Article

Understanding Speech-Language Pathology from the Standpoint of Families: A Systemic Analysis

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Abstract: The Inclusive Early Childhood Service System (IECSS) project is a longitudinal institutional ethnography that studies disability services in early childhood, and the interactions between these services and other systems, from the standpoint of families. In this paper, we examine speech-language services as part of a system of services and a site of participation for disabled children. We use longitudinal data from annual interviews with 117 informants to map Speech and Language services over the first six years of children's lives. We report that speech and language pathology (SLP) as a professional discourse holds cultural significance and influences the organization of disabled children and their families. The analysis of the data illustrates the pervasiveness, organizational structure, and governance of speech and language pathology (SLP) in early childhood, leading to professional discourses of childhood and disability in early intervention, preschool, and school-based services which reinforce individualized pathology as the dominant way of understanding development. We discuss how the professional practices of SLP-related services could help to disrupt disabling constructs of childhood development and colonial practices in early childhood disability services. We emphasize how speech and language development emerges in relationship with individuals and socio-political contexts. We suggest possibilities for SLP to operate within community contexts where speech and language services contribute to reducing family workload, increasing the participation of all children, and disrupting ableism in practice.

Keywords: language and communication; disabled children's childhood studies; systemic ableism

1. Introduction

This paper examines how speech and language pathology (SLP) is positioned within a broader system of family and child services to regulate the everyday interactions of disabled children and their families. This analysis is relevant for understanding how disability is constructed across different professional discourses from the very earliest moments of children's lives. This study is situated in Canada, which is a relatively wealthy nation with investments across education, health, and social services, albeit with wide differences in material and geographic privilege. This analysis holds potential for understanding how these types of investments can lead to unintended consequences for disabled children and their families in the form of bureaucratic processes that are trans-local, and that follow children and their families across services systems and over time.

Most research on SLP services examines the clinical outcomes of intervention. By contrast, this study examines SLP as an actor in the early years system of services, in three provinces and one territory in Canada, where there is variable access to early childhood

services. We are interested in how SLP services function in relation to discourses of disability and influence participation in early childhood education and care, and intervention more broadly. This study examines systemic constructions of the examination of disability in the early years, through analysis of speech and language services, but the analysis holds relevance beyond speech and language services. Our contribution is in understanding how disability is constructed socially across institutional environments and beyond individual interactions. We identify how the categorization of some children as disabled moves with them, and is persistent, over years.

We use data from the IECSS project, a longitudinal institutional ethnography, which examines how early childhood service systems organize families with disabled children through procedural and professional interactions. The everyday experiences of families provide a unique standpoint from which to see how institutions are implicated in the construction of disability, and to understand the work of families as they access or participate in the organization of children in early educational contexts (Underwood et al. 2020).

Our study is situated in the social worlds of disabled children, and the socio-political context in which understandings of disability and childhood are produced. We begin by describing the importance of SLP services to the early childhood education and care system, and understanding disabled children's experiences in these systems. We suggest that SLP discourses and practices are determined by the social, political, and historical contexts of childhoods in Canada. We then present empirical findings on the position of SLP within the broader services system and social context to offer an analysis of how SLP might be positioned to disrupt ableism and how it could act to provide continuity and support across service systems that are actively engaged with disabled children. Our analysis provides a launching point from which to consider how SLP professionals might be uniquely positioned to disrupt the ways in which children and their families enter disability experiences and develop disabled identities in childhood.

2. Socio-Political Contexts of SLP Discourse and Practice

Clinical research evidence supports the efficacy of early intervention in children's speech and language development. For example, Rinaldi et al.'s (2021) systematic review of the state of research on early language intervention found that early intervention is effective overall, but with inconsistent outcomes, in supporting phonological expressive and receptive language skills. Other studies have shown the efficacy of specific curricula (e.g., Frizelle et al. 2021; Wilcox et al. 2020) and speech and language interventions for children with language impairment diagnoses (e.g., Binns et al. 2021) on SLP with Autistic children (Crowe et al. 2021 on SLP with multi-lingual children). While these clinical studies provide useful evidence to support SLP intervention, they come out of the professional discourse that is informed by and directed towards a specific norm for children's speech and language development, embedded in culture norms that value speaking over signing, or alternative forms of communication, and that are often removed from disabled people's social, political, and cultural movements (Duchan and Hewitt 2023a).

By contrast, critical disability scholarship is an important intervention into rehabilitation discourses. Kafer presents us with a hybrid political and relational model of disability that imagines disability futures as something different from an individual problem to be fixed, and disabled people as having needs to be managed. This approach honours the medical interventions that disabled people seek and ask for, while disrupting professional discourses that define disabled people through diagnoses, pathologies, and deficit descriptors. These distinctions, however, are situated within neoliberal contexts of early childhood education and care, which call for bureaucratic categories of access, particularly for disabled people. Sims and Sammy King Fai (2017) call for active resistance to this neoliberalism in the early years.

Speech-language services are one of the most frequently accessed early interventions in Canada (Statistics Canada 2006) and they are situated across many institutional sites, including hospitals, clinical therapy, childcare and other early years programs, family

support, and schools. The clinical scope of SLP practice in Canada (see Speech-Language and Audiology Canada 2016) positions it as an authority when assessing and constructing children's language as impaired and, therefore, perpetuating the normative framing of children's development across early intervention, early education and care, and school-age services, as well as being internalized by families. We argue that speech, language, and communication should not be separated from children's cultural, social, political, and historical contexts, and are influenced by growing scholarship that combines rehabilitation and critical disability scholarship (Mosleh 2019).

Speech-language services must be responsive to the complexity of children's identities, communities, and sense of belonging. For example, disability and race have been shown to be conflated in speech and language services (Privette 2021; Yu et al. 2021), where disproportionate numbers of Indigenous (Adams 2015; Ball and Bernhardt 2008), Black (Privette 2021; Towe 2021), and racialized children and youth (Farrugia-Bernard 2017) are diagnosed with speech and language impairments. Scholars have suggested that SLP training programs must actively work to decolonize/deconstruct assessments and practices to work with children in a way that meaningfully integrates their social, cultural, political, and economic realities (Ball and Lewis 2014; Ball and Bernhardt 2008).

