

# TRANSCRIPT

## FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

### **Inquiry into services for people with autism spectrum disorder**

Swan Hill — 14 February 2017

#### Members

Ms Maree Edwards — Chair

Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

#### Witnesses

Mr Scott Alexander, chief executive officer, and

Ms Nicole Doolan, services manager, Murray Human Services.

**The CHAIR** — Welcome, Scott and Nicole, to our public hearing 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. Nicole Doolan, services manager at Murray Human Services, thank you for attending as well. We will hand over to you for a 15-minute presentation.

**Mr ALEXANDER** — Scott Alexander is my name. I am the CEO of Murray Human Services. Murray Human Services is a disability service provider. I am accompanied by my services manager, Nicole Doolan. Thank you for this opportunity. We will use it to put a disability service provider's perspective, with particular emphasis on the adequacy of current services for people with autism spectrum disorder (ASD), and we will also give a brief nod to the promise of the national disability insurance scheme.

First, just a little bit about our organisation. Murray Human Services, more commonly known as MHS, is a not-for-profit incorporated association. It is now in its 50th year as an incorporated body. We provide services to approximately 200 people in Swan Hill, Kerang, Echuca, Kyabram and surrounding districts. The common denominators for the people we support are that they are all adults and they all have some form of intellectual disability. The services MHS delivers cover day services, supported employment, residential accommodation, training and education.

The prevalence of ASD amongst the people we support in Echuca is 24 per cent and in Swan Hill, 18 per cent. This makes clients with ASD by far the single largest cohort of clients MHS provides support to. The trend is for that proportion of ASD clients to increase. In recent years there has been a discernible and obvious trend increase in that proportion.

I am proposing to briefly allude to our experiences with two autistic clients, and the purpose here is to put into practical context where current services have been adequate and, by contrast, less than adequate. There is also a useful contrast with their respective experiences with MHS and how MHS has endeavoured to respond to their particular needs. We have also selected these two clients as examples, particularly because they illustrate typical, almost routine, problems we encounter in service delivery to people with autism.

John, not his real name, arrived at MHS in 2008. He is non-verbal. He had in the previous year graduated from specialist school. There he had a routine and structure, and he was comfortable around and obviously well-known by people who knew him. There was, however, no transition plan for John's move to Swan Hill and specifically to MHS. So when he arrived at MHS we had behavioural problems due primarily to the change in his routines. Further, staff did not have adequate information about John to enable them to support him adequately.

Over the ensuing years, happily, things have progressively improved and changed for the better for John. He has a routine five days a week at MHS and he participates on those five days in programs he enjoys. A speech pathologist trained MHS staff in key word signing to improve communication with John, social stories are routinely used to prepare John for events such as a visit to the doctor and close collaboration by MHS staff with the staff of the house where John lives ensures consistency between the two staffing groups. After resolving over a long period of time these transition problems, it has been a good outcome for John. We continue, however, to find it difficult to have sensory assessments completed for him simply because there is no-one in Swan Hill who can provide that service. The nearest provider is in Bendigo.

From John we go to Betty. Betty has very challenging behavioural problems. Her family, together with the Department of Health and Human Services and disability service providers, struggled to cope and to provide the support Betty needed. It was resolved that Betty, who was then living in another regional area, would move to Echuca specifically to come into the care of MHS. MHS's strengths have come to the fore with the whole-of-life support of Betty: day services, supported employment, training and education opportunities, community access support and support in her independent living home — all of which are provided by MHS. External support from other providers has also been good, and frequently exceptionally good — Victoria Police, ambulance, Echuca Regional Health, Victorian Dual Disability Service, DHHS and mental health.

But Betty still, on occasions, has very challenging behaviour and the limits to what MHS can provide have been exposed. The impact on MHS, and in particular our staff, has on occasions been profound. In a small regional township the pool of specialised skills is shallow. Betty requires specialised support in crisis intervention but there is no specialised funding for that. Similarly, with other support providers, such as the police, they are not trained in how to deal with assaultive behaviour by someone who has autism. The current funding system responds at glacial speed, if at all. In a crisis you need swift action and additional funding, and frequently it takes months to arrive, if at all. MHS, in responding to what are critical and attritional events, has to draw on a small number of appropriately skilled staff and provide additional support, frequently inadequately funded or entirely unfunded, to Betty. We need to increase the depth and skills of our staff, but there is no funding to support that.

