

## **ASD and Family Quality of Life Discussion Series**

Saturday, January 18, 2014 from 1 pm - 4 pm

Panelists:

Dr. Grace Iarocci (Associate Professor of Psychology, SFU)

Emily Gardiner (Doctoral Candidate, Psychology, SFU)

Dr. Pat Mirenda (Professor of Educational and Counseling Psychology and Special Ed at UBC),

Amelia Poitras (Learning Support Teacher at Westcot Elementary School)

Jody Langlois (Assistant Superintendent for the Sea-to-Sky Highway District):

Evangeline Torres (Director of Learning Resource Centre at BC Christian Academy)

Colleen Fuller (Parent and Counsellor)

Jodie Wickens (Director of the ABA Support Network)

Attendance (including panelists): ~60 people

Start time: 1 pm

Introduction by Chantelle Tisshaw (Executive Director of Laurel Foundation): Discussed that the Foundation's funding goes towards research programs, including this project. Discussed the previous initial information session from April. Discussed the format of the day and assured that all questions participants have will be answered either today or by email.

Grace Iarocci (Associate Professor of Psychology, SFU): Thanked participants for coming to the session. Next presentations will be on "Transitions" and "Mental Health" expected to roll out in March. Offered guidelines for the discussion - each panel member will have 5 minutes to discuss their perspective on schools and then participants will have the opportunity to ask questions. Asking participants to be solution-focused and as concise as possible with their questions and comments. Notes taken today will be available on the website.

Emily Gardiner (Doctoral Candidate, Psychology, SFU): Welcomed all participants. Based on original family quality of life event issues to be discussed have been broken down into more focused topics. Discussed how family quality life is the goal of her research and that we are looking for ways to meet the needs of families.

Pat Mirenda (Professor of Educational and Counseling Psychology and Special Ed at UBC): She has been working with kids and families with ASD for close to 40 years now. The issue of quality of life especially as it relates to kids with schools has to do with 2 things: if the relationship between the personnel and the school is supportive and collaborative then the families will do better than if they have to advocate and fight constantly. The other factor that is important is whether the child is making progress and succeeding in the school environment. One question: what do we know about families' priorities for kids to learn in school? Looking at the research, there is a lot of agreement including the basics: eating, sleeping, and toilet training. Although this seems to go without saying, there are still many kids who aren't able to

do this and this limits their and their family's life. Another issue that emerged from the research was peer interaction, specifically to have quality relationships and to feel safe and engage in safe behaviours. Families also desire better quality verbal communication, reading, writing, and having good social skills at school - to prepare the child to work but also to be able to retain a job. In a broad sense these are the things that families want schools to accomplish with their children.

Amelia Poitras (Learning Support Teacher at Westcot Elementary School): Considers her job to be a very special job - it's all about relationships. Potentially a student entering into kindergarten can work with her until they graduate from that school. She tries to meet with the families as much as possible. The first meeting is really about letting the families talk - to learn about what the big and little issues are, it can be very emotional. After that they meet on a regular basis to talk about the issues that need to be focused on but also the positives. It is really important to share the good things that happen each day. Three key things brought up by parents: 1) whatever area their child has a deficit in affects the whole family; their time and energy. It forces them to be advocates. 2) There is a struggle between being an advocate and being a loving parent. 3) It is important to remember the positives and make connections with the teachers and the school.

Jody Langlois (Assistant Superintendent for the Sea-to-Sky Highway District): Has lots of experience working with different families and it has been an honour and pleasure to work with everyone. It is important to remember that it can also be hard for the schools as well to figure out how to support the students. When it derails for the student at school it also derails the entire family. Sometimes at schools they get caught up with how it affects the school (ex. the rest of the school hearing a melt down by a child). Parents can really blame themselves and it can affect their marriages. The schools need to be aware of the impact that they have on the family. Discussions need to focus on how can we do this together, not us vs. them. How can we have honest, open, and respectful discussions? Ultimately the goal is the same: the success of the child. When the family and school can work together then the child will have a much better chance at succeeding.

