

STATES OF JERSEY

Health, Social Services and Housing Panel Respite Care Review Sub-Panel

Session 4

FRIDAY, 2nd MARCH 2012

Panel:

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

Witnesses:

Services Manager, Autism Jersey
Vice Chairman, Autism Jersey
Trustee, Autism Jersey
Secretary, Autism Jersey

Present:

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

[15:30]

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

Thank you very much for attending our scrutiny panel hearing this afternoon. It is a public hearing. So I just have to guide everybody to the code of behaviour for members of the public that is displayed on the wall. I think everybody is familiar with the rules and we will start by introducing ourselves formally. I am Kristina Moore. I am the Chairman of the panel.

Deputy J.A. Hilton of St. Helier:

I am Deputy Jackie Hilton. I am Vice Chair of the panel.

Mr. S. Jones:

I am Sion Jones. I am advising the panel on their review.

Deputy J.G. Reed of St. Ouen:

I am James Reed, panel member.

Ms. F. Carnegie:

I am Fiona Carnegie. I am a Scrutiny Officer.

Ms. K. Boyden:

I am Kellie Boyden, Scrutiny Officer.

The Deputy of St. Peter:

If you would be kind enough to introduce yourselves.

Services Manager, Autism Jersey:

I am the Services Manager, Autism Jersey.

Vice Chairman, Autism Jersey:

I am the Vice Chair of Autism Jersey.

Trustee, Autism Jersey:

I am a Trustee of Autism Jersey.

Secretary, Autism Jersey:

I am a Trustee of Autism Jersey.

Vice Chairman, Autism Jersey:

Can I just say something before we start? Both myself and Sue are public servants and we would just like to make it clear to the panel that we are attending here in our private capacity on behalf of Autism Jersey and that any views we express are on behalf of Autism Jersey or ourselves and not our employer.

The Deputy of St. Peter:

Thank you. Really, I guess the best place to start is what you think of the current provision for respite care for children and young people on the autism spectrum at the moment.

Vice Chairman, Autism Jersey:

Can I just say what we have done is we have kind of brought a broad range of us from Autism Jersey and each of us have got different sort of professional areas of interest, but we have each got personal areas of interest as well. We have prepared some notes because we want to make sure that we have got a set agenda of things that we want to get in today, but how would you like us to play this? Do you want us to answer specific questions or would you like us to present to you the services that we, as Autism Jersey, offer so you can have an understanding of the context of how we operate? We are quite happy to do either.

The Deputy of St. Peter:

If you do make your presentations initially, that might be useful to set the scene for us and then if you want to decide who is most suited to answer each question as we progress.

Vice Chairman, Autism Jersey:

Do you want to go ahead with the presentation of what we provide?

Trustee, Autism Jersey:

Yes. Obviously we are a local charity, funded locally and very much based in Jersey. In terms of our provision, we do not employ a large workforce. So many of the provision is provided by volunteers, willing volunteers of all ages and all interests. Our sort of jewel in the crown is our befriending service and that really is looking to offer support to children and adults and their families and carers who live with autism. The idea of befriending is that we are looking to offer, in particular to younger people, an opportunity to have a friend so that a family member can go about their daily business, as any other person would. So it could be as simple as a young lady with perhaps a child who has an autistic sibling and, therefore, cannot go into town once a week and go to a shop. It may be that a family cannot go to a restaurant together. So a befriender is associated with a family, very closely matched through a rigorous process, having had training and, in some respects, you could say that that is a form of respite. Some of our concern is that that can become a form of respite and it should be a friendship. So at the moment we do have situations whereby families will approach us with a dire need to have some respite and befriending, on occasion, could be used for that purpose, but also Social Services approach us and try to encourage us to use befriending as a respite service. That is probably worth highlighting there. It is a very successful service. Many, many youngsters who are in education, perhaps looking to go to university, become befrienders and give us a service for possibly 2 years or so before they go off to university. So it works very well, but we have befrienders of all ages and what we do is we look to match the befriender very closely with the individual. So it is about common interests so that somebody can enjoy something they are passionate about in a safe environment, possibly once a week. Sometimes it is once every fortnight. So it very much is about family need. On another level it could be that mum gets a chance to go and have a cup of coffee with somebody and just relax, quite frankly, for an hour. Then we are involved in ...

Services Manager, Autism Jersey:

Sorry. Can I just say that we offer that to 50 families now, which is the only respite that those 50 families get. But I think from a scheme that started off with 8 volunteers to develop to 50 is huge.

The Deputy of St. Peter:

Do you have 50 volunteers over ...

Services Manager, Autism Jersey:

We have more than 50 volunteers. We have 50 matched families. We have families still waiting and we have volunteers that are still waiting because unless it is a good match it will not work. That is why we also cannot guarantee it. So if a family says to us: "We want a befriender," we could have 12 people on the list but none of them would suit it and it only works if it is matched well. It is the same as I cannot say: "Oh, you will be my friend," because we might have nothing in common. It has got to be a match.

The Deputy of St. Ouen:

Just for us to be clear about how many people you are supporting, you are saying that currently 50 families gain access to the service out of how many?

Services Manager, Autism Jersey:

I cannot tell you how many families there are because we only know the people that are members of Autism Jersey. One per cent of the population in Jersey should be autistic.

The Deputy of St. Ouen:

You say you have a waiting list?

Services Manager, Autism Jersey:

Yes, we have families on the waiting list and some people would like another befriender because if you are a young adult and your only social activity is one hour once a fortnight that is not an awful lot of ...

The Deputy of St. Ouen:

That is what the service is, is it, one once a fortnight?

Services Manager, Autism Jersey:

It is a voluntary service, so a volunteer will give what they can. Some volunteers say: "I can do once a week," but some people say: "I can only do once a fortnight." What we always say is: "Give us your minimum," because you can always increase that but if you say: "Oh, I can do once a week," and it is really working well once a week but if your work commitments are different and then you have to cut it back the person with autism thinks they have done something wrong because it has been taken away from them.

The Deputy of St. Ouen:

So how many people are on the waiting list?

Services Manager, Autism Jersey:

I cannot tell you the exact figures but more than 10.

Trustee, Autism Jersey:

I think when you are talking about a waiting list you have got these 2 parties. You have got families seeking support and you have got individuals who have volunteered. The volunteers who are going to befriend have to go through a training process. They cannot just befriend.

The Deputy of St. Ouen:

No.

Trustee, Autism Jersey:

So they are being trained and then the waiting list is almost we have got 2 receptive parties but they have to be matched. So they are waiting to be matched rather than there is no service.

