

**FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE**

**Inquiry into the provision of supported accommodation for Victorians with a disability  
or mental illness**

Melbourne — 22 October 2008

Members

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Ms M. Sheridan, deputy chief executive officer, general manager organisational policy, planning and development, and

Ms M. Sproule, eastern region manager of individual support services, Yooralla.

**The CHAIR** — Good morning everybody, we will get the proceedings under way. First of all, thank you very much for turning up for the public hearing. The committee is looking into issues such as the standard, range and adequacy of care and accommodation currently available; the appropriateness of the current service providers; how unmet need is managed in Victoria; accessibility and appropriateness of accommodation for rural communities, ethnically diverse communities and indigenous Victorians; and the impact of the current service provision on families and carers. The committee is an all-party investigatory committee of the Victorian Parliament and is due to report to the Parliament by 30 June next year, after which the government has up to six months to reply to the committee's report and recommendations.

All evidence taken at these hearings is protected by parliamentary privilege as provided by the Constitution Act 1975, and further subject to the provisions of the Parliamentary Committees Act 2003, the Defamation Act 2005 and, where applicable, the provisions of appropriate legislation in other Australian states and territories. Any comments a witness makes outside the hearing may not be afforded such privilege. The evidence will be recorded and a proof version of the transcript will be provided to each witness at the earliest opportunity so it can be corrected as appropriate.

I have great pleasure in welcoming Ms Marsha Sheridan and Ms Michele Sproule. Marsha is the chief executive officer and general manager, organisational policy, planning and development, and Michele is the eastern region manager of individual support services, Yooralla. I invite you to make verbal submissions or opening comments, which will be followed by questions.

**Ms SHERIDAN** — Good morning, and thank you for the opportunity to come to discuss this important issue with you this morning. Today we are going to concentrate our comments not on the issues of carers. The reason for that is not a lack of interest in our carers, but rather that we know that Carers Victoria is presenting this afternoon and it will do an exceptional job of presenting its requirements. Instead we would like to concentrate on four key points. The first is in relation to the lack of capacity to enable effective planning for service growth and development and the impact of that lack of planning on people with disabilities and their families and carers. The second point is about the need for genuine choice in service options. Thirdly, we would like to discuss, very briefly, approaches to better meet the needs of special interest groups. Finally, we would like to add a contribution to the conversation about how challenges arising from our unmet and undermet demand can be satisfied, so we would like to move to a solutions phase.

There can be no doubt that planning is hampered by the capacity of those in the current system to plan for and effectively respond to emerging demand. We see this as one of the fundamental issues in the service system at this point in time. Rigorous systems for planning, such as the population-based planning that is used in aged care, would certainly assist in maintaining awareness of the need for systematised investment in service development.

Our current system depends on people self-nominating for consideration for the current register or being placed on that register by intake or case-management staff. This means that currently a lot of people are not listed on the service needs register. This is an important point. Secondly, others choose not to be registered on this list because they know friends or community members who have been waiting for years and they see no point in registering on this list. This means we do not have an accurate representation of needs on that list.

This is compounded by another change in the way we collect data. That change is in relation to the service needs register itself. The previous service needs register approach allowed people to register their need when they knew they would have one, whether it was now or five years into the future. This allowed us to collect data on when somebody might require a service and therefore project into budget years. We now have what is known as the disability service register. This new system can predict demand only one year out. This is because the requirement for entry to that register is that there is a current need — not a future need, a current need.

The difficulties with this particular approach are really quite clear. First of all, from the date that a new shared supported accommodation service is approved in terms of funding, it takes a minimum of two years — often longer — to get it up and running. It takes two years to plan it, to build it and to select the residents and move them in. This means that we are building in crisis. A system that takes need one year out and takes two years at minimum to respond is building in crisis. This is the opposite of what is intended by the Disability Act 2006.

There is another point about how planning is defeating us and that is in terms of individualised planning and response. This is a really good innovation. Please do not mishear me on this; I believe in individualised funding. But in terms of its impact on achieving accommodation services, the reality is that it does not build in the complexities of accommodation services. The support packages themselves do not provide for people with medium-to-high support needs, which means that they are never sufficient to allow people to move away from the family home. Instead we continue to rely on carers, who are increasingly tired and ageing, to fill the gap left in our funding methodologies.

Similarly, there is short-term thinking in relation to capital development. This is denying many the opportunity to live the lifestyle of their choice. In recent years, apart from My Future My Choice — which, as you are probably aware, is to do with younger people in nursing homes — there has been a reluctance to invest in housing capital and a view that any new accommodation should be at least partially funded by the already stretched not-for-profit sector, rather than through full public investment. We question this as a responsible strategy.

