given that this committee is focused on the disability services division, which has responsibility for funding services other than school-based services for children with a disability aged 6 and above. We have a different service system for children aged from 0 to 5. Something that the Attorney-General's report did not look at in detail but probably should have looked at is how we could get much better at the transition between that system for children aged from 0 to 5 and the system for when a child turns 6, because disability as a service system should be reasonably easy to plan.

We do not know them all, but we know who most of the children identified with an intellectual disability at age 6 or 7 are when they are 2, 3, 4 or 5. For some the diagnosis comes to light only in later years, but those families of children with a severe and profound disability at age 2, 3, 4 or 5 know they will be turning 6, 7, 8, 9 and 10. We know that once the kid who is permanently in a wheelchair turns 13 or 14 and gets over a certain amount of kilograms in weight, mum and dad are going to get a very bad back and will not be able to lift that child without a hoist. So the system ought to be able to put in place those basic planning mechanisms.

At the moment we do not have any system for making sure that the children we know aged under 6 who have a profound and severe disability are automatically brought in to the service system in a planned way at age 6, and that is something that I certainly think we need to look at. It should be easy enough to do. I guess thereafter we are looking for a mechanism that would assist families to plan in advance in a cooperative way throughout the life cycle — from the system in place at ages 2, 3, 4 and 5 to when the child turns 6 — and of course incorporating school. A big part of the life of a child aged 6 through 18 is school, and the system talked about in the Attorney-General's report does not make much mention of school. However, in terms of the way families live, school is a very big part of their life, and we would like to see much better cooperation in the way the disability service system works and indeed in the way the education and school system works for families of children with a disability.

Just by way of one example, despite a system that in Victoria is reasonably good — it is not perfect, but it is reasonably good at including children with a disability in mainstream primary schools — we are tragically seeing a lot of children in the transition to secondary school not being able to be maintained in a mainstream secondary school environment. Despite having a positive experience of a mainstream primary school, parents find, or indeed the young people themselves find, that they want to make a choice to go to a special school for secondary schooling. This goes against all the rhetoric and the impetus of the state plan, which is about including children with a disability and families of children with a disability in a whole-of-community context. That is happening out there with kids aged 11, 12 and 13. Yet the disability system does not interact well enough with the education system in working together to say, 'How can we make sure that every child with a disability has genuine access to and a genuine opportunity to attend a mainstream secondary school as well as a mainstream primary school?'. That just does not happen. There is no system that automatically says, 'Let's get our act together between the disability-based case management system and planners, the non-government sector and the school-based system'. That is another transition point — from 5 to 6 is one transition point, and another crucial transition point where the system could be much better is when a child goes from primary school to secondary school.

There are other comments I would like to make — and I will try to keep them brief, because I know you have been here all morning and you probably have a lunchbreak scheduled soon. Working backwards from the adult-based accommodation system, we are seeing a tragic cycle where the lack of availability of decent accommodation for adults with a disability means that young families are looking at that system and feeling a sense of hopelessness. They are feeling that unless and until — I hope this quote does not come out wrong — they have 'some sort of nervous breakdown or major family crisis', their options to access accommodation for their child or young person will be very limited. In other words, the system is so crisis driven when it comes to accommodation that your family and you as a parent really need to be in a bad way before you will even be considered for the meagre accommodation resources that are there. That has a ratcheting effect right the way back through the system. Some younger families, perhaps prematurely — this is tragic for children and young people with a disability — are feeling like they have no other option but to leave their children in a respite house and not pick them up from respite. That is a big decision that families make in a crisis situation, but our service is contacted by families who are contemplating this option. It is a very difficult and heartbreaking scenario.

We have asked the department for figures on how often this has happened and how many children are living in respite facilities. I have yet to receive an answer which I am completely comfortable with in terms of the way the statistics read and our experience on the ground. I am not sure we are doing the counting right between the department and ourselves. What is happening then is that if young children are living in respite without access to accommodation they are taking up a respite bed, which reduces the availability of respite to other families. This means some families which have been used to getting respite once every two months in a respite house are now getting less and less, which then adds to the cycle.

