

## **Transitioning Work of Families: Understanding Trans-institutional Power in Early Childhood Programs and Services**

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### **Abstract**

*This study examines transitions to school from the standpoint of the work of families. We identify systemic differences constructed through state responses to childhood disability. Based on data from a longitudinal institutional ethnography conducted in Ontario, Canada, these differences illuminate the ways in which ability and disability are constructed in early childhood, and how these constructs are reinforced through procedures, policies, and documentation. Ultimately, we identify five key phenomena in the study: implicit messages of exclusion, the work of families, the supremacy of labels, a fallacy of choice, and the flexibility of institutions to adapt for children. These findings are taken up in the context of broader discourses of school readiness and transition to school with the intention of expanding our conversation about transitions.*

Researchers and advocates in early childhood education, care, and intervention have long held that positive child outcomes require that services for young children and families be comprehensive, inclusive, integrated, and family-centered (Bricker, Xie, & Bohjanen, 2018). Yet, many early childhood and kindergarten programs are excluding children from important sites of social, cultural, and community participation. Of particular interest to researchers has been the transition from early years services into school kindergarten programs. Transitions into kindergarten happen at an important developmental time in

children's lives, and research shows that children's development at school entry can be directly linked to later school outcomes (Brownell et al., 2016; Caspe, Lopez, & Chattrabhuti, 2015; Janus, Labonté, Kirkpatrick, Davies, & Duku, 2017). This research is translating into international interest in early years programs and the potential to impact inequality through early intervention and inclusive early childhood services (Lombardi, 2018; The Lancet, 2016; Wertlieb, 2018; World Health Organisation, 2018).

We hypothesize that the transition to school provides an opportunity to understand the power that institutions hold over children and their families, particularly for children who are perceived to have development outside of what is conceived as a normal or typical developmental trajectory. This article presents findings about transitions to kindergarten, gleaned from the Inclusive Early Childhood Service System (IECSS) project, a Canadian longitudinal investigation, which seeks to understand broader social responses to disability through mapping institutional interactions from the standpoint of families. In this article, we examine institutional practice in early childhood and kindergarten programs and the transitions between these two state-organized stages of life. We argue that these institutional procedures illuminate important sites of power and dominant ways of thinking about disability that ultimately impact the degree to which families are managed and included through the transition process.

### **Transitions to School**

Research on transitions typically focuses on two key areas. The first is the transition activities that educators implement, and second are the skills or capabilities that will make children successful in and beyond the transition into school. Educator transition activities commonly include information sharing through orientation events or sending information home, and sometimes home visits (Little, Cohen-Vogel, & Chris Curran, 2016). However, higher intensity activities such as visiting a child at home or extended visits to the classroom in advance are less common (Little et al., 2016). Kindergarten transition is of particular concern for families whose children had special needs (note this term is widely used in institutions to describe disabled children and those who are receiving atypical services; McIntyre, Eckert, Fiese, DiGennaro Reed, & Wildenger, 2010). In these cases, higher intensity transition activities may be of particular importance to families who have participated in early intervention services, partly because their expectations have been set through longer histories with professionals, and because the relationships with professionals in the early years are often more welcoming to families than those in schools (Janus, Cameron, Lefort, & Kopechanski, 2007).

The research links transition activities to better outcomes that are typically defined in terms of academic achievement (Schulting, Malone, & Dodge, 2005) or social skills (Wildenger Welchons & McIntyre, 2015a, 2015b). Current research into what are considered best practices around transition activities is scant. Any implementation of transition-related activities appears to be of benefit, particularly from the perspective of parent satisfaction (Kang, 2010; McIntyre et al., 2010). However, in one study, schools described as under-resourced were found to engage in fewer transition activities (Little et al., 2016). Further, McIntyre et al. (2010) found more transition concerns for families whose children were identified with special needs. In addition, McIntyre et al. found

these families were more likely to be racialized and to have lower education and lower incomes, raising concerns about the intersectional nature of relationships for families with disabled children at the point of transition.

In addition to research on educator activities, there is a body of literature on the skills that children, families, and educators may need for successful transition into school. For children, these skills are often described as school readiness, a concept that is widely critiqued but that includes social and developmental competencies, understanding of rules, and behavioural dispositions (Dockett & Perry, 2001). Criticism of the school readiness discourses raises concern that it does not “recognize difference and diversity as positive aspects of educational communities” (Evans, 2013, p. 172). For example, research has linked school readiness to family- and child-level characteristics including sex, age, and socio-economic status (e.g., Janus & Duku, 2007). In early primary programs, individual characteristics, particularly children’s behaviour, are better predictors of school success than school transition practices (McIntyre, Blacher, & Baker, 2006). Parents also raise worries about children making friends, following directions, and making their needs known (McIntyre et al., 2010).

