

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Melbourne — 29 August 2016

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Ms Katie Koullas, founder, Yellow Ladybugs.

The CHAIR — The committee welcomes Katie Koullas, founder of Yellow Ladybugs. Thank you, Katie, for attending this afternoon. 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. We invite you now to make a short presentation to the committee.

Visual presentation

Ms KOULLAS — Thank you so much for giving me the opportunity to speak on behalf of the Yellow Ladybugs. I wanted to just briefly mention quickly who Yellow Ladybugs is. I am the founder, and basically we are dedicated to the happiness, success and celebration of autistic girls and women. It was founded by myself as a volunteer last year after realising there was not enough services dedicated to girls on the spectrum. We support identity-first language, which is very common now, and we also uphold the values ‘nothing about us, without us’, in other words, giving a voice to the lived experience. I self-identify as an autistic woman, although I have not had a formal diagnosis, and I have got two girls both with diagnoses. So that is pretty much about Yellow Ladybugs. The submission is a combination of my own lived experience and that of our community. We have approximately 300 members in our group since last year.

I am pretty much just going to go through some really key issues facing autistic girls at the moment. As you may or may not know there is currently a ratio of 4 to 1 — 4 boys to girls — diagnosed with autism. Although Tony Attwood, a leading expert, says that this ratio is probably closer to 2 to 1. The main reason is that girls do get underdiagnosed, and this has caused a lot of issues for people in our community. So they are getting missed.

The CHAIR — Can I ask why? Sorry to interrupt.

Ms KOULLAS — They are getting missed because the diagnostic tools created to assess children or women, adults, is based on many, many studies on the way boys presented. It used to typically be considered a male condition way back when. Studies are starting to catch up to include more girls in their studies, so the way girls present is differently to the way boys present. Therefore sometimes the diagnostic tools have not been created to take that into account, and therefore they get missed. So there is an issue there with getting missed, and I will talk about my own personal experience with that in a minute.

So diagnosis is sometimes not accessible or affordable, particularly for girls, because as some of the speakers may have mentioned there is only a few specialised psychologists who understand the true way girls present, and so to actually afford them is really hard. For example, my story with my youngest daughter, is she presented as having issues from kindergarten. Probably earlier, now that I look back, but in kinder definitely had the social issues, a lot of the traits, but was not picked up. No-one mentioned the word ‘autism’ at all to me and I did not know anyone on the spectrum at the time, so it is not something that I picked up on.

I went to my local council asking for support. I was sent on many parenting courses. I went to many paediatricians, psychologists and GPs, who would all just say, ‘She’s hot’ — because she used to have sensory issues. They said, ‘She just gets hot easily’ or ‘You just need to implement this parenting strategy or that strategy’. So it felt like I was going around and around and the issues were getting worse and worse in kinder and right through to primary school. So I probably ended up seeing so many different people until I finally got the right support and the answers that I needed. It was not until one paediatrician, who understood how girls present, picked it up within 5 minutes of seeing her in the waiting room — —

Mr FINN — How old was she then, could I ask?

Ms KOULLAS — She was nearly six. So I had been looking for answers for three years, and that is just because I am a really determined person. A lot of people may have given up or thought everything was fine, and we now know how important it is to get that early support at a younger age. And also I could afford to. Not that I am rich by any stretch of the imagination, but I actually had funds to pay \$400 for paediatricians here and there. You know, it ended up costing me thousands of dollars to get that support that should have been available if the signs were more obvious or available to kinder teachers to begin with.

So my daughter was misdiagnosed with general anxiety. She was misunderstood at school. She was considered naughty. I was often called in to pick her up, because she was defiant. Also, she was just having sensory overload at the time. The school did not understand what was going on and so she was considered naughty. Even after diagnosis, the public school we went to, one of the first things they said to me was, 'You won't get any funding'. Straightaway, that was basically the answer: 'You're not going to get any funding. There's nothing we can do'. And it was a really hard battle for me to have an understanding that they would support us through it with or without funding.