The IECSS project has also documented the ways that audism and colonialism are enacted in early childhood disability services. Audism and disability discrimination have been documented specifically in the context of language, such as when cochlear implants or hearing aids are depended on without prioritizing sign language, which hinders deaf children's language abilities (Murray et al. 2020). Similarly, SLP services have denied children's deaf culture and access to deaf communities, as well as access to adequate education and care (e.g., Snoddon 2021; Snoddon and Paul 2020). Duchan and Hewitt (2023b) have examined the historic origins of ableism and racism in speech and language professional discourses. Empirical evidence links disability exclusion further to racism, classism, and sexism (Parekh 2023).

Explicit policies to stop Indigenous children using their own languages, constituting cultural genocide, are part of Canadian history and have ongoing effects (Ball and Bernhardt 2008; Charnley 2006; Haque and Patrick 2015). There are, however, models for language intervention that are emerging from the rejuvenation of Indigenous languages in Canada (Ineese-Nash 2020; Whalen et al. 2022). Indigenous scholars are publishing important work that recognizes Indigenous ways of conducting language assessment, early intervention, and creating developmentally rich language environments (see for example, Peltier 2017; Stagg Peterson et al. 2021). Similarly, Black communities and other racialized communities are developing SLP and early intervention services that are premised on the recognition of intersectional identities (Carroll n.d.). Research has identified concerns both regarding the lack of access to SLP services in a profession that has not been very successful in acknowledging that race matters in terms of who is delivering services and who is receiving them (Feinberg et al. 2011), but also how racial identity is considered in the context of delivering SLP (Latimer-Hearn 2020). Finally, disability itself is part of identity, and research suggests that rehabilitation professionals need to be more mindful of their role in supporting children's and families' emerging understanding of their own disability identities (Forber-Pratt et al. 2018).

3. Disabled Childhoods

For the most part, disability discourses in early childhood education and care have centred on inclusive programming and the enrollment of disabled children in 'regular' childcare programs, rather than disability justice, which positions every body and mind as whole and of value (Sins Invalid 2019). When justice is centred in early childhood spaces, the need to normalize disabled children's development is disrupted and the organizing of children into certain programs based on ability shifts (e.g., Brown et al. 2019). Disabled children's childhood studies integrates childhood studies and disability studies with other areas of critical theory, and aims to recognize that disabled childhoods are an important

standpoint from which to identify ableism (starting from birth), but also to celebrate the valuing of disability communities, identity, and experience (Curran and Runswick-Cole 2014; Douglas et al. 2021; Runswick-Cole and Goodley 2018). The treatment of disabled children in health and intervention is linked to our collective goal of avoiding disability in adulthood (Kafer 2013). Families are then put in the position of enacting these goals with the pressure to ensure interventions that normalize development and avoid becoming future disabled adults (Balter et al. 2023).

Children's social worlds are vital to their language, communication, and relational development. These social connections are an ultimate goal of language development and early education; however, the colonial goals of academic achievement and career success are intertwined with relational connection in our society. The analysis presented in this article aims to disrupt the normative goals of early intervention that cause ableist harm, and to work toward a more just future for disabled children (Chordiya and Protonentis 2024). Further, relational outcomes are subverted by the systemic need for the documentation of deficit and outcomes that are normative and individual, as described above. The professional discourse of speech and language pathology, found in much of the research on preschool speech and language intervention, is disconnected from the everyday experience of children's language. All children hold social and political identities that are important in their development of language, communication, and relationships. The SLP profession has the potential to disrupt normative constructions of language that may be hidden in the discourses of cultural relevance.

4. Methodology

Institutional ethnographies are not guided by specific research questions; rather, they explore a *problematic* that emerges from informants' everyday lives (Rankin 2017). Since the inception of the IECSS project, we have been cognizant of the prevalence of SLP services in the lives of disabled children, leading us to consider what role SLP services play in the social organization (Campbell and Gregor 2004) of disabled children from birth through childhood, and across different institutional spaces. Institutional ethnographies are concerned with the power, or ruling relations, that institutions have in interactions with people.

The IECSS project began in 2014 as a study of the work families undertake to gain access to early childhood disability services. From the outset, we recognized the importance of the family standpoint to understand how the social participation, disability identity, and economic and educational experiences of disabled children and their families are implicated in their institutional engagements. We began by recording the experiences of families and mapping out the institutions that are present in families' lives. The result was the documentation of a very large network of services that are not clearly planned as a "system" because they are funded, managed, and organized by different authorities. We have categorized them broadly into the following groups: health; pre- and postnatal; therapeutic, early intervention, and disability services; early childhood education and care; school; family support; grants and subsidy; and community, social, and justice services (inclusive of recreation, housing, food security, family courts, immigration, police and penal systems, emergency services, etc.).

Through this process, we became aware of the prevalence of families accessing SLP services, both across service systems and over time. We noticed that SLP was available through the formal preschool early intervention systems and was also accessed in the context of other systems. In addition, when we asked families to describe their children (our open-ended first question), they often responded using clinical or medicalized language that reflected their interactions with clinical and intervention services. In a pilot analysis, conducted in the second year of data collection, of six informants' interactions with SLP services, it was revealed that, for many young children, SLP services were the first or only early intervention children received and, accordingly, it functioned as a central service in their experiences of early intervention (Jones 2018).

As the IECSS project continued, we saw that children who were participating in many different services would access SLP over and over again. We identified that 91 percent or 117 families in our larger project dataset of 128 informants accessed SLP services at least once. It was part of what we called the "quintuplet" of services that included speech and language therapy, occupational therapy, physical therapy, behaviour therapy, and mental health services that are repeated in various institutional settings across the early years for disabled children (Underwood et al. 2019a). Of these services, SLP appeared to be the most prevalent, to appear the earliest in children's lives, and to be the most frequently accessed into children's school years. We wanted to understand how SLP functioned to govern other services and the interactions of children beyond the stated goals of the SLP profession, and the policy aims articulated locally.

