

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 12 September 2016

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Witnesses

Ms Rosemary Doherty, and

Mr Chris Doherty.

The CHAIR — Welcome to the public hearings this afternoon, Rosemary and Chris Doherty. Thank you very much for presenting to us today. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. I invite you to make a brief statement to the committee. I note that we have received your written submission, Rosemary, which was submission 12. If you could perhaps just generalise around the written submission, that would be great, thank you.

Ms DOHERTY — I have got some notes here that kind of reflect that as well, so I will just read from those if that is okay. I am the parent of Chris Doherty, who was diagnosed at 24 with high-functioning autism. Chris is now 29. Prior to his diagnosis and when he was about 15 years of age we struggled with trying to work out what was wrong with his health and his ability to function in what we considered to be usual, normal, everyday situations. Chris was experiencing debilitating headaches. He slept for long hours. He was less active and found it hard to think and concentrate, and he was becoming more and more isolated from his peers, families and friends.

Some examples of what we were experiencing included at family events he would stay for a while and then he would end up in his room on his own. If no-one spoke to him, he would remove himself from the situation. At school when he arrived late and had to walk into class, he would feel embarrassed and awkward. He had to give up subjects at school that he previously excelled in and achieved well in because of his declining attendance; he was not there for the instruction and the learning time. So from around the age of 15 until he was 18 he was seen by paediatricians at the Royal Children's Hospital adolescent health unit.

They tried to treat the symptoms that he was presenting with — sleeping, severe headaches, hard to concentrate, fatigue. At appointments Chris was spoken to on his own, and when I was called in at the end of the consultation I was always told to keep him out of bed and to make him get to school — to get up and go to school as much as possible. Because of his age, I was not part of the initial consultation time. When he left the Royal Children's Hospital we were left on our own. There was no recommended support or diagnosis. Our link to any medical professional assistance was through our GP, who we later changed because we wanted to find someone who cared and was willing to problem solve and work out what was happening with Chris. We just felt we had no answers, no support and things were not getting any better.

As a parent there was a strong sense that there was something else going on. For us, Chris achieved his milestones. He was active, involved in life. He had regular sleeping patterns, seemed happy, compliant and achieved and interacted well at school. When he was a young adult we could not find any medical assistance or anyone experienced to give us direction, to find out what was happening with him, and Chris saw many professionals. There was and continues to be no-one who can oversee a young adult who presents with complex issues — social, emotional and medical. Over many years we have seen specialists in isolation and have been left to try to make important decisions based on limited or no understanding. All this has taken a lot of time, effort, money and emotional strain.

At the moment Chris regularly sees a GP, a psychologist, a psychiatrist and a sleep disorder specialist. Fortunately they write to each other and they talk so that they are all aware of the plans that are in place, the medication and what each other is doing. There still, though, is not one person, that expert, who has a big picture or an overview of Chris's situation and history.

Presently we see a psychologist at the ASD clinic in Kew who keeps us on track with many things, and I do ask him regularly if he knows who else we can see or where else we can go to get support for Chris, particularly at the moment, at his age, for him to get work. Chris this year has gone back to university to complete an honours degree in history at Deakin University. There was a selection process to be accepted by the university to do this course, so their intake includes students who have high marks. Although Chris's marks were lower than what was required, they reviewed his performance and accepted his application, as he had shown improvement over time and also because he had done all his study off campus, with little or no assistance from university staff.

The reason why Chris is studying this year is that he has been with a disability employment service for over 18 months. He has attended fortnightly meetings that usually go for about 10 minutes, and he has not really been given any assistance with or direction for applying for jobs or any job interviews. He needed to be doing

something other than staying at home in his room, sleeping long hours and not leaving the house, and that belief of others around him that he has the capacity to be involved in the world — to work and to contribute.

At APM, that is the disability employment service, they still see him. He attends each week for about 5 or 10 minutes and they sign him off so that he can get Centrelink payments. The résumé that they assisted him with initially we have rewritten as we regarded it as appalling. They have not helped him apply for one job, and they will not offer him any additional skill development as they say that he is too skilled because he has a bachelor degree. We find this confusing as he is seeing them to get work, and we also thought that they would know what employment opportunities would be around for him, given his qualifications.

