MAPPING THE EARLY INTERVENTION SYSTEM IN ONTARIO, CANADA

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This study documents the wide range of early intervention services across the province of Ontario. The services are mapped across the province showing geographic information as well as the scope of services (clinical, family-based, resource support, etc.), the range of early intervention professionals, sources of funding and the populations served by the services. Results of the study provide a picture of the range and scope of early intervention service in the province and identify variability of services across the province. The study highlights systemic variables that are of interest across Canada in early intervention practices, at a time when significant focus is on the importance of the early years, particularly for children with disabilities. The study aims to identify the scope of early intervention services across the province of Ontario. In the international literature on early intervention, there are frequent references to early intervention systems (for example in the Part C programs in the US, described by Bruder & Dunst, 2008). In Ontario, and other Canadian provinces, it is difficult to define one system of early intervention services. This is because early intervention has no federal guidelines or funding, and at the provincial level, there are is no defining legislation that ensures early intervention services or defines a system of services. Early intervention is a growing area of interest in research on special education and disability in educational settings (Guralnick, 2011). Interest in the early vears stems from the understanding that the years preceding elementary school-age are formative and learning in these years can set an educational trajectory for life (Willms, 2002). This is a deterministic view of child development, and ongoing research in early intervention is warranted. However, in some jurisdictions there is not a clear "system" of early intervention services, which makes it challenging to investigate the efficacy of these approaches. This study aims to identify both consistent and variable characteristics of a system of early intervention services in Ontario, Canada, which provide a starting point for analysis of systemic issues in early intervention practice. This mapping of services is designed to identify the scope of organizational characteristics that make up the early intervention system in Ontario.

What is Early Intervention?

Providing good quality early experiences is now widely accepted as important for human development (Camilli, Vargas, Ryan, & Barnett, 2010; McCain, Mustard & Shanker, 2007). In the case of children with disabilities early supports are all the more important because they can potentially prevent additional developmental difficulties and ameliorate existing developmental conditions. There is almost universal acceptance of EI as important for children with disabilities, although the type of EI programs that are best is sometimes contested. The World Health Organizations (WHO) classifies EI programs into primary prevention of disability, secondary prevention of additional impairments, and tertiary prevention to minimize the impact of disability. There has been a significant amount of research on the success of all types of EI programs and it is now widely accepted that EI programs are effective as a preventative measure (Guralnick, 2000; Guralnick, 2004; Feldman, 2004). Claims about the efficacy of EI programs include decreased referrals to special education programs and possible gains in developmental outcomes for all children in inclusive early childhood settings (Fuchs & Deshler, 2007).

Early intervention is multidisciplinary. This is an important difference from school age supports for children with disabilities and/or special educational needs. In schools, while there may be itinerant supports such as child and youth workers, social workers, speech and language pathologists, and psychologists, the primary service providers are teachers. In early intervention, services are provided directly by a range of professionals. Lindqvist, Nilholm, Almqvist, and Wetso (2011) have identified distinct differences in professional views of service delivery for children with disabilities. For example, Lindqvist et al. found that preschool teachers, teaching assistants, special education teachers, and special education coordinators vary in their beliefs about how best to meet the needs of children, where children should be placed in programs, how the programs should be delivered, and who should be delivering programs. In Ontario, there is no information about the prevalence of different professional groups serving children in early intervention services. Having knowledge of *who* is delivering services to young children can help us to better understand the professional knowledge, and attitudes that shape the early intervention system. It will be useful for advocacy, and for understanding the experiences of children and their families.

In addition to a broad range of professionals providing early intervention services, these programs and supports support children across a broad range of developmental domains. In this study, I refer to both "disability" and "special educational needs". Disability is defined here using the language of the Convention on the Rights of Persons with Disabilities, "disability is an evolving concept and [...] disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (UN, 2007, preamble). Disability refers to an interaction between and individual and other people or their environment. The early intervention system is one of these environments. The term disability, however, in my experience, is sometimes shied away from in early childhood, because young children may not have a diagnosis (of impairment as identified in the definition above), or they may not have experienced discrimination. Further, impairment in development can arise from adverse social conditions such as poverty, or exposure to harmful environments, and early intervention may be in place to prevent disability. The term *special educational needs* is used here to refer to the broader range of experiences that are addressed in early intervention.