How do these two case studies illustrate the pressure points for MHS in the provision of support to people with ASD? To put it another way, what do we need? We desperately need more appropriately skilled staff and funding for training in those ASD-specific skills — that is, skilling the staff we currently have. There will be no funding under the NDIS for such training. A separate issue is attracting and retaining staff at a time when we are anticipating that demand for our services is likely to increase, and again we are endeavouring to draw from a shallow pool of potential recruits. It would also be beneficial for other community service providers, particularly the police, to have training in responding to the needs of people with disability, especially those with intellectual disabilities. This is not a criticism. I hasten to reiterate that MHS has had exceptional support from the community service providers, most notably Victoria Police.

We need, for transition, especially from specialist schools, funding for extra support staff to permit graduating students to spend time in the company of familiar teachers in MHS's workplaces. We need to commence that transition process at least 12 months prior to specialist students' graduation. We would benefit greatly from improved support and funding for the establishment of communication schedules and routines prior to a person commencing services at MHS. We currently endeavour to do that through our communication coordinator role, but frankly, that is inadequate and there are financial constraints on improving the resourcing of that role.

To conclude, one almost entirely unrelated suggestion — that is, assistance in planning for the future. MHS has acquired a lot of property and infrastructure over the course of its 50 years. We are of course endeavouring to plan for the future. For example, in Echuca and in Swan Hill we have big-barn facilities — large buildings from which we run site-based programs and activities for people with intellectual disabilities. Making evidence-based decisions on the future of such facilities is not easy. It requires the collection, collation and analysis of research and data from which we are endeavouring to distil trends in the numbers of particular types of disability and what is best practice in supporting such people not just now but what will be best practice in five years time, in 10 years time and longer. Having a resource which makes the collection and analysis of such evidence easier and more likely to produce good outcomes would be very welcome indeed. Thank you again for this opportunity.

**The CHAIR** — Thank you. Nicole, did you have a contribution, or are you just happy to answer some of our questions?

**Ms DOOLAN** — Yes.

**The CHAIR** — Thank you, Scott, particularly for your submission. The survey was really interesting. I think the results of that have given us quite a bit of information, so thanks very much.

**Mr ALEXANDER** — Good. Thank you.

**The CHAIR** — You referred in your submission and indeed in some of the suggestions within that to supported accommodation, particularly for people with ASD who also have an intellectual disability. I just wonder if you can elaborate a little bit on the KeyRing model of housing that you referred to.

**Mr ALEXANDER** — Yes. I will defer to Nicole.

**Ms DOOLAN** — The name KeyRing comes from the fact that there is one house that acts as a hub and then different houses where people live come off that. So there is the picture of a keyring in the middle and other keys coming off that. The hub generally provides 24/7 support for people who require that level of support, so

there are always staff at that house when anyone is living within the KeyRing. They are your highest support clients.

Then those that live coming off that hub can live more independently and may need support, for example, for a couple of hours per day, or if they contact the staff person during the night and just might need transient support for rolling or for some sort of personal care, and then the staff can go back to the hub house.

**The CHAIR** — And you have this facility operating where?

**Ms DOOLAN** — In Echuca we have two houses that we consider to be hubs.

**The CHAIR** — Based on this? Okay.

**Ms DOOLAN** — Yes. So the positive thing about the KeyRing model is that any person can come and join the KeyRing and they rent or own their own home within that KeyRing. So it meets the changing needs of clients very well, or if they can, they can purchase their own home. They can stay there, for example, if they need transition training for independent living. We can provide that training and then ideally they go and live independently with no support.

**Ms McLEISH** — Are all the houses close to the hub?

**Ms DOOLAN** — Yes.

**Ms McLEISH** — How far?

**Ms DOOLAN** — Within walking distance, depending on the needs of the client. It can be up to a couple of hundred metres away if their needs are relatively low. Obviously if their needs are higher, they need to be in closer contact with the staff.

