

Title **0037**
by **Kathryn Underwood** in **Inclusive Health Research 2024**

Original Submission

Score n/a

1. The Entry

1 1. Lead organisation or Institution chiefly responsible for submitting this entry Toronto Metropolitan University

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Type of Organisation Academic/research institution

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1.2 Chief Contact Person Kathryn Underwood

Chief Contact Person's Job Title/Post Professor

1.3 Name of project or programme Inclusive Early Childhood Service System project

1.4 Date that the project or programme began	2014 (ongoing)
1.5 Countries in which research / implementation was undertaken	Canada
1.6 About partners and collaborators	Here you should name up to three collaborating organisations and provide a contact email address for each one that you name. We will then send a request for a supporting statement, which will be taken into account in the scoring of this application.
Partner organisation/institution #1	Keepers of the Circle
Type of Organisation	Clinical (non-teaching)
Website URL	https://keepersofthecircle.com/
Partner organisation/institution #2	Niwasa Kendaaswin Teg
Type of Organisation	Other Charity
Website URL	https://niwasa.ca/
Partner organisation/institution #3	City of Toronto
Type of Organisation	Other
Website URL	https://www.toronto.ca/
The Case Study	
1.8 The Title of Your Case Study	Inclusive Early Childhood Service System project (IECSS)

1.9 Simple Summary	<p>The Inclusive Early Childhood Service System project is a partnership that began in 2014 and continues as a longitudinal study of how healthcare and early intervention services respond to childhood disability. The project was co-designed with community partners including Indigenous-led organisations, early child development agencies and municipal government. The project aims to understand structural aspects of exclusion, the ways that disability is constructed in these contexts, and the possibilities for ensuring access in all aspects of community, access to intervention and therapeutic services, while also ensuring that disabled children build positive disability identity.</p>
1.10 Introduction	<p>Early identification, intervention and education are all concepts that have emerged from western medicine, with the aim of ensuring children have the “best start” in life -- a phrase is used in many government and early intervention campaigns. Without a doubt, the early years of life, before children enter school, are an important time for development. However, normative frameworks for understanding early development, are perpetuating social norms with relation to what is a good childhood and who is a good parent. This means that we believe that early intervention that is informed by community, and by people with lived experience are best positioned to develop early intervention programs, activities and support.</p> <p>We have documented that many children in Canada do not have access to early intervention services, especially in northern and remote communities, but also in urban settings where many private health insurance is the primary mechanism to access early therapeutic intervention. We have identified the complexity of the early years system for disabled children and their families, and we are committed to early childhood health and care that works for the children in their communities.</p>
1.11 Key Words	early intervention, disability, childhood, Canada, rural, remote, urban, family support
Which category best fits this project or programme?	Addressing a specific unmet health need
2. Unmet Health Need Case Study	<p>These will typically fall in to one of three groups: Group 1: Understanding needs and context Group 2: Designing and conducting research Group 3: Translating research into impact The various suggested sections which follow will not be equally applicable to all groups. We have given an indication of which sections may be most crucial to each but you should use your own discretion and judgement. We are seeking case studies that can be published, so please write your entry as summary, rather than a series of statements addressing the questions. You do not need to repeat information across sections. We do not expect everyone to be able to address all of the questions, as not all will be relevant.</p>

2.1 Who should benefit from the project or programme?
(Applicable to groups 1, 2, & 3)

In Canada, close to 20% of the population are estimated to experience disability and approximately one third of children are estimated to be at risk developmentally as they enter school. At the same time, health care, education, and social service systems are stressed to a breaking point. We have been studying how are Early Childhood Education and Care (ECEC), family courts and child custody, immigration and citizenship, other judicial systems work with or against access to early healthcare. For health and early clinical services to effectively address the structural mechanisms that exclude children and their families from health care, school, and the economy, it is essential to disaggregate locally by social characteristics, such as race, socio-economic status, and geographic location. The IECSS project does this through an innovative, long-term partnership that is grounded in respect for the value disabled children and their lives. IECSS aims to understand the interactions that children and their families have with health, education, and social services with the goal of transforming systems rather than focusing solely on individual intervention. We have made substantial contributions to social policy and to improve service accessibility and the material reality of disabled children, and their families thrive in society.