Beyond the definitions of disability and special educational needs, this study seeks to identify particular categories of impairment or special educational needs that are supported within the early intervention system. Patel and Corter (2011) define early intervention services within three broad categories: clinical services, targeted services, and universal services. These categories, as described by Patel and Corter, serve different populations. Clinical services are designed for children with specific diagnoses or disorders; targeted programs are designed for children who are "at risk" or those with special educational needs as described above; and universal programs are those that are designed to support healthy development for all children (Patel & Corter, 2011, p. 2-3). The distinctions made by Patel and Corter highlight the variability in early intervention services. In Ontario, these distinctions are not clearly defined in the literature or in information for families. Each of these approaches has a distinctly different philosophical approach, and it is important for researchers and families to understand these differences in the early intervention system.

Considering the range of people working in early intervention, and the range of children and families who are served by the early intervention system is important, but this study would not be complete without also investigating how these services are funded. One of the reasons that the early intervention system is so fragmented is that there are multiple mechanisms for funding early intervention services. There is little information to tell us how many programs and supports are funded by private money, and how much control families have over their own services. This study also examines the funding structures in the early intervention system.

Objectives of the project:

The objective of this project is to identify the "early intervention system" in Ontario. The research question is: What is the breadth and scope of services that make up the early intervention (EI) system in Ontario? The study identifies funding sources, types of professionals working in EI and the populations being served by early intervention services across the province of Ontario. The resulting description of the early intervention system in the province provides a starting point for future research in early intervention, which has not been as broadly conceptualized in the past.

Early Intervention in Ontario: The Context

Federal funding and legislation in the United States has resulted in mandatory EI programs in every US state. While it is acknowledged that implementation of these services is sometimes uneven across the US, it is also clear that a formal system of EI as mandated by federal legislation has increased the number of EI services available to children with disabilities (Hanson, 2003). Canada does not have this type of legislation, in part because our education programs are governed by the provinces. However, it has been argued that we could and should have a federal mandate and funding for early childhood programs due to the significant effect these programs have on children's development (Cleveland, Corter, Pelletier, Colley, Bertrand, & Jamieson, 2006; Friendly & Lero, 2002). Currently in Ontario we have both formal systems for EI services through regional Infant and Child Development programs as well as an informal system delivered through other agencies and organizations such as children's hospitals, specialized agencies serving people with particular disabilities, rehabilitation facilities, and childcare settings. Thus EI services in Ontario are based on organizational initiatives rather than legislation. This system is similar to what is found in Australia (Johnston, 2003). Early intervention in Ontario is provided through a fragmented system of services and varied organizations in the province. Many of these services are funded through the provincial government. The Ministry of Children and Youth Services (MCYS) tracks children through data collected by agencies who MCYS funds. Additionally, organizations like the Ontario Association of Infant and Child Development (OAICD) through their own research and membership have a good understanding of where early intervention services are being delivered in the province. The challenge is that not all early intervention services are funded through the MCYS and membership in OAICD is voluntary. The data collected by the provincial government is not publicly available. Early Intervention (EI) is described in this study as those services that support children with disabilities in the early years of life, from ages zero to six years. These services primarily target children in the years before school entry, however, the study includes the transition from pre-school to school age and the changes or consistencies in the services as children transition to school. Children who access these services may have cognitive, linguistic, physical/motor. sensory or mental health disabilities, but they also have widely different social circumstances associated with their families and their communities.

Method

This study is exploratory in nature, as it aims to define a system that is yet undefined in the general literature. The study can be defined as an environmental scan, which is an approach used in a number of different sectors and is growing as a tool for understanding the organizational context for doing business (Albright, 2004; Muralidharan, 2003). However, there are no guidelines for conducting environmental scans of services for research purposes. It is therefore necessary to outline the steps taken in the scan.

This study draws on the methodologies outlined in systematic reviews of literature, in order to define the approaches taken to scan early intervention services. There are a number of different approaches to scanning literature, depending on the goals of the literature review. Adapting the purposes of "scoping studies", this exploratory study aims to better understand the scope of services in the early intervention system. Arskey and O'Malley (2003) in their framework for scoping studies, a methodological approach to mapping key concepts in literature, outline the purposes of these studies. They say that scoping studies: examine the range of research activity; determine the value of undertaking a more comprehensive full review; summarize and disseminate findings; and identify gaps. Adapting these four aims of scoping studies, this environmental scan examines the range of services, determines the value of a more comprehensive scan, summarizes the findings and identifies gaps in our understanding of early intervention services in Ontario.