A vicious cycle results from the lack of careful planning and investment. In effect, the systemic lack of data, whether it is based on expressed need, relevant demographic shifts or population-based planning, ensures reliance on crisis-led responses. Indeed, the criterion for placement in an accommodation service right now is generally homelessness.

The notion that resources are diverted from service delivery to gatekeeping, eligibility assessments and crisis resolution is one that requires very careful consideration. It strongly implies that were resources redeployed to constructive support the unmet demand and with it the frustration of all stakeholders would be lessened. Instead the mode of operation is crisis response, an approach that inevitably results in more expensive service solutions for distressed individuals and carers. The solutions are seldom the response required or the choice and they do not reflect the preferences of those individuals. Transitional support in crisis situations is virtually non-existent and this increases the feeling of disconnection. Nevertheless, once they are placed, regardless of the solution or its relevance or appropriateness, the needs of that individual are no longer desperate and so the emergency solution becomes the permanent solution.

The use of respite facilities to provide crisis accommodation is both inappropriate for the individual and for those who use the service. Reduced capacity for genuine respite means that other families cannot access it. Their need for respite is unmet, their coping capacity reduces, and another crisis is born. Without effective planning, housing stock is also not refreshed or created in a timely manner or in a timely place, and it is usually a generic solution that fails to meet the emerging requirements of individuals.

There is one other thing I would like to say about personal planning. Personal planning has become a panacea. It is enshrined in the act at different levels. It is important because it allows us to understand what the person is looking for, but we do not systematically collect that information and use it to create service options and service solutions. Instead we have raised expectations, and those expectations are seldom met. The packages are seldom efficient, and the outcome is a general level of dissatisfaction with an unreliable service.

Much of the rhetoric in today's disability services is about personal choice, but in the end it is not a question of genuine choice if it is about the limited range of choices that the system is prepared to offer at that point in time. For many people, the traditional shared supported accommodation

model is still a service of clear preference. If we accept that people need to have the right to choose the service option of their choice and the style of service they would like, then we have to respect that choice. The current approach fails to respect that choice.

**Ms SPROULE** — And fails to acknowledge that that is a genuine need for some people; that that is the only option that will meet their need.

**Ms SHERIDAN** — New investment is required to ensure that this choice becomes a reality, and when we do make that investment we need to ensure that it is choice beyond just service style. It is also about choice of location, about living arrangements, about housing design and who people will live with. It should also be about choice of staffing arrangements. Investment in creative new options will enhance choice and outcomes for individuals within the system. For others, an individualised funding package is the preferred option, and that is fantastic. But what I have to say about that is that it seldom comes together with the housing arrangement, and if it does, it probably is not sufficient to meet their needs. In fact, flexible support options — although there are higher support packages of 70 hours a week, approximately — are insufficient to support someone independently and individually. If we are genuine about saying individual choice, individual lifestyles, then we have to be talking about genuinely supporting people at a much higher level. At some place we have to be transparent in these discussions and in these decisions.

In considering choice we also need to identify and address unmet need and undermet need. Here I would like to talk about the ageing clients in our residential services, or any place else, who simply do not have the choice to retire. They cannot ease off work like the rest of us because their services are not geared for that change. They have to stay at their day services, at work, until such time as government finds a way to resource their residential services so that they can stay at home.

Another area of lack of choice would be in the area of group activities. You live in a house with five other people and most of the time you have to go out with the same five other people, doing the same activities that they want to do because there is not the staffing support for one-to-one service in most services. The reality is that within their service arrangements there is not a lot of individualisation possible.

I am going to turn very briefly to meeting special needs, and I am going to concentrate on the fact that whether you come from a CALD background or you have an indigenous background there are service providers who have very good ideas on how to meet people's needs. They understand the nuances of each culture and the support arrangements that would best meet those cultures. What they generally are not is experts in the provision of disability services, so we need to marry their skills. We need to create genuine partnerships that allow the requirements of the Disability Act — the compliance requirements in relation to all policy and regulation — to be achieved effectively: good rostering arrangements, good quality, but taking account of the specific needs that the other service provider can provide. Genuine partnerships with clear roles and responsibilities should be fostered to achieve that aim.

