



## **Health and Social Security Scrutiny Panel**

### **Assessment of Mental Health Services**

### **Witnesses: Shelter Trust, Jersey Alzheimer's Association, Autism Jersey**

Thursday, 10th January 2019

**Panel:**

Deputy M.R. Le Hegarat of St. Helier (Chairman)

Deputy K.G. Pamplin of St. Saviour (Vice-Chairman)

Deputy C.S. Alves of St. Helier

Deputy T. Pointon of St. John:

**Witnesses:**

John Hodge, Director, Shelter Trust

Trevor Garrett, Trustee, Shelter Trust

Sean Pontin, Manager, Jersey Alzheimer's Association

Lionel Gomes, Interim Director, Autism Jersey

[11:01]

**Deputy M.R. Le Hegarat of St. Helier (Chairman):**

Good morning and welcome to the Health and Social Security Scrutiny Panel team that are still reviewing mental health services in Jersey. This morning we have Shelter Trust and Jersey Alzheimer's, and hopefully Autism Jersey will join us. What we will do first, this is being live-streamed and we will introduce ourselves so that both the people within the room and also the public will know who we all are. I am Deputy Mary Le Hegarat, District 3 and 4 St. Helier, and I am the chairman of the Health and Social Security Scrutiny Panel.

**Deputy K.G. Pamplin of St. Saviour (Vice-Chairman):**

I am Deputy Kevin Pamplin of St. Saviour No. 1, and vice-chairman of this panel.

**Deputy C.S. Alves of St. Helier:**

I am Deputy Carina Alves of St. Helier District 2. I am a member of the panel.

**Deputy T. Pointon of St. John:**

I am Deputy Trevor Pointon of St. John. I am a member of the panel.

**Deputy M.R. Le Hegarat:**

I will also advise that there are staff in here from the Scrutiny team and also for the live-streaming, and I will ask the representatives if they would introduce themselves please.

**Director, Shelter Trust:**

My name is John Hodge. I work for the Shelter Trust.

**Trustee, Shelter Trust:**

I am Trevor Garrett, I am trustee with the Shelter Trust.

**Manager, Jersey Alzheimer's Association:**

I am Sean Pontin from Jersey Alzheimer's Association.

**Deputy M.R. Le Hegarat:**

Just for you to be aware, this broadcast does work under the remit of States Assembly privileges. We will ask a number of questions and we will ask each organisation to contribute to those questions. Some may be more specific to certain organisations as opposed to others but if you have some contribution to make feel free to do so. If you have any questions of us, again, please feel free because obviously this is for us to gain as much information as possible. There may be something that you feel that would be of benefit to us while doing this review. I will start with the Jersey Alzheimer's Association, if I might. In general, how is the demand for the services you provide changed over the last 2 years?

**Manager, Jersey Alzheimer's Association:**

Services for people with dementia generally, people coming to us asking for service has increased I would almost go as far as to say exponentially really. We quote a figure of 78 per cent increase in our services in the last 3 years from people dropping into the office that we have at the top of town, to people asking for support, whether they are people with dementia, people anxious about maybe having dementia and probably the majority of people we support are people who are caring for

people or friends of people with dementia in some way. What we are seeing is quite a boom and quite a pressure on our service. What we can quite clearly say, not just in Jersey but across the world, is that those services are going to be well needed in the future. The number of people being diagnosed with dementia is increasing. We know that the numbers that are quoted in Jersey, in the U.K. (United Kingdom) and around the world are quite terrifying in a way. Looking at a twofold or threefold increase before 2050 of the people diagnosed with dementia. As we also know, when you are looking at that in the same timeframe of the amount of people of working age decreasing and the amount of people living longer increasing, for me that is creating a worrying future and I think we are beginning to see that, as we are coming through the work that we are putting into the community.

**Deputy M.R. Le Hegarat:**

I will ask the same questions of Shelter.

**Director, Shelter Trust:**

In 2017, 364 people spent at least one night with Shelter accommodation. There was a further 108 people who accessed other kinds of services and support from us. Our initial January figures for last year, 2018, show a significant increase on those figures from 2017, although they are not ready yet for public consumption. But what I would say is that in both sets of figures a significant proportion of those people would be challenged by mental health problems.

**Deputy M.R. Le Hegarat:**

I think you have already provided us some information in relation to this, but what do you think are the reasons for this change in demand?

**Director, Shelter Trust:**

Generally in homelessness.

**Deputy M.R. Le Hegarat:**

Across the board and with mental health?

**Director, Shelter Trust:**

Across the board. For us, we have seen a significant increase in the number of young people who are homeless, which is of particular concern to us and, by young people, we would define that as people under the age of 25. I think some of the reasons for that, it is difficult to attribute certain definite reasons to it, is that many of the young people who are coming to us have been known to the care system, coming up through their formative years, and have struggled with that transition between being adolescent, young adult into being an adult who is functioning in a mature way, unemployed, unable to hold down their own address and have positive relationships and the rest of

it. That is one aspect of that. For other people who are homeless it is about availability of affordable appropriate housing. It is about some of the attendant issues that they present with, and that could range from mental health issues through to alcohol and drug dependency issues, and a whole bunch of stuff in between. Sometimes all of those things together in the one person. So I would say that there are many contributing factors leading to the increase and those are the some of the reasons why we have seen the increase in recent years. I think one of the challenges for us is to try and work more efficiently and effectively with the other agencies that we work with to see people for as short a time as is practically possible before getting them back into mainstream accommodation. Because I think coming into a homeless hostel or medium-term hostel accommodation is not a good place for anyone to be. It is incumbent on us to have people with us for as short a time as we possibly can make it.

**Deputy M.R. Le Hegarat:**

Is there anything else you wanted to add in relation to why you think the demand has changed?