The environmental scan was done using a systematic approach. Through access to publicly available information, the researchers gathered information about the following programs: 1) regional early intervention programs, 2) disability specific programs (autism, speech/language, hearing, mental health, physical disability, intellectual disability), and 3) professional organizations. Data sources included but were not limited to websites with lists of service agencies (eg. Ministry of Child and Youth Services, Ontario Association of Infant and Child Development, Children's mental health agencies, Children's Aid Societies, and Community Action Program for Children (CAPC) programs); personal experience with agencies; and online searches by population criteria (such as disability categories). Many of the websites included links to additional organizations. A database was developed to record information about the organizations and to identify attributes of the EI system, or the general characteristics based on the aggregate data.

Two research assistants (RAs) were employed in the study. These RAs were selected as a result of their professional experience in the system, working in larger multi-service agencies. Two phases of data collection were employed. The first search for organizations, who listed early intervention as one of their services, resulted in a database of 228 organizations. The second phase of data collection involved cleaning the data. The categories were revised, organizations were searched, and duplicates, which resulted from organizations being listed on multiple sites, or programs that were offered as part of collaboration between organizations, were consolidated and/or deleted. In addition, during the second phase of data collection, many additional organizations were identified. This systematic approach resulted in a database of 361 organizations. Missing data points indicate where public information was not available.

The findings are community level documentation of services, presented using maps of the province. Community level factors in work using the Early Development Index (EDI) have been linked to child outcomes across Canada (Janus, Hughes, & Duku, 2010; Janus & Offord, 2007; Lloyd, Irwin, & Hertzman, 2009). Mapping is a method that is borrowed from geography and has been very useful in understanding community level factors that contribute to outcomes for individuals. Mapping in particular has been useful in showing patterns of difference. For example, David Hulchanski's work has shown the changing demographics in Toronto since the 1970s with a dramatic polarization of income across the city (Hulchanski, 2010). These studies, as well as the study described in this paper, fit within the tradition of geographers who aim to understand human diversity and difference in relation to place (McDowell, 1995).

Using postal code data, each organization was assigned to a postal code zone and assigned to a region of the province. The frequencies are reported within five regions of the province: Eastern (postal codes beginning with K), Central (postal codes beginning with L), Toronto (postal codes beginning with M), Southwestern (postal codes beginning with N), and Northern (postal codes beginning with P). In future research, more sophisticated mapping technologies may be employed to better understand the options available to children and their families at the community level. It will be possible to compare rural, suburban and urban communities, in addition to regional comparisons.

Limitations of the study

The study does not include information about the number of children served in each organization. This means that the size of the organization is not accounted for in the analysis. This limits the interpretation of the frequencies, making it important to emphasize the range of choices available to children and their families over the number of services available. The reason this information was not collected is that in most cases it was not available from public information about the services. While information about the number of children and families services should be collected in future research through a questionnaire to each organization, the current study provides the database necessary to do a questionnaire.

At the time of this study (2009/2010), the provincial government and other community organizations had been doing a number of studies that involved questionnaires, which presented a risk of research fatigue in the community. These studies, however, have limits because they were designed to identify information relevant to the organizations who conducted the studies. A broader scan of the early intervention system for the purposes of research in the academic community is needed. The work of other organizations was used as a starting point for this study (see data source above). In addition to the timing of the study, the method of searching publicly available information ensures a more comprehensive scan, because it is not reliant on return rates of questionnaires, and the criteria for including organizations is not limited by criteria such as the funding agencies, or membership in a professional body.

Findings

The early intervention system in Ontario is characterized by widely diverse types of programs delivered by a range of service professionals. The range of services is in turn funded by many different sources, both public and private. The system serves many population groups including diverse geographic populations as well as children with particular diagnoses. The Early Intervention system does not serve children across populations with the same level of service. These findings are divided into the diversity of programs and professional affiliations; funding sources; and populations served.

Residential placement services rofessional Consultation Communication therapies School/childcare support 'arent support/training Mental health services Medical Treatment & 3ehavioural services hysical and sensory social work services 'legregated school/ Region by Recreational/social ase management postal code evelopmental ind Education ehabilitation sessment **Jiagnosis** BI/ABA, reschool eferral missing Eastern Central Toronto South-west North

Table 1. Types of Early Intervention Services by Region of Ontario

Diversity of programs and professional affiliations

The US based organization, Division for Early Childhood (DEC, of the Council for Exceptional Children) states that "inclusion, as a value, supports the right of all children, regardless of abilities, to participate actively in natural settings within their communities. Natural settings [...] include but are not limited to home, preschool, nursery schools, Head Start programs, kindergartens, neighborhood school classrooms, child care, places of worship, recreational and other settings" (Sandall, MacLean, & Smith, 2000, p.1). Does this mean that all services for children should be delivered in natural settings? The DEC statement on inclusion goes on to explain that services must support families and children to access these settings, but presumably the services do not need to be in these settings. In Ontario, services are sometimes delivered in natural settings but more often early intervention is delivered in centre based or clinical settings. These settings tend to have more intensive interventions but the outcomes are not necessarily better. Blackman (2003) says programs that support environmental adaptations by families, caregivers or teachers are as important as programs that target individual development in children.

