

STATES OF JERSEY

Health and Social Security Scrutiny Panel Autism Jersey

MONDAY, 24th JULY 2017

Panel:

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

Deputy T.A. McDonald of St. Saviour

Deputy J.A. Hilton of St. Helier

Senator S.C. Ferguson

Witness:

Chief Operations Officer, Autism Jersey

[14:05]

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

This is the inquiry into the Long Term Care Fund conducted by the Health and Social Security Scrutiny Panel, of which I am the vice-chairman, Geoff Southern. My apologies first on behalf of the chairman. He cannot be here, he is in the U.K. (United Kingdom) attending to a family matter. But just for the sake of ... you have a notice in front of you on the terms under which you give witness here today and normally what we do is just introduce ourselves around the table for the recording. I am Deputy Geoff Southern, vice-chair of the panel.

Senator S.C. Ferguson:

I am Senator Sarah Ferguson, member of the panel.

Deputy T.A. McDonald of St. Saviour:

Deputy Terry McDonald, member of the panel.

Deputy J.A. Hilton of St. Helier:

I am Deputy Jackie Hilton, member of the panel and, while I think about it, I think I need to declare that I have been invited by Autism Jersey to join a committee at some time in the future. So I just think I ought to declare that.

Scrutiny Officer:

I am Kellie Boydens, Scrutiny Officer.

Chief Operations Officer, Autism Jersey:

Paul Sullivan, Chief Operations Officer for Autism Jersey.

Deputy G.P. Southern:

Fire away.

Deputy T.A. McDonald:

Good afternoon, Mr. Sullivan. Could I just ask you to give us a brief overview with the services you offer and how they relate to the long-term care scheme?

Chief Operations Officer, Autism Jersey:

I will do my best. I have never done this before, okay, so bear with me. I work for Autism Jersey. I have been there for 2 years. We provide a variety of services to people with autism and their families across the Island. Our mission statement is: "Championing a full and inclusive life for people with autism, their families and carers." We currently employ 65 staff; 20 of those work in what we call our short break service. Services we provide include the short break services for children. At the moment we support 15 children and we support 13 adults in our short break service. Five years ago we supported one person for 5 hours a week or 20 hours a month. In June of this year we provided 355 hours of support to children and 1,048 hours of support to adults. That is 1,403 hours in a month compared to 5 years ago, 20 hours. So you can see we are developing very quickly.

Deputy T.A. McDonald:

Could I ask: where do you do that work?

Chief Operations Officer, Autism Jersey:

The office is based in Bath Street, Britannia Place. But on Monday of next week we are moving to Patriotic Street to new offices. Our current office accommodation has been sold by the landlord so we are moving to much nicer offices, which are much more user friendly for staff and for people to come to visit.

Deputy G.P. Southern:

You say you support people with autism. What does that support entail?

Chief Operations Officer, Autism Jersey:

It can entail 3 hours a day support in terms of leisure activities. It can be 3 hours of support to go shopping, to go to the cinema to give mum and dad a break. Every child with autism or a disability in Jersey gets 3 hours a week short breaks. I mean 3 hours a week is good but you cannot do a great deal in 3 hours. By the time you have got to where you want to be it is time to come back, especially if you are using public transport. So sometimes a respite break unfortunately can be getting on the bus to St. Ouen. By the time you get there it is time to come back.

Deputy J.A. Hilton:

Is it correct that during the holidays children get 6 hours per week?

Chief Operations Officer, Autism Jersey:

It is, yes.

Deputy J.A. Hilton:

Do you provide overnight respite breaks?

Chief Operations Officer, Autism Jersey:

No, we do not do overnight respite.

Deputy J.A. Hilton:

Okay. So the longest period of time you do is just 3 hours then during the week?

Chief Operations Officer, Autism Jersey:

For a child it would be 3 hours.

Deputy J.A. Hilton:

What about a child with significant needs?

Chief Operations Officer, Autism Jersey:

It depends on what the States will pay for, but they will only pay for 3 hours. If I give you an example. We have got one young man who ... I have been in post now just 2 years this week. I had been in post about 10 months and it came to my attention that we were supporting a young man, a child with autism, and we were providing support on a 2-to-one basis. That was because my colleague had

decided that in order to support the young man safely he needed 2 to one. That was not funded by the States so when I realised that support was not being funded by the States I spoke to colleagues in the States and they suggested I complete a M.A.S.H. (Multi-Agency Safeguarding Hub) referral, which I did. It took 10 months for the M.A.S.H. referral to be addressed. That M.A.S.H. referral was addressed in April of this year and my point would be that the support that I requested when I made that M.A.S.H. referral should have been paid for when I made that M.A.S.H. referral. The States of Jersey have said that they will not pay for that but they will pay for 3 months as of April this year.

Deputy J.A. Hilton:

So they will not pay for the care that you provided prior?

Chief Operations Officer, Autism Jersey:

No.

