

STATES OF JERSEY

Health, Social Security and Housing Scrutiny Panel Respite Care Review

Session 1

TUESDAY, 28th FEBRUARY 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:

Deputy A.K.F. Green of St. Helier

Also present:

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

[10:16]

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

Thank you so much for coming in today. So we formally have a record of who is in attendance we will ask you just to briefly introduce yourself for the record.

Deputy A.K.F. Green of St. Helier:

Andrew Green, and I am talking in my capacity as a carer for my son [name redacted].

The Deputy of St. Peter:

We will run through ourselves. Chairman, Kristina Moore.

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

I am Deputy Jackie Hilton, Vice-Chair.

Mr. S. Jones (Adviser):

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

Deputy J.G. Reed of St. Ouen:

Deputy James Reed, panel member.

Ms. F. Carnegie (Scrutiny Officer):

I am Fiona Carnegie, Scrutiny Officer.

Ms. K. Boydens (Scrutiny Officer):

Kellie Boydens, Scrutiny Officer.

The Deputy of St. Peter:

Tell us a little bit about [name redacted] and your care involved.

Deputy A.K.F. Green:

It is unfortunate really that my wife could not be here today, but we have another caring role inasmuch as it is a lovely one, a grandson, so she is looking after him today. I guess what I wanted to do today, if that is okay, and I will talk about [name redacted] in a minute, is cover 3 areas, but I will be guided by you. The family experience and what we are doing with [name redacted], the constituent contacts I have had and the difficulties they have had, and also the way ahead as I see it. I hope that fits with you, and if it does not just shut me up when I go off track. My experience with [name redacted], our family experience with [name redacted], just to give you some background. We are an ordinary couple with 2 children at the time, [name redacted] was 9 and [name redacted] was 7, so we had 2 children when [name redacted] had a road traffic accident. That would be at the very last day of June 1987. The immediate care ... I mean he was unconscious, he was not expected to live the night. I insisted that they flew him to Southampton. In fact I even found the plane and the pilot, and that is another issue, which has been significantly improved since. He remained unconscious in Southampton for a month. The immediate care, the acute care, the trauma care was second to none. Absolutely first class, you could not fault it. When [name redacted] came home he was severely disabled, physically, had lots of mental health issues and aggression and all the rest of it. I am pleased to say that within a very short time that he was out ... from being told he would never walk again, within a very short time he was ... a few months he was out of the wheelchair walking and now plays football for the Island's disabled team. So in that respect it is a very good recovery, and I think that is part of the problem, because he has what I call a hidden disability inasmuch as he presents well. If you only see him for a few minutes you think, good looking young man - I mean he is 33 now - with no problems, everything is fine, he has made a good recovery. In many ways he has made a good recovery. The immediate care after [name redacted] came out of hospital was fine, inasmuch as we went, and in fact the support at Education was fine, insomuch as they identified that [name redacted] had particular special needs by then. I had a little bit of a battle but eventually he went to a school in the U.K. (United Kingdom), Lingfield, for children with epilepsy because, as a result of the accident, he had epilepsy. That is something we discovered on the way or, I have to be honest, someone may have told us. But there is a lot going on in life when this is happening. We had to make over £40,000 worth of alterations to accommodate his wheelchair at home and all those sort of things were going on, so they may have told us he was an epileptic, they may not, we missed that. But then we get to the long-term situation. By now

[name redacted] is 10 or 11, still has not gone to Lingfield and we asked for respite care. Now I have to say that for the first 5 years the only social worker contact we had was 5 minutes, came in: "You are coping well" and we never saw them again. We kept asking if there was something ... we could have 2 types of respite we wanted. We wanted an overnight so we could have a night off. When you have a child that has severe grand mals, and during the night as well, severe behavioural problems, aggression, because that is part of brain injury - it improves over years but it is part of brain injury - where his sister, which is part of the reason why [name redacted] went to school at Lingfield as well, is under constant threat of attack and you get absolutely no support, no night off. We asked for support initially. Not for holidays for us but for him to attend something during school holidays to enable us to have a break, because you could argue, to some extent, that we as a family had a slight break when he was at school. I know some families do not get that. And you could argue that. But of course [name redacted] never really got a break from it. So we asked for holiday help, there was none. Is it Oakfield or ...

The Deputy of St. Peter:
Oakwell.

Deputy A.K.F. Green:

Oakwell, we approached them, they did not take people with brain injury; and that is how it went and that is how it always went until Paddy Callamaine(?), the head teacher at Bel Royal at the time - and I know I have sort of bounced around but I have to get it out - realised that we were in absolute dire straits and he put [name redacted]'s name forward to go to Lourdes with the APRO(?) and that did give us a week off. But that was because the charity was running it and because Paddy identified a specific need, and I have to say we would always be very grateful for that week. So [name redacted] went off there. He came back and said he had never been so bored in his life, but it was lovely for us. So despite requesting respite time and time and time again it was never available, ever, and to that day it has not changed.

The Deputy of St. Peter
How do you know that?