Early Intervention happens in Ontario in traditional childcare and nursery school programs, kindergartens and primary grade classrooms as well as in special education or specialized intervention programs. Specialized programs are available through community based programs and family support programs as well as through clinical programs in health care settings.

A range of professional groups are associated with Early Intervention in different settings. These professions include but are not limited to Early Childhood Educators (ECE), Occupational Therapists (OT), Physical Therapists (PT), Speech and Language Pathologists (SLP), Physicians (MD), Psychologists, and Psychiatrists. Each of these professional groups has their own standards of practice and a tradition associated with the history of their profession. However, in many cases children are accessing services from a number of these professionals at the same time. In addition, there are many names used to describe this profession, including Resource Teachers, Developmental Consultants and Early Interventionists to name a few. The status and pay of these professionals also varies by the funding and administrative agencies. The result is that different programs may ascribe to very different philosophies of practice, which can result in children with similar characteristics receiving very different services. Differences in accessibility, quality and consistency of services may in turn affect inclusion of children with disabilities in our society.

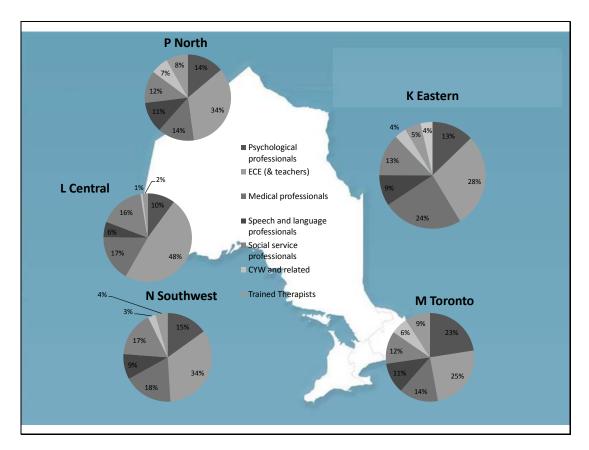


Figure 1. Professional Representation in Early Intervention Services by Region

Populations served

Early Intervention services may target a particular population or they may be delivered through universal programs. As described above, EI often happens in "natural settings". However, across the province many EI services target children with particular disabilities, cultural affiliations or in particular geographic regions. This may be a result of targeted funding. For example, the Ministry of Child and Youth Services has dramatically increased funding to intervention programs for children with autism compared to other disability categories, and yet many parents see autism supports as being inadequate (Ministry of Child and Youth Services, 2008). Funding will be discussed further in the next section of this paper. In the school years, most intervention services are delivered through the school system where the majority of services are delivered in school settings. This is a dramatic shift from the early years and may affect accessibility of services for families who experience disruptions. The transition from the early years to school age services is often the responsibility of families because of concerns about confidentiality and the lack of coordination amongst organizations (Janus, Lefort, Cameron, & Kopechanski, 2007).

It might be expected that services targeting children with particular diagnostic categories would have prevalence in proportion to the occurrence in the population. The Participation and Activity Limitation Survey (PALS, 2001) is the most recent available data on prevalence of disability in the Canadian population. The incidence of disability in for children from birth to four years (as reported in Government of Canada, 2006) was 1.6%. Of these children, 12% had disabilities related to hearing, 8% seeing, 63 % chronic illness including asthma, allergies, complex medical conditions, cerebral palsy, autism, heart conditions, and spina bifida, 68% developmental delays, and 8.9% had disabilities of an unknown origin. One would expect services to exist in proportion to the prevalence of disability in the society. However, from our data to date, it appears that the majority of services are for children with communication disorders including speech and language services and services for children with autism. This should be investigated further.