Evangeline Torres (Director of Learning Resource Centre at BC Christian Academy): Her first exposure to special ed was as a parent. All families are seeking answers to the question of what the future holds for their children. In order to help a child with ASD or other learning challenges there is a requirement to support the whole family. Visits from the parents are just as important as the time spent with the kids. Children are all individuals, we have to get to know what the parents expect so the school can make a plan. As an administrator, she has to learn the way to advocate properly for this child. It is also important to be open to learning as this collaborative process goes on, there is always something new to try or to be learned.

Colleen Fuller (Parent and Counsellor): Has a 14 year old son with high functioning autism. Her son had a good experience at an independent elementary school. The transfer to public high school has changed everything - the support team is gone and she has had to become more of an advocate for her son. As a counsellor she is looking to start a practice to help families with

autism. Her Master's thesis found that parents with autism have incredibly high stress scores and determined that there are five main factors that contribute to this. The least mentioned factor, interestingly, by the parents were child related factors. Mostly the parents focused on external factors such as the school, the neighbourhood, other family members, relationships etc. Another factor mentioned was the burden that parents felt, the parent's journey - the enormous amount of personal growth that the parents had to go through from the moment of diagnosis. The most mentioned factor was parent role expansion/explosion: have to be not only parents but teachers, therapists, mediators, trainers, etc.

Jodie Wickens (Director of the ABA Support Network): Speaking today about the advocacy side of things. She has an 8 year old son with ASD - the journey from diagnosis to treatment was very stressful. The amount of stress and hardship that arose from the entry into the public school was totally unexpected. Her experience was that she failed and the school team failed and she had to pull her son out and put him into a different environment. This is how she became connected with the ABA Support Network, which matches experienced parents with inexperienced parents. This group has grown and often discusses the school system, in particular the importance of advocacy. The group has approached the school board with petitions and although not everything has been granted yet, small steps have been made. As a parent you have to advocate for the child at the school level. It has to be a focused and supportive method (e.g., with other parents helping you, can even be small things like a token system), the empowerment that you will feel from that is immense. Change will only come from parents, we need to stand together as parents and focus so that children can get the evidence based support that the children need.

Grace Iarocci: Opened up the floor for questions and comments:

\*Bolded and numbered items below are comments or questions from audience members

**1) We automatically correlate advocacy with fighting. My personal experience is that it is really difficult to establish meaningful relationships between schools and parents. We need to talk about how to establish meaningful collaborations. The entire school system is not really designed to support children in need. How do we work with schools and get systems into place that will serve our kids?**

Jody Langlois: I think you will find that there is huge agreement with everything that you just said. There is a document that the Ministry has asked us to create, the will is there but the practice is far from perfect. We need to educate educators on how to work with differences. A lot of issues arise from ignorance. However, schools are constrained by external issues. The Ministry is moving away from a concrete education plan and to a more flexible education plan so there can be individual learning environments for each student. There has to be a shift in thinking to get that individualized attention. I'm hopeful that some of the constraints will be lifted.

Amelia Poitras: There has been a big shift at the school in terms of the amount of kids needing specialized attention. What these kids need is not actually that different from what a typical child needs. The school is starting to look at self-regulation as a school wide goal. Five years ago to

get systems like a token system was very difficult but now it is common practice. In the five years that I have worked there I have seen a huge shift to focusing on what the children need.

## **2) What made it difficult 5 years ago? The teachers?**

Amelia P: Now that we are looking at what all kids need to be able to learn and to be able to socialize appropriately. Changing the focus to seeing that not only will it work for this child but the whole class.

## **3) How did you get the whole class on board?**

Jody L: Educate, educate, educate.

Pat M: Many parents think that they need to convince the teacher to do what is necessary for that kid. Often we miss the impact that the leadership level for that school and the district has. This is a trickle-down situation. Advocacy efforts directed at a teacher will not be as productive as aiming at the levels above that. In this case, the district probably embraced self-regulation. If the district embraces it then the principals will embrace it and so on. It will become a priority and the kids will benefit. Sometimes we fail to appreciate a strategic approach to get the benefits not only for their child but for everyone else. Don't forget the huge influence of this top-down system.

Jodie W: When I talk about advocacy - a huge part of it is education. It is a huge mistake that I have made as a parent to think that others should know what it is like. In the past I have shown the school videos of how well my child does at home so they can see how effective certain strategies are.