My own view is that the massive underfunding of our accommodation system for adults with a disability and families of adults with a disability — I understand you had presentations from families of older children earlier this morning, from families in that demographic, where the parents are 80, 70, 60 and 50 — is having an effect right the way through to where younger families wonder what chance they have of getting accommodation. Those of us who have children who do not have disabilities expect that as part of normal life they will move out of home and establish themselves in independent accommodation at some time — it used to be 18 or 19, but these days it might be young 20s. By 25 you would hope that your young person would have established themselves independently. We do not have the same planning approach or the same rights approach. A young child with a disability is expected to go to kindergarten and to school, but when it comes to accommodation planning we do not build our system expecting that young people with a disability have a right to a choice to access an independent home sometime up towards the age of 25.

Our whole system is crisis driven. We say let us try and provide some resources to families so they can hang on as long as possible, and when that breaks down, or when families give up or when families suffer real hell, then we will have a look at what resources we have for accommodation and prioritise who is at the top of the queue. My view is we have to get into a system that plans and funds in a way that as a community we say young people with a disability will have as a normal part of life — as normal as going to kinder and school — a genuine choice of moving to alternative accommodation by the time they turn 25. I would like to see that being something normal. If we could do that, I suspect it would reduce pressure right the way through the system in the earlier years.

The CHAIR — Thank you very much. My first question goes to the point you have just concluded on. Would you say that following the Auditor-General's report where he talked about planning for individuals and protecting their rights that the single most important item yet to be addressed is normalising moving out of home for the person with an intellectual disability and for their parent? If you think that is the case, do you have examples of where either in Victoria or internationally you have seen that work well?

Mr GOURLAY — It is a double-barrelled question. Let me have a think about that — —

The CHAIR — You might like to take it on notice. We do not even expect ministers to answer every question straightaway.

Mr GOURLAY — I do think completely absent from our whole discussion of disability around this accommodation issue is what is considered a normal family pattern. If we are talking about normalisation, if we are talking about people with a disability and families of children with a disability being able to be given access to public resources to assist their family to live their lives as normally as possible as part of the community, I think we have to build in genuine choices around access to long-term accommodation for the young person as just a normal part of our system. In terms of families and best practice, I know many families of younger children with a disability who are already actively planning and saying they cannot rely on this government system to provide support for their children so they have to look at some creative alternatives now and start planning for some creative alternatives. I think that as well as thinking through this issue of rights to accommodation we also need to think about creative ways where families are both willing and able to put some of their own resources into their child and young adult's long-term accommodation.

There is not an assumption that the government should pay 100 per cent of every cost associated with their child's disability and accommodation forever and a day. Obviously different families have different capacities, but we have families who ring up and say, 'We are planning our will, our child is three, we want to plan for when we are not here, and we want to plan for when our young person is an adult'. In the same way as some of us might think about our superannuation for retirement they are thinking about where they can put money away to assist with accommodation. Our system currently does not cope with thinking about the ways families want to input, the creative ways families want to contribute and the way governments and families could be partners in terms of some of these solutions to long-term accommodation issues.

The CHAIR — Is there an answer or do you want to think about whether it is the most significant item?

Mr GOURLAY — I think if we could build in a resource and support guarantee for families of children and young adults with a disability that they would have access to a level of funding required to have a genuine choice about access to independent accommodation from the age of 25 onwards, if we could deliver that, it would be a real way forward for our whole system. It would have an effect right the way through the system.

The CHAIR — That was not my question: it was what was worrying. Mr Forwood, do you have a question?

Mr FORWOOD — The issue that I am interested in is that in November 2000 the Auditor-General produced a snapshot of the system as it then existed. Four years later we are having a look at it, and I want to know whether you think it has got better. He was quite specific in the things he said ought to be done and — —

Mr GOURLAY — If you look at the early recommendations in the report around general service plans and the case manager model of the department, what we see four years later from my perspective is that in the department, in trialling the support and choice model, which is a very small trial in the overall context of the system, there is almost an admission that it does not believe the full implementation of the case management model and the general service plans of the original act as recommended to be followed up in the Auditor-General's report is the way forward. That seems to be the implication. So if you did an audit now of every person with an intellectual disability who is associated with Department of Human Services disability system, you would not see too many good quality general service plans either in the government sector or the non-government sector.