**The CHAIR** — Thank you. You mentioned the transition from school to adulthood and the community and the requirement for one-on-one workplace training programs. What do you think of the suggestion that has been put to the committee that students with ASD and intellectual disability comorbidity should not have to leave school at 18 but that we could be a little bit more flexible about allowing them to stay until they are 21 or whatever? Do you have a view on that?

**Ms DOOLAN** — I do, yes. I think it is a fantastic idea. I know all the services we provide are tailored to the individual and based on their needs, not on an age or any type of label that someone has given them. It is based on their need, and I believe all services should be provided on that basis.

**The CHAIR** — Including the education system?

**Ms DOOLAN** — Yes.

**Ms COUZENS** — Thank you for that presentation. Just getting back to the KeyRing housing, is the hub bit purpose built?

**Ms DOOLAN** — Not necessarily, no.

**Ms COUZENS** — Okay.

**Ms DOOLAN** — We have one house that is purpose built, so it is for very high support needs, particularly physical needs, but it does not have to be. Particularly if it is someone on the spectrum, it can be any house in the community.

**Ms COUZENS** — Okay. How many people are supported in what you have existing now?

**Ms DOOLAN** — In the purpose-built house we have six adults with disabilities living there and we currently support two clients from that hub. The other hub is currently supporting one person, and she is on the spectrum, and there are currently no other keyrings coming off that. That is just an indication of how fluid the model can be in responding to needs.

**Ms COUZENS** — You talked about crisis intervention, skilled staff and training, which we have heard about before. You are saying there is no funding under the NDIS for staff to be trained. What do you think is the solution to that? I mean, there are a lot more of what we know as services popping up here and there. I know from Geelong's perspective there are lots of new organisations moving in, I suppose, to cash in on the NDIS, and there is a concern around non-skilled staff working in those areas. Have you looked at firstly what would be ideal, and if that is not an option, how you might get over some of these issues with staff training and actually keeping skilled staff?

**Mr ALEXANDER** — Did you want me to have a first crack at this?

**Ms DOOLAN** — Yes, that is fine.

**Mr ALEXANDER** — Okay. We have our own registered training organisation. That was set up some years ago to have dual focus: to train our own staff, and also to provide training and education opportunities for the people we support. We have a very strong mantra within our organisation about the need for our staff to continuously learn and upskill. But it is a paradox that with the scheme coming in, with so much more money coming into the sector, there is actually going to be a paucity of funding for upskilling our staff. We remain committed to providing upskilling opportunities. We will retain our registered training organisation to provide certificate-level courses and diplomas.

We are investing now in online training, so that is very directly a response to the need for us to deliver what we consider to be mandatory training but much more cheaply than we have in the past. That sort of training is manual handling, infection control and administration of medication, but then we get into training which is more specialised, which is more of a dilemma for us, I would suggest. We definitely need autism training, and we have not yet adequately sourced or worked out a way to provide that in a cost-effective and efficient way which has effective outcomes for our staff.

**Ms COUZENS** — Is that a cost issue rather than a curriculum issue, or both?

**Mr ALEXANDER** — It is definitely a cost issue. Sourcing any external providers tends to be extremely expensive, so us sourcing training via online solutions saves us a lot of money without necessarily compromising the quality.

We were investigating becoming accredited with autism services through Amaze, but Amaze have in the last year or 18 months dropped their specialist accreditation. That was going to be quite an expensive and arduous process to get that accreditation, but we are so keen to get skills amongst our staff — upskill and become better known as being a provider of these services — that we wanted to commit to that. But that now is no longer available, so we have an unfulfilled need in that area at the moment, so we continue to explore it. It is definitely a need that we do have and we are committed to filling. Do you wish to add anything, Nicole, to that?

**Ms DOOLAN** — Perhaps referring to the crisis response that has got referred to a lot in his presentation, so an example of how the organisation is trying to deal with upskilling staff. In response to that, the organisation trained me, for example, on non-violent crisis intervention and how we support our clients better leading up to within a crisis and after. So we have certainly done everything we can to improve that within the boundaries and constraints that we are asked to work within.