Colleen F: Anything that can be done to get this into the teacher education is important. They need to be taught from the beginning that all children will have special needs.

## **4) Question for Amelia, are there more kids in the system due to a growing number of kids with these issues or are the kids attracted to your school in particular?**

Amelia P: Some started at the beginning, some came because they knew people there, some came because of our reputation as a good team.

## **5) For Jodie, my wife and I are basically alone. We don't have family in the area at all. I will definitely be getting into the ABA support network.**

Jodie W: I call it a community. We as parents can be just as vulnerable as the children are. The only answer is to build a community. You are more than welcome to join us.

## **6) For education you need funding. Without that you cannot have education. Has any research been done to see if parents in a better financial situation... is that better for the children? Has there been any research done between BC and other provinces or Canada**

**and other countries - if there are places that are doing better with these issues? We need to have more funding to support the teachers. We have to challenge our representatives to recognize this as a problem.**

Pat M: Funding has eroded dramatically over the past years. No question about that. That's throughout Canada. In a lot of ways BC is better off than many other provinces. The health care system is so clogged up as well. There are huge issues for the education and health systems here. It affects the people that work in the schools and trickles down to the families which makes their lives much more difficult. I don't know if there is a solution but it is definitely a huge issue.

**7) For parents in the room - funding is not our issue. There are a lot of issues about accountability. There are creative ways like the ABA support worker role in Surrey which are cost neutral which has been incredibly successful. Not sure why other districts are not looking into that?**

**8) I am a parent of a 15 year old. High school has been a completely different story, very negative. All of these wonderful things are happening at the elementary level but not much at the high school.**

Colleen F: No one was prepared for my son, no one was expecting him. He has basically been on his own. Theoretically there is a resource person that he can go to but this is clearly not going to happen. No one is checking in on him. The school is receiving thousands of dollars of funding but there is no assistance for him. When you have a child that is not appropriate for a specialized program there does not seem to be a middle ground.

Jody L: I am not going to excuse the high schools but I think we need to understand why things are so different for high schools vs elementary schools. We need to appreciate those differences to create change. I have 180 kids on my case load, the teachers are feeling very stressed. Teachers are judged by their provincial exam marks, so it is very difficult for them to understand how not to be so rigid with students with special needs. In elementary schools the model is much more like a family. High schools are not flexible which creates a lot of issues. I am really hoping with this new personalized learning that this will force change in the high schools. I have had teachers break down crying when I speak to them about adaptations because they feel like they are failing. There isn't a fast fix, we have to keep educating. Fighting gets you nowhere.

**9) My personal situation is that I am a parent of a son with autism. I now work in the school district. The autism student population brings in a lot of funding to schools. To look at the spiking numbers, the funding is going to have to come from somewhere. It is great that we are talking now but there is a huge demand coming in the future. When I was hired there was 35 positions and there was only 17 of us to fill those positions. For those parents that need the support they may still not get the help they need. Somehow we have to change things so that the position is more desirable to fill. We have to start at the elementary school level and expand upwards to the high school level. If a child has a**

**support worker that is working then they shouldn't necessarily have to switch to an SEA - why not stay with the worker that is helping?**

**10) One of the panelists mentioned the high level of stress. I am a parent of a 4 and 5 year old with autism. It is incredibly stressful to start school. We are asking parents who have incredibly high levels of stress to advocate at all these levels, it is totally unreasonable to ask us to do the advocacy. It is incredibly hard to be powerless trying to speak to all of these people with power.**

**11) What is the role of POPARD (i.e. Provincial Outreach Program for Autism and Related Disorders, <http://www.autismoutreach.ca/>) in the school system? Research has shown that it works but it does not have a big influence or being deployed in the schools.**

Jody L: POPARD as a structure gives you a certain amount of days and they are very structured. SD 48 is actually using POPARD. They are using them in consultation and utilizing the days for training. Again, it is back to the resources. What I like about it is the ability to build capacity within the district. We need to start doing things differently. How can we use our resources differently so we can continue to grow?