Deputy A.K.F. Green:

Because he still does not get respite. Now, are we part of the problem or are we part of the solution? The problem is now we know we have Highlands where he could go, but he is 33 now. He has never been on any respite care, he does not want to go to Highlands and how do you make a 33 year-old man who is stronger than I am go to Highlands if he does not want to go to Highlands? It is not part of the way we do things now, he has never been away - if you know what I mean - other than when he was at school. Had it been part of the normal every day, every week, every fortnight or even every month - because I will come to what I feel our family need - care then this would be the norm for him now but at 33 it has never happened; when we suggest it, he does not want to know. He has got quite unrealistic expectations or perception of his capability, totally unrealistic, and we are

partly to blame for that because we try and make life as normal as possible for him. He cannot drive, for example, and all that sort of thing. Health are also partly to blame because they keep telling him he can live totally independently but he cannot; he has only got to miss one lot of medication and he would have a seizure. He is in danger of having them anyway but just one lot of medication missed and he will have a seizure. He cannot remember from one day to the next, one hour to the next, whether he has taken his medication, we are very disciplined about it. He is not capable of doing those sort of executive planning and functioning things so he could not live independently, he could only live in a flat if there was 24-hour care. They would not need to be there all the time but they would have to be there to make sure he took his medication in the morning, make sure he took his medication in the evening, and some sort of alarm system if he had a seizure. So he is not capable of living independently as Health say. To be perfectly honest it would be on the record that we have completely disengaged with Social Services completely now because my wife has got absolutely fed up of going to meetings after meetings where very well crafted action plans are produced and not one part of it ever delivered. I really am too busy to write fictional care plans that are just not going to happen. The argument I get when I query is: "Well, yes, that is what he needs but we do not have the resources to do it." Well, I am too busy for that. The one thing he did have that worked quite well for a short while, and I think it came via Mental Health, he had a buddy on a Thursday evening that used to take him out and try and build up some social skills. I have brought a copy of a memo here; that was withdrawn by just one memo, no discussion, just one memo email, you can keep that. I queried it at the time and it was reinstated for about a month, and I think that was 2004, and then the plan was that they would reinstate something else that was more structured to develop [name redacted]'s skills. Now, no rational adult can argue with that. If you are going to put something in that develops somebody's skills, it is much more structured, much more measurable, you have to accept that. I am still waiting and that is 2004.

Deputy J.A. Hilton:

Sorry, Andrew, is that Mental Health Services, you said?

Deputy A.K.F. Green:

I think it was, yes. I think really, to be perfectly honest, because I was working in Health it came via an unofficial source to start with.

The Deputy of St. Peter:

You mentioned earlier that you had 5 minutes contact with a social worker. That is the sum total of your experience?

Deputy A.K.F. Green:

No, that was the sum total for at least 10 years. As we are getting older we are finding it harder to cope, to be perfectly honest, because nobody understands what it is like never to be able to have a meal in peace because people with brain injury - and I know I am generalising and I am talking as the National Chairman of the Brain Injury Association - people with brain injury are often inappropriate, lack the skills to enter into conversation properly, and

I know I am generalising because there are exceptions to that. So you cannot even have a discussion about anything without [name redacted] putting in his normal strap lines and in the end you just give up. So just to have a meal in peace without worrying about ... I said this morning, because Jill has got a bad back, the family is not very well at the moment, all of them different things, nothing serious; and I said this morning: "You lot are killing me, I am running around like an idiot" and [name redacted] was on his high horse straight away as though I had criticised him and only a parent that lives with somebody like that would understand that. You have got to watch every word you say otherwise you will spend ... in our case we will spend 24 to 48 hours with the police looking for him because he disappears and not getting his medication and all the rest of it. That has happened time and time again. So for at least 10 years we had no social worker contact and then as a family I created a little bit saying: "Look, we have got to have some support, we have got to have some respite" and respite for me, we would be happy with a week off a year to go on holiday. We do go on holiday but we have to take him with us. So they appointed a social worker who came and talked to us, and I think had a fairly good understanding of what we wanted, but because we did not sign the report off - which could have been signed off at the next meeting - we went to the meeting, we had not signed it, they withdrew all social work support and that is on the record.

The Deputy of St. Ouen:

What was the report, Andrew?

Deputy A.K.F. Green:

The report was a statement of the carer's needs, but we had not signed it to say we agreed with it and we did not disagree with it, I just had not got around to signing it. We go to the meeting and they said: "Because you have not signed we have withdrawn the service." This is a colleague in Health, I was working in Health, a senior manager in Health at the time.

The Deputy of St. Peter:

There was no opportunity for redress?

Deputy A.K.F. Green:

No, none at all, and that is it, so we have had no further contact for us. [name redacted] could have further contact with the Brain Injury Service but, as I say, I have no more time to go and write fiction and until there are some resources there to write a proper care plan and deliver then we will not engage. The one dread that we have I think in common with most parents is what is going to happen when we can no longer cope or we are not around.

[10:30]

But, in fact, to be honest the kindest thing that could happen is for [name redacted] to go before we do and then we know everything is nice and tidy, and I mean that. So that is my family situation, I am happy to answer any questions.

The Deputy of St. Peter:

Can I briefly just ask, you mentioned earlier that you felt sheltered housing would be the only appropriate accommodation for him out of your family home, so I guess other than the worst scenario which you have just described, him going before you, I guess that would be the only thing that would keep your mind at rest?

