WAITING LISTS AND WAITING TIMES

FOR

EARLY INTERVENTION THERAPIES, INFANT DEVELOPMENT PROGRAMS

AND SUPPORTED CHILD DEVELOPMENT PROGRAMS IN BRITISH COLUMBIA

by

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ABSTRACT

Children at risk of developmental delays or disabilities require intervention services to enhance their growth and development. Long waits to obtain these services are a concern to both parents and service providers. The purpose of this research was to investigate the nature of waiting lists and waiting times within the context of selected early childhood intervention services in British Columbia (BC).

This study utilized qualitative and quantitative data (questionnaires, focus groups and administrative data) focusing on referral and intake information for infant development programs (IDP), supported child development programs (SCDP), physiotherapy (PT), occupational therapy (OT) and speech-language pathology (SLP) services.

Data availability posed a significant challenge in this study. Overall, this study demonstrated that most children referred in 2003 and 2004 have experienced some degree of waiting for these services in BC. Specifically provision of SLP and OT services faced a consistent challenge with regard to waiting times. Furthermore, waiting times varied widely across programs and regions; estimated median wait times in this study ranged from 12 days (95% CI, 7.31-16.69 days) for SCDP to 180 days (95% CI, 62.84 – 297.16 days) for OT. The median wait times for IDP, PT and SLP were estimated to be 70 (95%CI, 55.61-84.39), 57 (95%CI, 41.97 -72.03) and 112 (95% CI, 108.0 – 115.90) days respectively.

Wait time variations for IDP and SLP services were also analysed by Cox regression. Inter-agency and regional variations in wait times persisted after adjusting for child factors. Agencies' characteristics explained some of the wait time variations across agencies and regions. Variability in wait times due to demand changes (i.e. changes in the population and awareness of services) was also suggested. Referral by family was consistently associated with shorter wait times than referral by professionals.

A common framework of identifying various waits along the service pathway emerged through focus groups. Further research on wait time definitions and improvement of data system to address the gaps in data availability in this field is urgently needed. These findings offer policy-makers some useful insights into developing tools for managing and monitoring waiting times for early childhood intervention services.

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BC	British Columbia
BCACDI	British Columbia Association of Child Development and Intervention
95% CI	95% Confident Interval
CDC	Child Development Centre
CPABC	Cerebral Palsy Association of British Columbia
EIT	Early Intervention Therapy (PT, OT and SLP)
HR	Hazard Ratio
ICF	International Classification of Functioning, Disabilities and Health
IDP	Infant Development Program(s)
IQR	Inter-Quartile Range
LBW	Low Birth Weight
LINKED-DISC	Linked Information Network for Kids Electronic Database – Developmental and Intervention Services for Children
NIDCAP	Newborn Individualized Developmental Care and Assessment Program
NDT	Neurodevelopmental Treatment
MCFD	Ministry of Children and Family Development
MOH	Ministry of Health
OT	Occupational Therapy
PH	Public Health (Unit or Centre)

PT	Physiotherapy
SCDP	Supported Child Development Program(s)
SLP	Speech and Language Pathology
SWL	Surgical Waitlist Registry

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CHAPTER 1

INTRODUCTION

Every year in British Columbia, over 10,000 infants and young children living with or at

risk of developmental delays or disabilities require extra supports to help them meet the

physical, intellectual, communicative, behavioural, and social challenges through early

childhood intervention (MCFD, 2006). Early childhood intervention generally refers to

any "non-medical and non-protection" but primarily "developmental" services that are

used to assist infants and young children with special needs and their families (Brynelsen

et al., 1995). The objective of early childhood intervention is to provide access to these

services as soon as possible once concerns about the child's developmental status have

been raised. Research has demonstrated positive effects of early childhood intervention in

reducing the likelihood of secondary disabilities or potential adverse developmental

outcomes later in life. If a child must be on a lengthy waitlist before receiving services,

he or she will completely miss an opportunity or experience delays in receiving the full

benefit of early childhood intervention. Waiting lists and waiting times for early

childhood intervention services have not been studied widely despite the recent surge in

health care waitlist literature in Canada. This study will examine the issues and the

current state of knowledge regarding waiting lists and waiting times for early childhood

intervention services in British Columbia. The early childhood intervention services in

this study include infant development program, supported child development program,

and early intervention therapy services (physiotherapy, occupational therapy and speech-

language pathology) provided to children living with or at risk of having developmental delays or disabilities from birth to 6 years of age in British Columbia.