**12) I went to a POPARD discussion that was filled with teachers. In the US if there is a particularly challenging behaviour with a child there has to be a functional behaviour assessment. I have not seen that here with my son. There was no higher level of expertise.**

Jodie W: There is a need for things like POPARD but our children need child-specific interventions and trainings. Although POPARD can be a valuable resource for districts, what is even more valuable is the discussions between schools and behavioural analysts and to be open.

Jody L: Some families don't have those resources in which case POPARD can help. We need to start educating - whether it's through a POPARD course.

**13) There are courses at Douglas College that could help teachers.**

Pat M: Unlike in the US where there is a federal mandate, we don't have federal or provincial laws to guide these things. Therefore it's on a district by district basis. Some have the expertise, some do not. That's not going to change - there will never be a federal education law.

**14) I had a behavioural analyst who also worked in the school. Now when I talk to school employees I don't know what their expertise or background is.**

2:35 pm: BREAK for half an hour

3:05 pm: restarted the discussion

Grace I.: Reminding the audience to keep the discussion as solution focused as possible.

**15) In my situation getting a child diagnosed was very difficult. The doctor tried to convince me that my son was deaf and that I had munchausen by proxy. It took 6 months to see a pediatrician after that and then a 36 month wait after that for Sunny Hill. We are fortunate and were able to go privately and even that was a 6-8 month wait list. If we were a typical family that could not afford that - then that child would be starting school with no intervention or treatment. Maybe we should start educating doctors as well because my doctor is wonderful but even she said that I was the professional in autism not her.**

Pat M: I'm trying to let people know about the screening app that is available for the IPAD: "M-CHAT". It is an evidence based autism screening tool (not a diagnostic tool). It asks parents a series of yes/no questions and at the end you can email it to your pediatrician. If you email this to the doctor the week before you go and they have some data then that might help. In the States this method is becoming more commonly used. This is a good strategy to share with families.

Grace: Dr. Tony Bailey at UBC is trying to get more education to the medical profession as they are hard to reach. GPs have to deal with a lot of issues and they aren't necessarily trained for autism specifically.

Pat M: In the US the pediatricians are being told that they should be screening ALL children at 18 months. The Canadian Pediatric Society has not made that recommendation. Advocating for universal autism screening at 18 months is a really great idea.

**16) I work as a job developer for people with disabilities at the YMCA. Personally, I have two sons with ASD. You need to learn to speak as you are in a film, movie, or a play. I used to speak very bluntly but I have learned to think about how my words will affect others. I am starting to use this method with all of my clients. With my sons I socialized them, even when they didn't enjoy it so they would become comfortable with it. Thank you all for being here and sharing your information.**

Evangeline T: To add to the situation with the doctors - you can also ask your child's teachers and support workers to document situations with the children to share data with the doctor.

**17) My child was diagnosed with autism at 10 which was too late for intervention. His teachers said that they knew but were not allowed to say.**

Evangeline T: The teachers can't say what they think the diagnosis is but they are allowed to write down what they observe.

**18) I don't know how many people in the room have ASD but it is important to listen to older autistic people to learn what worked from them.**

Grace: We are hoping to invite someone with autism to join our panel in the future.

**19) A lot of you have spoken about the added stress of working with children with disabilities. I think a lot of this stress arises from the loss of control and power. My question is: what do you think we could do to better prepare parents to deal with school policy?**

Jodie W: it takes so much time to understand policy and the makeup of the district. Who to go to, what are the responsibilities, etc. Right now I am creating a parent resource on the ABA Support Network website where they can go and click on a district to be able to obtain the information about who to contact. We are working on this at the ABA Support Network.

**20) How will parents know about this?**

Jodie W.: There are parent-information sessions that will inform them about this.

**21) It is very difficult to find out all of this information. Jodie is going to try and link this to other district websites.**

Colleen F: There is an idea that comes out of cancer treatment, people called "cancer navigators". It would be extremely helpful to develop "autism navigators" who can help others.

**22) That would be a god-send. When we got our son's diagnosis we still had other children to take care of. In the past two years I have seen my social worker once for only a 20 minute visit. I haven't seen her since. I had to start figuring out how to help my son. There is nobody to help me.**

**23) Some school districts have a navigator but they sometimes do not have enough experience with autism. To have a navigator in the school district would be really helpful.**

**24) But before we get to school would be the preference.**

Colleen F: There are key transitional times - it would be really helpful if there was a navigator to help during those times.