Institutional ethnography is concerned with examining institutions from the standpoint of those who are most engaged with the work of the institution, and how they, therefore, can act as informants in relation to how institutional processes and procedures govern the actions of those who are working in, for, or with the institution. In our case, we examined the workings of the institutions of early childhood. Griffith and Smith (2005) share that institutional ethnography:

"does not stop with what people know from their everyday lives. Rather, experience becomes the ground from which to explore the social relations and organization beyond the local settings of their everyday world. A sociology for people brings into view the relations of ruling that enter and shape their daily worlds, and the ways our daily experiences participate in and construct those translocal social relations." (Griffith and Smith 2005, pp. 2, 3).

The overarching problematic explored in this study centers our interest in understanding the ruling power of SLP across the lives of disabled children and their families. We are particularly interested in considering the possibility of SLP services to enact an anti-ableist stance and disrupt the deeply embedded medicalized approaches that are evident in early childhood education and care.

5. Informants and Standpoint

This study reports on families' SLP access and navigation from the IECSS project, a longitudinal institutional ethnography which uses the standpoint of informant interviews.

In this paper, we examine data from the 117 informants selected because their children have accessed speech and language services from the IECSS project. We collected between one and eight interviews for each participant beginning when their children were preschool-aged. Informants live in and/or access services in six provinces (Alberta, British Columbia, Ontario, Manitoba, New Brunswick, Quebec) and one territory (Northwest Territories) in Canada. Informants were recruited through community-based childcare, family support, early intervention, and local media (online, radio, and print).

Interviews were conducted either in-person at their homes, work, or a public location such as a library or coffee shop (prior to COVID-19), or over the phone (during and after COVID-19 shutdowns). Informants were asked to describe their experiences of trying to acquire support for their child who is preschool-aged, and who was identified as, or suspected of, having "atypical development", "special needs", "disability", or "gifts" (n.b., this language reflects terminology used in community rather than our theoretical orientation in the research). Informants were predominantly mothers, but also included fathers, grandparents, step-parents, foster parents, and kinship guardians.

In the interviews, we asked parents/guardians open ended questions about four areas: (1) Tell us about your child; (2) Tell us about the programs and services your child attends and why; (3) Tell us about the processes and procedures involved in gaining entry to services, including assessments, forms, and relationships that are required to participate in services, and (4) Tell us about any experiences your family has that are unique and that effect your engagements with these institutions. We used probes to ask about the detailed actions and processes. The interviews were designed to illuminate how SLP services act to

rule over or to organize the activities of families, a key aim of institutional ethnography, by asking about the procedural aspects of access, and the work that families undertake to gain that access. In addition, we asked about the assessments and classifications of children that operated as gate-keepers for entry into speech and language services, but also operated beyond those services, with SLP assessments being used in many trans-local spaces to position children as eligible and appropriately placed, or to keep them out of localities of intervention if they did not appear to be in enough "need". These assessment texts are powerful, acting as ruling texts that are relational: "Ruling relations identifies the institutional complexes (emerging from the development and elaboration of capitalist economies) that coordinate the everyday work of administration and the lives of those subject to administrative regimes" (DeVault 2007).

All interviews were transcribed. The transcripts were then used to systematically build a database of experiences informed by the interactions of those who are organized by these services. We achieved this by recording each agency or organization, professional and staff person, qualifying criteria and assessments, time spent in services and the organization of programming, and the referrals both into and out of programs in a table of systems attributes. We then used these attribute tables to map the early childhood system from the standpoint of the informants. The attribute tables developed over 9 years of data collection, including more than 100 variables for each service accessed by a family and multiple data collection points for each family. Services are organized by category: health; pre/postnatal; therapeutic, early intervention, and disability; school; early childhood education and care; family support; grants and subsidies; and community, legal, and social. The database currently includes more than 200 services with descriptive information about each of the following: information about access to services (e.g., referral, waitlist) as well as qualifying criteria (e.g., assessment, diagnosis, and other records of disability produced), and contact with the service (e.g., time in service, start and end date of access) as well as who interacted with the family (e.g., professional categories, administrative staff). For each family, we then build a map that is a visual representation of these data. We examined all maps for the N = 117 participants who accessed SLP services to discern the patterns of where and when SLP emerges in the lives of disabled children.

We then returned to the transcripts to understand the narrative that families attach to these experiences. In this case, we selected five families who had described intensive engagements with SLP services over time. These interviews (with up to 9 years of interviews) were read in-depth for the rich description of the rhetorical and discursive constructions of children through the texts and regulations that were conveyed to families. Our focus was on family interactions and the work required to access SLP services, and the production of children as in need of services that, at the same time, were elusive and required advocacy to access. We were attentive to the unique position of SLP in the early years, with the pressure to ensure intervention at a young age or miss the opportunity to "fix" children. Our iterative process allowed us to examine what SLP services look like from the standpoint of families, how SLP services fit into the bigger service system, and what the implications are of the pervasiveness of SLP across the early years. Note that, in institutional ethnographies, our interest is in the ruling or textual relations that are evident across systems.