Deputy J.A. Hilton:

You said you made the referral to M.A.S.H. Was there a safeguarding issue involved here?

Chief Operations Officer, Autism Jersey:

Yes, because in order for us to get the additional funds I was advised that I needed to make that M.A.S.H. referral, which is exactly what I did.

Deputy J.A. Hilton:

Autism Jersey had to finance the difference, I presume. Did that amount to a considerable amount of money that you were left out of pocket?

Chief Operations Officer, Autism Jersey:

About £1104

Deputy J.A. Hilton:

£ 1104

Chief Operations Officer, Autism Jersey:

Over the course of that period.

Deputy J.A. Hilton:

Because they basically refused to fund it?

Chief Operations Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

Can I just ask you a question: you know Maison Allo, which is run by Les Amis, was set up specifically for children with mild to moderate learning difficulties, which included children on the autistic spectrum? Are you aware that they just do not get the referrals through Health and have you been involved in that in any way and have you ever suggested that maybe the families who might require overnight respite should try and get it through Maison Allo?

Chief Operations Officer, Autism Jersey:

Very much so. I do have a good working relationship with Les Amis so I am aware that that facility is not used to its full capacity.

Deputy J.A. Hilton:

Are you aware that there are children or families that would really like to be able to access that service but for some reason they are not?

Chief Operations Officer, Autism Jersey:

Yes, because they believe that the only support they can get is by the short break services.

Deputy J.A. Hilton:

I am just wondering how, if a family required to have a weekend of respite, maybe they are going to a big family occasion or something and the child, for whatever reason, cannot go. I am just wondering how they manage in those circumstances.

Chief Operations Officer, Autism Jersey:

I have got a really good example of that for you. It is a 21 year-old man who States of Jersey knew for 20 years that he was going to become 21 yet his mum and dad could not go to the 21st birthday party together. They had to go separately. If you cannot do something in 21 years there is something desperately wrong. So for me the States of Jersey, as a whole, should have been able to provide support for that family to go to the 21st birthday party.

Deputy J.A. Hilton:

So Autism Jersey, because I know you do a lot of work out of the community, presumably you are providing respite care for those families who have either got long-term care or they are ... is it level 4? Level 3 or 4 on the Social Security level of support ...

Chief Operations Officer, Autism Jersey:

We have got a couple of young men who we support ... who we have got level 3, level 4, so in addition to the short break service we provide supported living services. So the supported living services we used to ... this is where it gets complicated. We used to call them residential services but we changed that last year because I believe if we change the word from "residential", residential implies care giving. If you change it to "supported living" it infers that you provide support rather than care. You do give care as well but it changes the emphasis for people who I employ. They see themselves as being enablers rather than purely carers. There is a big difference between caring for somebody and enabling somebody. So we provide supported living 24 hours a day to 4 people at the moment and then we provide supported living to 4 other people but that can vary from 5 hours a day to 50 hours a week. It can be 10.30 in the morning to 12 noon, and then for the same person it can be 5.00 to 7.30 or whatever.

Deputy G.P. Southern:

Can I just go back to the beginning? Who funds your services?

Chief Operations Officer, Autism Jersey:

Entirely funded by the States of Jersey. That is our only source of income. If we did not ...

[14:15]

Deputy G.P. Southern:

And it is funded through a grant for you?

Chief Operations Officer, Autism Jersey:

No, we do not get a grant. The only money we get from the States of Jersey is that contracted money in terms of the short break services and the supported living services. We would run at a deficit if it was not for the donations that we get from banks, local institutions, people on the streets and that would be a significant deficit that we would have.

Deputy J.A. Hilton:

That is covered by those charitable institutions and fundraising basically?

Chief Operations Officer, Autism Jersey:

My salary is not paid for. My salary is funded by a financial institution, as is my H.R. (human resources) manager, my fundraising manager, my family support services manager.

Deputy G.P. Southern:

You talked about getting some extra services through M.A.S.H. Where does the normal funding come through? What type of award?

Chief Operations Officer, Autism Jersey:

For children it comes through Children's Services. For adults it would come through Adult Services.

Deputy G.P. Southern:

So it is a payment from Health?

Chief Operations Officer, Autism Jersey:

It used to be, but now it is changing to long-term care. That causes a problem, and this is Autism Jersey being selfish, because for every hour of support that we provide we get £24 from the States of Jersey. That used to be Health and Social Services but now it has changed into long-term care. We still get the £24 but long-term care does not include ... will not pay for travel expenses, so we pay ... I pay my staff 35 pence a mile to go support young people or adults in the community. But in order to be able to pay them to get there, in order to pay them, for that £24 if a member of staff does 10 miles that £24 then becomes £21.50. So automatically we lose money ... we lost £1,757.56 because the States of Jersey said it was not their responsibility to pay for travel and that it was long-term care, and we have not been able to recover money, and that was in November of last year. At the moment we still, when we support somebody, we automatically lose money. That should not be the case.

