

STATES OF JERSEY

Health, Social Security and Housing Scrutiny Panel Respite Care Review

Session 2

TUESDAY, 28th FEBRUARY 2012

Panel:

Deputy K.L. Moore of St. Peter (Chairman)
Deputy J.A. Hilton of St. Helier (Vice-Chairman)
Deputy J.G. Reed of St. Ouen

Witnesses:

Senator P.F. Routier

Also present:

Ms. K. Boydens (Scrutiny Officer)
Ms. F. Carnegie (Scrutiny Officer)
Mr. S. Jones (Adviser)

[11:31]

Deputy K.L. Moore of St. Peter (Chairman):

Just before we start, we are going to divide it into 2 sections: a public and a private, so would you prefer that we spoke about wider issues in the first half hour and then your personal experience in the ...?

Senator P.F. Routier:

Yes. I am very happy to do that. There may be some stuff I will say publicly about my personal stuff as well which I am quite happy to say, but there might be something later on that I might prefer to keep quiet.

The Deputy of St. Peter:

Yes. Fair enough, absolutely. Okay. So we are ready to go. So we will publicly welcome you to our hearing. Thank you very much for attending. I do not know, do we need to introduce everybody again? Yes. For the record.

Senator P.F. Routier:

Yes. Senator Paul Routier.

The Deputy of St. Peter:

Deputy Kristina Moore, Chairman.

Deputy J.A. Hilton of St. Helier (Vice-Chairman):

Deputy Jackie Hilton, Vice-Chairman.

Mr. S. Jones (Adviser):

I am Sion Jones, I am here advising the panel on the review.

Deputy J.G. Reed of St. Ouen:

Deputy James Reed, Panel Member.

Ms. F. Carnegie (Scrutiny Officer):

Fiona Carnegie, Scrutiny Officer.

Ms. K. Boydens (Scrutiny Officer):

Kellie Boydens, Scrutiny Officer.

The Deputy of St. Peter:

So we were just discussing the role of the third sector in providing respite care. What is your impression of the resources that are available to families who need access to respite?

Senator P.F. Routier:

Perhaps I should just make it clear at the outset, as you might be aware, that I was Chairman of Les Amis for many years, who provide respite care, and also President of Mencap, but I am here as an individual and not in those positions, because I stood down from those positions last year. So what I say cannot be interpreted as being a view of Mencap or Les Amis, so you would need to speak to them; just to make that very clear. Certainly, I think from the outset of trying to establish respite care, which I was involved with probably about 20 years ago, I think it is, it was a struggle to get the need for respite recognised but that has been recognised now, I think, to a certain extent. But it has been a mixture of the state provision and third sector provision. When I first became involved, we managed to persuade the Health Committee at the time to establish Aviemore Respite Service and that came about through speaking with the Headmistress of Mont à l'Abbé School at the time, Trish Davis, and she was recognising that there was a growing need for respite care. What was happening at the time was children were being cared for by some of the teachers for just the odd weekend, that they go to their house or go for tea or whatever, and it was just sort of very ad hoc and a service like that. But that was because it was being recognised by the teachers that there was the need for some sort of respite at some sort of level. So, eventually, we managed to push along campaigning for a respite service and Mencap and Health managed to refurbish Aviemore and establish the respite service there. Then, I think ... what came next? Well, the need grew, obviously, I think it was the Variety Club established Oakwell for children who had more profound difficulties as opposed to mild to moderate disabilities at Aviemore.

The Deputy of St. Ouen:

Sorry, Paul. Aviemore, when it was established, what age group did it cater for?

Senator P.F. Routier:

It was from school age, I think, through to 18, I recall.

The Deputy of St. Peter:

So 5 through to ...?

Senator P.F. Routier:

Yes. That is what I seem to recall, yes.

The Deputy of St. Ouen:

Thank you.

The Deputy of St. Peter:

Roughly when was that?