Deputy A.K.F. Green:

Yes, it has to be proper sheltered housing, not what we call sheltered housing in Jersey where we provide a home with ... I have got 7 units for people with brain injury that have been adapted to enable people to live independently. That is one thing but there are some that need care beyond the adaptation and in fact [name redacted]needs no adaptations, he could live in an ordinary home, as he does. Our home is an ordinary one; okay, we made it a bit wheelchair friendly and that, but he can live in an ordinary home but he needs an awful lot of support. He would not wash without being told to; there are inappropriate behaviours to deal with as well but he would not wash without being told to. He can cook basic meals, I insisted he get his own breakfast every morning, which is just cereals and coca cola in his case, he will not drink coffee. On some Saturdays and Sundays he does egg and bacon; it does look a little bit like a disaster on the plate but he does it and I guess lots of lads are probably like that. But he needs to be prompted to do everything because of the memory and because he has an unrealistic understanding of his capability. It is the medication I worry about more.

Deputy J.A. Hilton:

You have obviously got some experience and knowledge of group homes operated by places like Les Amis and Health; would that type of environment be suitable for [name redacted]?

Deputy A.K.F. Green:

I think it would for [name redacted].

Deputy J.A. Hilton:

They have different levels of care and supervision but obviously in some of them there is 24/7 supervision so that there is somebody there prompting people to do certain things and when it comes to medication. So do you think in those circumstances that would probably be all right for him?

Deputy A.K.F. Green:

Yes, I do and I think I would prefer something like that for him because it can be incredibly lonely at 33 when you have been in the family home for all that time and suddenly find yourself on your own. So I think if the right support was there and the other residents were picked carefully, because [name redacted]can be totally inappropriate, in common with lots of people with brain injury, he says exactly what he thinks. Many of us might think these things but we would not necessarily say them, he will say them. I could keep you amused for hours with some of his comments and indeed I use some of them at conferences and whatever; but some people would take offence at some of the things he might say.

Deputy J.A. Hilton:

Have you ever spoken to Health specifically, because I suppose placements go through the social work team? Have you ever discussed with them the possibility of [name redacted]going into residential care?

Deputy A.K.F. Green:

Yes, and they did some work with him on developing his skills, he went and stayed 2 nights, I think it was, it might have been 3, but 2 nights at the flat at Overdale but then nothing came beyond that.

Deputy J.A. Hilton:

So it was just a random 2 or 3 nights and then nothing happened?

Deputy A.K.F. Green:

Yes, nothing happened.

Deputy J.A. Hilton:

So they never came back to you ...

Deputy A.K.F. Green:

Because the facilities do not exist at the moment, Jackie, that is the problem. They exist for people with learning difficulties and you could perhaps put [name redacted]in there with learning difficulty because he cannot read or write properly. But they exist for some groups but they do not exist for others and there is nothing there at the moment. Health are quite adamant, or at least the Brain Injury Service is quite adamant he could live independently.

The Deputy of St. Ouen:

These are the experts that are saying that?

Deputy A.K.F. Green:

I think I am an expert more than they are but, yes.

The Deputy of St. Ouen:

No, but I mean, in inverted commas, it is the professionals.

Deputy A.K.F. Green:

The professionals, he could live independently.

The Deputy of St. Peter:

How do they deal with the issue of his medication?

Deputy A.K.F. Green:

Not to worry about it, it will sort itself out.

The Deputy of St. Peter:

I presume if he goes without medication say for a day ...

Deputy A.K.F. Green:

Not even a day, just one miss, he is that on the borderline because it is a borderline between them sort of being sort of alert and with it and he works with machinery and we are very lucky he has got sheltered employment at J.E.T. (Jersey Employment Trust) with the gardening, extremely lucky in that respect; but if you up the medication to reduce the risk of seizure then you affect him in other ways. He is right on the borderline and even then I had to fight all the way for that because he was having seizure after seizure after seizure and nobody here would listen and in the end I wrote one of my very curt letters, which most people do not want to receive, and he was referred to Southampton General. We were there for one 20-minute session, it is a day trip but we were there for one 20-minute session and his seizures have significantly reduced from the change of medication.

Deputy J.A. Hilton:

They could not do that here for you?

Deputy A.K.F. Green:

They could not do it here, no.

Deputy J.A. Hilton:

Because they did not have the expertise?

Deputy A.K.F. Green:

They say they have got the expertise but they would not accept there was a problem. Sorry, it is a catalogue of disasters.

The Deputy of St. Ouen:

Andrew, can I ask, you are pretty critical about the respite service and you say that you have had to ask. At any time has anyone communicated to you what respite services are available and provided you with information to help support you, your family and the ability to then select ...

Deputy A.K.F. Green:

I tried to find a letter this morning and it may have been an email, and unfortunately when I moved from Health into States I asked that all my emails be transferred over and they got lost and I have not got them. The only communication we had was when I said we would like to have a holiday and is there any way ... I mean, we have said this time and time again but this particular occasion; they came back with a positive: "Yes, you can have some but you would have to pay for it, but you could bring somebody into your home while you are away." Now, that is perfect for us because [name redacted]likes being at home, he likes being in his bedroom and if someone was to make sure he had his medication in the morning, went off to his sheltered employment - he would have to be taken because there is no bus service - and picked up, medicated, and someone slept there overnight - not a huge job - that would be fine. So they sent us some leaflets and I could not find them, I really cannot, it is something like £500 a day we would have to pay.