Deputy J.A. Hilton:

That is simply because you choose for all the right reasons to pay for travel in the car?

Chief Operations Officer, Autism Jersey:

Yes, otherwise ...

Deputy J.A. Hilton:

35 pence a mile.

Chief Operations Officer, Autism Jersey:

Yes. It used to be 65 and then a year ago we reduced it to 35.

Deputy T.A. McDonald:

Was that through lack of funds or ...?

Chief Operations Officer, Autism Jersey:

Through lack of funds but also at 65 pence a mile I thought was high anyway. 35 pence a mile is more reasonable. Then on top of that we also provide a range of services for ... we have a couple of social clubs who meet on a Tuesday and Thursday. For the people who attend those, they are adults, and very often those 2 nights are their only social outlets. The only time they meet other people. We have a play scheme which started today and it is running for 3 weeks in the summer. We have got a siblings group, which hopefully starts in the next 3 or 4 weeks. We have a befrienders group, which supports people in the evenings and at weekends. That can be somebody like yourself who just wants to get involved and befriend somebody. We have a family support service. We support the Jersey Adult Autism Service at the drop-in sessions that they provide. So while I might appear to criticise the States of Jersey I work very, very closely with them. Personally we have really good relationships with them. We also have the library in terms of books, videos, DVDs, toys, and then we provide training to local organisations. For example, I was with the police 2 weeks ago. Last year we spent £35,000 on staff training. All staff access a course called Ask Autism, which was developed by the National Autistic Society, 3 staff have completed a post-grad certificate in education for adults or children with autism at Birmingham University, 13 members of the wider management team ... we do not have a big management team, there are only 5 of us, but the wider management have done resilience training and then we have got the Q.C.F. (Qualifications and Credit Framework) training that people need to do and then all the mandatory and statutory training. That is in order to develop a knowledgeable staff team who hopefully will stay with us because we have given them the skills to do what they need to do, and give them the relevant qualifications in terms of autism. We may not be the best provider of services by any means but I believe we are the best provider of services to people with autism in Jersey. We have got a long way to go in terms of knowledge and understanding but we are a young organisation and everyday people come to work we are gaining in experience. We learn from experience. We brought a young man back from the U.K., back to Jersey, which has been a phenomenal piece of work, together with the States of Jersey but the young man who has been off the Island came back to Jersey, was really excited to come back to Jersey but it was not the Jersey he left because the Jersey he left was with his mum. He has come back to Jersey not to be with his mum but to be with adults, i.e. Autism Jersey. So he has had a difficult 18 months. He is doing well now in his own home. It is a very ... no 2 days are the same. It is a really interesting job. We are looking to recruit and retain appropriately qualified staff.

Deputy G.P. Southern:

Where do you see that staff coming from?

Chief Operations Officer, Autism Jersey:

Jersey has a really small pool to get staff round and people move from one charity to the next, or one organisation to the next, so I have been lucky that I have managed to get a couple of people from the U.K. and other local organisations But it is a massive problem recruiting and retaining staff.

Especially when your biggest competitor is the States of Jersey who pay overtime, pay bank holidays, pay evening and weekend pay, pay sick pay, there is a pension scheme.

Senator S.C. Ferguson:

How many autistic clients do you have in Jersey?

Chief Operations Officer, Autism Jersey:

We support 65 but statistics will say that there are about 1,000 people in Jersey with autism or Asperger's Syndrome.

Senator S.C. Ferguson:

You have how many staff?

Chief Operations Officer, Autism Jersey:

Just over 65. It grows every day. I think it would be about 70 today.

Senator S.C. Ferguson:

So you have got 70 staff and 65 clients?

Chief Operations Officer, Autism Jersey:

Yes.

Deputy G.P. Southern:

It is intensive.

Chief Operations Officer, Autism Jersey:

It is very ... most of the work we do is on a one-to-one basis. We do very little group work, and that is partly because most of the people find it very difficult to be in groups. The group work we do do would be with J.A.A.S., with the Jersey Adult Autism Service, and that is a service that meets every Tuesday at the St. James Centre, and people come to that. They stay for 10 minutes or they stay all afternoon, from 1.30 to 4.00. But the majority of the work we do is one to one unless it is a social event.

Deputy G.P. Southern:

You say you are not the only provider of support but you are the best for autism.

Chief Operations Officer, Autism Jersey:

But I would say that, would I not?

Deputy G.P. Southern:

I am not questioning that. That is what I am saying, and how do you see the competition?