Senator P.F. Routier:

That would have been ... it is roughly, because I have not written it down, it was mid-80s. Yes. I could probably find out for you if you wanted an exact date, if that is what you want, but that was about it. So we went from that, so Oakwell was opened and then there was, in more recent times, Mencap, because we were fortunate to have been left a house at Maison Allo, and that was established for respite care there. There has always been a need to recognise the different levels of respite that has been required by various parents and children, or families as a whole, really. There has been the odd tea visits, which has been welcome, and then developing into weekends and then moving on perhaps, if need be, for a full week, or something like that. There was a stage whereby we needed a longer break than that, for personal reasons, and the Aviemore service was able to offer that and so that was a great benefit to our family at the time. But I think, in general, the point I would like to get over is that there needs to be a mix of provision, whether it be in a facility or perhaps in an individual's home. I know there is a difference of view on that but I think it is down to personal decisions and needs. I can recall people fighting quite strongly: "We need to have a provision elsewhere to give the parents a complete break" and they would not want somebody going into their own house to look after the children while they were there or whatever, because they would not feel at ease and would not feel relaxed enough. The complete break, they felt, was the best option. But over the years I have come to recognise that a mix of provisions is probably a good thing because everybody's needs are different. I think I have rambled on a bit there and I am not sure that I answered your question. **[Laughter]**

The Deputy of St. Peter:

We were talking about the third sector, I think, initially.

Senator P.F. Routier:

Yes. Sorry.

The Deputy of St. Peter:

If we could just go back to that point because we thought that your position would possibly help throw some light on it, because we were discussing co-ordination between the third sector, really. We were aware that the Chief Minister's Department were discussing appointing a body or a person to fulfil that role but we did not know where we were in that process.

Senator P.F. Routier:

Yes. Well, I have literally just come from a meeting of the third sector, of all the agencies that are involved in the establishing of that, and the Association of Jersey Charities have taken responsibility for appointing a third sector co-ordinator. There is an advert out currently, I think, to establish the committee before they go out and advertise for the professional person who is going to be the co-ordinator. So they have had the first tranche of the funds passed over to them at the Association of Jersey Charities, and so I have asked to see the job description of that. Because I started off by talking about I am here as a parent, but I know I have got lots of conflicts of interest here, because my responsibility is to work with a third sector co-ordinator as well, and I have asked to see the job description of the third sector co-ordinator because we are only really just getting that established at the present time. So although it is going to be appointed by the Association of Jersey Charities, we are going to sort of have an oversight of how that is going to work. But the relationship between the third sector and the States generally has always been a rocky road. Over the years there have been times when we have needed to have extra provision provided, and negotiating that has sometimes been very difficult. But I think with the establishment of the third sector co-ordinator, who will have responsibility for overseeing the service level agreements and trying to get some co-ordination with the service level agreements - which I think is desperately needed across not only respite services but the third sector generally - there needs to be a better flow of information between the States and the third sector providers. Also, with having a service level agreement, there needs to be a smoothing out of the way the funds are allocated and paid over, because sometimes there can be a slowing down of funds passing between the States and the third sector organisations, for whatever reason. But I think part of the work that the third sector co-ordinator will do, and I will do on behalf of the Chief Minister, is to ensure that those problems that have arisen over the period are smoothed out, really.

Deputy J.A. Hilton:

You were talking specifically about bundling of services that may be ... well, are you talking about potentially cuts in funding? Is there some sort of conflict between the third sector and the current ...

Senator P.F. Routier:

There is a need to get the right budget in the first place agreed between the ... and that sometimes can be a challenge. So it is that understanding of what service is needed to agree how many rooms, how many children, how many families who are going to be supported. I think that is a big piece of work that needs to be done. But then there is the practical side of it of, when all that is

agreed, to ensure that the money flows through at the right times. That can also cause a difficulty for the third sector.

The Deputy of St. Peter:

Would you support the idea of a budget being allocated to each individual case and that budget following them through for the rest of their life or their term of need?

Senator P.F. Routier:

Ideally, yes, I think that would be a good thing to happen. Yes, certainly. I have always felt that that is the right thing to do; it is a big change from what we currently have because the way it happens is that the third sector provider will provide a service and then each family will be allocated, or not, a time in the services if it is available. I think that has been one of the crunch issues over recent times is the services getting clogged up and not being available to the parents who have usually received the service. That has been a bit of a problem.

