

STATES OF JERSEY

Health, Social Security and Housing Scrutiny Panel Respite Care Review

Session 1

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

Witness:

Ms. G. Waters

Present:

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

[10:30]

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

Thank you very much for coming in to speak to us this morning. I just have to deal with some housekeeping issues, if I can locate them. Thank you to the public for attending and showing an interest in this review. I would like to just draw everyone's attention to the code of behaviour for members of the public, it is displayed on the wall and in particular the following points, all electronic devices including mobile phones should be switched to silent. The taking of digital images or audio recordings by the public will not be permitted. If you wish to eat or drink please leave the room. Finally, I would also ask that members of the public do not interfere in the proceedings and as soon as the hearing is closed, please will they leave quietly. Members and witnesses may wish to make themselves available afterwards but any communication should take place outside the building. So, just for the record as well, we will all introduce ourselves. My name is Kristina Moore, I am the Chairman of the Panel.

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

I am Deputy Jackie Hilton. I am Vice-Chairman.

Mr. S. Jones (Adviser):

I am Sion Jones. I am here to advise the panel on the review.

Deputy J.G. Reed of St. Ouen:

Deputy James Reed, panel member.

Ms. F. Carnegie (Scrutiny Officer):

Fiona Carnegie, Scrutiny Officer.

Ms. K. Boydens (Scrutiny Officer):

Kellie Boydens, Scrutiny Officer.

Ms. G. Waters:

I am Gay Waters, I am a retired head teacher of a residential school in the U.K. (United Kingdom) between the years 2000 and 2008. The school was for challenging behaviour and severe autism. So autism really is my expertise area and that is really where I am pitching the talk today really because I appreciate there is Oakwell with the P.M.L.D. (Profound and Multiple Learning Disabilities) children as well.

The Deputy of St. Peter:

We are really grateful to have your expertise and to hear your point of view. You also have worked, I think, in a number of establishments in Jersey as well.

Ms. G. Waters:

I was a teacher at Mont à l'Abbé School and we identified 4 young people to transfer to start up the communication provisions at Rouge Bouillon School and then on to Grainville School. Then I had oversight as Co-ordinator for Autism Services on the Island up until 2000, and that is when I left the Island. That has grown again, as you know, to St. Saviour's School and to Haute Vallee.

The Deputy of St. Peter:

Why have the numbers grown in your view?

Ms. G. Waters:

The numbers have grown because there is more awareness. There is better diagnosis. Also the autism spectrum has widened. So we are taking in very high level youngsters at the high functioning end, Asperger end, your professors at university end as well as down to the children with severe learning difficulties alongside of autism. So broadening that spectrum and bringing in other diagnosis to say it is within the spectrum has made the numbers more. It is also a genetic situation at times. The research is still sketchy on everything, on the causes, but what we are looking at really is that may add to the fact but really it is about better diagnosis and broadening the spectrum.

The Deputy of St. Peter:

We have heard from parents and people who are involved in education of children on the autism spectrum that there are varying degrees of the problems. In your view, when a child is showing severe levels of autism, what is the best way to care for them?

Ms. G. Waters:

It is understanding autism to start with. If they are showing severe challenging behaviour at that stage you need to know why because there is always a reason. These children have massive sensory difficulties, really big sensory difficulties so even a touch may be hurtful, sight and hearing. You see sometimes children with their hands on their ears, it is hurting their ears. So these sensory difficulties impact across their whole lives and it may just be one thing, one specific noise like a hand dryer in a loo that sends a child into high anxiety and when they get to high anxiety they have to blow and they have to go into that overload situation. Really the way of coping with autism is understanding their difficulties, understanding all of the sensory problems. So you would have a really good assessment of their sensor difficulties, their level of communication and then put in a programme to make sure that their anxiety stays within a management level. If you think of a time when you have been sick to your stomach with worry, and most of us have at some stage, that is where most of these youngsters live on a daily basis. So it does not take much to lift them into that situation where they are: "I cannot hold anything more, I have gone over the top and I have to do something" and it might be a withdrawal, a complete withdrawal, or it might be a physical challenge at that situation.

The Deputy of St. Peter:

When you say "a complete withdrawal" do you mean into residential care or ...

Ms. G. Waters:

No, in that situation I was meaning the child withdrawing into themselves and they will shut down. That is really frightening as much as a physical challenge is frightening, if they shut down and they do not respond to anything then that is a real ... you have to get in and see what is the bottom line of that difficulty.

The Deputy of St. Peter:

Sorry to distract you slightly but I should have alerted you to the notice that is there just to talk you through the process.

