

STATES OF JERSEY

Health, Social Security and Housing Scrutiny Panel Child and Adolescent Mental Health Services

MONDAY, 10th MARCH 2014

Panel:

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

Deputy J.G. Reed of St. Ouen

Witnesses:

Operations and Business Development Manager, Autism Jersey

Family Support Officer, Autism Jersey

[11:59]

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

Thank you very much. Welcome to the public hearing of the Health, Social Security and Housing Scrutiny Panel's review into C.A.M.H.S. (Child and Adolescent Mental Health Services). We will start by introducing ourselves around the table. If you would introduce yourself and with your title. I am Deputy Jackie Hilton, Acting Chair of this Panel.

Deputy J.G. Reed of St. Ouen:

Deputy James Reed, Panel member.

Scrutiny Officer:

Janice Hales, Scrutiny Officer.

Operations and Business Development Manager, Autism Jersey:

Heather McClelland, Operations and Business Development Manager for Autism Jersey.

Family Support Officer, Autism Jersey:

Jo Thorpe, Family Support Officer for Autism Jersey.

Deputy J.A. Hilton:

Thank you very much indeed. I would like to draw the public's attention to the notices on the chairs and your attention to this notice that is positioned in between you there. Before we start, I would like to give apologies on behalf of the Deputy of St. Peter who, sadly, at this time is not well, so she is not here. Thank you very much for coming and speaking with us. The first thing I wanted to ask you was what is your involvement in assisting children on the autistic spectrum?

Operations and Business Development Manager, Autism Jersey:

The last time I spoke to you was for the Respite Panel; I was the manager of everything. Since then, we have expanded hugely, so now I am developing new services for people with autism and supporting our staff who deliver those services, and I respond to tenders that come through your States portal for services for people with autism, if we deem that they are appropriate for us to provide them. Jo has taken over the role that I used to have in supporting families, so I would tend to be more concerned with supporting adults now, although I will come into supporting children if Jo asks me or if it is a case that I historically have relationships with.

Deputy J.A. Hilton:

So, Jo, you are involved in supporting children and their families that come to Autism Jersey?

Family Support Officer, Autism Jersey:

Yes, definitely. We look holistically at how we support, so we look at the family as a whole, particularly looking at sibling support as well. Normally, I am the first sort of point of contact for any new families coming into the world of autism, so part of my role will be to signpost any other agencies that need to be involved, for example C.A.M.H.S., and obviously work with schools and the families to make sure we are giving the correct support.

Deputy J.A. Hilton:

How do people normally come to you? Are they referred by other agencies after a diagnosis, or ...?

Family Support Officer, Autism Jersey:

Yes, sometimes they will have gone through the C.A.M.H.S. system and they will be told to contact us, other times it will be word of mouth, or they will literally Google “Autism Jersey” and they will find us that way and come to us for advice.

Deputy J.A. Hilton:

Yes. Do you find that most of the children and young people who are referred to you come with a diagnosis?

Family Support Officer, Autism Jersey:

No. I would say most of the families that contact us are pre-diagnosis and just looking for what on earth to do.

Deputy J.A. Hilton:

Oh, right, okay. I am just trying to get an idea of numbers. Would the majority who contact you pre-diagnosis already be in the system, type of thing?

Family Support Officer, Autism Jersey:

No, not all of them. No. Some of them will have only just got the idea that autism might be an issue so they are really looking for advice. Others have already done a lot of research and are pretty sure their child has autism and want to know what to do and where to go.

The Deputy of St. Ouen:

How do you handle that sort of situation where the parent is looking for a diagnosis?

Family Support Officer, Autism Jersey:

Well, obviously, at Autism Jersey we cannot give a diagnosis, which I think a lot of people think we can because we know a lot about it. Obviously, they have got to go through the correct channels. So normally by the time parents have contacted us they are pretty worried and pretty concerned about what is happening in their family home, so delicately would be the way I handle it. It is really just assuring them that there is help and support out there and how to go about accessing it.

The Deputy of St. Ouen:

Are you talking about signposting?

Family Support Officer, Autism Jersey:

Yes.

The Deputy of St. Ouen:

But if individuals have been referred to you because for various reasons a diagnosis has not been given and the parent is looking for a diagnosis, who do you signpost them to to get them that advice and support?

Family Support Officer, Autism Jersey:

Well, the only place for diagnosis for young people is C.A.M.H.S., so they would be referred to C.A.M.H.S. I would normally say for the school to refer them to C.A.M.H.S. or for their G.P. (general practitioner).

The Deputy of St. Ouen:

Again, just talk me through what happens in practice. C.A.M.H.S. may refer parents to you because the parent is looking for a diagnosis?

Family Support Officer, Autism Jersey:

No. If they have gone through the C.A.M.H.S. process and have a diagnosis or do not have a diagnosis, C.A.M.H.S. may refer them to us for additional support and help. If they do not have a diagnosis and we are their first port of call, then we would suggest that they then go on to get a referral to C.A.M.H.S. Does that make sense?

The Deputy of St. Ouen:

I am just a little bit worried that it could be a continuous circle, could it not?

Family Support Officer, Autism Jersey:

I think, as no doubt we will discuss later on, the limitations within C.A.M.H.S. services and what they can offer is why they often tell families to get back in touch with us, because of the support that we can give them that often is not available through C.A.M.H.S.

Deputy J.A. Hilton:

So in your experience when you have parents, families coming to you pre-diagnosis and you suggest to them that they get referrals to C.A.M.H.S. through either school or their G.P.s, what sort of length of time is normally involved with families that you have dealt with before that happens?

Family Support Officer, Autism Jersey:

It is normally quite a lengthy process. Quite often by the time parents come to us they are at breaking point because they have tried to cope the best they can up until the point they think: "We

do need some help here.” So I am not sure how long the initial contact is from the date the referral is received into C.A.M.H.S., it varies, but from feedback from parents, it is too long, is the bottom line, I think. The message we get is that: “We wait months and months and months for that initial consultation.”

Deputy J.A. Hilton:

For the initial consultation?