Unfortunately it is a similar situation for many of our community members, where they either have to take them out of state school and go to a Catholic school to be able to get given an aide or have to home school because the children have school refusal. That is what we actually did. We took my daughter out of state school and we went to a Catholic school, even though we are not Catholic, because now she has got an aide in the classroom. To paint the picture, last year before we moved she had anxiety every day and was throwing up every day before school and at school for six months, and that did not qualify for any support in the classroom.

Like I mentioned with girls, they do present differently, and one of the ways Tony Attwood describes it is that they are less disruptive in the classroom. Because they are less disruptive in the classroom it causes the issue to not get support with aides. As we know, at the moment, if you have got a language score above 70, you are not necessarily given access to a special school with autism. I know from our case and many, many others that is what we have been told. But also within primary schools at a state level, a government level, you do not qualify for disability funding arrangements if your IQ or level of speech is above 70 with an autism diagnosis. Even then, the third option might be if their behaviour is disruptive, then you could possibly get support with an aide at a public school if that is the case, but we do know from leading experts that girls internalise a lot of their anxiety. They are less disruptive and do not therefore get access to the aide under extreme behaviour.

I will give you an example of one of the Yellow Ladybugs girls who absconds from school often daily due to anxiety, and even though her language is above what you would expect for a student of her age and her IQ is high, she is not able to perform to the best of her ability because she has got such extreme anxiety. She does not have any aide or support because of those issues. So this is a real issue for our community, and it is not just this one example — it is many, many stories from our parents. Here are two quotes which were in my submission. The top one:

No wonder so many girls are homeschooled or have school refusal ... the cut-off for a funded aide is a significant disadvantage ...

And again the second quote:

I had to pull my daughter out of public school and put her in Catholic (despite being an atheist) because she didn't qualify for an aide.

So parents are really calling out for this issue to be addressed for this subsector of the community.

The three main issues according to a study for girls at school are, like I have mentioned, internalising symptoms — they have got anxiety and depression but they do not show it. They might fall apart at home because they have held it together so much in the classroom. They also have difficulty with peer relationships, including social communication, and again with bullying obviously, with exclusion being an issue. So that is based on a study. The funding model does not take this into consideration. Even though there might be some schools that support this, it is not consistent across the board, so one child may get the support they need but we need to make it consistent across all schools.

There is another quote I have got here that says:

My daughter rarely made a fuss in class. Always head down, not to get noticed, but what people didn't see is the internal anxiety she was holding in, which impacted on her throughout primary school. The difficulties she had making friends, and the constant bullying or exclusion she faced. She had no aide, because she didn't disrupt others, but she needed one. She was bright, but not learning to her potential — not by a long shot, and during the important social times — like lunchtime, where her anxiety was at its peak, she should have had support. But she didn't.

Perhaps with the right support, she would still be in school, but without funding or true understanding of her needs, she now has school refusal, and so we have to homeschool. She is self-harming and has depression. The psychological, social and economic impacts stretches beyond her, it impacts our entire family now. A cost that needs to be considered, when deciding if an aide is appropriate for girls who are quiet and seem to be functioning.

So that is a good example of what our community are facing at the moment and something we need to address as the vulnerable teenage years are fast approaching many of our Yellow Ladybugs community members.

Just to close off on this particular topic, there are lots of studies in this place, but a key study on girls with autism at any mainstream school says the key issues that do affect their ability to succeed are class rules, working collaboratively, completing tasks, working with peers and a lot of executive functioning issues. Like Narelle mentioned earlier, I also have this issue — I am amazing in some areas of my life but I have got problems with executive functioning in other areas. They just seem so invisible because it appears that we are functioning. So if we can give this support at an early age, then we can definitely set up our girls for success as women in the community. So we really want to make sure girls are not overlooked just because they are not as disruptive and therefore get access to less support.

Ms McLEISH — Can I just ask: are they Australian studies or overseas?

Ms KOULLAS — This study was — —

Ms McLEISH — You have got a couple of them there.