In addition to the international literature on transitions, Canadian researchers have begun to examine the structural considerations that might lead to more complex thinking about early childhood disability experiences. For children who have experienced disability in their early years, and their families, the transition into kindergarten can be fraught with anxiety, contradiction, and uncertainty. Janus et al. (2007) noted that little is known about the process of complex transitions into kindergarten for these children. Literature informs us that systemic, administrative, and individual barriers exacerbate the challenges faced by families during these transitions (Janus et al., 2007; Siddiqua & Janus, 2017). Parents of young children identified with developmental disabilities and delays state that the lack of information and communication they experienced at transition into kindergarten forced them into advocacy roles (Villeneuve et al., 2013). These parents note that after an initial inter-professional meeting to plan the transition prior to school entry they had little contact from the school to follow up on planned decisions, and they did not know which professional in the school to contact to facilitate these plans. Parents also hold concerns around scheduling and staff openness (Kang, 2010).

Finally, while transitions are a time of immense change for all children and families, parents of disabled children report more concerns with the transition than families of non-disabled children (McIntyre et al., 2010). Parents’ satisfaction with relationship and quality of services are also tied to transition services (Siddiqua & Janus, 2017). What may be most challenging, however, is that these families who are likely to have had much more interaction with professionals (as noted above) are in the position of having to re-learn what is expected of them in their new role, a key part of transitions (Hirst, Jervis, Visagie, Sojo, & Cavanagh, 2011; McIntyre et al., 2010). Authentic collaboration between schools and families is considered crucial for smooth transitions, but this may be a mechanism for assimilation into school routines and practices rather than for collaboration and partnership (Hirst et al., 2011).

## **The Context**

The full-day kindergarten program in Ontario is relatively new. The implementation of the program for 4- and 5-year-olds was rolled out in a limited number of schools, in 2010. Full implementation was complete in 2016. Early intervention services in Ontario are delivered in a range of settings, which has led to concern that services are fragmented (Pascal, 2009). A number of reports and strategies have aimed to address this concern, including a recently developed coordinated care strategy (Government of Ontario, 2017). In the 2010 plan for full-day kindergarten, inclusive early childhood education and care was also to be enacted within child and family centres. The plan was intended to expand access to services for children with special needs (such as early intervention, speech and language, and other developmental services), as well as to integrate services across childcare, family support, early intervention, and kindergarten (Pascal, 2009).

Unfortunately, when full-day kindergarten was implemented, none of the recommendations that referenced special needs were adopted, and the full-day kindergarten implementation did not include any structural changes to schools that would support the full participation of all children. Ultimately, the program is a two-year full-day program with one teacher and one early childhood educator in a class with up to 30 students. A new pedagogical framework is being used in the full-day kindergarten program, which calls for “providing inclusive learning environments and experiences that encourage exploration, play, and inquiry” (Government of Ontario, 2014, p. 16). Further, the framework notes, “Early years settings can play a key role in promoting the visibility, inclusion, and active participation of young children in society” (p. 19). Although Child and Family Centres were implemented in 2016, they did not include any of the features described above that were intended as part of an inclusion strategy (Government of Ontario, 2016).

## **Methods**

The IECSS project uses multiple methods to analyze data collected through institutional ethnography (Smith, 2006 and 2009). Institutional ethnography is a method with social justice aims, enacted through examination of the everyday work of institutions to understand how they function and hold power. The intention of institutional ethnography is to understand institutional cultures and practices from a particular standpoint, in this case the activities of families as they interact with institutions. Institutional ethnography holds particular assumptions, including that texts, such as assessment documents, progress records, and intake documents, are the drivers of action in institutional practice, and that institutions’ relationships to individuals govern action (Grahame, 1998). In this study, we are interested in the interactions families and their children have with institutions over time, using a longitudinal approach with repeated annual interviews.

## **Participants**

Family members were recruited to the study through distribution of flyers at early childhood and family support programs. Families then contacted our office and we set up a time to meet. At each interview, starting with the first cohort in 2014, we asked

participants if we could contact them the following year for another interview. In our first cohort of families we recruited 67 families from five communities in Ontario, Canada, including urban, rural, remote, and Indigenous communities. Family members were from a broad range of economic as well ethnic and racial backgrounds. This analysis is based on the experiences of 36 participants who were interviewed before and after the transition into school.<sup>1</sup>

## **Data Collection**

Data were collected through open-ended interviews in which we asked participants to tell us about their child and to describe their interactions with institutions, which we define as any organization with regulations, rules, and organizing practices (Smith, 2006, 2009). The interviewees were prompted to share how they accessed each service, about the requirements and activities they participated in to gain entry and to maintain participation, and about the challenges they faced in gaining access to particular services or programs. Family members shared with us who they interacted with, what was asked of them, which documentation was created in their interactions, and generally the work they did to gain access and participate in the activities of institutions. We asked about services for disabled children, but we also heard about services for all members of the family because from the standpoint of the family, these interactions were inseparable. Verbatim transcripts of these interviews were completed, and from these we mapped the processes, textual records, and activities of children and their families in these interactions.

