## TRANSCRIPT

# FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

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

Melbourne — 21 November 2016

#### Members

Ms Maree Edwards — Chair Mr Paul Edbrooke
Ms Cindy McLeish — Deputy Chair Mr Bernie Finn
Ms Chris Couzens Ms Emma Kealy

#### **Staff**

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#### Witness

Mr Stan Pappos, senior manager, high risk and support services, Australian Community Support Organisation.

**Ms McLEISH** — I welcome Mr Stan Pappos, senior manager, high risk and support services, ACSO. Thank you, Stan, for attending today.

Mr PAPPOS — Thank you for the opportunity.

Ms McLEISH — All evidence taken at this hearing 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 in contempt of Parliament to provide false evidence. Recording of these 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. The microphone before you is for Hansard. Thank you, and I invite you to make a 15-minute statement.

Mr PAPPOS — Sure. I will probably need less than that, but that is okay.

Ms McLEISH — That is no problem as well. We are a little bit behind, so that is fine.

Mr PAPPOS — As you have outlined, I am employed by the Australian Community Support Organisation. We are a unique support service provider in that we work to prevent and divert people from the criminal justice system, and we also work with those who have entered the criminal justice system. With that said, we work with a broad range of people across Victoria and, in more recent history, across New South Wales and Queensland.

In Victoria we provide a range of different supports and services, and in terms of people with autism spectrum disorders, they include intensive residential services, which are 24-hour support services; clinical services and behaviour support intervention; and individualised and flexible outreach services. In total we work with a very small percentage of people with autism spectrum disorders. It would probably equate to about 20 per cent of all the participants we work with that might have a disability or an intellectual disability. Of those with the autism spectrum disorder approximately 50 per cent have an intellectual disability and other concurring comorbidities.

We often see the participants we work with interfacing with the criminal justice system, and that occurs for a whole range of reasons. There is not any concrete evidence as to why people with autism spectrum disorders interface with the criminal justice system, but some of the research, particularly by Guy Hall at Murdoch University, points to the deficits in communication, in social skills and in sensory and perception skills.

Certainly one of the things that we have become accustomed to seeing is people with autism spectrum disorders, when they do come across the criminal justice system and mainstream services, having their diagnosis mistaken for other things, including mental illness and substance use, and that is problematic in that when people with autism spectrum disorders are interfacing with these services, quite often there is not an awareness around how to interact or how to engage. A lot of the issues or behavioural presentations are seen as problematic rather than linked to the person's anxiety or lack of understanding and ability to make the connection around the supports or the services that they are interfacing with. That also extends to police involvement. Quite often Victoria Police, without the knowledge of the person's diagnosis, may take a very different approach to working or to engaging with these people when they are engaging with the criminal justice system.

Certainly the people that we presently engage with have had a unique sort of history in that it is not simply down to their autism spectrum disorder that they have come into contact with our services; it is also a combination of other things. There has been a pattern of prior offending behaviour, a history of trauma, a history of family violence, and all those things have culminated in them entering our service. Notwithstanding those issues, I would like to think that they would be more inclined to be accessing specialist and mainstream services that are more generic in nature rather than our organisation, which specialises with those interfacing with the criminal justice system. That probably concludes my submission at this stage. I am happy to field questions.

**The CHAIR** — Thank you very much. Sorry, Stan, I missed the start of your presentation, but I think ACSO presented to our last committee inquiry, so thank you for coming along again. Do you work with clients once they are released from prison?

Mr PAPPOS — Yes. Not all of them are released from prison. Some of them may be in the community, at risk of contact with the criminal justice system.

**The CHAIR** — How do you assist those who are being released, particularly those on the spectrum? How do you help them with housing, employment, support services after transition from prison?

**Mr PAPPOS** — Our practice is to undertake wherever possible comprehensive assessment of the person's individual needs and to develop a holistic support plan — we call it a One Plan — that looks at all of their various treatment needs and individual support goals.

**The CHAIR** — So you bring in mental health services, you bring in — —

Mr PAPPOS — Behaviour support services, occupational therapists, very rarely speech therapy services, but where required certainly we try to tap into those specialist services and bring them around the table. It is becoming more challenging now with the National Disability Insurance Agency in that they have made it clear that, where there are criminal justice needs, they will not be funded under the scheme. So where you have someone in custody, for example, and there is planning required, it may be considered but it will not be formally funded.

**The CHAIR** — So they will not get any support while they are in prison?

Mr PAPPOS — That is correct.

**The CHAIR** — To assist them with once they are released?

**Mr PAPPOS** — That is correct. It is certainly a concern of ours, because under the national disability insurance scheme, if someone does not have housing prior to release and the necessary supports, then in terms of ensuring that they make a successful transition it is going to be incredibly problematic.

**The CHAIR** — The criminal justice system is not actually part of our terms of reference, but nevertheless I guess what I am getting at is: what supports are there within the justice system for people with ASD?

Mr PAPPOS — My understanding is that there is a specialist unit out at Port Phillip Prison, the Marlborough unit, that works with people with disabilities in general. It is a 35-bed facility. They have some specialist supports, and there is the disability pathways program — it may have changed its name now — that Corrections Victoria offers, but it is quite limited. In terms of the detection of people with autism spectrum disorders through the criminal justice system, it is not a very well-recognised or sophisticated way of diagnosing and identifying those.