Ms. G. Waters:

Okay. Again, these are my personal views. I am a member of Autism Jersey and I know that the group are coming in this afternoon but these are my points of view from being the professional within the field of autism and knowing what those kiddies need at the levels. If we are talking about respite, if you put in respite in the right level then you can keep those children's anxieties down, you can keep the family's anxiety down, you can keep the siblings in a good place to be able for families to continue, and to continue to have the children at home. If there is not the respite then everything goes into

meltdown because the children's routines have changed, the anxiety is raised, the family's anxieties are raised because they are not getting a break. That is what has happened on the Island at the moment, because the small amount of bed space they have for children with autism had to be taken away for a specific child and rightly so because that child was in crisis and the family were in crisis and something had to be done. But there was nowhere else for that child to go. So he took over the whole of Eden House and at that stage everybody else's respite finished. Now that was October, all the way through Christmas, it is a highly anxious time, you know, flashing lights and everything happening, so again it is a really difficult time for families. They missed all of their respite resulting in another 2 children having to be placed off Island which is not the policy really but also in that situation there were lots of families affected. Lots and lots of families. To some degree of: "We are having this family reunion today and it is going to be great because youngster is being looked after somewhere else" that has stopped, up to mothers having to take tranquilisers again and other things to help them through this problem of not having a break.

The Deputy of St. Peter:

You say lots and lots of families, how many families are you aware of in the Island who have been affected or who would normally access respite and have not?

Ms. G. Waters:

Yes. Well there is so many families that would like to access respite but really cannot get it. I think within our books, within the provisions, there are lots of children in the mainstream provision but we are also talking about children in Mont à l'Abbé School. So you could be looking at at least 30-ish, if not more.

Deputy J.A. Hilton:

Would you be surprised if we told you that we are being told by senior officers in the children's services that all need that was being catered for prior to the crises in October is now being met?

Ms. G. Waters:

I would be surprised. I do know that 2 of the children that were in crisis as well used to use the respite as well so they are not on Island any more. Yes, I would be surprised because I was chair of Autism Jersey and we were often having ... we have drop ins for families to come to and the families are worried that they have not got anywhere to go to have that break and they have to then make a massive case for it if they do need it. It is about who shouts loudest at times who gets through, who gets the places. But for me it is about saying money by putting in this respite because if you have that constant there, if you have enough beds plus an emergency bed, because autism is so unpredictable that you need an emergency bed to be held so that a child can be taken in overnight if something has happened. If you have enough of that then you can move forward. The staff are absolutely brilliant at Eden House. They work so hard but they can only work with what they have got, with the space and everything else.

The Deputy of St. Peter:

What do you think of the facilities?

Ms. G. Waters:

I do not think they are adequate, I think that they are only really suitable for primary aged children. I do not know if you visited there. I have got ...

Mr. S. Jones:

This is Eden House you are talking about now?

Ms. G. Waters:

Yes, I am talking about. There are national minimum standards all the way through for everything to do with childcare. The standard about providing a suitable physical environment, and this is across all children's homes, that sort of thing and obviously from the U.K. I have just made a few notes. Initially that building was totally unsuitable for purpose but the staff have changed it. They have put in vision panels, they are putting key fob entry and things like that. The windows go to the floor and are easily kicked from an anxious child but also if a child has big sensory problems of either too hot or whatever, they will strip off completely. So in the lovely situation of being in a residential area but if you see children constantly with no clothes on what message does that give. It is about dignity and respect of the child. So I do not think the windows should be as they are. The bathroom was totally unsuitable but they have put in a wet room now. The heaters are jutting out into the corridors and it is a health and safety situation for staff who are trying to do a physical escort to move a child out who is in a difficult time, they will hit those heaters. They are very sharp and also the stairs are not wide enough for a 2 person escort, which would be 3 going down the stairs. So that concerned me. The children also think that this receptacle on the wall is for urinating in anyway so sometime that can happen which is not very healthy. So the size of the corridors, the stairs and that sort of thing. I would have recommended vision panels and the key fob situation as well as a safety factor. But within that situation they would not meet the standards.

Mr. S. Jones:

Would they meet the standards of primary age children ...

Ms. G. Waters:

When everything has been done but still the width of the corridor, the jutting heaters and the stairs because the youngsters who have been sent away are primary age and if they are in a total challenge situation where they have gone and 2 staff need to escort them to safety or to a better space then they can do that but with difficulty because of the size of the space.

Mr. S. Jones:

So just to clarify, the problems you are outlining, they are problems relating to even having primary age children there and if you were to have older children there are more problems again?

Ms. G. Waters:

Yes, it is because of the size of the youngsters. Very small children, it would be easier to escort and sometimes you can move a child with one person if they are smaller so smaller children. It is a lovely place with a lovely atmosphere and they have done a lot for this kiddie that is there in the flat, but, as I say, they can only work with what they have got and they have had to change so much from the original building.

The Deputy of St. Peter:

Have you been to Aviemore recently?

Ms. G. Waters:

I have not recently but I do know the youngsters that are there. Again the young adults that are there are mixed with older people, a different mix of ages as well as level of ability. There is a young man there who went to Southlands School, which is one of group schools who are high functioning Asperger, living with young people who are non verbal and much lower ability.

