Disabled Children's
Participation in a
National Childcare
Strategy.
What are we learning?

Kathryn Underwood, PhD
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Kids Included Inclusion Summit
Policy Day
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### Agenda

- Research overview
- Key concepts to consider:
  - Organization of disability services in early childhood
  - Critical policy analysis
  - Standpoint
  - Dysconsciousness
- Recommendations from families

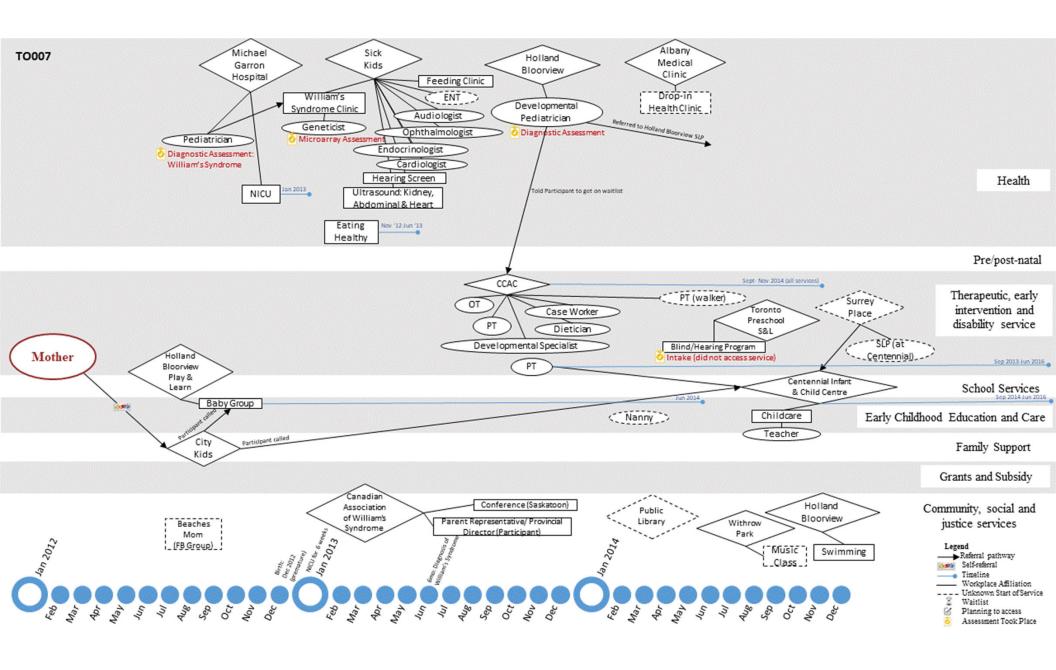


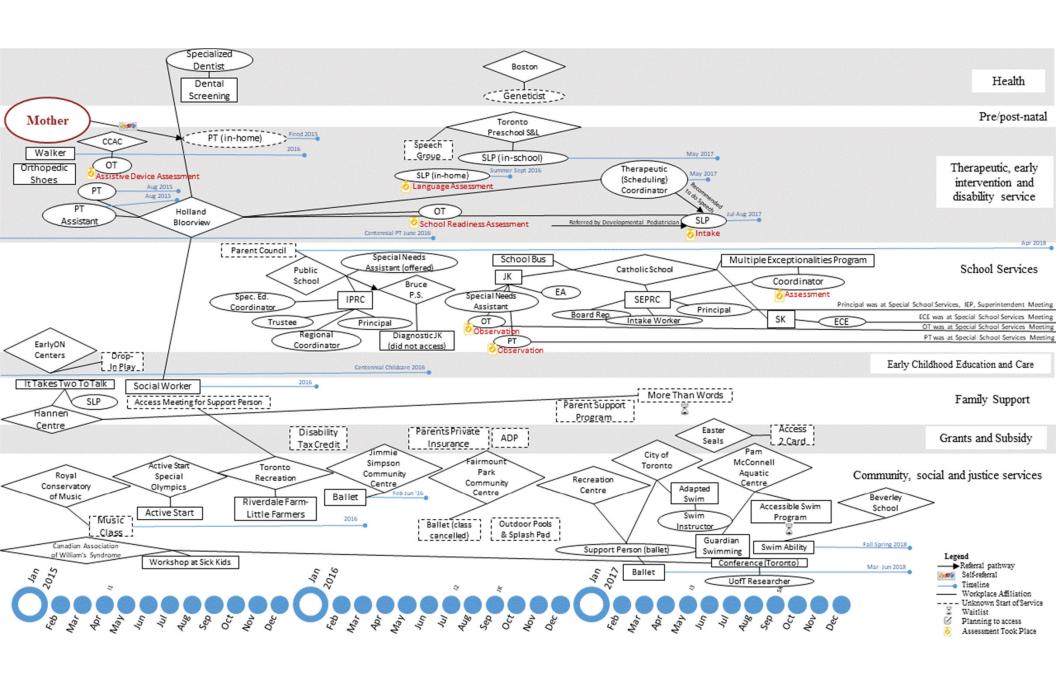
Institutional ethnography questions

Who does the work of the system?

What processes make the system work?

Which worldviews are valued in the system?





## Organization of disability services

Inclusion needs to focus on the experience children are having not a checklist of practices.

Inclusion is not a placement alone.

Inclusion is about efficacy not than "supports" and "services".

### What do families contribute to the system?

- The system works because families and mothers work
- The family contributes Time, money, energy, etc.
- The more services a family has, the more the system needs from them



### How do the institutions work/hold power?

- The early intervention system operates on a medical model that is deeply entrenched
- The institutions have processes that families and frontline workers must comply with in order to gain and maintain access.





### What processes lead to action in the system?

- The system is generic,
   i.e. the "quadruplets"
- Geography and social identities affect how the system works
- The early intervention system operates on a medical model that is deeply entrenched



## Critical social policy

Interrogates how problems are framed, who gets to define them and who benefits or is marginalized as a result.

#### What we have learned through IECSS

**Assumption 1:** More service is always better

Assumption 2: The relationship with institutions is neutral

Assumption 3: Disability equals service "need"