**The CHAIR** — Does that mean that you find that you are working with the same people, recidivist offenders, over periods of time?

Mr PAPPOS — Yes, quite often, or the more likely scenario is they might be assessed as having an intellectual disability and post release we might identify that there has been a historical diagnosis of autism spectrum disorder. Sometimes we are fortunate in that, if they have been recidivist offenders, quite often there is some background information and assessments that are available.

**The CHAIR** — What is the housing support like for someone who is being released from prison who might have ASD or has ASD?

Mr PAPPOS — Unless they are accessing specialist services or disability residential services, it is quite limited, so they are tending to have to access the same mainstream housing services that everybody else coming out of custody is accessing. That is problematic. We operate, as I said — I may have not mentioned this — 10 residential services across Victoria. One of them is very specific to those with criminal justice needs, so wherever possible if someone is identified as needing that sort of framework, we advocate very strongly that they transition into that service. Our aim wherever possible is not to see people become warehoused in these services; we want to build capacity in people and see them transition to independent living where that remains a realistic possibility.

**The CHAIR** — Do you do assessments on those that have been in prison, gone through your service and are back in the community? Do you do follow-up?

Mr PAPPOS — Yes, quite often we are involved in providing after-care support. We might be funded to do so under individual support packages, where they exist. In other scenarios where that funding may have expired we might continue to provide some form of phone-based support, where we continue to link in with the person just to ensure that things remain on track, and in those cases more often than not those participants are engaged in some formal programmatic activity, so it might be education, employment — —

The CHAIR — So you have data on the number of people with ASD within the criminal justice system. Do you have data on how many you have supported to actually get out of the criminal justice system?

Mr PAPPOS — I am happy to say that the majority of people with autism spectrum — and, as I mentioned in my opening remarks, it is a small percentage that we work with — have all remained incident free, if you like, in terms of re-engagement with the criminal justice system.

**The CHAIR** — So are these a lot of adults who have not been diagnosed as autistic but come into the system, as you said, with comorbidities and then are diagnosed?

**Mr PAPPOS** — Yes. Some of them have a diagnosis. It is not consistent, though. So some do have a prior diagnosis; others are diagnosed or the clarification around their diagnosis may occur post release from custody. As I mentioned, there is often a misunderstanding around people's presentations, so it might be attributed to psychiatric illness or other neurological issues rather than autism spectrum disorder.

**The CHAIR** — Are you dealing mainly with adults, or do you deal with young people?

Mr PAPPOS — Predominantly adults.

**Ms McLEISH** — I just want to clarify a couple of things for my own benefit. When somebody enters the justice system and they have a diagnosis of autism spectrum disorder, is that ticked on a box somewhere?

Mr PAPPOS — My understanding is intellectual disability will be identified. Regarding the autism spectrum, unless there is prior knowledge that the person has autism spectrum disorder, it may not necessarily occur. There are neuropsychiatric services that are engaged in custody, so where there might be concerns around someone's interaction style, certainly I am aware of cases where neuropsychiatrists have been engaged for that specific purpose.

**Ms McLEISH** — And you said also that the police may not recognise either and often it is assumed that it is something else.

Mr PAPPOS — Yes. Victoria Police I think have done a fair bit of work in the space to skill up their members to identify intellectual disability, mental illness. I think autism spectrum disorder is one of those things that still has not evolved to that level. Similarly when people are interfacing with the mental health system, if they have an intellectual disability and autism spectrum disorder, usually the behaviour that is being displayed will be labelled as behavioural rather than as a formal diagnosis.

**Ms McLEISH** — So if I have entered the system and I would benefit from some OT or some speech therapy, would I get that through the justice system?

Mr PAPPOS — In some cases it might be acknowledged. Again I do not think it is formally case managed that consistently in the justice system.

**Ms McLEISH** — With the number that have been diagnosed that you know of, are they male, female?

**Mr PAPPOS** — Predominantly male.

**Ms McLEISH** — And what levels of the justice system have they been in?

Mr PAPPOS — Again, varied. Some have served time in custody, others have just been considered at risk of contact with the criminal justice system and in some cases they have been found unfit to plead under the crimes mental impairment legislation.

Ms McLEISH — Do you think that there has been quite a lot of misunderstanding at the front end?

Mr PAPPOS — I would say yes. I think there is not a wealth of information and research available to inform how practice should shape up in this area. Certainly I think we have made vast improvements in the way we might interface with people who might have mental illness in the criminal justice system and even intellectual disability. Regarding autism spectrum disorder, it feels as though we are still very much behind the eight ball.

Ms McLEISH — So with custodial sentences have there been many or for long periods of time?

Mr PAPPOS — Again, it has been varied. Over the journey that I have worked in the sector we have had some individuals who have been in custody for quite serious offending behaviour and have therefore served a significant period of time. The more common one that we come across is non-custodial supervision orders where people might be subject to those for a nominal term and then, upon review by the County Court, the County Court has continued that non-custodial supervision order.

