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From the Editor

The article, *Inclusion is an Experience not a Placement* in this eceLINK peer reviewed collection is timely. At the provincial level, recent Conservative government actions have raised many questions about the inclusion of children with Autism Spectrum Disorder in school settings. In addition, there are continuing concerns about the exclusion of young children with complex disabilities from early childhood settings. Many early childhood educators who hold inclusion values, struggle to include children with disabilities in the every day life of a program limited by a medical model that regards disability as a pathology. The meaning of inclusion is, therefore, highly contentious at the political, policy and practice levels in Ontario. I know from experience in co-writing a textbook on the inclusion of young children with disabilities that the meaning of inclusion in early childhood education and care frequently shifts in response to historical and social changes in understandings of disability (Paasche, Langford, Nolan & Cipparrone, 2019). This issue's article written by researchers from the School of Early Childhood Studies at Ryerson University offers a current perspective on the meaning of inclusion. As Frankel, Chan and Underwood write it is their hope that thinking about and practicing inclusion as an experience "will add to the public discourse by drawing attention to procedures, power, and practices as early childhood services aim to fully include all young children and families." We invite you to read and find out what it means when inclusion is an experience for children, families and educators.

Rachel Langford PhD

Inclusion is an Experience, Not a Placement

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Abstract

Early education, care, and intervention programs are part of a complex system of services as experienced by children and their families. Based on a study of institutional processes and relationships from the standpoint of families with children who are thought of as disabled in the Inclusive Early Childhood Service System (IECSS) project, this article highlights common components of inclusion as an experience rather than merely a placement in a class. Early childhood educators and childcare programs are encouraged to play a critical role as part of this system providing accessible, equitable and integrated services to children.

Key words

inclusion, early years, childhood disability, early intervention system

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Inclusion is an Experience, Not a Placement

Many early childhood educators express concern about how to include and accommodate activities for children with disabilities in high-quality programs for all children. Early intervention programs that assess and provide diagnostically specific services to children are available in some communities, but many early childhood educators are not aware of how early intervention fits with their own practice. For this reason, inclusion as one component of a fully accessible and integrated system of early intervention, childcare, preschool, kindergarten, and family support remains elusive for many young children with disabilities. And many early childhood educators are not aware of where their institution fits in a larger system of services accessed by children with disabilities and their families.

Considering Inclusion

Inclusion has been described as an integral principle of early intervention in early childhood and family support programs for young children in Canada (Underwood & Frankel, 2012). In recognition of the importance of providing inclusive services the government of Ontario's policy set as an objective the promotion of inclusion in early years and childcare settings (OME, 2017).

This article on inclusion is informed in part by findings from the *Inclusive Early Childhood Service System* (IECSS) project, which seeks to explore institutional processes from the standpoint of parents seeking access to early childhood and disability services. The IECSS project is a longitudinal study that began in 2014. The project is a broad partnership among community, university, and government organisations. To date the project has interviewed parents from nine communities across Canada. In this article, we draw our findings from the first cohort of the study, which includes 67 families from Toronto, Wellington, Hamilton, Timiskaming, and Constance Lake First Nation. We continue to recruit new families from these communities in Ontario, and we have expanded the study to include families in Manitoba, British Columbia, and the Northwest Territories. The families in our study live in urban, rural, and remote communities. The first interview conducted with a family occurs when their child is in the preschool years. We then invite the family to participate in subsequent annual interviews for up to six years (or when the child is in grade three).

Our purpose in the study is not to seek family opinions of services but to capture the everyday experiences of families and children as they interact with professionals in early childhood education, care, intervention, health, and family support. We are interested in the meta discourses that govern the activities of families and workers (usually produced through social policy but also via other social relationships that hold power). But perhaps of more interest to us are the ways that families are governed by the daily processes that frontline workers use to manage their work.