Deputy J.A. Hilton:

So just to clarify, the Chief Minister's Department is financing the post of the third sector co-ordinator ...

Senator P.F. Routier:

No. The way that has happened is that the Treasury have passed money to Health and Social Services who are passing money to the Association of Jersey Charities who are forming a committee who are then advertising and employing a third sector co-ordinator.

Deputy J.A. Hilton:

Okay. Thanks.

[11:45]

The Deputy of St. Ouen:

Just sticking with the third sector for a minute and, as well as charitable organisations, we are keen to understand first of all which charities are offering support to parents with children with special needs or behavioural difficulties and, secondly, how that is communicated, or if it is communicated to the parents so that the parents are aware of the support on offer. Can you just first tell us of your experiences?

Senator P.F. Routier:

Yes. The third sector provider, Mencap or ... there is a mix there: Health and Social Services provide the Aviemore service off their own bat with no involvement with the third sector, that is my understanding, and I have probably lost track of how those resources are allocated now and to which children, because I think it may have been being used for children with behavioural difficulties now more than people with learning disabilities, possibly that may be what has happened. So, in fact, that put the pressure on that service so that is what made Mencap develop Maison Allo, which is

totally run ... well, they have now asked Les Amis to provide the service. So Mencap were left a house by a beneficiary and we (I say "we" because I cannot stop saying "we"; **[Laughter]** I keep talking about Mencap and Les Amis, but I am not there) refurbished the house and made it suitable for 5 rooms ... you have been more recently than me.

The Deputy of St. Peter:

Five full-size rooms.

Senator P.F. Routier:

Yes. So we provided that service but how children and families get to find out about it is through the Social Services Department; they have to refer people, we cannot take anybody directly from the community, it was always through reference through the Social Services Department.

Mr. S. Jones:

So if I am a parent looking for some kind of respite care, is there any avenue for me to get respite care other than going through Social Services?

Senator P.F. Routier:

No.

Mr. S. Jones:

Nothing at all, even thinking about the kind of very broad definition of what respite care is, is there anything that might give you a break for a couple of hours or ...?

Senator P.F. Routier:

Not that is formalised, that I am aware of, whether there is ad hoc things that happen, there may well be. In fact, I am talking a long time ago, my son is 35 now, but that is what it used to be like; it was ad hoc services, friends, teachers.

The Deputy of St. Ouen:

Are you aware of any charitable organisations that provide funding for a parent to purchase respite or additional support?

Senator P.F. Routier:

No. Not that I am aware of. I mean, Mencap's commitment to helping to provide respite has been to provide the building and to maintain the building and they look to Health and Social Services to provide the funding to pay for the staff.

The Deputy of St. Ouen:

The revenue.

Senator P.F. Routier:

Yes.

Deputy J.A. Hilton:

Am I correct in thinking that Mencap currently have a project to provide another house?

Senator P.F. Routier:

Yes. We all recognise children grow up and I know your remit is going up to 18, or something ...

Deputy J.A. Hilton:

No, it is 25, so it is children and young adults.

Senator P.F. Routier:

Yes. Fair enough. So Mencap do have a project. They announced a couple of years ago a £1 million pound project to find a house. Unfortunately, with the climate that we have today, they have not raised sufficient money to go ahead with that project. But there is a possibility (well, there was when I was involved) of refurbishing some of the Les Amis building at Five Oaks to provide respite for children or adults over 18. That is in the mix, I understand, presently because there needs to be more provision for permanent residents within Les Amis, so I am not sure when that is. You would really need to speak to them to ...

Deputy J.A. Hilton:

Okay. Because Les Amis did used to provide respite, but it was for adults, over 18.

Senator P.F. Routier:

For adults, over 18, yes. They still do.

Deputy J.A. Hilton:

Yes. So they still do?