## **Analysis**

For this article, our analysis focused on the transition between early childhood services and school-based services. We specifically examined the interviews from the year prior to school entry and compared them with interviews after school entry. Using interview transcripts, we recorded the attributes of institutional responses to children. Recorded attributes included which services families contacted, met with, were referred to, and received service from. We recorded the amount of time spent in a service; whether they were waitlisted; and which documentation, assessments, and intake procedures were required to gain entry. We recorded the location of each service, the distance from the family home, how they travelled, and any costs associated with the services. Additionally, we recorded any procedural outcomes from interactions with institutions including additional referrals, rejections for service, barriers to participation, and referrals to child protection. We also recorded other family experiences that impacted these interactions,

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<sup>1</sup> At the time of writing we have 122 participants in the study including 67 from the first cohort starting in 2014, and 53 from recruitment of a second cohort. Our ongoing recruitment efforts are taking place in 11 communities from 4 provinces and one territory. Some of these participants have not yet transitioned into kindergarten. Some participants also did not continue in the study, or we have missing data from the years prior to school entry. We have included the 36 participants for whom relevant data has been collected (i.e., we have one interview from the year before school entry and one from the year after). Note that we are funded to interview families for up to 6 years and that our mapping activities reflect all interview data collected to date.

including job loss and changes in employment, education, housing changes and concerns, and other social services, as well as changes in the family such as divorce and separation, death or birth of family members, and the health of other family members.

The maps and corresponding attributes tables were then systematically reviewed to identify the patterns of institutional interaction that are present across the sample. In this case we were interested in whether our method could illuminate new understanding of the transition challenges for disabled children that have already been identified in the literature. While several studies have explored these issues, we wanted to examine the structural issues that may provide new thinking for understanding how institutions operate through these transitions. The Findings section below outlines the structural aspects of these transitions. We also examined the differences between early years and school-based services. In this case, we were working from the standpoint of children (informed by our structural understanding) in order to identify how institutions develop disability constructs (norms and expectations of parents and children). In the tradition of Institutional Ethnography, we describe these differences across systems and the construction of norms as problematics (Rankin, 2017). Our discussion focuses on these problematics through a comparison of institutional interactions in the early years and in schools. The discussion relies on participant voices as well as on the literature for an analysis of the structural features of the system of services that are evident from the maps.

## **Findings**

### **Findings Part 1: Mapping the Institution**

The maps created from the everyday experiences of families show disability specific systemic responses to early childhood in the pre- and post-school-entry years. While our analytical strategy involved mapping each individual participants' interactions, Figure 1 presents a summary map that shows the system of services that we have identified as the collective experience (Figure 1). Three key features of the system of services for young disabled children are evident in the maps: first, the quantity of institutional interactions is vast; second, the breadth of disability specific services is narrow; third, institutions have control over decision making.

**Breadth of institutional interactions.** Figure 1 demonstrates that an extensive number of services make up the preschool years system. Many of the institutional interactions we identified in the project were for services that related to families as a whole or to members of the family other than the child with a disability. The programs are typically community-based and serve geographic areas where they may be more accessible than centralized services, which is typical of health, and increasingly, education systems. Many other social services, such as employment, housing, food, legal immigration, and cultural services, may be necessary in order to make disability and general early childhood services more accessible. The breadth of services indicates to us several features of the early years system. First, the procedural and the relational requirements of families to engage with multiple systems in the early years changes as children enter school. In the early years, there are far more procedural requirements

(some of which are discussed in depth below), and families must engage in many more relationships with professionals.