**Manager, Jersey Alzheimer's Association:**

I suppose in many ways, it is like many things, especially in a small island, but generally as awareness as grown people are more aware of dementia, people ask themselves questions quite early about: "I am beginning to forget things, beginning to do things slightly different, might I have something going on?" I have to say in a positive way, I think services generally across the Island have improved in the last 18 months so I think you probably are seeing more people coming through the right doors, which puts them on people's agenda. That will lead to an increase in diagnosis and an increase in signposting. So that is good. It is good news from that point of view. I think there is better awareness in terms of where dementia might be occurring, not just in older people, so I think you have medics in other parts of the community thinking dementia might be a factor when previously they might have had a patient or a client stuck in a neurology route or a mental health route, people are thinking it might be that someone is experiencing mental health behaviour, so to speak, but we might need to send them down a more physical route. So you are seeing people signposted to better places where you get a proper diagnosis.

**Deputy M.R. Le Hegarat:**

In relation to Shelter, you did touch on young people using the Shelter. Are you able to give us a little bit more about why you think that is the case? In particular, how this will affect their mental health?

**Director, Shelter Trust:**

We think at Shelter stable accommodation is one of the very basic needs that everyone requires to live a reasonably satisfied life and I think it does not change for young people. There has been

loads of research into this but certainly 45 per cent of homeless people accessing services in the U.K. have been diagnosed with mental health issues, and I would not be at all surprised if that figure was similar here in Jersey. Certainly that figure feels familiar to me with the numbers of young people who are accessing Shelter. In 2017, which is the year we have definite figures for, 64 of the 364 people who spent time with us were young people. So of those 64, I would say it would not at all surprise me if 45 per cent, 50 per cent of those young people had a diagnosed mental health issue. That would range from everything at the quite severe end of having been inpatients down to having access of mental health services via G.P.s (general practitioners), and the outpatient services in between. I think homelessness can cause mental health issues and mental health issues can cause homelessness. Our job, at least in some part, is to sort of discern what is causing what and then to signpost people properly to the services that can intervene on their behalf together with ourselves, to get people back into mainstream accommodation. But I think if someone, for instance, is struggling with mental health issues, to be discharged, for instance, as an inpatient to a homelessness facility, is hardly an ideal start for a recovery and a person's sense of well-being, I would say would hardly be enhanced or people would not feel too much better about themselves in the sense of well-being if they had been an inpatient for mental health reasons and then subsequently are discharged to a homeless hostel. If that is the case, if there are no other options for that person, then fine, we need to get that transition right and sometimes that transition is not as right as it might be, that discharge planning element of people coming to us perhaps is not as good as it should be.

**Deputy M.R. Le Hegarat:**

Is there a lack of facility then for people who are discharged when they are coming out? Is there a lack of facility, do you think?

**Director, Shelter Trust:**

I would say that we certainly see more people than we should coming to us from recent episodes of mental health illness. So I would say that there is at least a kind of anecdotal set of evidences that there might be a shortage there for people who have been inpatients in mental health services coming out to something other than homeless hostels. Obviously not everyone who has been an inpatient is coming to Shelter, that is just not the case. But it happens more often than I think is healthy for those discharged patients.

**Deputy K.G. Pamplin:**

Just curious about the referrals, identifying about 50 per cent of these young people could have a mental health diagnosis. How do those referrals happen if you were going to just look at them? So are people just phoning you up? Is it just parents phoning you up? Are they self-referring? Or is it coming from doctors, hospital, how can you break that down?

**Director, Shelter Trust:**

All of those. So quite often it is self-referral but when you get beyond the idea of or get beyond the practical sort of getting to know the person, we find out that they have been in services for significant periods of time. Quite often we are referred to by people like Children's Services, Adult Social Services, concerned other agencies such as churches, parents, people who know the family, police service, all sorts of areas of referral. The prison service, mental health services, so the streams for the referrals are broad and wide.

**Deputy K.G. Pamplin:**

So when they contact you and they suggest that maybe this person has a mental health illness or there is a concern, say they are coming from C.A.M.H.S. (Child and Adolescent Mental Health Services) or something like that, what is the process? How do you then meet with them and determine that that is the right place and you can help them? Do you bring them in, meet? How does it work?

**Director, Shelter Trust:**

So that is exactly what we do. We send them a set of papers, it is a referral document. That referral document is completed by both the person who is going to become the service user but also by the referring agent.

[11:15]

We then meet the person and we take it from there. Although I do have to make clear that people refer to us for accommodation but I guess our sense of that is that accommodation is such a critical part of somebody's sense of well-being that it should be much more to the forethinking of, we hope, mental health professionals and others because it is such a key element of someone's sense of being or care.

**Deputy K.G. Pamplin:**

Hopefully a foot in the right direction where they can build up their esteem. So how long would you say, on average, these young people are with you before you are happy that they are going off on to the next stage of their life?

**Director, Shelter Trust:**

I guess that depends on the individual. It depends on what the presenting issues are. So we use a licence system at Shelter for the Strathmore facility, and that would be a licence for 3 months, 6 months, 9 months or a year. So that young people can put their stuff together again and then launch

themselves out on mainstream accommodation and mainstream life because living in a communal hostel setting is not mainstream life, it is a bit of a goldfish bowl and if it becomes a permanent or medium-term result for that young person it is not a good developmental thing for that young person.

**Deputy K.G. Pamplin:**

What would you say is the percentage of those young people who do go out but then have to come back to you because they have had a mental health relapse or the support that they were hoping to get has not happened and you get returning people back to use that?

**Director, Shelter Trust:**

We do get returning people back to us but attributing that to mental health issues is not something that we currently undertake.

**Deputy K.G. Pamplin:**

Do you get people coming back to you because something has gone wrong and they come back?

**Director, Shelter Trust:**

Of course, we do get people coming back to us. That is because when people become homeless it takes people a lifetime to reach out and sometimes it takes more than a few days or few weeks for people to sort out those things. To sort them out permanently sometimes it takes more than a second chance. Well at Shelter we believe in ninth and tenth chances sometimes. But for young people, particularly, we take it very seriously that we have to get those young people back out and reconnecting with their life, their families, if that is appropriate, employment, training, purposeful use of their time, I could say social relations, and the rest of it. All of those things contribute to a person's sense of mental health well-being. So that is a task for young people and we do have returnees.

