

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 6 March 2017

Members

Ms Maree Edwards — Chair

Mr Paul Edbrooke

Ms Cindy McLeish — Deputy Chair

Mr Bernie Finn

Ms Chris Couzens

Witnesses

Ms Kim Mestroni, Victoria Division Manager, Occupational Therapy Australia;

Ms Lisa Vale, Paediatric Occupational Therapist and Clinical Services Manager, Splash Occupational Therapy;
and

Ms Johanna Rouse, Senior Occupational Therapist and Autism Spectrum Disorders Coordinator, Orygen Youth Health.

The CHAIR — Good morning, everyone. Welcome to the final public hearing for the Family and Community Development Committee's inquiry into services for people with autism spectrum disorder. This is the 11th public hearing to be held by the committee. In addition to hearings in Melbourne, the committee has travelled to Geelong, Bendigo, Shepparton, Morwell and Swan Hill to meet with stakeholders and hold public hearings.

On behalf of the committee I thank all of those who have contributed to this inquiry — the over 150 people and organisations who made submissions and the over 120 witnesses that have appeared at public hearings around the state.

From the outset of this inquiry the committee has been keen to hear from people with ASD and from families living with ASD. I am pleased to say that the majority of our witnesses have been people with ASD and families living with ASD.

We thank all of those who have submitted to us and presented to us and who have shared their personal stories with the committee. These proceedings today are covered by parliamentary privilege, and as such nothing that is said here today can be the subject of any action by any court or subject to any proceedings for defamation.

If you have any special needs today, please see the committee staff who will assist you. We have made available a separate room as a quiet room if anyone wishes to make use of that today. The room today is the multipurpose room, which is just down the hall from this room. Again, please see our staff if you require assistance.

I would like to introduce on behalf of the committee our first presenters this morning: Ms Kim Mestroni, Victoria Division Manager, Occupational Therapy Australia; Ms Lisa Vale, Paediatric Occupational Therapist and Clinical Services Manager, Splash Occupational Therapy; and Ms Johanna Rouse, Senior Occupational Therapist and Autism Spectrum Disorders Coordinator, Orygen Youth Health. That is a mouthful! Thank you very much for coming along this morning.

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.

Thank you again for coming along this morning, and we will hand over to you now to make a presentation.

Ms MESTRONI — Thank you for the opportunity to speak about services in Victoria for people with ASD today. I am Kim Mestroni. I am Victoria division manager for Occupational Therapy Australia.

I am joined today by our two occupational therapists, one who currently works with children with ASD and the other with adults. Lisa Vale, as we have just heard, is a paediatric OT, and Johanna Rouse works with adults at Orygen.

Planning for future services in Victoria for people with autism spectrum disorder is of particular interest to occupational therapists and Occupational Therapy Australia. We are mindful that this planning is occurring within the context of the rollout of the NDIS and that this generational change is influencing the way that occupational therapists provide services to people in Victoria and Australia. OT Australia, or OTA, is a professional association and the peak representative body for occupational therapists in Australia. As of December 2016 there were over 19 000 registered OTs in Australia, 25 per cent of whom work providing therapy services in Victoria.

Occupational therapists are allied health professionals who take a functional and an occupational focus to using evidence-based interventions. These interventions promote the participation of individuals, including children and adults with disabilities, in meaningful and productive activities. This means that for people with ASD, occupational therapists can assist the child or the adult to participate in their school or their work environment, understanding that people with ASD commonly have individual needs with their sensory processing, their ability to complete tasks and their social communication. The occupational therapist has expertise in supporting the adult and the child to learn strategies to manage their sensory issues whilst also ensuring the task is at the

just-right level for task achievement. This promotes the person's learning and can minimise behaviours of concern.

The occupational therapist can then work with the individual and their carers, their teachers or their employers to recognise triggers and to develop appropriate strategies to respond. These can be preventative strategies, such as designing the person's work or school or home environment to minimise unwanted sensory experiences. OT intervention can also be an exploration with the person to develop an awareness of the signals that they are becoming uncomfortable, to determine strategies to mitigate unwanted behaviours, to elicit socially appropriate responses and to optimise the best learning, working and social environment for that particular individual.

In recognising the way that OTs work with people with autism spectrum disorders, Lisa will now turn our focus to the recommendations that we have highlighted in our submission.

Ms VALE — Occupational Therapy Australia's recommendations to the inquiry included the need for person-focused coordinated, cross-sector services for people with ASD. That is services that are designed around the person's need that are really free of the barriers that can be coming with bureaucratic processes within the service delivery systems. Currently the health, education and disability sectors do not provide a seamless service for children with ASD and their families.

Building upon the concept of person-focused services — or in paedics we call it child-focused services — OTA also recommends that therapy services need to be provided within the most appropriate context. Occupational therapists focus on the occupation of the child where that takes place. Also, because people with ASD have difficulty generalising skill, the most important thing is to provide intervention in the context that it happens — at home, at school or in the community. In that way we can have a look at that interaction of the environment and the activity that the child is undertaking and work out what is their individual need so that we can help them develop in their competency and also show families, teachers and employers, carers and other relevant supports how to have the person participate most fully.

