

STATES OF JERSEY

Health and Social Services Scrutiny Enable Jersey

WEDNESDAY, 26th JULY 2017

Panel:

Deputy G.P. Southern of St. Helier (Vice-Chairman)

Deputy J.A. Hilton of St. Helier

Deputy T.A. McDonald of St. Saviour

Senator S.C. Ferguson

Witnesses:

Ms. L. Bratch

[14:03]

Deputy J.A. Hilton of St. Helier:

I just saw him there out of the corner of my eye so I think we will probably start again. Is that okay?
Sorry.

Ms. L. Bratch:

Yes. No, that is fine and as long as nobody minds me using my notes either.

Deputy J.A. Hilton:

We have started, we just introduced ourselves but we are going to start again because I just saw you out of the corner of my eye. Okay, so we will start again. So I will need you to ...

Deputy G.P. Southern of St Helier (Vice Chairman):

To do the introductions?

Deputy J.A. Hilton:

Yes. Well, no, we will just all name ourselves.

Deputy G.P. Southern:

You have done it already?

Deputy J.A. Hilton:

Yes. I apologised on your behalf.

Deputy G.P. Southern:

Thank you, appreciated.

Deputy J.A. Hilton:

So do you want to start right from the start? Apologies. Yes, right from the start.

Deputy G.P. Southern:

Apologies from our chairman who has to be in the U.K. (United Kingdom) on family matters. We normally introduce ourselves for the tape. I am Deputy Geoff Southern, the Vice-Chairman of this panel for my sins and ...

Senator S.C. Ferguson:

I am Senator Sarah Ferguson, panel member.

Deputy T.A. McDonald of St. Saviour:

Deputy Terry McDonald, panel member.

Deputy J.A. Hilton:

Deputy Jacqui Hilton, panel member.

Scrutiny Officer:

Kellie Boydens, Scrutiny Officer.

Ms. L. Bratch:

Afternoon. I am Lesley Bratch from Enable Jersey.

Deputy G.P. Southern:

We are here to listen.

Ms. L. Bratch:

Right, okay. Well, I have written some notes out. I have followed the questions that were sent me so I will answer those as we go. Then, obviously, if there is anything you want to stop me on as we go along just let me know. So just as a general comment I just wanted to say that we appreciate the work that the States are doing in putting the long-term care benefit together. It is, we feel, very much a work in progress. As a general comment we would like to say that the problems, we feel, lie a lot around the lack of personalisation, the lack of choice and that, therefore, has this effect on the quality of life for all involved. We would like really to see people getting the choices put back to them so that they own and can put together the control around their lives. So, as I have said, I am going to answer the questions as sort of put to me in the email. Some of the responses I do feel sort of merge a bit so I will try not to keep on going over the same thing. So to start with you have asked what Enable Jersey do in relation to long-term care. We have a development officer. She provides support and assistance around long-term care and that is a very generic sort of way of saying that it is help around form filling out. It is signposting if people sort of say, you know: "We may have to require long-term care, who do we go to? What hoops do we need to jump through?" So it is general problems around that. I have asked her how many phone calls, how many questions she has around long-term care. As far as ongoing support she is giving about 4 families ongoing support but aside from that she has numerous, numerous, phone calls; just one-off inquiries. So just to look at 2 instances of families that are requiring ongoing support at the moment, they were recently contacted by 2 families who had been presented with bills, one for £17,000 and one for £29,000 for back-payment in care fees; that is on behalf of their care homes. That was because their care levels were increased approximately 2 years ago but the payments were made into their bank account, they received a letter from Long-Term Care explaining the increase in their care level and that it was their responsibility to pay the care homes the fees plus whatever sort of top-up that there was. Unfortunately what happened was that the care homes were not advised that the 2 families had had their fees increased because their care levels had changed so, therefore, they had been billing at a separate rate, the lower rate. As far as we are concerned that raises 2 questions; one is, is it Social Security's responsibility to inform the care homes of the increases in levels but the other one as well, which we feel is very important, is if the care home is billing for the lower level what level of care were they providing to the families? Are they increasing their fees because they found out that the person was on a different level, even though were still providing the lower level of care? Again, we feel that if the families themselves had more knowledge of how the system worked that they would be more empowered to say: "Excuse me, what is sort of going on here?" if there was a better understanding of maybe what the care package contains. So we feel that the care home fees are not transparent and that information and communication between all those involved could be better. If you want to ask me anything around that.

Deputy G.P. Southern:

Yes. Can I just stop you there to make sure that I am clear about what you were saying? So the persons concerned were reassessed and it was decided they needed a greater level of care; that was communicated to them directly from the social workers who did the assessment.

Ms. L. Bratch:

I think it was a letter through Social Security as well.

Deputy G.P. Southern:

That Social Security ...

Ms. L. Bratch:

Advised them of the change in their level.

Deputy G.P. Southern:

So they communicated with the family and Social Security, Social Security had communicated to the family but not to the caring organisation.

Ms. L. Bratch:

Yes, that is right, the provider.