[10:45]

That mix for me is not right; they need a peer group for them to be living alongside. There is a very much older person there as well, I understand. I have not been to Aviemore since we used to use it for holiday schemes and things like that. I know it has changed a little but I think that a lot needs to be done with that situation.

The Deputy of St. Peter:

At what scale on the autism spectrum do you think that a family should have access to regular respite?

Ms. G. Waters:

That is difficult to tell because you can live in quite a happy state for so long and then, oops, something happens and you need help. Then they can come down again and again. Puberty is a horrible time for these young people and going through that it often causes lots of extra difficulties to them. In the early years with just being diagnosed, the terrible 2s become right the way through to 5 or 6, if not longer. It is really looking at every individual case and some people will need respite most of the time. Often that will be your non verbal children with lower functioning. Whereas some of the children that are high functioning or have Asperger Syndrome may be able to cope because they have the support of the schools and the provisions but I still would say that it is no joy living with any part of autism and that at times every parent will need a break because having lived with 50 children on the mainland 24/7 I do know what it is like. You can see that just one little thing might happen, something might change and that child will become highly anxious and that family are then in crisis really. For me, looking at the system as it is, it is crisis bashing rather than planned. Planned transitions and planned respite that parents can look forward to and know that it will definitely be there because it is ... the staff are having to cope with all of this over anxiety and they are having to cope with all of these crises and all of a sudden the telephone call comes through: "You have to take this child." Then the telephone has to get hot saying:

“Sorry, your respite is cancelled because we have this” and I really ... in that situation the families just fall apart.

Deputy J.A. Hilton:

Can I just ask you a question, please? We had the situation back in October that a family did go into crisis and that had a knock on effect, we have been told that as a result of that 2 children were sent away to the U.K. for school placement. In your opinion, do you think in normal circumstances that Jersey should be able to provide the care for all the children it currently has on the autism spectrum? We know that situation should not have arisen because we are being told that one of the children who was sent away to the U.K. went into crisis because their respite was pulled and so we are being told that if their respite had not been pulled that child would not have gone to the U.K.

Ms. G. Waters:

I would agree with that. I think we do need some services on the Island that cater for these challenging children. When I was overseeing the autism as an Island oversight, we wrote a 10-year plan and at that stage highlighted the youngsters who are now in adult provision and highlighted them as needing full residential care at that time.

Deputy J.A. Hilton:

So how long ago was that?

Ms. G. Waters:

That is probably 15-20 years ago.

Deputy J.A. Hilton:

Right, okay, so there was plenty of warning then.

Ms. G. Waters:

Yes, we were highlighting those youngsters as knowing that they would need full residential care. I would say now that professionals in the field would have highlighted those youngsters who have gone, the one who is in respite now, maybe, and you can see the children who will need ... but it also means for me that there should be a distinction between full residential and respite. They are 2 different things and there must be a full residential service for youngsters, the ones that are off Island, the one who is in the flat at the moment, other youngsters that have gone through and are now in adult full provision, and keep the respite as a separate entity. You know, on the main land from April 2011 all authorities have been tasked as a duty of care to provide respite care for children with disabilities.

Deputy J.A. Hilton:

Is that in law?

Ms. G. Waters:

I have copied this, I thought you could look it up. It says: “From April 2011 local authorities will be under a duty to provide a short break services to carers of disabled children.”

Deputy J.A. Hilton:

Thank you very much.

Ms. G. Waters:

But if you provide a short break service then, as you have been told, I would reiterate that, the children and the families do not go into crisis as much. But knowing the kiddies that I have in the school, because they were the children that could not be educated in their home counties ... so I had children from all over the U.K. and Guernsey in my school. But they were at the sharp end of autism, but you can diagnose those children and know with foresight that they will need this type of provision. I was a party to or in the meetings on the young man who is in the flat, supporting mum, and in those meetings it was suggested that a school on the main land was looked at. In my opinion, at that stage in the initial stages that child should have gone off Island because we did not have anything else for him at all here. Now, if he had gone into a residential school I know he would have blossomed because I know what would have been put in because it is the specialist occupational therapist that we have not got, you know, into sensory difficulties and the specialist speech and language which we have got, but putting it into the care situation. The staff are well trained at Eden House and that is why it has made a success of what it has done. But I still feel there is a need for the next level of residential in that situation. If that child had gone off Island the respite would not have been stopped for anybody else. One of those youngsters was heading towards residential care in September time. Mum had given that warning because of the child getting larger and stronger obviously. But in that situation I think it would have saved 2 going and also this young person is in his teens and so, again, Eden House is not really the right place for him. They are younger children that have been sent off Island and I really do not think that is right.