**Assumption 4:** Access to service lessens risk

## Standpoint

Critical policy analysis leads to policy-based recommendations that present the possibility for systems of care that are informed by the people who use them.

An inclusion strategy should focus on reating access and the right to participate in communities.

All children and families have something valuable to contribute.

## Dysconsiousness

An uncritical habit of mind (including perceptions, attitudes, assumptions, and beliefs) that justifies inequity and exploitation by accepting the existing order of things as a given

#### **Origin stories**

- This is not a theoretical but an experiential stance
- Comparison
- Diagnosis, medical intervention
- Community

# Adults are uncomfortable with talking about disability

#### **Institutional definitions of support**

- Consider whose "needs" are being met
- Consider what assumptions are made about families, including when they are resistant
- See the child as a whole human being

#### **ECEC Framework for inclusion**

#### **Service integration:**

 IECSS recommends integrating services like early intervention into existing settings like Early Years and Child and Family Centres to provide embedded learning opportunities and avoid the need for families to navigate multiple systems.

#### Family-centered approach:

 The project emphasizes the importance of understanding the experiences and perspectives of families with children with disabilities to inform policy from the outset, not as an afterthought.





## ECEC Framework forconsultation

#### **Inclusivity and anti-ableism:**

 Policy recommendations work to re-imagine inclusion through the lens of disabled childhoods and address issues of ableism, exclusion, and procedural bias that families face.

#### Inequality



- Private funding is embedded within the public system
- Families with economic resources have different tools to access support and to care for children at home
- Economic well-being is connected to racism, ableism, and other forms of structural discrimination

### Recommendations from families

The majority (79.5% in our study) of families are experiencing some form of exclusion. What do they say needs to happen?