Descriptions in institutional ethnographies use informant standpoints to illustrate and examine problematics: in this case, the pervasiveness and significance of SLP services. The design of this study was informed by community partners who identified the need for longitudinal research from the standpoint of families. Grahame (1998) provides insight into data analysis within institutional ethnography and shares the following:

> "The principal tasks of institutional ethnography include describing the coordination of activities in the everyday world, discovering how ideological accounts define those activities in relation to institutional imperatives, and examining the broader social relations in which local sites of activity are embedded". (p. 347)

6. Findings

We began the analysis for this article with a review of the full dataset as described in the identification of the problematic. In this case, this was the role SLP services play in the social organization of disabled children. Figure 1 shows a map for a single family in the years before school entry. Interestingly, this example was selected because the mother, despite the complexity of interactions and the evident ableism in the childcare system, told us that their experience was the "best case scenario".
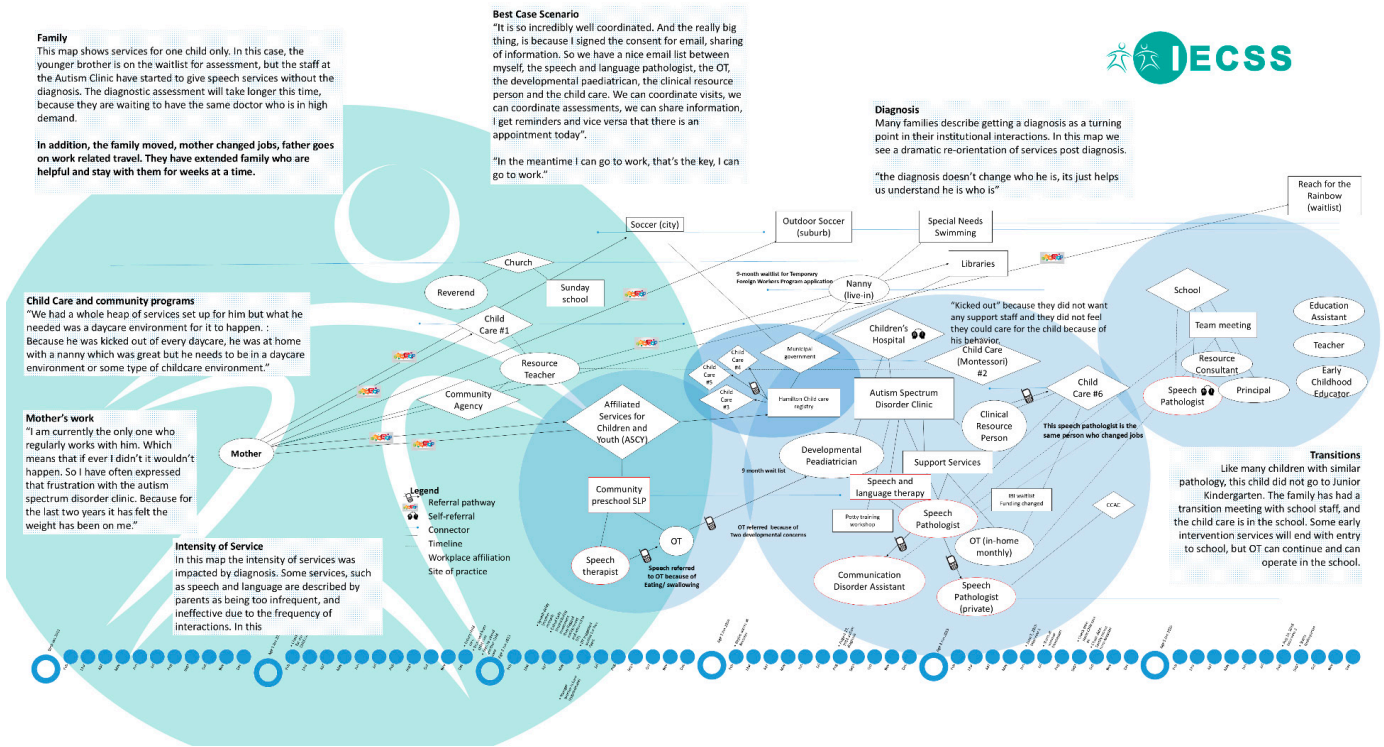

Figure 1. Map from one informant developed from the first 3 years of interviews. Note, a version of this map was first presented in Underwood et al. (2019b). In Figure 1, the circles show different systems, with the first system being the family and services which the mother found on her own. The second sphere is the early preschool speech and language system, which is the first formal disability service. The map shows that SLP was one of the first services they accessed, was often a point of referral to other services, and appeared in several different service systems, including within publicly funded preschool early intervention services, autism services, as a private service, and in school. This map also shows that the child had been excluded from multiple childcare centres, in this case, in response to perceived behaviour concerns. This system supports them to find childcare, but, in this case, the child was asked to leave two childcare centres, and then they were not allowed to enroll in other childcare centres when the mother disclosed her concerns about her child's development, but they were then included in childcare once they had an autism diagnosis, illustrating the medical model at work.