**Deputy K.G. Pamplin:**

It is fair to say if we think about homelessness, and we see the U.K. picture and we see people sleeping on the streets, yes, we know of people who do sleep outside but it is slightly different over here, is it not? There is a stigma involved but also we do not see them lying around but the reality is because of the high cost of living and low accommodation available that there are these people who literally have nowhere to go if they want to start their life again.

**Director, Shelter Trust:**

Absolutely. I think one of the major successes in Jersey has been the lack of prevalence of people rough sleeping because Shelter Trust and Jersey Homeless Outreach provided an outreach service, which ensures that those occasional people who are rough sleeping are offered a bed at the emergency hostel immediately, and that we can keep the numbers down. So you do not see people

sleeping in doorways in big numbers as we used to do in Jersey. That is a success. But I think it is still the case that there are way too many young adults accessing homelessness services for us to think that things are going well.

**Deputy K.G. Pamplin:**

If you are going to put a finger on it, why is that the case in Jersey, which is often described as an affluent, lovely place to grow? It is safe, no crime, why are young people ending up with nowhere to go?

**Director, Shelter Trust:**

Jersey is all of those things of course. It is all things at once. I think there are many reasons. Mental health, sense of well-being, is definitely one of them. There are self-esteem issues. There is an epidemic of self-harm - male as well as young adult females - all contributing to the prevalence of people who are presented to us with both homelessness and mental health issues.

**Deputy K.G. Pamplin:**

What is your greatest worry if you looked at the next 5 years?

**Director, Shelter Trust:**

I think we would be looking to reduce significantly the number of young adults under 25 who are accessing homelessness services. So our biggest worry would be the converse of that, and that would be that the numbers of young adults presenting would continue to rise. That is not to say we are in any way ignoring over-25s. But it is a particular worry for us with under-25s.

**Deputy K.G. Pamplin:**

So for argument's sake, if there was a mental health strategy with a mental health facility supporting, for example, it would lessen the burden and these people would have that early intervention?

**Director, Shelter Trust:**

Yes, and other options other than Shelter.

**Trustee, Shelter Trust:**

Can I just comment on looking to the future? There is well-established research available around the world that shows that young people who become homeless are likely to return to homelessness at various periods during their life unless effective measures are put in place at an early stage to solve their problems. What you will find is that periods of homelessness will be interspersed with periods of imprisonment, possibly time spent in a mental health facility, whatever, but it is a long-term problem. My great theme, my great push really, is that the emphasis should be given to

prevention so that people never get to Shelter because they are identified as having difficulties, having stresses and strains in their relationships with parents caused by mental health or whatever, and that affected measures are put in place so they never reach homelessness. Nothing would please me more than, as a trustee, not for any financial reasons whatsoever, but because of a lack of need, than to close Strathmore, which caters for young people. If we could close that because there is a lack of demand that would please me no end. I think it frightens me slightly that in my lifetime I can recall homelessness as being a mature adult issue in the 1960s and 1970s. Suddenly we have got a whole bunch of young people. That is worrying. You worry where it is going in the next 10 years.

**Deputy K.G. Pamplin:**

Do you think also there is a problem with the culture of failure? That if you fail it is such a huge stigma and, as you have just alluded at the beginning, it is human to start, you dip, but that is fine because that is part of the growth process, that you will have these downs. We should be holistic in that to say: "That is okay." But are you sensing because these young people are more worried about the culture of the Island, its failure and not living up to expectation, it has a huge detrimental effect?

**Trustee, Shelter Trust:**

I think there is a pressure on youngsters today about success. I think some people see the success of their peers and their seniors. I know of young people who, as they are coming to the end of their education, will look around and they will see people earning huge sums of money and enjoying a fantastic lifestyle. That is where they want to be but there is a massive gap both in years, experience, knowledge, training and all the rest of it, between where they are at that time. They want to move into that affluent part of life and the pressure to get there, I think, is enormous. I share John's concern about sort of the mental health issues with young people and I do worry about the future.

**Deputy K.G. Pamplin:**

That aligns with the self-harming, does it not, because it is the pressure of peer pressure, expectation that is put on that you need a certain wage to survive in Jersey, so to speak, and if you make a mistake in Jersey because we are a small community, everybody sees it and then you are put down. Then you seem like you have failed. From what you are suggesting, we have to break this and say: "Failure is okay, it is part of your learning growth and you are going to be okay down the future." I think you touched upon it earlier about the early intervention and changing of culture that it is okay to fail.

**The Deputy of St. John:**

Trevor, we are very interested in what you are saying about prevention and that there needs to be more work done to prevent homelessness. Young people specifically are a concern. But what is

also interesting about the concept of prevention is that talking to mental health services they see the Shelter Trust as part of their prevention effort. I wonder where you see yourselves in relation to the mental health services? What would you see as preventative measures from your point of view?

**Trustee, Shelter Trust:**

I do not want to steal John's thunder but I see Shelter Trust as being a support mechanism for people who have already reached a fairly low point in their life. What I would love to see is an intervention coming before they start too far down that slippery slope towards the lowest point of their life. Now I do not have all the answers. I cannot say what would be effective. But there is research out there on what works in the area of mental health to improve the life of youngsters and prevent them reaching that point where they are homeless. Shelter Trust is a wonderful support facility but that is there for people who have reached that low point. I would like to see people not reaching that low point, not going anywhere near that low point where they become homeless. That is outside the remit of Shelter Trust.

**The Deputy of St. John:**

But it would be interesting to know what you felt would be ... whose remit it would fall into.