**Ms COUZENS** — Thank you.

**Ms McLEISH** — I just want to continue down the training element. You have to put a certain percentage of your budget towards staff training every year?

**Mr ALEXANDER** — We do, yes. Yes indeed.

**Ms McLEISH** — Where does that money usually get directed? You have got this deficit with skills, and you are saying that you have got a big need to upskill and give specific types of training. What typically do you use that money that is in the training budget for now?

**Mr ALEXANDER** — Typically we have four training days a year, and in those full training days Nicole would deliver non-crisis intervention training, we would have manual handling, we would have infection control, we would have workplace behaviour — a range.

**Ms McLEISH** — So people do not go off individually and get particular specific skills? They are all quite generic?

**Ms DOOLAN** — That happens as well.

**Mr ALEXANDER** — We have those large training days, which are designed to deliver generic training to a large number of staff. Yes, there are other staff, usually senior staff, who will be sent off to acquire specific skills in small groups or individually.

**Ms McLEISH** — What is the cost? They usually go for one day, four days, three days? What sort of cost are you looking at per staff for something like that?

**Mr ALEXANDER** — For a staff member going to a training day, typically you would send someone — —

You correct me where I get wrong, if I am wrong here. I am just thinking. Most typically they would go to Bendigo or to Melbourne. There are a lot of subsidised training opportunities at the moment as a result of the scheme coming in. You would say that it would cost anywhere up to \$200 to be involved in a subsidised training. If it is training in Melbourne, there is a consultancy firm called Disability Services Consulting who would run training and workshops. The cost of a day would be around \$400 a day. On top of that we have transport costs, accommodation costs and of course we are paying their salary. Melbourne training for us is problematic. We do that fairly regularly, but that is costlier, so you might be looking at at least \$1000 a day as a rough guide.

**Ms McLEISH** — What are the skills that are lacking that you most need additional training for? You have constantly talked about the need for this, so what specifically are the types of skills that you think they need?

**Ms DOOLAN** — Responding to crises, particularly for people on the spectrum. When I say responding to crises, that is not quite right. Preventing crises in the first place is the ideal situation, so being able to support people on the spectrum so that they do not become anxious and then in turn have the behaviours and things that we talk about. There is a real need there in helping staff understand how people on the spectrum perceive the world.

**Ms McLEISH** — And that would cut across other clients as well, I would imagine, the crises?

**Ms DOOLAN** — Yes.

**Ms McLEISH** — You have also talked about the shallow pool of potential recruits. Can you expand on that a little bit? Is that because people do not want to come to the country areas, or are there are not enough people with those skills in the country areas?

**Mr ALEXANDER** — We decided two years ago that we would not recruit on skills, we would recruit on values, and that has been successful for us. We get people with the right values and then we train them up. But even getting people with the right values in a regional centre is becoming difficult.

Our most recent recruitment drive in Echuca and district was a disappointment in terms of the numbers of prospective employees. That was startling for us, because up until then we had been really encouraged. I would be saying up until the start of last year — correct me if I am wrong here — we were recruiting strongly good people and, even more encouraging, more males. It is a very strongly female-dominated workforce in the disability sector, which is reflected at Murray Human Services. There has been an unusual number of males coming in and applying for work, which was really encouraging, but mid last year and onwards it has dried up. It is too early to tell whether that is a trend that is going to be sustained or is just a blip.

My suspicion, and the advice we have been having for some years now, is that there is going to be more pressure on the workforce and on recruiting. There are going to be more organisations seeking to recruit more staff, so there is going to be pressure on what is a limited pool to draw from in regional areas. My view is that is probably the way of the future, and it is also probably the way of the future that we will be working even harder to retain the staff we have, let alone recruit new staff.

**Ms McLEISH** — Thank you.

**Ms DOOLAN** — There is a real tension between providing flexible service to individuals with disabilities, which is the foundation of the NDIS and one I totally agree with, but when you are trying to staff that, there is a real tension between providing security for staff and permanent part-time or full-time contracts versus casual. That is something the organisation is struggling with.

**Ms McLEISH** — And something that we have heard too. Can I commend you on recruiting for values. I think that is really positive. Just a final question from me: you mentioned that the police are not trained in dealing with assaultive behaviour. Have you had that discussion with them?