You are starting to see with Support and Choice — and we have over 4000 members of our association — ordinary mums and dads and families with children with a disability. So as you can imagine, quite a few of those have been chosen for the Support and Choice package. So far our experience of those families who have been involved with the Support and Choice package has been a positive start for those families where they feel like the focus is really around the individual needs of their family, and they are being encouraged and feeling encouraged to think creatively and laterally about the way they live and what is right for their particular family, as opposed to ‘How do we fit what our family needs into the different boxes of the system?’. That is an encouraging start for that system, but it is a very small trial. What we would say right now is that pending the results of that trial, we still have in terms of the current day-to-day operation of the system really inadequate attention to good quality general service plans in both the government and the non-government sector. The recommendation in the report about having those general service plans done well and implemented well is still a long way short of where we should be and the sort of benchmarks the Auditor-General would have expected in the year 2000.

Mr FORWOOD — I will just take that one step further if I may. Are you concerned that the legislation review will lead to a diminution of the statutory responsibilities such as general service plans that currently exist in the act?

Mr GOURLAY — We remain open to the possibility that within one new act you could maintain and expand the best of the IDPS act and all the statutory benefits that it provided to people with an intellectual disability and their families. We represent families across all types of disabilities, and there are a range of views within our organisation about the new act. As you could imagine, most families finish up lining up around — depending on their experience and their particular child as you can imagine. It is a big ‘if’. We have not seen the new act, and you would certainly, from the point of view of people with intellectual disability and their families, want to make sure that every single bit of the best of that original act is included and in there — absolutely in lights — in any new act. Yes, there is a danger I think in the approach to say, ‘Let us try and do all disabilities well’ that you could water down some of those provisions, particularly around planning and allocation of general service plans, so that is something that we will certainly be looking at very closely to make sure that it does not go by the wayside.

Mr MERLINO — I go back to the issue that you talked about of the transition from primary schools to secondary schools, and I would just like to have some information on what the impediments are on the ground. Is it because primary schools are systemically more geared towards providing for children with disabilities, or is it because there is an issue about teacher aides and lack of teacher aides in the secondary system compared with the primary system? What are the impediments?

Mr GOURLAY — Look, there is a long story and a short story. The short story is that secondary school is inherently more difficult because you are moving from class to class. The primary school environment is an easier environment to include a disability in; there is no doubt about that. You have predominantly one teacher in primary school, whereas in secondary school you go into six or seven different classes, so you have six or seven different teachers who have to know the ins and outs of the child. It is inherently a more difficult environment. You also have natural factors in terms of young people’s attitudes.

Generally speaking the attitude of young people who do not have a disability towards children with a disability in primary school is instinctively and naturally generous. When adolescence kicks in early secondary school you start to see some difficulties there. So our response to that is, ‘Yes, it is more difficult, and therefore we need a concentrated effort, especially in those first two years of secondary school, to make that a genuine choice’. I would say that with the way our education system is at the moment, where there is a review in grade 6 of children with a disability, often their level of funding for education goes down a level in grade 6, when we would probably say it needs to go the reverse. It needs to go up a level as part of having a few additional resources to be able to provide for schools and to be able to give the child a genuine chance in early secondary school.

Mr BAXTER — You referred in your opening remarks to some people in respite care being dumped, for want of a better word — that is a pretty alarming situation — and you said that there was some difficulty in ascertaining numbers between what the department might tell you and what your gut feeling might be. Is it anything greater than 'very isolated'?

Mr GOURLAY — I do not think it is very isolated, no. The information that we have received to date suggests that there is one region — the eastern region of Melbourne — where there seems to be a higher number of these compared to every other region. Again, I am still unclear to this point on exactly what the figures are and exactly what we are counting in terms of different situations, because there are some children who move to transitional houses who probably then are not counted, and so and so forth. So there are a few definition issues to go on with, but it is an issue across the system, and it is not isolated.