Our method of analysis involves creating institutional maps of services accessed by families from the time their child is born. These maps reveal how children are depicted and documented not only in terms of development and disability but also as members of their families. The maps also show how the texts used to describe children and the decisions that are made every day by frontline staff create an image of the child. The maps are then analysed to identify where the power is held in the everyday processes of institutions, which is manifested in the work that is asked of families. We have written elsewhere about how families are asked to engage in the everyday work of programs and services, particularly when workers view the child as outside of the "norm" (Underwood, Church, & Van Rhijn, in press). We have also identified institutional maps as a mechanism to understand how systemic processes impact inclusive practice (Underwood, Smith, & Martin, 2018).

Much of the literature on inclusive practice defines inclusion as a *placement* (Nilhom & Göransson, 2017). But, through our mapping, we can define systemic inclusion in the complex ways in which professionals hold power, which is experienced differently for different families, with implications for understanding geographic disparities in access to services. We can also see colonialism embedded in the work of early childhood educators, and, perhaps most striking, how the social status of families and their communities are implicated in the everyday experience of institutional processes.

This article is primarily a conceptual paper that combines findings from the IECSS project and prior research conducted by the authors with the literature on inclusive early childhood education and care practice. It describes common values that have emerged to support changes in thinking in disability studies and early childhood inclusion. It is our hope that this knowledge will add to the public discourse by drawing attention to procedures, power, and practices as early childhood services aim to fully include all young children and families. Our focus is on factors to be considered by early childhood educators when trying to achieve an integrated, equitable, and accessible system for all children and families.

Inclusion is a human right.

Canada is a signatory of both the *United Nations Convention on the Rights of the Child* (UNCRC, United Nations, 1989) and the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD, United Nations, 2007). These conventions stipulate the right of all children to an early, inclusive education, with early identification and disability-specific support services (Underwood & Frankel, 2012). As a signatory, Canada must ensure that these international mandates are implemented through the *Canadian Charter of Rights and Freedoms* (1982) and local policies and programs (Noel, 2015).

Both the UNCRC and UNCRPD make statements that are relevant to children with disabilities. The UNCRC states that all children have the rights to protection, provision, and participation. Specifically, Article 23 states that children with disabilities should have access to special care and support such that they are able to live a "full and decent life" (United Nations, 1989). Further, in the UNCRPD, Article 7 states that children with disabilities should have rights equal to those of any other child, including opportunities to express their views on matters that affect them. Inclusion of children with disabilities is discussed in Article 24, which asserts that children with disabilities have equal rights to "access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live" (United Nations, 2007).

Are these rights to services being upheld in Ontario? In the IECSS project, families from all jurisdictions spoke about how a diagnosis facilitated access to services, but it did not guarantee intensity or quality of services or that long waitlists for disability services and childcare could be avoided. For many, accessing early intervention services required them to travel long distances to services only found in major centres in the province. For others, when a childcare centre would not accept their child, parents described their inability to return to work. Further inequities became evident when families spoke of the need to access private practitioners to support their child's progress, even if it was at great financial hardship for the family. When services for children with disabilities and their families are not available or are insufficient either because of onerous diagnostic or qualifying procedures, long waitlists, or services being geographically distant from the family's home, the rights of the child and family to inclusion are not being upheld (Underwood, Frankel, Spalding, & Brophy, 2018).

Inclusion is about capability.

Inclusion is more than diagnosis and placement. Although parents in our study often had months or years of "chasing the diagnosis" in order to establish their child's eligibility for specialized services, they seek a range of quality early childhood and disability services, including childcare. Many of these services do not need diagnostic information to deliver their program. The need to diagnose the child stems from a medical model of disability that defines the child by deficits and limitations. A diagnosis appears to be specific, but in reality, it is a label for conditions with diverse physiological origins that affect individuals differently (Rosenbaum & Gorter, 2012). Understanding a child through categorizations based on medical deficits does not account for other aspects of the child (Reindal, 2008), and information about a child's strengths is especially valuable for understanding the disability (Guralnick, 2017). In the IECSS study, parents reported that institutional regulations about who will and will not be served or seen often cause parents and professionals to represent the child in highly negative terms in order to gain admission to a program. When the focus is on the medical model of disability, the child's individual characteristics and capabilities may be ignored.