**Ms McLEISH** — Do they generally understand?

Mr PAPPOS — At times I think there is an awareness that some of the behaviours they have engaged in have contributed to their interaction with the criminal justice system. Again I think it differs from person to person. I cannot say in a general sense that it is consistent across the board, because it is not. Certainly where there is therapeutic intervention that is provided or clinical intervention, there is an understanding around the person's preferred interaction style. There is covering that gap around the person's theory of mind. Then certainly there is an enhanced understanding that these sorts of steps, for example, 'might lead to my engagement with the criminal justice system'. So certainly we have found that where we have provided that individualised intervention, it has worked quite well.

**Ms McLEISH** — Given that there is a whole range of diversity, what about backgrounds, culturally?

**Mr PAPPOS** — Culturally most people are of Australian background. There has only been a small percentage of people who come from other non-English-speaking backgrounds.

**Ms McLEISH** — And what about family involvement? Have they still got family who are, I guess, there for the journey with them?

Mr PAPPOS — Again, the experience is varied, and sometimes it is based on family burnout. They may have seen a pattern of behaviour over a long period of time where it has just made it incredibly difficult to maintain a good relationship. We do have some people that we work with who are on the spectrum that certainly share a really good relationship with family and interact quite frequently, and in other cases it is non-existent.

Ms McLEISH — We have heard from a couple of families who have said that they are really worried, because of their child's behaviour, that they might end up as part of the justice system. That has been very scary for them. The parents are really quite worried about that.

Mr PAPPOS — The interesting pattern there is that we have seen that certainly prior to 18 years of age there is probably more of an understanding around the person's behaviour, and because they are under the age of 18, less likely to have that formalised contact with the criminal justice system. Once they hit 18 years of age and beyond, the behaviour is considered more serious. Again it depends on the nature of the behaviour. If it is sexualised sort of behaviour, it is certainly not something that is dealt with in-house, if you like; it is a criminal justice issue.

Mr FINN — I think just about all of my questions have been answered, but I have got one — and I think you have probably answered that as well. That involves the understanding of autism and how that impacts on people — by law enforcement officers, by the judiciary, even by court staff and the people who are in the cells looking after those who are incarcerated. Do you find that that is lacking? As I said, you have probably answered this, but do you really think we need to lift our game there substantially?

Mr PAPPOS — Certainly I think it would be good to raise awareness and education. There are some good examples of broad engagement. I do not think it is necessarily specific to those with autism spectrum disorders. But in the court context there are specialist aides that are integrated in that environment to support the person with autism spectrum disorder. They are quite independent from the judicial process. They can call for breaks if

the person requires that or if they can see that there is a lack of understanding. Certainly when we have supported people in courts, we find that there is a real lack of understanding. Making the connection between when they first came in contact with the criminal justice system to the date they actually appeared in court, which could be quite a lengthy duration, is problematic. The comment often is, 'I don't quite understand why I'm here today', or, 'Well, that was in the past'. So certainly I think if we had those mechanisms and those sorts of resources in place, it would assist in envisioning a person's deficits and enhance their understanding.

**Mr FINN** — Do you think we have changed, where I suspect in years gone by we saw jails full of people with autism, because basically they were misunderstood and nobody knew what autism was back in those days?

Mr PAPPOS — I think the issue is that there is still a lack of research around the area. The consensus is that they are overrepresented in the criminal justice system, but the precise percentage that exists in our prison system, I do not know that it is that clear. Perhaps there are some people out there who are conducting academic research as we speak. Certainly that would be of use.

**The CHAIR** — I just have a couple more questions. This brief I have here says that you provide employment services to clients with intellectual disability.

**Mr PAPPOS** — That is right.

**The CHAIR** — Can you tell me what those employment services are?

**Mr PAPPOS** — So they are disability employment services.

The CHAIR — Social enterprise?

Mr PAPPOS — It does include some social enterprise. We operate a cafe and a pantry service.

The CHAIR — Whereabouts?

**Mr PAPPOS** — In the Richmond area. It is, I suppose, open to a broad range of people, so not exclusive to people with autism spectrum disorders or disabilities. But we do have some people with — —

**The CHAIR** — Is that specifically for people who have come out of the criminal justice system?

**Mr PAPPOS** — We are interfacing with the criminal justice system, yes.

**The CHAIR** — The other question I had was: is there any autism specialist within the system from other services, or what are the other services out there?

Mr PAPPOS — Formally, I do not think there is any other service that interfaces with autism.

**The CHAIR** — So you are it.

Mr PAPPOS — I think there are a few services that probably do not realise they are interfacing with people with autism spectrum disorder, so I would not be so quick to say we are it. I think there are other organisations that do some good work — Amaze, for example. We have consulted with them, and we have had them involved in providing training. I think they have got a good understanding that people with autism spectrum disorders are certainly not immune from interacting with the criminal justice system.

The CHAIR — I have no more questions. Thank you very much, Stan. It is much appreciated.

**Mr PAPPOS** — Thank you; thanks for the opportunity.

**The CHAIR** — Well done on the work that you do. Thanks very much.

Witness withdrew.