The Deputy of St. Ouen:

But while they are waiting to be matched they are not able to access the service?

Trustee, Autism Jersey:

They are not getting a benefit from the service because that matching process has to be very, very appropriate.

Mr. S. Jones:

How long would that process typically take, from when somebody comes to you and volunteers to be a befriender to the time when there is a match?

Services Manager, Autism Jersey:

There is not a typical because you could have somebody who wants to go to the Miniature Train Collectors Club, which happens twice a month on a Wednesday night, and if you have not got a volunteer who is really interested in going to a Miniature Train Club on a Wednesday night ... and then we get fantastic volunteers who say: "I can do anything on a Tuesday night between 8.00 p.m. and 10.00 p.m." Well, that takes out all of the children. People with autism that are working are often too tired to do a social thing on a Tuesday evening. So you might have a fantastic volunteer with lots to offer but they have only got that time. There are lots of things that have to go into account.

The Deputy of St. Ouen:

I have got it. Thank you.

Mr. S. Jones:

But how long does the training take?

Services Manager, Autism Jersey:

The training is a training that we have written. It takes 6 weeks and it is a 2-hour commitment a week for 6 weeks and the volunteers also have the enhanced C.R.B. (Criminal Records Bureau) check done as well. The training covers everything from autism awareness to child and adult safeguarding to risk assessment.

The Deputy of St. Peter:

So that is the befriending service.

Services Manager, Autism Jersey:

Sorry, Sally.

Trustee, Autism Jersey:

No, no. We are a team. Then the Youth Inclusion Project, which you may have heard of already, is run by the Jersey Youth Service but Autism Jersey part-fund that service and Hannah Clarke from Youth Service is one of our trustees. It has 2 aims almost. One is that it provides a specialist youth club provision but also, for some individuals, it may be that they are supported in an open youth club situation. So they will have somebody to support them so that they can access their local youth club in the way that anybody else would access. How long has that been going for, Heather?

Services Manager, Autism Jersey:

It started as the Uno Club, which was specifically for children with autism, 10 years ago and it just started as a 2-hour-a-week thing but it proved to be such a successful thing that it then developed into the Inclusion Project. So it is 10 years but now it includes anybody with any form of disability.

Trustee, Autism Jersey:

Then leading on from that, because we are quite passionate about the idea of a life-long service, is that we set up, a few years ago, an adult youth service; a drop-in centre really. So for adult social intervention, we call it the Adult Social Club and that is for adults. Initially it was supported just by willing volunteers. Now it has been formalised and we employ a sectional facilitator who co-ordinates that activity, which can include indoor activity or outings. So it is looking to meet the needs of adults.

The Deputy of St. Ouen:

Adults meaning what age group, 18 plus?

Trustee, Autism Jersey:

Anybody that has left that youth service. So potentially we have got a system whereby they go to the youth service and once they become old enough to leave the youth service or approach that then there is a transition rather than it just stops: "You are now an adult, you do not get anything." That is very successful.

Deputy J.A. Hilton:

Can I just ask you a question around the Youth Inclusion Project? We have had a couple of families in to speak with us who had children on the autistic spectrum who I believe attended the Youth Inclusion Project but I think their needs were considered to be too great. Are you aware of any families with teenagers who cannot access it for that reason and, if you are, do you know what there is for them?

Trustee, Autism Jersey:

My initial response would be that we have to risk assess anything we do.

Deputy J.A. Hilton:

Of course.

Trustee, Autism Jersey:

Some individuals, perhaps the environment would not be appropriate or it may be that there is not that care ratio available, because it has got to be funded. In terms of an alternative, I have no idea what an alternative would be.

Deputy J.A. Hilton:

So nobody has ever approached you? None of your parents have ever approached you?

Services Manager, Autism Jersey:

No.

Vice Chairman, Autism Jersey:

The Mencap project, 50-50 Club, would generally pick up people who maybe have a dual diagnosis of autism and a learning disability who may not have sufficient verbal ability to access the social club.

Services Manager, Autism Jersey:

But they have not recently come to us. I cannot say historically but ...

Deputy J.A. Hilton:

Okay. But recently you have not had any parents come to you and sort of express any concern?

Services Manager, Autism Jersey:

No, not in the last year.

Deputy J.A. Hilton:

Thank you.

Trustee, Autism Jersey:

Then another service that we offer is an informal parents' drop-in, sort of a coffee and chat drop-in. We offer a free phone service. We have a list of approved babysitters and we have a free advocacy service so that we can support parents, carers, individuals, particularly around education and Social Services reviews. Often particularly that coffee and chat drop-in session is where we identify a new family who perhaps needs some support. It could be a family that is reaching a crisis situation for whatever reason, but it is a safe place to talk with people who understand and perhaps are in similar situations.

The Deputy of St. Ouen:

Can you just explain to us about the free advocacy service? I mean is that linked to their Records of Needs?

Trustee, Autism Jersey:

Some of that would be.

The Deputy of St. Ouen:

Can you just elaborate on what services is included in that?

Trustee, Autism Jersey:

It is on a needs basis. So if a family comes to us and perhaps they have got a formal meeting with one of the States departments and have no experience of what is expected, so it could almost be a friend sitting beside me. It could be, in terms of the educational service, that we have got people who have had close involvement with education and know more about Records of Needs, how to access services, et cetera, et cetera. So it very much depends on what the individual needs.

The Deputy of St. Ouen:

Income support?

Trustee, Autism Jersey:

If need be, and housing. I mean at times it might be that we support somebody about a housing ... It is on a needs basis.

Vice Chairman, Autism Jersey:

The service we provide generally comes from out of the board of trustees, or members of our staff on occasion.

Services Manager, Autism Jersey:

We do not have an advocacy worker. So a family will come with whatever the problem is and we will assess who is most appropriate to support that person.

Vice Chairman, Autism Jersey:

Assess who is most appropriate and has the most experience to support that particular family.

[15:45]

The Deputy of St. Peter:

So quite a busy board.

Trustee, Autism Jersey:

We are.

The Deputy of St. Peter:

How long has Autism Jersey been going?

Vice Chairman, Autism Jersey:

Since 2005. We established Autism Jersey when we broke away from the National Autistic Society. We formed the National Autistic Society in 1999.

Services Manager, Autism Jersey:

No, 19 ... 86 plus 7, 1995.

The Deputy of St. Peter:

I guess your range of services has grown through the needs that you have seen and you have responded.

Trustee, Autism Jersey:

I think one thing we are is very responsive but clearly we need to have funding to be responsive and in many respects it is about people helping each other who have been in similar experiences and perhaps understand a bit more about what is required.