The Deputy of St. Ouen:

When was this?

Deputy A.K.F. Green:

I had been in the States for a year so about 4 or 5 years ago.

The Deputy of St. Ouen:

But prior to that, when people were aware, because obviously the doctors and various individuals were aware of [name redacted]' difficulty?

Deputy A.K.F. Green:

Nothing, no. [name redacted] never sees our G.P. (general practitioner) because he is never ill.

The Deputy of St. Ouen:

But when he was at school there was some determination about what you would need?

Deputy A.K.F. Green:

The only thing we had was that week when he went to Lords.

The Deputy of St. Ouen:

But while at school presumably individuals were trying to work out what his needs might be?

Deputy A.K.F. Green:

Not with us, no.

The Deputy of St. Peter:

Did you not have an annual review?

Deputy A.K.F. Green:

No.

The Deputy of St. Ouen:

So how did they know which school to place him in?

Deputy A.K.F. Green:

I kicked up such a fuss ... well, I have to go back a little bit; Jill saw an article in one of the nationals about Headway, we were going through very difficult times with [name redacted], very violent, very aggressive, this is before he was going to school in the U.K. and what have you. I did not know when I came home if all the windows would still be in the house when I got home, televisions flying through windows. I had to put a lock on my daughter's door so she could lock herself in a place of safety when he went off on one. She read an article by a chap called Colonel Lacey(?) at the time who was having a similar problem and we made contact with them and they suggested that [name redacted] saw a neuropsychologist rather than just a normal paediatrician, and he was about 10 or 11 then. Most of [name redacted]' care has been like this; from the medical side, if I initiate something I usually get support but I have to initiate it. From the care side it has been non-existent.

But I went to Clifford Spratt at the time and said: "I think [name redacted] should see a neuropsychologist" and he said: "Well I think that is a very good idea and I can think of half a dozen others that would benefit from it" and he brought over Professor Neville - I think he has retired now - from Great Ormond Street; because we suggested Professor Reed from Bristol, not because we particularly wanted Professor Reed but because that was a name we were given. He said: "No, we can go better, we can go to Great Ormond Street." It was Professor Neville that recommended that the family could not go on the way it was, that [name redacted] was in distinct danger of injury and that it would be helpful if [name redacted] went to a school that would understand teaching epileptic children because he was having lots of memory problems - he still has, but not quite as bad as they were - and he was having lots of aggression and other problems. I have to say, I suppose you could take going to Lingfield as respite at the time, although I said we had none. We had 2 different lives, we had a life the 3 of us and another life the 2 of us because it would just be me and [name redacted] when he came home; we were all still in the same house but I would take time off to make sure that during school holidays I kept him as supervised and as entertained as I could. So from the medical side I feel I have initiated most of his care but had support; from the caring side it does not matter what we say, nothing ever happens.

Deputy J.A. Hilton:

Just going back slightly, Andrew, what year was [name redacted] born?

Deputy A.K.F. Green:

1979.

Deputy J.A. Hilton:

So he was born in 1979 and he had the accident in 1987?

Deputy A.K.F. Green:

Or it might be 1988, he was 9.

Deputy J.A. Hilton:

So he went to school at St. Ouen prior to the accident?

Deputy A.K.F. Green:

He was at Les Landes and then he went to Bel Royal when he came back.

Deputy J.A. Hilton:

So how long was he in Lingfield, when did he go there?

Deputy A.K.F. Green:

They normally go to secondary school at 11, he went there at 12, he stayed at Bel Royal an extra year.

Deputy J.A. Hilton:

So it was secondary education he went to Lingfield?

Deputy A.K.F. Green:

Yes.

Deputy J.A. Hilton:

So that was 12 until he was 16 or 18?

Deputy A.K.F. Green:

Yes, I pulled him back at 16 and that was my decision because I was conscious about he had absolutely no friends in Jersey by this time and they had started a new unit up at Highlands for people with difficulties, and I wanted him to go there for a year at least and have some local friends. He is not very good with relationships, as lots of them are not, but it did work, he has got 2 friends. He does not initiate anything but if I were to suggest that he phoned one of those friends he would phone them and they come around to each other's homes from time to time.

Deputy J.A. Hilton:

I am just recapping in my own mind; you have never had any respite, barring the week that [name redacted]went to Lourdes despite asking for it?

Deputy A.K.F. Green:

No.

Deputy J.A. Hilton:

You had asked for a week but you had said that the cost of ...

Deputy A.K.F. Green:

£500 per day to bring someone in from the U.K.

Deputy J.A. Hilton:

From the U.K. they suggested to come in, okay, I just wanted to recap on those facts, that was all.

Deputy A.K.F. Green:

I mean, it would have cost us far more than the holiday would have, it was just out of the question for any ordinary couple.