1.1 WHAT DOES EARLY CHILDHOOD INTERVENTION MEAN?

The range of programs and services available to infants and young children with or without special needs varies considerably across Canada and elsewhere.   Thus, different nomenclatures regarding early childhood development and intervention exist depending on whether the programs and services have a focus on prevention, education, and/or health promotion (Choi, 2002; Little, 1999). The terms "early childhood intervention" and "early childhood development" are sometimes used synonymously. Both terms embody programs and services that attend to the health, education, nutrition and social development of young children (Anderson et al., 2003; Bailey et al., 1999; Britto & Gilliam, 2008; Choi, 2002; Currie, 2000; Reynolds et al., 2004). Early childhood development may be seen as an umbrella term encompassing promotion, prevention, and intervention approaches in coordinated health, education, and social services for ensuring the wellbeing and holistic development of all children from the prenatal period to school entry (Britto & Gilliam, 2008; Choi, 2002; Little, 1999). However, not all early childhood development programs and services are early childhood intervention. Attendance in a preschool or daycare program, for example, can be seen as enhancing early childhood development but not as, per se, early childhood intervention. The universal programs of early childhood development often refer to services consisting of different combinations of nutrition services, prenatal care, family supports, early childhood education, and/or childcare for all children under the age of 6. Some of these programs are designed to

enable parents to remain in the work force, to prepare children for school entry, to teach

new parents/caregivers parenting skills, and/or provide social and peer interaction for all

young children. Regulated centre-based child care programs, kindergarten, Aboriginal

Head Start programs[1], preschool/nursery schools, neighbourhood playgroups, prenatal

nutrition programs, and family resource programs make up a large part of the early

childhood development programs and services in Canada (Beach & Bertrand, 2000).

For children with known special needs or for children who are at risk of developmental

delays or disabilities, specialized programs and services are available to provide extra

supports to meet their specific clinical and developmental needs. These are the "early

childhood intervention" programs and services. Early childhood intervention programs,

like early childhood development programs, are designed to promote the social,

emotional, intellectual, and physical growth of children but are targeted on different areas

of development and populations (Anderson et al., 2003; Bailey et al., 1999; Goelman et

al., 2005; Guralnick, 2001; Majnemer, 1998; Parry, 1992).

The exact definition of early childhood intervention also varies depending on the program

philosophies and target populations. Individual programs differ considerably, but, in

general, they involve coordinated multidisciplinary or transdisciplinary[2] input by health,

education, therapy, and social services to special needs children and their families as well

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[1] Head Start programs in the U.S.A. are designed for children at risk of developmental delays due to environmental factors. In Canada, the Aboriginal Head Start programs are designed as culturally-appropriate early childhood development programs and are not conceived as intervention programs targeting children who are at environmental risk of developmental delays.
[2] Transdisciplinary approach: Several professionals provide integrated services to the child/family with one person acting as the service coordinator (or the key worker). Multidisciplinary approach: Different professionals work with the child/family independently of each other (Moore, 2005).

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as children at risk due to socio-economic factors such as poverty. These programs provide individualized health and developmental services to children and supports for their families. The provision of individualized services is one of the important features that differentiate early childhood intervention from the broader definition of early childhood development. Programs can deliver services directly to children or work indirectly with them by focusing on their parents or other caregivers. Some programs do both (Gray & McCormick, 2005).

The phrases "early intervention" and "early childhood intervention" have also been used interchangeably by some authors and have, thus, been defined differently. This may be due to the inconsistency in defining the term "early" in early intervention. The term may mean early in a child's life or early in the onset of developmental concerns (Little, 1999). The European Agency for Development in Special Needs Education thus defines these two terms more distinctly to avoid confusion with the general concept of "early intervention" (European Agency for Development in Special Needs Education, 2005). They define "early intervention" as necessary action or intervention provided as early as possible to any children during any time of their education (from preschool to about age 19) whereas "early childhood intervention" has a focus on young children with special needs from birth until a maximum of six years of age.

Shonkoff and Meisels (2000) have also defined early "childhood" interventions as multidisciplinary services provided to children from birth to 5 years of age to promote special needs children's health and well-being, enhance their emerging competencies,

minimize developmental delays, remediate any existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning. These intervention goals are achieved through individualized and mutually agreed upon strategies (between families and service providers) and service plans provided by child developmental programs, clinical and educational programs, and therapy services (Shonkoff & Meisels, 2000).