Vice Chairman, Autism Jersey:

I think one of the benefits as well is because we are not only providers of service we are also consumers of service. So we know exactly what is

required and we know exactly the levels of trust and confidence that we need to provide in order to have our parents access the service. Of course, we are not profit-making as well. Anything that we do make at a fundraiser we push back into the charity in order to develop extra services and Gay Waters gave you an example this morning of the play schemes, a hugely crucial need that was removed from our families and we have been able to fundraise for that and develop a service to support our membership.

The Deputy of St. Ouen:

Do you have any partnerships with the States or other organisations?

Vice Chairman, Autism Jersey:

Yes, we do. At the beginning of the year we were awarded a States of Jersey contract to deliver the Life and Social Skills Pre-Employment Training in conjunction with the Jersey Employment Trust and we have been able to recruit senior support workers to provide assessments in that area. We have recently put in a bid for the respite services specifically for autism, because we feel that we have a role in being part of the solution to the provision of respite and we are trying to form some very positive relationships with Health and Social Services. I have to say that our experiences of the management of the States contracts so far has not been particularly positive. On some occasions we have not been paid. There are some contractual issues that we feel should have been sorted out and we will certainly look very closely at future contracts.

The Deputy of St. Ouen:

What stage are you at with regard to the tender process?

Vice Chairman, Autism Jersey:

The Invitation to Tender went in on 28th February, which was the closing date. So we submitted the Invitation to Tender and we are just waiting to hear.

The Deputy of St. Ouen:

Can you just talk me through the process? You got an Invitation to Tender, then there is a formal tendering process based around ... or are you already very aware of what they require and what they are looking for?

Vice Chairman, Autism Jersey:

No. I say we put in an Invitation to Tender. We have adopted a different approach. It is impossible for us to tender for a service that is going to be based on individual need. So until we are acutely aware of the individual needs of the people we want to support we cannot identify how much that service is going to cost. Clearly our service is going to be based on the personalisation agenda and what we know is that, based on our experience, we can offer imaginative solutions and things that are not necessarily going to be formal. Certainly the traditional experience of respite is a bricks-and-mortar service so that there is a house and if you want respite your child will go to that house at this particular time when we can take him or her. What we would like to do is look for something more flexible than that because respite

... Unfortunately what we have at the moment is a kind of one-size-fits-all approach and, although everybody speaks very highly of the staff and very highly of the service - we cannot fault the quality in the majority of occasions - certainly there is not enough of that service. There is not enough to go round and it is only delivered once a family are very close to crisis or in crisis. Certainly the approach that we would like to take is becoming involved at a very much lower level and we are looking at things like therapeutic fostering models. We are looking at informal fostering. Things like the befriending, development of that, that does not cost a lot of money but can deliver a lot of benefit to families in a very positive way.

The Deputy of St. Ouen:

So with regards to the youngsters that are suffering with autism and for the parents involved, Outreach with support in one's own home can be as useful as respite. Is that the case?

Vice Chairman, Autism Jersey:

Yes. I mean it depends entirely on individual circumstances. You know, some people may have children that are so challenging that the only alternative or the only option is for them to be removed from the home. Other people may require a service where it would be really nice if they went for tea at somebody's house every Sunday afternoon for a month. One of the ideas that we have looked at is recruiting foster families that would become involved with very young children so that as the children grow they can spend a Sunday afternoon with the family. They have got to know that particular family. They have got to know the children in that family, you know, the dog, the cat. So it is a planned process. I think one thing that has concerned us is any kind of lack of strategy for the provision of care and respite for any of the children. They should not be a surprise. You cannot suddenly say: "Eighteen, whoops, where did he come from?" They have been in the system since they were toddlers and it should not be a surprise and we should not be having this fight for service. It should be a properly-managed transition programme.

Secretary, Autism Jersey:

They also should not get to 18 and suddenly say: "You are not a child now. You are an adult, so you do not need respite." That is the biggest thing.

Services Manager, Autism Jersey:

It is not just respite. All services for people with autism should be life-long. There should not be a cut-off, change of social workers. It should be a life-long service.

Vice Chairman, Autism Jersey:

You do not suddenly stop being autistic because you achieve our 18th birthday. It is a life-long disability.

Deputy J.A. Hilton:

I just want to sort of understand this tender. Have Social Services just asked companies or individuals to tender?

Vice Chairman, Autism Jersey:

It went to a tender portal. We were registered on the tender portal as people who would be interested in offering care services and then the *Invitation to Tender* document was published there on ... I am tempted to say 1st February. Initially the closing date was on 21st February, which gave us a very tight window, but they did extend it. Another issue that I think that is worth mentioning in the provision of service is when you are a very small charity it is very challenging for us to be able to find the space to prepare these tender documents. You know, if you are a private provider, you have dedicated people. That is their job. So it was an issue for us that that timescale was quite tight.

The Deputy of St. Peter:

Is this the tender to provide adult respite?

Vice Chairman, Autism Jersey:

Yes, and we have been very clear we would only be looking to deliver respite to adults with autism and we would not be looking at providing physical disability. But, as I reiterate, the focus is not about a bricks-and-mortar solution. It is about an individualised approach and it is about giving parents choice because at the moment if you are a square peg you will fit into that round hole called Eden House or you will fit into that round hole called Aviemore or what have you.

Services Manager, Autism Jersey:

Or you will not have anything.

Vice Chairman, Autism Jersey:

Or you will not have anything at all.

Trustee, Autism Jersey:

I think you can also add to that if somebody hits crisis then your expectation has to change very quickly. You were perhaps supposed to be coming to us on Friday afternoon, phone call: "That is not on, that is not happening," and the repercussions of that can be very, very significant.

Vice Chairman, Autism Jersey:

Sue has a recent example of that, do you not, with your respite, Sue?

Secretary, Autism Jersey:

Yes. My son is 18 and we were supposed to have a transition into adult. He has gone into Adult Services now and so we were supposed to have a transition into Adult Services respite and in October, because of the crisis that happened at Eden, I just got a phone call: "No, we cannot take him [name redacted]orrow." He only had 4 hours a fortnight but: "We cannot take him [name redacted]orrow," and then a fortnight later no one turned up and I rang and said: "What is happening?" "Oh, we cannot take any children," and it stopped and when I spoke to the lady from Eden who was running it and said, you know: "Well, there was supposed to be a transition. You cannot just

stop,” and she said that she was not aware that he would need respite when he went into Adult Services.

