

# The voice of disabled children transitioning to school

*Starting school should be an exciting time for young students and their parents, but for disabled children and their families it is fraught with challenges and anxiety. It shouldn't be. Disabled children should have access to services that support them and their families through the transition process and ensure their full participation in both early childhood and school programmes. Researchers in Canada, mapping institutional interactions of disabled children and their families over several years, have worked with disabled youth to make recommendations for a more inclusive system.*

For the parents of any young child, the transitions to kindergarten and then 'big' school are exciting moments. Knowing their child is growing up brings an eagerness for them to embrace what is ahead. However, while early childhood education and care and more formalised school environments offer many experiences and opportunities beyond learning, they are also competitive and laden with written and unwritten rules. For any parent worried whether their child will cope and fit in and whether the school and broader education systems are organised to include them, these moments lead to worry. Many parents contemplate whether they will need to advocate for their child's full participation.

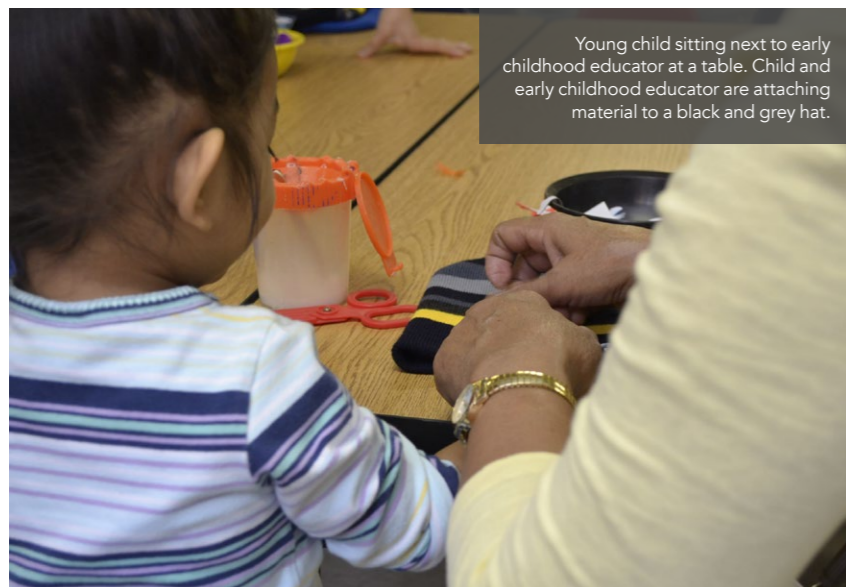
A team of Canadian researchers has been mapping the institutional interactions of disabled children and their families over several years to better understand their experiences of early childhood education and care and the transition to school. Their insights look to shake our understanding of how disability is constructed in school environments.

Dr Kathryn Underwood is a professor in the School of Early Childhood Studies at Ryerson University in Toronto and Project Director of the Inclusive Early Childhood Service System (IECSS) project. The IECSS project is a 14-year-long longitudinal study interviewing families of disabled children once a year for nine

years, starting from before school entry up to grade 6. It is framed by a theory of disability that recognises the value of disability experiences and the ways that disabled childhoods can teach us about how society and institutions respond to children. Disability is experienced in interaction with an individual's many social identities, including their economic conditions, racial identity, gender, and access to community social capital, such as early intervention services and childcare. The project uses an institutional ethnography methodology – it examines how the rules of institutions shape everyday lives, in this case, those of young disabled children and their families.

Inclusivity is critical to the project – it is built into the name. So, research partners include other researchers and governments, as well as community organisations supporting Indigenous families, families living with low income, families who experience racism, newly immigrated families, and families in rural and remote locations. It covers families with disabled children in urban centres and those in smaller towns as well as First Nation communities in provinces and territories across Canada. The families all have managed services for their children who have diverse disability and deaf identities, including neurodiversity, blind and low vision, language impairment, and physical and intellectual disabilities. Furthermore, the research partners invited the input of three advisory committees: a Youth Advisory Committee, an Indigenous Elders' Council, and an International Advisory Committee.

The outcomes are thorough, broad, and ongoing insights into how disabled children access activities and services during their transition into early schooling. Part of that insight has been published in a recent paper, *Systemic knowledge at school entry: learning from disabled*



Young child sitting next to early childhood educator at a table. Child and early childhood educator are attaching material to a black and grey hat.



Two young children are playing with water in a large clear container. One child is holding an orange cone toy and water is dripping down into the container. The second child is holding a blue plastic toy close to the water.

*children and their families*, by Dr Underwood, IECSS project coordinator Abneet Atwal, and two of the project's youth advisors, Kalea Davies and Gregory Doucet. The paper presents an earnest reflection of how, in one of the world's most developed countries, institutions designed to help disabled children fail to do so adequately and are sometimes even detrimental.

## LIVING A GOOD LIFE

An evident outcome from the research is that from the moment disabled children enter an early interventional system designed to address their needs, especially concerning education, they become locked in an institutional network of waiting, filling in forms, consultations, constant referrals, and repetition of services. This all takes time and a significant amount of work. The IECSS report presents occupational therapy as an example – something offered by community early-years programmes, clinical developmental services, and healthcare settings. Families of disabled children say it's not uncommon to move from one

agency to another and receive the same intervention, yet each requires its own intake and assessment processes. This happens with other services such as speech and language, physical therapy, and children's mental health services. The outcome is a waste of resources

**Impairment-specific healthcare, intervention and support shouldn't dominate disabled children's way of life, just help them live a good life.**

within the institutions and psychological and physical exhaustion for the children and families. There's another potentially damaging outcome: the wasted opportunities for children to do things other children are doing, such as social interaction through play.