With the 117 participants who accessed SLP services, we mapped the collective experience of SLP services as an aggregate. Figure 2 shows the results of this analysis in a high-level map of the points at which SLP services might be accessed and the discourses connected to those experiences. We present our findings chronologically, with reference to the discernable patterns of service delivery, and to illustrate the pervasive developmentalism that is evident in SLP and which, in turn, influences all early years education and care systems.
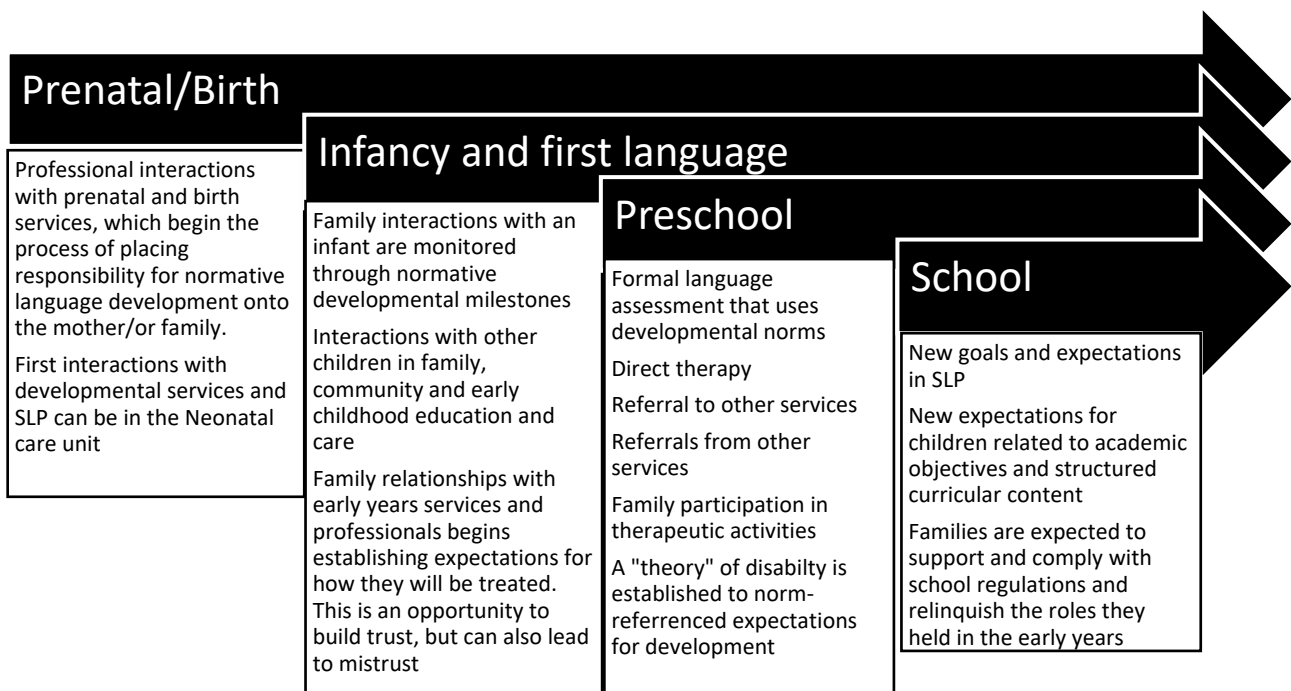
Prenatal/Birth

Professional interactions with prenatal and birth services, which begin the process of placing responsibility for normative language development onto the mother/or family.

First interactions with developmental services and SLP can be in the Neonatal care unit

Infancy and first language

Family interactions with an infant are monitored through normative developmental milestones

Interactions with other children in family, community and early childhood education and care

Family relationships with early years services and professionals begins establishing expectations for how they will be treated. This is an opportunity to build trust, but can also lead to mistrust

Preschool

Formal language assessment that uses developmental norms

Direct therapy

Referral to other services

Referrals from other services

Family participation in therapeutic activities

A "theory" of disabilty is established to norm-referrenced expectations for development

School

New goals and expectations in SLP

New expectations for children related to academic objectives and structured curricular content

Families are expected to support and comply with school regulations and relinquish the roles they held in the early years

Figure 2. Speech and language engagements over the early years (derived from maps).

7. Experience of Families over Time: Mapping the Ruling Relations

SLP services are typically the first early intervention sites that a child is referred to, making it an entry point into other early intervention, education, and care systems. We organized these services by time: from developmental stages and ages from prenatal and birth to infancy and first language and communication, through the preschool years, and then school. This presentation of services by age and stage does not account for the differences between children or the diversity of experiences families have in engaging with them. We begin with a descriptive presentation of SLP services at several stages of children's lives. Figure 2 is developed from the 117 informants and illustrates the patterns observed related to speech and language across the prenatal to schooling stages of life.

7.1. Prenatal, Infancy, and Early Language

Even before children are born, families are given messages about their children's development through prenatal directives about mother's behaviours, in utero screening processes, and information about parenting norms. These messages are internalized early, and this institutional discourse becomes part of how families describe their children. For example, some families had contact with speech-language pathologists as early as infancy, particularly when the child was diagnosed pre-term or at birth with characteristics that might affect their communication or language. Families report that screening for developmental delays also begins early and continues throughout the early years.

SLP can begin at any age; however, there are several times when it is more common by design. For example, if a child is diagnosed with a condition at birth that commonly leads to speech and language referrals later in life, a family may have a speech consultation. We heard from a parent of a child with Down syndrome that they had been waitlisted for SLP services at birth, with an in-hospital referral to early intervention services (e.g., Infant and Child Development Program), based on the assumption that they would need the service. This pre-emptive referral is based on the fact that the system has long waitlists, and that medical and clinical documentation is needed for these referrals. These types of referrals influence which services, professionals, and even environments a child and their family will spend time in. However, while early identification and referral can mobilize access to the system, it also produces assumptions and impressions based on diagnostic

information, apart from the local experiences of the child in the community. These early engagements between SLP and families begin the process of constructing disability as a systemic category.

7.2. Preschool Speech and Language Services

The next point at which SLP referrals are common is around the age of two because, at this age, there is an expectation that children are talking. Preschool SLP is delivered through publicly funded early intervention, but can also be accessed in child development centres, specialized early years services, childcare, EarlyON centres (family support programs), and health care settings such as hospitals. Some children will access SLP in several or all of these settings, with SLP repeating at home, in clinical settings, and in childcare. It is common to have a publicly funded SLP while also accessing private services to supplement the limited funded sessions. The regulations for SLPs indicate that, if there are multiple SLPs treating one child at the same time, there must be a different scope for each (Speech-Language and Audiology Canada (SAC) 2023). Families will often pause private speech when their "turn" comes up for a publicly funded service. If a child has a chronic health condition or multiple diagnoses, they are likely to be referred to services in multiple settings. These different sites of SLP practice have different methods, goals, and communications to families, as well as different requirements for participation, including differences in the expectations of parents to enact treatment plans. Referral pathways include self-referral by parents in the community, or referrals by early childhood educators, or through children's services, clinical referral, or family doctors. Each of these people may have a different professional discourse. The location of services can also influence the referrals that SLP professionals make. These pathways can lead to more community-based services, to further involvement with social services, or into health care. Each site of practice is governed by a variety of policies, regulations, and funding structures.