On the other hand, social models of disability seek to understand the social and relational constructions of disability that are critical to inclusion (Underwood, Valeo, & Wood, 2012). Underwood et al. (2012) applied the *capability* approach to early childhood inclusion. This approach posits that each individual has a unique set of capabilities that is defined as "actions or states of being that are valued by an individual" (p. 292). These capabilities can be abilities that are already gained or potentials to be realized, and an inclusive setting should provide children with the freedom to realize their potentials. This view on inclusion also takes children's rights into consideration because it focuses on what children value. Hence, a truly inclusive environment not only takes into consideration what is valued within a child's geo-political context but also does not make assumptions about what they can achieve.

Inclusion is the recognition of unique cultural, spiritual, and social identities.

An inclusive childcare or kindergarten setting does not stand alone but is embedded within a community that has cultural, spiritual, and social contexts within which a child's identity develops. Inclusive communities can provide children with disabilities opportunities to engage in meaningful interactions with peers of their choosing (Underwood, 2013), and these meaningful interactions often occur naturally (Wiart, Kehler, Rempel, & Tough, 2014). It is through cultural, spiritual, and social experiences and reciprocal relationships with others in their community that children formulate their own sense of self. This may occur in early learning and care programs when children with disabilities are provided with opportunities to make friends, engage in play, and socially interact with their peers (Koller, Le Pouesard, & Rummens, 2018; Kwon, Elicker, & Kontos, 2011).

Moreover, understanding the uniqueness of disability identity is an integral part of inclusion. Disability is a part of a child's identity and should be understood as well as supported in the context of the whole child, which includes his or her unique cultural, spiritual, and social identities. Children should be allowed the opportunity to congregate with groups of individuals like themselves through inclusion. Quality inclusive early learning and care programs and services foster children's social interactions with peers who have similar interests and worldviews. This emphasis on social interactions has origins in the social relational model of disability, which asserts that inclusion is about with whom you are interacting and about who gets to decide with whom you interact (Snoddon & Underwood, 2014).

In the IECSS study, many parents reported that they did not want a professional to "fix" their child. They enjoyed their child's unique character and temperament while professionals with more power in the service relationship were telling them the child had to change. This view of "fixing" the child has origins in the medical model of disability. It has limited utility because not all conditions can (or should) be cured, and it is difficult to pinpoint concrete causal connections between intervention and outcomes (Rosenbaum & Gorter, 2012). Further, it has underpinnings of ableism, or discrimination toward disabled people, that potentially may be learned by other children, families, and staff in programs.

In addition, families should have the ability to make choices about with whom their child interacts. However, families in our study were often told that their child could enter an early learning program or kindergarten but told at the same time that there would not be any resources for the accommodations that are the child's right. In some cases, this led to a child's attendance in segregated programs, which was not their family's intention, although families ultimately saw this as a more desirable option than sending their child to a childcare centre or kindergarten where they were not welcome. A choice that does not provide a quality inclusive service is not a true option for parents.

Inclusion is individual.

Inclusive settings also encourage the active participation of each child, which can include giving children opportunities to practice their skills, engage in physical activities, interact with their family members, have fun, and make friends (Rosenbaum & Gorter, 2012). One of the main goals of early education and care programs is to support children's learning. To achieve this goal, learning should be defined flexibly for individual learners and opportunities should be provided for children to engage in a range of learning activities that account for diverse interests and varied abilities as new skills, relationships, and power dynamics emerge in a classroom.