**Trustee, Shelter Trust:**

From the research that I have done, it can start as young as infancy. Authorities can become aware of vulnerable families, families that are struggling that may result in some later stage in difficulties manifesting itself with children. So that early intervention can start with infancy and go right through the education system and right through until, if they are in care, then the transition from care to independent living, that needs to be handled with great care and with incredible support. We are looking at a very vulnerable group. If the problems, the issues, can be identified at an early stage by whatever authority, whether it is Children's Service, Education, mental health, whatever, and appropriate measures put in place to prevent them going to that low point, nothing would please me more than not seeing any homeless young people.

**Director, Shelter Trust:**

If you take the example of the young people that we are working with up at Strathmore, quite often we, as a community, have had many opportunities to intervene positively in that young person's life through the formative years and perhaps if they are a vulnerable family and have had contact with social services and the rest of it. I think for us, in terms of the early intervention Trevor is talking about, is making best use of those opportunities and coming up with solutions and the support that that family needs so that they never arrive at our door. If they are to arrive at our door then I think an example is if someone becomes an inpatient as a mental health patient and they go into that inpatient episode as someone who is precariously housed, I think it behoves the mental health

services to be thinking about that person's housing from day one, when they are an inpatient, so that when they are no longer an inpatient they go back to stable accommodation rather than coming to Shelter.

**The Deputy of St. John:**

That very statement suggests that they are not doing that.

**Director, Shelter Trust:**

On occasion for sure, yes. On occasion for sure there are opportunities missed and that sort of creates obviously because I think the recovery of the person who has been discharged in some sense has to be less than ideal if they are coming back into being temporarily housed in an emergency hostel situation or even in a medium-term hostel situation. I think there are opportunities which should be exploited, which are not being at present.

**The Deputy of St. John:**

How much more support do you need from mental health services?

**Director, Shelter Trust:**

I think mental health services are a completely vital relationship for Shelter and homeless people, and mental health services and how we react as support for homeless people. So I would like to see more collaboration, more established and create ways of working so that we can introduce a sort of process standard, which is not hit and miss or less hit and miss than it is at present. I would like to see more certainty about what happens to someone when they are a mental health patient and they are precariously housed. How does that work and can we establish and agree ways of providing that person with accommodation? I view mental health services as vital and a relationship as reasonably solid and positive, which requires significant improvement.

**Deputy M.R. Le Hegarat:**

This is a good point to welcome Autism Jersey.

[11:30]

If you would like to just introduce yourself so that the public listening to the live stream are aware of who you are. Then I will ask you the same questions as I have asked the other groups.

**Interim Director, Autism Jersey:**

Thanks. My name is Lionel Gomes, currently interim director of Autism Jersey who provide a variety of support services for children and adults on the autistic spectrum.

**Deputy M.R. Le Hegarat:**

We have just asked the other organisations what changes they have seen over the last 2 years in relation to demand for their services, and obviously we will ask you the same question.

**Interim Director, Autism Jersey:**

I think in autism there has been increased demand, partly due to recognition of the need. But it is an ongoing demand as well. There are similar demands out there in the community that is unmet. That is something that we come across weekly, if not daily.

**Deputy M.R. Le Hegarat:**

What do you think the reasons are that the changes are to demand? Why do you think that that is happening?

**Interim Director, Autism Jersey:**

It can be down to a lot of different things but obviously the way in which people live. The way in which families cohabit. A lot of individuals want to live independently. Society expects people to have a job, live independently, access community and function in their community. So we look at how we can support those individuals to do that. But there is a growing need out there so that is a cultural change, which has an impact. I think the recognition of the impact that other conditions might also have on autism and be associated with autism and the impact and the recognition of that, then starts to step outside of our remit of what we can deliver in terms of autism support, especially when, if we are focusing on the mental health side, there is autism but there are also people with autism who suffer from mental health as well. In the research of autism that is being identified more and more and the ability to identify that whereas historically potentially it was just labelled as autism, whereas now we are able to have the tools to identify different mental health conditions within autism as well.

**Deputy K.G. Pamplin:**

Almost similarly to Alzheimer's and dementia, it is now more known about so the awareness factor of it, if you were to go back 15 years, we probably would not know what on earth it was.

**Interim Director, Autism Jersey:**

Absolutely.

**Deputy K.G. Pamplin:**

Now it is a recognised thing. In that, obviously when that becomes an awareness factor identified you get busier and people start to understand it but alongside that is the caring because having a

charity background myself, it is the support put in place and the actual mental health is therefore needed for the parents or the carers. If you could delve into a little bit of that, because that is where I feel the impact really starts with.

**Interim Director, Autism Jersey:**

We have noticed that and recognised that. As a service, we have looked at how we can support that. So we have introduced our own provision of counselling for parents of young children, and there is a need to expand that so that we can offer the counselling and support for individuals, adults with autism as well. It is a very specialist field. Currently we do not, I think, have that support network on-Island, especially in complex cases. So that is kind of a huge area of need currently which we are looking at and want to work closely with the States of Jersey in developing.

**Deputy K.G. Pamplin:**

Because the culture, we talk about culture change as well. I know lots of people contact various States Members, myself included, because they are struggling with their child at school and the lack of support and understanding. As a charity, are you starting to see a different approach by schools? It is a very difficult subject of course for schools to tackle but are you starting to see or is there more work needed to put support in place, especially for parents of young children?

**Interim Director, Autism Jersey:**

I think there is more work needed. The relationship with Education, it requires further development in terms of how it is identified and who is best placed to address the need. But there has been an improvement. The States of Jersey have employed autism specific teams to work with families in the school setting but again that is something we can help to support. I think it is improving, it is just there are still people in crisis. There are still people out there with huge needs. It is those individuals that we come into contact with who are in crisis, who may require assistance immediately, and it is not available and that is the toughest part is when you are speaking to a parent who is in absolute desperation for support.

**Deputy K.G. Pamplin:**

It is going to them and it is informing parents in that moment of crisis what help is available because a big problem we have is that issue of where do we go.