His study this year has been on campus, which is really positive. He has been attending lectures and tutorials. He has received extraordinary support from the university staff. They have set high expectations for him, at the same time acknowledging and understanding his autistic behaviours. For example, Chris was required to come to Melbourne and do a formal presentation in front of other students and university professors about the research he is studying, and his lecturer organised to pick him up and drive him to Melbourne. There was lots of encouragement and acknowledgement, knowing that he would be anxious, but it was followed up with some really positive feedback. They were extremely impressed, and he was very articulate and showed a deep knowledge of his research project.

Chris is on anxiety medication, and it allows him to have more control, he is more social and it takes the edge off things. When Chris has to do something for the first time, we practise it or we go through it with him. We model and talk through situations like meetings, servicing his car or buying a pair of shoes. He does not always have the right words to use, but once people know of his autism and once he is engaged in a two-way conversation, things are usually fine.

This is another example of trying to find someone to help us. We had a meeting with a group associated with the Gordon Institute who work with people to get employment. The upshot of that was we were basically told that finding a job is really hard and that you probably need to know someone to get a job. So they are just some observations and comments from us that over the time it is likely that his headaches and the other symptoms that he experienced in his teens were related to his anxiety and the autism, but this was never recognised nor treated. Sorry, Chris's diagnosis was at 24, five years ago.

He is intelligent, and his impairment presents in his pragmatic language skills and in his aspects of day-to-day life. There is not a quick fix, and we need to be reminded constantly that Chris's difficulties will always be there, but we also need to understand and continually support him. As parents we have the capacity to assist him with many of the things he needs, but we cannot do some of the work for him. It is hard because of his age. We cannot be included because people have to talk to him. He has to give permission for us to be involved. We believe that he needs support from outside the home so that he can realise his potential.

We live in the west, and we find that there is limited access to groups that can help out there. We do not know whether to tell people that he has autism when he applies for work. We question whether that would work for him or against him in the process. We have accessed and seen things like on Facebook, on the internet and the groups. We have made comments, we have made phone calls and asked for assistance and guidance but never really received anything that has been helpful or something that we can get into.

We question our decision about going through Centrelink and recognising his autism as a disability, and going to a disability employment service, because we think maybe that has disadvantaged him more. For example, a disability employment service does not know about graduate disability employment schemes and opportunities, and that has been a missed opportunity for him because he has missed all the cut-off dates to access any of those. Then by them we are told that he is too skilled to get support, so then we asked, 'Well, where do we go to get support?'

We know that he needs a structured, good routine working environment. We know that if he does get a job somewhere, that the support is going to have to be exceptional. Chris does not know how good he is. He does not really know what is possible. He does not feel the drive and the urge and the instinct, as other people do, to want more for his future, but we feel that he will only see this and know what it means and understand his potential and capacity when he actually is working. Chris will need an understanding work environment as he will misunderstand usual, everyday comments and directions that he has not experienced before. He is very trusting and very literal when he is interacting with people.

Employment opportunities for young adults with autism — you can spend a lot of time searching the internet for help and not get far, nor can you always find someone who you can actually ring and talk to. Trying to find a phone number, trying to find a name and all that sort of stuff can be difficult. I cannot find anyone who I can pay to sit with him and go through the process and work with him to actually physically apply for jobs. I can pay someone \$2000 to teach him interviewing skills, but that is something that I think my husband and I are quite equipped to do — that we can do that. Even his application that they helped him with, we were told that he would not get an interview with that, so we sat down and redid that and worked through that and have been given advice that it is at a good standard now.

With volunteer opportunities, we have been trying to get him involved in interacting in different ways, but that is limiting as well. Once again it is hard to find someone to talk to because when you go over the internet you get the information but you actually have to email somebody. If I email somebody, they will know that I am the parent, not the actual person, so there is another issue with me having to explain myself, and I am not comfortable with that sometimes. He has volunteered at the Wyndham library. He was given a job there through a really supportive interview process that was wonderful, but the job that he had for six months was coming in and shelving books. The other thing is if you try to get him involved in volunteer opportunities, they also require training and an interview process, and that is another hurdle that you have to get over even to be a volunteer.