Chief Operations Officer, Autism Jersey:

I think until recently there was not any competition. So I think competition is a good thing. I think it is good that people have now got a choice to go to another provider. For example, New Horizons who, like ourselves, are a young organisation but they do not specifically support people with autism. My organisation is accredited by the National Autistic Society. The only other organisation on the Island who has got that status is the States of Jersey, Adult Services and Children's Services, at the moment. But we are the only third sector provider who are accredited by the National Autistic Society. We have got another review coming up in September. I also work for the National Autistic Society as what they call an accreditation panel member, are used to decide if a service meets Autism Accreditation standards. The NAS supports services in Kuwait, Singapore etc. That is what I used to do before I came to Jersey. I used to be an adviser to organisations in terms of autism.

Deputy J.A. Hilton:

How many of your 65 clients are on long-term care?

Chief Operations Officer, Autism Jersey:

Not very many. I know you have already met with one of my trustees.

Deputy J.A. Hilton:

Yes.

Chief Operations Officer, Autism Jersey:

So you are very familiar with her story. I think we have got 5 other people who are in a very similar situation. We have got one young man who we have just started working with. We are working with him for 15 hours a week at the moment, but that is 2 members of staff, 15 hours a week.

Deputy J.A. Hilton:

Does that person live at home with his parents?

Chief Operations Officer, Autism Jersey:

He lives at home with his parents. They have been told that they have got to go on to long-term care. That means that they will, almost immediately, when that happens, will be financially penalised because the care component from Income Support will be lost. That particular family are really concerned because the plan is for support to increase over time so that eventually it will be 24 hours

a day but every time there is an increase in his hours the social worker has to present that to the High Cost Panel who then make a decision as to whether to fund it. Again, that has an impact on us at Autism Jersey but I cannot imagine the impact it has on the family, constantly worrying about whether their son is going to be able to receive the support that he requires in the way that they want him to. Again, you have received a submission from that family so I will not go into too much detail about that.

Deputy J.A. Hilton:

Are you aware of many cases that have gone to the High Cost Review Panel from Autism Jersey? Are they generally receptive or ...?

Chief Operations Officer, Autism Jersey:

[During the Hearing the witness advised that there had been no cases which had gone through the High Cost Review Panel however has since advised that some cases have but not always]

Deputy J.A. Hilton:

So you have never been successful in the High Cost Review Panel increasing costs?

Deputy G.P. Southern:

And not a small group, I think, those who have failed to deal with the High Cost Panel. Were you doing the job you are doing now under the old system before long-term care came in and how do you personally compare the 2 systems? You were talking about the carer's component you could get through Income Support, we are talking about impairment level 3 or 2 - 2 or 3 - certainly I have dealt with a case where somebody was autistic and seeking at least level 3. I think they did in the end. That source of income which are flexible, you can spend it how you see fit and long-term care is not flexible. It has to be spent on a care organisation and delivering that care. How do you see the ... you have already mentioned this family will be losing some money when they transfer to long-term care; how does that fit? How do you view the differences?

Chief Operations Officer, Autism Jersey:

For me, it takes all the ... the days at long-term care takes away the personalised element of support and takes away the opportunity for people to be able to direct their own support. That is what the world is about. It is about enabling people to add more input in their own lives, to be able to live more fulfilled lives, to be making more informed choices and decisions. Not just about money but about the lives they lead, the employment opportunities that are available to them or not available to them. I just think long-term care can be quite restricted. It is very narrow, or it appears to be very narrow. It is very prescriptive about how you can spend the money. Not everybody wants to spend their money in a certain way. I think if somebody wants to ... and as long as there are safeguards

in place you should be allowed to pay your brother to support you. That is difficult because back in the U.K. that has happened in the past, and that can be problematical.

Deputy G.P. Southern:

That has happened in the past?

Chief Operations Officer, Autism Jersey:

In the U.K., yes.

Deputy G.P. Southern:

So that is family involvement with a payment.

Chief Operations Officer, Autism Jersey:

As long as safeguards are in place and the situation is monitored properly. I feel it is a disincentive really. There is a danger that it can hold people back and I do not think ...

[14:30]

I know the intention is there to enable all those things I have talked about but the reality is, it does not. People have said to me: "It is like trying to fit a square peg into a round hole and it is not fit for purpose." That is not me saying that, that is what people have said to me.

Deputy G.P. Southern:

We referred earlier today that someone described the long-term care system as designed for the elderly but that it does not suit young people, it does not fit young people. What do you say to that?

Chief Operations Officer, Autism Jersey:

It is designed for the extremely rich extremely wealthy elderly. I might be totally wrong because when I read the 20-page booklet on long-term care you need a degree to read it and understand it. So how people who are less able than myself ever get their heads around it I do not know.

Deputy J.A. Hilton:

I think people struggle with it, it has been a common theme that everybody ...

Chief Operations Officer, Autism Jersey:

The information document.

Deputy J.A. Hilton:

The information document that Social Security give out.

Chief Operations Officer, Autism Jersey:

In answer to your question it appears that it is targeted to older people. I do not mean older wealthier people disparagingly.