We would like to take a few minutes now to speak to the OTA's recommendation that services be provided in a coordinated manner across sectors and in the most appropriate context. That is particularly in regard to children with ASD when they are at school.

Currently a clear example of the lack of service coordination, resulting in a lack of a child-centred approach to therapy, exists for children who are accessing education and disability separate-funded therapy services. Unfortunately scenarios exist whereby, due to sector policies, children who are eligible for both education and disability services may often require two different OTs, and sometimes have duplicate sets of equipment and duplicate demands on the family, and a real separation of things that happen at school to things that happen at home. As we know, that is not a holistic way to view the child and family.

A clear requirement from the Victorian department of education for therapy in schools is for it to be focused on the educational goals and the curriculum. That really is very interesting with children with ASD, because it does not recognise the complex and interconnected nature around their deficits in social interaction and social communication, particularly when we see a lot of our children have difficulties on the yard or at playtime. Often within the school setting, that can be the time — and it is no offence to the teachers about having a break — that often the kids are left to go outside, but often for the kids with autism that yard or playtime is really a core area of their need. Again, it might not be so established to the curriculum, but it is part of their whole learning at school. It can be the same around toileting and self-care skills. Sorry — just going off script there.

Unfortunately occupational therapist services are not funded by the department of education. You may well be aware that psychology and speech pathology are. It is basically an historical thing. It is really, really difficult when schools now have to either have private services that the families fund — and our video will show that — or services that the school might contract. But again it is very piecemeal. When you look at the NDIS you will see that you might have 10 children with autism at a school who might have 10 different occupational therapists, and the school will actually not allow that to happen. So it is very much a barrier for us to provide service where the occupation is taking place. Currently we are not providing OT where we should be in that most relevant environmental context.

Ms MESTRONI — The Bracks review released in April 2016 named *Greater Returns on Investment in Education: Government Schools Funding Review* supports OTA’s recommendation for person-centred supports provided in a most appropriate environment. It states:

Research suggests that the diagnostic criteria underpinning the PSD are not necessarily aligned to meeting the learning needs of individual students, and that a more effective use of funding would be to consider a student’s functional needs — that is, their needs in relation to body function, daily living skills, social and educational participation.

This is the primary focus of OT, yet, as Lisa has just said, the department of education in Victoria does not as a rule fund OT services in Victorian government schools, and that is particularly so for mainstream schools.

This differs greatly from state to state. The January 2016 Senate Education and Employment References Committee report, *Access to Real Learning: the Impact of Policy, Funding and Culture on Students with Disability*, states on page 11 that:

... the use of occupational therapists (OTs) in schools varied considerably from state to state. In Queensland, the Department of Education and Training employs nearly 70 full-time equivalent OTs to work in state schools, while other states have limited access for privately engaged OTs to schools at best.

In fact when Occupational Therapy Australia contacted the Victorian Minister for Education’s office in September 2015 we were advised that the department:

... does not have any readily accessible data on the employment of OTs by schools; however, it is likely to be a very small percentage of the allied health workforce and it would be unlikely in mainstream schools. Specialist schools employ physiotherapists and may employ OTs from their student resources package.

They went on to say:

The department does not directly employ OTs. In respect to the employment of other allied health staff, the department and school networks employ approximately 450 EFT employees in the areas of psychology, social work and speech therapy (student support services). The department also employs approximately 200 EFT school and maternal health nurses that have transitioned ... from the Department of Human Services under machinery of government changes in 2007. Schools, through their student resource package ... also employ student support staff in the wellbeing area, mainly in nursing and psychology.

As the department of education in Victoria rarely employs OTs, parents often request non-department OTs to come in and see their children in school settings. Unfortunately we have also found through OTs feeding back to us at OT Australia that there are disturbing requirements by some schools for OTs to sign what they call school licence agreements, which essentially are 17-page long agreements where OTs basically have to hire the school’s space, as you would if you were a sporting organisation or an outside kind of organisation, to come in and just provide services on school grounds — —

Ms McLEISH — This is in Victoria?

Ms MESTRONI — In Victoria, yes.

The CHAIR — Has that always been the case?

Ms MESTRONI — I do not know if it has always been the case. This was reported to me last year. Apparently the department has had these types of policies but they may not have been enforcing them until more recently. I think probably the kick-off for that has been the NDIS and certainly the Barwon experience, where a lot of OTs have started to come into schools at the request of parents.

The rationale for the department of education’s lack of recognition for OT’s contribution for services for students with ASD in schools is not clear, but certainly the impact is reported regularly to us by OTs. OTs have said things like student-funded services that they have worked in have stopped providing a service to children with autism because they expected that the commonwealth funding would kick in and that certainly the state funding was not required anymore.