Deputy J.A. Hilton:

Playing Devil's Advocate here, with the child we are talking about currently at Eden House, presumably though if the parent is absolutely adamant the child stays in the Island what ...

Ms. G. Waters:

The parents were not at that time. At crisis initially mum was ready, she had looked at schools we had talked about on the internet and had designated one that she would like to have looked at in that situation but then because the wheels did not move and it was obviously looking for keeping costs down then in that case the child was put into Eden and they did a fabulous job with him. It is just that everybody else's respite stopped. Perhaps that was the difficulty.

Deputy J.A. Hilton:

So in your professional opinion when it was made quite clear before the child went into crisis that the parents were in agreement that maybe this was the best way to go, residential, the department did not move quick enough to facilitate that and so then he did end up going into crisis?

Ms. G. Waters:

Yes. I think so. It was a combination really as well because educationally the school has to say: "I cannot educate him any more" as well as the Social Service side saying: "We do not have anywhere for him" or this is all we can do. So it is a combination thing and it would have been nice to have seen the 2 sides coming together and talking through the best way forward because it should have been a residential school, so it is a case of - happening often in my school - children were paid for educationally by the Education Department and the care from Social Services.

Deputy J.A. Hilton:

Can I just ask you another question around that? We know that there are now 3 individuals who require residential placements, 2 in the U.K. and one currently here, in your professional opinion once those 3 individuals are catered for, if nothing else happens, do you think we are going to be faced with this crisis again a year, 2 years down ...

Ms. G. Waters:

Yes, because there are children recently been diagnosed and quite severe little ones. They will always be there. I think the numbers will grow in that area, but it is having an autism friendly residential provision that is right for those youngsters because once you give the right environment you see them just ... the anxiety goes. I was lucky to have 28 acres and horses and all sorts of things in my school but it is space that these youngsters need. They do not need to be in cramped situations, they need space, their own space, and a way of working with them that makes sure it is a very therapeutic environment, that it is calm, it is consistent and everything is as smooth as it can be to bring them down.

The Deputy of St. Peter:

In your professional opinion, you said we have the skills here in the Island, if we could find a suitable location, do you think we as an Island are capable of offering a residential care environment for those children?

Ms. G. Waters:

To a certain extent I think we would need better occupational therapy specific for autism. We have some good occupational therapists on the Island obviously but not really fully trained in the autism. So that for me is a big thing, to ensure that they get the sensory input and understand that totally and have a programme to alleviate that. Children in my school would all have individual programmes before school. Some might be with the horses, some might be having music, some might be having massages, some might be having foot massage, it was all different because these children are very, very individual. So it is about providing that. The staff that are in Eden are well trained with the programmes that are running and they are going into higher level training as well, which is great. So I think that side of it could do ... it is just where you would fit ... I think it would have to stay that it is school and home rather than set up a residential school on the Island, I think that is way above what we could cater for. But if you had a specific residential place sent

up for children with autism in the care sector and made sure that it was managed at the highest level with an understanding of autism, it could work.

Mr. S. Jones:

So how big do you think that residential setting would need to be?

Ms. G. Waters:

The residential one at least 5 beds, I would say. At least 5. But then it would also be about having the respite service as a separate service and making sure that you had your emergency bed there.

Mr. S. Jones:

The emergency bed at the respite?

Ms. G. Waters:

Yes, or if you have got a free space in your residential then ... but it then depends on who is running what and whether it is the States providing or whether it is a combination of States and third sector or whether it is outsourced. I think perhaps the residential side could be and the respite I am not sure about.

Mr. S. Jones:

For the residential side you would expect it to be slightly older children living there?

Ms. G. Waters:

Probably because they have gone to that crisis point. They are sort of around 11, are they not, and at that stage when puberty kicks it is a really difficult time and sometimes they can come out at 18 and be calmer but it usually flows that if they are in residential at 11 they will need it for life and it is just moving up through.

The Deputy of St. Peter:

How important is the outside environment and space? You mentioned that at your school in the U.K. you had horses and 20-odd acres of ground.

Ms. G. Waters:

It is important if you can find it. The use of the space that the staff have done at Eden is good because they have got outside areas separate, et cetera, but that still is too cramped.

[11:00]

The bedroom in the flat is ... I think the flat is super now for this youngster. It is that sort of space for each child. You are talking about a lot of space then. But if you do not do that then sometimes if they do not have space to move then it is all too much for them.

The Deputy of St. Ouen:

I am interested to just ask a couple of questions, first of all about Eden House because it is quite a new facility. What I am struggling to understand is that you have raised a number of concerns about the layout, construction, set up of the building, are you aware if any advice was sort from Jersey Autism or any other organisation of expert individuals in the area while they were developing the actual facility?

Ms. G. Waters:

I do not know because I was off Island at the time so I could not really say. Sorry.