One informant's description of how the system operates illustrates the power that the system has:

> "Our system is completely broken. By the time the children get services, they're completely aged out of the system. They keep [you] begging for money, and funding, and services. [Interviewer: Last year you had mentioned she was getting private speech therapy. Is she still getting private speech therapy?]. Speech therapy is always happening because it is out of our pocket [as compared to other services described earlier in the interview]. They can communicate immediately. If you have money then you don't have any problems. If you don't have any money then there's a problem. Now we have stopped it because we don't have money you know. Maybe six months back we stopped because you know we don't have money. We are doing ABA therapy right now, therapy is going on, behaviour therapy. My child started speaking a little bit you know so at least she has some basic communication right now, finally at least so I was very happy. You know but it does not mean she's speaking. She is very, very delayed at the age of 6 she's speaking like a 4-year-old. So she's 2 years delayed, 2 or 3 years. She's really delayed."

As described by the informant, it is common to hear that a child has been diagnosed with "moderate" or "severe" delays. These medical or clinical quantifiers are then used to determine the level of service. Our informants, however, tell us that these quantifying criteria do not capture the complexity of their children's language abilities, or the dynamic nature of their communication and relational engagements with language. The children in our study who received consistent and more intense SLP services from infancy to school age all have a medical diagnosis (e.g., Cerebral Palsy, Williams syndrome, Tetrasomy 9p, Cleft Palate). Specific disorders, such as apraxia of speech, lead to intensive intervention. Some families told us that, in retrospect, they did not need that level of intervention, while others were very frustrated with the lack of intensity of services. Children routinely undergo repeated assessments, which produce a textual record of the child that is institutionally

produced and oriented toward the organization of services rather than the individual traits of a child. Finally, this quote demonstrates the pressure for a child to speak.

The organization of publicly funded preschool SLP services is typically in blocks (where children receive services for a set number of weeks and then are required to take a break for a set number of weeks until the next block can begin, or they are reassessed). The services may be delivered in 1:1 therapy, group therapy, online therapy, in-home therapy, in-early-education or care-based therapy, and in-school therapy. The delivery of the services is based on the relationship between where the child gained entry and the referral mechanism through which they gained access. For example, if a parent calls the preschool SLP service directly, they will likely be put on a waitlist for the local publicly funded system. If they attend a specialized childcare, they may receive SLP as part of the daily program. If they are referred in hospital, they may receive SLP in a clinical setting or through a private provider. While the latter example is likely the most intensive, it also comes with participation in settings outside of the early childhood education and care system, which leads to further influence over the pathways to which the child and family will be directed in referrals.

In addition, families must engage in the labour of coordinating and building relationships across each site of service. For their children to have access to early speech and language intervention even once, families need to respond to telephone calls, fill out paperwork, and/or go through an intake process. This work is governed by the regulatory environment of the service system into which children, families, and educators must conform (Nilsen 2017). More intense services mean even more work for families. Several informants told us that they had to reduce their work hours, leave their jobs, or become self-employed in order to have the flexibility to manage services and to handle multiple appointments for their children.

7.3. School-Age SLP

In early childhood, SLP services focus on the physiology of speech and the development of language, which are often quantified (e.g., number of words spoken). In school, SLP services shift from a focus on speech utterance and functional communication in the home to academic skills such as reading and writing and language skills to participate in the school environment. This change in goals is not related to the children, but to the institution they are enrolled in, and their age. These assessments qualify children for programs, and yet the assessment is not used to inform the program itself. Instead, the programs are informed by the location of the services, for example, children's mental health or child welfare sites, children's treatment centres, hospitals, and other clinical sites.

At school entry, there is little continuity from SLP services in the early years. In the early years, if a child meets speech and language milestones, or they are unable to maintain their attendance in SLP services, they will be discharged. The family must then begin the process of finding their way back into SLP services if they are needed or wanted again. Entry into this new system of SLP requires a referral through school staff—early years referrals are typically not accepted. For the most part, school-age SLP does not begin until Grade 1. The school system requires recommendations and documentation from SLPs, but does not always accept this documentation from the early years. Rather, they often require new assessments to meet speech and language criteria in the school system. There is a very clear separation between early years and school services. Often, the children in our study who received preschool SLP services experienced a gap in services while waiting for school-based SLP services to begin. Some children who accessed SLP services in the early years did not meet the school speech and language criteria. For example, one child who qualified for intensive SLP services in the early years was declined school SLP services when they entered Kindergarten. The mother shared the following: "I think if anyone should have speech it would be him who came from a very high level of speech involvement a year before but certainly nobody has contacted us".

In school settings, families can request SLP services, but they do not make the referral and are not directly involved in the process. Some informants never met the school SLP who worked with their child or, in some cases, did not know their level of involvement. One mother told us that her child was placed on an SLP waitlist in junior Kindergarten but was "not sure what is going on with that" months later. Another informant told us in more detail about their experience:

> "I didn't know this, once you receive supports in the school you have to wait 12 months before you can put in another application for support. So she spent all of SK with no OT, PT, or speech support. Then once you finish your cycle of support, you have to wait 12 months to reapply for more support. [Interviewer: So that means it's only possible for you to have the support every second year.] Yes. [I: Can they apply early?] No. So the principal had the date on her calendar, she had me pre-sign the forms, and when the date came she submitted them on the day of the 12 months and one day."

When families have contact with SLPs, it is typically during larger school team meetings that are broad in nature—meetings that assess and identify student educational placements and organize accommodations, as one informant described:

> "There was an IEP [Individual Education Plan] meeting and then there was educational placement, and then there was a superintendent meeting. So there were four official meetings about this undertaking. [Interviewer: Okay and who was at that meeting?] So that meeting was the ECE from her class, the OT, the PT, the school special education coordinator, the school psychologist and the principal. Speech was there, yes. I haven't seen them all in a year. She had no support through Senior Kindergarten whatsoever."