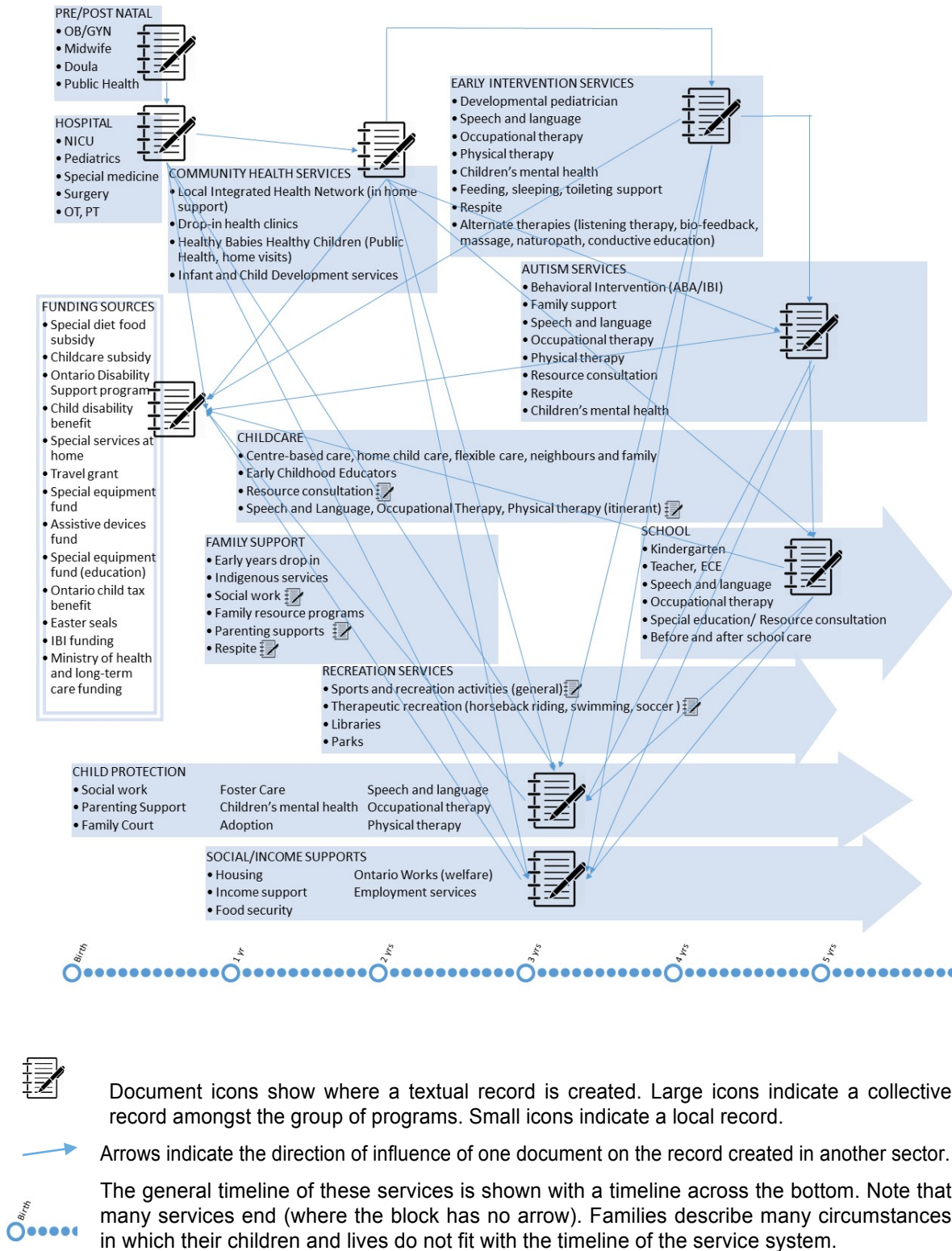
**Narrowness of disability-specific services.** Another feature of the early years system is the distribution of impairment-specific or rehabilitation supports across different service sectors. We have identified a quintuplet of services that are repeated in multiple program settings: speech and language, occupational therapy, physical therapy, behavioural intervention, and children's mental health. However, these services may have different goals in each setting, partly as a result of the aims of the institution through which they are delivered, and partly due to assumptions about what children need at a particular age. Families tell us that while a child and family may be accessing one type of service in a range of settings, it is in fact a very different service from agency to agency.

In the kindergarten years, the maps indicate a severing of relationships with health care, community, early childhood intervention, and social services that is abrupt and that changes the role of the family as well as the expectations of professionals. For this reason, some families delay kindergarten entry. We identified that of the 36 participants who are part of this analysis, 12 of them did not attend the regular full-day kindergarten program. Instead, these children attended specialized programs, stayed in childcare, or went to alternate programs including programs funded under the Ontario Autism Program (OAP) because the waitlist for this program is long and the funding did not materialize until they were kindergarten age.

**Institutional control.** Families who have relationships across many agencies are often accessing more intensive therapeutic intervention, while families who are accessing these services in a non-specialized setting may not be getting child-specific therapy. Instead, specialists may be conducting consultation to the educator with the goal of making a more inclusive environment rather than rehabilitation for the child. Many families supplement these publicly funded services with private therapies, when they are financially able, and if they live in a geographic area where private services are available. From the families' standpoint, integrating intervention into non-specialized settings requires a more comprehensive early intervention plan, which includes other systems such as child welfare.

At entry to kindergarten, many services are centralized in the school system with the effect of taking control from those families who have had access in the preschool years. While ownership and control of decision making are sites of empowerment, we have heard in our interviews that perceived class, economic status, colonial structures, race, citizenship, custodial relationship to the child, and perceived ability of the child and parent are implicated in how these relationships unfold. This was described by participants through reference to not being able to afford some services, not being able to travel to a service, feeling they could only trust services that were designed for low-income or culturally specific groups, and examples of negative interactions with institutions that constituted discriminatory practice and resulted in a lack of trust for other institutions. Centralizing procedures into the school in the kindergarten years takes decision-making power back into the institution, which can alleviate the work of families but also leaves them exposed to the power imbalances they experience in society as a whole.