The Deputy of St. Ouen:

All right, that is something we need to find out. Secondly, it is to do with the assessment because you rightly point out that unless you understand the demand and the needs of the particular individuals it is very difficult to address them. In your view do you think that we have got a good and robust system in place at present to assess youngsters who may be showing symptoms of autism?

Ms. G. Waters:

How do you mean? In the diagnosis side or assessing whether they need respite?

The Deputy of St. Ouen:

Both.

Ms. G. Waters:

Both, okay. There is a reluctance on the Island to give a diagnosis of autism, coming back I have been quite surprised that that is still there because often alongside of a diagnosis you get services. So if your child is just ... the Education point of view is if a child has record of need and it meets their needs then that child is being catered for. That is right but unless you have autism in the diagnosis then the difficulty then becomes for the parents to have more support sort of into care, et cetera, and also understanding the disorder and understanding for themselves what is happening with their child. So I am finding that there are fewer people ... if they are at the very sharp end and if the parents are very lucid and can get their message across, or take their child to the mainland and get a diagnosis then they will have autism on their record of need. But it is not everybody that is getting it. So then what we found is a new psychologist came to the Island for adult services and she was finding she had a queue at her door of 18 year-olds saying: "I know I have got Asperger Syndrome, please give me a diagnosis because I have never had one." This psychologist is in our service and she can reinforce that that she had lots of people at the door asking for a diagnosis. Often these young people need a diagnosis to know what they have because otherwise they think ... one child said to me: "You mean I am not going mad?" You know, because when they know and they can relate to it and know other people can relate to it, it does support them getting through and understanding their own difficulties at that stage.

The Deputy of St. Ouen:

We have heard much about various assessments and we know that within the educational environment there is an annual meeting which focus on records of need, we have also had individuals that suggested that it is not as comprehensive as the U.K.'s equivalent which is a statement of need and I suppose the question I would like to ask you is that in your experience within our education system and working with the record of need process, do you believe it encompasses all the needs of the individual or is it solely and simply focused on the educational aspects?

Ms. G. Waters:

It is only really the educational aspects, I feel. The statement of need in the U.K. is a legal document and that is what the parents of children that came to me could wave in the air that if they had autism on their statement plus all the need then you had to provide that need. That is where tribunals and things would go to to support the children coming.

The Deputy of St. Ouen:

If we have got a system that is there to consider the needs of the individual already in place, why do you think it has not been possible to integrate the other needs and the other agencies at that meeting so we can deal with and assess the overall needs of the individual? What have been the barriers to achieving that?

Ms. G. Waters:

I would say probably the relationship between Education and Social Services for many years. I think it is much better now than it was but years ago, in the early days, Education thought they were the be all and end all et cetera and so did Social Services but people were not talking together. What was amazing about the youngster who first went into crisis last year was we had a multi-disciplinary meeting, there were 15 people around the table at very short notice, in all the right areas of both Social Services and Education all working together and that meeting was so productive. It was fabulous to have that meeting. It was just about that time. That, again, was encompassing the care needs of that child as well as the educational needs. So it was needed and I think multi-disciplinary meetings should be held on some of these children who are liable to go into crisis at the sharp end of autism.

The Deputy of St. Ouen:

If there is a key individual or professional that should be linking in with the family and the child, who should that person be?

Ms. G. Waters:

Probably the psychologist, but if we had a specific social worker as well for autism - and there are some super people in the disability team but things change so much they keep changing the scriptures of things. I know the social worker in the case with the child worked extremely hard and he co-ordinated the meetings, brought everybody together. The Psychology Department should be able to cross over from Education into the care side as well. But it is very difficult to get that cohesiveness without somebody, as you

say ... on the mainland for transfer between children services and adult services, there is a connection service that comes into play and works with both of the social workers who would ... and that transfer then is much smoother because you are getting people together. It needs that mediator in the middle.

Deputy J.A. Hilton:

Can I just ask you some questions around transition and the facilities for young people in transition and respite that is available for them at the moment because our understanding is once they have reach the age of 18 Eden House is no longer available to them so they would either go to the Lodge at Les Amis, which I understand does cater for some children on the autism spectrum, or some go into Highlands. Do you have a view on using the Highlands type of residential care as respite for children on the autism spectrum?

Ms. G. Waters:

It is still a big place, is it not? I think again it needs looking at individually because these people are all very individual. The transitions, I do not think, are planned and are early enough. Usually in my experience if a child is in year 9 then we start to bring in the adult services so that you can that you can see that through until they leave the children's service. So there is a full warning: "This child is coming your way, these are their needs" and each child would then have a personal plan to go forward. A personal placement plan that is all about them, their needs, their likes, their dislikes, their aspirations if they are able to do that. So it is about having all of that package out there so that there is full warning.