Deputy G.P. Southern:

Okay.

Deputy J.A. Hilton:

So you mentioned 2 families. You mentioned sums of £17,000 and £29,000 back-payment for care fees. So the Long-Term Care Fund has paid the families or the clients those sums of money but it was not passed on to care home.

Ms. L. Bratch:

Well, that is what I said to our development officer. She said that they were sort of older couple and they have got quite confused as to what is going on basically. So I think the money went into their bank account but I do not think they quite understood what is going on.

Deputy J.A. Hilton:

All right, okay.

Ms. L. Bratch:

I can find out more information for you because I do not want to give you anything that is not correct.

Deputy J.A. Hilton:

These clients, are they in residential homes?

Ms. L. Bratch:

Yes.

Senator S.C. Ferguson:

Do you deal with any who are living at home?

Ms. L. Bratch:

There will be some as well, yes, that the officer will be dealing with. I have not got absolute details but I can, if you would like me to, find out anything more.

Deputy J.A. Hilton:

I think, if I recall correctly, we were told 2 different stories by residential homes yesterday; one that Social Security paid them direct, I believe ... is that correct? The other one that Social Security paid the Long-Term Care Fund to the client, I believe. So there does not seem to be any sort of consistency in how they pay it. So basically what you are saying is these clients were paid this money under the Long-Term Care Fund which they did not pass on.

Ms. L. Bratch:

Yes, it was then their responsibility to pay the balance of the care fees to the home.

Deputy G.P. Southern:

But they never did that because they were never billed.

Ms. L. Bratch:

They were billed on the old level so they were paying a lower amount.

Deputy J.A. Hilton:

So is it Social Security saying that you have to pay back the £17,000?

Ms. L. Bratch:

It is the care homes that are requesting back-payment.

Deputy G.P. Southern:

The payment has been made and has not been transferred in ...

Deputy J.A. Hilton:

Yes, okay, but they were only billing for the old level of care.

Ms. L. Bratch:

For the old level so whatever level they were on they were billing at the lower level of care but then that begs the question as to what care were the people receiving and ...

Deputy J.A. Hilton:

Yes. Why did not they not query it?

Ms. L. Bratch:

Yes, and what do you physically receive for that higher level of care.

Deputy G.P. Southern:

Because we had numerous complaints in the last couple of days about the social workers communicating with the client and their owning of the benefit to do as they wished but not telling the care providers what was going on so they were saying: "Hang on, they have had an assessment but we do not know what that assessment is. Our estimate of what they should be having is this but we do not know definitely it is the same as the way they have been assessed." So a lack of communication again somewhere down the line.

Ms. L. Bratch:

Yes. I would say there is a lot of lack of communication in all directions.

Deputy J.A. Hilton:

Yes. Before we move on Enable, is that a registered charity?

Ms. L. Bratch:

Yes. It used to be the old Disabled Society. You see the minibuses going around. We have just had a name change.

Deputy J.A. Hilton:

Okay. Yes, I just needed to be clear about it. Yes, that is fine. So it is basically a charity but you have got a development officer and ...

Ms. L. Bratch:

Yes, and she does the ... hang on, what do we call her? She is assistance. She goes out and she ...

Deputy J.A. Hilton:

She assists people.

Ms. L. Bratch:

Yes.

Deputy J.A. Hilton:

Okay. Thanks very much. Okay, all right.

Ms. L. Bratch:

Okay. Are we all right on that one? Right, okay. So moving on to the long-care itself and how it meets the needs of people with lifelong conditions. So I mean broadly speaking I would say this is just such a generic question that I cannot say that it does not suit anybody. So very generally I would say that there is an inflexibility around long-term care. There is a lack of personalisation. These are both very significant. It is restrictive and it does not take into account the human element of the people behind ... you know, that are receiving the benefit. On a personal basis as well I have seen a "use it or lose it" attitude that either use your benefit in the week it is given to you or that is it, it is gone but life is just not like that. So I have seen along the way significant pieces of work that are going on that are very much needed to support people particularly in their own homes. These are work around transition. So it is so important for the department to know who is coming through with significant health needs. There is no way that they can plan financially what people want and look to the future if they have no idea of who is coming in the system and what their needs are. There is also an equipment review because supporting people to keep their loved ones at home, supporting the providers to provide the right type of support, you cannot do that safely without the correct type of equipment and that will hold up the care of people in their home. It will hold up people getting out of hospital if there is not correct adaptations and equipment available and that is for either formal carers or informal carers and that will affect the ability of people to keep their young people, their young adults, at home.