I guess my own view is that while we would never ever encourage that, families do it as a way of managing access to resources. You can see a thought pattern that says, 'The only way I am going to get high up in terms of access to accommodation for my child is if I do this. If I don't do this, I have no chance of getting anywhere near the top of the list for long-term supported accommodation'. I guess my view would be that that thought pattern that some families go through is a comment on the inadequacy of our overall system and our overall approach. I think we need to examine that reality and try and put in place a system that gives families that are looking long-term at the long-term care of their child as an adult some hope that a decent level of resourcing will be available to that family throughout their life cycle. That is the key to assisting families at that point.

Mr BAXTER — They need to be given some confidence, otherwise equity is going to go out the window, is it not, because some people are going to think that they have no option but to do that. Others who do not do it are then very much disadvantaged.

Mr GOURLAY — It is possible. I am not saying it is likely, but it is possible that numbers will increase because families will say, 'Yeah, that led to someone getting an accommodation place. Obviously that is the way to do it; the support needs register does not give you the result'. That is obviously a family tragedy, it is a tragedy for the child and it is a tragedy of our system at the moment.

Ms ROMANES — I have a question also about some better systems and planning for the needs of individuals. If we were to have better systems and planning for the needs of individuals, if we were to have a better whole-of-government approach, are there other critical milestones and/or situations where other departments could play a much more positive role in terms of transitions? You mentioned education, but are there other areas where more cooperation and a whole-of-government approach would assist?

Mr GOURLAY — Certainly I think in notes here I have another half a hour's worth of discussion which I will not go into, but the mental health section of the Department of Human Services and child and adolescent mental health services have many improvements they could make for children with a disability who may not necessarily have an intellectual disability but may be on the fringes of eligibility for an intellectual disability. So I think the connections and the cooperation between the disability section and the mental health sections need to be improved significantly. I think cooperation with the education department needs to be built in as a fundamental part of the way the system works with families. That goes without saying, I think. Then lastly another area that really concerns me going forward with the system is what we have known in the past as the Futures for Young Adults program, and the connections there with the federally funded system for employment support for people with a disability. I am worried about the potential for erosion in the Futures for Young Adults program that touches on day services and the funding of what adults with a disability have access to during the day, because it is kind of connected to the accommodation debate.

I certainly think we need to get good cooperation with the federal government around employment and that system to make sure that those two systems are working and funded well together in a seamless way so that young adults with a disability have access to meaningful employment and/or other day activities upon leaving school. At the moment we get this bit of a tit for tat where the federal government seems to be blaming the state government for holes in that system and the state government seems to be implying that there are some holes in the federal employment system. Meanwhile families are at risk of missing out and getting access to decent day support services through the Futures for Young Adults program and other day services. That is another big area, I think. It is not just whole of government. It is across government.

The CHAIR — Thank you very much for your contribution this afternoon. You did mention that you have additional information. We are constrained with time, but you are free to lodge that with the secretary should you wish to do so.

Mr GOURLAY — I will take up that opportunity, thank you.

The CHAIR — We will be sending out a transcript as soon as it becomes available, and we thank you very much for your attendance. We appreciate it.

Witness withdrew.

CORRECTED TRANSCRIPT

PUBLIC ACCOUNTS AND ESTIMATES COMMITTEE

Follow-up of Auditor-General's Reports Subcommittee

Auditor-General's report no. 53 — Services for people with an intellectual disability

Melbourne – 29 June 2004

Members

Mr W. R. Baxter	Mr B. Forwood
Ms C. M. Campbell	Mr J. Merlino
Mr R. W. Clark	Ms G. D. Romanes

Chair: Ms C. M. Campbell

Staff

Executive Officer: Ms M. Cornwell

Witness

Mr W.Lawler, rural access officer, City of Latrobe.

The CHAIR — We welcome Mr Bill Lawler to this public hearing. I place on record the appreciation of the committee for your coming back from holidays yesterday and picking up copious emails and voice messages and managing to be here from Gippsland in such a short period of time. That is noted and appreciated. All evidence taken by this subcommittee is taken under the provisions of the Parliamentary Committees Act and is protected from judicial review. Any comments made outside the precincts of the hearing are not protected by parliamentary privilege. Evidence given today is being recorded and a transcript will be provided to you as soon as it becomes available. Mr Lawler, would you like to make a brief presentation, particularly in relation to the Auditor-General's report and your work since the Auditor-General's report has been delivered to the Parliament?