Deputy J.A. Hilton:

Can I just, so that I am completely clear in my mind about this, you are providing 355 hours of support to children, which is mainly made up of the 3-hour ... every special needs child gets 3 hours a week respite.

Chief Operations Officer, Autism Jersey:

Yes. Short breaks, it is not respite.

Deputy J.A. Hilton:

It is short breaks?

Chief Operations Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

Okay, that is what we call it, not "respite"?

Chief Operations Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

Then 1,048 hours are provided to adults?

Chief Operations Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

Just so that I am completely clear on this: that is financed ... the Children's Service finance the children's bit and the Adult Services finance the 1,048 hours.

Chief Operations Officer, Autism Jersey:

A couple of those adults may be on long-term care.

Deputy J.A. Hilton:

On long-term care. But would it be fair to say that the bulk of those hours are paid for by Health? I am just wondering which fund it comes from. That is what I am just trying to understand.

Chief Operations Officer, Autism Jersey:

I would say, yes, but I stand to be corrected.

Deputy J.A. Hilton:

But some of that 1,048 hours, because you mentioned ... I think you have one client who has 4 people providing 24/7 care and obviously that particular client must be on the long-term care fund.

Chief Operations Officer, Autism Jersey:

Yes. But that person came ... we actually got 2 people but they were funded by the States and before ...

Deputy G.P. Southern:

Previously they were funded through ...

Chief Operations Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

They have come back from the U.K., they have come here and they are now funded by ...

Chief Operations Officer, Autism Jersey:

Just the one has come back from the U.K.

Deputy J.A. Hilton:

By the long-term care fund.

Chief Operations Officer, Autism Jersey:

So the majority of people ... sorry, I have confused you there. The majority of people, we send an invoice month on month to the States of Jersey for their payments.

Deputy J.A. Hilton:

So those people, whether it is ... I understand about the children. It is almost statutory 3 hours but with the adults who decides how much support ... do they have to go through the system with the social worker as well, to get the 3 hours per day, I think we said that they get?

Chief Operations Officer, Autism Jersey:

Yes, they do.

Deputy J.A. Hilton:

It is the social worker who decides?

Chief Operations Officer, Autism Jersey:

The social worker will make an assessment.

Deputy J.A. Hilton:

Right.

Chief Operations Officer, Autism Jersey:

Of an individual's needs. And then they will come up with an indicative budget, and that causes me a problem because the indicative budget is always the same.

Deputy J.A. Hilton:

For all of them?

Chief Operations Officer, Autism Jersey:

For all of them. In fact, an indicative budget, the Social Care Institute for Excellence says that: "An indicative budget is a budget which has been the amount of money generated for an individual from the resource allocation system [that is the R.A.S. system]. This gives an estimated [that is the key word 'estimated'] amount to allow the individual to develop the support plan." The States of Jersey I believe have chosen to use that indicative budget as a ceiling rather than an indicative budget.

Deputy J.A. Hilton:

Okay. So let us take an adult using your service, they do not all get 3 hours a day support, do they?

Chief Operations Officer, Autism Jersey:

No. Adults?

Deputy J.A. Hilton:

Yes, adults.

Chief Operations Officer, Autism Jersey:

No, some people get 5 hours, some people get 15 hours. Some people get 50 hours a week, some people get 24 hours a day.

Deputy J.A. Hilton:

So the Health Service is paying for the care that is delivered by your organisation and so, I am just trying to understand this, so basically those people ... they are on low income support are they, and they get an impairment component?

Chief Operations Officer, Autism Jersey:

Most of them have got severe autism, but not all of them.

Deputy J.A. Hilton:

I am just trying to understand the money side of it. I understand Health pay for the care.

Chief Operations Officer, Autism Jersey:

At the moment, there is the young man who is receiving support via the States of Jersey, Health and Social Services, he will be supported by 3 or 4 staff over the course of the day. We have been asked to support that man for 50 hours a week on a one-to-one basis at £24 an hour.

Deputy J.A. Hilton:

Right, on a one-to-one basis he has been supported 24/7 with how many staff?

Chief Operations Officer, Autism Jersey:

At the moment he would be having support from at least 3 staff on a day-to-day basis. There are other staff but they do not ..., for example, when he was admitted it immediately went from one to one, because I was supporting him on the day that he was admitted, to 2 to one. So 2 to one support in a secure or safe environment.

Deputy J.A. Hilton:

But they are asking your organisation to take this person but only financing it on a one-to-one basis?

Chief Operations Officer, Autism Jersey:

On a one-to-one basis at £24 an hour.

Deputy J.A. Hilton:

Why do they think that that is ... why do they think that is going to work when under the Health model there are far more resources going in?

Chief Operations Officer, Autism Jersey:

You will have to ask them that. I do not know. But they will say to me that they can only give us £24 because that is what long-term care says they give you.

Deputy G.P. Southern:

Because that is the budget, that is the indicative budget.

Chief Operations Officer, Autism Jersey:

That is the one.