Senator P.F. Routier:

Still do, yes. That is in accommodation which is totally unsuitable, that is why the project was established. Les Amis building was built in the 1970s to provide accommodation for children who were coming from St. Saviour Hospital, so it was long corridors with small rooms off and the bedroom sizes are tiny, they are not really suitable for an adult to be in, they are not. It is currently being used that way; that is why we need to have a better adult respite service.

The Deputy of St. Peter:

You say that is conflicted by a need for more residential beds.

Senator P.F. Routier:

Yes. More permanent residential beds, yes.

The Deputy of St. Peter:

Why is that happening, in your view?

Senator P.F. Routier:

Well, the population is growing up and people have a different attitude to living with parents until they die, they are growing up, things are changing and I think people want independence, and the adult wants independence as well, they want to get away from the parents, quite rightly so. Yes, it is all about independence, really, and the Les Amis model does try and give independence to adults to do whatever they want to do with their lives; that is what the whole ethos is: whatever a resident would like to do, we try and enable that to happen.

The Deputy of St. Peter:

I know that you are not with the organisation at the moment but how do they find the working relationship with organisations like J.E.T. (Jersey Employment Trust) and finding constructive employment and independence for young people and that sort of ...

Senator P.F. Routier:

I think it is okay, it is just a matter of there is not enough of J.E.T. facilities. If you look at it down to an individual, how their life is - because that is what I always like to try and do whenever I am thinking about big projects and all the rest of it, I like to think what happens to the individual - and whereas the J.E.T. day services used to provide a 5-day-a-week service for adults, that is not the case any longer; the adults will now have a few hours here and a course there, and a course there and a course there. There are lots of gaps within the week which, to my mind, is not ideal because there are adults who are currently living within accommodation or living with their parents, who do not have a full week filled up. I find that very difficult. I have always been a busy person myself; perhaps some people like to sit at home and do nothing, but there is, I believe, a great demand on day services generally and opportunities for them, whether it be working in the community somewhere or working voluntarily somewhere. I do not mean the traditional old day services-type situation, I mean, just opportunities to do more things in the day time.

The Deputy of St. Peter:

I presume, if it is that bitty approach, then transportation becomes an issue.

Senator P.F. Routier:

It certainly does.

The Deputy of St. Peter:

Because they need somebody often to ferry them from one place to the next.

Senator P.F. Routier:

That is a challenge for the Les Amis team, certainly, it really is.

Deputy J.A. Hilton:

I just noticed in our timetable, Sue Moore is coming from Jersey Mencap, but I do think there is anybody coming from Les Amis specifically.

The Deputy of St. Peter:

No.

Senator P.F. Routier:

That might be an idea to get somebody.

Deputy J.A. Hilton:

Do you mind just answering a couple of questions around Les Amis? I am just trying to understand the respite that is available there at the moment. This is for purely adults, 18 and over, is it not?

Senator P.F. Routier:

Yes, it is.

Deputy J.A. Hilton:

So it comes within our remit. So how many beds are there available at the moment?

Senator P.F. Routier:

My understanding, it is 5.

Deputy J.A. Hilton:

So there are 5 beds available.

Senator P.F. Routier:

Yes. For mild to moderate. There were 2 rooms on the ground floor which were for severely disabled people as well as learning difficulties, but that has not been used recently because of the circumstances of particular families and I think that is the area that they were looking at refurbishing to have as a ...

Deputy J.A. Hilton:

But as far as you are aware at the moment, those beds are still being accessed for respite but they are looking to do a major refurbishment of that service?

Senator P.F. Routier:

Yes.

Deputy J.A. Hilton:

And are Les Amis paying for that refurbishment or ...?

Senator P.F. Routier:

Yes, well, Mencap is, it is between the 2.

Deputy J.A. Hilton:

Yes, the 2. All right. Instead of providing the house, the project that they originally had?

Senator P.F. Routier:

Yes. Because we have not raised anywhere near the £1 million, so it was just ...

Deputy J.A. Hilton:

Again, whoever accesses that respite has to go through Social Services?

Senator P.F. Routier:

Yes.