Mr LAWLER — As an opening remark, the state government provides support to people with disabilities in various ways, obviously. Sometimes they provide direct support, and sometimes they fund other organisations to provide the support. I suppose something that I am involved in which is reasonably new is providing funding for community building and community development initiatives. I have been invited here today to talk a little bit about those community development initiatives and how they can impact on the lives of people with intellectual disabilities. More specifically, I work in rural access. The other programs are metro access and DAF access, and to some extent the triple A program is a similar model, which is not funded by — —

The CHAIR — Triple A being the access for all — —

Mr LAWLER — Access for all abilities, which is funded by Sport and Recreation Victoria in partnership with the Department of Human Services. Although a lot of people with disabilities need support services, there is a group of people with disabilities that may benefit greatly from a more inclusive community, or a community which has the capacity to meet their needs, rather than having to use specialist disability services. I think rural access is making some progress in eliciting much more community support for people with disabilities than previously. Hopefully it is building a lot of partnerships outside the disability field, because I think for too long there has been a lot of community planning around everybody who lives in the community, and people with a disability have been just something different.

I think the challenge for us is that when we talk about community planning we want to talk about community planning for everybody. Local government is obviously in a good position to do that. When local government does community plans of recreation strategies, which are for the whole community, we need to make absolutely sure that the needs of people with a disability, obviously including people with intellectual disabilities, are included in that community planning. For some people that may lessen their need for specific disability services. I think there is a bit of a continuum — —

The CHAIR — Can I just cut to the chase?

Mr LAWLER — Sure.

The CHAIR — Can you give us examples in your presentation of where people with an intellectual disability have, as a result of your work and the work of others, been able to access other, more inclusive opportunities? We have a tight schedule.

Mr LAWLER — One sector I want to talk about in particular is the health sector. We have been doing some work locally with the local hospital to ensure that the local hospital has the expertise and the training and facilities to meet the needs of people with an intellectual disability. We are just about, in this coming year, assist the hospital to do disability awareness training for staff. Also we have done a lot of work locally with some of the health services, doing some education with the community nurses about making sure that the programs they develop are inclusive of people with an intellectual disability. We have also been doing some work with the local police to ensure that their responses to people with an intellectual disability improve and that the police can play a bigger role in directing people to support services, if required. We have also been doing some work, talking about the education system, trying to improve the linkages between school and post-school options with regard to employment and further training. That is just an example of some specific projects. Another one we have been doing is disability awareness training for Monash medical students right across Victoria so that when GPs open their practices they have a much wider knowledge to meet the needs of people with a disability, including people with an intellectual disability. That is an example of some of the sorts of work that we are doing through these community development initiatives.

The CHAIR — Thank you. In my first question I want to pick up and get you to expand on — I cannot give you the page but the Auditor-General made reference to it — the importance of medical services and an understanding of people with intellectual disability. Can you give us specific examples of what you have been able to achieve in your region? Have you got any evaluation methods that you will be following post your training of medical students and medical personnel?

Mr LAWLER — Unfortunately, with the Monash medical students we started with year 1 students last year so it is going to be a few years before they actually graduate. One of the projects we did locally was with some of the local health services in regard to women's health — making sure that women with disabilities were included in those programs and that those programs were promoted. I am not aware of the increase in numbers of those at this stage but we are hoping that the statistics will show that there has been an increase in the number of women with disabilities attending those programs. I think the statistics show pretty clearly that some people with a disability experience pretty poor health. A lot of it is due to social isolation and disconnectedness with their community. We are doing a lot of work with the health services and also community safety to ensure that people can take advantage of health services and also increase their community connectedness so that they can remain healthier for longer.

Mr BAXTER — Where is rural access funded from?

Mr LAWLER — It is funded through disability services, Department of Human Services.