Deputy G.P. Southern:

That says the senior years, that is only one person, and not 2.

Chief Operations Officer, Autism Jersey:

Yes.

Deputy G.P. Southern:

Again, that is the social worker doing the assessment and not hearing what your organisation has to say, is it?

Chief Operations Officer, Autism Jersey:

That is right. That is the case. There is another young man who lives independently and there was an assessment of need done in terms of the long-term care and I asked: "Could I have a look at the assessment?" and the social worker said, no, I could not look at the assessment. I did not agree with the assessment even though I had never seen it. I asked that that assessment be redone and I was told: "No, it cannot be redone." The assessment process is supposed to be open and transparent.

Senator S.C. Ferguson:

Do they talk to you when they do an assessment?

Chief Operations Officer, Autism Jersey:

No.

Senator S.C. Ferguson:

All the people who are going for assessment you presumably know most of them or one of your staff does.

Chief Operations Officer, Autism Jersey:

Most probably, yes.

Senator S.C. Ferguson:

But the social worker ... are you having problems with continuity of social workers?

Chief Operations Officer, Autism Jersey:

Yes. Do you remember I said about the young man who came back from the U.K.?

Senator S.C. Ferguson:

Yes.

Chief Operations Officer, Autism Jersey:

Well, he had a social worker, he worked with him all the time he was in the U.K. Within 2 weeks of him coming back to Jersey, massive transition, that social worker had been moved off. So then he got a social worker who came over on a 6-month contract, did not actually survive the 6 months and then left. This is support for a young man who has gone through a massive change in his life, still is going through a massive change in his life, and he is now on his fourth social worker in less than 2 years.

Deputy G.P. Southern:

Not a good recipe.

Deputy J.A. Hilton:

There must be occasions when you are asked by the Health Department to take on a certain client where you think that: "No, we are not going to take this client on" because they are not putting enough resources into the care?

Chief Operations Officer, Autism Jersey:

2 years ago when I first came, we did not have the expertise. We have now got a staff team with 2 years plus of experience. People can now tell you what autism is. When I first came some people could not tell you what autism was. So they think what is special about Autism Jersey was the word "autism" in the title but now every single member of staff should be able to tell you, without thinking about it, what autism means to the people they support. That is a massive difference.

Deputy G.P. Southern:

You are describing a situation which is not a nice one to hear in terms of the way the system is or is not working. If I was to ask you ... if you were sitting down with your 5 managers in a team and you are saying: "Where do we want to be in a year, 2 years' time, and how do we get there?" what would your picture be?

Chief Operations Officer, Autism Jersey:

I am 60 years of age now so I would like this to be my last job, but it is not going to be. My contract is for 3 years but I would like to see that Autism Jersey is able to sustain itself financially, is able to provide bespoke services to people, like we do at the moment, but more bespoke complex services to people who currently may be off the Island or may live on Jersey I believe that we, as we develop in 3 years' time, we will have more expertise than anybody else on the Island in terms of supporting people with autism, and I suppose that is a certainty. But we will not have that until we can fund ourselves properly and we cannot do that on £24 an hour. My salary will never be paid out of that £24 an hour, as will the other people ... you know, my H.R. person, my fundraising person, my family support manager. Those salaries are all met from external sources. Without being melodramatic, unless things change in terms of funding, and I recognise funding for everybody is really, really tight. But unless things change ... because the banks will eventually stop giving us money. One bank has given us substantial monies over the last 10 years, People will only give so many times.

Deputy G.P. Southern:

I am trying to put myself in the shoes of social workers, and not a very comfortable position either. When I am talking about support in the home for people with a physical disability I know that the department will pay for 2 people; this is a 2-person job if I have got to use a hoist or because of the risk that they might get arrested, it is a 2-person job and that is accepted on sort of physical grounds. But you seem to be saying that, hang on, 2 people are not ... 2 to one on different grounds is just not even in their equation.

Chief Operations Officer, Autism Jersey:

On what side is that ... sometimes people do not realise that people with autism can have learning disabilities, can have mental health issues, can have a physical disability. Somebody in the States said to me: "Why would you want a hoist in this new building?" and my response was: "Not everybody with autism is ambulant." It is just so narrow mindedness in thinking that. In order to have autism you have got to be able to walk, talk. In order to have Asperger's Syndrome you have got to be able to walk, talk, read and write, and be able to tell the time.

Deputy G.P. Southern:

You are saying it is not just a spectrum. You are saying it is complex.