Deputy J.A. Hilton:

Because I spoke to you last week, did I not?

Secretary, Autism Jersey:

Yes, you did.

Deputy J.A. Hilton:

I asked you because my understanding is that your son was getting respite.

Secretary, Autism Jersey:

Yes.

Deputy J.A. Hilton:

It stopped when the crisis happened and he has not had it since.

Secretary, Autism Jersey:

Nothing. We have not had a minute since October.

Deputy J.A. Hilton:

We have had department officials in here and specifically asked the question: “Are all the families who were receiving respite before the crisis ...” We were told quite categorically that all those families that were receiving respite just prior to the crisis are now receiving it again.

Services Manager, Autism Jersey:

No, they are not and they are getting closer and closer to crisis themselves.

Deputy J.A. Hilton:

This is just so ... because I knew, because I had spoken to you.

Secretary, Autism Jersey:

No, we have not had a minute since October.

Deputy J.A. Hilton:

So we need to understand how many families are affected. I knew there was you. We had spoken.

Secretary, Autism Jersey:

Yes.

Vice Chairman, Autism Jersey:

It is very difficult when you say: “How many families are affected.” For example, my family have never received respite because we have never needed it. We have a particular family situation that we do not need respite, but you only know about the people who have reached crisis and require it. There are many other families that are members who feel that they are being punished for coping because if you are coping, with copious amounts of

Prozac, you will continue to be left to cope. I think what we need is having some sort of universal assessment that catches everybody. Not people that are falling through the net but assesses people at the point of diagnosis and are somehow navigated through the system and that needs to be a life-long system. At the moment parents of adult children are expected to take the lead for the provision of care for their adults and it is not an acceptable situation.

Trustee, Autism Jersey:

It also impacts on people's ability to earn a living. There are many situations whereby you are faced with a situation where the child is no longer in school because they are an adult and there is no other option than the parent - and not all parents are on income support, they have mortgages - has to give up a job.

Vice Chairman, Autism Jersey:

Which significantly reduces their income and then, of course, the corollary to that is then people are obviously needing Carer's Allowance.

Secretary, Autism Jersey:

Which is what has happened with myself because what happened [name redacted] was going into Adult Services and I could not get a proper provision for him because he is severely autistic and does have challenging behaviour and there was then: "Oh, you will have to drop him off here one day and drop him here another day." There was no way and I was starting to panic and then, when all the respite and everything ... I mean through the summer holidays I had to fight every single summer to get more than a Saturday a fortnight. Just to get like a half a day they wanted to charge me all sorts of amounts of money and things and I just knew our family was going to fall apart if I did not do something. So I have, which I did not want to do ... I have not given up work but I have taken an evening job that I work 3 evenings a week so my husband can look after my son and I am claiming the Carer's Allowance. It was something that I never wanted to do, but I just could not see how my family would survive if I did not do something to try and pull it back together. Therefore, I am on Income Support in effect where really I am perfectly capable of working and would have liked to have carried on working, but then my son has to come first and my family.

Vice Chairman, Autism Jersey:

In the 18-pluses we have had situations where we pulled the Education Law and insisted that children stay at school, at Mont à l'Abbé, until the time that they are 19. Now, when they are supposed to have had 5 years to effect a transition into Adult Services and nothing has happened and they go from a very lively, very productive, very encouraging environment to something like a day service provision, which was built in the 1960s as a training centre, you know, parents were very distraught, absolutely distraught, at that change in circumstances and Sue is not alone, as she knows. Many, many of our families have had one parent or a grandparent have to give up work in order to transport their adult children around to the different areas of pockets of provision and provision does not tend to be a full morning. It tends to be 9.30

a.m. to 11.30 a.m. and then they will not take you for lunch because that is education and they do not support that. That is Support Services because you in education and you get on to this merry-go-round when you cannot have a needs-based service.

The Deputy of St. Ouen:

Just going back to something you said earlier. First of all you said you had 4 hours every 2 weeks. Is that the basic session or length of session that people are offered?

Secretary, Autism Jersey:

It really depends. There does not seem to be any criteria whatsoever to who gets what. My personal experience is those who shout loudest get the most and those who cope and do things with their kids and try and manage get the least and they are the first ones to be cancelled, which is where I fitted in.

The Deputy of St. Ouen:

The other question I need to ask you is mentioned about buying hours or time.

Secretary, Autism Jersey:

Yes.

The Deputy of St. Ouen:

Can you just explain about that? Are people able to buy respite?

Secretary, Autism Jersey:

Personally, at the time when I asked for it, it was coming up to summer holidays and every summer holidays was a nightmare because if he was not in school I had him for 6 weeks. You know, obviously my husband took a week off but the rest of the time I had him with me.

[16:00]

He is not one that obviously has got friends. My parents are elderly. They cannot take him out. So I said to a Manager at Health and Social Services could I have every Friday morning - he was going to give me every other Friday morning. So I said: "Well, can I not have every Friday morning," because another child that was in with my son, who had a very similar condition, was getting 4 full days a week respite. So I said: "Could I just have the extra Friday mornings," and he said: "Well, no, I do not think we can do that because we have not got the funding." I stupidly said: "I do not mind paying," because I was thinking along the lines of the play schemes, because they put a play scheme on at the school but [name redacted] could not access that because of his challenging behaviour. So they sort of paid I think it was like £18 a day. So I said: "I know," obviously meaning I would pay that. So his actual words were: "Well, obviously you are in a fortunate position that you can pay for it." That was his words and I said: "Well, I would not say I was in a fortunate position. I have a son who has severe autism who I need a break from, but if that is it what it needs I have to do something to get a break." The

next thing I got an email back and it was £790 and there was no way I could afford to pay that.

Services Manager, Autism Jersey:

But can I also ...

The Deputy of St. Ouen:

Hang on, hold on. Sorry. £790 for what?

Secretary, Autism Jersey:

For 3 Friday mornings, because I had to pay for 2 people to be with him because he needs staffing 2:1 if he goes out and I was not allowed to just pay 9.00 a.m. until 1.00 p.m. I had to pay the full shift, 8.00 a.m. until 2.00 p.m. I have an email.

The Deputy of St. Ouen:

So they said to you: "If you want more we will charge you £700 and whatever and as long as you are prepared to pay it we will provide it for you"?

Secretary, Autism Jersey:

Yes.