**Ms DOOLAN** — Yes, regularly.

**McLEISH** — And they think that too? They concur?

**Ms DOOLAN** — They do, generally speaking. Of course it depends a little bit on who you have the conversation with. The problem we have in Echuca is the turnover of police. So we get a group that we talk to and communicate well with, and then Betty has periods of time when she goes well, so we might go a couple of months without a behaviour, but when we go back into that crisis, there is a new lot of police on board — —

**Ms McLEISH** — You start again.

**Ms DOOLAN** — And we start again; that is exactly right.

**The CHAIR** — Have you run any social enterprise programs?

**Mr ALEXANDER** — No.

**The CHAIR** — They are all just support programs that you have?

**Mr ALEXANDER** — Yes. The closest we have would be our supported employment, and that model of social enterprise is something we are considering.

**The CHAIR** — And you have involved the families of the adults with ASD and intellectual disability within your organisation. Do you involve the families in the determination of what is best for them?

**Mr ALEXANDER** — Yes, and, Nicole, will you elaborate on that?

**Ms DOOLAN** — You would be the best to talk about things like that that we have done.

**Mr ALEXANDER** — Look, I can talk to that; indeed I can. So over and above the formal planning processes that families are involved in on an annual basis, in the last 18 months we invested heavily in having a consultant deliver what was called the CX project, which is a customer experience program. That is very heavily designed or emphasises customer engagement, so customer engagement here being obviously clients but also mums and dads, carers and other people who are part of the broader MHS family.

We are endeavouring to make sure that we are an organisation that is bottom-up driven, not top-down driven. In the past we have imposed solutions on the people we support. We are trying to turn that the other way around. There is a behavioural change hopefully happening within our organisation, which actively engages not only with the people with intellectual disabilities we support but particularly with that broader community of mums, dads, carers and others, who are all part of that community and who we need to actively seek input from, listen to, learn from and then distil that information and produce outcomes that suit better the people we support and also their circles of support. Is there anything we should add?

**Ms DOOLAN** — As Scott did mention, our formal planning process, but currently MHS programs all change six monthly. So twice a year we change all of our programs — not all of our programs; there are a core lot of programs that work very well and we maintain. But in response to feedback and the data collected from person-centred plans, we change those programs to respond to that.

**The CHAIR** — Just one last question: do you draw clients from across the border?

**Ms DOOLAN** — Yes.

**Mr ALEXANDER** — Yes.

**The CHAIR** — And is there any difference in, for example, their support packages, or are there differences between what they are receiving in Victoria and those clients who come from New South Wales in terms of support packages? Obviously NDIS will change all that, but at the moment?

**Ms DOOLAN** — Generally speaking Victorian clients are funded much better. We have historically made a decision that New South Wales-funded clients we service at a loss. We do it as a community service. So they will come with three days of funding but require five, and we service them with five days of funding.

**The CHAIR** — An estimated number of clients that you have that will transition to the NDIS?

**Mr ALEXANDER** — In excess of 200.

**The CHAIR** — And that is a percentage of the total, being?

**Mr ALEXANDER** — No.

**Ms DOOLAN** — One hundred per cent.

**Mr ALEXANDER** — Yes, we anticipate all of ours will be eligible.

**The CHAIR** — So every client will be eligible?

**Mr ALEXANDER** — Correct.

**The CHAIR** — Given that Loddon is rolling out in the middle of the year and Mallee in 2019, have you had information sessions for your clients around the NDIS?

**Ms DOOLAN** — Yes.

**Mr ALEXANDER** — Yes.

**Ms DOOLAN** — And we have done that in a range of ways, from larger meetings to smaller focus groups, to one on one.

**The CHAIR** — Is it your understanding of the NDIS that adults with ASD and intellectual disabilities will be better off?

**Ms DOOLAN** — Generally speaking, yes, but I have seen both sides of the coin.

**The CHAIR** — Thank you so much.

**Mr ALEXANDER** — Thank you very much.

**Ms DOOLAN** — Thank you.

**The CHAIR** — We really appreciate your time, so thank you.

**Witnesses withdrew.**