Limited funding and supports for children with ASD who are high functioning in particular in the area of social participation have a huge impact on mental health, school participation and then, later, work participation. Lisa is now going to show a short video from her private practice of a child receiving ASD therapy.

Ms VALE — It is interesting to explain that we have clinics in Werribee and in Essendon and we have a school service in the east, and of course from the sort of demographic and the socio-economic pattern it really differs. So this is a school in the east, where the parents fund the therapy but the school agrees for us to provide it on site. This little boy is being taught the primary school occupation of handwriting — high-functioning autism — and we have the overview from his mum talking.

Ms McLEISH — That is a government school?

Ms VALE — No, a private school.

The CHAIR — Can I ask what school it is?

Ms VALE — Bialik, the Jewish school. We will just go to Jo now. Jo works with adolescents and adults with autism spectrum disorder at Orygen.

Ms ROUSE — Thank you. It is considered a professional and ethical responsibility of occupational therapists to consider work-related issues for all relevant clients. Some of the roles performed by occupational therapists working with people with ASD may include: providing information about sensory, social and emotional issues impacting on work performance; exploring interests, vocational histories and experiences, and goals; identifying barriers to employment performance and developing collaborative plans to address these; performing environmental assessments of workplaces, including sensory environments and social culture; and also support systems of the workplaces. It also includes referring to and liaising with employment specialists and clinical teams and providing education and consultancy to other professionals in regard to the impact of disability on employment.

Occupational Therapy Australia's recommendations for the enhancement of services for people with ASD seeking employment are consistent with our recommendations made in OTA's recent submission to the federal Department of Social Services on proposed reforms to disability and employment services — that is, occupational therapists should be contracted to work alongside employment consultants to perform job assessments and make recommendations to improve the likelihood of safe and successful engagement and sustained employment in the workforce.

In making this recommendation OT Australia is identifying that there is a need for individualised attention for young adults with ASD, particularly in periods of life transition. Individuals with ASD often possess extensive skills and qualities which lead them to have significant vocational potential. A university or vocational service's access to OT expertise can be the crucial factor which perhaps supports a person to display less behaviours of concern or might impact positively on their social skills deficits to help them adapt to their mild intellectual impairment. This can set them on a path to meaningful work and economic participation in the future. Services such as Orygen Youth Health recognise that this in turn gives an individual a sense of purpose and can be an important preventative influence for illnesses such as depression and other mental health conditions.

We must at this point highlight that there are very few targeted services for adults with ASD. This means that services such as Orygen, which has a primary mental health focus, find it very difficult to discharge people with ASD and refer them to appropriate follow-up services, as they do not exist.

Finally, we would like to acknowledge that further recommendations made in our submission, such as funding for programs to promote and support the employment of people with ASD, are consistent with the NDIA's commitments under the information linkages and capacity-building program. This is focused at the population level to build capacity in the community for acceptance of individual differences and supports, which can enable participation for individuals of all ages and capabilities.

Currently it is unclear how the ILC commitment will roll out, but we remain optimistic. I now want to illustrate via a case example the importance of targeted interventions towards an individual's life goals and wellbeing. Amy is a 25-year-old young person with a diagnosis of autism spectrum disorder without an accompanying intellectual disability. Amy lives with her partner in private rental accommodation but has experienced periods of homelessness in the past. Amy is currently unemployed and disengaged from her previous studies. Amy was referred to a public mental health service in the context of a severe depressive episode and an associated suicide attempt. Amy reports that she has experienced previous depressive episodes, particularly in her adolescent years, which she associates with academic stress and social difficulties at school.

Amy was diagnosed with an ASD as a child and has significant difficulties with social and communication skills, which often contribute to interpersonal conflict in her relationships. Amy also presents with difficulties in regulating her emotions, understanding the perspectives of others and rigid behaviours and thinking. Treatment at the mental health service is focused on treating her depressive symptoms, psychosocial interventions and setting up a support plan and team for the long term. Although her depression is now in remission Amy is unable to be discharged from the public mental health service due to minimal long-term community support options. Amy has been assessed as having a superior IQ and thus is ineligible for support from disability client services in her region.

Amy would like to seek employment. Amy has a talent in mathematics, is a perfectionist and takes great pride in her ability to pay attention to detail. However, she has been unable to maintain jobs in the past due to her significant social and communication impairments and difficulties with executive functioning — so planning, problem solving and organising herself in day-to-day activities. Again, Amy is ineligible for disability employment services as she has been deemed to be too high functioning.

Without access to coordinated support such as case management and targeted disability employment services Amy is therefore at risk of maintaining disengagement from meaningful activities such as work, study and socialisation. This increases the chances of her developing a subsequent depressive episode and of her further functional decline and reliance on mental health services and welfare.

Ms MESTRONI — This completes our presentation of the points that we wish to highlight from our submission. Thank you for inviting us to speak today and we look forward to answering your questions.