Family Support Officer, Autism Jersey:

Yes.

Operations and Business Development Manager, Autism Jersey:

We must not get mixed up with C.A.M.H.S. and T.A.A.S.C. (Team for Assessment of Autism and Social Communication) because it is T.A.A.S.C. that do the diagnosis and C.A.M.H.S. are just one part of the T.A.A.S.C. team.

Deputy J.A. Hilton:

So the T.A.A.S.C. team is under C.A.M.H.S. umbrella, though?

Operations and Business Development Manager, Autism Jersey:

No. It is a multidisciplinary team, N.I.C.E. (National Institute for Health and Care Excellence) guidelines for the diagnosis of autism is that it should be a multidisciplinary team, so called into that team are whoever is appropriate. So it could be the educational psychologist, it could be speech and language therapy, it could be one of the consultants from the hospital, it could be an occupational therapist; it depends on the other things that happen. So all of those people do their own reports and come together as T.A.A.S.C. to then give the diagnosis, so it is a multidisciplinary team that gives the diagnosis.

Deputy J.A. Hilton:

It is the T.A.A.S.C. team that gives the diagnosis.

Operations and Business Development Manager, Autism Jersey:

The T.A.A.S.C. team gives the diagnosis, yes.

The Deputy of St. Ouen:

I hear what you are saying, but if you are an educationalist, you are not going to be able to give a mental diagnosis or ...

Operations and Business Development Manager, Autism Jersey:

No, the educational psychologist will look at the child in school and do a report on that and they will bring it to the meeting. If there are some medical things, the medical person will do their report on that and everybody will bring their reports and discuss them together to make a multidisciplinary diagnosis.

The Deputy of St. Ouen:

But if it is a mental health issue there must be, within that team, one individual who ultimately is the professional.

Operations and Business Development Manager, Autism Jersey:

I do not know the answer to that. I do know that a lot of the professionals doing this have to do this on the side of their desk, so they have got their normal job plus this. A personal opinion is that I think maybe that could be one of the reasons it takes so long, because they have to do it as well as doing their other job. I do not know that there is some administration dedicated to it, bringing everybody together. This is a personal opinion; I do not know if that is how ...

The Deputy of St. Ouen:

Just to get a feel of how many people Jersey Autism supports, are you able to provide us with any numbers on youngsters under the age of 18?

Operations and Business Development Manager, Autism Jersey:

No. The only thing that we can give you are the national statistics. It has come down to one in 80.

The Deputy of St. Ouen:

You do not hold any specific records with regards to how many clients you support, or ...?

Operations and Business Development Manager, Autism Jersey:

No. This is an issue that keeps coming up, because I know you need numbers to plan for the future, and things like that. When we have autism strategy meetings, the different States departments probably even get a lot of ... Education know about the numbers in school, Health maybe know about the numbers that get respite through them, so you just have to make approximations.

The Deputy of St. Ouen:

Are you able to gather that information?

Operations and Business Development Manager, Autism Jersey:

No. We cannot; it is all data protection and ...

The Deputy of St. Ouen:

No, sorry. Is it Jersey Autism's plan to start gathering the information about your clients and the number of your clients that you support?

Operations and Business Development Manager, Autism Jersey:

We are trying to get more information about what we do, but that is only on the things that we do, that is not ... Then you can get double numbers, can you not, because this family has been referred to C.A.M.H.S., the sibling comes to Jo's support work, the child with autism has one of our Befriending ... and the mum comes to the coffee morning support, so that is one family but 4 numbers. I am not good enough with Excel spreadsheets yet to work that out. **[Laughter]**

The Deputy of St. Ouen:

You spoke about some of the services, just briefly outline the services that Jersey Autism currently offer.

Operations and Business Development Manager, Autism Jersey:

We are sort of split into 2 now, and this has happened really as a result of the last Scrutiny Panel about respite things, so there are the things that we provide as the charity, so for that we have to go and look for the funding from One Foundation Lloyds TSB, the way charities ... So Jo, as our family support worker, is the biggest part of this and one of Jo's roles is to attract volunteers to help her deliver the services as well. Do you want to talk about that? It is better you telling it, then.

Family Support Officer, Autism Jersey:

Yes. It has all now come under the Family Support Programme. Originally it started with the Befriending scheme, which is volunteers that are trained as mentors and buddies. So with that scheme, we are at the moment providing service for about 37 individuals and families with that scheme. Also under the family parent programme we now offer drop-in sessions, coffee mornings, Linx, which is our sibling support group, which we managed to secure funding for. We run training, family seminars, parent-specific training, things like that. A lot of my job is to go out and meet families face-to-face and just give them some support, really, and advice. We have also got an online support network as well which we started. A lot of my work is just going out to the family home and looking at their living environment and how we can change it to make it more autism-

friendly, and strategies and how to help with challenging behaviours and the impact that the autism is having on the family, because it is not just the person with autism, it is everybody.

Operations and Business Development Manager, Autism Jersey:

Jo is just about to go to train with the National Autistic Society to be an early bird trainer, so she will be able to deliver a National Autistic Society family support programme in Jersey. Then we also run the adult social club twice a week, but we are aware that that club now needs to divide because it has got bigger, so there are different clientele. So we are about to do a second adult activity. So for all of those, we have to attract funding to enable that to happen. Then we have our short break services, which offer respite. We started off with the adults but now we are preferred provider with the children as well. That was looking at the alternative type of respite out in the community, in the family home, saying to the parents: "Well, what do you want? Where do you want it and what do you want us to do?" That has been quite successful. We do the Steps programme for Social Security, which is funded by Social Security to the penny; we bill them exactly what it costs. That is all sorts of life and social skills around employment, so somebody might be capable of doing a job but they are not capable of getting the transport to get there or knowing how to look after your presentation or interview skills, all of the grey things around employment. Then we have just got our first bits of tender for a 24/7 provision for a young man that is moving out of full-time care with the States, so we are just starting that one. We are gradually providing more and more.

Deputy J.A. Hilton:

You have really expanded your services in the last couple of years, it has really changed.