The Deputy of St. Peter:

In your experience with Headway and meeting other parents I am sure and now as a Deputy, have you found that you have not been alone in experiencing these problems with your care?

Deputy A.K.F. Green:

No, I think we have probably coped better because unusually - and Mrs Jones might know this better than me - Jill and I are still together; most people going through this, 80 per cent of brain injury survivors' parents split up after a year or 3 years or so. I think we have coped better. Also we have other lives, like Jill has got her Guides and I still help with the Scouts and I think that helps, although it made us busier. I have been contacted by numerous constituents that if they have been allocated regular slots regularly lose them, that is the

problem. So if they had been allocated say a Thursday evening, because somebody needs intensive care or perhaps long-term care or whatever they lose that slot. These are conversations that I regularly have and I know you have seen some of them, or if you have not seen you are planning to see some of those people.

Deputy J.A. Hilton:

Is that recent as well?

Deputy A.K.F. Green:

Yes, very recent.

Deputy J.A. Hilton:

So families with young children who were accessing respite ...

Deputy A.K.F. Green:

Well they are not all young and this is another issue to be discussed. They are not all young; some of them are teenagers, some are growing into adulthood. But there does not ever seem to be a recognition either that things change, that disabled children become disabled adults, and there is no provision. In fact I would say sometimes that to pass them on from one service to another, the haste is almost indecent, and I am sure that is a budgetary thing.

Deputy J.A. Hilton:

You mean from transition, from children's to adults?

Deputy A.K.F. Green:

Yes, I am sure it is a budgetary thing and it is part of respite - I know you are looking at respite - I believe that when a child is identified with a problem we have to accept that very often those children are going to become young adults, not always but mostly, and a budget should go with them to buy the services that are required for them, be that respite or whatever. There are many families that would be quite happy, some want to have their child to go to a place so they can relax at home themselves, but many would be quite happy to have someone come into the home so that they can go out or, as I suggested, take a couple of days off or a week off or whatever.

[10:45]

The Deputy of St. Peter:

What would you like to see happen?

Deputy A.K.F. Green:

Well I would like a number of different things to happen. First of all I would like Health to accept that there is a problem because you cannot solve the problem until you accept there is, and they do not always accept there is a problem. I would like to see a range of respite available for some people - such as ourselves, we are so used to it now - that a week off every now and again would be fine. We do not need to build grand institutions; we need to

be quite creative around that and put support into some homes. That will not suit everybody. My mother-in-law, her life begins and ends at her front door and her idea of relaxing would not be to go out; her idea of relaxing would be to stay at home. Well that is no help if you are having someone there to look after your youngster; you are not going to give up looking after it even if someone else is there doing it. That would not work for everyone but for some, somebody to take over at home and run the ship for a week or a weekend perhaps even, that would be a good start. That is one thing. The other thing is that we have to accept that there are not enough social workers. There are just not enough to go round and although I have been very critical of them, I feel quite sorry for them really because we either have to accept that we are going to resource them properly or not bother to do it at all because you build up false expectations.

Mr. S. Jones:

You said early on that you only had about 5 minutes' contact in the first 10 years because they said you were coping fine. Do you think the reason they said that was because they knew they did not have the resources or did they just give that judgment?

Deputy A.K.F. Green:

I am not sure to be perfectly honest. We were coping, just, but we were coping. I do not know. At the time, of course, when that comment was made the first contact was a social worker with Education rather than with Health or it might have been a child care officer, whatever they call them, and then we did not see anybody for years and years and years. So I do not know why they ... but there is definitely a resource problem. There is definitely a resource problem and it must be incredibly frustrating for those that are trying to do their job, knowing what is needed, not being able to deliver.

Deputy J.A. Hilton:

Are you aware of families at this present moment in time who either (a) would like a social worker and just have not been granted one and (b) would like respite are just not getting any or have had it withdrawn, where they have been told that there are not enough?

Deputy A.K.F. Green:

Well, no, I am aware of one, but I know she is coming to see you, the way it has been withdrawn for a period, then reinstated and then withdrawn and then reinstated but I know she is coming to see you.

Deputy J.A. Hilton:

So it is not consistent basically?

Deputy A.K.F. Green:

No.

Deputy J.A. Hilton:

Okay.

Deputy A.K.F. Green:

But there is a whole raft of people out there that should be getting some sort of support that are not even coming into the picture.

Deputy J.A. Hilton:

It is trying to get a handle on that number because I know there are ... because you have obviously ... I think they have looked at you and thought this family is managing. They see what they want to see and you have done an absolutely brilliant job in what you have had to do but, at the end of the day, you are entitled to have some quality time with the other members of your family. Last week at that meeting, we had families talk about the effect on the siblings and there is a huge effect on siblings, you know, just normal family life.

Deputy A.K.F. Green:

I do not think [name redacted] has ever got over it. She was 7 when her brother had his accident. It has severely affected her frankly.

Deputy J.A. Hilton:

Yes and obviously with [name redacted] having gone to Lingfield and you said in a sense that provided respite, did it not, in term time.

Deputy A.K.F. Green:

It did in a way, yes.

Deputy J.A. Hilton:

That has been a reoccurring theme that has come up. Everything is great while the children are in full-time education because there is some break.