Ms KOULLAS — One was an Australian study. There are not a lot of studies in Australia, unfortunately, for girls. But there was one person — I quoted earlier from her study. This is from Pamela Jacobs and she is in Australia. She is in Bali at the moment, but she just messaged me her study. She is finishing off her PhD in this area so there are more studies coming through. I will not read these quotes out again, but they are all in the submission. But hopefully it shows that we do need to focus on our girls at an early age because they present differently to boys, and we just do not have that access to the support. They are slipping through the net, and it is really important to give them that support. A lot of girls get diagnosed at a later age typically because of the issues I mentioned and therefore miss out on that early support. I was actually lucky to get my youngest daughter diagnosed at six. My other daughter was diagnosed closer to eight — my older daughter — and that was just because my other one was more obvious. We hear stories of 12 years and upwards to getting that assessment usually.

My recommendations are: a greater understanding of autistic girls and associated traits; working at how we can get earlier diagnosis for girls, affordable diagnosis — it should not cost \$1500 to get an assessment, and that is what stopped me going forward with my own; funding based on needs, not IQ or language score; better resources and training for schools to understand the female presentation, and that is something we would love to support to happen in our community; and support for programs — and I am biased here — such as Yellow Ladybugs. We are really trying to make a change in girls' and women's lives. It really was born because there was not anything out there like this. It cannot be sustained on zero funding at the moment, because I also work and I am a mum of two girls with autism. But the impact we are having on families is amazing, and I would love to continue it, but it definitely needs government support because the potential is so huge. We have got interest from every state in Australia as well as UK and America, but it is only a couple of volunteers at the moment and it is not sustainable, so we would need that support. I think that it could be a model that is used to inspire, engage and really change the lives of autistic girls and women. Thank you.

The CHAIR — Thanks very much, Katie, and congratulations on the work that you are doing with Yellow Ladybugs. I think it is really important that the issues around women and girls with ASD are highlighted, and I think you are doing a great job as volunteers with that work. You talked a lot in your submission and your presentation around the current education system. The previous presenter mentioned her daughter going through puberty, which is a challenging time for young girls. There is clearly no support for parents or for young girls going through that transition, and also there does not seem to be any support specifically for girls — young women — with ASD when they are transitioning to higher education or employment. I am just sort of wondering what you think could be put in place — how do we actually support young girls who are on the spectrum who are going through that very significant physical and mental change in their lives? And then, beyond that, how do we assist them through higher education, if that is possible, or into employment?

Ms KOULLAS — Good question. I actually am a higher education teacher, so I do agree with you that there needs to be more support for transition stages. There is a model in the UK. It is called Felicity House, and I would like Yellow Ladybugs to take this model on in the future. It is a drop-in centre for girls and women and it helps them through transition stages — so finding a job, getting into a course they like, further study — and it basically has a place that women or girls can go to, or parents, so that they can access support in these areas.

What is really important, and I think we need to keep this in mind, is that it is driven by user-led communities. So actually having autistic women involved in it is also really important so that the voices of the community are represented equally, and that is what Felicity House does in the UK.

I would like Yellow Ladybugs to be a model like that, where it is giving women support but also true understanding through the lived experience. That is what I think could be the best way to support our community. So maybe specific training or support around those transitions or interview skills, because that is a massive barrier for women or people on the spectrum — passing that interview stage where you are expected to look people in the eye or behave in a certain way. We need to advocate for modified interview techniques, and that is where I could see a body that focuses on that in partnership with the actual person trying to apply for the job. I think that we have got a goal of trying to set up something for children, but our model going forward is trying to be the leading service provider to support girls and women through all stages of their lives, including motherhood. I know Narelle mentioned that and that is something that is on our agenda to introduce in a couple of years.