The CHAIR — Thank you. We have some trouble with the video. I think in about two minutes we should be able to watch that, so we will start with some questions while we are waiting. Thank you very much for your presentation and thank you for the submission that you gave to the committee. I found it very interesting.

One of the things I am curious about in terms of OT and the provision of OT for people with autism given the broad spectrum is: is there a defined number of hours or engagement with an OT that a person might need who has ASD? Obviously children who have intellectual disabilities as well or ADHD would perhaps require greater or more intense occupational therapy involvement. So is there some way that you determine a person's —

Ms VALE — Quantify it? Yes.

The CHAIR — Yes.

Ms VALE — Generally really with the concept now it is not so much that anything magic happens in an hour of one-to-one intervention, because it is really that you are trying to work with the parent and the family and the school around getting those strategies out. So generally, particularly in early intervention, children might have a session a week, being about an hour of face-to-face intervention. Then we follow over at home. We work in goal-directed blocks, so often for, say, three to four goals that you are working on, that might be a term's worth. So it is not a lot of time in essence. It could be like 15 to 20 hours per term, and that is generally really adequate in that way because you are talking around empowering the parents and the school to follow over the strategies.

The CHAIR — So it really is that person-centred approach in that each individual sets a goal, their family sets a goal —

Ms VALE — Goal-directed, totally.

The CHAIR — and then you come in and actually work towards that goal.

Ms VALE — Exactly. So really in paediatrics it might be that we need independence in toileting, they might want to be able to write their name, they might want to be able to do a turn taking a game with a peer. So we might have those three goals and that might take us about a term to work on.

The CHAIR — And the goals will vary obviously, determined by the level of autism.

Ms VALE — Exactly.

The CHAIR — And how closely do you work with speech therapists?

Ms VALE — So closely, with speech and OT particularly, because once the child with autism has their communication system established everybody needs to be using it. So if we are going to be using signing or picture exchange or the use of visuals, again nothing can happen in a bubble. So we need to know about that — very closely with psychologists again when you are looking at behaviour management. Really it is for us teachers, teachers, teachers, because the primary occupation of children 0 to 18 is to be a student. And you can probably see — I have noticed that other people have submitted to you — that things work best when it is an integrated program, so when OT is part of the team. You are on site, you are accessible, because a lot of it is about consultation and support for those people who are teaching the children or working with them in that way.

The CHAIR — And what you are teaching the children then, or the young adults or the adults, is a family-centred approach as well?

Ms VALE — Yes.

The CHAIR — So the parents or the carer are learning the OT way of helping the person with ASD.

Ms VALE — Exactly, yes. In research you would call that a parent-mediated approach because again they are not coming in and handing the child over to you; we are working with the parent. We are saying, 'I'm bringing my expertise; you're bringing your expertise as the parent', and we put that together. So we are not dictatorial as in, 'This is what is going to work in your family and your culture' — that setting.

The CHAIR — And how do you find that, with cultural differences?

Ms VALE — It is fantastic. We learn so much. But also particularly because OT is focused a lot on self-care, things are different around feeding. We would really promote cutlery use by age three or four, whereas in some families the mother will feed the child. So it is very good to be very culturally sensitive, but again you are just saying, 'Typically what independence would you see about dressing?'. You are just working from within the family. So we have got all our knowledge. We call it PEO — the person, the environment and the occupation. We bring that and then they give us the context.

The CHAIR — Very good. This is a bit more of an in-depth question. Your submission clearly discusses the inadequacies and the shortcomings of the current funding models for people with ASD, including the PSD. I just want to perhaps ask you if you could outline your key areas of concern and outline for the committee, if you can, what you consider to be the crucial elements of a more appropriate model.

Ms VALE — When you are looking at schooling we really want to have a way for the OT to be an integrated part of the team. We would probably like less focus on things being strictly curriculum — that the OT help has to be just around access to the curriculum — because we think there is probably broader social stuff that can happen and self-care things that can happen. We do not want to go that way of the NDIS — that the school might be having 10 or 15 different people coming in. So we really want to be part of the team.

The CHAIR — Is that being worked through with the education department in relation to where we know that there are OTs going into schools for students that are funded through the NDIS now?

Ms MESTRONI — I have been down to Barwon and had a chat to — I think they are called — the transition coordinator. At the moment — rightly so, because the family and the child obviously have the choice and control over their plan — the onus is on the parents and family to actually advocate and talk to the principal at the school should they want to have their child have therapy at school through their disability funding. It sounds really good in theory, and we certainly would support that. It is just then again it is capacity building for the family and enabling them to certainly see the advantages of it but also be able to articulate to the principal why they think it is appropriate in a positive way, if they do feel obviously that it is appropriate.

The CHAIR — So given that speech therapists and psychologists are funded through the education department — and you might not be able to answer this — is there an issue arising around families who are already with the NDIS bringing in their own speech therapists or their own psychologists?

