

## Dr. Kathryn Underwood: A Discussion on Disabled Children's Childhood Studies

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Dr. Kathryn Underwood:

Okay, so I'm gonna start again just because of the timing and I hope to save a little bit of time so that we can have some final discussion. I should start by telling you that I am kind of stealing the agenda here today because the agenda today it was to talk about Tillie's book, and what I'm gonna talk about now has nothing to do with Tillie's book [laughing]. It is about my current research project, which many people in the room are a part of. You can see up at the top, I am the principal investigator of the Inclusive Early Childhood Services System project, co-investigators include Elain Frankel and Magdalena Janis who are in the room, Kathryn Church she is in the room. She's also been very influential in the project and as a collaborator, as you heard at the beginning when we did introductions there's many people in the room who are employees of the project, so that's how we filled all the seats. We paid people to be here [laughing].

So, I'm going to introduce the project and then in addition— here's why I am stealing the agenda. The first two presenters are both people who I have solicited to become part of the project. So, this is like all of you witnessing my sales pitch to them to get them to engage with the project [laughing]. So I took up the opportunity to talk about it while they are here because they have both been invited to be part of the next phase of this research work. So this is bringing together people in this room. And so this project is about experiences that families have interacting with institutional services when they have a child who is thought of as disabled. So, it's got a long title but I didn't want to drop any of the words in the title. They all were important to me. That's why the title is so long. So, inclusion is a complicated word, as Kristin's described, and some of the students who are in the undergraduate course who are here—I briefly had a conversation with them. The undergraduate Disability Studies course that I'm teaching is a hybrid course, so I put ideas out there, and I'm not always sure if people are engaging with them or not that's the tricky—I'm very new at online teaching.

So I've put a few ideas out there in terms of inclusion, particularly related to work that Kristin and I had done together, including having one of our articles on the reading list that include the idea that inclusion is not just a placement. It is about who you are interacting with and having the ability to make choices about who you interact with and who gets to decide who you're interacting with. So a lot of inclusion work has been focused on placement, where children get service, and often, in history, it's been defined as being with your typically developing peers. And there's lots of problems with that. One of them is who are these typical, mythical people? Because all of us are different, right? And it depends on what we're measuring on who becomes

the typical ones. But in addition to that, there are lots of reasons why people want to be with other people who they are like, for lots of reasons and the notion of superdiversity I think captures that because each of us has many identities and find other people to connect with for lots of reasons. We can't always decide that just by looking at somebody, by even knowing who their families are. So, how do we get to a place that's called inclusion, and so I like to think that rather than thinking about inclusive programs, we have to think about inclusive lives. And so that's what I mean by the term inclusive here. Only an individual can decide if they feel included, and I actually think that none of us feels included all of the time or excluded all of the time. This is a dynamic relational process.

So, the project that has been developed and collaborated with a number of people in this room in addition to four Municipal governments, including the City of Toronto, the City of Hamilton, Wellington County, and the District of Timiskaming in Northern Ontario, which is about a six and a half hours straight drive North from Toronto and Constance Lake First Nation, which is several hours past that. I'm looking at Nicole. It's her home community [laughing]. It's far away from this centre. In this project, we've asked families from these five communities about their experiences, and it's a longitudinal study, so we've asked them over a number of years. Most of the families started when their children were age two intentionally, because around the age of two we expect children to walk and talk in a normative sense, and if they don't, we start to refer them to services. Other children are born with disabilities, and we know in advance that they're unlikely to walk and talk or other things, but around two we start to get enough children that we can see, that it's easy as researchers, to sample. We also, purposely wanted to talk to people before they went to school because there's a lot of research about school, and there's not nearly as much research about what it looks like before you go to school, to be a person with a disability.

The concept of disability is largely defined by the institutions we interact with. So this study influenced by Kathryn Church became an institutional ethnography. We were interested in how that interaction with the institution was actually starting to construct disability and also the daily practice of interacting with institutions. And Kristin talked about how important it is to speak with families. We felt the same way. Well, I come from a School of Early Childhood Studies, I think it is important to talk to young children, but as Tillie said we can't ask children to be responsible for the service system. We certainly aren't going to ask two year olds to be responsible for the service system. So I think there are some good questions to ask of young children, but think the questions in this study are appropriately asked of parents. We have 67 families in these five communities who we've been talking to over a few years. We're just starting our third year of data collection, and so most of the families have started to— the children have started to age into schools. Although, we have a number of parents who we've reached out to this year with the expectations that we are going to hear about their experiences with school, and their children are not going to school because the schools told them that they couldn't help children with their needs. So that's a surprising thing for us—well, I don't know if it is surprising. It's a concerning thing for us to be hearing.