Figure 1. Institutional Processes in Early Childhood





## **Findings Part 2: Problematics**

Five phenomena or “problematics” (Rankin, 2017) are apparent in the institutional organization of services gleaned from the experiences these families had transitioning between early childhood and kindergarten. While many issues and insights were raised in discussions with participants, this article focuses specifically on procedural power evident in experiences of transitioning from early childhood education, care, intervention, and family support programs to kindergarten programs. These phenomena include forms of systemic exclusion and the illusion of choice, the undervaluing of the work of families in contrast to the overvaluing of medicalized labels and identification of disability, and the lack of flexibility on the part of schools to adapt to children and their families. The power of school institutions to determine whether children with varying forms of disability will be included, cared for, and accommodated is a problematic that cuts across all of these concerns.

**Implicit messages of exclusion.** Study participants had a wide range of experiences of the transition process itself. In some cases, parents described high levels of support with transition teams in place who regularly met with parents and the professionals who knew the child best. They discussed teaching strategies, equipment, logistics, and staffing. Typically, this level of support was initiated and managed by a clinical program that the child had been attending prior to school entry. In the best cases, these teams were available to the families after the children entered school and sometimes for several years after, if other transitions occurred over the next couple of years as the child further integrated into the school system.

More commonly, families had no contact with the school or met with school staff to be told that the kindergarten program was not a good fit for their child. One mother was told in two different school districts that they “did not have a program” (1.003<sup>2</sup>) for her child with cerebral palsy. Another mother reported having a meeting to decide, “Should he be in the diagnostic classroom (segregated) or the regular classroom. But [the Vice-Principal] said, ‘I suggest you put him in the diagnostic classroom.’” The parent did not want this option and noted, “He needs to be [in regular class], because when I saw those kids [who] didn’t have words. I felt like, ‘Why are those kids separated’” (1.002).

Another child was described as thriving in kindergarten for a year, when the mother was encouraged by the principal to seek out a special school:

They told me it’s a good decision to try to get a placement for him for the special needs school, because they are normally busy and it’s not early [in the year] to get the placement, and then make a decision if you want your child to go to that program or you want to keep him in just a typical school. (1.009)

Sometimes, families met with a school team only to find that the people who had set up the transition plan did not work at the school in the fall. Families were told that staffing could not be guaranteed, that their child would be grouped with other children in

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<sup>2</sup> Quotations in this article are slightly altered for readability and are cited using participant identification numbers in parentheses following the quotation. Pseudonyms are used when names are referenced in the quotation.

order to be efficient in allocating resources (rather than as a good fit), or they were told that there would be no support for their children in the kindergarten program. We also heard that the continuation of services from the early years, such as specialized equipment, speech and language, occupational therapy, and physical therapy, resulted in significant changes to the therapeutic service. For example, one mother said,

I tried to tell them like in terms of equipment, I can tell you what he has. You don't need to decide, we know this is what he has. And they're like, "Well, we'll see him in September." Like you shouldn't have to do all of your own assessments and waste the time to get all of that stuff, too.

The same mother noted that in terms of transitioning services from the early years to kindergarten, "It won't be therapy. *If* the therapists have specific recommendations, *if* the EAs have time, they will carry it out" (2.015).

**The work of families.** In order to gain entry or participate in this system of services, families must interact with a large number of agencies (see Figure 1). This requires that family members do paperwork, set up appointments and follow up on connections, travel, and engage in relationships across the programs and services. In the context of children whose development is perceived to be non-normative, parents are tasked with engaging in a series of requirements on the part of institutions. They must act as advocates for their children while simultaneously complying with the structural requirements of programs. Many of these programs make claims about rehabilitation that will lead to "normal" development. Families are making continual micro-decisions to comply or to resist the power of the institutions in which they are engaged (Underwood, Church, & Van Rhijn, 2018). Compliance involves families seeking out those services that are deemed necessary by professionals. This system of referrals, assessment, and rehabilitation works because mothers and families do this work.

As children transition to kindergarten, we see a shift in the nature of the work that is asked of families. Parents' work changes as a function of changing processes. As children enter school, family members are no longer asked to directly apply for therapeutic or support services. They can request these services, but the responsibility is removed. This may seem like a benefit (it is less work). However, it also removes the control that families have to be decision makers and the access that families have to the procedural aspects of the system. While we would not argue that the early years system is a model of parent empowerment, we see that the power that parents held to gain entry to a broader range of services in the early years is not evident in kindergarten. In fact, the promise of accessing therapeutic intervention or specialized services is often how parents are pushed to accept a segregated placement (see the section on choice below). The result is that mothers and family members who have gained institutional, clinical and relational knowledge through the early years are treated as "blank slates" upon entry to school.

Initially they were totally gung-ho and "Yes, come and see the program in action" and "We'll meet Vincent" and "Send us his speech language stuff," and then all of a sudden they put the brakes on and really backpedaled. And I don't know if somebody else got involved or what happened, but what they wanted me to do was put him into school, which is what happens for all the other kids, right? They go into the school, they get identified by the teacher, they get a referral that this might be a kid who's eligible for this program, then

they get the assessments internally, then they decide whether this kid should be placed at some point in the next couple of years. And I was trying to tell them that I understand that's the policy, but this is very different when you have a kid who comes with all of the assessments, who was receiving active speech therapy, where you can call his speech therapist and see who he is, what are his strengths and weaknesses, right? (2.015)

Our maps show that work of families is socially constructed. In our study, it is mothers who are asked by these institutions to do the work. It is not that fathers and other caregivers are not part of the lives of children, but participants told us that this is gendered work, with an expectation that mothers both can and are willing to do this work, and also that fathers are not.