For people with complex medical needs or behaviours of concern — and this is the growing population — we need a more sophisticated approach to service delivery that recognises that the fundamental quality of the service is predicated on consistent, skilled and dedicated staff. Instead, our funding mechanisms recognise no difference, and in reality what happens is that these services where quality staff are most urgently required have the most transient staff. The training bill goes higher and higher. People are at risk of being injured by clients with significant behaviours of concern, and in fact the constant changes exacerbate those behaviours of concern. Where people with complex medical needs are concerned it is quite simple: we are escalating the risk of a serious injury if we cannot get quality staff to stay in a service. We need to recognise the additional skills and responsibilities those staff have. Addressing these issues will result in a substantial improvement in service quality for these cohorts

The area that I would like to concentrate on, I suppose, is the way forward in the conversation about better options. Yes, without doubt, better housing design will improve outcomes, and this means that we need to move away from the current disinclination to invest in housing as a start. Secondly, we need to be more creative in what we are building. We do not need to have 5-bedroom CRUs to meet the need for shared accommodation. What we need to do is invest a little bit more, get some more private units, a couple more double-bedroom units so that people have genuine choice. We can still get the efficiencies, the economies of scale with the staffing arrangements; we just need to invest a little more up-front, and in doing so we may well reduce some of the recurrent costs of continued crises arising out of incompatibility and poor property design.

Rural areas need a more creative approach that allows local solutions in local areas. There are areas with no shared supported accommodation whatsoever, and this is an important point because they have to move 2 hours away. How often do they get to see their families? How often do they keep in touch with their networks? They have to start again, and I do not think that is appropriate either. Our submission covers an alternative approach to that. We need to improve our planning systems, and we need to be held accountable for what those planning systems are telling us. We recommend that an annual report to Parliament on the real need is essential in understanding what the need is and developing some momentum towards a willingness to address it.

The final option — and this, I think, is probably closest to the best solution that we have available to us at this time — is the adoption of a state or national disability insurance scheme. We have seen a number of tax cuts lately. We have also seen an emerging climate where people believe in the reinvestment of that money into a service system. There is talk about a disability insurance scheme for people with catastrophic injuries. That is a very small proportion of the population. I would like us to think broader; I would like us to think about people who were born with a disability and those who acquire a disability, through neurological or any other causes — not just catastrophic illness — because I believe that if we invest in this option, we will remarkably change the system. All of a sudden instead of investing in crisis response — always expensive, always inadequate — we will get a redevelopment of the service system.

If you take an actuarial approach, you are going to be investing as soon as possible in reducing the impact of disability. Instead of two — if you are lucky, four — hours a week of early intervention for a child in Victoria, we would see a mammoth investment in early intervention for children because we know it will have a positive impact on their independence in later life and therefore their reliance on paid support. We would see service systems reoriented from keeping people out — mammoth bureaucratic structures keeping people out and diverting them from the service system — to giving them a response. So it is not all about new money; it is about redeploying our existing funds to achieve a better outcome. We believe that such a solution would genuinely respond to people's needs in a dignified, tailored and responsible way. To us, this is a management solution. Yes, it would take some political will, but I believe that if it is presented correctly and the cost is analysed properly, we will see that it is affordable and acceptable to the general community.

I would like to just finish with one observation, borrowing from Kenichi Ohmae, if I can, and paraphrasing accordingly. I note the reference in the terms of reference here that says 'compared to other states in Australia'. I do not believe we can take comfort from the fact that Victoria is doing better than other states. I think we need to ask what more we can do, because if our maturity as a state and as a community is measured by how well we support our citizens with disabilities, then we still have a very long way to go. Thank you very much.

**The CHAIR** — Before we take questions, would you like to make a comment?

**Ms SPROULE** — No, I am happy just to answer questions.

**The CHAIR** — All right, so we can direct questions to both of you?

**Ms SPROULE** — Yes.

**Mrs POWELL** — Marsha, thank you very much for that really comprehensive submission. It is important for the committee to know all of that. I will just touch on a couple of issues that you spoke about. You talked about ageing parents who are looking after children who may be 40 or 50 and said that as they age they need to find accommodation for them. One of the areas that you looked at was the choices of accommodation and the need for that. Do you believe there is any role for a large facility of, say, 20 or 30 beds, with all of the proper safeguards, for people with a profound disability or a profound mental illness, and if not, where could you see people like that being housed appropriately?