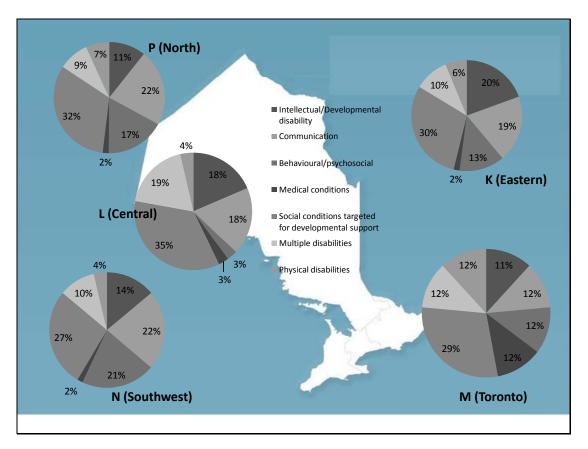


Figure 2. Prevalence of Services for Children with Diagnosed Disability Category by Region Funding

EI services are funded through a variety of sources. Across the EI system there are four different Ministries of the provincial government who provide funding depending on the age the children and the type of service. These provincial funds are administered by multiple agencies and organizations with vastly different philosophical orientations. The four government ministries include the Ministry of Child and Youth Services, the Ministry of Community and Social Services, the Ministry of Health and Long-Term Care and the Ministry of Education. The funding for Early Intervention services is administered differently from each source resulting in some sources of funding being accessed directly by families, but the majority of funding being administered through the agencies providing the services. In addition to funding from the province, many of the organizations who provide Early Intervention are supported by private donations and direct fundraising campaigns. This has implications for setting policy across the EI system.

Discussion

Frankel (2004) notes that there is a public policy framework in Canada that supports inclusive practice in early childhood education and care. However, in practice Frankel identifies three factors that can either support or deter inclusion. These are government funding, staff training and attitudes, and resource supports and consultative services (Frankel, 2004). These barriers are evident in the findings of the study given that there is variability across the province in all three areas. Similarly, Killoran, Tymon, and Frempong (2007) found that, despite the policy context, the majority of Toronto pre-schools are not inclusive of children with disabilities. Killoran et al findings that the barriers to inclusion are largely related to availability of resources and attitudes of centre directors is consistent with research by Irwin, Lero, and Brophy (2004) that found similar barriers across Canada.

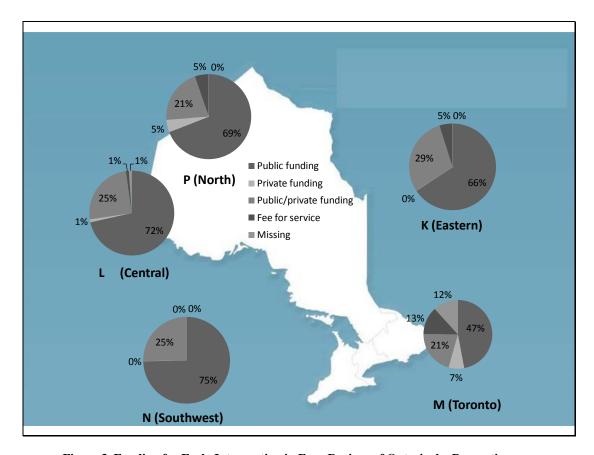


Figure 3. Funding for Early Intervention in Four Regions of Ontario, by Proportion

The findings of the study indicate a degree of variability in services in several areas: where funding comes from, who is delivering the services and how the services are designed and for whom. This variability means that children and families in different parts of the province may be having very different experiences. It is important for families and service providers to understand the variability in the system in order to target advocacy and lobbying efforts to ensure that children have the supports they need. The range of professionals and funders in the province provide a starting point for policy makers, researchers, and families to identify where to target their efforts when trying to bring about change, or to conduct research, in the early intervention system.

Additionally, this type of information provides a framework for understanding the many programs that are supporting children in early intervention. Research in early intervention in Canada has tended to focus on a few high profile programs that have been documented by researchers (Patel & Corter, 2011). These programs have been very important in supporting public policy in the early years and in education. However, the studies that focus on specific programs do not necessarily illustrate the scope of supports and services in the early years in the province. The lack of information about early intervention services may put these programs at risk if the public do not see the value of investing in them.

Future research in this area should expand the scope of understanding by collecting information about outcomes and documentation of successful programs and services. Individual family experiences should also be documented with a focus on equity, and the effects of political trends on the services available in the province. Finally, issues of transition to school should be understood better in relation to the variability in early intervention services identified in this study. More sophisticated mapping techniques will allow evaluation of community factors such as population density, affluence of the community, and achievement levels in schools. Funding should also be tracked over time to assess impact of political decisions on targeted funding for particular types of service and outcomes for children and families.

With an expanded scope, a better understanding of the early intervention system will allow strategic decisions to be made for the province. This work builds on the local knowledge that is embedded in many of the programs and services that are in place. Additionally, a better understanding of the early intervention system in Ontario may allow better communication with schools.

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