Some of those children then went to private schools or to special schools, but we have heard a number of stories about people going into their home school in the community and being told, "We don't have services for children who are like yours." So, what I have behind you— I'm not going to talk about all 67 families. We have an enormous amount of information about each of

these families, but using this approach called institutional ethnography, we've started to map the experience that families have. So what you have behind me on this very complicated slide that I'm going to describe to you is one of our maps. And this map is from a particular parent, one of the parents in the study. She happens to live in Hamilton, and so we selected this particular example because this mother told us that she had the best situation. So I want to point out that—not all families are angry and feeling upset about their services, but I think even embedded in this story, there is a lot of the construction of childhoods and the construction of disability that were talked in the previous presentations.

So, I'm just gonna describe what's on this map to you a little bit, and I'm gonna tell you about the questions we're asking from the research point of view. Along the bottom is a timeline and each of these circles is a birthday for the child, so you can get a little bit of the sense that the open circles, the donuts are annual time points. And so around the first birthday, the mother said, "My child is not doesn't have great language skills," and the child actually went to— she took her child [laughing]. So just before age two, the child went to child care. This is child care number one and in that child care centre, they said to the mom, "You know, your child's got a lot of behaviour problems and is very difficult," and so they would call her quite a lot and ask her a lot of questions about her child and she would say, "well, I don't know I'm trying to figure it out." So, here all these lines are referral lines and the mother over here. Every line that is attached to the mother are places the mother found herself, so that's a lot of work that this mother did to find a soccer program that would take her child. to find child care where her child could go. And this first child care centre eventually, the situation became so untenable that she removed her child from the child care. It was a mutual removal. The child care centre didn't think she should be there either. But they did have what's called a resource teacher. Some of you've had training in resource consultation. There was a resource teacher, and the resource teacher said, "Yeah, this child has a behaviour problem." The mother said, "I can see that, but I think there's a language problem." So she contacted the agency that runs preschool speech and language services in her community, and she did a self-referral to what is called Early Words. So the child started going to Early Words, and that seem like it might help, and so she got into this circle of services, which is speech and language services, which is— I'm looking at Michelle in the room, she's doing her Masters research paper on, specifically speech and language services because they're typically what everybody gets referred to in the early years. This is the starting point. You talked about entry points, Tillie, in terms of institutional interaction, speech and language services seem to be in an entry point for almost all of the children in our study. It seems to be central in terms of where people get sent, probably because of our normative ideas about language. And Kristin's done some research on what it looks like for Deaf children to be referred to speech and language services, but I think that it is important for us to recognize all children getting referred there are getting particular messages about childhood and what is normal. So they go there, and then this problem happened. She got kicked out the child care centre, so she doesn't know what to do. She does go to church, and the church is very helpful. And that's one of the places where she's always felt included. And her child goes to Sunday school. They're very open at this [church], and they don't care about the diagnosis.

Over here we see child care number three, number four, and number five. These are all places where she tried to get someone else to take her child, and she was told, "Sorry, behaviour problem." Nobody wants people with behaviour problems, and this is to do with that social relationship, right? If you don't seem like you're gonna be easy to relate to, then people don't

want you and we start that *very, very* young with children. So, we have a whole set of services in here that relate to the city of Hamilton. They have a child care registry to try and help parents get child care, but up here is a live-in. So in terms of institutional interaction, she couldn't find anybody to care for her child. She ended up becoming involved with the foreign trained professionals program and learning all about how to support somebody to immigrate to Canada to work in her home because that's who she could find who was willing to work with her child. So that's a big thing for somebody to do, right?

Some of you may have immigrated to Canada yourselves and know what that experience is like; maybe you don't, but it's not a simple thing to just say, "Oh, I can't find a child care so I will help a person immigrate to this country to care for my child." That nanny happened to have worked with a child who had autism in Hong Kong before coming to Canada, and they said she was very patient and found this child not be at all have a behaviour problem— I don't who she worked with before she had some—there was some connection to that in this story. But this group here also then referred her to an occupational therapist— and these telephones mean a professional referral happened, formal professional referral. So the speech therapist sent them to an occupational therapist and the occupational therapist said, "This is more than a language problem. We need to get you sent to a developmental pediatrician." So they made a referral to a developmental pediatrician who worked at McMaster Children's Hospital. And McMaster Children's Hospital— this circle here is a big, big circle with a lot of boxes and lines and stuff happening in it. You don't need to know everything about that. That's just characterizing it. It purposefully complex, this picture, so you can get a sense of how messy this story is. This is where she said, "Wow, things have finally kicked into place." She got an autism diagnosis. That autism diagnosis changed their world.

