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.

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 theoretical lens that recognises the value of disability experiences and the ways that disabled children 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, such 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 children and their families, by Dr Underwood, IECSS project coordinator Abneet Atwal, and two of the project’s youth advisors, Kalia 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 intervention 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 and 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, and personal and financial 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.

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

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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 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 contact with disabled children and their families to support the exciting transition into school.

References


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 children with disabilities.
4. They are 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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