**25) One of the most stressful things about getting diagnosed with autism is that you get funding but there are no standards/regulations to ensure that you are getting quality treatment for your child. It is all up to you.**

**26) You have to deal with the ministry not paying people on time. The workers aren't getting paid on time. So you have funding but you have to find a new person and retrain them which drains your funding. Workers are getting burnt out.**



**27) In some parts of the whole system there is a culture of delaying. In particular in the medical community. My son was diagnosed the week before he entered kindergarten. It was clear to us much earlier that he had ASD. If we delay therapy the problems are worse later on. If we can get kids to therapy early then it is better than dealing with serious issues later on down the road. We feel lucky that our kid was diagnosed. The diagnosis is the reason why he has support in the classroom. My question is: what can we do to reduce the struggle in getting a diagnosis for our children?**

**28) The ministry has set goals of timelines for diagnosis. One way is to advocate with the ministry.**

**29) I phoned them every day. They got sick of me calling and I got my son in to see a doctor after 3 months.**

Jodie W: A tip for the diagnosis process: I documented when I started going to the pediatrician. When Sunny Hill told me it was going to be a year I sent them my documentation and they backdated to my documentation.

**30) I just want to compliment the Laurel Foundation and SFU for this discussion. I work for Coquitlam school district. I want to comment on the navigator role in the district. One thing that we do have in place is the “Coquitlam Autism Spectrum Team” - these people work in a collaborative process between families and teachers. This isn’t necessarily the answer but it’s one way that we are trying to reach the needs of your children. It does not fit our philosophy to hire an ABSW.**

**31) I work as an SEA. I started in a school and did not receive any training. One thing that we could improve in school districts is mandatory training for SEAs. I have 5 children at one school one with ASD and the others not (although it is just the child with ASD that has funding).**

**32) I see both sides - everything needs to be above board. If a worker is assigned specifically to a child they shouldn’t be doing anything else other than helping that child. It always comes down to your administrator at the school - you need them on board to make things happen.**

**33) I am a parent who resides in Surrey. If something is amiss there is a system in place for parents to go if the school situation isn’t working.**

**34) Surrey has just hired a BCBA to help parents that don’t have a support worker.**

Pat M: That model of school districts hiring BCBA’s is becoming more common in the Lower Mainland. That thinking is starting to spread.

Emily G.: An audience member asked what are some things that people are doing just generally? Like self-care to promote their quality of life?

**35) Sleep - giving melatonin has helped so much.**

Pat M: If your behaviour consultant isn't working on "sleep, eat, pee" then it is your job to make that clear to them.

Jodie W: Community cannot be stressed enough. The journey can be isolating. My friends and their children can all get together and they have their similarities. You don't feel like you have to intervene. It helps to know that you have people to rely on.

**36) My youngest son did not sleep through the night until age 9. I would say to parents to be aware of how you are modelling your behaviour to them. Don't try to fix everything in one day.**

**37) For self-help, information is key. A functional assessment, like ABA, is critical. Any resources are amazingly helpful.**

Amelia P: A lot of my parents use our meetings as an emotional release. Sometimes people just need to talk about things. You have to be okay with asking someone for help. Even if it is just to ask someone to listen.

**38) Ask your therapist to help train you to give you the tools to help your children. This may reduce your stress a little bit.**

Jodie W: There is also the opposite side to this - there are also a lot of times that I realize that I am doing the "wrong" thing with my kids. It is important to give yourself a break from being the "therapist/teacher".

Colleen F: There is a thing on Youtube called "1 minute meditation". You have to find those moments when you can stop being responsible for everyone and everything.

**39) I recommend consultants because they can give an outside/objective perspective. Also you need to have a set pattern/consistency to make things easy on yourself. It's not easy but it will help.**

**40) About the navigator - there is a program called "Parents in Residence" that pairs parents with other parents to try and build relationships with schools.**

Grace: Wrap up and thank you to audience and panelists.

Meeting ended at 4 pm.