Chief Operations Officer, Autism Jersey:

Yes, very much. As the population ages, whether it is the autistic population or whatever, I met my first person with Asperger's ... sorry, with autism and Alzheimer's back in the U.K. about 5 years ago. Until that first case came up nobody ever thought of people with autism getting Alzheimer's. That is a massive thing. Why will people not be like the rest of ... with autism, why will they not be like the rest of the organisation? Why will they not get Asperger's ... sorry, Alzheimer's and start peeing in the corner? Sorry, to be crude, but when you pee in a corner in my work people say that is challenging behaviour. Unless you recognise that it is a change in somebody's mental condition then you will treat it as challenging behaviour rather than as being a cognitive degeneration. That is a massive ... the other bit in our work again is you will hear the term "challenging behaviour". To me challenging behaviour is when a person with autism becomes so anxious that that explosion is the only way they can express their anxiety. Getting people to recognise anxiety rather than it being purely challenging, that is a big challenge and that is what we have been doing in Autism Jersey, is getting people to recognise when Deputy McDonald does this it is because he is really, really anxious.

[14:45]

It is not because he is being a tinker, he is displaying challenging behaviour, it is just that he is very, very anxious and it is the only way he can express that anxiety. In the old days, when I worked in the long-stay hospitals, if Deputy McDonald expressed his anxiety in that way, that challenging behaviour, 6 people would have physically restrained him one on each arm, one on each leg, one on his head, and then the charge nurse would have come along and put an injection in his bottom.

Deputy G.P. Southern:

I can assure you he is already distressed. He has his back to the door. His anti-terrorism trained says always have his back to the wall so he can see anybody coming in.

Deputy T.A. McDonald:

Sadly, you are speaking to an old policeman who was there in those days, we used to have the padded cell, the A.P.U., the Adult Psychiatric Unit, and that is exactly ... and then how it became the "chemical cosh" and I know exactly ... I can picture it, I can smell it, I can almost taste being there. I have not come far.

Deputy J.A. Hilton:

Are you involved in any way at all in ... if somebody comes in who is going to come in and do long-term care, like in the assessment process, are you involved in that in any way at all?

Chief Operations Officer, Autism Jersey:

No.

Deputy J.A. Hilton:

So you are not really able to offer an opinion on the assessment process?

Chief Operations Officer, Autism Jersey:

I have been to a panel, I supported a young man at the panel, which went really well but the anxiety that that ... knowing that he was going to the panel caused ...

Deputy G.P. Southern:

What do you mean "panel"? Medical Board?

Chief Operations Officer, Autism Jersey:

Yes, Medical Board.

Deputy G.P. Southern:

I can imagine that was extremely stressful. It would be stressful for most people.

Chief Operations Officer, Autism Jersey:

But we worked together on that one. I have done some work with Will Lakeman at Social Security. Will and his colleagues went out of their way to give me a one-to-one tutorial ... in fact, it was a 3 to one, there was 3 of them and one of me.

Senator S.C. Ferguson:

I am sure you coped well.

Deputy G.P. Southern:

Were you able to give them a lesson in terms of dealing with autistic clients?

Chief Operations Officer, Autism Jersey:

We are in the process of arranging another meeting, he was really receptive.

Deputy G.P. Southern:

Because that is certainly one of the issues in day-to-day running of any department, particularly Social Security where you are not recognising what you might call challenging behaviour is a result of stress of having to have gone in and attended. Somebody came to me the other day and said: "I

did 10 minutes waiting and I was just going to explode. I had to go.” A 10-minute wait was just beyond his capacity.

Chief Operations Officer, Autism Jersey:

Your system here works really well. Because at 2 o'clock that door opened and ... because I was told by yourself that the door would open at 2 o'clock and somebody would come out and say “hello” to you. That is exactly what happened and that is what people who I work with, that is what they need. Because we have made that rule. We have said: “We will see you in 10 minutes.” If we break that rule and do not see them in 10 minutes we are the cause of that challenging behaviour, that anxiety, that appointment being missed.

Deputy G.P. Southern:

It is another aspect of not all disabilities are visible.

Chief Operations Officer, Autism Jersey:

That is it.

Deputy G.P. Southern:

You do not know what is going on in his head.

Chief Operations Officer, Autism Jersey:

Again, we talked to the police 2 weeks, ago, the probationers, and we were lucky that we could talk about some of the people that we have got in common. It just totally changed the perspective of what they were dealing with and their attitude. Not that they are poor attitudes but that they have become the frontline in terms of when people are in crisis it is the police who get called in. In fact, if we all worked together it would not move to crisis in the first place.

Deputy G.P. Southern:

There is also a thing that happens with claiming benefit in general, is that people do not want to admit to impairment, to disability, and will say ...

Chief Operations Officer, Autism Jersey:

“I am okay.”

Deputy G.P. Southern:

And what they are talking about are the good days and the variability in people's conditions that operate. A number of people I have seen have said: “Hang on, you said they are -- now talk to me about that bad day. What happens on your bad days?” “I cannot get out of bed.”

Chief Operations Officer, Autism Jersey:

We support people, who for example may not have been able to leave their bedroom for 3 years or to leave the house for 7 years. . That just brings on all kinds of mental health issues, the harder ... the longer you do not work the more difficult it becomes to work, you become mentally ill, you become depressed, you become suicidal. You try and take your own life. Sometimes you succeed, most times you do not, but sometimes you do. You are right, people do not like to, as we said in the old days, sign on.