Deputy J.A. Hilton:

As far as you are aware, is it well-utilised, Les Amis is?

Senator P.F. Routier:

Yes. It is.

Deputy J.A. Hilton:

It is. Okay. Thank you.

The Deputy of St. Peter:

How accessible does the organisation find Social Services and that connection to people? Because you must come across individuals who you would expect would need respite or access to certain services. In your opinion, does that connection work well?

Senator P.F. Routier:

I think there are always challenges because the Social Services Department, from my point of view, is under-resourced. That is the way I read it; I need to be proven wrong, but I just feel that they are under a lot of strain. There are demands on them to assess various children and adults. I know when there was a need to assess every resident within Les Amis, they could not achieve that by themselves and they had to call in social workers from outside the Island to carry out an assessment of each of the residents, and assessments need to be done on a rolling basis. It is all very well saying: "Oh, we have done it once" and tick the box; it needs to be done continually because people's circumstances change all the time and their needs change. So there is, I believe, a need to increase provision of Social Services.

Deputy J.A. Hilton:

Are you aware of any families that have asked for respite, recently, say in the last year or so, but not been given it or have had what service they were being provided withdrawn, for whatever reason? Are you aware of any?

Senator P.F. Routier:

I am not personally aware of anybody, no.

Deputy J.A. Hilton:

No. Okay.

Senator P.F. Routier:

On a personal level - I do not know of any particular cases - I just have an impression that ... well, obviously, there is the Oakwell experience which has happened where there have been people who have been using the facility on a more permanent basis and they have obviously reduced the availability for people to have their regular once a week, twice a week, sort of, respite. That has, I think, caused a lot of problems for people. I think generally, I am not sure how it could be achieved, but whether there needs to be a spare capacity built into it for when there are these emergencies. Because if you have an emergency - I know it is easy to say, it probably costs some money to have a spare capacity building for people waiting to be called upon - but when there is an emergency, it does create so many knock-on effects and it blocks a bed or room, or whatever, it does create so many problems for the rest of the families.

The Deputy of St. Ouen:

Can I ask, how would you describe the level of support provided to children with special needs?

Senator P.F. Routier:

The level of support ...?

The Deputy of St. Ouen:

Yes. Provided generally to parents with children with special needs?

Senator P.F. Routier:

There are always areas where you can see improvements but, in general, I think Jersey does provide a fairly good level of support, but there are hiccups which create a lot of problems sometimes when services do get full.

[12:00]

Although I say it is a good support, but there is never enough; there is always need for more. Without speaking to an individual parent and asking them how it affects them, you can only make a judgment from that.

The Deputy of St. Ouen:

You being linked with Mencap or Les Amis and obviously, like other parents with children with special needs, you tend to be aware of general views, so are you suggesting to us that the general view of parents with children with special needs with regard to the services or the level of support provided is good?

Senator P.F. Routier:

It is good at times and then there are times when it falls down.

The Deputy of St. Ouen:

Where are the gaps, in your view?

Senator P.F. Routier:

Certainly for over-18s the facility for respite is not good; I can say that quite clearly, because the building it is in is not appropriate for adults to be in that service. I have lost touch of the younger age group, I am afraid, because I have not spoken to many parents that are a younger age group than mine, and circumstances; I have moved on. But yes, I can recall, I suppose, in the last couple of years there have been cases, times when Maison Allo has been full and there have been people saying they are not getting enough, that has happened, I can recall that. What else ... of course, we also know about the Oakwell situation as well, whereby it has got ...

The Deputy of St. Ouen:

Can I ask about social workers, personal support that surrounds the family?

Senator P.F. Routier:

Yes. I am not sure that there is sufficient support for families from social workers. I think there are the reviews that happen. When a child is at school, I think that is probably better than it is as soon as they leave school. As soon as they leave school, I think it falls down. Because you have got the whole school team around the child and there are regular meetings and things can get picked up, but once a child leaves school, I think it becomes very difficult.

The Deputy of St. Peter:

I think is this a good point to enter into a private meeting since we have closed the public hearing.

[Meeting proceeded in camera]

[12:03]