We can plan for things to happen — for example, for him to attend training sessions for the volunteering, and we might support Chris with practice and strategies. Sometimes this works and sometimes the anxiety can be too great for him if he is left on his own and it takes over. I just feel that there are a distinct lack of services for people Chris's age who present with similar experiences and history. We do not know what we do not know and as such we have been seeking help as to how we can find employment for Chris and support his future as someone with autism. Yes, that is it. Is that enough?

The CHAIR — That is fantastic. Thank you, Rosemary. It is wonderful to hear your support for Chris. Chris, I am sure you acknowledge that your mum is a great support for you. I also want to acknowledge that you are doing your honours this year. That is no small feat; that is a pretty big thing. I know when I did mine it was hard going, so I congratulate you on being enrolled to do your honours this year.

Mr DOHERTY — Yes, just doing my bachelors was hard enough. My psychiatrist says my mum could probably do my bachelors just as well as I can by now with all of the support I get.

The CHAIR — That is because she was your support.

Ms DOHERTY — I did a history one as well.

The CHAIR — An honours by association. Chris, I just wanted to ask you a question. What kind of job would you like to have in the future?

Mr DOHERTY — Academic researcher, working in the archives because as part of my honours and bachelors I went to the national archives at Footscray and I enjoyed it. So that is something I could see myself doing.

The CHAIR — What was enjoyable about that? Was it the environment or the support that you had from the employer or the person where you were going to do that work? What sort of environment do you think you need and then what sort of employer do you think you need to help you to work effectively and to support you?

Mr DOHERTY — I like the academics, so something research based. The archives I can see myself working at because I just could not see myself getting disinterested in the job. I like reading and I like learning, so something like that where I am helping people access the archives and learning. I am learning different things at the same time. It is something that would keep my interest.

Ms DOHERTY — What about the environment itself?

The CHAIR — Is it because it would be a quiet environment?

Mr DOHERTY — Yes, I think quieter, less stressful.

The CHAIR — Where you could do your own thing a lot of the time — do your own research?

Mr DOHERTY — Yes.

The CHAIR — Do you think the staff at the university have been helpful? Do you think they have understood that you have ASD?

Mr DOHERTY — They have been outstanding. When I graduated in 2005 from year 12 — this was before I was diagnosed — I tried to do a bachelor of archaeology through La Trobe at Bundoora, but between the travel, not having a diagnosis and just the headaches and stuff, as they were back then, it was just impossible to complete the degree. But even then, there was a difference I noticed between Deakin and La Trobe. Deakin has well-structured, supportive off-campus study opportunities. When I looked for that through La Trobe it was not really there. There was potential, but, at least back then, compared to what Deakin offered later, it was like night and day; it was completely different in the level of support and organisation offered.

Ms McLEISH — Thank you for coming before us today. I read in the submission, and you mentioned it as well, that during the non-diagnosed period at around 15 years of age you went through all sorts of specialists, doctors and whatever. What do you think that they missed? Why do you think they missed something? Were they rushing their assessments?

Ms DOHERTY — I have asked that question. When we saw the psychiatrist for the first time, I was trying to go over everything because it is quite hard to remember everything that is happening. I am a teacher. I was in the classroom at the time. I had a kid in my class with autism. I said to him, ‘That was 10 years ago. The knowledge was not as prevalent then’. Even in the classroom there was not a lot happening there, and that is the analogy that I made. He turned around to me and he just said, ‘Actually, no, you were going to the adolescent health unit at the children’s hospital. If anyone is going to pick it up, they’re the people who should know’, and they did not. I cannot explain why it was not picked up.

Ms McLEISH — What about your doctor? I noticed you mentioned that you changed family doctors. Once he was diagnosed, was the doctor surprised?

Ms DOHERTY — Different doctor.

Ms McLEISH — Yes, the second one.

Ms DOHERTY — I think I have had more surprise from the people who know Chris and who know us and from teachers that have taught him that are still friends and things like that. Some of them will say, ‘Really?’, and they are quite shocked. Others are not surprised. It was teacher friends that encouraged us to go further with the diagnosis. They had seen a video at their workplace on something, and they just said, ‘You need to go and do something about it. This is Chris. This is what he presents like’. So I suppose it was them outside of us looking in and seeing that behaviour.