Also one of the things we are actually working with the Moreland council on and we would like to expand is talking to kindergartens and schools about the different ways girls present, because personally if my daughter's kinder teacher had said, 'Have you thought about autism?' — because she is only hanging around the teacher, for example, not any other peers — then that would have saved so much of my time and money and given us access to support earlier. So we would like to do that as well, with those transition pathways: kinder, primary school, high school, tertiary, jobs, motherhood. We sort of see it as a life cycle of support for girls and women.

The CHAIR — And there are some good models overseas around that?

Ms KOULLAS — There are, yes, including Limpsfield Grange, which is a school. I know that is a hot topic and you have already discussed it quite a bit, but there is a school dedicated to girls, a high school just for girls with a language score above 70, where they have got a place where they can come together and really share their journey and understanding. It is amazing if you hear from the principal and the girls themselves. It is definitely a stretch goal of ours to start a school like that. It is on the 2030 plan, but it is there and I think it would work.

Ms McLEISH — Thank you, Katie, for coming in. Just following on from the comments that you just made about some of the transitions, what sorts of support do you think that girls with ASD need when they are transitioning to higher education, for example, or to the workforce?

Ms KOULLAS — Well, it would be great to get the support earlier on so that those transitions are less needed. I think if we could get the support in earlier, then by high school and the workforce hopefully it is then more seamless. Assuming that that is already in place, I think that, like I was explaining, possibly some training specifically on the barriers that they might face, or support on how to overcome that — I think that is really important — and a possible mentor role relationship where they have got someone that they can go to and ask for advice, someone who has already lived through it, possibly.

Ms McLEISH — Who do you think would deliver that sort of service? Where do you see it fitting?

Ms KOULLAS — Yellow Ladybugs. We could do it. I literally would see women who have lived through this experience — —

Ms McLEISH — So would you see schools coming to you, or how would you see it? Would you see you going into schools?

Ms KOULLAS — Yes. So, for example, we already are planning to go into schools, high schools and primary schools but not tertiary — I do not think we have actually tackled that area yet — and basically offer an opportunity to mentor or speak on general awareness or on a mentorship role to actual girls.

Ms McLEISH — Can I just get some clarification? You talked about a language score of 70. Is that just on the regular IQ test, and they pull out the language component?

Ms KOULLAS — Yes.

Ms McLEISH — So which ones do you use, the WISC or the WAIS or — —

Ms KOULLAS — I do not know what it is called but I know my daughters did a language assessment when they were diagnosed and that was above 70. I do not know if that is a WISC.

Ms McCaffrey (from floor) — It is separate.

Ms KOULLAS — It is separate.

Ms McLEISH — It is a completely different one.

Ms McCaffrey — It is another standardised test.

Mr FINN — It is a debacle; that is what it is.

Ms KOULLAS — There were so many tests at the time — I cannot remember — but I know that if you got below 70 it meant you did not get access to an aide, but I think it was well above.

Mr FINN — While we are on that subject, Katie, of the 70 and surrounds, and there are both boys and girls who are being disadvantaged to a very large degree by what appears to me and most other people to be a total and unmitigated debacle, do you have any suggestions as to how we can make this fairer and give those children a fair go?

Ms KOULLAS — I think that we cannot just put a blanket rule on it that if your language is above 70, then you do not need that support. I think that we need obviously an individualised approach, but also giving teachers the right support or tools so that they can pick up on the subtle cues where people may need more support. It is not that obvious. Some people may be more disruptive or have a meltdown or show signs that they need that support. Not all students do that, so there are some subtle signs or cues that we could train teachers in to be able to pick up the needs or just regularly checking in, for example, with girls to see how they are going with the change of plan — or boys. I think that making it a more individualised approach is definitely a fair way of giving them the support they need, rather than a blanket rule. Having that statement from so many teachers saying, ‘She’s fine’ is really unfair because we know what is going on underneath the surface for a lot of girls. It is hidden and then it comes out later when they are older and there is higher anxiety.

Mr FINN — So it all comes back to a basic understanding of the young person involved, and what they are going through?

Ms KOULLAS — One hundred per cent, yes, definitely what they are going through and being able to pick up on the subtle signs. Not everyone presents the same.