We also see that poverty and the perception of parent education levels can influence how professionals view the capacity of family members to do the work of early childhood service systems. For example, after one family received a recommendation that their child have three services (physiotherapy, occupational therapy, and speech and language therapy) once a week, the parents sought assistance from the developmental pediatrician to determine how they can best achieve funding. As the mother explained,

One of my concerns was if we're gonna pay for private, where's our money best spent right now in her development. So, what's our best course of action to fund this because we can't afford to fund all three. And even, like we can't afford to fund all three, so lots of people can't afford to fund all three.... We are not rich, but we are privileged in this situation. (1.007)

**Supremacy of labels.** Key to institutional ethnography is identifying the texts that lead to institutional action. These texts shape the ways in which people are organized and described, therefore holding substantial power. In Figure 1, most of the services are “high-threshold” (Bulling, 2017), meaning they require documentation of need and have qualifying criteria. Even in those services that do not have these qualifying criteria, such as drop-in play programs, we have heard that families may find the program is not accessible or inclusive of some children, and families can only encourage the institution to act to remove barriers if they have some form of disability documentation. Regardless of how good a relationship is with a family, some of the normative processes that drive the system, including processes that support childcare programs to adapt, are not responsive to individual family cultures and structures. Without even knowing the child, there is an assumption by the system of what educators need in order to include a disabled child. These high-threshold processes often require the child's characteristics to be documented as “deficits and needs” and require the family to do the work of finding documentation. Parents describe this as the “chasing diagnosis phase,” which can last for years and often provides vague or partial information. Many parents are told that the documentation does not fully represent the child but allows them to be referred to and to access services. This construction of disability can be erroneous when looking at the individual child. This documentation is typically a written diagnosis, but it may also be a designation of developmental difference documented through an educational record such as an Individual Education Plan (IEP) or an identification of exceptionality. While these documents, which are produced through assessments of many kinds, can provide valuable information for medical and therapeutic intervention, they also have a gatekeeper function across many of the services.

Further, access to these services requires that a child qualify based on need. Families described the relationship between the identification of need and access to funding. As one mother described,

So Josh was diagnosed with moderate to severe autism at age 2. Realistically he's probably mid-spectrum. Unless you have the word severe in your diagnosis you don't qualify for a lot of funding and resources, so our pediatrician made it quite clear she was adding that word to help us. (1.024)

While the identification of need appears to be key to the institutional relationship between assessment and funding, families report that the assessment or identification of severity does not necessarily provide information needed to get to know the child well. Families, however, must comply with institutional processes if they are to gain access and participate in program expectations (Underwood et al., 2018). Families also described a hierarchy of identifications or diagnoses as they relate to access to services and support. One mother noted that responses differ between diagnostic categories:

The approach is like, we won't even talk to you until you fax us the diagnosis; the one that says autism, you're golden. Gates are open for you. These are all the things we can offer you, but they won't even basically talk to you until you have sent that golden sheet of paper.... If it just said GDD [global developmental delay] the response would be, "sorry." (1.022)

The documents, identified in the Figure 1 map, contain a particular way of thinking about human difference that is embedded in medical discourse. The recognition of differences in human development as deficit is not universal. We found that many families did not share the view that their children's differences needed to be fixed, but that human difference is a valued part of their identity. In education documents we often see lists of strengths and needs as a way to bring balance to the document, but we heard and saw that these institutional lists of traits did not capture the true character of children. What arises is a tension between documenting deficits in order to qualify for service, and the person who is behind the document.

**Fallacy of choice.** During the early years and the transition to school, parents are often told that they have choices. Most of the services in Figure 1 are voluntary, including kindergarten. While this creates a context for parents to choose whether they participate, there is a fallacy in the claim of choice. Parents are able to gain access to services if they comply with the procedural aspects of the system, which often requires multiple forms of privilege. Equally, many families feel pressure to conform with professionals' recommendations about what children need, and it takes privilege for parents to resist.

At the point of transition to school, we see parents again working to gain entry into the best programs for their children. These choices are not easily accessed, so parents will work to get choice: for example, between Catholic and public schools (through claiming of or denouncing a faith-based identity), or from one community to another by selecting an address in a different catchment (through family members), or by choosing on-reserve or off-reserve schools (by choosing between one's community and the services available outside of Indigenous communities). In all of these examples, and more, it is evident that all choices are not equal. If every school were prepared to take every child, then the families in our study would not be doing the work of gaining entry into schools that are

not in their neighbourhood, or that do not fit with their constitutional right to attend the local school with appropriate disability accommodations.