Ms MESTRONI — There will be because what will happen is that some principals will just refuse. It is their right. You can understand it is their right. So for the people who have the NDIS funding, if the principal

does not want those external consultants coming in, that will be the same. So what was happening in Barwon with school attendance is that families often were taking their children out of school for the day to sort of have a therapy day, which is not ideal and which was affecting school attendance.

Ms VALE — Or otherwise the kids were having to go after school, and that was just too fatiguing. They were getting really tired having spent a day at school and then going to therapy. The other thing too that really was affecting just the general, I suppose, coordination of the plan was that OTs were not really invited or even asked to consult for the planning meetings for that — I cannot remember what it is called — requirement for the education department funding to actually have a plan and some goal setting. So even if an OT made recommendations, sometimes they were not particularly interpreted in the right context. We had a lot of OTs coming back and saying that a child may need support for things like toileting, but rather than encouraging that child to be more independent and doing it from, I suppose, a therapy-based perspective, they were just maybe getting a support person to go in and actually —

Ms VALE — Wipe their bottom.

Ms MESTRONI — wipe their bottom and help them with their clothes, and do it for them rather than enabling them to do it for themselves. There were those types of miscommunications happening as well.

The CHAIR — There is one last question from me, then I will hand over to my committee members. On the role of an OT in the life of a person with ASD, how crucial do you see that as being?

Ms VALE — Well, I am biased.

The CHAIR — I thought you might say that. I know, but given the spectrum — —

Ms VALE — Yes, exactly, because we are talking about the fact that 75 per cent of people with ASD have an intellectual disability, so we have got to think about that as well as for the children and adults who are very high functioning. People will tell you — and hopefully we will hear Ezra's mum on the video — it is just about that very practical everyday focus and support. So it is nothing airy-fairy. It is about: what do you need to do, what do you want to do and how can we facilitate you to do that? Particularly in those early years when parents are adjusting to the diagnosis and really making that foray into that world, we really think it is crucial, and the research is showing that through that goal-directed, very practical focus is where the wins are on the board.

The CHAIR — And amongst people and families with ASD, is there a broad understanding that occupational therapy is part of a holistic approach?

Ms VALE — Yes. I think we have been really lucky to be recognised through the commonwealth Helping Children with Autism funding as a primary service with speech and psychology, so it is fantastic. OTs are getting more involved with diagnosis. For us it is often a case of fighting more the medical establishment and the education establishment in getting ourselves recognised, and you then see the follow-on with families. But with the NDIS, in our private practice parents can self-refer, so often there is no barrier either.

The CHAIR — Okay.

Ms MESTRONI — That is often where we are finding that people actually do realise what OT has to offer — when they have actually come in through other funding models.

The CHAIR — Is that video ready to go? We will watch that and then go from there.

Ms VALE — Ezra is just at school having support with his writing and his mum is talking. It does not seem to be working. I have got it on my phone.

The CHAIR — Maybe what you could do is perhaps send a copy of it to Greg and then he can forward it on to us to have a look at. That is probably an easier way given our time constraints. Is that okay?

Ms VALE — Yes, thank you.

Ms McLEISH — Thank you for coming in. Just following on from the last lot of questioning from Maree, do you think there is a blurring out there of speech therapy and OT?

Ms MESTRONI — That is an interesting question.

Ms VALE — No.

Ms McLEISH — Kim said it was interesting, and you think no.

Ms VALE — Do you?

Ms ROUSE — No, I do not think so. I think it is interesting that you ask that, I think. I can answer from Orygen's perspective. We do not have a speech pathologist employed in our mental health service, whereas the other CAMHS and CYMHS — or child and adolescent mental health services, I should say — do. From a diagnostic perspective and an intervention perspective, in our ASD service we really notice the difference around not having a speech therapist on hand to help us out. So from a diagnostic perspective, I guess we see people with probably more high-functioning autism, and they come into the service with another mental health condition. They are often people who maybe have slipped through the gaps and have not been identified early on. What we find is that with a lot of the people that we assess, we do not have a speech language therapist so we can only suspect that there might be an undiagnosed expressive and receptive language disorder that we cannot actually diagnose.

So that is very clearly delineated in what we do, and then we need to provide intervention around that. When we think about some clear interventions for young people and adults with ASD, often we think about social skills training and being able to communicate and interact in the environment. If we do not have a clear understanding around what a person's speech and language level is, we cannot make clear recommendations about how we should be intervening around social and communication issues — because talking and communicating is essential.

I do not know if that answers your question, but I certainly feel like we really miss it in our service and it is something that I am going to be advocating for in the years ahead.

Ms McLEISH — I am just thinking about private practitioners working in this field. Do you know how many of them, percentage wise, are actively engaged with people with ASD?

Ms VALE — In paediatric private practice it would probably be like 99 per cent.

Ms MESTRONI — The majority, yes.

Ms McLEISH — So what are the waiting lists like?