The other thing I think of is that we had a home life that was well structured. There was routine. We were a working family; it was boom, boom, boom and all that sort of stuff. There was lots of language happening. But we can and do look back at some of his behaviours that we might have thought were a bit quirky. We might have thought, ‘Yes, he likes these things. We will just immerse him in them’. There probably were elements there that you could consider to have been autistic. But it was more prevalent at 15, whether puberty and all that sort of stuff had anything to do with it. He does not have any friends from secondary school anymore, but I think that is because their social skills and interactions maintained what kids do, and Chris’s did not — they kind of plateaued and stayed.

Ms McLEISH — Chris, what kind of support would you have liked when you were at school?

Mr DOHERTY — It is hard to say. Like Mum said, I had a well-structured home life. I had a small group of good friends who I could hang around with.

Ms DOHERTY — His school supported him reasonably well. However, I would say to them, ‘He needs a mentor. He needs someone to help’. Chris would go to bed happy, and he would wake up with a headache. We had to get him out of bed and get him to school. I spent years, every day, trying to get him to school, and he would be tired, fatigued, grumpy or whatever. I would say to the school, ‘He needs a mentor. He needs somebody there that he can actually talk to and who can help sort out things and put some organisation into

things and what have you'. When it came to actually supporting him, they tried, I think, to the best of their capacity to support him in the school setting. Does that answer you?

Ms McLEISH — Yes, thank you.

Mr FINN — I am just wondering, either Rosemary or Chris, if you could give me an idea of the sorts of attitudes that you have encountered from potential employers.

Mr DOHERTY — Since the diagnosis I cannot really say much of anything because over 18 months the problem is that I have not had a single job interview.

Mr FINN — That possibly tells us all we need to know on that front.

Ms DOHERTY — There has been nothing.

Mr DOHERTY — The Wyndham library, the people there, they were really supportive, but again, there was not really a job there to do. I feel like if I managed to get a job there, they would have been supportive about it. But yes, again, it is about getting a job.

Ms DOHERTY — Chris at one stage did apply for a job to work in the library, and he did get an interview. Unfortunately we were away at the time the interview was on, so we were not able to talk with him, set him up, give him strategies and discuss what might be asked. He went to the interview on his own, and he did not get the job. You did not have a diagnosis then, though, did you?

Mr DOHERTY — That was before the diagnosis.

Ms DOHERTY — At one stage he worked at a petrol station, so we know that he has got the capacity to be regular. He had to open up. Was it at six in the morning?

Mr DOHERTY — It was 5.30 a.m. I had to be there by 5.

Ms DOHERTY — So he had to do the security. He was there on his own. He had to do all the money, the transactions, the phone and everything like that, and at night he had to measure the petrol levels. So we know that he can do those sorts of things, that he can be trusted to do them and that he can do them well.

Mr FINN — You mentioned before that out in the west, where I come from as well, the services are minimal. Can you give the committee an idea of what is available in Werribee, for example?

Mr DOHERTY — Our psychiatrist comes over from Kew to do home visits once a month.

Ms DOHERTY — He does home visits once a month. I really do not know, because Chris was diagnosed at 24. I know, because I work with somebody who runs a business based around assisting families of kids with autism, that it is up to 12 years old. There is money or funding or whatever. We have had none of that. We have gotten none of that, so I do not know.

Mr FINN — Is it safe to say that once somebody with autism has left school, they almost fall off the radar as far as funding and governments are concerned?

Ms DOHERTY — Yes, and even from a parenting point of view you expect your child to finish year 12 and go on to uni. You say, 'Come on, grow up and get out there. You should be able to do this, this and this'. That is what we did with Chris. When he went to La Trobe we paid for him to go and live there for six months, but he kept coming home.

Mr EDBROOKE — They always do that. Everyone does that.