Operations and Business Development Manager, Autism Jersey:

Yes. When we came to you last time I think there was myself, Jo at the time, and the way that we are able to do this is we have quite a large bank of trained support workers; but, no, it is quite a large staff now.

[12:15]

The Deputy of St. Ouen:

Just one question around the Befriending scheme: you said there is a national statistic that identifies the percentage of individuals within a community that may have autistic tendencies. Seven families does not seem a lot.

Family Support Officer, Autism Jersey:

Thirty-seven.

The Deputy of St. Ouen:

Thirty-seven; that sounds better. [Laughter]

Operations and Business Development Manager, Autism Jersey:

We are limited by the amount of volunteers that you can get because it has to be an appropriate volunteer who can do our training and then can commit to at least a year volunteering.

The Deputy of St. Ouen:

Okay. So it is a resource-limited support service. Right, okay.

Family Support Officer, Autism Jersey:

With that service, because although they are trained, they are volunteers, so we will only support a very low level of need. A lot of the befrienders will be matched with brothers and sisters, which we find incredibly valuable because, as I say, autism affects the whole family, and brothers and sisters often have a bit of a raw deal, so by them having their own befriender it enables them to access things that they would not be able to access with their autistic sibling.

Operations and Business Development Manager, Autism Jersey:

Since the Respite Scrutiny Panel, Children's Services have done a 4-level of need, so if you are at level 2, you may access a certain type of support and I think level 4 is maybe the full-time care. So we now only offer the voluntary one to the people who do not qualify for respite. Historically, we were going into some families with quite severe problems for 2 reasons: one was that we had very capable volunteers, who now work for us they were so capable, but also we knew the crisis that family were at. So now that family should be getting access to respite.

The Deputy of St. Ouen:

Your experience to date, is it that they are?

Operations and Business Development Manager, Autism Jersey:

Yes. There was a pot of money made available straightaway, was there not, after your Scrutiny, so we did support some children using that pot, but the actual new way it is done is just coming online now.

Deputy J.A. Hilton:

Is that the new Health White Paper money?

Operations and Business Development Manager, Autism Jersey:

Yes. So now we are referring M.A.S.H. (Multi-Agency Safeguarding Hub) policy on to ... I know who she is, I do not know what her title is. She decides whether it goes to the panel, so that is just coming online now.

Deputy J.A. Hilton:

With regard to C.A.M.H.S., what sort of direct involvement do you have with C.A.M.H.S.? Is there much?

Family Support Officer, Autism Jersey:

There is more, purely because a lot of families now are asking me to attend meetings with them when they go to C.A.M.H.S. Obviously, if you are taking a child with any special need, but particularly autism, into a strange environment where they are going to be asked questions, it is a very emotional rollercoaster for the family. So obviously I know the families pretty well and have had quite a lot of contact with them, so when we are in the meetings, I can back them up on: "Oh, do you remember when you told me this?" kind of things, because otherwise they are going to forget things that they have reported to me that I have said: "Oh, you make sure you tell C.A.M.H.S. that when you go" kind of thing. So more and more support from me going into C.A.M.H.S. with them and decoding what they are being told as well.

Deputy J.A. Hilton:

Is that just general meetings or is it after diagnosis, or ...?

Family Support Officer, Autism Jersey:

Well, last week it was for the initial assessment. I have got one this week where it is the review meeting when all the professionals come together, all the T.A.A.S.C. team come together to give their findings to the family. Obviously, if you are there and you are just about to be told your child has got autism, they are going to need somebody there to support them. Because I think you battle so long to get through the C.A.M.H.S. system and then you are given the diagnosis, or not given the diagnosis, and then it stops and you presume that the support is going to continue, and it does not. So for a lot of our families their world falls apart a bit because they are told their child has autism and then off you go, kind of thing.

Deputy J.A. Hilton:

Is that generally at the point where C.A.M.H.S. encourage newly-diagnosed families to go to Autism Jersey? Is that what happens then?

Family Support Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

So generally speaking then, young people who are diagnosed with autism, in your experience, is that the end of their involvement with C.A.M.H.S., more or less, because it is something you have to learn how to live with?

Family Support Officer, Autism Jersey:

Yes, very much so. I think families will come to me and go: "Well, what are they going to do for us now?" and I normally have to say: "Very little." There might be involvement further down the line if there are more behavioural issues and we need to look at Applied Behaviour and what have you, but generally the services stop and their case is closed. So for families, they have just got this diagnosis, and that is really the beginning of their journey of a life of autism, and they seem to be just left in the dark a bit. So it is great they are being referred to us, because we can pick those pieces up and say: "Right, this is what we can do." I think one of the things that I do hear a lot from the families is that C.A.M.H.S. say that there should be certain services provided for them after the diagnosis: psychological support, counselling support and things, and then when I have asked the families: "Well, what have you got?" they have turned round and said; "Nothing." So it seems that C.A.M.H.S. are maybe advising that these things are going to be needed and then have not got the resources to provide the services they are recommending that they have.

Operations and Business Development Manager, Autism Jersey:

I have seen reports that Jo has seen from C.A.M.H.S. that said: "This person should have support, particularly at this time" but you have got to remember, though, that if the recommendation comes from T.A.A.S.C., it might be Education who should be providing that support or help. Not everything always falls at C.A.M.H.S. If it is a multidisciplinary group saying that the support should be there, then a multidisciplinary team should be providing.

Deputy J.A. Hilton:

So who supports the families in those scenarios where maybe it is Education, or something, that there is a recommendation for something to happen and it does not? Who generally would support the family in those circumstances?

Family Support Officer, Autism Jersey:

We do.

Deputy J.A. Hilton:

Generally speaking, do you find that you have success in obtaining the help and support that your clients ...?

Family Support Officer, Autism Jersey:

Mixed, I guess. If something has been recommended, then we can chase it up. I do not think we have any more clout than anybody else does when it comes to getting the services provided. A lot of people do end up looking for private counselling or psychotherapy and things like that, because there is just not the availability through the health system here.