[14:15]

Financially, if you look at the change from the income support system as you move through to long-term care we have got families that obviously then lose their impairment and ... at least the care component of impairment and though you can say: "Well, that makes sense because care is being paid for through long-term care." There is an awful lot of other elements of care that are not included

within long-term care and that really put vulnerable families in a very difficult sort of situation. We are unfortunately vulnerable in the first instance without having more and more landed on top of us. So I mean just ... maybe like you might be thinking: "Well, what does this all mean?" If you are looking after somebody at home that has a disability you have got extra heating costs, you have got extra doctor's bills, you have got added things like washing. You know, my daughter and her sheets, 2 or 3 times a day. Then you have got the question of disposable products which I have got a family with 2 children who are profoundly disabled and they have up to £800 a month in costs, incontinence products, feeding tubes that have historically, because the care element has gone into their bank account, been used to subsidise these pieces of ... well, we will not call them equipment because we will get confused but these disposable items and they really do not know how they are going to manage. As far as other ... there are larger items, like house adaptations and vehicles, and again this impacts on the ability of people to be able to keep their young people older adults at home living with them if they cannot financially upkeep the home and all these extra items that are needed. There is another problem within long-term care that we have come across is care off-Island is that, you know, some people might think that maybe going on a holiday is a luxury but if you are living with a life limiting condition or long-term condition you know you want to have the same type of life as other people. We are not talking about a cruise around the Caribbean, we are just talking about maybe a weekend off in the U.K. There have even been problems around getting support to take people to hospital appointments because care can only be given on-Island but if you have not got a support ... or you need a support worker to take you off-Island how does that get paid for if long-term care does not cover it? We believe that whatever your age a good quality of life should be expected but it feels at the moment more that it is like a luxury. If you are talking about people living in homes, living in community homes, they get an allowance of £4.88 a day and I mean that ... you know, I do not want to come across as greedy that we want this and we want that and ... but unless you have got families to support you what happens about clothing. I know one of the charities used to do a clothing allowance but that has had to be stopped because of the way things have gone and the change in funding. You know, just even like having your hair done, going out with your mates, you get an element of mobility within your income support but that still is not very much when you are looking at the cost of taxis and getting out and about. We do not want people ... okay, they are on long-term care and thank you very much for that but just sitting at home because they cannot go out with their friends. There is a lack of inclusion and a lack of understanding of what people need.

Deputy G.P. Southern:

It is a minimum income system, is it not, that is looking at this which mirrors, as far as possible, a normal life? What do ordinary people do; that is what I should be sharing in, you should be sharing in.

Ms. L. Bratch:

Yes.

Deputy J.A. Hilton:

So just so I have understood correctly, so a young adult on long-term care, not working because of their disabilities, only receives that £4.88 a day ...

Ms. L. Bratch:

£4.88 is when they are living in a home or in a community home. If you are living at home you get the adult component which is about £90-something.

Deputy J.A. Hilton:

Yes, it is just going up to £95 I think. What, if you are on long-term care you still get that?

Ms. L. Bratch:

You get the income support, the adult component. As a level 1 for clinical costs you get £6-something a week.

Deputy J.A. Hilton:

Oh, I did not think you could get both. I thought you were either on low income support with the components and ...

Deputy G.P. Southern:

No. The impairment component gets replaced by long-term care.

Ms. L. Bratch:

Well, the care component of impairment gets replaced. Only the care. You get mobility, which is £20-something and you get your clinical costs.

Deputy G.P. Southern:

Mobility you get, yes. Clinical costs remain. The doctor's costs ...

Deputy J.A. Hilton:

Remain. Okay, if you are living at home, okay.

Ms. L. Bratch:

Yes.

Deputy J.A. Hilton:

All right, okay.

Deputy G.P. Southern:

But the old system was flexible. You could spend it on some care or support as you saw fit whereas the new one is strictly: “You have got to (2:20:37 inaudible).”

Deputy J.A. Hilton:

Yes, the long-term care so you have to go for the approved provider basically, yes.

Ms. L. Bratch:

You go through the approved provider framework but our problems are with the families that either have these huge bills for subsidised disposable products and they are losing their care component which historically has paid for these such items.

Deputy J.A. Hilton:

So how are they going to pay for it?

Ms. L. Bratch:

They have no idea. They are looking through ... their social worker is going to go down to Social Security to look at special payments because that is something that has been mentioned to us before when we have met with Will Lakeman but it does not seem to be that straightforward. It was such a huge bill that they not too sure about it.

Deputy G.P. Southern:

The trick to do, I think, is to go for discretionary payment from the Minister. The Minister has powers of discretion even though everything is written in law and regulations so you can go for a special payment. Special payments are very tight and there is a list about 8 items long. If what you want is not on that list, and it probably will not be, then what you need to do is go for a discretionary payment where the Minister has the power to use discretion to say: “I know the law says you cannot have this but I am going to replace it with this at my discretion so that that need is met even though the law says you are not eligible.” So discretionary payment is there; possibly the way to go.