**Interim Director, Autism Jersey:**

That is it. So the signposting, I think there is a need for improvement around signposting, but also expertise. I have worked with quite a number of complex individuals and it gets to a certain level and there just is not the level of expertise to be able to deliver the mental health support that that individual needs. The parents might be signposted to places like Talking Therapies, which do a

great job but they have a waiting list of 6 months. These parents cannot wait 6 months. We do try and ease that somewhat. We do have an in-house counsellor who can provide those counselling services but when it comes to complex individuals, I think we need to look outside of Jersey for that guidance and support. They are out there.

**Deputy K.G. Pamplin:**

That leads me on to Alzheimer's and dementia because I think it is a key point to explain that there is a difference between what dementia is. They are very common but obviously mental illness and dementia ...

**Manager, Jersey Alzheimer's Association:**

Yes, it is a tricky one, because you can scour the internet and read various bits and bobs on mental health issues, mental illness and dementia, all very closely linked and they all have lots of overlap. To be fair, the fact that Jersey puts dementia services within the mental health bracket is not uncommon. In many other places that is put in the same box because it is the easiest place to sit and there is a lot of synergy and there is a lot of overlap, but we feel it is important to recognise that dementia, being an umbrella term for a number of different types of dementia - Alzheimer's being the biggest and one of - is a physical illness, which may well present with mental health issues, either for the person with the diagnosis or, as everyone else is saying, for carers, family members and friends.

**Deputy K.G. Pamplin:**

Is it not curious that dementia and Alzheimer's is the biggest killer in the U.K. last year, the ageing population in Jersey, but as you have talked about before, there is no local dementia strategy and as we go forward with those things I have just alluded to, how dangerous is that? Given what we are expecting down the line with the ageing population.

**Manager, Jersey Alzheimer's Association:**

The organisation has been saying for some time, and to be fair there is recognition across the piece that a focused dementia strategy is needed. Unfortunately we have had a number of false starts in getting there. We have had 2 false starts this year alone and I have only been in post 9 months. There is the recognition within Health and Social Services that it is needed and I think, as I have said to other people, and I think I said in my submission, and when I was reading how many times the word "dementia" was used in the last strategy, it is there. But it is not greatly in bold and it is not used that many times. To be fair, when you listen to my colleagues and knowing what else is going out there in the local community, acute mental health problems, children, young people, self-harm, homelessness, I would worry where dementia would tumble in that pecking order. Especially if we want to continue to think that dementia is an older person's thing, it is one of those natural things

that happens. There are real risks generally, let alone when you look at the numbers we are talking about, and you have rightly looked at, that ticking time bomb, as I have described it, is a real bother. For us and the impact on the community as a whole there is an absolute need to continue to recognise dementia as a serious issue now and in the future. It needs its own focus. I was lucky enough to be at an Alzheimer's Europe conference a couple of months ago where some of these ... I was sitting there thinking it is great to be here. I felt guilty being there, being from a charity, but it was good to be there. I suddenly thought to myself: "Do you know what, I should be here, great, but I actually should not be here." The States of Jersey should be here. The people I was sitting with, and there were 800 people from 50 different countries, but it was good for different charities to be here but as the States, as the people that make these decisions for the public, needed to be sat next to us. But nobody knew it was happening. Some of the things that we talked about, about what is going on in research, what needs to happen for the future and people comparing their strategies, I could do it. I sat with my chairman and I said: "That is it, I will come up with our strategy. I went back to my hotel room and I wrote a 20-point strategy, just bullet points." Then I said to him at breakfast the next day: "I have thrown it away." "Why?" "Because it is not our strategy." What I have probably just written by mistake from listening to lots of other people is the States of Jersey strategy. It is not for us to take on board. We want to be part of that. We absolutely are prepared to lead some of it but we have to be careful where we are at the moment because we are propping a lot of things up.

**Deputy K.G. Pamplin:**

Coming from your background into the charity sector how much burden of responsibility is on these charities who are filling in the gaps where the States have not put these services in place and we could name probably all of them; Cheshire Home, Headway, you guys. So there is the money required to do that but you are a charity so you have to fundraise. You are constantly prioritising.

**Manager, Jersey Alzheimer's Association:**

Having worked for public service for 25 years and doing other things and then coming into here, it is a real shift. However much as a public servant for all those years you might complain about: "I have to save this amount of money and I have got to do this amount" there was always money coming in some shape or form and there was some security with it even though you might not feel it. All of a sudden ... we have just had team photos taken this morning. The team photos we have just replaced from 2 years ago had 4 people. We have just had 9 people including volunteers and other people we had to recruit. The amount of money it is costing us to run the business has gone from £200,000 to £300,000 a year. £15,000 of that comes from the States of Jersey to run a part of the service which costs us £50,000. All those sorts of things do not stack up. I am not suggesting that Jersey Alzheimer's should be doing everything or should be doing things massively differently,

but for all of us in this row there needs to be some fairness in that pecking order, so to speak, in the way our funding works and our relationships work. I think that is ...

**Deputy K.G. Pamplin:**

And a fairness, would you suggest, because you are a gateway to people where there is more trust involved, having had that experience myself, and you have that relationship because it is not government and all that sort of stuff, you have the people ...

**Manager, Jersey Alzheimer's Association:**

There is that.

**Deputy K.G. Pamplin:**

But then by doing that you should therefore have fairness when it comes to sitting down with the ...