Ms VALE — In private, generally there are not significant waiting lists.

Ms McLEISH — What does that mean?

Ms VALE — There would not be a wait for therapy, for private practice.

Ms McLEISH — So I can ring up today and get in tomorrow, type of thing?

Ms VALE — Probably next week.

Ms MESTRONI — That has been changing with the NDIS. Certainly in Barwon there was a stage where there were waiting lists for OT because all of these children had been funded who had not been funded previously in that area, but OT itself as a profession is going into private practice a lot more than it ever has done in the past.

Ms VALE — Because we have not had — yes.

Ms McLEISH — Okay. So are there enough OTs out there, do you think, to meet the demand at the moment?

Ms VALE — With the introduction for us of the NDIS there probably will not be, but at the minute, because we are just in the rollout phase, yes.

Ms McLEISH — What is the cost of a session?

Ms VALE — It is \$169 to probably \$175 per hour.

Ms McLEISH — So is that not an initial assessment — that is each assessment after?

Ms VALE — Yes. Initial assessments would vary, but ours is \$253 for an initial assessment. That is with a report.

Ms McLEISH — Is that a scheduled rate?

Ms VALE — No.

Ms McLEISH — No-one puts it out? Individuals can just charge what they like?

Ms VALE — Yes, but with the NDIS a lot of it will be capped.

Ms McLEISH — I mean, when you look at it there are a lot of people who are not going to be picked up in the NDIS. I am not focusing on the NDIS; I want to just pull it away and have a discussion around the others.

Ms VALE — Yes, sure.

Ms MESTRONI — So no, it is up to each individual practice.

Ms ROUSE — And I would probably also like to add that there is a significant lack of private occupational therapists who work with young adults and adults. So if we are thinking about a clear need to refer somebody on from Orygen, for example, for particular occupational therapy input, there are barely any, I would say, across Australia.

Ms MESTRONI — We often have members of the public calling and saying things like, ‘My 16-year-old has just been diagnosed’ or ‘we suspect has ASD’, and it is really quite difficult for us to find an OT who is working with adults rather than children.

Ms McLEISH — With regard to the profession, how long does it take somebody to be skilled up to be working in that area? You go to university, you get your degree, and then how long?

Ms ROUSE — The degree models have changed over the last 10 years or so. Now often people are doing — I am thinking about La Trobe off the top of my head as an example — a two-year kind of generalist health sciences degree, and they will go on and do a masters of occupational therapy practice. So it takes about four years, and then from there people go on and start to work in the different fields that they choose to work in. That is where expertise is really developed.

Ms McLEISH — So how long would it take somebody to do?

Ms ROUSE — It has taken me 10 years to get to where I am as a senior clinician and autism spectrum disorders coordinator at Orygen, and I would say that only now would I feel confident enough in working with people with ASD to then go into private practice. It is a long period of time — 14–15 years all up.

Ms McLEISH — How many graduates come out every year?

Ms VALE — This is a big problem. Too many at the minute — a lot.

Ms MESTRONI — Yes. It is changing. I guess the traditional models of clinical field work education within the education setting are actually what Lisa is referring to in terms of the trouble. We are finding it really difficult to skill students while they are still undergraduates in a lot of different areas of OT because there are a lot more OT schools right now. Having said that, I think it is just that the industry is changing. Certainly the more traditional roles that OTs went into when they first graduated have dried up in terms of being public sector funded medical kinds of rotation models. We are looking more at these types of roles where students are going to work in organisations like the two that we have here today.

Having said that, we as an association are trying to support private practitioners to have good models of student support and new graduate support within their business models, because OTs just have not needed to think that way prior to now. They have had government-funded, I suppose, student and new graduate support models to skill up the workforce.

Ms McLEISH — My final question is around referrals. Do you have an idea about the percentages of people that refer to you? Do doctors refer or do parents self-refer?

Ms VALE — Yes. In our paediatric private practice it would be paediatrician referrals, speech pathology referrals or direct parent referrals.

Ms McLEISH — At what age usually?

Ms VALE — Age for us is really from two upwards.

Ms McLEISH — What about non-paediatrics — somebody who is not working as specifically as you?

Ms MESTRONI — I think there is probably a lot of self-referral or referrals through non-traditional kinds of tracks.

Ms McLEISH — Word of mouth?

Ms MESTRONI — Word of mouth often. We have people phoning the association saying, ‘My neighbour — whoever — has said that possibly an OT could help my son/daughter. Can you tell me why?’, then we have to chat through with them what is going on.

Ms COUZENS — Thanks for coming along today. You mentioned earlier I think, Kim, about teachers identifying triggers in the classroom. Do you think training for teachers is worthwhile? If so, what sort of training would you suggest is required for them to be able to identify those triggers?

Ms MESTRONI — Absolutely. I think that this is one of the reasons that we think that a more coordinated approach would be really helpful. I do not know what you would prefer to actually talk about.