We heard from many families that what are presented as choices, are often tactics used by schools to relocate children to other programs. Many families told us that school principals or other staff reminded them that it is not mandatory to send your child to kindergarten (mandatory education begins at age 6, or Grade 1 in Ontario). Often the choice put in front of parents is to choose the local school with no accommodations or to attend a segregated program that has a therapeutic focus. This is not a true choice. For the most part, we have heard that the only form of support that is offered is an education assistant, and this type of support is allocated at the board level with limited resources. Few other accommodations are offered. One parent visited an autism program in which

[the principal] said to me, “Listen, I don’t care if your kid comes here or not; that makes no difference to me. You have to do what’s best for your kid.” But all I heard was “I don’t care if your kid comes here.” (1.024)

Kindergarten is described as a choice because attendance is not mandated by law. However, the general messaging about kindergarten is that it is central to academic, social, and developmental futures for young children. The rhetoric suggests that for other children it sets them up for success in the school system (Government of Ontario, 2017; Pascal, 2009), but this is not necessarily extended to all children. One mother was told that her child could stay in a community kindergarten but have a reduced day, or she could go for the full day to a special education school. The first option was not in fact a true choice. One mother told us, “This school that he should be in with the catchment area is not accessible and they just told us it’s not accessible and I was shocked that a government building can just tell you that they’re not accessible” (2.015). Another mother explained to the principal that “we would like her to [be in] community school. It is her right. And she should also be able to get some autism intervention and she should be able to be safe there” (1.022). In this case, the principal called her to say that they had found a spot in a segregated program for her child.

**Institutional flexibility.** Parents in the study told us, “I don’t want my child fixed, I want them included.” What we saw was a significant difference in the organization of approaches to including young children between the early years and schools. While many families had spent years organizing services for their children prior to school entry, almost all of that work, both on the part of families and of children, was not continued into kindergarten. Kindergarten programs indicated that they were not obligated to adapt in order to prepare for particular children. In fact, some families’ experiences indicate that the lack of kindergarten support is intentional with the goal to document the failure of the program and send the children to a special education placement. The result is that families reported that children are expected to be prepared to participate in the kindergarten program by having developed particular abilities including independent toileting, feeding, and dressing. One mother explained that if her child required a change of diaper in kindergarten, it would not happen: “The teacher or the EA [education assistant], like in a typical kindergarten they can’t help the child. They can’t touch them. So they would just have to guide him verbally through cleaning himself up. That would

not work” (1.024). There is a lot of pressure for the family to ensure that children have intervention that leads to this kind of “school readiness.”

In the transition to school, we see that the labels assigned through diagnostic and therapeutic notes hold power. As noted above, there are structural differences between the early years and kindergarten in terms of what is perceived to be “appropriate” programming or “support.” In the early years, services associated with disability fit with a developmental approach. With the exception of medical intervention at birth, most children are first referred to speech and language services. This is consistent with the expectation that one of the first developmental milestones will be spoken language. Next, children may be referred to occupational or physical therapies in line with an expectation that children will sit, then crawl, then walk. Finally, children are expected to engage in social interactions and, if these interactions are perceived to deviate from developmental norms, children will be referred for behavioural or mental health services. This pattern changes upon entry to school. While many of the same services exist in schools, the goals of the services shift. As parents have described, entry to kindergarten marks a shift from services linked to developmental progress to norms connected to school performance. Rather than a focus on individual child development, services are called on if the child is believed not to fit into the kindergarten program. We argue that both systemic responses to human difference are embedded in a construction of the child as disabled.

The early years system has two outcomes. The first is that these special services discharge the child with the expectation that they have achieved the requisite competencies to transition to school. This is often the case, but if a child is discharged they do not enter the school system with the paperwork that indicates they had previously been identified as having special needs. Without this paperwork, should a family have concerns about the kindergarten program, they will have to start the process from the beginning without support from early years programs or staff. For other families, they enter kindergarten with a formal diagnosis or a record of developmental services that can lead to actions on the part of the kindergarten staff. For example, they might get an education assistant, or equipment, or the teacher might adapt the program by changing communication strategies for accessibility. In the latter case we heard that this was often part of the plan in transition meetings, but few parents described this happening in practice once the child entered school. One mother told us,

They said, you know, he can go in and he’ll be assessed like the other kids and, if he’s eligible for speech services, then the referral is to be put in place. It came down to basically just brushing us off saying because he’s got other medical issues: This is probably not the best place for him. (2.015)

Finally, the flexibility for programs to adapt needs to be in response to children, but also to their families. One of the mothers who had accessed a very large number of health, rehabilitation, and special education services prior to school entry noted that family support was the one area that was lacking. Programs that are designed specifically to support families, such as family resource programs, can play a central role in helping families with the work that is asked of them in the preschool years. Family support is about valuing each member of the family, not just the child who is enrolled in a program. However, while family support may need to be enhanced in the preschool years, it is not

identified as an important part of the kindergarten program, which is a significant change in the nature of institutional interests between institutional settings.