**Manager, Jersey Alzheimer's Association:**

We are happy to be here, and I have talked a lot and tried desperately not to interject when you guys were talking, so I have lots of questions. There are so many similarities. What I have been talking about, what we have been talking about, is the need for affectability in service. I know in medical terms there is talk of step-up step-down services, and that is right. We have been talking about it in terms of dementia because what we are seeing is not just ... and Jersey Alzheimer's services, when I have looked at them in the last 9 months, the majority of them are aimed at meeting the social needs of people over the age of 65, and that is great because that is still where the majority of people are. But it is not where everyone is. What we have got is a growing number of people being diagnosed and thinking about they might have dementia in their 40s and 50s. We have not got anybody that comes to our services that speaks a different language. We do not have people from different cultures. There are not very many people in the Portuguese. The community is very well established over many years. If we are into second, third, fourth generations why is it we are not seeing them? Maybe some of the other populations or communities or cultures in the Island are newer and maybe we do not see the older people, but we are certainly seeing other people coming out. Where are we grabbing those sorts of things? When we started to look at and talk to the younger people being diagnosed, I think the youngest people in Jersey are in their late 40s, early 50s, not some of the early 30s that I met when I was away earlier in the year. But there is a point it is so fundamentally different to the day centre on Saturday, to the musical memories group that is massively packed out on a Friday night, arts therapy, swimming, all those are fantastic for different people. Okay, I am 50 this year, I am working with people the same age as me, main breadwinner, I go to work, I have a social life. I might like going for a drink. I might like going to watch football. I have got kids, they might be in young, in nursery, might be in school or I might be supporting through

university. All of a sudden, I have just been diagnosed with what is a terminal illness while we do not say it out loud.

[11:45]

What we have to offer them is a day service, musical memories, so what we need to do is to create a far more flexible service because when that person is diagnosed now he or she might not need care and support in the way that Health can deliver it, for one year, 2 years, 5 years, 10 years. But what we are seeing and what we are hearing is about what is going on for us in the middle of that because you have just told me effectively I am going to die? But I do not need any support. There is nothing you can do for me effectively. There are medications which will slow things down but there have been no new medications for Alzheimer's in over 10 years. It is one of the highest levels of terminal diseases without a cure. So we are saying to someone: "You are going to die." But we are not giving them a mechanism to talk to anyone. So when they want to phone the memory clinic because they have a question. "I have a question right now: 'My husband is just doing something different and I do not know what is going on.'" There is that mechanism to try and weave your way through the health service to get an answer, that it is just unfathomable at times. I understand the effect on resources and maybe it is where Jersey Alzheimer's sits in that middle bit if we want to grow that bit, and I think we do. However, maybe John feels it as well with some of the people he works with and the same with A.J. (Autism Jersey). There was a danger sometimes that the consistency of service and partnership is not always there. If you have a conversation about a referral or someone that you want to talk to, do not leave it too long before you go back to them and ask them another question because they have changed and then you are starting again. I started the same conversation about our £15,000 a year contract 5 times in 2018 and I only started in June. What I have said to people, and I have had this conversation with them, I said I am lucky and they are probably quite lucky because I came from that service 3 years ago, so I understand the other side of the coin and I understand what is going on from my ex-colleagues in Health and Social Services; at the moment, it is tough out there. But it is not right that I have that same conversation with 5 different officers about my contract that only lasts for 12 months and it is £40,000 less than it needs to be. It is not right, that 12-month rolling contracts. What does that mean for a member of staff? How do I employ people and give them consistency? How do I help them to live their life that we have talked about, they need to live in Jersey and pay their bills? But in reality, I do not know what has happened. We should be able to say quite clearly that there is a need for a day centre on a Saturday for people with dementia for more than 12 months because these numbers are terrifying for 2050. Somebody somewhere might be able to get me a slightly longer contract than that. To be fair to colleagues, I know the new regime in Health; I have every faith in and the conversations we are having in that direction are really helpful. But in terms of building a service, let alone a service that is having more and more demands on it, it is really tough out there, really tough.

**Deputy K.G. Pamplin:**

You are beating a different type of will now, are you not? The time for talking about it has happened, there have been multiple strategies and constant bits now time for decisive leadership.

**Manager, Jersey Alzheimer's Association:**

Absolutely, we need to get in and lead right now because that ticking time bomb that I keep talking about is here, it is ticking. I know that the services are developing but we need to look at that step up, step down, that flexibility, that ability to say: "Do you know what, you used to like going to the pub once a week and it was really important to you but can you get a long-term care, someone rather to pay to do that? Can I do that? I am not quite sure. Would it not be good if I could continue with a buddy or someone that could help you just to do that because I am no longer confident to let you walk because you might get lost?" But when you need more than that, that same person or that same organisation is also there, so I do not have to then say: "Do you know what, you can do that bit but I need a care package and also, do you know what, you guys might be able to do that? Now you need to have an overnight stay because I am absolutely exhausted and I need a break or let alone I have just ended up in hospital. You cannot do overnight but John might be able to do overnights." By the time you want to have a conference or a conversation about family you have multiple agencies involved. I understand that but would it not be good if there were lots of overlaps in that community, hubs so to speak, that provided that consistency for people in this sort of situation?

**Deputy C. S. Alves:**

Sean, in your evidence you also made some points about the private sector services in mental health, could you explain your concerns in relation to that?

**Manager, Jersey Alzheimer's Association:**

I suppose it is a question, as well as a concern. I think it is good to have a mixed market. I think we need to have a mixed market and a mixed economy and care steps without a shadow of a doubt. My only concern is that if that becomes more of a focus than services that are available and free at source. For want of a better word, the common person out there might not be able to afford to go to a private organisation that can respond today. You talked a moment ago about that person that is on the phone today that needs that support today or this week and not in 6 months; that person then has that choice. It is good to have a choice because there is now another mechanism and there has always been private counsellors and therapists out there but there are now clearly bigger animals in the market and that is good that people have that choice. I just would not want people to be driven down that road and have to put their hand in their pocket that is already struggling or empty because it is the only thing they can do to preserve themselves and their family. Because they

predicted he has got a 6-month waiting list and because the sort of thing that is being offered is not the sort of thing that they perfectly fit into, whereas someone else where you can pay for the privilege can be more flexible. It is good to have choices but I just have a slight anxiety that all of those things need support and growth. I just think private primarily does not necessarily mean this should stop.