Ms VALE — I think there is a lot to be said, we feel, within teacher training but also once you are in the classroom, because we feel around that approach of universal design that you might be helping the one child with ASD but you are probably helping about 10 other children in the classroom. We think that through consultation, through PD and just through working with them in a joint sense is a great way to get that sort of knowledge translation across to the teachers.

Ms COUZENS — Johanna, you talked about Amy in your case study. Is there something that can be done to help Amy with the challenges that she is facing now?

Ms ROUSE — In thinking about the services that we work in, we have a lot of services in-house that we can offer to support somebody like Amy. We have a group program that Amy can come to and work on social skills and relationships. We actually have a vocational consultant in-house who will work with her while she is still with Orygen, but what we struggle with every time we see somebody with ASD is thinking about where to from Orygen — what options are out there. I think essential things for somebody like Amy, as I mentioned, is access to a disability employment service that clearly understands her unique needs. Amy has lots of skills and abilities and lots of strengths that could be really valuable in a workplace setting and could lead to her being quite productive and getting a lot of meaning out of life by going to work, but because of her problems with social and communication skills the intervention ends at the discharge point from Orygen and then is not taken into the context of future workplaces and is not supported by a skilled-up disability employment consultant or an occupational therapist in that context. It is going to be really hard for her to maintain and sustain employment.

Ms COUZENS — Did Amy have early intervention? I do not know if you know that.

Ms ROUSE — I am not sure, actually, because she come to us so late in the piece and I am not sure how much early intervention she had. I think she is one of those ones that because of her superior intellectual functioning had gotten by in lots of ways, done quite well in lots of ways at school and academically could perform in certain subjects which she was skilled in, but it was really for her — and she talked about it in terms

of her history and looking back on things — that the social settings at school and the ability to complete day-to-day tasks were really challenging for her because of her executive functioning problems. Just to plan and organise her day and make sure that she knew what tasks needed to be completed, what homework tasks needed to be done, that was really stressful and overwhelming for her and she thinks contributed a lot to her depression.

Ms COUZENS — Did she have any of those supports in place while she was at school?

Ms ROUSE — Not that I am aware of, no. A student wellbeing counsellor is what she had, which is often the case for the people we see.

Mr FINN — Thank you for your contribution today. You do not have to convince me of the importance of OT at all. I am just wondering how many children in the state do you think need OT and do not actually get it?

Ms MESTRONI — That is a very good question.

Ms VALE — I was going to say just having a look at the prevalence in Australia, if we think it is 5 to 10 per 1000, we would really be guided by that figure when you are looking at post-diagnosis.

Ms MESTRONI — If you are looking at these types of things that we have discussed today, particularly with people that have comorbidities, if you like, certainly a majority of those would benefit from having OT. I guess it comes back to our discussion about the school setting too and that early intervention. If we are looking at not being able to provide services in that setting, that is where we feel that people are really missing out as well.

Mr FINN — I was very interested to hear your comments about the education department and how they relate to people with autism and how OT impacts upon them. Do you find the education department inflexible with regard to these matters? We have found this in a number of areas — that they are set in their ways and they are not going to shift come hell or high water.

Ms VALE — I suppose because it is such a big bureaucracy everything has to have criteria.

Ms MESTRONI — Yes, which is understandable.

Ms VALE — We really get that. But it is very difficult to work with. It is very hard. You are just very lucky if you strike an individual principal or an individual class teacher and also you have a parent who is a very good advocate for their child. Once you get into that great working relationship — for example, at Bialik College where we are really ingrained — it is so positive. But it is just the barriers, and you spend a lot of your time in the coaching of the parent to sort of really enable their access for the child.

Mr FINN — What do we need to do to change that?

Ms VALE — I think you have to employ OTs in schools and get them to be part of the team, because unfortunately with education — and it can be like that with medicine as well — it is just this very dominant paradigm. But we have to have a look at that interlinking of the allied health support with the education support and see it as one. So that is what we think would be a great advantage.

Ms MESTRONI — Part of it too would be again in the undergrad curriculum for teachers. I think it would be really helpful to have more of a disability focus in there so they can even recognise when an OT may be needed. There are lots of things that they can do themselves and that OTs can be more of a consultant for them for, so there is a double-edged approach there.

Mr FINN — Johanna, you mentioned your work with getting people with autism into employment. What is the attitude of employers? That, I would imagine, would be a significant barrier. How do you overcome that?

Ms ROUSE — It depends on the client, really, in lots of situations. Some clients are really happy to disclose a diagnosis of ASD and happy for an employment services provider, even a clinician, to have contact with an employer and sit down and talk through the deficits they have and the strengths that they have and think about the workplace environment and support the employer to think about modifications that might need to be made or how to provide tasks that suit the young person's strengths. I think that that is pretty important. I think that that is probably what is lacking at the moment. I am not sure.