Deputy J.A. Hilton:

A lot of the parents that we have spoken to, in fact all of the parents that we have spoken to have praised the staff at Oakwell, Eden and Aviemore. Without exception everybody said the places are great, the staff are great, but ... I have forgotten my train of thought there. I will have to think about this. I was thinking about transition, yes. No, I am sorry I have completely lost it so somebody else will have to ...

Ms. G. Waters:

I mean in my experience of people who have gone through that transition process they find it frustrating because sometimes the educational side is being put down as this is the route they are going but the meetings do not take place to make that enough of a forerunner, to make it smooth.

Deputy J.A. Hilton:

What I was going to say is almost without exception everybody said how fantastic the services were, Mont à l'Abbé fantastic school, and they leave at 18, 19 and there is a lot of concern about what is available to young adults when they leave Mont à l'Abbé School. There is a lot of concern around that and I was wondering about your experience at your school in the U.K., it sounds absolutely fantastic, and obviously it was very specialised, at what age did the children leave the school that you were head at in U.K. and what

opportunities did they have when they left there? How does it compare to here in your experience?

Ms. G. Waters:

I am talking every sharp end children obviously that we had so when I went the children finished at 11 and moved on to one of our secondary schools but a lot of the children wanted to stay and the parents wanted them to stay so they moved our remit to 18. Then from 18 they would often go ... sometimes go back into their own counties where they were or the London Borough that they had come from if there was provision but also the Cambian Group had got adult provision that the youngster could go straight on to and then they would access ... the youngsters who have been at Southlands were all accessing university type places. So they were at that level. But youngsters would go into work experience and they would start that within the school anyway at 16. The post-16 programme was as it would be over here as work experience et cetera.

The Deputy of St. Peter:

What do you mean by university type level?

Ms. G. Waters:

Well, they went to university, yes. With a mentor but supported. They needed the support to go because it is not just about the academic work that they can do standing on their heads, it is about the whole social scene and understanding where they need to be and how organised they need to be to get essays et cetera done.

The Deputy of St. Peter:

They are generally very bright children.

Ms. G. Waters:

Never underestimate a child with autism.

The Deputy of St. Peter:

Tell me a little bit more about the role of a mentor. This is slightly out of our remit but it is quite interesting.

Ms. G. Waters:

Within the educational system, this is with severe youngsters who are paid to be in a residential situation, they would have a mentor, a key worker, with them and they would support their journey into university. But on the mainland there are some systems in place where mentors are just a buddy, like the Haute Vallee buddy system, which is brilliant. To go with them and just help them through the social scene and that situation: "Have you got so and so ready?"

The Deputy of St. Peter:

So it is not a 24/7 ...

Ms. G. Waters:

No, no.

The Deputy of St. Peter:

I see, okay. Going back to your view of the provisions that we have here, in your submission you explained that you were quite shocked to see very little had changed in the time you were away from the Island and that some services would have been shut down had they been in the U.K. Would you be happy to give a little bit more detail on how and why you ...

Ms. G. Waters:

That was mainly about the physical environment and the standards. I obviously have not been party to all the other things to do with supervision and everything else so I have not put that on but it was really about physical environment that would not have passed. If you want that particular standard, that is the standard. It just shows what is needed in any residential situation. Obviously you take it to another level when you are dealing with people with autism.

The Deputy of St. Peter:

This has come from?

Ms. G. Waters:

It is the National Minimum Standards.

The Deputy of St. Peter:

The National Minimum Standards for Children's Homes.

Ms. G. Waters:

You can have it all if you like.

The Deputy of St. Ouen:

In your view, could the third sector, the voluntary and charitable organisations, play a bigger part in the support provided to parents with children with special needs?

[11:15]

Ms. G. Waters:

Yes, as part of Autism Jersey we do an awful lot to support parents and I feel we do more than we should, but it is needed. A for instance is the holiday schemes, we are now taking on the full funding of those schemes because they have been stopped. I have had loads of meetings with E.S.C. (Education, Sport and Culture) and we are being well supported on premises and H.R. (human resources) to provide payment for the staff but Autism Jersey are going to fund it completely whereas Autism Jersey funded it partially before. So we are doing that because holiday schemes is respite. It is respite for parents that cannot cope with a 6 week holiday in the summer unless they have ... these children need the predictability and routine. It is routine to go to school, it is holiday time, a little bit different but we are going to holiday school.

Mr. S. Jones:

Is this the 4 week block that it is currently in the summer?

Ms. G. Waters:

We do a week at Easter and 3 weeks in the summer but this is the first year we are doing it ourselves and are having to register as a provider.

Deputy J.A. Hilton:

Can I just ask you a question about that because we had people in talking about the holiday schemes and it was our understanding that there was just a 4 week holiday scheme operating in the summer but nothing at half term, Easter or Christmas. So the 4 week holiday scheme that you are talking about, is that the same one that we have been told about?

Ms. G. Waters:

You have been talking to parents from Mont à l'Abbé School.

Deputy J.A. Hilton:

Yes.