Ms. L. Bratch:

Okay. Thank you for that. Right, so I would like to move on to point 3 which is the scheme’s weaknesses and here it was a little bit difficult to know which were issues and which were weaknesses. I would say administration has been a weakness and when I say that I am looking at access of information, so that is access of information for us as the individuals using the scheme, also providers and other people sort of involved in that sort of triangle of care. Communication has

been an issue between the departments, families, providers. Lack of understanding of how the scheme works and that is, again, within all involved and even, in some cases, we have found within the department itself that we get mixed information back. I mean I am here under Enable but to just sort of clarify this as an example because we are using long-term care and for data protection I can quite happily quote myself whereas I would rather not quote other people always. I mean it has taken us over a year to try and work out how our long-term care benefit for [REDACTED] works and the information that we have had fed back to us has been shambolic, misinterpreted, rude, arrogant and it has only been really through the Finance Department, a very nice lady there, has managed to unpick things. We got to the point we had to lose 2 months respite because we could not get any clarification as to what was in the pot and we know that if we overspent at any moment we would have Social Security knocking at the door and we would rather underspend, not have our respite, than put ourselves in that position. So that is when I say that there is a lack of communication, there is a lack of understanding. There is poor administration and I am sure people are working on things and with my previous hats on, working with S.N.A.P. (Special Needs Advisory Panel) we have had numerous meetings with Will Lakeman and things have moved on, things have got better from when the first long-term care came in and we saw numerous bills of when people were being moved on to long-term care but still receiving the impairment and then suddenly somebody caught up with them and masses of bills and people were forced to foodbanks and all sort of situations and I am hoping that that is in the long grass and that has gone but having said that there is still room for improvement. We still need to move forward on communication. People say a lot about JOD, you know, that all the information is on JOD but you talk to people about what JOD is and you will probably get at least 75 per cent of people who will not know what on earth JOD is. We still find that people find that gov.je is hard to navigate. It is quite complex unless you know where you are going.

Deputy G.P. Southern:

Yes, if you know where you are going you can get there.

Ms. L. Bratch:

People perceive long-term care as being complex, which it is, but I have discussed this with the development officer and we feel it does need to be complex because you are looking at so many different families with so many different needs and that is one thing that as Enable we do not go out and give anybody any false hopes about what they might receive or not because we are not 100 per cent au fait with their financial background so all we can do is give pointers and advice. So I think information needs to be fed to people in a user friendly way appropriate to what their needs are. You are going to be coping with people who do have disabilities, who do have onset of Alzheimer's. You cannot expect them to be able to sort of read through an encyclopaedia, it has to be presented in an unpatronising but easy user-friendly way. There is inflexibility. There is a lack of choice and a lack of personalisation. Any changes, as you go along, always have to go back through the social

worker, which is fine if you have got one but sometimes that process can make a change quite difficult to meet if it is a change that is needed as an emergency change. Due to financial constraints, as we have said before, it is difficult for families to keep their loved ones at home and we also find that under-65s respite is a problem because of availability. It is, where do you get under-65s respite came out of the Carer's Strategy recently as one of the top problems and the top needs and the top recommendations is to look at the right sort of respite for people. Respite, from my point of view, delivered at home, it is not respite because we have still got everybody at home, carers coming and going. We have still got our young person at home. It is not the same. It is not the same as them going out and getting that independence away from the home because, you know, with the best will in the world we are not ... and other families are not always going to be able to be there for them and as much as we can develop that independence. Having said that there will be people who will be saying respite at home is absolutely what they need and absolutely what their young person older adult needs. But it is like we have said, it is not a one box fits all because we are all different.

Deputy J.A. Hilton:

Can I just ask you though, Lesley, where do you get respite at the moment then?

Ms. L. Bratch:

At home.

Deputy J.A. Hilton:

Not away from the home?

Ms. L. Bratch:

There is nowhere for [REDACTED] to go. There is only Mourant Lodge and I would ... probably at a public meeting, I cannot really go into the details though, it would not be appropriate.

Deputy J.A. Hilton:

Okay. What about Maison Allo because I know they converted their garage into a fully disabled unit.

Ms. L. Bratch:

Yes, but that is under the same provider. We have no choice of providers. If there is a problem with the provider you have no other choice.

Deputy J.A. Hilton:

Right, okay. Because we have been told they are changing the age range. They have got 18-plus.

Ms. L. Bratch:

Yes, they are. They had to change it again. Yes, because it was going to be a transition home but apparently people were not using it and that is probably a question for a whole other scrutiny panel. I think that takes us back, it is a bit déjà vu really.

Deputy G.P. Southern:

We have been talking about the respite in general for at least 8 years.

Ms. L. Bratch:

Well, probably more than that. I think Senator Routier would probably be saying that is probably where he came into it when he first came in to politics.

Deputy J.A. Hilton:

So at the moment your respite is delivered in your own home?

Ms. L. Bratch:

At home, yes.

Deputy J.A. Hilton:

Yes. So what happens if you want to go away for a week or a weekend? Is that possible?

Ms. L. Bratch:

Well, we do have 14 days written into our care plan that we can go away but the inflexibilities of the scheme is that because like we receive a ... or at least, we do not receive it, because Social Security look after that pot of money, they scoop off a little bit each week and sort of put it in to a pot and that is like the holiday pot but that means that once you have used it, as with, I suppose, any household budget, you have to start saving again but if we wait until after our annual review date the understanding is that we will lose that money.