Deputy J.A. Hilton:

In your experience, people might be told, families might be told: "You would benefit from a level of counselling" but, in reality, there is not any, or very little.

Family Support Officer, Autism Jersey:

Very little. I did have one family that were in major, major crisis and throughout the battle eventually they did have some family therapy, but it had to get to the point where the child was removed from the home and put into foster care before their needs were met. This is historically what has happened: that people have had to get to that point before anyone will listen. So rather than being proactive, we are reactive all the time, picking up the pieces.

Deputy J.A. Hilton:

That must be very frustrating for you both as an organisation out there to support families, to see that sort of thing developing and, as you said, reaching a crisis point before anything happens.

Family Support Officer, Autism Jersey:

It is very frustrating and I think because we kind of know what the system is like, we can talk them through it and say: "Look, the chances are this is going to take this amount of time" or whatever: "We will put in what support we can. We will put befrienders in when we can to just relieve some of the pressure that is building." Obviously, I will go in and support Mum and Dad as much as possible.

Operations and Business Development Manager, Autism Jersey:

A big step is that we can refer you to M.A.S.H. now; historically a voluntary organisation could not do things like that, so that is a positive step forward so if we think we are supporting a family that needs respite, or something, we can put that referral in. It does not mean it will work, but at least it bypasses having to refer to somebody else to do it.

The Deputy of St. Ouen:

Can you just talk us through the advice that you give to parents that are coming to you with a child that is obviously displaying certain issues that may or may not be autistic? You spoke about signposting; just talk us through what you do and where you point them to.

Family Support Officer, Autism Jersey:

I would get, obviously, a full history of what sort of behaviours the child was displaying and the impact it was having on the family. Often there will be reports from school as well that they have been to parents' evening and teachers have said this, that and the other. So my question would always be: "Have the school done anything about it?" Unfortunately, 9 times out of 10 no, they have not. The first thing I would always advise anyone to do is to start keeping a diary, videoing any challenging behaviours, because the thing with the T.A.A.S.C. team is they will all assess in different ways but, as far as I am aware, none of them will assess the child at home. They will look at them at school and in different environments but quite often the behaviours are kept inside of school and when they get home is when the young people explode. So, yes, keeping diaries, taking videos wherever possible as proof, really, so when we do go into C.A.M.H.S. or their G.P., or whatever, they can say: "Look, this is what my child is doing and this is what we have done to try and counteract these behaviours." We will look at strategies on how to help them cope with regard to routines, with regard to hanging their coat up in the same place every day, and all these food fetishes and fads and what-have-you. So we will look at all of those kind of autism characteristics and how we can help them to cope with them and, as I say, the impact it has on the other children about not turning the telly over or having the volume on 20 and no more, no less, and all those kind of things. That would be my first interview with them, but normally they would come into the office and it would just be Mum and we would sit and have a long chat. Then I would arrange to go out and meet the family and see them in their home environment, see them as a whole, look at the child for myself. They will say: "Has he got autism?" that is normally the big question, or: "Do you think he has? Is it me being crazy, or is there something there?" Obviously, I cannot at any point say: "Yes, I think he has" "No, he has not, definitely" or whatever, but you kind of get a gut reaction when you are used to seeing it. So I would say: "Look, I think it would be worth you speaking to your G.P. or your E.N.Co (educational needs co-ordinator) at the school and seeing if they have noticed anything or if they would refer you through." By that point, the

parents are normally pretty sure there is something; it may well not be autism, it may be A.D.H.D. (attention deficit hyperactivity disorder) or any of the other co-morbid things. They would then look at going through into the referral process, and throughout that time they will be contacting me asking for support. We try and get them on to the S.P.E.L.L. (Structure, Positive, Empathy, Low arousal, Links) training as soon as possible. We run those very regularly, which is the N.A.S. (National Autistic Society) training framework. We get them on there as soon as possible so that they can start getting answers to why these behaviours are occurring. It is sometimes like a bit of a light-bulb moment, and they realise: "Oh, if I just do not put the cutlery down there [or whatever it might be] we can stop this meltdown." Sometimes very simple strategies that they just do not know about will make a profound difference in the way they live, and that will keep getting them through. As I say, support for the brothers and sisters is incredibly important, so they are invited along to our Linx sibling support group, our parent drop-ins and our parent coffee mornings as well. Just hearing other parents, some without their child ever having a formal diagnosis, but we will still support them, and they will just sit there and go: "God, yeah, my child does that" and: "What do you do if he does this?" and just having that support network around them is incredibly important because a lot of our families become incredibly isolated because they just cannot leave the house due to their child's behaviours and the judgment made by others.

The Deputy of St. Ouen:

Just to recap, when the parent first comes to you with a problem, obviously you look at the problems; you do not carry out some form of analysis.

Family Support Officer, Autism Jersey:

Yes.

The Deputy of St. Ouen:

Then, dependent on what you see, you will suggest that they go and talk to either the school or G.P. or C.A.M.H.S., is that what you are saying?

[12:30]

Family Support Officer, Autism Jersey:

Yes. Normally, it is easiest to go through school, unless they see their G.P. regularly. Obviously, school spend an awful of time with children so it is quite easy to go through that route and get the school to refer and they will refer it to the educational psychologist straightaway, and then they will assess and then put them through to the T.A.A.S.C. team if they think it is necessary.

The Deputy of St. Ouen:

Okay, great. So, right, that has happened and through the referral route they have gone to a school, school has then referred them to C.A.M.H.S ...

Operations and Business Development Manager, Autism Jersey:

No, to T.A.A.S.C. T.A.A.S.C. is a multidisciplinary ...

The Deputy of St. Ouen:

T.A.A.S.C. is what? What does it stand for?

Operations and Business Development Manager, Autism Jersey:

Do you know, I have no idea what it stands for.

Family Support Officer, Autism Jersey:

I cannot remember.

Deputy J.A. Hilton:

Here we go, it stands for Team for the Assessment of Autism and Social Communication.

The Deputy of St. Ouen:

Right. Okay, thank you very much.

Operations and Business Development Manager, Autism Jersey:

Well done.