Deputy A.K.F. Green:

Breathing space, yes.

Deputy J.A. Hilton:

But after that, there is not. There is this huge gap and that also has quite a massive effect on families.

The Deputy of St. Peter:

During school holidays as well.

Deputy A.K.F. Green:

Well, school holidays, we asked for help and there was none.

Deputy J.A. Hilton:

No.

The Deputy of St. Ouen:

Can I ask, Andrew, you speak about your 33 years of experience and over that time and listening to obviously constituents and others in a similar position to yourself, is it your view that Children's Services and the support services around children with special needs have improved over that time?

Deputy A.K.F. Green:

Yes, certainly from the Children's Services I have seen improvement. It needs to go a lot further but I have definitely seen improvement from talking to people. But there is still this ... then they become adults, it all sort of collapses again. There is not enough ... well, there is not enough support for children but there is even less for young adults and families.

The Deputy of St. Peter:

How many young adults are you aware of with brain injuries or ...

Deputy A.K.F. Green:

Well, brain injury we are dealing ... it depends what you call young but we are working regularly at Headway with 100 families. Now, probably because I do not deal very much locally now as the national chairman, probably 20 of those would not be regarded as young adults. They would be at the older end of the scale, some retired, but you are talking about regular ... but you see, it is wider than that. Now you have got me on a roll because sometimes it is the adult that is injured but the effect is on the children and that adult still needs to have respite and the children need to have respite from the adult and that is missing as well.

The Deputy of St. Ouen:

We are obviously looking at respite, we normally focus on the under-18 age group. From what you have been explaining to us, it seems to be that the most significant concern is what happens after they leave full-time education.

Deputy A.K.F. Green:

Yes.

The Deputy of St. Ouen:

Is that the case?

Deputy A.K.F. Green:

Yes, I think so although I say we had no respite when [name redacted] was in full-time education, you could have regarded going to school as respite and, indeed, you could regard going to sheltered work as respite. The only trouble is we are all at work at the same time but at least you know he is safe and in a good place. But there are lots of people not getting support when their child is a child, less so, but it has improved from what I hear, but it completely collapses when they are 18: completely collapses. Now, part of the problem with [name redacted] is even if he went into a group home, he would have to be incredibly carefully managed now because he does not want to leave home any more. He did, he wanted to leave. He did not have the skills but he wanted ... he had the same aspirations as every young man. He does not want to now. I do not know how we are going to get round that one.

Deputy J.A. Hilton:

That is a difficult one, is it not, because he is 33.

Deputy A.K.F. Green:

He is 33, yes. He has carved a niche out for himself.

The Deputy of St. Peter:

You explained that the idea of going to Highlands does not suit him?

Deputy A.K.F. Green:

He will not even entertain it.

The Deputy of St. Peter:

No. Why is that?

Deputy A.K.F. Green:

I have no idea other than he just will not even discuss it.

The Deputy of St. Peter:

Has he been there?

Deputy A.K.F. Green:

I have taken him up when it first opened because I was quite impressed with it and in terms it is a nice facility. I do not know what the service is like in terms of access or anything. He just did not want to know; he did not want to know.

The Deputy of St. Ouen:

Andrew, if I could explore the involvement of the third sector in providing support to those parents and children. Now we know obviously your links with Headway but can you point us to other organisations that offer support to parents and children with special needs?

Deputy A.K.F. Green:

Mencap is probably the main one to be perfectly honest who you will no doubt be talking to. Mencap is the main one.

The Deputy of St. Ouen:

There is the likes of Autism Jersey for argument's sake?

Deputy A.K.F. Green:

Yes, Autism Jersey.

The Deputy of St. Ouen:

What would they ...

Deputy A.K.F. Green:

I do not know what services they provide but they are very active.

The Deputy of St. Ouen:

They are?

Deputy A.K.F. Green:

Yes.

The Deputy of St. Ouen:

And Headway, what ...

Deputy A.K.F. Green:

Headway deals with children ... they tend more to be young adults because statistically, and in fact it is borne out, most accidents happen ... most brain injuries are caused by traumatic accident and most of those accidents happen between about 14 and 17 unfortunately. So we tend to deal with ... I suppose they are still children but young adults mainly.

The Deputy of St. Ouen:

What about what I call the other charitable organisations? I am not suggesting that parents should be encouraged to approach charitable organisations for support but the likes of Lions Club, Variety, other groups?

Deputy A.K.F. Green:

Yes, they do not provide respite, they provide ... they will help the charities with funding to do different things like respite and they will provide funding to help families buy things but they do not provide a service as such.

The Deputy of St. Ouen:

No but have you ever been offered ... would you know of parents who have been offered support from these organisations to, as you suggested, buy in help.

Deputy A.K.F. Green:

Well, I have arranged for people to receive funds or equipment, more likely the funds, from the Lions Club and from Rotary Clubs and places like that.

The Deputy of St. Ouen:

Do you know how active they are in supporting or is it very limited?

Deputy A.K.F. Green:

No, there are activist people contacting them. They are prepared ... if you contact them and you have got a good case, you will get support. They do not provide the services. They will happily provide the funds usually to buy equipment so ...