One way to encourage this range of learning activities is to follow the three main principles of Universal Design for Learning (UDL), which highlight supporting diverse learners. The UDL model posits that learning can be addressed through multiple means of engagement, representation, as well as action and expression. The dimension of engagement supports learners' motivation by harnessing their interests and fostering their effort and perseverance during learning. Using multiple ways to display the information, the representation dimension emphasizes the importance of using various languages and symbols to present the knowledge, which can support understanding and generalization of the materials learned. After grasping the notion that knowledge can be represented in different ways, learners should have opportunities to demonstrate what they know through multiple means (CAST, 2018). A UDL approach should be paired with differentiation of activities to support each child with the recognition that accommodation and accessibility need to be features of any classroom.

Individualized program planning must also recognize the likelihood that teams of professionals may be working with a child and their family. As one parent in the IECSS project reported, after her child was asked to leave a childcare centre and rejected from several other centres, she finally found an inclusive childcare program that fostered communications between her and all the professionals working with her child. As she noted, "It is so incredibly well-coordinated. And the really big thing is, because I signed the consent for e-mail, sharing of information. So, we have a nice email list between myself, the speech and language pathologist, the OT, the developmental pediatrician, the clinical resource person, and the childcare." This process highlights the importance of collaboration amongst parents and all professionals on a team providing individualised service (Frankel, Underwood, & Goldstein, 2017), but also the reality of a complex system.

Inclusion is valuing.

In a truly inclusive setting, children with disabilities are not simply tolerated; they are valued members of the classroom (Underwood et al., 2012) and their uniqueness is viewed as an asset. It is important to distinguish between toleration and inclusion because the sentiments behind those concepts are different. *Toleration* implies that children are in the classroom but are not viewed as capable of contributing positively to classroom dynamics. In contrast, children who are *included* are not only welcomed but are viewed as members who will add to the class's learning experiences. A sharp distinction in service delivery models between children with and without disabilities should not be present. Rather, all children should be viewed as unique individuals whose strengths are valued.

Moreover, inclusive educators recognize that social interactions amongst the children in the classroom are the context within which learning happens. The way educators address social dynamics in the classroom affects whether children feel that they are valued members of the classroom (Lee & Recchia, 2016). Educators grapple with the challenges of maintaining consistency within the classroom while being flexible enough to adapt to the needs of all children (Molbaek, 2018). Further, educators are working within the context of a society that values highly normative understandings of achievement and ability. The Ontario Human Rights Commission (2018) notes that disability is the most frequently cited grounds for discrimination in Ontario, and that significant violations of the dignity and valuing of students with disabilities are ongoing in Ontario schools.

Inclusive educators are not only knowledgeable about the strengths of the children in the class; they also value their own ability to plan activities to highlight these strengths. It has been well documented that educators who have a positive attitude toward inclusion will more readily include children with disabilities in their classrooms. For instance, Welglarz-Wards, Santos, and Timmer (2018) investigated early intervention providers' perspectives on supports and barriers for inclusion in childcare settings. They concluded that childcare providers' willingness to have children with disabilities in their programs affects how well the children are included. Thornton and Underwood (2013) found that educators who hold beliefs aligning with the social model of disability will more likely make accommodations for children with disabilities than those whose beliefs align with the medical model. Inclusive educators will also actively seek out community resources for all children in their classrooms. Gal, Schreur, and Engel-Yeger (2010) suggest that educators not only need to possess a positive attitude, they also need to identify environmental barriers in order to provide creative solutions for inclusion.

Both pre-service and in-service training of educators play an important role in promoting inclusive practices. The pre-service education of early childhood educators and kindergarten teachers has been shown to impact acceptance of inclusion. For example, Frankel, Hutchinson, Burbidge, and Minnes (2014) found that pre-service early childhood educators and elementary teacher candidates who had completed course work and practice related to children with developmental disabilities and delays expressed a positive sense of confidence and competence in teaching such children in inclusive childcare and kindergarten programs. Crawford, Stafford, Phillips, Scott, and Tucker (2014) also suggested that training and continuing education for childcare staff in caring for children with disabilities and facilitating play is important for fostering inclusion for all children.