Now some of us might say, "well that's a very normative thing to happen," but from an institutional standpoint, it was a complete turning point. All these child care centres that said it was a behavioural problem over here with an autism diagnosis might have looked at him in a different way. They might have treated him in a different way, but pre-diagnosis, he was a problem, post diagnosis he's a different kind of problem [laughs]. But a different kind of problem that comes with money and services and some other notions of what that means. So here, why she said this was so good it's that—I'm gonna sort of summarize the picture I'm describing to you in a second with these quotes from the mother. Why she said this was so good is this group of people who were at the autism clinic at McMaster said, "You need to be in child care." That's tricky, right? [laughing]. She's gone from child care to child care, she couldn't get in to child care. She got this live-in nanny and they said, "What you really need is child care." And why, because all these services they were delivering they know from research are better, more effective if they're delivered in a child care in a more natural setting where there are social relationships taking place.

So they helped her to find child care number six who actually believe in this approach, and so it all came back together here with child care number six. All of these professionals working with the family, they signed consent agreement so they could share information, and she feels that she's got the best thing going. What she has is all these professionals talking openly with each other, having conversations with each other, including the staff in the child care centres, the supervisor and she said it's just so warm, they care about her, they care about her child and her child is flourishing in that environment. But from an institutional pathway, it's a little bit ironic that

she ended up at this place where what she needs is child care when what she had was child care. So I think it's worth considering what happens in between and how our institutions operate. How we think of children, how we think of disability and how we construct them in these environments.

So, this particular person we have not interviewed for the third time. What we have over here, though, is a final box, which just represents a meeting, and that's an intake meeting for school. Magdalena's nodding. Magdalena and Elaine both have lots of expertise in this area of transition to school. She finally got all of this going over several years, and now she's gonna go to school, and the whole system's gonna change. How those services are generated, who she's qualifies for, what the child qualifies for, how that gets generated is all gonna change again. And what we know from research by other colleagues and team members is that typically, the services, there are far fewer services, and when you do get services the intensity of those services is less. And the interaction with the families is most certainly is less because in our school system, in our education system, we don't see the family as the client. The family are just a means to an end. The family are good for fundraising, and we need to send them report cards, but they're not actually in need of services from schools nor do schools offer services to families, for the most part. Whereas in early childhood, we do tend to think of families as being part of the work that we do. So you can this institutional shift over time.

So I'm just gonna read a few of these. Some of them are quotes and some key ideas that we pull from this particular case. So she calls this the best case scenario When she gets to this circle she says, "It is so incredibly well coordinated, and the really big thing is because I signed the consent for email, sharing of information, we have a nice email list between myself, the speech and language pathologist, diagnosis. Many families described getting a diagnosis as a turning point in their institutional interactions. In this map we see a dramatic reorientation of services post-diagnosis. Many children will not have a diagnosis at this age, and we know that they are big differences. You also need to know that this map was in Hamilton, which is a big city, not as big as Toronto, but it is a pretty big city. What this looks like in other communities in this province is not the same. So we do have families in Northern Ontario, Indigenous families living on reserve, who get a diagnosis and no services follow that until school. So, the geopolitical context really matters.

Child care and community programs are important. All this got lined up when there was a child care centre involved in this. So often we think about services as being clinical, but it was really critical for this family to have a community space. "We had a whole heap of services set up for him, but what he needed for it to happen was a daycare environment because he was kicked out of every daycare. He was at home with a nanny, which was great, but he needs to be in a daycare environment or some type of child care environment." The last point I'm gonna make here is that overall one of the questions that we ask is, "How does this system work?" And we know that this system works because the mother's doing all this work. Embedded in this system is a huge amount of work from the family so the mother says, "I am currently the only one who regularly works with him," meaning doing therapy, "which means that if I ever didn't do it, it wouldn't happened. So I often expressed that frustration with the autism spectrum disorder clinic because for the last two years it has felt that all of the weight has been on me." And so I think when we talk about families, it's important to recognize that families both are being put in this position of doing the work, but also, they are the context in which children experience their

childhoods. And so we need to be careful about what we're asking families to do and to be. We don't want families to be clinical environments. We want families to be places where children learn because all children learn in their families, but what is it that we're asking of families and I think that's important question to ask.