

FAMILY AND COMMUNITY

DEVELOPMENT COMMITTEE

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**INQUIRY INTO SUPPORTED ACCOMMODATION
FOR VICTORIANS WITH A DISABILITY OR
MENTAL ILLNESS**

Witness:

MR PHILLIP NOYES
Parent Carer

BENDIGO

WEDNESDAY, 19 NOVEMBER 2008

THE CHAIR: I'd like to call upon Mr Phillip Noyes. Thank you very much for coming along. I'm not going to do the introduction because you were already here since this morning.

MR NOYES: I've heard it several times, thank you very much.

THE CHAIR: You've got five minutes to make a presentation.

MR NOYES: Well, thank you for the opportunity and there is a lot to fit into five minutes, but we'll try. I'm Phillip Noyes. I'm a parent carer of a 28 year old young man with autism, intellectual disability, epilepsy, and Type II Diabetes. We've been at least 12 years on the disability support register awaiting accommodation; for seven of those years, urgent. That is to the best of our knowledge. We're not always aware of whether we're still on the register or not, but that is our understanding of the situation. It may not be the department's understanding. We have worked through a great many things and we have reached a situation where we now have two nights a week care – in fact, we've now got three nights funded, we've just managed to get an increase, but we have yet to get that actually in place.

We are concerned about a great many things for our son. We are concerned about him ending up in a poverty trap if we try to move him into accommodation, rental accommodation, on a disability support pension. It's just not possible to do that on the open market. He also has extremely high support needs. The Supports Intensity Scale that Ian mentioned has been used to assess our son's need. He comes in at needing more support than 97 per cent of people with a disability, so pretty high. And that was a very useful tool, both from the point of view of identifying things that are needed and from just being able to say, "Yes, we do need the funding." It was really useful for that.

What really concerns us most, though, is that things seem to be so ad hoc. We've achieved a great deal in the years we've been working with our son. I've been a fulltime carer for my son now for 10 years. I gave away a career to do it. He has a history of challenging behaviour which we have worked a great deal to overcome and we've got a long way down the track, but the progress that we've made in terms of achieving these two nights a week of care, the progress we've achieved in obtaining programs for him, has always seemed to be ad hoc. It has never seemed to be in response to the expressed need, to the plans that we have put in. The two nights a week came about quite serendipitously at a meeting with several managers working on our son's program.

We had this on the agenda that we were looking for a shared care type model and a case manager who was just about to leave her post said, "There's a place here three nights a week." I just wonder what would have happened if she'd left her job six

weeks earlier; would we still be waiting? As I say, there is just no sense – even things that we’re going through now, it seems to be in response to us knocking on a door rather than a planned approach. Now that said, there are some wonderful things happening. I didn’t want to just focus on the negative stuff. The individual support packages, the individual approach, the person-centred approach is giving us enormous power to try and plan things and to make things happen, an enormous power to go and negotiate things for our son.

Ian spoke about the practice coaching, and that was absolutely fundamental to the success of the shared care program that our son is now in. Without that, I think there would have been an enormous amount of challenging behaviour, that ongoing coaching role. So we support very much the idea – and you asked Ian, “How do we do that?” We support very much the idea that you need to fund – as well as the hours of support, you need to fund the little add-ons, the staff meetings, the shadow shifting, the practice coach, an extra worker who’s there doing – it’s additional cost. It’s the – the problem with the individual support package model, and leaving it to families to try to get all of the funding stuff together, is that organisations are often left having to ask families to put in submissions for these add-on things that really are quite fundamental.

So we really would encourage you to support the funding of those sorts of things, and it’s also the overlap hours. Joolee spoke about the day program issue. Our son doesn’t need a full day program. He really cannot cope with doing a day program five days a week. Now, at the moment, he’s home with us part of the time, but there will come a time, whether it’s because we drop dead or whether it’s because we finally give up and just walk away, where he will be out of our care, unless of course he dies first, which is a possibility. There will be times when he needs to be in whatever accommodation he’s in rather than the day program, so that needs to be staffed and funded, and that 3 o’clock time is an absolute nightmare, because the day program runs out at 3, accommodation starts at 3, but people actually have to get from A to B, and that’s not just people like our son.

That’s often the workers. Many of the workers are sessional, part time, and are working for more than one agency, so they’re having to rush off from one to get to another, and there is this no man’s land. So again, we need these overlaps funded, so it takes extra money. I’ll just finish off – as I say, the practice coach coordinator, fantastic, and the individual support package with its faults, nonetheless very, very empowering, and that sort of approach we really value highly. Thank you for your time and for listening.

THE CHAIR: Now, just one quick one. You mentioned the ISP. There are certain things that organisations don’t want to do because the ISP or the money gets to you. Is that right? Is that - - -

MR NOYES: Yes. The funding doesn’t come directly to us, although I’m aware there are – there have been trials in that direction elsewhere. It’s still a very early process. People are learning a great deal about it. We’ve just gone through putting

in our latest funding package and got it approved, and the department has its unit costs. It approves a certain amount of money per hour for supporting in-home or in accommodation. Now, if you're dealing with an agency that, for one reason or another, is charging more than that, then you're going to come up against a shortfall, and that unit cost may be based on just simply providing the support. Our son needs a lot of one to one support, so however much that support is per hour, that is what is being paid.

But that doesn't build in the extra bit for the staff meetings, which again, if staff do not share information about our son, they don't know what's going on. So we put in our submission and asked for them to cover such things as the staff meetings, the practice coach, etcetera. But because that doesn't fit within the unit cost, and because the organisations are still coming to terms with this, there's a bit of a gap there. We're going to be okay this year because it's going to take so long to get the thing off the ground that there is going to be a little bit of flexibility. But next year, those little bits around the edge are going to be very, very difficult to cover, and it's going to be an argument between the agencies and the department over that.

We do our bit to say, "We need it." That is what's working. It's working well. If I may beg your indulgence, there is one other thing that I forgot, which is really important, and it was alluded to by Steve, I think. The change in personnel at management level in the department, but also in the agencies, particularly in the middle level management – that meeting that we had about our son where that two nights a week was identified, there were eight managers involved with my son at that stage. Within 12 months, seven of those had gone. And with them, the memory of what we were trying to achieve. We had to teach a whole new crowd. In one agency, the managers changed three times in a year. That is really difficult to battle. So that institutional memory – the case notes are there, but people don't have time to refer to them or don't understand where they came from. The history becomes really important, and that is very, very difficult to maintain. Thank you.