Ms. G. Waters:

Yes, so that one is different and it is outsourced. That has been always been going, as far as I know. The one that Autism Jersey is involved with is the children from the provisions in the mainstream and it is only primary age. We are only able to do primary age but we do one week at Easter and 3 in the summer. That is just the children from the provisions or the outreach that the staff know. We use the same staff from the provisions to do this holiday scheme, because that is the continuity.

Deputy J.A. Hilton:

So it does not involve primary school children at Mont à l'Abbé with autism?

Ms. G. Waters:

No. The one at Mont à l'Abbé, who will be the parents you have spoken, it is a different scheme. My worry at the moment is that we are not providing anything for the 11 plus, but we are having to walk before we can run and set this up first and then have a look. We were supported very much by the Youth Service last year because as Autism Jersey again are paying for a Wednesday club from 11 plus from the provisions. Hannah Clarke who is in charge of the Youth Inclusion Project - I am Chair of the Inclusion Project so I see both sides of that - she has extended that through the summer and kept it going, again for respite for those 11 plus, but that is all they have had.

Deputy J.A. Hilton:

Yes, this was brought up by a couple of our families who had children aged between say 11 and 16 on the autism spectrum with communication difficulties that there really is very little for that group of children at holiday time. So ...

Ms. G. Waters:

It is very difficult. When I was at Mont à l'Abbé I used to run the holiday schemes, I used to work in school time 4 days a week and it suited me that time but I worked through every holiday. That worked really well because I knew the children in school and I knew them out, and then in the holidays I could keep those programmes going. That was when Mont à l'Abbé was all on one site. So it worked really well but through the years those holiday schemes have changed so the management of them has changed, it has not been ... it is not internal now within Education, it is outsourced and so the difficulties have come in with that outsourcing because you get youngsters, as we have just said, you know puberty, autism spectrum at Mont à l'Abbé already, they are going to be challenging children. They are going to have to have staff who understand exactly what they need. That is very hard to produce out of the air for students that you have in a holiday scheme situation in an outsource situation. So there is not the continuity of the staffing as we provided for these youngsters because that is what we feel works for those youngsters. So I would think it would be very hard to do and I know that some youngsters have been told they could not go because they were too severe.

The Deputy of St. Ouen:

I want to just touch for a moment on other options for respite which is the Outreach where you will go and support the family within the home environment. Do you have views about how that fits with the general respite available?

Ms. G. Waters:

I think it is another service. It is part of the service and it is a part of the service that the staff would like to do but have not got the facility at times. Again, it is individualised. Some families need the child to be away from the home to have that real break and the siblings can be in their own home doing normal things, other families it is nice to have somebody come and take the child out or be within the situation so the family can go out. So it is all very individual. Autism Jersey run a befriending service and that befriending service with 40 to 50 families within Jersey having a befriender who would go into the home once a fortnight - or sometimes once a week but mostly once a fortnight - and that sometimes is the only respite that that family get and mum can have a bath on her own. Simple things that they want to do. The befrienders would either play with the child in the house or befriend the sibling, because often siblings are the ones who miss out and take them out and go shopping or do something with them. So it gives the whole family a break. That sort of service is working really well here and has worked really well for a long time, again through Autism Jersey.

The Deputy of St. Ouen:

You say that and I would be interested to know, are you aware if there are formal agreements in place between the States and Jersey Autism to provide a range of services or is it just a case that Jersey Autism has seen a need and sort to fill it?

Ms. G. Waters:

The latter. Yes, definitely. The need has come from the parents and the membership, and people tell us what they need and the befriending service was from the N.A.S. (National Autistic Society) originally but actually in the U.K. they have nearly all petered out. But it is so successful here because it keeps going and the children are matched. Having said that, there are some children that you cannot match very easily and they are your children that need the residential. We have come across that situation, or young Asperger teenage boys who would like somebody who looks like Beyoncé and we cannot quite provide that. **[Laughter]**

Mr. S. Jones:

Can I come back and ask you about what provision for respite Jersey needs in future? We talked earlier about the need for a long-term care facility and that would help take some of the pressure off the existing respite facilities. We also talked about Eden and the fact that it is not really suitable for older children and there are even some problems there for primary age children. Does that imply that in addition to Eden there is a need for another respite facility for children with A.S.D. (Autism Spectrum Disorder) but who are a bit older and of secondary school age?

Ms. G. Waters:

I would say so. Yes, a separate provision with more space and with the staff being able to do what they need to do if the child is then in an anxious situation. Again, the young adults in Aviemore not being mixed with very older people and also the mix of your high functioning youngsters. I know Eden have tried to do that, on certain nights there are some youngsters that would be there. But, again, that is quite difficult to do when you have to spread your time over the weeks. But they do it well.

Mr. S. Jones:

Does that then follow the need for more residential facilities, do you think?