**The Deputy of St. John:**

We have been giving a lot of attention to this over recent months in different committees and most of the discussion driven by the proposition back in 2012, P.82, that describes the description never changed sector community services; primarily they have changed sector community services. Some of those things have happened but what we are doing to demonstrate that something big is happening is we started developing a hospital, for which all of the other services were designed to try and reduce demand on the hospital. We have not got those services. We continue to rely on the third sector to support the aspirations of people who run the government or run the civil service. I am just wondering what your influences are with the officers and with the government in relation to how you provide services. You just mentioned a limitation on your finances, not just how you provide services but what influence do you have? What is your belief about the influence that you can have with a new order? There is a new order about. But it is whether the third sector is being listened to and I think that is important for development of the services you are talking about.

**Manager, Jersey Alzheimer's Association:**

I will just jump straight in, if you like. Certainly in the last few months there has been the opportunity for people from the third sector to meet with colleagues from States of Jersey and, without a doubt, I was at a couple of meetings.

**The Deputy of St. John:**

There have always been meetings.

**Manager, Jersey Alzheimer's Association:**

Yes, meetings that worked up, yes. I think there is a serious group to some of that but only populated by certain people but then that might be the only people that responded to the invite, so there is a yin to the yang, I suppose. I find it quite an interesting meeting, yes, lots of good ideas about how we work together better because undoubtedly we can. I think, to be fair, I was listening to a fair number of my charity head colleagues who probably also need to take a good look in the mirror, if I am totally honest. We all need to look at what we are doing. It is very easy to throw a bomb in certain directions but there are some people who also need to sort of look at things in a more modern way and reform what they do. I think sometimes it is too easy. As I said before, I have faith in some of the people I have met in health in terms of commissioning sense. I am one of those people that trusts from the outset until I have a reason not to, so I am hoping that does not get to that point.

**The Deputy of St. John:**

You do not have to name names. We are talking to the Minister this afternoon, so ...

**Manager, Jersey Alzheimer's Association:**

Sure, yes. To be fair, I have met with the Minister and soon after he and his team came into post, I opted to introduce what we were doing and he has been very receptive. It does not necessarily lead to anything but it is not fair for everyone, 350 charities go banging on every door.

**The Deputy of St. John:**

How are Autism finding their relationship?

**Interim Director, Autism Jersey:**

I would agree, I think there is an openness to those relationships that I have experienced in developing those partnerships. Those partnerships are key to the success in any particular area. I think, like you said, you take it at face value but, again, it is the action that is needed. But I say there have been meetings before, there has been talk before. I think it is largely positive. I think there is a momentum with it and, hopefully, that will continue. It is that action, I think there is a slightly more modern approach to running a charity, which is in partnership with the States. But, again, it is changing attitudes and changing culture of the charities there to prop up the States provision. No, we are not, we can work together on this. We can be experts in our field and work together and within the States there are experts and outside of Jersey there are experts and let us bring this all together. I think it is looking healthy but I think that the proof will be in the pudding.

**Manager, Jersey Alzheimer's Association:**

Yes, and it needs to come quite quickly.

**The Deputy of St. John:**

Comment?

**Director, Shelter Trust:**

But I have a slightly different perspective and I have to say in fact, going back to Sean's point earlier about continuity, I think that is a key aspect of what is happening. I think it does boil down to resources. I think that the States do not properly recognise that in the third sector a little bit of resource goes a long, long way, much further and better and broader and deeper and value for money, than it does in the States sector. I think that for us I am looking forward to the change in terms indirectly, your question you posed, I would like to think we could exert much more influence than we have been able to thus far. Certainly I would agree with the idea that we are heard, the

doors are really always open and people are happy to hear us but the change coming up behind that, so as a semblance of partnership but perhaps the substance is not there quite often. Because the resources required to follow that change and the ways of working needed to follow that change and to establish improvements for the public and service users is not always followed up in the way that it might be. I would take the idea to go broader. We think a relationship with Health and Social Services is perfect, it is far from it. It is good, it is positive, we are heard but I think there is a case for significant change and the substance of that change being more than lone words and a listening ear.

**Trustee, Shelter Trust:**

If I can comment as well. I think there is a great openness post recent election, insofar as we were recently party to a meeting on homelessness to talk about the development of a homelessness strategy in the Island. Shelter Trust has been in existence for more than 25 years and this is the first time the Island has been talking about a strategy. The strategy until then has been for Shelter Trust and we are not the total answer. We are happy to participate, we are happy to support but there needs to be an Island strategy to start looking at the causes and the issues which drive homelessness. For the first time I have been really heartened by the work that is being undertaken in that area.

**Deputy K.G. Pamplin:**

That is a really interesting point you made there about the time, so you know my background with Headway Jersey and the Brain Tumour Charity. Headway was started 21 years ago itself by a group of parents going through a terrible situation, which now, 21 years later, is a vital lifeline to people who have had head injuries. The biggest problem we had or the charities have had over the last few years is seeing that recognition that we are not just a charity who bake cakes and support people, we are a vital service. The collective will over the last few years is to get to that front door and say: "If we were more aligned we would not have people just turning up all the over the place and we would understand what each charity does and how they can all interlock." It is great that we are starting to see that recognition coming over. I guess the fear is, again what you were alluding to, is the overburdens going back to the charities. We have got a new Charities Commissioner, we have got the new register; there are 340-odd we roughly presume. There is a breaking point obviously of how many charities this Island could probably sustain but if more pressure comes down the line and then the Government say: "Here, here is some more stuff, you can do that". But if the financial ...

**Manager, Jersey Alzheimer's Association:**

Yes, and I suppose we do not get the point. A good example for us and stress for us at the moment is the Saturday Club we run on a Saturday. We are open for 20 people with dementia. We are the

only day service that runs on a Saturday. The States day centre for dementia runs Monday to Friday, would prove my share of the clients. But I know for a fact that States day centre is running with 9 people, with 9 clients; 9 clients a day versus my 20 on a Saturday.