One participant described the impact of the lack of responsiveness on the part of the school:

When he was here in the kindergarten, sometimes I packed his lunch and he brought home the same as I put it in his lunch bag [in the morning]. [Interviewer: And you don't think anybody helped him?] No, because if someone helped him he will eat. And I ask the teacher "How come"—cause it happen a couple of time. I ask her, "Please help him cause he doesn't know how to go and get his lunch bag and eat his food." And she said when it's lunchtime she's not there, it's another staff who comes in and does the lunch. (1.002)

This expectation of independence points to the philosophical shifts that happen from the preschool years into school age. First, there is a shift from an expectation that *families* be compliant with institutional process, to *children* being expected to comply. Second, there is a shift from families being *central* to children's well-being to families being *peripheral* to the process of supporting children. This is very evident in the roles that are asked of families, but also in the focus of the programs and the expectations of children.

## **Discussion**

The IECSS has used institutional ethnography to map the services, processes, and the textual record of the child. Through this method we are able to identify the power that institutional processes hold over children, families, and professionals. As Canada moves to increasing the number of childcare spaces in order to honour our obligations and the rights of children under international conventions, we must ensure that each new space created considers the broader system of services. This can ensure that children are included not only in individual programs but throughout the system. Figure 1 shows a broad range of services that hold theoretical positions about what makes a good parent (described in the section on parents' work), what constitutes disability (as described in the section on labels), and the misrepresentation of choice for families. Taken together we can identify structural discrimination that is constituted through a shared effort of normalizing children and excluding children who do not fit norms.

The research collected through the IECSS project highlights the division in expectations, pedagogical approaches, and responsibilities between early years programs and kindergarten. It illuminates the institutional control over development, social participation, family engagement, and accommodation or adaptation. Additionally, it urges us to recognize the systemic mechanisms within which families are asked to engage. For many families, a great deal of labour was required to establish a formal diagnosis of disability before they could receive access to funding or support. However, many families identified that the assessment did not appropriately characterize their children, nor did it provide adequate care or pedagogical direction for educators. While the establishment of a diagnosis appears to be of paramount importance in the hopes of attaining services, many times families found that the diagnosis did not result in enhancing access, but was sometimes used to exclude children from services. The education system's emphasis on diagnosis also requires families to adopt a highly medicalized and deficit-oriented construction of disability. A deficit-oriented construction of disability can diminish how

educators think about children's capacity, and how their perceived abilities are measured and evaluated, and assumes a rigidity in aptitude.

The number of services that are focused on impairment specific rehabilitation or support is significantly different in kindergarten. First, all of these services are delivered in one institutional setting, which gives a lot of power to the school. Second, most of these services are in the form of consultation to the teacher rather than direct service to the child. Consultation as a model focuses on the environment rather than pathology of the child, with the aim of including the child. Inclusion is known to be an effective strategy and a right for all children (Guralnick, 2001; Mitchell, 2008). However, the abrupt shift from intervention in the early years to kindergarten classes with almost no specific services is part of the argument that is used to exclude children from kindergarten.

In addition, the large number of children in our study who did not attend kindergarten is inconsistent with the promises of the full-day kindergarten program to be inclusive of all children (Government of Ontario, 2014; Pascal, 2009). These findings are consistent with data from the Toronto District School Board that 1.5% of students enrolled in kindergarten were in a segregated special education program, and 2% of students who had an Individual Education Plan (IEP) did not have any specific special education provision (R. S. Brown, personal communication, 2019). We do not know how many children did not enrol in kindergarten at all. While the numbers do not give us any information with which to evaluate the program efficacy, they do give some indication of the scope of placement outside of the full-day kindergarten program.

The educational opportunities that children receive are deeply influenced by medical aims of rehabilitation and treatment. Qualities determined through evaluation and assessment are then often used to set children upon a trajectory of educational opportunities or exclusions, over which families have little control. It is through labeling and placement, as well as other procedural aspects of transitioning into kindergarten, that families lose control over decisions about their children, despite ample opportunities in early childhood for them to be enculturated into institutional regulation. One mother, realizing the impact of her child's kindergarten placement on her future educational trajectory, stated,

While they [identification and placement team] agreed with me that if they decided to put her in a diagnostic kindergarten that there would be no way that she could ever go to college, and there were children with her syndrome that got to college. And we had to make a decision in that meeting as to whether we believed that she would tell us whether or not she goes to college or the room would tell us whether or not she would go to college. They still placed her in a diagnostic kindergarten. (1.007)

Finally, kindergarten programs are oriented toward educational attainment in primary grades and further distance families from the community-based and family support programs that are part of the early childhood system. Furthermore, recent research suggests that once children enrol in inclusive early childhood and kindergarten programs, they are more likely to transition to inclusive classrooms in the early elementary grades (Guralnick, Neville, Hammond, & Connor, 2008). As interviews in the IECSS project continue with families when their children move into the early elementary grades, future findings will provide further insight into the functions of institutions that govern children and their families.



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