**Ms SHERIDAN** — I am going to try to answer that from the perspective of choice. Firstly, people do not have to be accommodated in big settings to get high levels of support in an efficient and effective manner. However, it is not my life — and I keep coming back to that. These are their lives, and it is about what they want and what their parents want. For some people, living in a larger setting affords more choice in terms of people to communicate with, to go out with and to share an interest with. I have been involved in the redevelopment of larger-scale facilities, and one of the things that people say is that they feel they do not have as much choice there. However, the major point of giving people choice is about community connections; it is about outward thinking, not inward thinking. Aged-care facilities are inward thinking. We do not expect them to get everybody out, meeting other people and doing other things in the community. It is end-of-life service. This is still beginning-of-life service, so what we want is to ensure that they remain engaged. Do I have an opinion about whether there should be large, small or medium-sized facilities? I believe it is not up to me to make that choice; I believe it is up to the people who will use the services.

**Ms SPROULE** — I would add that if you were to look at that sort of model, you would need to be very mindful that it was not 20 people all together in one building, in which case you would be just creating another institution. For good reason we have moved away from institutional care. I would not rule out the fact that you could co-locate quite a number of people as long as they were in individualised settings. It may be a combination of people living in an individual unit with on-site support — a set of individual units. That is a model that we have a few of — very few of; far too few of — and that is a model that is exceptionally successful for people who do not live very well or compatibly with other people with disabilities, as long as there is consideration of the design and it is not just a boarding house-style affair but consists of individualised houses, units or whatever, with the opportunity for people to engage in the normal rhythms of domestic and community life.

**Mr NOONAN** — Marsha, I had the great pleasure earlier this year to attend the reopening of the Altona North early childhood development centre, which you run very successfully. Part of that redevelopment was allowing a doubling of capacity for young people. In a roundabout way, in terms of this inquiry and our hearings in Gippsland yesterday, what I am trying to come to terms with is supported accommodation in the home. When you talk about genuine choice, I wonder if you could comment on both the out-of-home services that can be provided to assist families, particularly where they are caring for someone at home with a severe disability, and also what might be the deficiencies in the in-home care arrangements or respite arrangements. I am so sorry that that is a bit convoluted and long-term, but what I am trying to come to terms with is: what would be deemed truly supported accommodation for those individual families if — as in many cases we heard yesterday — they really do not want to have their family member out of home?

**Ms SHERIDAN** — I think that is an important point. Some people really do want to keep their son or daughter at home. In fact that is why we have so many ageing carers. They have done the system and their young person an incredible favour keeping them at home, looking after them and really enjoying family life. Now that they are getting older, that is becoming a problem. For many it is a point of tremendous fear, as you would be aware.

Firstly, on the planning front we need to be aware of the fact that the carer is ageing and, while they want to keep them at home and we want to do everything we can to support them to do so, it is not a never-ending piece of string and we need to be planning for that day when perhaps they cannot look after their son or daughter. That was the first point.

The second point is there has been very little investment in out-of-home facility-based respite in a very long time. Fundamentally it is an approach that a lot of people do not necessarily believe we should have. In effect that is putting paid to the fact that most carers are saying that this is a service option that does suit them from time to time — to be able to allow their person to stay in a facility-based respite service. I will let Michelle in a minute talk about the demand on facility-based respite.

In terms of out-of-home supports for people remaining at home the first problem we have is a staffing issue. Let us be frank about it: there is a labour market shortage. These short shifts, which are often casualised work, are not in alignment with what many people, particularly young people, want from work today. It is an isolated environment with poor opportunities for interaction with other colleagues and with 1 or 2-hour shifts — sometimes 4-hour shifts — on an unpredictable basis. The fact is we have difficulty filling these shifts. For carers, that makes it really difficult to know if they can depend on someone coming when they need them, if they will know what they need to do and how to do it properly, and if they will know their son or daughter. These arrangements in this particular employment environment are difficult to sustain. That does not mean we do not need them. We need to find creative solutions for that problem. I would like to say that that is a major point for people to be aware of.

The next thing is that many carers do not want a paid carer in their home. They feel like they have to run around and clean up the whole house before someone comes in. It adds to the burden, particularly if they are constantly telling someone how to look after their son or daughter. We need to be aware of the impact on them. Many people would prefer that their son or daughter was taken out into the community. There often is not the transport support necessary to do that. That raises yet another problem for them. There are some significant challenges to be considered and managed within these individualised arrangements.

**Ms SPROULE** — Yes. The first thing to say is that for some families the individualised packages do meet their need. Some families are in the very fortunate position of being able to attract and retain the same staff to meet that need. They have full confidence to leave their family member in the care of that person who knows what to do. Consider, if you will, what the needs of some of those people with disabilities are. They may have very high medical or physical support needs, or they may have major behaviours of concern that mean that community access is very difficult. They have to be completely confident in the care that comes in.