The Deputy of St. Ouen:

So they have been to that group, then that group will make another referral ...

Family Support Officer, Autism Jersey:

No, they will assess.

Operations and Business Development Manager, Autism Jersey:

But from the first referral to that assessment could be 2 years.

The Deputy of St. Ouen:

Two years?

Operations and Business Development Manager, Autism Jersey:

Yes. Last year they shut the waiting list for the waiting list. Basically, they shut the waiting list so there was a waiting list to get on to the shut waiting list.

The Deputy of St. Ouen:

Okay, so 2 years is up, they then move on and they are assessed, then after the assessment, what happens next?

Family Support Officer, Autism Jersey:

They will get the diagnosis or not get the diagnosis, depending on the findings, and that will be through C.A.M.H.S. but it will be part of the T.A.A.S.C. team.

The Deputy of St. Ouen:

But it is C.A.M.H.S. ultimate responsibility to diagnose, is it?

Family Support Officer, Autism Jersey:

No. It is the T.A.A.S.C. team and C.A.M.H.S. is part of that team.

The Deputy of St. Ouen:

If I am looking for someone to hold accountable ...

Operations and Business Development Manager, Autism Jersey:

I think it depends on what has been recommended. So if they recommend that you need specialist placement at one of the provisions at Education, that is not C.A.M.H.S., that is Education should be doing that. If it recommends that you have speech and language therapy support then it should be that department. If it recommends that you need psychiatric or medical help, I believe that would be C.A.M.H.S.

Family Support Officer, Autism Jersey:

I do not know who you would hold accountable, I do not think there is any one person.

Operations and Business Development Manager, Autism Jersey:

This is the other thing: I do not know how we know that is true; there is not a transparent list ...

The Deputy of St. Ouen:

All right, so I am given the assessment.

Family Support Officer, Autism Jersey:

No, they can ask for the assessment at the end.

Operations and Business Development Manager, Autism Jersey:

We are telling you the way we think it happens, so ...

The Deputy of St. Ouen:

No, I understand. It would be useful perhaps for us to see a report of the assessment carried out and whether or not they identify a particular body or department to provide the support, let us say, for a child ...

Family Support Officer, Autism Jersey:

As Heather said, I think it depends on where. Because what happens, all the individuals will do their individual reports, so there is lots of different input, which is really important that one person does not assess the young person. So you have got this multiagency, so they all do their reports and they are brought together at a review meeting where they will discuss their findings and decide whether they have a sensory processing disorder, whether they have autism or whatever it might be. Then, as Heather said, depending on where the problem or issue is more predominant, then that agency ...

Family Support Officer, Autism Jersey:

Yes. But I do not know who takes on the responsibility for writing the report from that task, really. I do not know who that is, but that report should then signpost the way forward. Now, you have seen some of those reports, have you not?

Deputy J.A. Hilton:

Yes.

Family Support Officer, Autism Jersey:

You have also got to remember that it could be from 3 to 18 years, so the support you need to give a family of a 3 year-old is very different to the support that is needed for a family of a 16 year-old, so it is a bit of a minefield.

Deputy J.A. Hilton:

It seems like an incredibly long wait to get some form of assessment.

Family Support Officer, Autism Jersey:

Especially when you are living with the challenges of this and you are waiting and waiting and waiting for appointments. Then often someone will go into the school and assess your child and the teacher may say: "Oh, so-and-so came in" and you would not be aware that they were going in. Certainly, I have heard of a young man coming home saying: "There was a woman sitting in the back of my classroom writing notes. She was not meant to be looking at me, but she was." The parents are not aware when these assessments take place because, as Heather said, as far as we are aware, they are doing it off the side of their desks, so they are fitting it in when they can, which is obviously what takes so much time then to get all these different individuals to do these individual assessments and then find the time that they can all come together and discuss their findings.

Deputy J.A. Hilton:

Well, we were aware that that waiting list was closed last year because of the weight of sheer numbers, which is very disturbing, to be honest, because some of these families, as you said, are living through this day-to-day. One wonders how on earth they manage. Have you any evidence with the families that you have been dealing with over a period of time of the negative impact that it is having on families?

Family Support Officer, Autism Jersey:

I am well aware a few have gone off-Island to get diagnosis, Great Ormond Street they have been to, and they have got a diagnosis within 2 days.

Deputy J.A. Hilton:

What, because they have just given up waiting, the wait has just been so incredibly long?

Family Support Officer, Autism Jersey:

Yes.

Operations and Business Development Manager, Autism Jersey:

Or it is another way: that child had something else that they had to go through Great Ormond Street for, so they were able to say while they were there.

Deputy J.A. Hilton:

Yes. In circumstances where families go away for a diagnosis, which may not be on the autistic spectrum, in your experience, when they come back with a diagnosis, does that help them fast-track the help and support that they need?

Family Support Officer, Autism Jersey:

No. It misses out the whole T.A.A.S.C. thing ...

Deputy J.A. Hilton:

Which can save you 2 years.

Family Support Officer, Autism Jersey:

Yes. But then, historically, it seems to have been a little frowned upon if you were not diagnosed in Jersey, then: "Well, we are not sure if that diagnosis is correct so we will have to do our own thing." I think that has changed now and they are taking diagnoses from elsewhere, because I probably get maybe one or 2 phone calls a week asking if there is anyone that can diagnose privately on the Island.

Operations and Business Development Manager, Autism Jersey:

But the way T.A.A.S.C. diagnose is the correct way, they follow N.I.C.E. guidelines, so the way it is eventually done is the gold standard, it is the correct way.

Deputy J.A. Hilton:

It is the correct way, yes, but it is just an unacceptable delay; no family should have to wait for that ...

Operations and Business Development Manager, Autism Jersey:

Yes. The other thing is the lack of support in those 2 years.

Deputy J.A. Hilton:

In the meanwhile, yes.

Family Support Officer, Autism Jersey:

There is not. They may be sent a letter saying: "Your appointment is ..." someone got one the other day for November, so ...

Deputy J.A. Hilton:

November 2014?