Most school-based SLP services described in our study are consultative in nature, rather than direct therapy, with recommendations for the educator to suggest strategies. The implementation of SLP strategies for school-aged children can hinge on educators' willingness to engage with recommendations and use them in the classroom. For example, one informant noted the importance of "buy-in" on the part of the teacher to use assistive devices (see Chung 2023 for further discussion of communication and other assistive devices).

In addition, speech and language can become the fulcrum upon which placement is determined. This means that other important aspects of the child's well-being are not being attended to, including participation in their own communities. For example, one child was moved to a Grade 1 speech and language class for one year and then moved back to their community school. Speech and language support, in this case, was perceived to be the most important goal, and the intensity of services was only offered in a segregated class/school.

8. The Discursive Disjuncture Between Institutions and Children's Everyday Lives

The organization of SLP services is of interest in our study for two reasons. First, its prevalence illustrates the possibilities for SLP discourses to hold some power over the construction of childhood disability and the governance of early childhood more generally. Second, it shows how families are positioned to *enact the needs of the service system*, rather than *having their needs met by the system*. This happens when there is a disjunction between systemic discourses and children's everyday lives.

SLP services are important in supporting children's speech and language development, but can also be implicated in the pathologizing of children's development in early childhood. The prevalence of SLP means that a large number of children participate in this service, whether or not they go on to other disability services, or identify as disabled later. Regardless of the intensity of service, speech and language becomes institutionally positioned as a site where disability identification and professional communication with families begins. Despite their own characteristics, identities, or future pathways, all these children and their families are exposed to the discourse of SLP professionals, a discourse

that is clearly situated in individual development and normative developmental research. It is important to recognize the power that SLP professionals hold in influencing how families think about their children's development and disability in general, and the influence they can hold over whether families ascribe to a medicalized or pathologized understanding of disability.

Because SLP is frequently one of the first early intervention sites for disabled children, the documentation of children's development in SLP services establishes some of the discourse that is linked to the construction of disability in the early years. Our analysis shows how this discourse can build over time with repeated engagement in clinical services from birth through the elementary school years. These assessments and clinical information then follow children into other early childhood education and care sites, as one informant noted:

> "There's a system, and they don't generally diagnose ADHD for anyone until the age of six because, there's that emotional development versus the diagnosis development. They don't proclaim kids to have a label when they could just grow out of it. She will not be growing out of it, I know that. It doesn't bother me for her to have a label. Um, but to ensure, that the--to have it in writing in that meeting to say that we need to discuss her ADHD diagnosis which will be coming and her teachers saying "yes there is no question, that that's an issue for us in the classroom" then it means that it's all on paper and they can't ignore it in terms of her level of support."

The prevalence and early entry point that marks SLP services in early years service systems means that it could be a site of disruption for discourses that value normative developmental trajectories to the exclusion of other ways of engaging with disabled children. There are examples of SLP practitioners who are disrupting the normative disability discourses that are embedded in this system (for example, Harriet Richardson, a neurodivergent, neuro-affirming SLP blogger, Richardson n.d.), but there is a need to disrupt the systemic ableism that is entrenched across many systems, including healthcare, education, and childcare, which rely on SLP services as a response to disabled children.

SLP services could take up a systemic role in recognizing important contextual factors in communication, language, and speech development. These include the community and identities influencing the language a child is learning, such as deaf communities, Indigenous communities, racial identity, and other cultural groups. Currently, SLP services are organized as a response to individual children. What is not recognized in the way that SLP services are organized is the many differences in children beyond their speech and language and the differences in families that allow them to do what is expected of them for their children to participate.

Speech and language are important for children's participation in their culture, social groups, and society, but the fact that SLP services are often delivered outside of the early childhood education and care system, through clinical or therapeutic settings, means that children are often separated from their community and peers to receive services, and the activities or knowledge of SLP programs are not integrated back into early education and care. In other words, children and families lose time in community programs learning from community members, and opportunities are missed to support all children's speech and language more broadly in early childhood education and care environments.

Developmental norms are evident in the informants' use of SLP terminology to classify their children's speech and language. For example, informants referred to expressive and receptive language and spoke about different speech and language assessments:

> "So [they] did the Test for Auditory Comprehension of Language. TACL-4. So vocabulary was moderate delay and he scored 4. Grammatical morphism was score of three, severe delay. And elaborative phrases and sentences was a standard score of 2 which is a severe delay with his receptive language."

This illustrates the family's immersion in the SLP discourse of norm-referenced child development. Children differ in the timeline for their development, but our research found

that families described these differences with assumptions that their children's language and communication inherently needed fixing.

Families are evidently aware of the requirement to categorize their child's language as impaired (or non-normative) as a mechanism to access services. Documenting delays, disorders, and milestones is informed by socio-political and cultural contexts. Some of the families in this study agree with these assessments, and some disagree with the construction of their children as impaired. In our study, we heard from many families whose worldview differed from this medicalized way of seeing their children (see Ineese-Nash (2020) for a fulsome discussion of Indigenous worldviews of childhood disability, and Snoddon and Underwood (2017) for a discussion of deaf childhoods). For some families, there is concern about how far "behind" their children are, and there is a sense of urgency to "catch up". This may be because of their concern that communication and language are foundational skills for participating in social and academic life, which should instead lead to an intervention response directed towards children's participation in communities, rather than interventions that remove them from community relationships.

Other families noted concerns about the goals that were being addressed in early intervention. There is social pressure around normative development which reflects a view that spoken language is better than other forms of communication including sign language or alternative forms of communication. Families may differ from SLP professionals in their desire to focus on spoken language, sounds and words, or reaching normative milestones. When families disagree with the inherent view of the Western medical paradigm, we observed that they may not participate in assessments or intervention services.