Mr FINN — I was fascinated to hear your comments about receiving an aide by going to a Catholic school. Are you telling me that a child is not able to get an aide in a government school but that the same child with the same problems by going to a Catholic school can get an aide?

Ms KOULLAS — That is exactly what happened to me and exactly what has happened to many of our members. I did not get an aide for my daughter. Same issues, and literally pulled her out of the school because I tried my very best to get the support she needed, and walked straight into a Catholic school and she has got an aide.

Mr FINN — When you went to the Catholic school and said, ‘Well, this is the problem’, they had no problems offering you an aide?

Ms KOULLAS — I had four schools say they were full and turn me away — my local schools — but then I found a school that was willing to accept her and say, ‘Yes, we can’, because the Catholic system has a different funding model and they have kept that funding for children with language above 70. So they said they just literally put the application in and they get it. It is not based on that language score at all.

Mr FINN — That is truly staggering, I have to say.

Ms KOULLAS — Like I said, it was my story and also another parent’s story — exactly similar. But there are so many of these examples. It should not have to be that you go to a Catholic school to get the support you need. She shares it with another student in the classroom, but that is enough for her. But I will say that it is

important for all schools to understand that the peak time of anxiety and stress is lunchtime, so that is when they need the aide, not always at the start of the day.

Mr FINN — When they are left to their own devices and do not quite know what to do?

Ms KOULLAS — Yes. Socialisation is a hard one, and it is really important to give them that support — if the aide could have lunch an hour early, for example, and have that time. It is not always possible, but it is just something I would like to note because it is definitely something that is brought up a lot in our parent sessions. I have heard, though, that the Catholic school might be looking at the funding of aides, so I do not know how much longer it will be there either.

Mr FINN — That is a worry.

Ms COUZENS — Thanks, Katie, I appreciate your coming in today. Can you just tell me what Yellow Ladybugs does for the membership? Is it having support meetings or — —

Ms KOULLAS — I have got a video, but it will go too long; if you want to see, I can put it on.

Ms COUZENS — I do not think we have got time.

Ms KOULLAS — Another time. Basically my daughter was often — and we hear this a lot back — not included in birthday parties at school. After one particular day I decided I would like to create once a month birthday party-style events so any girl who misses out can come along. We have events that happen at the National Gallery of Victoria, the museum, Lego, where once a month they come. It is in a sensory-friendly environment and it has just exceeded my expectation. We have on average 70 girls spread across the day at the events. We have got one this Saturday and we have got 70 girls registered at the gallery. The interest is really there and there is usually a wait list. It books out in 24 hours and there is a wait list. So what that shows me is that there is definitely a need in our community for this. That is why I need to make the decision now whether we expand it and get the right support to do this, or whether it is too much for me to do on my own.

The CHAIR — Every child who goes to those events, they have been diagnosed?

Ms KOULLAS — Yes, every child has been diagnosed and attends a mainstream school. What we are trying to do is support the kids who are not quite getting the funding to go to a special school. They might meet peers or might meet other kids — those who might never meet another autistic girl in particular, for example. As Penny Robinson said, it took until university to meet another girl, because when you go to a lot of the therapy sessions it is mostly boys, with maybe one girl. It has just been amazing to see them all come together. It is really special. We just need that support, I think.

Ms COUZENS — Thank you. And the NDIS?

Ms KOULLAS — I do not know anything about the NDIS because we are not eligible until 2018, but what I find peculiar is that my daughter stopped her FAHCSIA funding last year and we have got literally nothing from that until 2018. But I am sure it is going to help when it is introduced.

The CHAIR — Thanks very much, Katie. We appreciate your time today. Congratulations on the work you are doing with Yellow Ladybugs and thank you for your submission as well.

Ms KOULLAS — Thank you.

The CHAIR — That draws to a conclusion today's public hearings. I thank everyone for their support today and thank those in the public gallery for their attention.

Committee adjourned.