#### The Inclusion Process

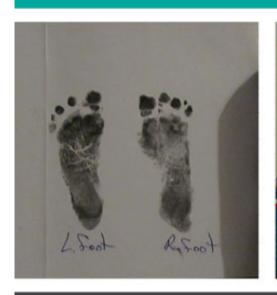


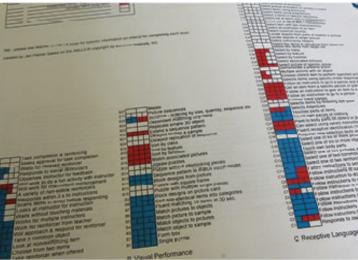
### Policy considerations from our data

- Cultural principles
  - Need for Understanding and Support
  - Access to Services
  - Advocacy and Empowerment
  - Community and Connection
  - Systemic Barriers

- Family recommendations
  - Streamlining Access to Services
  - Improve Wait Times
  - Enhancing Childcare Options
  - Advocate and Support for Parents
  - Inclusive Programs
  - Mental Health Support
  - Collaboration Among Services
  - Increased Awareness and Information Sharing

## childhood



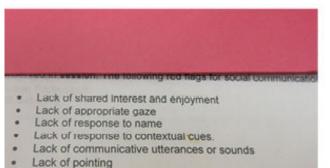


#### Childhood is ruled by developmental "norms".

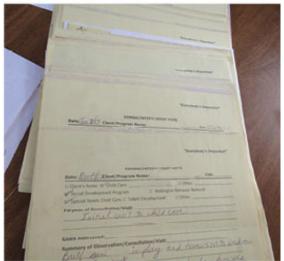
"Norms" feed professional practice. They govern professional actions in early childhood education, care and intervention services.

The parents we talked to were troubled by "norms." They know that learning and human development are embodied experiences.

### documentation



ne total number of correct responses in a test. This can be converted into a standard scores between 85 and 115 are considered average for a child's age on a test with a group of children of similar age. Percentile ranks between

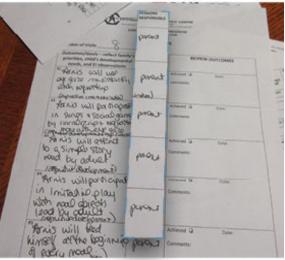


### Institutions thrive on documents; human beings thrive on connection.

To be a disabled child is to be continuously documented. But documentation separates "conditions" from whole lives; it fosters disembodied decisionmaking. The medicalized and normative language used masks the child as an active member of family, community and programs.

### work





#### To be a good parent is to produce a normal child.

Regardless of the child, the parents we talked to had learned that to be a good parent is to produce a normal child.
Faced with this tremendous

responsibility, they can either comply, and gain access to institutional resources, or resist, and be left on the outside. Either way it's hard work.

## participation

"That people are happy for [disabled children] and proud of them. And they are proud of themselves."

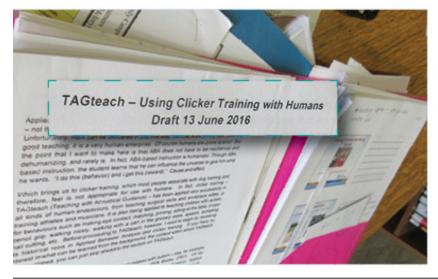


#### Hey! Look what I did!

Institutions often use the stories of disabled children to market their services. The "supercrip" narratives of this kind of promotion are challenging — and can

be challenged. We discovered resistance in the medals that a disabled child was given for a triathalon. Not as a superhero. Simply a participant.

## humanity



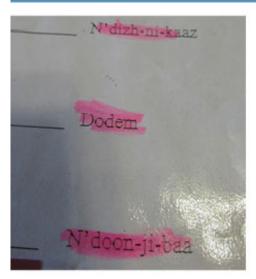


#### Some things are not made to measure.

The clinical trials of medicalized research can reduce individuals to body parts and cognitive functions. The doll in this image

was made by hand and gifted to a disabled child who was in hospital. It was lovingly crafted to represent her as a whole human being.

## culture





#### In our language is our belonging.

While language is often a focus of early intervention, it is much more than a developmental domain.
Crucial for formal education, language is also about

communicating in daily life, passing knowledge between generations, and connecting with each other. As one Elder told us, "language is everything". Thank you

Email:

kunderwood@torontomu.ca

Website:

https://www.torontomu.ca/inclusiveearly-childhood-service-system/

# **nature** awards inclusive health research

In partnership with

### **Shortlist**

Kathryn Underwood Inclusive Early Childhood Service System project