[14:30]

So like my daughters were talking about: "Well, let us not go on holiday at a particular time next year let us go in September" but we cannot because by that point we will have passed our annual review date. So we do not have any ... we have very little control over our lives because our lives are devoted to our young people. So I am not talking particularly of myself. This is across all the families. But we have even less control over our lives because now the States are controlling it. If we went through the route of the High Cost Panel, because we could receive more funds, a way to support ██████ that would be even worse because things would have to be even more dotted and

crossed. We have kept to the highest level that we can receive out of Social Security because, believe it or not, that is less restrictive than going through the High Cost Panel.

Deputy J.A. Hilton:

So you are currently on level 4 of that, are you?

Ms. L. Bratch:

Yes.

Senator S.C. Ferguson:

So you cannot sort of say: "Well, we are going to have a special holiday in 2 years' time. We would like to keep our money to pay for it."

Ms. L. Bratch:

Not that I am aware of, no. Unless, like Geoff is saying, that we could ask for some sort of ministerial intervention but having said that, to be honest, you get fed up with having to ask and ask for things. We are not like a benefits family. We do not want to be on that path. I am not saying anybody wants to be on it but it is making you feel even more vulnerable. It is not a nice position to be in.

Deputy G.P. Southern:

Right, hang on. Again I am getting confused; it is probably because I am stupid.

Ms. L. Bratch:

Well no. It is not complicated but it can appear complicated.

Deputy G.P. Southern:

The theory says that the award of a benefit is to a person. The person has control of that benefit to spend as they see fit ...

Ms. L. Bratch:

I have not seen that.

Deputy G.P. Southern:

... with the right provider of support.

Deputy J.A. Hilton:

With the Long-Term Care Fund?

Deputy G.P. Southern:

Long-Term Care Fund.

Deputy J.A. Hilton:

Our understanding is you get the award after you have been assessed by the social worker and that benefit goes to the client who then chooses the services they want, as long as it is with an approved provider.

Ms. L. Bratch:

Yes. Well, we do that far, yes.

Deputy J.A. Hilton:

Yes, okay.

Deputy G.P. Southern:

Now, you seem to be saying that Social Security have taken charge of that pot of money and are doing what they see fit with it but that is taking it away from your daughter's control.

Ms. L. Bratch:

Well, as far as I am aware, nobody has any control over their finances with Social Security. We do not see any money. It is not paid to us. We have no control over the money.

Deputy G.P. Southern:

That is what we picked up yesterday, is it not, that ...

Deputy J.A. Hilton:

No, today; this morning with the carers. So the money is paid directly to the care agency who provides the ...

Ms. L. Bratch:

It is. It is paid via the Finance Department.

Deputy J.A. Hilton:

There is a difference. There seems to be a difference because in the residential homes it seems to go to the clients.

Ms. L. Bratch:

No. They have said it does not come to us.

Deputy J.A. Hilton:

So it does not go to you; it goes straight to the care provider who is providing the care for the family member.

Ms. L. Bratch:

Yes. There is a finance lady that sort of looks after, I am sure, everybody's or maybe a certain amount of clients and what she is doing now is sending us a copy of the invoices that come from the provider so that we can keep an eye on how monies ...

Deputy J.A. Hilton:

So you can agree, yes.

Ms. L. Bratch:

But we have always asked if we could have statements from Social Security so that we can be part of the managing the funds because I do [REDACTED] hours about, say, a month to 5 weeks before they are due to be provided to us. We have 29 hours a week. I keep within that because that is how the money is allocated and we know that we have funds to pay for that. We have one weekend's respite a month. We know how much that costs. That is fine as well. What is more of a grey area is what we call the "holiday pot" which is where they siphon off a certain amount and put it aside. What I would be liking to see, which I would be doing at home, is I would have a bank account for the weekly, a bank account for the monthly and a bank account for the holiday pot and I would be able to see how we are spending that money and making sure we are not overspending or equally underspending but we have no ... we have asked. We have no authority to see anything.

Deputy J.A. Hilton:

So can you contact Social Security and say to them: "How much is in our holiday pot?"

Ms. L. Bratch:

I have contacted the finance lady. When I was going through Long-Term Care I was getting nothing but unpleasant emails really and emails that made no sense whatsoever saying: "That by the end of the year you are going to have £15,000 sitting in your holiday pot and you are going to have to pay it back to us and if you do not use it it is deemed that you do not need it", and the figures made no sense whatsoever. They did not tie up to anything. We have had no letters from them detailing anything about [REDACTED] long-term care. She has been on it since November 2015 and the only letter we got was a random letter in July last year when we asked for the respite to be added to our long-term care and then we got one saying that our daily amount had been upped because of this but the

figures made no sense because we had had no original letter, no follow through letter. We have had no communications other than via email.

Deputy G.P. Southern:

Is it one of those, your new award is and you look in vain on the paper to say: "What was it?"

Ms. L. Bratch:

Well, sort of. It was a box here with a change of the amount per day but it made no sense because we had nothing to compare it to.