Services Manager, Autism Jersey:

But can I just add to that, Sue is saying that she needed it for a break, which you did. But you had a daughter as well. It is a sibling ... you know, it is the long summer holidays and nobody has looked into the lives that these siblings lead and how they can never go out or: "Do you know what? I am just used to being hit before I go to school because that is what my brother does every day." That is just normal life. So it is really important. Yes, you have got the mother on Prozac and keeping it all together, but we have got some children having not very nice lives because of what happens.

Secretary, Autism Jersey:

Their lives are very different. To a degree they have to fit in, the siblings.

Trustee, Autism Jersey:

You have also then got parents. If it is a family with 2 parents, the other thing that happens is mum goes out with the other children and dad stays at home with the child. So you have got split families.

Vice Chairman, Autism Jersey:

Split families who do not do anything together.

Trustee, Autism Jersey:

Yes, because you cannot do anything together.

The Deputy of St. Peter:

Can I just ask one more question about Sue's situation because I am interested in Eden House post-October last year?

Secretary, Autism Jersey:

Yes.

The Deputy of St. Peter:

They seem to consider that you have moved on to Adult Services. Have you been contacted by Adult Services and have they suggested a plan?

Secretary, Autism Jersey:

I finally got a social worker. So I have spoken to the social worker who is now looking into what would be available. Obviously [name redacted] is very people-minded. He has to have people that he knows. So the idea was that they would sort something out before he got to that age so that the staff from Eden that he is very familiar with whom he could have a transition into adult respite services with. Because obviously he has got no road sense and things like that, but they would know him so they could start introducing him to the new environment and new people; where now we have got no one to introduce him into the new environment if they do find something. So it is going to be down to me to be going with him for weeks on end until he gets to know the building, the people, the place, you know; where really it should have been a smooth transition from: "This is where [name redacted] will get his respite." What I find really hard when they say: "Oh, we have got a crisis," there is no other thought. It is: "We have got a crisis. We have got a child in Eden so no one else can have any respite." You know, even if they had come and said to me: "Right, Saturday morning I will take [name redacted] for 2 hours down to Aquasplash. He can have a swim and I will bring him home," 2 hours. They do not need to go anywhere near Eden House. But it was: "No, nobody else is getting respite," and we never heard ... you know, I had to keep ringing her and then she said to me: "I will keep you in the loop" and you never hear anything and then it is gone. I mean, as I say, we have not had a minute since October. So every minute that [name redacted] is not in Adult Services he is with me or my husband.

The Deputy of St. Peter:

How has he responded to Adult Services?

Secretary, Autism Jersey:

He is getting there, yes. I mean it has not been ideal but he is getting there. It is a different provision but he is there and he is sort of fairly settled now. So it has taken this length of time for him to settle and there was a few sort of hitches along the way, but he is doing okay. It is not the ideal thing but it is somewhere for him to go. If he was not there he would be with me and I think he gets fed up with being me, never mind being with him. I think he is sick of the sight of me.

The Deputy of St. Peter:

He is a teenage boy at the end of the day.

Secretary, Autism Jersey:

Of course he is. He does not want to be with me everywhere he goes, stopping him doing this, that and the other.

Deputy J.A. Hilton:

When we talk about Adult Services, you mean in Le Geyt?

Secretary, Autism Jersey:

Yes, he is at Le Geyt.

Deputy J.A. Hilton:

Is he there 5 days a week?

Secretary, Autism Jersey:

Yes, 10.30 a.m. to 3.30 p.m.

Vice Chairman, Autism Jersey:

Which is not a day. That is not a day.

Secretary, Autism Jersey:

I know. That is why I had to give up work because it was in the day as I was worried about hours that he would attend and where he would have to be dropped off.

Vice Chairman, Autism Jersey:

That is not a day and one particular issue as well, it is all very well having these services but a lot of our members cannot access the service and there is no transport provision. So for children who cannot use taxis unaided they would require a carer in the taxi and certainly one of our families was offered a package that was going to cost them £112 a day and that was just to provide a transport service up to access Highlands in the morning and back home for lunch and then back up to Jersey Employment Trust in the afternoon and then back home, because of course you cannot just phone up Yellow Cabs and say: "Can I have a taxi now, please?" It has to be planned and also the carers, you know, for a 20-minute taxi journey, you are having to pay a 2 or 3-hour minimum callout for a carer who has to support that person. I mean there is patient transport up to day services but our children are not patients. Again, for people who are not able to transport their children or young adults there is a wait in the system for that as well. So your time at day services may be limited to when they can come and pick you up in patient transport.

Secretary, Autism Jersey:

I transport [name redacted]. Today, to come here, my husband has had to take the afternoon off so he can fetch him so that I can come here because he gets picked up at 3.30 p.m.

Vice Chairman, Autism Jersey:

We were going to bring him with us, were we not, Sue?

Secretary, Autism Jersey:

No, you said you were going to bring him. No, he was not coming here.

Deputy J.A. Hilton:

Does [name redacted] go to Le Geyt 50 weeks of the year, 49 weeks of the year, 48?

Secretary, Autism Jersey:

They say you have got to take them out for 4 weeks.

Deputy J.A. Hilton:

Right, okay.

Secretary, Autism Jersey:

So he is taken out but, because this will be his first full year, I will probably take him out for sort of a few more weeks than that because he needs a break as well from being in there every day. But the provision is 48 weeks really. He has to have 4 weeks off.

Deputy J.A. Hilton:

Okay.

The Deputy of St. Peter:

Were there any other presentations that you wanted to make?

Vice Chairman, Autism Jersey:

I think one of the things that we did want to point out was just ... you have certainly heard some of the challenges that we face but there are some more strategic areas that we face and one of them is do with the legislation vacuum in Jersey. There is no legislation in Jersey related to autism or even disability per se. Now, in the U.K. (United Kingdom) you have Autism Acts, you have Disability Discrimination Act, you have got a Mental Capacity Act. We have got a Draft Discrimination Law that does not mention disability. We have an Employment Law that does not cover a maternity provision let alone disability. It makes our task all the more difficult because we have got to motivate and influence departments to provide service because they want to, not because they have to. I know Gay Waters spoke to you this morning about the record of need. The record of need has no legal backing at all in Jersey. We have never signed a record of need. We refused to sign it and I am not the only one at this table who is the same. We have never signed one in goodness knows how many years and it makes absolutely no difference what goes into that record of need. Yes, of course staff are excellent and they try to provide what you are saying your child needs but the downside is if there is no money you will not get the service no matter what.

Deputy J.A. Hilton:

They are not bound by law to deliver it, are they?