Through a longitudinal Institutional Ethnography we have been documenting the following questions, that are relevant to building inclusive healthcare systems:

- Who has power and control when a child and family are transferred to a new service or professional?
- What work are families doing to gain access, and participate in access, referral and participation? What resource, power and relationships do they need to be successful in their participation, e.g. through socio-economic advantage?

Young disabled children are underrepresented in disability justice discourse, in part because most children are being cared for by adults who are not disabled, and our systems are designed by health clinicians with the goal of curing disability rather than building positive disability identity. IECSS seeks to fill a major gap in how health, education and social services systems fit together and affect disabled children and families. As governments and international organizations invest in disability specific services, it is critical that we have access to the experiences of disabled children and their families to inform the design and implementation of interventions.

2.2. Engagement (applicable to groups 1, 2, & 3)

IECSS is a multi-disciplinary, national, and community-driven partnership that is directly informed by our longitudinal study of early child systems from the standpoint of families who have disabled children. Our partners, including municipal governments, Indigenous-led organizations, and developmental service organizations, have driven the research design, analysis and dissemination. Working in four different advisory groups, they are from nine different communities across Canada that span urban, rural, remote, and First Nations communities.

Indigenous communities, particularly the Knowledge Keepers from the District of Temiskaming in northern Ontario, have been leaders in the project. These Elders, who comprise one of the four advisory committees, have guided our work with traditional knowledge and interpretation of data and informed our goal of ensuring that each child's well being is dependent upon access to health services within their community and embedding in the project the value of cultural perspectives of childhood and disability. As a result of this leadership, the Elders co-hosted a three-day gathering to share the experiences of disabled Indigenous children, youth, and families (see weblink below for the Let the Rivers Flow gathering). This event led to development of a website and public report, and a campaign to address the lack involvement of disabled children and their families in creating the policies that support them.

The IECSS project has three other advisory committees (Youth, International, and Black experiences) who support our analysis of findings and work to mobilise our research with communities who are affected by the findings. Each of these committees determines their own interests, and agenda and, as a result, they have carried out distinct activities. These activities are outlined on each of their webpages on our project website (see below).

For the IECSS team, engagement with community partners has led to more than 50 community presentations as well as advising roles at the municipal, provincial, and federal government tables, with a focus on childhood disability, poverty, integrated health systems, childcare, family support and early intervention. For example, we have shared our findings with communities as the re-design early years systems to better integrate health and care services, and to provide more appropriate family support. One of our approaches to knowledge sharing involved a photo exhibit which presented some of the documents used in service systems (see web link below). This exhibit has been presented in children's hospitals, in clinical psychology grand rounds, and in professional development workshops for early interventionists.

2.3. The Research
(Particularly relevant
for groups 2 & 3)

IECSS is a longitudinal study that conducts annual interviews with families of children who access disability and developmental services. In these interviews, we ask about the actions they have taken to access institutions on behalf of their children. Our methodological approaches produce empirical evidence of the ideology, processes, and social relations (Grahame, 1998) in early intervention, care, and education for children with disabilities, guided by Institutional Ethnography.

This study of institutional practices draws on more than 1000 interviews with 156 mothers, foster parents, fathers, adoptive and guardian parents, and grandparents. We transcribe the interviews, transposing the interview information into an attributes table that has more than 100 variables related to intake processes, wait-times, funding, service allocation, etc. The includes other family members who may access institutional services, which is a unique contribution as it affects the capacity of a family to carry out the work needed to find supports for their children. In addition, we collect demographic information about disability, race, economics, education levels, and employment. The approach to data collection was informed by our community partners who noted the critical importance of understanding disability in childhood from the perspective of families first, and analysed through critical theory, including critical disability theory, childhood studies, and Indigenous worldviews.

We use this information to develop maps of service interactions, in order to visually understand family interactions with institutions (i.e., the institutional processes and pathways they take within them). These maps have been developed over nine years of interviews, which allows us to see changes over time as well as patterns between participants (e.g., disability diagnosis seems to be a focus of professional discourse but has relatively low impact on how and which services are offered) and between communities (e.g., better access to private services in urban communities).