Mr BAXTER — Just listening to what you say, we seem to be emphasising a lot on training medical students, training other people. Are we actually delivering on the ground? I get the impression that this is all very much in house.

Mr LAWLER — It is probably a lot about attitudinal change. It is about getting the community to understand that people with a disability are pretty much the same as everybody else in most ways and helping them provide the services they provide to everybody, rather than having people with a disability sometimes excluded or discriminated against as far as services go. If you were to talk to most people with a disability — and we have done this many times in forums — they will tell you that the biggest barrier they face, and I am not talking about all people, is community attitude and community ignorance about their needs. If we can change people's attitudes, then we might get some real change in the community as well. That is where we are coming from.

The CHAIR — How would you evaluate, for example in the medical area, the success or otherwise of this training and attitudinal change?

Mr LAWLER — I think we would — people's satisfaction rate with visits to doctors or visits to hospital, we could measure the change. That is something that we would certainly like to do in the future.

Mr MERLINO — I want to go back to community planning and the role of rural access in terms of getting participation and dialogue with mainly local government plans about recreation et cetera. Is this a formal partnership that you have with local government in rural Victoria, or is it simply a case of your organisation keeping an eye out for local government plans that are advertised in local papers? Is it a formal thing where it is a real partnership, or do you have to make sure that you get in there on the ground floor?

Mr LAWLER — I actually work for local government, for Latrobe city, and I would have to say that I think it is a formal partnership between the Department of Human Services and local government. Most of the rural access workers and possibly all of the metropolitan access workers will be based with local government. I cannot speak for all local governments but obviously there is a commitment by both sides. When we talk about integrated community planning, when we are talking about local government, state government, federal government and non-government organisations, local government is obviously in an ideal position in a local community because it is involved in most things that happen in a local community. People like myself need to make sure that when an opportunity comes up to participate in any type of planning, the needs of people with a disability are included in those processes and that they are mixed in rather than off to the side.

Mr MERLINO — How does that happen? Is it the people representing rural access or is it direct consultation with people with a disability?

Mr LAWLER — Both actually, but we would much prefer it to be direct consultation with people with a disability. Part of our job is not to be the person giving the information but actually to take a lot of people with a disability along — —

Mr MERLINO — Ensuring that it happens.

Mr LAWLER — Absolutely. A good example of that would be recently Latrobe city was developing its public municipal health plan, but as well as the public municipal health plan it extended that process to a community plan. I made sure that people with a disability were involved in those consultations and were also involved in completing questionnaires and sending them back into that process. In addition, we are doing a recreation strategy, and just the other day the recreation manager came in and said, ‘We are doing a recreation strategy. We need to make sure that people with a disability are involved in the process. Can you give me some names and addresses of people we should contact?’. That is where the strengths are I think.

The CHAIR — This will be the last question. That is the Auditor-General’s report which is particularly about providing resources for services. If you look at paragraph 5.21 on page 8 where it says the department should look at day programs — that is too small for you to read?

Mr LAWLER — I just wanted to add that obviously we are trying to encourage service providers to take a more community development approach to what they do. As well as providing services to the people, it is maybe trying to expand what they do to try to make sure the people who use their service, if possible, are able to take advantage of the community supports which are there.

The CHAIR — My apologies. Paragraph 5.21 refers to day programs and says definitions used in assessment processes should be clarified to remove the potential for misinterpretation and suggests the funding assigned to the six need levels be reassessed et cetera. My question goes to the work that rural access has done and achieved in the past couple of years. Could you give us any examples of where alternatives to what are traditional day programs may have been implemented as a result of your work?

Mr LAWLER — A lot more people in day programs are able to access more community-based programs rather than centre-based programs. That has been a bit of a trend for a long time. We have been working with neighbourhood houses and places like that, craft groups, the Country Women’s Association and all of those types of organisations trying to open up the doors so people with an intellectual disability can participate in those sort of programs. That has been quite successful I believe.

The CHAIR — In the interests of time we are going to have to invite you to make a written submission if you wish. We have run out of time today. I place on record again our appreciation of your coming up. Thank you and good afternoon.

Committee adjourned.