Ms. G. Waters:

I think you need a residential facility definitely that is separate to respite. You could carry on with Eden with little children and then have a separate one, larger space wise, for your teenagers.

Mr. S. Jones:

With a similar number of beds to Eden or ...?

Ms. G. Waters:

I would like to see at least 5 in each. At least.

Deputy J.A. Hilton:

We have been told that for the children with these needs, it is better for them to have smaller units, so that is one of the reasons there is only 2 beds at Eden House. So how did you manage that in your residential school, you say you had about 50 children, did they have ...

Ms. G. Waters:

They had separate houses, yes. So the children were in house between 4 and 6 mostly in each house with a separate care team with a care manager in charge of each house. Then the education part of the school was in a separate part.

The Deputy of St. Ouen:

It was on the same site?

Ms. G. Waters:

Yes.

The Deputy of St. Ouen:

Is it usual or helpful to mix ... I understand there is a full range so we have to recognise that, but is it helpful to mix youngsters with different needs together?

Ms. G. Waters:

They are all going to be individual and different so it is hard to get a cohesive group. I used to go out and assess children and think about the class group, house group, that they were going to come into. Again, you could not take in 6 children at that level of difficulty all at once. So you would have to bring them in one at a time and make sure that that was safe and calm before you then took any more. So it is about managing that situation. You can manager having a different mix but your young people who have very high I.Q. (intelligence quotient) and have Asperger Syndrome understand themselves more. They have insight into their difficulties, whereas the children with autism are happy to have autism, happy to be autistic, and they do not have that insight. That is why some of these youngsters can get depressed in teenage years because they are not having the same relationships that they see out there in the media. So it is about meeting those needs of those youngsters and making sure that they have peer groups that they can be with and that they have people who understand that they can talk to.

The Deputy of St. Ouen:

It is a big challenge ultimately, and I know obviously with both children and young adults it is what happens next. It is a transition, it is what is real life all about and is it going to be ... we provide this quite comprehensive support linked to education and there needs to be an expectation of what their lives can be like and we can provide for them after full-time education. I am just trying to understand for myself how you balance our preparation and the support that we provide for the youngsters in full-time education with what happens next.

Ms. G. Waters:

I think it is putting them into a situation that is real life so in my school we had one of the houses ... well, 2 houses were on a housing estate so when they reached 16 they would move into these houses in Blandford and then they would live there, they would come in to post-16 in school, so this is a transition from being on one site to then having this house in the community and then they would go out and do their shopping, they would do their

cooking, they would live in that situation. They all had their own rooms and ensuites and it is highly successful. So successful we bought next door and so there are now 2. But those houses are on a big housing estate, one where my deputy lived as well so it was part of a big community and it was easing them into real life from that situation. So the next step on. Because they were very sheltered, living in school in that situation, and you have to shelter them to a certain extent, but these were all extremely violent children when they came to us but to go out and live in a house on an estate like that was moving them through and showing that they had moved on tremendously really.

The Deputy of St. Peter:

Thank you very much for coming in ...

Deputy J.A. Hilton:

Can I just ask one last question? It is about the Inclusion Project. I know about the Inclusion Project, it is a fantastic project and obviously it is providing an environment for those very young people you have been talking about to mix within their own peer group and everything else. We have had a couple of parents in who have had children at the more severe end of autism and they did mention that there is no facility for their children to access some sort of youth club provision because the current inclusion provision does not really cater for their needs, because they are too extreme possibly. Has Autism Jersey thought about possibly setting up in conjunction with the Youth Service some other small project, youth project for those children who are ...

Ms. G. Waters:

My understanding was that if they did not fit into the inclusion that they went to the Mencap group, because an awful lot go to the Mencap Youth Group. They run a youth programme as well.

Deputy J.A. Hilton:

That is interesting. I think with a couple of these parents they felt that because there had been issues around their young children, they were boys - I think they were both boys, were they not? - that their difficulties were too complex for the Inclusion Project and they said it would be a great help if we had something. In fact one of the mums did say that she would be happy to take part in it if that were possible. So I was not aware ... I knew Mencap did run a youth project, is that the one that is at Mont à l'Abbé?

Ms. G. Waters:

No, I am not sure ... Sue Moore is on the Inclusion Project as well and she talks about the group that meet. I am not sure if it is not Maufant.

Deputy J.A. Hilton:

Right, okay, thank you. We can ask her when she comes in.

Ms. G. Waters:

They always used to have one at Maufant but whether it is still there. Because we have one that meets there, that is the Wednesday group.

Deputy J.A. Hilton:

Okay, thank you. It has been really useful.

Mr. S. Jones:

Yes, thank you very much.

The Deputy of St. Ouen:

Thank you.

Ms. G. Waters:

Thank you.

The Deputy of St. Peter:

Sorry, we have to formally close the meeting. **[Laughter]** Thank you, James.

[11:31]