Family Support Officer, Autism Jersey:

Yes. What happens till then? Absolutely nothing.

Deputy J.A. Hilton:

I was going to ask you that: so in the meanwhile, do they receive any support from any of the agencies?

Family Support Officer, Autism Jersey:

Only us.

Deputy J.A. Hilton:

So the only support they receive is on condition that they have got a diagnosis, basically, or if they have been seen by the T.A.A.S.C. team, would it be fair to say that?

Family Support Officer, Autism Jersey:

Yes, and even then they do not always get the support that they need.

The Deputy of St. Ouen:

Is that even once they have had a diagnosis?

Family Support Officer, Autism Jersey:

Yes.

Deputy J.A. Hilton:

Is it just down to resources; is that it, there is a lack of resources?

Family Support Officer, Autism Jersey:

Yes. There is a lack.

Operations and Business Development Manager, Autism Jersey:

It is not a lack of skill or anything else.

Family Support Officer, Autism Jersey:

No, it is a lack of resources. I think it is very difficult that when you are living with autism you are in this cocoon and you just need something done now, and 6 months down the line is no good. When you ring up one family that was in crisis, they were absolutely desperate for help, to the point that they said: "Right, we will drop our son off at the police station and you deal with him" because there was no one or nothing to support them. Certainly, after 5.00 p.m. in the evening, you are stuffed, or weekends.

Deputy J.A. Hilton:

Yes. We were aware that there is no out-of-hours service, as such, but that they use the adult psychiatric team, I believe, over the weekend.

Family Support Officer, Autism Jersey:

Well, that is what I had heard but, in practice, I am not sure it happens. There was one instance of a 16 year-old young man taken to A. & E. (Accident and Emergency) at 3.00 a.m. for psychiatric assessment, was told nobody was available and for his safety he was put in the cells at Rouge.

Deputy J.A. Hilton:

Really? Is that recently, is it?

Family Support Officer, Autism Jersey:

Yes.

The Deputy of St. Ouen:

I just want to continue to explore the signposting and look at trying to pick out the different examples, and Jackie might be able to pitch in if I miss one out. But, right, once the young person has been diagnosed after going through the whole system obviously, as you rightly say, it does not end there because then that means, okay, now we know what the problem is, we now should aim to provide the support to that individual. So where would you signpost the parent to go and look?

Operations and Business Development Manager, Autism Jersey:

It does not mean you get support because you have got a diagnosis. We referred a family, or Jo referred a family for children's respite and the answer came back no, because at school there can be 2 children to one support worker but at home the family dynamics are an entirely different thing.

The Deputy of St. Ouen:

So even though you receive a diagnosis, there is no support.

Operations and Business Development Manager, Autism Jersey:

You do not necessarily get a place in education.

The Deputy of St. Ouen:

Let us just explore the other angle: right, you have had your assessment and they have said: "No, it is just a behavioural issue. It is not autism, it is not A.D.H.D." Where do you point them to then?

Family Support Officer, Autism Jersey:

I think if they have a lot of autistic characteristics, we will continue to support them as best we can in helping them with strategies, because if you can support the autistic characteristics then you will diffuse a lot of the other behavioural issues, so that will help. There is also the Applied Behaviour Analysis team and Positive Support team which ...

Operations and Business Development Manager, Autism Jersey:

You have to have a diagnosis for Positive Behaviour support.

Family Support Officer, Autism Jersey:

Through the States, but you can pay for them privately.

Operations and Business Development Manager, Autism Jersey:

Yes.

Family Support Officer, Autism Jersey:

But that, again, is another lovely waiting list to be put on.

Deputy J.A. Hilton:

That is the Positive Support Group?

Operations and Business Development Manager, Autism Jersey:

Positive Behaviour Support. Health fund those posts.

The Deputy of St. Ouen:

What is going through my mind is that it is clear to see that Jersey Autism has sought to try and provide an element of support that clearly was not there before. I am just sitting here thinking: that is great if I have got a child with autistic tendencies, but what if my child does not fit into the category?

Operations and Business Development Manager, Autism Jersey:

This is a problem that we are now getting: we are getting phone calls from families of children with other disabilities for whom there is nothing set up for that disability, could their siblings come to our sibling group. We are having to be very strict and say: "No, we are keeping to autism" because if we start putting in our volunteers ...

Family Support Officer, Autism Jersey:

It opens the flood gates, then.

Operations and Business Development Manager, Autism Jersey:

Yes, it opens the flood gates but then it diminishes what we can do for people with autism because all of this that we are talking about is still done as our charity arm, so that is why we are rattling the buckets and doing all of this. All of those things are funded free.

The Deputy of St. Ouen:

So it is a case of even for those youngsters with autism, they do not necessarily get the support that they should be getting and there is another group of people out there who get none at all.

Operations and Business Development Manager, Autism Jersey:

That have less. Yes.

Deputy J.A. Hilton:

Is the evidence there to support the fact that there are families who are just not receiving ...

Operations and Business Development Manager, Autism Jersey:

I do not know, I just ...

Family Support Officer, Autism Jersey:

In the last week I have had a couple of phone calls asking if parents of non-autistic children could come to our parent drop-in because, obviously, if there are any learning disabilities or any form of disability, they do overlap a lot but as Heather says we are having to say no because we do not have the time and resources to take on everybody else. Certainly, there is obviously service lacking with regard to supporting brothers and sisters, because I have had inquiries about other children coming to Linx.

[12:45]

The whole point of that project is it is children affected by autism, so they can sit and they can support each other and talk about what it is like to live with it. So we cannot have other people in there, because it would diminish what we are doing, and that is all about the young people sitting there talking about their brothers breaking into their bedrooms, or whatever it might be.

The Deputy of St. Ouen:

I would just like to talk a little bit about resources and funding. Currently, do you receive any funding from the States?

Operations and Business Development Manager, Autism Jersey:

Only for services we provide, so that is the tender for the residential provision that we have taken on, that we can ...

Deputy J.A. Hilton:

The respite?