The Deputy of St. Ouen:

So just to build list, we have got Mencap. We have got ...

Deputy A.K.F. Green:

Autism Jersey, which is very active.

The Deputy of St. Ouen:

Autism Jersey.

Deputy A.K.F. Green:

But at a specific group again you see. If you do not fit the mould, you do not get it.

The Deputy of St. Ouen:

Then we have got the general funds available from Lions Club.

Deputy A.K.F. Green:

Rotary Club.

The Deputy of St. Ouen:

Rotary and Variety.

Deputy A.K.F. Green:

Yes, those are the ones that would make specific individual things. I mean there is Lloyds TSB and places like that that would have organisations but in terms of individuals you have got 3.

Mr. S. Jones:

But as a carer, can you access respite care from any of these organisations?

Deputy A.K.F. Green:

No because it is not there, is it? So it does not matter how much money you have got.

Mr. S. Jones:

So apart from going to Social Services, there is no other route ...

Deputy A.K.F. Green:

There is no other route at the moment, no.

The Deputy of St. Peter:

In the situation you face, you asked about a holiday and they said: "Oh yes, for that it will be £500 a day." Did you consider going to a third sector organisation for assistance in funding?

Deputy A.K.F. Green:

Well, there is nobody in Jersey that would do it at the present time.

The Deputy of St. Peter:

No, but what I am saying is say you went to the Rotary Club and said: "Do you have any ability to help me fund this opportunity?"

Deputy A.K.F. Green:

Oh, no, I did not, no.

The Deputy of St. Peter:

Why would you not have done something like that?

Deputy A.K.F. Green:

Well, because there are people far worse off than me that need that money. How can you justify ... because I say £500 a day, that would not have covered the whole 24 hours so you could easily be talking £5,000 or £6,000 for a week. How can you justify that when you have got people wanting lifesaving equipment like oxygen and ... I just could not do it. I am happy to buy reasonable service. I am in a position to be able to pay somebody. One of the issues that I did not mention was that we need to get some consistent advice for families as well because Jill had to give up work, as you can imagine, and we were told that I was earning too much by a few pounds to get any support in terms of financial support. In actual fact, that was incorrect information. We found that out years later because it was [name redacted]'s income, not mine, but claims cannot be retrospective. So he does get some disabled support but it was years before we got it because we were told by a social worker you were not entitled to any.

The Deputy of St. Ouen:

Is financial support available for parents and children with special needs means tested?

Deputy A.K.F. Green:

I do not know.

The Deputy of St. Ouen:

Are you ...

Deputy A.K.F. Green:

Some of it, some of it is.

The Deputy of St. Ouen:

Okay. Are there any mechanisms in place at present that provide you with additional financial support that recognises [name redacted]'s needs?

Deputy A.K.F. Green:

No, the only thing we get as parents ... [name redacted] gets now some sort of disability allowance around income support, which is linked to what he earns in his sheltered employment and that is not profit. The only thing we get and I cannot remember the amount but we get a small ... but new carers do not get it, only those that were getting it on a certain date get it. We get a small tax relief as carers but that does not apply ... if you suddenly find yourself a carer today and you have never claimed it, you cannot claim it now, you cannot access it.

The Deputy of St. Ouen:

Are you saying that our benefit and taxes do not recognise that parents with children with special needs are faced with additional costs?

Deputy A.K.F. Green:

No, it does not recognise it now. I get - I cannot remember - something like £1,500 allowance but new carers ... identical situation to mine but happening today would not get that. There is no tax support at all.

[11:00]

I have to go down and ask for a special form because it is no longer on the income tax form and you are only allowed to have that form if you have claimed it before.

The Deputy of St. Ouen:

Talking about holidays, just picking up on charitable organisations, in our parish, St. Ouen, we have Maison des Landes, which offers a sort of a respite type of environment.

Deputy A.K.F. Green:

Yes.

The Deputy of St. Ouen:

Has anyone ever suggested that you make use of ...

Deputy A.K.F. Green:

Yes but you have to send a carer with the person. Maison des Landes will not take a person without a carer. So we do use it, Headway uses it, but you have to ... it is not respite because the person has to go there with their carer. It is certainly a change in environment, which suits some people and it is nice because your meals are cooked for you and you go off on a coach tour every day. As you know, it is only 150 yards from me anyway.

The Deputy of St. Ouen:

But with [name redacted] or anybody else for that matter would they have to be a direct carer or could it be a ... it could be any carer?

Deputy A.K.F. Green:

Maison des Landes would not care as long as the person turned up with a carer.

The Deputy of St. Ouen:

Right, okay, thank you.

Deputy A.K.F. Green:

Yes, as long as Maison des Landes knows that that person has got someone supervising them, it does not have to be their normal carer if that is what you are asking.

The Deputy of St. Ouen:

Right, yes, thank you.

The Deputy of St. Peter:

Is there anything else that you would like to add?