What makes the IECSS insights so worrying is that disabled children and their families report that they understand the need for early intervention programmes and value them. They see such services as crucial to development, participation, and growth. Lack of balance between accessing disability-specific supports and full participation in education is a source of frustration.

Part of that frustration comes from a lack of coordination between different levels of government to ensure a fully inclusive system. The system could rectify these things if those designing, managing, and implementing these services were able to be more responsive to what families and children have to say. Disabled children and their families want and value services, including special education. Care should be taken to integrate those services to avoid repetition

and to ensure they don't interfere with children's participation in other, more social, activities. In essence, impairment-specific healthcare, intervention and support shouldn't dominate their way of life, just help them live a good life.

## DISABILITY, DISCREPANCIES, AND DISCRIMINATION

One of the more sobering insights from the IECSS research is that not all children can access these services equitably. Some families cannot allocate the time and other resources needed to engage with them. The system is also not immune to discriminating against families and individuals based on race, citizenship, custodial status,



Young child is sitting in the lap of an early childhood educator on the floor. The child is clapping hands above their head and the early childhood educator is holding the child's hands.

and disability. Furthermore, the Western medical approach prevails – with many services requiring a medical diagnosis as a qualifying criterion.

Overall, institutions focused on providing support systems and early childhood education seemed intent on treating conditions and putting children on a segregated path for further development – one requiring ongoing, specialised care. Families and children prefer to be integrated into a broader education system. This, however, would place them within a system currently limited in its capacity – either physically or in terms of human resources – to provide the services needed.

The researchers also encountered discrepancies between the offerings of public and private agencies creating inequality in access. They also noted that public agencies needed more funding and all services need to understand children's needs as expressed by the children and their families to better support them in a transition to a new school. Failure to do so risked young children feeling excluded.

Once at school, another critical component in the transition process comes to the fore: how those disabled children viewed themselves and how their peers and the systems viewed them.

**DISABILITY IS SIMPLY DIVERSITY**  
When interviewing families of disabled children on the issue of identity, IECSS researchers were struck by discrepancies about identity. At most points, the system sees disabled children as different and deserving special

## Disabled children recognise their differences but view them as another contribution to society's rich diversity.

attention and ongoing institutionalised help. On the other hand, disabled children recognise their differences – be they physical, neurological, or intellectual – but view them as another contribution to society's rich diversity. Disability, considered a need for help by the system, is deemed positive by those the system wishes to help. The voices of disabled children and their families in the report are clear on this matter: disability is rarely included in

conversations about diverse identities. Just as issues of race and culture have become overdue talking points about respect and encouraging diversity, so should disability be included in those considerations.

Importantly, according to Underwood and her team, these discussions should be happening within education systems to break down any stigmas attached to those considered disabled. Disabled children simply want to be treated as part of a school's diversity and not objects to be prodded, avoided, or ridiculed. They want other children to

be comfortable asking them questions and discussing disability openly and constructively.

The work of the IECSS project documents the experiences of families and we should listen carefully to what they say. All early childhood and school services should be designed in close consultation with disabled children and their families to support the exciting transition into school.

# Behind the Research



Dr Kathryn Underwood

E: [kunderwood@ryerson.ca](mailto:kunderwood@ryerson.ca)  
T: +1 416 979 5000 ext 552519

W: [www.ryerson.ca/inclusive-early-childhood-service-system](http://www.ryerson.ca/inclusive-early-childhood-service-system)



Abneet Atwal

E: [abneet.atwal@ryerson.ca](mailto:abneet.atwal@ryerson.ca)

T: @IECSSproject

## Research Objectives

The Inclusive Early Childhood Service System (IECSS) project examines the organisation of young disabled children and their families.

## Detail

### Address

Faculty of Community Services  
350 Victoria St, Room KHS 363C  
Toronto, ON M5B 2K3, Canada

### Bio

**Kathryn Underwood** is a Professor in the School of Early Childhood Studies at Ryerson University. Through critical disability theory, Dr Underwood investigates how society responds to and constructs childhood in social institutions. Dr Underwood has conducted several studies that focus on parent viewpoints and family experiences of institutions.

**Abneet Atwal** is a PhD candidate in Child and Youth Studies at Brock University. She is a project coordinator on the Inclusive Early Childhood Service System project at Ryerson University. Her research focuses on childhood disability, disability and culture, migration, and disabled children's participation.

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### Co-authors

- **Kalea Davies** is a BA candidate at Guelph-Humber University and a Youth Advisor for the IECSS project hosted by Ryerson University, Toronto, Canada.
- **Gregory Doucet** is a grade 12 student at Maple Secondary School and a Youth Advisor for the IECSS project hosted by Ryerson University, Toronto, Canada.

### Collaborators

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### Co-investigators

Tricia van Rhijn, Virginia Caputo, Elaine Frankel, Gillian Parekh, Karen Spalding, Magdalena Janus, Brenda Poon, Patricia Douglas, Martha Friendly, Arlene Haché, Joanne Weber, Nicole Ineese-Nash



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## Personal Response

### In your opinion, what is the most pressing concern in helping young disabled children transition to school, and why?

- // The following recommendations are based on our research findings and conversations with our youth advisory committee:
1. Families and young disabled people want disability-specific services.
  2. Disability and special education services should not impact participation in other activities.
  3. Educators need to consider what and how much they ask of families because institutional interactions are a lot of work.
  4. It is important to directly ask children about their experiences.
  5. Educators should discuss positive representations of disability with all children.
  6. It is important to recognise disability as a part of identity.
  7. Disability rights are connected to other forms of discrimination.
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