Ms MESTRONI — We certainly identified as a risk the disability employment services when they went out for tender, and we identified that there was a lot less emphasis on having that disability support within those employment services and having the expertise of the professionals, even as consultants or as just some kind of pathway for access.

Mr FINN — Do you think it is worthwhile pushing the message to employers or potential employers that people with ASD actually can make an extraordinarily positive contribution to their business?

Ms ROUSE — Absolutely. I was just going to add that.

Ms MESTRONI — Absolutely.

Ms ROUSE — I think the general community awareness around ASD is increasing and improving, but I think that there is lots of work that can be done around skilling employers to understand ASD and understand that employing someone with ASD can actually be of real benefit to their company. Somebody like Amy who is really good at mathematics and who is quite a perfectionist and really detail driven, I think there are many roles that she could take on — data entry, computing, lots of different areas, even accounting — that could make her a real asset to a workplace. There are lots of misconceptions about people with ASD and their intellectual capacity.

Mr FINN — What do we need to overcome those misconceptions?

Ms ROUSE — Some more community awareness campaigns, I think, is probably where to head, or even if disability employment services could work with somebody who knows a lot about ASD, like an occupational therapist or a speech therapist or a psychologist, who could go out and skill up employers out there, or whether there are some incentives to even take on and employ people. I know there are other disabilities, and there could be an incentive package looked at to employ somebody with ASD.

Ms MESTRONI — You do hear about some innovative companies now that actually have quotas that they have established themselves.

The CHAIR — Three questions. Do the private schools or the parents employ the OT?

Ms VALE — Often the parents are the people paying for the service.

The CHAIR — In the private school setting?

Ms VALE — Yes.

The CHAIR — Cindy talked about referrals. I guess the question is around how can we get our GPs and our allied health professionals to be better at referring people with ASD to you. How do you prepare people and train them to do that better?

Ms VALE — We have done that at a local level by going and meeting our GPs. Doing a referral form can often help. Often with the medicos particularly, the more information you give them and the easier it is through the streamline system, the better. Most children will see the paediatrician, so often it is the link with the GP as well as the paediatrician. The Medicare programs have really helped to push people towards allied health. So I think it is just more shared communication too about the child's goals being reached and the benefit of it as well.

Ms MESTRONI — Tapping into the primary health networks.

The CHAIR — Bernie mentioned how many people are falling through the gaps. We do not know what we do not know, but clearly a lot of people might present to their GP but are not necessarily referred.

Ms VALE — Yes.

The CHAIR — And because symptoms of ASD are quite mild in some cases, it is not picked up as the initial diagnosis. So there clearly needs to be some change around identifying ASD — yes?

Ms VALE — And that is where at school they might identify more. That is what we are saying around that interlink, particularly for the higher functioning kids. We really need schools' information in that diagnostic stage too.

The CHAIR — Sure. The last question I have is: in your experience do girls and boys present differently with ASD?

Ms VALE — It is fascinating that with the girls they are often diagnosed later and often it is much more of a social, emotional regulation-type difficulty. But with the boys it is really often a lot earlier and very much delayed language or a bit more atypical language development. The girls often with their sensory processing can have a lot of difficulties around their self-care, their eating and their grooming. People explain that girls are socialised differently to boys and often their social skills are better, but as their peer group gets bigger and when they are trying to make better friends, it is all just falling apart.

Ms ROUSE — And that is when we see them at Orygen. That is why people present often to us with depression, or they might get misdiagnosed as having something like a borderline personality disorder. Then actually when you sit down and do an assessment and you take their developmental history it might become clear that there have been longstanding difficulties there that have not been identified, because girls often learn how to socialise and when they are growing up they often socialise around particular things that can be quite structured. You might be playing house or something like that and roles in playing house are clearly delineated, so girls can often adapt to that. Sorry, I am being a bit generalist here, but I think it is just something that we often see.

The CHAIR — So perhaps better at mimicking social norms?

Ms ROUSE — Yes, and learning. But when the complexities of social relationships change, they hit adolescence, they start to think about romantic relationships, sexuality and all those kind of things, peer groups become bigger and there are just more challenges involved, that is when we see them with a subsequent depressive episode. Anxiety is a big thing we see too.

Ms COUZENS — You talked about engaging the school and the parents when you are working with a child. Is it still possible to achieve the same when the parents are not engaging?

Ms VALE — In early intervention we would say it is a really big barrier. We would never practise without the parent present because really that parent mediation, that parent delivery of the service — —

Ms COUZENS — So if the parent is not there, you will not work with the child?

Ms VALE — Yes. Sometimes a child might be in foster care and come with a carer or something like that, but generally we are working with the parent as our partner. It is the same at school; we have got to be in partnership.

The CHAIR — Thank you so much. I have no more questions. I think we are finished for today. Again thank you for coming along today, and thank you for your submission. It has been very informative, so we really do appreciate your time.

Ms VALE — Thank you so much. That was great.

Witnesses withdrew.