Deputy J.A. Hilton:

There must be lots of families in a similar situation to yourselves then with regard to this holiday pot.

Ms. L. Bratch:

Well, I mean we are probably in possibly one of the more complex areas of care packages because, you know, of having somebody with high needs and a younger person as well. It is not sort of like great aunty so and so has got somebody coming in to get them up in the morning and put them to bed at night. It is very different and, like you said, it is about the supporting of [REDACTED] to do what she wants to do. So the rotas that I request are around activities that she wants. So things do not stay static, they do move, and we do have a provider that is willing to move around as long I give them notice what [REDACTED] wants to do. So if you are ready we can move on to 4, which is any improvements which could be made to the scheme. So we sat down and had a little think about this and we would be looking at individualised budgets; more flexibility; personal assistants who can support people; they can understand; translate what long-term care means to you; brokers; better understanding for individuals and families of their care packages because that puts them in control. Better in-house training for the department itself.

Deputy G.P. Southern:

Is that with dealing with people with disability in general, face-to-face so in terms of ...

Ms. L. Bratch:

Yes. The in-house training, you mean?

Deputy G.P. Southern:

Yes.

Ms. L. Bratch:

Yes. I mean better understanding; better in-house training so that the department understands and definitely understands the complexities of long-term care. Also the face-to-face discussions with clients. We would like people to have a better understanding of what their care package looks like. We have had problems with people, say, for example, where they are receiving say exercise classes within the care home that they live in as part of their care plan but they are having to fund it privately. So it is like, you know, if you are being told by your care plan that you should be having some form of physio, some form of exercise, but then you are having to fund it yourself. You need to know exactly what your package looks like and what is included. We need better communication between all and better access to information. So overall what I would say is that long-term care should not be a "sit-alone" or standalone" service. Long-term care needs to be working in conjunction with ... if you look at like mental health and the Triangle of Care you need to be involving everybody and for long-term care to work we need to be doing what we are doing here which is sitting down and talking about what people need, not just us as the service users but the providers of the services, the charities. I have mentioned further down, you have got the Care Commission that is starting up. Everybody needs to be involved because otherwise you will have that thing that somebody is sitting on a very relevant piece of information. If you wanted to look any further into what we have said about the individualised budgets and personal assistants and brokers ... I do not know if you have had time but I did send a link ...

Deputy G.P. Southern:

Yes, the Australian one.

Ms. L. Bratch:

Yes, about My Way and it is just something that puts people in control. They can ask for as much help or as little help as they want through a brokerage system. I think by the time that you have got Social Security spending so much time on administration and problems that if you had a brokerage system you had ... okay, the legislation that needs to be in place in the first place to allow people to have control over their finances in this way I think it would pay for itself eventually after a little bit of an outlay in the first instance. So moving on to 5, the main issues with the scheme is that we have found that there does not seem to be equity. We have some people that seem to be receiving huge care packages at home, far in excess of long-term care while others are restricted to the long-term care budget. We have also found that we have got some families that are still on the old income support and impairment scheme and by which I mean that are still receiving the care component but physically receiving care at the same time. So you have got this inequity even within certain sort of respite homes where you have got some families that are receiving all the money financially and the care but others that have been restricted and moved over on to long-term care. In discussions with the departments we have also found that there has been some problems with terminology. I do not know whether that has come up through you before but I know in Social Security and with our

discussions with Will that he has been in discussion with Health and Social Services over terminology of what respite and other words mean. It is almost like they are using different language and I think also they are coming from it from a completely different angle. You have got like the social workers that have an understanding of what people require at home and you have Social Security that just because of their mindset they are coming from a more legislative and budget controlled environment and it is just 2 very different departments that are getting together but terminology, if they are going to start changing what respite means we would like: "Well, what is this going to mean to people receiving the long-term care at home or in a residential setting?" Another issue that we have faced has been, as I have mentioned already, equipment but the problem we have found discussing things with Will has been over liability insurance; that people have not wanted to sign off on pieces of equipment. So it is a bit like: "Well, yes, this care package requires a hoist or it requires a standing aid" but it is then, who is going to sign off on liability insurance because Social Security are like: "Well, we do not know about anything about equipment. It should be maybe the social worker." "Well, we do not know anything about equipment so it should be the physio or the occupational therapist." So there have been some sort of difficulties over getting the equipment sorted out but our understanding is that equipment was always supposed to be part of care and part of the original law and there is an understanding that you cannot deliver the care without the right equipment. One of the other things is understanding people's needs, not just seeing the disability but understanding that people need to be part of society as a general thing, a lack of personalisation. This is from the staff's point of view and that face-to-face contact but also from the assessment process and the fact that it is a very black and white assessment form and things just are not black and white. That is my 5. I do not know if you have got anything you want to ask me on.

Senator S.C. Ferguson:

Yes. Do you find the social workers are sharing the assessment form with the carers and the care providers?