Deputy G.P. Southern:

And thereby be labelled.

Deputy J.A. Hilton:

Can I just ask you a question about the parents and carers of people on the autistic spectrum? What are the sorts of things that they will come to your organisation and express concern about?

Chief Operations Officer, Autism Jersey:

Accommodation, education, employment, relationships between mum and dad, relationships between the person with autism and the siblings, mental health issues, religious issues, anything ...

Deputy J.A. Hilton:

All sorts of things?

Chief Operations Officer, Autism Jersey:

All sorts of things.

Deputy J.A. Hilton:

So there is not one overriding issue that you have got several people coming to you saying: "I am really concerned about this?" A collective concern, if you like.

Chief Operations Officer, Autism Jersey:

Everybody is concerned about the future of their son or daughter. "What happens when I am not here?"

Deputy J.A. Hilton:

Their future, yes.

Chief Operations Officer, Autism Jersey:

And what people would like. Whether they are older people like myself or younger people, is to know that their son and daughter is going to be safe and supported in a way that they would like them to be supported.

Deputy J.A. Hilton:

Are there any group homes that cater specifically for people on the autistic spectrum or with Asperger's?

Chief Operations Officer, Autism Jersey:

Not specifically, not in Jersey, no.

Deputy J.A. Hilton:

No. So are there any residential homes that are currently catering for the needs of -- you mentioned Aviemore.

Chief Operations Officer, Autism Jersey:

Aviemore is run by the States of Jersey. Les Amis provides services and they have a significant number of people with autism but they are in group homes.

Deputy J.A. Hilton:

In the group homes, yes.

Chief Operations Officer, Autism Jersey:

But they may well be the people with learning disabilities as well as their autism.

Deputy J.A. Hilton:

So Aviemore is the only ... currently the only residential home provided by the Health Department? I do not know whether Eden House will still ...

Chief Operations Officer, Autism Jersey:

Eden House is a children's respite unit. Actually it is used for respite so children can go there for what respite should be, which is an evening or a weekend.

Deputy J.A. Hilton:

But they are not using Maison Allo?

Chief Operations Officer, Autism Jersey:

I think Eden House has been blocked for a while.

Deputy J.A. Hilton:

Sorry?

Chief Operations Officer, Autism Jersey:

Blocked. People being ... using it.

Deputy J.A. Hilton:

Not using it?

Chief Operations Officer, Autism Jersey:

No, they have used it.

Deputy J.A. Hilton:

Okay, thank you.

Chief Operations Officer, Autism Jersey:

The resources on the Island are really quite limited in terms of support away from home, away from mum and dad really. But not every mum and dad wants that. You know, mum and dad wants somebody to come in, stay in the house while they go shopping or while they go to the theatre or to take Tom over to Guernsey for the day or over to ...

Deputy J.A. Hilton:

Presumably they have got that choice anyway, with the 3 hours a week they get to choose how they use that 3 hours a week, that short break.

Senator S.C. Ferguson:

You cannot do much shopping in 3 hours.

Deputy J.A. Hilton:

Not really. You cannot do an awful lot.

Senator S.C. Ferguson:

You can do the household shopping and that is it.

Autism Jersey

You cannot go for a nice movie. You can as long as you are planning with military precision so you can get there and get back on time.

Senator S.C. Ferguson:

I would think planning with military precision is quite difficult if you have got people with autism.

Chief Operations Officer, Autism Jersey:

It can be. Especially if the police are going round with their alarms going off, because that sets most people off.

Senator S.C. Ferguson:

So how do you think the long-term care scheme is working as far as your clients are concerned?

Chief Operations Officer, Autism Jersey:

Being selfish in terms of Autism Jersey it does not work because it penalises the organisation and I do know that it penalises some parents or families financially. I do not think that is right. But that is just my personal opinion. I think the system was designed with better intentions but it is flawed and it does not work; it needs to be fixed.

Deputy J.A. Hilton:

For certain groups?

Chief Operations Officer, Autism Jersey:

Yes, for certain groups.

Deputy G.P. Southern:

I have got that quote. There is nothing else, that quote is sitting in the middle of the page somewhere. Anything else? Anything that you came to say that we have not touched on and for some reason we have not said?

Chief Operations Officer, Autism Jersey:

No. you have been really nice to me.

Senator S.C. Ferguson:

We are really quite user friendly.

Deputy T.A. McDonald:

What we are trying to do is help. It is an uphill battle, as I am sure you appreciate.

Deputy G.P. Southern:

Thank you for your contribution.

Deputy J.A. Hilton:

Yes, thank you very much for your time.

Senator S.C. Ferguson:

And if you suddenly think of something that you wish you had said if you would like to come back to us.

[14:55]