Operations and Business Development Manager, Autism Jersey:

No, this is 24/7. So that was an open tender that anybody could apply for. The life and social skills money which comes from Social Security just pays exactly what it costs. Then we provide respite for adults and for children, which is purchased by Health and Social Services; that is a set rate. But we have no funding, like: "Here is £15,000 to help you put on these parenting support groups" and things like that.

Deputy J.A. Hilton:

That is all financed through charitable donations, is it not?

Operations and Business Development Manager, Autism Jersey:

Yes.

The Deputy of St. Ouen:

Do you have discussions with the Health Department about some of the needs that obviously you are aware of and how to deal with them and provide the support necessary?

Operations and Business Development Manager, Autism Jersey:

We work very closely with Assumpta Finn in Adults, who have the lead for autism, and Richard Mills is the adviser for autism for Health and Social Services, so he comes over to the Island about once every 6 or 7 weeks.

The Deputy of St. Ouen:

For adults?

Operations and Business Development Manager, Autism Jersey:

He advises for Health, so it must be the whole range.

The Deputy of St. Ouen:

It would be children as well. Okay.

Operations and Business Development Manager, Autism Jersey:

There is the Autism Strategy Group that is trying to work together to put in place services for the future, but we do not sit down ... Often, when you are in discussions about certain cases, you will identify a need for that case, and then you look at the bigger picture and there is a bigger need. Just last week, we were talking about sex, but there is a huge need for specialist sexual knowledge for people with a learning disability and severe autism, so that may be something that we and Health do together. We have just been talking about things like that and we have worked to bring people over in conjunction with Health. We put on a conference in December all around personalisation; that was a joint day that we put on at the Pomme D'Or Hotel with Health. So we are trying to work proactively with them and we do have a very good relationship with Assumpta Finn to try and do ...

The Deputy of St. Ouen:

But when it comes down to what I call some of the basic needs that we spoke about earlier and the fact that parents need ... I mean, presumably you have spoken about these matters to the Health Department in the past. Would you have communicated that to them or ...?

Operations and Business Development Manager, Autism Jersey:

Some of them but a lot of them, like this training course that Jo is just going to go on with the National Autistic Society training, that was in conversation with Education, the Bridge, us and Health that there was this gap for this family support, but nobody had any funding to do it. So we as a charity were able to go to Jersey Child, who have given us some money to train 2 trainers in it. But this is what we are always telling the professional departments: "Sometimes if you have not got the money to do something, we as a charity might be able to go elsewhere and do things."

The Deputy of St. Ouen:

Training is one thing, and I applaud you for encouraging that, but parents are looking for action. After the training, should one expect to see some action or is it just ...

Family Support Officer, Autism Jersey:

There will be, there will be a 3-month intense parenting programme put on at least once a year after this.

The Deputy of St. Ouen:

Which will be maintained year-on-year?

Family Support Officer, Autism Jersey:

Hopefully.

Operations and Business Development Manager, Autism Jersey:

Hopefully. Again, that is out of our charitable funding.

Family Support Officer, Autism Jersey:

Every part of the parent support programme, we have to find the money to do it, so that is me standing outside Marks & Spencer shaking buckets; it does come down to all the summer fetes, all those kind of things, as well as the Lloyds TSB One Foundation, and stuff like that. So we are constantly having to find the money.

The Deputy of St. Ouen:

Do you get frustrated? You are aware of the need, as much as presumably the Health Department is of these parents, and yet the funding or the support is not provided.

Family Support Officer, Autism Jersey:

Of course we do. I do not think there are many charities that would not say that.

Operations and Business Development Manager, Autism Jersey:

Every charity will sit here and tell you what is lacking in the needs that they have.

The Deputy of St. Ouen:

I understand, but perhaps the difference is that in this particular case we have also parents doing the same, and I just try and understand why some of these basic needs have not been met.

Operations and Business Development Manager, Autism Jersey:

Another thing that drives me bonkers is that it is children and adult; autism is a life-long disability and C.A.M.H.S. is only children, is it not, and then they have to go on to the adult ... but you put in

place, even with the 2 respite things, where all the money is from the same pot at Health, but it has to stop when they are 18 and go to ...

The Deputy of St. Ouen:

Jackie was going to ask it but I will do it for you: can you just talk us through some of the challenges around that transition period from children to adult, in your experience?

Operations and Business Development Manager, Autism Jersey:

The family get used to a whole set of people, so the social worker or your family support worker, and then you get to 16 and then you have to do this transition through the transition worker into adult services. It is just that you have got this really good rapport and relationship where people know how it works and then you have to teach somebody else the whole thing. It is the same department.

Deputy J.A. Hilton:

How would you like to see it changed?

Operations and Business Development Manager, Autism Jersey:

Life-long.

Family Support Officer, Autism Jersey:

Get issued a case worker or a key worker day one and keep them, especially for autism because of the way you need to build a relationship.

Deputy J.A. Hilton:

It is really important for people on the autistic spectrum, is it not, that there is consistency?

Family Support Officer, Autism Jersey:

And that continuity. Also for parents. I have sat in review meetings round a table with 20 other professionals all talking about a child; half of them have never met that child before, but they have got the file, so therefore ... Poor old Mum and Dad are sitting there: "But he does not do that" or whatever. So, for parents to know that they have got one person, one point of contact, I think that is important, the point of contact that they can ring and say: "Where do we go? What do we do?"

Deputy J.A. Hilton:

Just one person to take responsibility.

Operations and Business Development Manager, Autism Jersey:

That is one of the things that comes back, that you phone in and leave a message and no one ever gets back to you.

Family Support Officer, Autism Jersey:

Yes. They do not follow up, or they say they will put things in the post, they will post a report, and it never happens. When people, families ask me, I just say: "Keep ringing, just ring every day" because otherwise things just do not get done.

Deputy J.A. Hilton:

But they should not have to do that, though, should they?

Family Support Officer, Autism Jersey:

No. If they are told that their report or their diagnosis, or whatever, is going to be in the post, it should be in the post that day. People have been waiting for weeks and weeks and just not received them.