Ms. L. Bratch:

Well, from the assessment form we get the care plan. The care plan is generated from that and the care plan goes to the provider. So I mean from what I am aware then the provider would not be able to provide the service without the care plan.

Deputy J.A. Hilton:

Are you allowed to see the assessments?

Ms. L. Bratch:

I have not seen the assessment. It sort of gets input and then the budget comes out from that. So I have not ever seen the assessment.

[14:45]

The care plan we get but that is completely different.

Senator S.C. Ferguson:

Have you asked for the assessment?

Ms. L. Bratch:

No, I have not.

Senator S.C. Ferguson:

It just struck me that perhaps ... are people sharing the information, the basic information, because are the assessors always getting it right?

Ms. L. Bratch:

I cannot answer that because I do not honestly know. On a personal level the assessment was done by the social worker and then she goes off and she inputs it. I would say that possibly if you doubted the level that you came out at, through the indicative budget, that that may be a way where you would question the assessment process but otherwise it has not been a tool that I have asked to see because I was quite happy on a personal level with what came out and also I have that good understanding, good relationship, with our social worker. But I cannot answer your question for other people.

Deputy G.P. Southern:

But as a group, have you been asked by clients to challenge an assessment saying: "They have got me completely wrong"?

Ms. L. Bratch:

No, not that I am aware of. I can always go back if that is something you would like me to raise. I can ask if an assessment has been challenged.

Deputy J.A. Hilton:

Do you know from the people that you are dealing with and when it comes to reassessment whether there is any particular delays around that, getting the reassessments done?

Ms. L. Bratch:

Well, further on in your questions you did ask about the assessing scheme and she did not have any comment because she said that her involvement was now out of date. She did not feel that she had anything that would be useful to you at this moment. Right, so respite services and how they relate to long-term care. Well, I mean we just feel, as we have said, that there is a lack of providers for complex needs, residential respite. It is difficult to access and is paid or was paid as a proportion, as we have said, as part of your budget which means that then if it is sort of gone it has gone and if you require emergency respite we do not honestly know how that would work for people. Again, we wanted to bring up the respite off-Island; that people do not have the option to be able to go off-Island for their care if they wanted to go away. We feel that if we were given the funds and the budgets that this would drive up sort of a supply and demand and also drive up the quality of care and even not talking about residential care but just that the home care providers that if you are holding the purse strings yourself, as the service user, that those providers might feel a little bit more obliged to maybe give a better service where things are starting to slip a bit.

Deputy J.A. Hilton:

Do you use the same agency for your provider? Do you use the same agency since long-care came into being?

Ms. L. Bratch:

Well, for a short period [REDACTED] moved out so that that is when she was in the community home. Then after that we have used the one provider.

Deputy G.P. Southern:

One of the problems is recruitment.

Ms. L. Bratch:

Yes, it is. So that is the main issue and we just feel that we would possibly command more respect if the money was sitting with us than with a third party.

Deputy J.A. Hilton:

So you have never changed your provider? Have any of the people that you are dealing with, have they changed their provider and how easy was that do you know?

Ms. L. Bratch:

People tend to stay with who they have got. There is a bit of a sort of better the devil you know.

Deputy J.A. Hilton:

Than the one you do not know. I just wondered how easy it was to change provider because presumably you have to get in touch with a new provider, they have to come down. There is a ...

Ms. L. Bratch:

Well, yes. I mean you would probably have to go through your social worker, then also you would have to make sure who is making the decision as well. So it has to come from the person receiving the care as long as they have capacity and everybody is deemed to have capacity unless it is assessed otherwise. So it is not probably that easy. You probably have to have a good reason why as well to move, that is what I was told. There needed to be a good reason why you wanted to move. Then also you have people with complex needs and then you have to start from scratch again with new support staff. It is not an easy thing to do. It is probably the same thing of people say: "Well, you should change banks" but it is like you say ... it is sort of similar to ... or doctors, yes. It is sort of similar to that. You sort of know you can.

Deputy J.A. Hilton:

But it is not easy though.

Ms. L. Bratch:

It is not that easy but I mean having said that, people need to do it and I think through information and knowledge and enabling, like we are Enable Jersey, want to enable people to be able to do those sort of things. The Care Commission coming into force. A lot of all of the work around that was about the commission being out there and being an accessible commission to people; not somebody that sits up there so that they can hear what people are saying and interact with the public. Yes, so it was just basically about stimulating the market because I do not honestly know where people would go and get respite that easily from. It came out of the Carer Strategy that respite, across the board, whether you talking about people with Parkinson's or dementia, or people with complex health issues and learning disabilities like we are talking about, across the board the problem was getting respite.

Deputy J.A. Hilton:

It is a worry, is it not?

Ms. L. Bratch:

Accessing the scheme; we had not got a comment and the assessment process we did not have a comment. On 9 we had communication between departments but I also wanted to include families and individuals on that because we are all part of this, what I see, as a sort of Triangle of Care that mental health rolled out and that my understanding is that they are working on communication; that things are getting better. They have learnt that Social Security and Health and Social Services need

to work together and they are doing this on the equipment review that is being undertaken on the subsidised products, on transition and on terminology and we just need this work to continue to move forward and together we can make the scheme, hopefully, more successful. Look to involve the Care Commission is what I have said as well. On the financial sustainability of the scheme we had some questions for you really, if you do not mind.

