**Check it Out Launch**

**Total Running Time: 11 minutes**

Dr. Kathryn Underwood:

Good Morning everybody and thank you very much, Michelle for that introduction I really appreciate it. Congratulations on the launch of the Check it Out tool. I know that a lot of work has gone into this and so I really commend all of you for that work and I’m really happy to get the opportunity to see the final product. In particular, I’m really looking forward to seeing how this tool is used to support families across the system. I’ve been asked to come today to share with you the perspective of some families who have been interacting with early years services over the past few years.

I’m the Project Director of the Inclusive Early Childhood Service System project, which is a longitudinal study of families experiences of accessing early childhood education, care, disability and community services. Our project focuses on the experiences of families who have children with disabilities and in part we have focused on those families because we know that they are accessing many services. For that reason they can actually be quite good informants on how the system operates.

So our study is really about taking up the viewpoint of families in order to better understand how the system operates. We believe that these parents have expertise that can be valuable for everyone. So I’m going to share with you a few of the things that we’ve been learning from one family as a case today. As I said the study has been going on for a few years and we’ve been working in five communities across Ontario including the City of Toronto, Hamilton, Wellington County, the District of Temiskaming and Constance Lake First Nation. In those communities, we have a first cohort of 67 families and we are now currently recruiting a new cohort in all of those communities, but we have recently expanded to British Columbia, Northwest Territories, and Manitoba. So, what do we do? We talk to families and we ask them about all of the services they’ve interacted with and we ask them to tell us about the processes that they’ve had to engage with in order to gain access to those services.

So, what I’m gonna do is I’m gonna show you a map of a single family. This map is quite complex, so before you see it I’m gonna tell you a little bit about what to expect. Okay, so I’m gonna start by showing you a map. This map is the story of one family and their interactions with institutions in the context of having a child who has William’s Syndrome, which is a rare genetic anomaly. So we’ll show you the map now.

Across the bottom of the map you’ll see a number of large circles. The first circle represents that child’s birth, the second circle is their first birthday, the third circle is their second birthday. So this map represents the first three years of this child’s life. What you can see is that it starts with the mother and this is true about almost every map that we’ve created. That at least one parent, usually the mother, because this work is often quite gendered, usually the mother notices something or has some questions about their child’s development and then they start to reach out and engage with other services. You can see that on this map they begin by interacting with Holland Bloorview, an agency many of you know. They reach out also to the hospital. It’s at the hospital where they get a diagnosis and you’ll see on the map there are some red words. Those red words are the places where the child is documented or diagnosed. For us that’s really important to track each of the places where there’s some kind of gatekeeper through processing for the children to participate in those services. So you can see that there are multiple points in the first three years of life that this child gets a diagnosis or a designation. That diagnosis or designation helps the system to then respond to the child and their family. You’ll see that the triangles are actually agencies. Each of those agencies also then offers programs, which are in squares or in people, which are in circles. When we look at this map, you can see that this family has interacted with a lot of programs and services. So one of our core findings in this study is that accessing services is actually quite a lot of work for families. We know that when we plan services we think about things like how much money it will cost to put that service together, how much staff we need, the materials we need, but I think it’s not that common for us to actually think through how much work it is for the family to access those services.

So for us, it’s critical for us to see- to actually map out the work of the family. The second thing that I want to point out here is that we believe that this system of services is predicated on an idea that children have a particular pathology. Some pathologies lead to more access to services than others. So, in this case, those red sentences have led that child to be accepted into programs at places like Sick Kids and Holland Bloorview; but we also know that children’s development is impacted by many social factors and many characteristics. But not all of those social factors or characteristics lead to that same kind of access. So it’s really important that we have opportunities for families to understand how to qualify for services, what things make them qualify for those services, and to get support in navigating how that access comes to be. So we’ll move to the next slide now.

This is the same family and this is the years from age three to age six. You see that the picture gets more complicated and that’s because the child is a little bit older. So they’re engaging in a lot more recreational activities and that’s the band across the bottom. That band across the bottom, many of those recreational services are adapted or specialized services and I think it’s important to recognize in this case this family seemed to be able to find many, many different kinds of recreational services to participate in. But we have families in the study who really haven’t been able to access that level of service and there’s other reasons, not just whether they qualify for services, but the work that families do to gain access to services has to do with families’ comfort in interacting with professionals. We also know that the neighbourhood they live in matters in terms of which services they might be interacting with. We have some families in the study who are- have been living in public housing and may have been moved by the city and when that happens that can interrupt the kinds of services that they are interacting with. So sometimes, we think about neighbourhood as being a place where you have connections but sometimes it is not by choice that you live in a particular neighbourhood.

We also know that there are cultural factors in terms of who feels comfortable to do this kind of work interacting with services. So one of the things that we have found is that for disability services in particular, there is a medicalized way of thinking about children’s development that may be inconsistent with some cultural groups. In our study, about a third of the participants identify as First Nations or Metis and we have found that many of them do not ascribe to that medicalized or Western way of thinking and that can lead to exclusion from those programs. Lastly, I’d like to point out that when we talk about being inclusive of children and families, I believe that we’re often talking about single programs and one of the things that’s really exciting about the Check it Out tool is that it looks at a range of programs and services and works across professional groups. So one of the things that we’ve seen through our maps is that families may experience inclusion in one program but not in many other places in their lives. So we’re interested in re-thinking the definition of what it means to be inclusive of the early years by thinking not just about having single programs that are inclusive but creating an inclusive community for all children and all families.

The last thing that I’d like to point out about this picture, particularly in the years from age three to six, is just how many different systems are interacting with each other. In this case, the child went to a Kindergarten program that was determined to be the best fit for that child and after spending a few months in that program the parents did not agree with it, and pulled their child out of Kindergarten they went to some other community based programs and they ended up sending their child to a different school district. I share that story because when something like that happens it is really supportive if there is many other professionals who already know that family. What you see in front of you is a picture of that family who has a lot of support in the community, but we know that some families are not in this situation. We also know that having supports in different professional categories can help people to navigate when there are problems across the system. So, I’ll stop there with this slide.

We have learned many, many things about families through taking up this position of thinking from the standpoint of families as we examine how the system works and so as a result of that research work I’ve become very interested in the ways in which the system as a whole operates. So, I’m really excited to see the work of the Check it Out tool and the group who are here today. I will be here this afternoon so I look forward to meeting many of you face to face and I wish you all the best.

Thank you.