Vice Chairman, Autism Jersey:

No, they are not bound by law to deliver it at all. So in the U.K. you have various pieces of legislation that you can hang your hat on and I think that is a real difficult situation for Social Services as well, particularly people coming from Social Services in the U.K. who are used to having this huge framework behind them that assists them in the delivery of service. You know, you come

here and there is a vacuum and certainly our experience is the Social Services managers are just as frustrated as ourselves that they cannot deliver what needs to be delivered. They know what needs to be delivered but, you know, for various reasons, be it lack of legislation or strategic oversight, it has not happened.

Deputy J.A. Hilton:

Just a point of clarification on something that was said a little bit earlier when you were talking the tendering and you mentioned therapeutic fostering and informal fostering. That is not part of that tender, is it?

Vice Chairman, Autism Jersey:

Well, it is something that we have suggested that we would look to develop if they were interested in engaging with us to provide services.

Deputy J.A. Hilton:

Okay.

Vice Chairman, Autism Jersey:

As I said at the beginning, we see ourselves very much as part of the solution for this and we want to work together with the States to deliver a really first-class excellent service to the clients and in order to do that we have got to be a little bit innovative and a bit imaginative. Certainly one of those fostering models is something that we would certainly look at developing.

The Deputy of St. Peter:

How have you found a pool of people who might offer those services?

Vice Chairman, Autism Jersey:

Well, no, we have not and we would be looking at a paid provision. We would be looking at recruiting and paying people to do that, but if you look at what was said about the Befriending Scheme we have never had ... I know it is a completely different ballgame bringing people into your home, but the Social Services have a fairly healthy fostering for typical children. They do not have fostering models for A-typical adults but certainly it is something that we could look at developing. It is models that are used in some of the Scandinavian countries as well, because people recognise the benefit of having people with disabilities in the community, contributing to building social capital and all those other benefits rather than simply putting people in an institution.

Services Manager, Autism Jersey:

It is different from the traditional fostering in that you are not committing to doing it 24 hours a day, 7 days a week.

Vice Chairman, Autism Jersey:

That is right.

Services Manager, Autism Jersey:

So you have people who would be prepared to do it one day a week or one day a fortnight.

Vice Chairman, Autism Jersey:

Say, for example, if we had been able to link [name redacted] in with a therapeutic foster family at the age of 5, this afternoon when Sue wants to come to this meeting his foster mum could have picked him up from Day Services and he could have spent some time with them and gone for a walk or whatever and then Sue could have picked up. You know, it is an extension of the friendship network, but it is something that we would look to pay people to do.

Services Manager, Autism Jersey:

But we are not saying that is the only way. We are very keen on the personalisation module where you find out from people with autism and their families what they like and then finding a creative way to provide that rather than just ...

Trustee, Autism Jersey:

One size does not fit all.

Services Manager, Autism Jersey:

No, it absolutely does not.

The Deputy of St. Peter:

So what would you propose to do? Would you sit each family down and sort of assess their needs?

Vice Chairman, Autism Jersey:

The issue of assessment is quite interesting because certainly the Autism Strategy that was written in 2006 sort of put the social worker at the heart of the assessment process and that clearly has not happened and certainly not all our families have social workers. The social workers are only ever appointed once you are in crisis but really somebody needs to be the navigator for people's lives and it is certainly something that Autism Jersey would be able to offer in conjunction with Social Services, because we are a charity and there are things that we should not be providing. There are core services that have to be provided by Social Services and we have heard about inappropriate referrals at the moment to our Befriending Scheme but we would certainly seek to work in partnership. Certainly we are looking into going into partnership with Health and Social Services to deliver the concept of the Autism Centre which will be a kind of one-stop-shop for everything autism-based in Jersey.

Services Manager, Autism Jersey:

But the core group, it should be the social worker that does it but for the personalisation you have everybody working together. So it is not that Day Services say: "Oh, we will do this at a certain time." You all meet together to get the personalisation. Also, in the U.K. they have gone on to the personal budgets where you have all your own money and you decide: "Right, okay, for 4 hours a week I want to be at the Aquasplash. So I will pay somebody 4 hours a week to take me to the Aquasplash. Then I need somebody to pick

me up and take me there, so I pay that.” So it is control of your own budget and buying in what you want, but it is working everybody together. So it is not us just saying: “What can we do for your respite?” We need to know what everybody else is doing for the daytime.

Mr. S. Jones:

Do you think that budget aspect of personalisation could work in Jersey?

Services Manager, Autism Jersey:

Yes. It has worked in the U.K. and they have found that it has brought down the level of financial support that the person has needed.

Trustee, Autism Jersey:

Because it is focused around independence, not dependence.

The Deputy of St. Peter:

Have you spoken to Social Security?

Vice Chairman, Autism Jersey:

Regularly.

[16:15]

The Deputy of St. Peter:

How helpful do you find your contact with Social Security?

Vice Chairman, Autism Jersey:

Social Security as in Income Support?

The Deputy of St. Peter:

Yes.

Vice Chairman, Autism Jersey:

The feedback that we get from our members is that Income Support is all done with smoke and mirrors. The application form is the stick. We have been in the daft situation of our own son having to sign. I mean he draws his name. He has no concept of anything that he is signing there at all. It does not strike us as particularly user-friendly and I think it is very difficult when you see 2 families who have almost identical needs receiving different levels of benefit.

Services Manager, Autism Jersey:

My son has just had his review and nothing has changed. He is in the same job. He is earning the same money, but he is now getting, I think, £11 less a week.

Vice Chairman, Autism Jersey:

Nobody knows why.

Services Manager, Autism Jersey:

Why? Nothing about him has changed except he is 3 years older than the last time he filled in the forms.

Vice Chairman, Autism Jersey:

Also just the physicality of the building; it is a very inaccessible building for people with autism. That is the last sort of environment you want to be in and it is a very broad-brush approach. They do not recognise well enough individual need.

Services Manager, Autism Jersey:

No. But it is not just Income Support, it is all allowances. You will go in as a family and you are usually in some form of crisis because you have had to give up work and you will speak to somebody: "Oh, no, you are not entitled to that. You get that." So you take those papers off and you go in the next time: "Oh, no, that is not the right one." They give you different advice every time about what things you can have. We have got a family that has done a very long fight and just been told: "Oh, yes, you should have been receiving that. So we will back pay you 2 years and 9 months," because they should have been ...

The Deputy of St. Peter:

That is terrible.

Services Manager, Autism Jersey:

Yes, it ended up with the Minister, but if you did not have the family prepared to keep fighting and saying this. There is no booklet that just clearly says what is available. So you do have families struggling and then they could have got ... and then there is this that is paid to the carer, but there are other bits that is paid to the child.