Further, how SLP services are organized leads to barriers in families accessing services. We have documented that the structural aspects of SLP and other clinical services are governed by assessments that serve the system, but not necessarily the child. Children having an SLP assessment, followed by no service delivered, or children having a few therapeutic sessions with a speech-language pathologist and being quickly discharged because they were assessed as being within a normal developmental range, were common experiences cited by informants. The often-cyclical nature of assessment as a qualifying criterion limits available resources and requires a lot of coordinating from families, often mothers. These assessments and documentation of deficits move children through referrals, but do not necessarily lead to access to services, or greater participation in early childhood programs and in community (Underwood et al. 2020). This is a process that (Nilsen 2017) and (Nilsen and Steen-Johnsen 2020) refer to as a feedback loop that reinforces particular discourses rooted in developmental norms, the discourse of rights to accessing services, and the social economy, but the loop is disconnected from the children themselves.

In our study, referrals for SLP came from parents' and guardians' self-referrals as well as from educators, medical professionals, and other therapists. In the case of self-referrals, most commonly made by mothers, we heard that the intake process can still act as a gate-keeper. Sometimes, the clinical intake leads to very short-term or minimal services, when parents are asking for more intensive intervention. In another example of the disconnect between parent and clinician perspectives, one mother was concerned about her son's speech and language, but there was no SLP referral pathway activated because the pediatrician did not agree. This experience was common in our interviews and shows how dismissive the health care system can be of family experiences. Our system is not set up to allow for these differences in experiences because funding, qualifying criteria, and services are organized around narrowly conceived clinical discourses, to the exclusion of systemic and relational approaches. There is no alternative pathway when this happens. SLP professionals and service systems can engage with institutional processes to disrupt the underlying ableism that positions individual children as disordered or deficient, and a system that excludes families who cannot participate in the expectations that are embedded in the procedures of SLP systems.

9. Discussion

Our research identifies that SLP is pervasive and is most often the first site of intervention that a child will access; it holds the possibility to disrupt the assumptions that are held across early childhood and disability services. This type of disruption could re-orient SLP towards disability justice with a focus on equity and the decolonization of services. Justice-oriented SLP would reduce the need for assessment as a qualifying criterion for access to services. For many children, SLP is a short-term therapy, and, given the prevalence of SLP, the services could be organized with universal access in mind. While some systems have attempted to enact this principle through self-referral, in reality, the system continues to have many barriers. Universal access would require embedding some SLP activities into community programs, with the goals of reducing the work families need to undertake to gain access, reducing the risk of missing out on community programs, ensuring greater access to services in rural, remote, and Indigenous communities, and delivering services in culturally appropriate programs with principles of self-governance applied, especially for Indigenous communities.

Further, our study demonstrates a disjuncture between the actual purpose of intervention—inclusion, relationships, and communication—and the experiences of these services. SLP is informed by clinical, not relational, approaches to communication and language development, and they hold a critical role in early childhood systems. Our interest in how the current professional discourse of SLP is activated in the lives of children and their families, and through them, into other early childhood spaces and relations, has illustrated the larger social architecture within which these services are situated. The informants in our study describe their children as situated within the discourse of developmentalism that governs early intervention, and lacks the contextual understanding of children in their communities and as active agents in their relational contexts (Nilsen and Steen-Johnsen 2020).

Given the prominent role of SLP in the early years, it offers the possibility to present to families, and to the community and other professionals, a broader set of values with relation to the diversity of developmental trajectories and the fact that there is tremendous variability in how people communicate and use language. There is a real need for SLP that engages with community, especially disability communities, and that recognizes the effects of ongoing colonization on children's development in the form of normative expectations for development and participation. Finally, one possibility is that SLP could engage directly with Indigenous Knowledges that promote a more holistic worldview with relation to children's development, language, and community than what is structurally designed into early years services at this time. We believe that disabled children's experiences, and those of their families, can help us to better understand ableism and inequality in early childhood and elucidate possibilities for action through a shift in SLP's professional practice. Our analysis identifies the possibilities for SLP to introduce these ideas into the lives of families and early years service systems.

For children who are accessing other intervention programs and disability services, or special education, it is very likely that they have accessed SLP at some stage in their childhood. The ongoing bureaucracy and management of services that are not designed to transition across ages and institutional contexts leads to an overwhelming workload for families. Our data indicate that it is also likely that children who are in precarious custodial relationships, especially child welfare or foster care, will have had some contact with SLP services. The documentation of children's development in SLP services can lead to discourses of disablement that are used in child welfare and family courts. Institutional expectations of children and their families in SLP services change over time and from institutional site to institutional site. Two key concerns are the cumulative effect of documentation on deficit in discourses of children as disabled. In addition, individual assessments often do not recognize the knowledge and experience that children and families hold from their engagements in these service systems over time.

The SLP profession has the potential to disrupt normative discourses and developmentalism through more holistic approaches to children's communities, relationships, culture,

and development. This can happen with an understanding of disability as a social and institutionally produced category, and active education on disability and ableism. The entrenched individual pathologizing in the system defines children's speech and language as "normal" or "disordered". Ultimately, the system as a whole perpetuates a medical model of disability without the recognition of the broader socio-political factors that are governing the relationships, communication, and development of children. This means that we look to differentiate what is normal and then we intervene to fix it (Haegele and Hodge 2016).

Understanding the structural function of one group of services, such as SLP, is not simply an opportunity to understand how policy is being performed. It also allows us to see how policy holds salient assumptions. Preschool speech and language services are part of a larger system of intervention services in the early years. This article examines SLP services as a site of the cultural production of disability in childhood. SLP also holds the potential to disrupt our normative and ableist constructions of disabled childhoods.

Ongoing research on how preschool and school-age speech and language services function to organize disabled children and their families by establishing disability discourses is warranted. The disjuncture between professional discourses and children's and families' experiences of childhood and disability in early intervention, early education and care, and school can inform future policy and practice. We conclude that speech and language programs have the potential to disrupt normative and ableist constructions of childhood. We emphasize how children's speech and language abilities emerge *in relationship with* individuals and socio-political contexts. We suggest that speech and language programs hold possibilities to disrupt particular ways of understanding disability that become entrenched in institutional processes and become hegemonic over time.

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