Deputy A.K.F. Green:

No, I think for me okay we have to look back to learn the lessons but for me it is what happens going forward in terms of increasing the provision and I know perhaps widening it from respite. I would like to see a budget given against an individual when their problems are identified. It might need increasing as time goes on at the moment but a budget always goes with them because that has always been the problem. The haste to get rid of them from Education to Health, for example, it is all about money, and if that budget goes with the person you are halfway there. But if the budget is going with them, because there has to be those services to buy, and at the moment they are not there. So that is something that will need to be developed whether that is to buy respite in an institutional environment however nice it is or whether it is to buy respite at home, which is what I think we would probably want mainly. Other people may have different views.

The Deputy of St. Ouen:

Just picking up on a point you raised earlier about [name redacted]. You were saying that [name redacted] was fortunate to be able to find some form of employment.

Deputy A.K.F. Green:

Yes.

The Deputy of St. Ouen:

I presume you are also aware that there are a number of individuals that that is not available?

Deputy A.K.F. Green:

I know that is why I used the term “fortunate” because he was found through Workwise a job on a farm, which I was very pleased about and the guy was very nice except that [name redacted] never got ... he was supposed to be paid. He never got paid and eventually I pulled him out of that and said: “I am not prepared for [name redacted] to go there.” Every day he was collecting eggs out of the chicken pens which he enjoyed doing and grading them and he would put them in the machine and he worked there for about 6 months and never got paid once. Every week I would ring the farmer up and he would say: “Oh yes, the cheque is in the post, the cheque is in the post.” It never came so I went back to Workwise and said: “This was unacceptable” and they agreed. The supervisor came out she said it was totally unsuitable, totally unacceptable and there was a vacancy at Acorn in the gardening section. Incredibly lucky because [name redacted] has been there ever since. But there are loads of youngsters who would value work that cannot get that sort of thing and they do not all want gardening either. You speak to them and I know you do, Jackie. You speak to them. Some want painting opportunities, some want gardening, and some want basic admin opportunities. I am sorry, it is a myth to say there is a job out there for everybody. There is a job out there for lots of people given the right support but there are some that will always be in sheltered employment and I do not care if it is not P.C. (politically correct) to say it. So [name redacted] has been incredibly lucky.

The Deputy of St. Ouen:

So I think just to pick up, so looking for a way forward, what are you saying that we must not forget that these individuals once they leave full-time education require meaningful activities or ...

Deputy A.K.F. Green:

Yes you have to ask yourself, and I know we are widening it, but you have to ask yourself why we bother to take them through the education system, build up their expectations and then say: "But we do not have anything for you." You have to ask yourself that. I think it is soul destroying frankly. We told them that they are going to be able to do this and they are going to be able to do that and when they leave, they sit at home because there is nothing there for them. We are incredibly lucky in that respect where [name redacted] has this job. But even then, when the minimum wage came in, he went down from a 5-day week to a 4-day week. Today is a problem for us, Tuesdays, because that is [name redacted]'s day off. He has Saturdays and Sundays off as well, but we are home. Today is a big problem for us on a Tuesday because he gets the same wages now as he did but he works less hours to comply with the minimum wage. That is not particularly helpful.

Deputy J.A. Hilton:

So you think that people like [name redacted] would benefit from a change in regulations in employment law?

Deputy A.K.F. Green:

Yes. I spoke to Paul Routier about it but he could not ... I mean, when you see him, he may have a different view now but he could not see it.

Deputy J.A. Hilton:

So you would rather obviously see [name redacted] working the 5 days a week and still get the same amount of money, even though it dropped below ...

Deputy A.K.F. Green:

I think we need a trainee rate.

Deputy J.A. Hilton:

A trainee rate, yes.

Deputy A.K.F. Green:

And I think Francis Le Gresley is looking at that at the moment. There is a balance between abuse, taking advantage, and ...

Deputy J.A. Hilton:

And really what is in the best interests of the person concerned and their family because obviously for you as a family and for [name redacted], it is better that he is working 5 days a week.

Deputy A.K.F. Green:

We have got round it by J.E.T. arranging for him - not at the moment because it is the winter - but John Troy the guardian up at Elizabeth Castle, John used

to work for me and through J.E.T. [name redacted]does work experience on a Tuesday at Elizabeth Castle.

Deputy J.A. Hilton:

Does he?

Deputy A.K.F. Green:

Yes, which works in the summer. John is very understanding. He understands that [name redacted]does not work very hard one day and then makes inappropriate comments and what have you, makes usually ... well, I will not say because there are lots of ladies here but because John and I know each other, but he gets that support from J.E.T.

Deputy J.A. Hilton:

Yes, absolutely.

Deputy A.K.F. Green:

But he does not get paid for it.

Deputy J.A. Hilton:

No.

Deputy A.K.F. Green:

He thinks he does and I do not let on but he thinks he does because it is easier.

Deputy J.A. Hilton:

Yes.

Deputy A.K.F. Green:

But I think you understand.

Deputy J.A. Hilton:

Yes I do.

Deputy A.K.F. Green:

Sorry if I have rambled on.

Deputy J.A. Hilton:

No, it has been really helpful.

The Deputy of St. Peter:

Very useful, thank you.

Deputy J.A. Hilton:

All right.

The Deputy of St. Peter:

Thank you very much for coming.

Deputy A.K.F. Green:

Okay, no problem, thank you very much for listening to me ramble on.

[11:08]