Inclusion is forming relationships with families.

Early intervention for children with disabilities is a problem-solving process that involves the family and staff working with the family (Guralnick, 2017). From early intervention professionals' perspectives, consistent communication amongst providers and family members is crucial for inclusion (Weglarz-Ward et al., 2018). Communication is the basis of a trusting relationship between parents and professionals (Haines, Gross, Blue-Banning, Francis, & Turnbul1, 2015) and is crucial for setting up consistent strategies at home and early years settings (Grace, Llewellyn, Wedgwood, Fenech, & McConnell, 2008).

The IECSS study shows that institutional responses to disability depend on the work of families. Families describe the work they must complete to follow through on referrals, make appointments with specialists, travel to appointments (which in some jurisdictions require them to travel and leave their communities for days), maintain documentation of all contacts, identify appropriate interventions, and continue therapies at home. Much of this work is provided by mothers. This insight requires educators and professionals to be cognisant of and empathetic to the extent that families must participate to keep the system working for their child, rather than holding additional, unrealistic expectations of the family. It also highlights the power that institutions hold over families.

Family support is also critical in providing safe respites for families. But families in the IECSS study noted that even respite programs have rules and regulations that must be managed in order to gain access. One parent reported that Saturday mornings were family time spent at a community drop-in program that she, her physically disabled preschool daughter, and her older son could attend. But as soon as her son turned seven, she was told that this centre would no longer welcome her with her son. The need for flexible and welcoming services in the community providing inclusive havens for all family members becomes paramount.

Looking Forward

The IECSS project has assisted us in understanding the role early childhood educators and kindergarten teachers play as part of a broader system of inclusive early childhood education, care, and intervention. Almost all children and families in this study at some point sought to access a childcare program either because the family was referred by a health professional who thought it would be beneficial to the child or because the parents required childcare in order to continue their employment obligations. But inclusion of children with disabilities in early childhood education and care programs is more than agreeing to accept and place a disabled child in a centre. Inclusion can best be achieved when it is viewed as a human right, when it allows for the expression of individual identities, when individual capabilities are honoured, when accommodations support accessibility and when teachers and families value inclusion and the contribution each can make.

Furthermore, with awareness of the complexity the system imposes on parents, educators can be more sensitive to families looking for access to childcare and kindergarten programs for their child. Compliance with institutional processes (such as intake procedures, schedules, forms, etc.) that is necessary for families to gain entry into programs can lead to discrimination through the imposition of particular ways of thinking about disability. Consideration must be given to the additional work, resources, and control educators may be imposing on parents each time they turn a family away. The relationships educators build with parents as they transition their child into a centre or kindergarten requires trust and valuing of the family and their child.

Childcare and kindergarten programs must embrace a systems view of services. Childcare programs and kindergartens are community institutions with their own eligibility requirements, rules, and regulations about who can enter, who cannot, and under what circumstances they will be supported. These processes and the services may be similar or different from every other organization with which the family interacts. Families in our study described a “quadruplet of services” that are repeated in various institutional settings across the system—speech and language therapy, occupational or physical therapy, behaviour therapy, and mental health services (Underwood & Frankel, 2018). Childcares and kindergartens have a role in providing these services within their program to eliminate the need for parents to attend at many different organizations. In collaboration with other specialists working with the child and family, adaptations can be implemented to support a child within the program. With new insights about inclusion, institutions can be transformative in visioning, designing, and implementing comprehensive services to improve interactions, eliminate power differentials, and deliver inclusive services.

Ultimately, early childhood educators can provide quality inclusive experiences for children when they work as part of a team with families, children, and other service agencies and view their contribution as a critical component of an inclusive early childhood education, care, and intervention service system, rather than merely as a placement for a child in their program. Developing a plan to transition all children into the routines and activities of an inclusive childcare centre and kindergarten is one part of working toward creating more inclusive communities.

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