For a small number of carers — and I am sure they will tell you all about it — that meets their need. The issues that Marsha just talked about — of labour shortage, of complex packages — mean that families will often get their support from a number of different sources. They may be using a range of facility-based respite, in-home respite, recreational respite and brokerage, and they pull it together to try and make it into one big package. Yes, that does work for some people, and it certainly does not for others.

As a major facility-based respite provider in the state, the demand on our services — particularly ours, because we are one of the only providers of active night care and care for people with complex medical needs — not so complex that people are hooked up to respirators, but below that, although having said that, we now run a ventilator-dependent service that does provide respite.

The demand is really quite massive on those services. We are able to meet very little of the demand. The pressure that places back on the family then is quite significant, and it then impacts on the decision to relinquish their family member because they are not getting enough support to

actually maintain that person at home. That person then becomes the person who is homeless in respite and who is then the priority for a shared supported accommodation option. That has not served the needs of the person with the disability, the family or the other families in any meaningful or useful way, in our opinion.

**Ms WOOLDRIDGE** — One of the things we need to look at as a committee is the appropriateness of government providing accommodation — shared supported accommodation — alongside the NGO sector providing it. I would be interested in your comments on what it means in relation to government being a funder, provider and regulator with you trying to operate independently, and what implications it has for your provision of those services.

**Ms SPROULE** — Do we go straight to funding and variation in funding?

**Ms SHERIDAN** — That is quite a question, Mary. I think there is an unequal playing field that results from government being really both a purchaser and provider of services.

First of all I think the most important thing here is to say that not-for-profit organisations provide high-quality services into which they have invested quite a bit of their own fundraising dollars, particularly in the way of capital. Secondly, we are constrained by our funding in a very strong way. There is a significant difference in the level of funding provided for salaries in particular. The difference is as great as 23 to 30 per cent for the same role in the same type of service. In addition to that, the conditions are far superior in the government sector. They have many more full-time positions, which are far more attractive to staff over a long time. They have better maternity leave, better training leave, so when it all adds up it is actually quite a substantial difference. There is no difference in the quality of service.

What does it mean when you are talking about meeting unmet need? One could extrapolate that to mean that perhaps even a compromise between the two funding arrangements could result in significant savings that could in turn meet additional needs. I think that is one issue. The other issue is that a lot of policy is developed on the basis that we are resourced in the same way as government itself. Compliance requirements for us are increasing dramatically, and continuously. Funding, on the other hand, in terms of functions and support compliance — that is, administration and so on — is actually declining on an annual basis due to the productivity or efficiency dividend. This is putting significant pressure on not-for-profit organisations.

**Ms SPROULE** — One of the challenges as operational managers is that because of the variation in funding income our ability to not necessarily attract but retain people long term is considerably less, because we can offer considerably less training, we can offer considerably less support — and we and many other organisations focus on the people whose needs are not easily met. We will take the people whom we see as falling through service gaps and we will try to make a service that works for them, and we are doing so without the ability to use a lot of our funding to provide support to the people who actually support the people with the complex needs. So our training allowance is minute and our ability to offer that level of training and support to our staff, who are the key to good service provision, is significantly lower than in the government sector. For us it is not a level playing field, just in terms of funding, but the flow-on effect then can be a reduced-quality service, only because we have those attraction and retention issues.

**Ms WOOLDRIDGE** — Could I just ask on that, do you see then that the client group that you are taking is actually a higher need group than perhaps the government sector? Do you see a differential in your client group?

**Ms SPROULE** — Traditionally the departmental services, as you know, are for people with intellectual disabilities, and the non-government sector does not limit itself to that. And I know that even now there is resistance within the department-managed services to take on people with other than intellectual disabilities. We have always taken people with physical, neurological, acquired brain injury and multiple disabilities, in addition to people with intellectual disabilities.

Also, because we are heartfelt — you know, organisations set themselves up because they believe in this — we will take people who do fall through gaps, and we definitely do. I would not say our clients on average are more difficult, but I would say that we do target that group in our organisation, and there are many others. I would hate to say anyone was more difficult than others; I am not sure it is meaningful really.

**Ms SHERIDAN** — I would say, firstly, in terms of forensic support, DHS is primarily the service provider for those with forensic support needs, and we would see that as being appropriate to its role and function unless a specific service could be established. Secondly, in terms of clients with complex medical needs — particularly things like the ventilator support service, which you may be aware of, or clients with high physical support needs and complex medical disabilities — they have traditionally been supported in the non-government sector, so we do deal with severe behaviours but also complex matters.