The study has yielded important findings about the ways that distinct systems interact with health care, such child welfare (Ineese-Nash, et al., in press), preschool speech and language (Underwood, et al. in submission), childcare (van Rhijn, et al.), occupational therapy and access to assistive devices (Chung, 2023). Ongoing analysis of our dataset has revealed unanticipated complexity of family service interactions over time and the effect of external factors such as policy changes, and public health effects on services, i.e., COVID-19. Ultimately, with a study of this length, there are new social experiences that arise that presents a unique site for analysis of ongoing social change.

2.4. Translating to Impact (Particularly relevant to group 3)

One of our most successful forms of dissemination has been in the form of policy and research briefs. Written in response to changes in early childhood and health services, and legal, government, or international initiatives that are relevant to the participants in our study, these policy briefs have been used to influence social policy decisions such as the organization of services in municipal governance, professional development for preschool speech and language services and early childhood educators, and for nursing and other clinical staff at a children's hospital. These changes have been led by our community partners, and their networks. These policy briefs have included a jointly authored letter with key municipal partners to the Minister of Education, to draw attention to the complexity of early disability experiences and the implications of health interventions on early childhood education and care.

In addition to direct policy influence, we aim to create materials that can support advocacy and training of professionals across health, education and social services. This work has been led by our advisory committees, including work of the Indigenous advisory noted above. The Youth Advisory committee, made up of 21 disabled young people, has developed a website for children, a children's book, authored a peer-reviewed publication, and written two research briefs. In addition, the Youth Advisory hosted an online webinar attended by more than 100 stakeholders working in early childhood disability services. Two members of the Youth committee represented IECSS at a Day of General Discussions at the United Nations. Engagement directly with disabled youth is critical given that the majority of clinicians and parents do not share the disabled identities of the young people on whose behalf they are making decisions.

The IECSS Black Experiences Advisory Committee is comprised of individuals who have lived experience as Black disabled persons, parents of children with disabilities, and professionals working with children and families. The committee was launched following our February 2022 online panel discussion, Black Experiences and Disabled Childhoods. In addition to this event, the Advisory committee has contributed to journal publications, and analysis of our data for municipal government policymakers.

The International Advisory Committee is responsible for supporting the interpretation of the findings for an international audience with varied geopolitical contexts. This committee considers the ethics of transferring research findings to countries in the Global South, including advising a team of researchers who are building from our methodology in Colombia.

2.5. The Future
(Applicable to groups
1, 2, & 3.)

The knowledge we have gained concerning early childhood disability services is substantial and continues to grow. We have several short- and medium-term goals. First, we have applied for more funding to continue our annual interviews with a goal of better understanding the nuances of disabled children's experiences in primary school vs. preschool. Second, proposed by our Youth Advisory Committee, we plan to create a centre to house the data in partnership with our advisory groups. This centre will support us in developing new models for early childhood health and intervention that are grounded in the perspectives of disabled people and families. At the heart of this model is building a team of disabled youth who can inform the design of services that are disability positive, more deeply responsive to intersectional identity, led by Indigenous theories of disability and childhood (Ineese-Nash, 2020).

We also plan to enhance training in Inclusive Practices that will be interdisciplinary and open access. We will design and implement a diverse range of training programs and curricula; develop and pilot new courses in inclusive practices; conduct training workshops and seminars for health care, psychology and counselling, and community practitioners; and collaborate with academic institutions in curriculum development.

We also plan to broaden knowledge dissemination on Inclusive Practices through diverse media, including developing an open access online hub for which we have applied for funding. We will also continue to publish research findings and articles; produce educational podcasts; host webinars and online workshops; and create and manage social media campaigns.

Our ultimate goal is the development of new thinking around care, the state, and social marginalization as related to childhood disability. Despite more than 100 years of advocacy, inclusive and community-based health services that are accessible to all children globally has yet to be realized. Through meaningful engagement with diverse communities and a dedication to research over the past decade, IECSS is moving closer that future.