Vice Chairman, Autism Jersey:

Then there is the concept of the household. Some young adults are allowed to claim the equivalent of the Housing Benefit that they would technically pay to their parents as rent and other young adults they have said: "Well, no, you are living with your parents. So you are not entitled to that." So you are either a household or you are not a household and, again, it is something that frustrates our members because it is this inconsistency of service provision. That runs right through, not just through Social Security. It runs through Social Services, respite and the like.

Services Manager, Autism Jersey:

If you are trying to get an adult independent living in their own flat, the Housing Benefit is £153 a week. Well, just look at the *J.E.P. (Jersey Evening Post)* because somebody with autism needs a decent place, somewhere quiet with some outside space that they go into and you find me a one-bedroom flat for £153. You find me a one-bedroom flat anywhere for £153.

Deputy J.A. Hilton:

The Housing Department are supposed to pick up anyone who has special needs.

Vice Chairman, Autism Jersey:

Actually, can I heap some praise on the Housing Department. Sue Le Mercier and her team, the Assisted Living Team, I have to say, are one of the most helpful States departments we have ever come across. They take the time to listen and to understand and to bend over backwards to find appropriate accommodation.

Services Manager, Autism Jersey:

But the States does not have a lot of appropriate accommodation. You know, on a big estate where it is noisy and there are children playing and all that stuff.

Vice Chairman, Autism Jersey:

Also, people with autism quite often display some very odd behaviour, which makes them very unsatisfactory neighbours. You know, so sometimes they are difficult to place.

The Deputy of St. Peter:

Is there anything else that you would like to ...

Services Manager, Autism Jersey:

I would like to praise the staff that do provide the respite. I know the respite they do provide is of fantastic quality.

Trustee, Autism Jersey:

I do think they have to cope because if things planned in advance are changed then you have a gut response, behavioural response from the individual. Therefore that impacts on the family before and after. It impacts on the carers before and after. You then have a cycle where you ... you know, you need some consistency and preparation. You need notice. We all know those things. They are all documented. All of a sudden they say: "Oh, by the way it has all changed. That is okay. Get on with it." So you might have your respite but it takes you 2 weeks to recover from the respite experience. What is the benefit?

The Deputy of St. Peter:

Thank you very much. That is really interesting.

Services Manager, Autism Jersey:

We have not touched on diagnosis or the lack of it.

The Deputy of St. Peter:

I think Gay spoke about that this morning.

Vice Chairman, Autism Jersey:

I think, to finish, I would say we are very positive about moving this forward and, although we have been critical of departments, I think it is fair that we need to be open and honest with you so you know what our experiences are.

But we do very much think ourselves part of the solution and I think there is a lot of positive work going on that will build and reap benefit in the future.

Trustee, Autism Jersey:

I think just before we finish what might be useful is to recognise that some of our individuals are very, very able; very intelligent individuals who have got a lot of talent. Some of them are focusing on respite, day services or whatever and I have certainly experienced it at J.E.T. (Jersey Employment Trust). I tutor at J.E.T. and do all sorts of things. I have had individuals who are Asperger's Syndrome - very high I.Q. (intelligence quotient), they have other issues - in a class with people who have learning disabilities and have no language and cannot read and right. Quite frankly, they sit in a class with 12 individuals and have one who really is not coping because they are in totally the wrong environment I find really unacceptable. There is a danger that our very able individuals are being put into situations whereby, quite frankly, I think anybody would behave inappropriately because it cannot possibly be the right thing.

Secretary, Autism Jersey:

But that is probably because they have not got an individualised programme. That is what we do need and they have to fit into a hole somewhere.

The Deputy of St. Peter:

I was going to ask something of you all. Forgive me. I know you are all very busy people but it just did strike me when we were talking about numbers of people who required respite we have been told, as Jackie said, that everybody who needs respite is being catered for at the moment. I know your membership does not probably cover everybody in the Island who has a diagnosis but perhaps if you could just do a straw poll through your membership and with your sort of hat on as if you were in that situation negotiating with social workers if you won the contract for providing adult respite care. I cannot remember the term you used. But if you could perhaps give us an indication of numbers of people who would benefit from a regular respite slot, do you think that would be possible?

Trustee, Autism Jersey:

Perhaps just backtracking, I do not know if you are aware there was a special needs services review a few years ago and I was tasked to be involved in the Aviemore review at the time while Eden House was setting up, but that draft report did not go anywhere. So we actually surveyed our members around their experience of respite, their need for respite. That is slightly out of date information but there is some very powerful information in those questionnaires of real cases, real stories, real experiences that perhaps you just need to aware of.

The Deputy of St. Peter:

That might be useful.

Vice Chairman, Autism Jersey:

I do not imagine they would have changed significantly.

Trustee, Autism Jersey:

No, it will not have changed.

Services Manager, Autism Jersey:

We could probably re-send the questionnaire just to the membership and ask.

The Deputy of St. Peter:

Would it be too time-consuming?

Trustee, Autism Jersey:

We could summarise the results.

The Deputy of St. Ouen:

A summary would be good.

Vice Chairman, Autism Jersey:

We have recently ...

The Deputy of St. Ouen:

We just have to be careful of the data protection.

Vice Chairman, Autism Jersey:

We have got a student from Highlands doing some work for us at the moment as part of a Social Science Degree and she is working on that. We have had some service and we should be able to give you something up to date.

The Deputy of St. Peter:

That would be fantastic.

Vice Chairman, Autism Jersey:

She is also doing some qualitative stuff as well, some face-to-face interviews.

The Deputy of St. Ouen:

Just going back to the tender process, you have had an invitation to tender. You have put that ...

Services Manager, Autism Jersey:

No, we did not have an invitation to tender.

Vice Chairman, Autism Jersey:

We had to register our interest.

Services Manager, Autism Jersey:

We registered on the States portal.

The Deputy of St. Ouen:

So your desire to tender.

Mr. S. Jones:

You registered your interest.

Vice Chairman, Autism Jersey:

We registered our interest.

The Deputy of St. Ouen:

Your intention to tender.

Vice Chairman, Autism Jersey:

Yes, and then they provided us with the documents, a list asking loads of questions. We have completed those documents and we have submitted them back into the States portal.

Trustee, Autism Jersey:

But what we have not done is provided, in that process, as a solution as such because we were not provided with information ...

Vice Chairman, Autism Jersey:

With enough information to do that.

Mr. S. Jones:

Is there another step within the process? You have expressed an interest now and they may come back with a specification, I guess, which ...