Ms DOHERTY — We wanted him to go there and have a good time like we did, but that did not work either. I feel like we pulled the mat out from his feet, because we backed completely down on the support that we were giving him. I have opened this up today and I have got things here about autism spectrum and communication. I have read through that, and I am thinking, 'Of course I need to be reminded'. We are dealing with issues at the moment to do with finance, and I am thinking, 'Hang on, you need to back off and think, "No, this is because he has autism"'. You do not just think, 'Okay, I've told you this; you need to do this; it's going to

happen', because in five or six weeks time it is like, 'It didn't happen', and then you have got to be reminded: no, it is not going to be like that; he does not do things that way; this is what we have to do to support him. I get that. What I am frustrated with is he is 29. He needs another adult, someone outside his family, supporting him and encouraging him and being part of him being in the world.

Mr EDBROOKE — Nice to meet you, Rosemary and Chris. Just a quick question for Chris: what do you think the disability employment services could have done more, or could do more, to help you at the moment? I have read a fair bit about what is going on, and it is not too impressive.

Mr DOHERTY — The first person I saw was only for like four or five sessions before I had to get changed over because she was getting overloaded, and she was good. She talked me through the process. Every week she could have three or four jobs and offered to help me go through it, but I wanted to do the applications myself. I probably should have got her help with it, but she did that. She started me on the résumé that the next person helped me complete. But, yes, it was the two people after that that I have had bugger all support from, frankly.

Ms DOHERTY — There has been nothing. Like I said, the thing that hit me was I went searching and found out that there are graduate work schemes that people can go onto and people, if they have got a disability, can actually go through, and I am just thinking: a disability employment service that doesn't know that? We found this woman, who looked through Chris's résumé and said, 'No, that is excellent; it is really good' and what have you. She said, 'Look, here' — for, I do not know, \$2000 — 'I can do' this, this, this and this with him. She said, 'I'll go to APM', the disability employment service, 'and I'll ask them if they'll put some money towards it to skill him because it will help him with employment', and she did. We gave her permission — Chris gave her permission — to ring, and when they rang they said, 'Oh no, he can't do that. He's too skilled because he has got a bachelor of education'. Well, he might have a bachelor of education, but that does not give you everyday life skills for employment.

Mr EDBROOKE — Yes, okay; thank you.

The CHAIR — Thank you so much for coming in today, Chris and Rosemary; we really appreciate it. Chris, Greg is going to get in touch with you, via email probably, with some ideas that he might be able to share with you around future support. So thank you very much for coming in today. I just have one last question, if you could quickly answer. Do you think that pre-diagnosis and post-diagnosis has changed anything?

Mr DOHERTY — Personally I think yes, because it has helped understand, like Mum said, all the little quirks that I have, and I think it helped also understand where a lot of the issues underlying the headaches and tiredness and anxiety came from.

Ms DOHERTY — Chris is the best he has been for 14 years. This is the best year he has had in 14 years.

The CHAIR — That is wonderful to hear.

Ms DOHERTY — But this first thing, the diagnosis — it explained to him why he felt like he did because he could never understand it.

Mr DOHERTY — Before the diagnosis I went to the funeral for my Dad's mother and everyone else was crying and I was just kind of thinking, 'Why am I not crying when everyone else is?'. After the diagnosis it was like, 'Oh, I don't quite have the same — —

Ms DOHERTY — The feelings — —

The CHAIR — Connection.

Mr DOHERTY — Yes, emotional thing, connection — not emotional connection, the emotional wavelength, I was trying to say, as other people.

Ms DOHERTY — Family and friends are so different now, because before they used to think, 'Oh, that's Chris. He's just gone into the room to' whatever, or they might have thought he was being rude or whatever, and they do not; they are not like that, now. They actually make the effort to talk to him. If you talk with Chris,

Chris will talk back and you will have a conversation, but if you just stand there and do not talk, he will just walk away because he thinks, ‘Oh well, why should I stand here if you’re not going to talk to me?’.

Mr EDBROOKE — That actually sounds pretty reasonable.

Ms DOHERTY — They can think that he is rude, but he is not. He is going to go back in his room and do whatever.

The CHAIR — Thank you very much, Chris and Rosemary; we really appreciate your time this afternoon.

Ms DOHERTY — Thank you very much.

Witnesses withdrew.