[12:00]

My £15,000 towards a £50,000 service, 2019 one or 2 weeks into the Regulation of Care Law, 19 application forms arrived on my desk yesterday. We are going to be regulated, rightly, do not get me wrong, rightly and it will help us to drive our quality and our service in a direction which will help the whole charity but that does not come free. Another wall that I have hit, the fees to register, the fees for the registered manager, the fee to register per place are exactly the same for me running a 6-hour day service for 20 people than they are for my States colleagues running a 5-day service, who are a big company, who is not a charity. There is something that is not quite sitting right there, I think, that it is going to put us under major pressure. We have had to employ a new manager who has a high level of qualification that we can take to a new qualification, which is going to cost money. The training implications for us are going to cost money. That is the yin to my yang; we are open to provide services for the people of Jersey because it is needed. We are open to the conversations that are good and are happening but it will not wait very long.

**Deputy K.G. Pamplin:**

No. If you could all picture for those listening and watching, if tomorrow every single health-based charity shut down because they have run out of money, the funding was not there, the volunteers were not there and the support was not there, so Cheshire Home, Headway, Alzheimer's, Hospice. If you could all individually state tomorrow you will say: "That is it, no fundraising, no money, no support", what would happen?

**Interim Director, Autism Jersey:**

Yes, it would be a crisis. Currently a lot of what we provide is a paid-for provision through long-term care support, so we have that. But the other side of our charitable work is unpaid, it goes unpaid, it is dependent on the fundraising and that is how it functions. We would like to work closely with the States, like I say, to provide a professional service that is value for money. I think we can do that but I think, as an organisation, we can do that but it is not something that we can continuously fundraise for. It is not sustainable, it needs to be a sustainable model, the same as it would be for any other business.

**Manager, Jersey Alzheimer's Association:**

I think what we are doing, rightly, is that we are mopping up and supporting those informal family carers that are invisible to the wider community. Unless A.J. is supporting the husbands, the wives,

the mothers, the fathers, the other children, the whomevers that are affected by someone with autism, unless we are supporting those husbands and wives of people that have got dementia and the family members, then, yes, you want to watch out because then you are going to have a tumble and children and young people that are going to tumble towards Children's Service and need heavy duty expensive placement. The amount of people that will need the care agencies that maybe are not coping, the amount of residential provision you have, unless there is recognition about that and the value of that informal care that happens in this Island, then there is my problem and hence why we need to get together and talk about what we are going to do about it.

**Deputy K.G. Pamplin:**

I guess the same for you ...

**Trustee, Shelter Trust:**

We could operate a sort of an ordinary shutdown. There would not be an immediate crisis because we have maintained some reserves, which would enable us to control the situation for a few months. But it would not be long before you would end up ... at the moment we are supporting 70 to 100 people per night, so can you imagine 70 to 100 people sleeping rough in the car parks or wherever or aggressive begging in King Street? It would happen. We certainly would not want to even contemplate that. I think there is a lot of goodwill within Shelter and there is a lot of goodwill within the community but I think there is probably a limit there somewhere.

**Deputy K.G. Pamplin:**

Is the reality of what a charity is, is it?

**Trustee, Shelter Trust:**

Yes.

**Deputy K.G. Pamplin:**

It is not what it was 50 years ago.

**Trustee, Shelter Trust:**

No.

**Deputy K.G. Pamplin:**

I just have one final question, have you all had contact with the Director of Community and Adult Services, Derek Law, who is the interim director at the moment?

**Director, Shelter Trust:**

Indirectly, I have attended meetings where Derek has been there but I have not had any one-to-one meetings with Derek as yet.

**Interim Director, Autism Jersey:**

Indirectly again.

**Deputy K.G. Pamplin:**

Okay, thank you.

**Manager, Jersey Alzheimer's Association:**

Is he still in situ?

**Deputy K.G. Pamplin:**

His interim contract is up at the moment, we are just waiting to see.

**Manager, Jersey Alzheimer's Association:**

I thought he left before Christmas.

**Deputy K.G. Pamplin:**

We do not know. We are trying to establish what the situation is because some interim posts have been appointed, like the new head of Health and Social Services, so just curious there, thank you though.

**Deputy M.R. Le Hegarat:**

Anything final from anybody?

**Interim Director, Autism Jersey:**

Just the early intervention thing you were mentioning before, I think across all of these services is things that we share, the similarities and there are huge differences but I think the key does lie in that early intervention and the cost effectiveness of that. I think we could all evidence the impacts the work that we do has on an individual. I think it is just recognising that initial investment and what that looks like and how that means that in future that person has a greater mental health, a greater quality of life and healthier mental health. I think it is really key that that is looked at as well.

**Director, Shelter Trust:**

I would underscore that just from a perspective, certainly for us better, deeper relationships with mental health services are key for our service users being well.

**Interim Director, Autism Jersey:**

Specific to the organisation, specific to the need of the individual.

**Manager, Jersey Alzheimer's Association:**

More consistent.

**Director, Shelter Trust:**

Yes, and in the context of Shelter, just to say at Shelter just now we have residents who have head injuries, we have residents who have spectrum disorder and we have residents who have a form of Alzheimer's and on the Alzheimer's spectrum through cortical psychosis and things like that. There is a whole range of diverse needs and complexities to the people that we are dealing with, making the case even more emphatically that early intervention and positive collaborative interest between ourselves and mental health services are vital for our service users.

**Interim Director, Autism Jersey:**

Across charities and other service providers as well, yes.

**Deputy M.R. Le Hegarat:**

Thank you very much. It has been invaluable for us, obviously with this review picking up from various organisations. I am sure for those listening as well it is exceptionally good to be able to hear because I think sometimes people do not necessarily know how many organisations there are and, fundamentally, what they are doing, so that is also very good from that point of view. Thank you very much. If there is anything that you feel at a later stage that you want to ask of us, we are always here and any one of us will be more than happy for you to approach us and speak to us independently if you wish. Thank you very much.

[12:07]