4. The Prize Fund

The award funds will support ongoing dissemination of our research findings, continued partnerships, and translation of we have learned from families into actionable content for healthcare and therapeutic professionals. The funds will help support an event for families, health professionals, and community members with lived experience to learn from each other. Funds will also support the work of our advisory committees that guide critical thinking about care and therapeutic support for all young children that is informed by disabled children's experiences, particular those who are racialized, live with poverty, and/or who have precarious citizenship or custodial status.

5. Your advice to others	Be open to the lived experience of your partners and participants and be willing to change course based on their involvement. Our initial interests were in early childhood education and care, but we quickly learned that young disabled children often spent more time in clinical settings and therapeutic environments than in childcare. We expanded the project to include all institutional interactions children experience and we now hold extensive expertise about child welfare, immigration, mental health, neo-natal intensive care, family courts, community based early intervention, and our community partners have supported the unique methods documenting the interactions of these systems.
6. Supporting Evidence	
6.1. Funders	<p>Funder: Social Sciences and Humanities Research Council (SSHRC) Partnership Grant #895- Grant title: Inclusive Early Childhood Service System project: A longitudinal study of familial viewpoints of early childhood disability services Award period: 2018-2025 Value: \$1.4 million GPD (\$2.48M cdn) https://www.sshrc-crsh.gc.ca/about-au_sujet/partnerships-partenariats/partnership_grants-bourses_partenariats-eng.aspx</p> <p>Funder: Employment and Social Development Canada (ESDC) Grant #1592486, 2018-2020 Grant Title: IECSS in Action! Community Action Evaluation project. Award period: 2018-2020 Value: \$72 thousand GPD (\$124k cdn) Weblink: Employment and Social Development Canada - Canada.ca</p>
6. 2. Academic/Professional Publications	<p>Publication title: Journal of Childhood Studies, 16-29. Date of publication: 2021 Article title: Pandemic effects: Ableism, exclusion, and procedural bias. Names of any authors who are listed partners on this application: Kathryn Underwood Weblink (and full citation) Underwood, K., van Rhijn, T., Balter, A., Feltham, L., Douglas, P., Parekh, G., & Lawrence, B. (2021). Pandemic effects: Ableism, exclusion, and procedural bias. Journal of Childhood Studies, 16-29. https://journals.uvic.ca/index.php/jcs/article/view/19970</p> <p>Publication title: Current Developmental Disorder Reports, 1-7 Date of publication: 2023 Article title: A review on early intervention systems Names of any authors who are listed partners on this application: Kathryn Underwood Weblink (and full citation): Tollan, K., Jezrawi, R., Underwood, K., & Janus, M. (2023). A review on early intervention systems. Current Developmental Disorder Reports, 1-7. https://www.torontomu.ca/inclusive-early-childhood-service-system/findings/publications/</p>

6.3. Other publications

Balter, A.S., Feltham, L., Parekh, G., Douglas, P., Underwood, K., & van Rhijn, T. (2023). Re-imagining inclusion through the lens of disabled childhoods. *Disability and Social Inclusion: Lessons from the Pandemic*, 11(1). 48-59.
<https://www.cogitatiopress.com/socialinclusion/article/view/5722>

Underwood, K., Ineese-Nash, N., & Haché, A. (2019). Colonialism in early education, care, and intervention: A knowledge synthesis. *Journal of Childhood Studies*, 44(4), 21-35.
<https://journals.uvic.ca/index.php/jcs/article/view/19209>

6.4. Other forms of communication, including conferences

Date: 2018
Publisher/host/programme: multiple sites
Title of article: Tensions in disabled childhoods [photo exhibit].
Weblink and full citation:
Church, K., Underwood, K., & Vorstermans, J. (2018). Tensions in disabled childhoods [photo exhibit]. Toronto, Canada.
<https://www.torontomu.ca/inclusive-early-childhood-service-system/findings/Photo-Exhibit/>

Date: 2019
Publisher/host/programme: Partner led action project implementing responses to research findings.
Title of article: IECSS in Action! A community action evaluation project
Weblink and full citation:
Underwood, K., & Ceolin, K. (Eds.). (2019). IECSS in Action! A community action evaluation project. Toronto: Ontario, Toronto Metropolitan University. <https://www.torontomu.ca/inclusive-early-childhood-service-system/findings/IECSSinActionReport/>