The Deputy of St. Ouen:

We have recently been told by the Minister for Health and Social Services that a lot of these youngsters are provided with individual care packages. Have you noticed that to be the case?

Operations and Business Development Manager, Autism Jersey:

That is the one I was just talking about, the 24/7 case that we just got. This is one of the new individual care packages and it is sort of trailblazing, so it is a very positive step but, as in all trailblazing, there have been problems along the way that have to be ironed out, but once we have ironed it out with this case then the next case that comes along should run smoothly.

Deputy J.A. Hilton:

So this is a new process that Health are going to adopt, then? There is a tender process for an organisation such as yourself to provide that service?

Operations and Business Development Manager, Autism Jersey:

These individual care programmes are not purely for autism. The conference that we had in December is around personalisation, so it is trying to move away from the old group. I mean, years ago you had St. Saviour's Hospital and then it was a big step forward into group homes, but now group homes are not that great. So the next step is around the needs of this person. It may be that this person always needs to live with 3 other people, but a lot of people should be in their

own appropriate home with the appropriate care put around them. So those are the packages that they are talking about. It is not just autism, it could be somebody with physical needs, it could be somebody with a learning disability.

Family Support Officer, Autism Jersey:

These individual packages can range from a couple of hours a week to fulltime, so it might be misleading when they say: "We are supporting X number of people with individual care packages" when that might only be 2 hours a week.

Operations and Business Development Manager, Autism Jersey:

Yes. That is that one, but we do 2 others in the community and one guy was put into his own bedsit in States housing and we started off 14 hours a week supporting him and it went down to 4 hours a week. So it shows that it is a good cost exercise. Yes, it was that much to start with but once he was taught how to live in his home and the different life skills that he needed, the support needed ...

Deputy J.A. Hilton:

Could tail off.

The Deputy of St. Ouen:

Coming back to the point made about transition, if every individual was provided with an individual care programme, then I would expect that perhaps the issues around moving from child to adult would be more seamless.

Family Support Officer, Autism Jersey:

If they had the same sort of staff, yes. But I think at the moment what happens, they have got children's services and they have got adult services so as soon as you hit 16 to 18 it stops and your whole thing changes. What we need is a life-long service that goes right the way through.

Operations and Business Development Manager, Autism Jersey:

Yes. So the 24/7 package is for somebody who is in children's service getting towards the end of it. This package has been put in place so we will be going to his home for life, no matter who is providing the support. We have a contract with the States of Jersey to provide that support but, if for some reason we were not providing it properly, then we can be removed from that and another appropriate support can be put in, but his home is secure. But at the moment he has a children's service social worker, he has representatives from school, his parents, the current placement in Health and ourselves at the meeting, plus the adult social worker because he is 17 now. When he

becomes 18, the children's social worker will have to step away, who has been supporting him for probably 11 years and knows him very well. So, at the moment, we have a child social worker and an adult social worker attending the meeting so that the adult social worker can get in.

The Deputy of St. Ouen:

If we are looking for the best model of support, care available, where would we look?

Family Support Officer, Autism Jersey:

Us.

The Deputy of St. Ouen:

No. U.K., Sweden, Norway, which country?

Operations and Business Development Manager, Autism Jersey:

No, you mean where to go to. It depends. There are bits of excellence all over the place, but it also changes. Autism is such a diverse thing: you have got your very high-functioning leaders of international I.T. (information technology) corporations, right down to somebody with no language and no communication. So you need to go all over; it depends what you are looking for, really.

[13:00]

Family Support Officer, Autism Jersey:

The support has to be as diverse as the condition, does it not, and the goal posts move constantly so you have got to think outside the box and you have got to change with your client.

Deputy J.A. Hilton:

I have just asked you what else you think we could do to improve the services for children and young people either with autism or with mental health issues. We have talked about diagnosis and the length of time, which is unacceptable. What else do you ...?

Operations and Business Development Manager, Autism Jersey:

They need support while they are going through the process and support at the end of the process because often you get the diagnosis and think: "Great" and there is nothing. And, like I said before, I think the people doing the role are quite good at it and the model that they have chosen is nice guidelines and stuff, but if it is on the side of your desk, then we are never going to get these waiting list times down. So I do not know, does it need a separate diagnosis team? It would not need to be a fulltime team but is one day a week ...?

Family Support Officer, Autism Jersey:

I think it comes down to resources: more people, more time is certainly needed around the C.A.M.H.S. area. The whole mental health around young people is a can of worms. There needs to be a lot more support. I know, YES project were in earlier and I know they have probably been earning their money in the recent months. It is brilliant that that service is there, but should it come under the youth service umbrella or just counselling that these young people need with what they are going through in society? Does that need to be more a focus under Health's umbrella rather than under the youth service umbrella? I am not belittling what YES project do at all, because they are absolutely fantastic but, again, they have got a finite amount of resources and mental health as a whole we are fully aware, certainly in Jersey over the last few months, what has been highlighted and the need for it is desperate. For the parents of those teenagers, it is desperate. When they are battling with a young person with mental health issues, they need support as well.

Operations and Business Development Manager, Autism Jersey:

It is the whole family needs support, and that is not just autism, that is everything, and it is often focused on the person with the disability, but you just forget how that impacts on the life of everybody.

Family Support Officer, Autism Jersey:

Again, one family in mind, an issue with mental health in the family, and the police have said yes, the social worker will pick up the brother within the week at school. This was December and the social worker still has not made contact with this young person. I think a family's "urgent" is different to the services they require as urgent when an urgent appointment at C.A.M.H.S. is a week away.

Operations and Business Development Manager, Autism Jersey:

And I suppose is there accountability? Besides, you know, you can come in and ...?

The Deputy of St. Ouen:

That is one of the areas we are looking at. I think it has been extremely useful.

Deputy J.A. Hilton:

It has been very interesting, very informative. Thank you.

The Deputy of St. Ouen:

Thank you for coming in and sharing some of your experiences with us.

Operations and Business Development Manager, Autism Jersey:

Okay. Thank you very much.

Deputy J.A. Hilton:

Thank you very much indeed. I close the meeting. Thank you.

[13:04]