Services Manager, Autism Jersey:

Yes. I would expect ... I mean I do not know how they are going to provide the specification because clearly there is not a lot of individual needs assessment going on.

Deputy J.A. Hilton:

But there are things that they do know about at the moment, we all know about and has come out in the evidence that we have listened to: the shortage of residential beds for children and young adults on the autism spectrum.

Services Manager, Autism Jersey:

But what we have put in the adult tender could resolve some of the problems in the children's service at the moment.

Vice Chairman, Autism Jersey:

We look at it that it has got to be a life-long service anywhere. I mean the principles are the same.

The Deputy of St. Ouen:

I am just trying to think. I would not mind having a look at this tender document.

Services Manager, Autism Jersey:

Here is one I prepared earlier.

Vice Chairman, Autism Jersey:

I have got a blank one with me, I think. I have got the questions.

Services Manager, Autism Jersey:

I personally do not think we will get it because I think the tender process is a monetary thing and somebody who says: "We will do you a bed a night at this price," will get it and that is not ...

Trustee, Autism Jersey:

That is not a solution we provided.

Vice Chairman, Autism Jersey:

That is not a solution and we have made that quite clear that ...

Trustee, Autism Jersey:

More of the same does not work.

Vice Chairman, Autism Jersey:

That is the half completed one.

The Deputy of St. Ouen:

Did you say you took it off the States website?

Vice Chairman, Autism Jersey:

No, it is off the tendering website which is ...

Services Manager, Autism Jersey:

The tendering portal.

Vice Chairman, Autism Jersey:

The tendering portal, which is interesting in itself.

The Deputy of St. Ouen:

Okay. We can get that.

Vice Chairman, Autism Jersey:

If you speak to Roy Towler from Shared Services he will provide you with the blank template and it is the I.T.T. (Invitation to Tender) submission document for the adult respite service for the adult care bed centre. Basically, they are asking your basic stuff about your commercial details but how you would provide a quality of service, what your performance and improvement procedures are, risk assessment and the like. The standard stuff, but things means absolutely nothing to us because unless we work within the parameters of the individual needs assessment we cannot possibly hope to have a service that is appropriate.

Trustee, Autism Jersey:

It might be worth us sharing with you just very briefly what is the criteria for assessment if somebody needs respite. So we have lots of anecdotal reports and being told, mainly by social workers, that: "If you are about to kill yourself

as a parent or your child is about to hurt themselves or seriously injure a sibling then we might be able you.”

Mr. S. Jones:

So it is death or serious injury?

Secretary, Autism Jersey:

Yes. In the same respect you have also got within the education setting that when you go to get some support, perhaps from C.A.M.H.S. (Child and Adolescent Mental Health Service) or something similar: “Has the child injured themselves? Have they hurt somebody else at school? Are they excluded? No. Come back when they do.”

Vice Chairman, Autism Jersey:

Also we have some parents who are advised to call the police to deal with behaviour management because once your child gets into the Criminal Justice System there may be a better chance of receiving some service.

Secretary, Autism Jersey:

But then if you look, I should imagine in Eden House and Aviemore those are the people that are in those provisions, the ones that the parents cannot deal with in the home anymore. But then you have probably got families outside who are still dealing with those behaviours but are terrified to say: “I cannot cope,” because they are going to be ripped out of their home, because that is what they are waiting for. Instead of putting a bit of support to help ...

Vice Chairman, Autism Jersey:

You have models where children are on 3:1 support in the educational environment and go back to mum, dad, or mum and dad for the rest of the day and the holidays. How does that work?

Secretary, Autism Jersey:

It does not work.

Trustee, Autism Jersey:

We have also had a recent child protection issue where somebody at school recommended, in a supportive way for a family, that they believed there was a child protection issue for the siblings and that was referred to Social Services, to C.A.M.H.S., and the response was - it was not even a response - there was a warning that this potentially is a serious ... we have child protection concerns and nothing at all has happened in that respect. You know, it is a disaster.

Services Manager, Autism Jersey:

It is, yes.

Mr. S. Jones:

Coming back to the criteria for providing respite, do you know if there are written guidelines for social workers?

[16:30]

Secretary, Autism Jersey:

No. There cannot be. I do not know if there is but there cannot be. On experience there cannot be criteria because ...

The Deputy of St. Peter:

Would you be able to give further evidence of when those quotes have been given, say a date or a person or something that we could back it up with?

Trustee, Autism Jersey:

They have been sent to me personally.

The Deputy of St. Peter:

Would you know the date or who said it?

Trustee, Autism Jersey:

I have got emails.

The Deputy of St. Peter:

You have got emails. Would you be happy to share them with us?

Trustee, Autism Jersey:

Yes, if I can dig them out. As long as I saved it.

The Deputy of St. Peter:

Yes. At least that would help us because we have been trying to get some idea of what those criteria are.

Trustee, Autism Jersey:

I think the point is that if there is not the resource to support what do people say when you need it? There has to be some criteria. I think our concern is if a parent has got to that stage and feels in many respects that potentially they have failed to cope when they should be able to cope, to have that sort of response is enough to push a parent over the edge. Also then why would you ever ask for help again because, quite frankly, if you are at that stage other things would have happened.

The Deputy of St. Ouen:

It is a bit back to front because you could easily argue you need a policy in place and then you work out how you deliver that policy and that determines the resource. You have to start with: "I have got this. Okay, here we go."

Vice Chairman, Autism Jersey:

It also links into the ...

The Deputy of St. Ouen:

I think that message has come across.

Vice Chairman, Autism Jersey:

It also links into the area of diagnosis as well that Gay Waters mentioned to you this morning. You know, with a diagnosis comes a signpost for service and it is very easy to shrug your shoulder when you do not have a diagnosis because it is just a ...

Mr. S. Jones:

So do you think that resource issue is affecting diagnoses of people, not diagnosing or because they know there is a resource consequence?

Vice Chairman, Autism Jersey:

I think that is a possibility.

Trustee, Autism Jersey:

If you have a letter from C.A.M.H.S. that tells you: "Go and speak to Autism Jersey and get some help," then why would somebody say you need some help and refer you to a charity for it? That is happening on a regular basis.

Mr. S. Jones:

So these kids are not being diagnosed with autism but they are being sent to you.

Services Manager, Autism Jersey:

Autistic-like features.

Vice Chairman, Autism Jersey:

It is like limp-like features, is it not? Is there anything else we can assist you with?

The Deputy of St. Peter:

It has been really helpful. Thank you.

Deputy J.A. Hilton:

Yes, it has been really good. Thank you very much indeed.

[16:32]