**Ms SPROULE** — We very rarely are unable to continue to provide accommodation support to a person, but on very, very rare occasions we have had to say, ‘We cannot do this any more for this person’, and that person will always go back to DHS, because it has a massive amount of resources that it can draw on to draw up a way more expensive and individualised service for people, and we do not have access to that economy of scale, if you like.

**Ms SHERIDAN** — One other point — and I can see that you do need to move on — is that when we have had to make those decisions, and I can only think of two or three occasions in my 20 years with Yooralla when this decision has been made, the reality of it is that a different physical setting would have solved the problem; the reality of it was that we needed a single unit. If we had had that, it would not have been an issue; it was an incompatibility with other clients.

**The CHAIR** — Individual packages are designed for people to stay with their family, extended family and friends as long as they want. You mentioned that individual packages are not allowing people to move away from homes, and certainly they do not need to. At some stage, when the parents or carers cannot look after them any more, they will have to move, but by that time they should have been captured in a needs register, so what is the difficulty in moving? Can you explain?

**Ms SHERIDAN** — It does not happen. There are a couple of things. There are many people being supported by their ageing carers, and you would have heard from some of them in Gippsland, but we are certainly familiar with ageing carers who are 90 years of age supporting people who are in excess of 60. Those situations are ongoing, and we are not necessarily aware of them. We have discovered them through an ageing carers initiative over the last couple of years in Gippsland. In addition to that, because the current disability support register only registers a current need, if people are saying ‘Yes, it is working for me, but in five years I am going to be 80, and I no longer want to manage this way’, they cannot register for a need.

If they cannot register for a need, then no-one is planning for it and no-one is funding it. The problem is that we are getting into a cycle where they cannot show they need something until one year before they need it, and the system simply does not allow a response within one year. I guess that is what I am saying about the system. Yes, some people want to cope at home, and that is fantastic; it is a great outcome just so long as it is not a question of lack of choice and becomes the only thing they can do. I think that is really where the system is headed because of the lack of correct collection of data about emerging need.

**Mrs POWELL** — Just following on from that, how do we solve that given a number of ageing parents who I have spoken to do not even see themselves as being carers. They see themselves as parents.

**Ms SPROULE** — Thank you.

**Mrs POWELL** — They are not aware until they are ageing that they need more support and somebody tells them, ‘You could have this and this’. How do we get to those people? We have that need because they do not know they are a carer. They simply see themselves as a loving parent until they get until their 80s and 90s and feel that it is in the best interests of their child, who may be 50 or 60 years, to be somewhere else. Then we have a crisis. How can we solve that?

**Ms SPROULE** — Usually what happens is that it comes to a crisis point, so to the person’s personal networks or that of the child. The child may be in a day service and it becomes clear there or through a doctor that there is an issue with the family and supports are offered at that point usually. But sometimes it is the case that the parent dies, although very rarely, and the person is found unable to cope. That is a very rare and unusual circumstance. Most people these days are not so isolated that people are not aware that their issue is there. The issue may be that the parent does not actually want to accept services at that point. As you said, they say, ‘We are a family’, but that is unusual.

**Ms SHERIDAN** — There is a very sensible technique that is being used in the United Kingdom right now. They call it a life book; we could call it any number of different things. The idea is about preplanning and knowing that the death of a parent can have long-term implications for a person with a disability. It means we need to be predicting earlier, not just in terms of planning for systems development but planning for families, giving them a chance to sit down and say what will happen, and if something happens to mum or dad and something needs to happen urgently, there are things like where is the medical history, where are the doctors, who are the siblings? No matter who walks into the situation there is a document that says, ‘This is what we have planned for the person. It is all set up. They are going to live with sister Mary’. We know what is going to happen because it has been planned.

Where do we find that information? You are right: we do not want to find out at crisis point. It is too late then. We need to find out before, and that means we need to work with the division of general practitioners to identify people who are in this position, and to offer good case planning and support to allow such mechanisms to be developed. They are then connected to the system; they know where to go, and someone checks on them about every three months just to say, ‘How is it going? Are you coping okay?’. Then you are going to pick it up earlier. The investment in that type of support is incredibly low. What it is is very proactive.

**The CHAIR** — I am conscious of the time, so thank you very much. We really appreciate your time.

**Ms SHERIDAN** — Thank you very much.

**Witnesses withdrew.**