Deputy G.P. Southern:

Fire away.

Ms. L. Bratch:

We can pop this back on to you. We would be very interested in learning more about the financials behind the scheme and the statistics. So how many people reach the universal benefit or how many people die before reaching that?

Deputy J.A. Hilton:

The care cost cap, you mean?

Ms. L. Bratch:

Yes. What is the average life expectancy of people moving into residential care? What is the average care level of people moving into care? Does Jersey have a high rate of level 3 to 4 care needs people compared with those in other jurisdictions and if so why? So we are particularly sort of looking at these questions around like the nursing care because obviously in Jersey people with nursing care, it is deemed, it is anybody with hoisting needs, but once people are up and about and they have been hoisted they may not necessarily have the level of nursing care needs that may be required under like U.K. law. We would be looking at personalised budgets and moving forward through some sort of brokerage scheme, as I mentioned before. I think that sort of takes it to the end of what we had to say unless there is anything else.

Deputy J.A. Hilton:

No, the financial questions are good questions and no doubt ... I mean obviously they will be addressed because we are addressing those through somebody else, another expert, who has assisted us. The whole financial side of long-term care.

Ms. L. Bratch:

Yes. Because I mean it is sustainability, you just do not know, do you really?

Deputy G.P. Southern:

No, you do not.

Ms. L. Bratch:

We have got an ageing population. We have got people living far ...

Deputy G.P. Southern:

Longer.

Deputy J.A. Hilton:

Yes, it is a terrible worry. It really must be.

Ms. L. Bratch:

Yes, it is and then other families that have come to us, they have had to give up their jobs. They have 2 people with disabilities, both partners have had to give up work to look after them but there is still only one carer's allowance coming in to the household. You do not have it for individual. So you have either got an income within the house that is drastically cut short because you have maybe like one person working or otherwise you, in some cases, have neither of the partners that are able to work. So it is huge financial pressure. It is emotional pressure on the family.

Deputy T.A. McDonald:

It is one thing leads to the other, is it not?

Ms. L. Bratch:

Yes.

Deputy J.A. Hilton:

Do you think ... because most of the people I think we have spoken to have said basically they think that the long-care plan is a good idea. Things need addressing. There are issues that need addressing. Would you agree with that?

Ms. L. Bratch:

Well, it is a good idea but I just think it needs to be turned into personalised budgets which is what I thought it was going to be in the first place.

Deputy J.A. Hilton:

Personalised budgets, what you mean by that is that the budget being paid to the client and not being managed by somebody else?

Ms. L. Bratch:

Well, yes. You would have the person assessed as to what their needs are but they would have control over the money and how they spend it. I mean it would not be like: "Well, we are going to go on this massive holiday." It would all be ... it would be overseen by the brokerage or however you decide to do it so that it would be spent in the right way and appropriate way on the person. It would not be spent by the carers inappropriately but I mean there are curatorships that I was involved in with my mum when she got dementia. There are ways of making sure that money is spent appropriately, ways of putting in your invoices so that when monies are spent on a piece of equipment or a car, whatever, that the monies are used in the correct way. It is not insurmountable.

Deputy J.A. Hilton:

Yes, of course. Yes, okay.

[15:00]

Ms. L. Bratch:

If you have a brokerage scheme as well you have got people that can say: "Well, yes, I would like to manage my staff. I would like to manage everything around my care." Or you have got people that would say: "Well, that is too much for me. The brokerage system, can they sort this out for us and we just receive the care." But ultimately it is that person that is deciding how their life works for them. So that is how we would like this to move forward.

Deputy T.A. McDonald:

Deal with the people involved and figures and theories and ...

Deputy G.P. Southern:

I thought that was the way it was supposed to work. I guessed that they know, I do not know, but we will see. Thank you very much for your ...

Ms. L. Bratch:

Right. I hope that has been helpful.

Deputy J.A. Hilton:

Yes, thank you, Lesley. It really has been very helpful indeed.

Ms. L. Bratch:

I mean I can go back and clarify over the assessments, if there have been any ... and I put a note down ... assessments that have been challenged and I will email Kellie if I hear anything.

Deputy J.A. Hilton:

That would be lovely. Thank you very much.

Senator S.C. Ferguson:

If you think of anything ... I mean have you said everything that you wanted to get across to us?

Ms. L. Bratch:

Yes, I think I have. I have my notes and I am quite happy with what I have said.

Deputy J.A. Hilton:

Thank you. That is lovely. Thank you so much.

Senator S.C. Ferguson:

If you think of something when you get back.

Ms. L. Bratch:

Yes. No, I will. I will pop a note to you, Kellie. Okay.

Deputy J.A. Hilton:

Thank you very much.

[15:01]