According to Guralnick's Developmental Systems Model, the central goal of early childhood intervention is to optimize three key family patterns of interaction so as to improve the developmental outcomes of affected children (Guralnick, 2001). The three patterns of interaction include: (1) Parent-child transaction such as warm social exchange between parent and child; (2) Parent orchestrated child experiences such as providing appropriate learning materials to suit the child's needs and interests; and (3) Parents ensuring health and wellbeing of their children such as receiving appropriate immunizations and proper nutrition, and protecting them from harm.

In Canada, early childhood intervention is also traditionally referred to as multidisciplinary programs and services provided to children from birth to 5 years of age who have known developmental challenges or are at risk of delays because of physical and developmental disability or psycho-social factors (Goelman et al., 2005; Marfo & Cook, 1991; Panitch, 1993). Early childhood intervention in Canada also encompasses a broad variety of service models and principles. These principles include but are not limited to the philosophies of family-centred practice, community and home based

service delivery, community inclusion principles, and multidisciplinary teamwork approaches.

In summary, the common themes regarding the definition of early childhood intervention include:

1   Targeting infants and young children aged birth to school entry,

2   Identifying developmental delays or disabilities of children at an early stage,

3   Enhancing children's emerging competences and functioning,

4   Maximizing vulnerable children's potential to learn,

5   Preventing further functional deterioration by minimizing the likelihood of secondary disabilities and potential delays in other areas,

6   Promoting overall family functioning, resilience, and the adaptation of caring for a child with disabilities,

7   Supporting families so as to enable them to meet the needs of their child as effectively as possible,

8   Promoting the health and well-being of affected children and their families, and

9   Promoting social inclusion of both children and families.

Ultimately, the goal of early childhood intervention is to maximize every child's ability to take part in activities independently and to participate fully in his or her home, school, and community. In this study, the term "early childhood intervention" will be used to identify programs and services provided to young children aged from birth to school entry (or aged 6) who have shown the first signs of physical and developmental

challenges and who are at significant risk of developing delays and disabilities due to biological, medical and/or socio-environmental factors.

Who can benefit from early childhood intervention?

Children requiring early childhood intervention may have well recognized chronic health conditions and/or rare genetic disorders or developmental disabilities such as cerebral palsy. Early childhood intervention services also provide supports to families and their children who are at risk of developmental delays due to, for example, prematurity and birth complications or other undiagnosed reasons. Some programs assist children who are at risk due to social and environmental factors such as living in disadvantaged families. The above represents the three broad target populations for early childhood intervention (Guralnick & Bennett, 1987; Majnemer, 1998).

In order to understand the service provision system for early childhood intervention, a common understanding of the terms "children with special needs," "developmental disability," "developmental delay," and "impairment" is required. The term for children with special "health care" needs has a very broad connotation. It includes children with chronic health conditions and children with developmental challenges and physical disability. In 1988, the US Federal Maternal and Children with Special Health Care Needs working group defined children with special health care needs as follow:

Children with special health care needs are those who have or are at

increased risk for a chronic physical, developmental, behavioural, or

emotional condition and who also require health and related services

of a type or amount beyond that required by children generally.

(McPherson et al., 1998)

In this definition, the risks refer to both biological and environmental. Biological risks include pathological and physiological abnormalities that have been shown to increase the likelihood of the future onset of chronic conditions or developmental problems. Examples of biological risks include low birthweight and existence of chromosomal or genetic abnormalities. Environmental risks are those social and economic factors as well as other characteristics of the child's environment that have been demonstrated to place a child at increased likelihood of developing chronic physical, developmental, behavioural or emotional conditions (McPherson et al., 1998). Examples of environmental risks are extreme poverty and placement into government care. The term children with special "health care" needs thus include children living with chronic health conditions such as asthma, diabetes, and childhood cancer; children living with a developmental disability (or delay) such as intellectual impairment, learning disability, Autism or Down's syndrome; and children living in a disadvantaged environment.

The term developmental disability is used to describe children with chronic disabilities relating to a child's development which results from mental, physical, and/or other health impairment or disability (Marfo et al., 1988; Sonnander, 2000). The World Health Organisation (1976) (WHO) describes "impairment" as any loss or abnormality of psychological, physiological or anatomical structure, or function. However, "disability" is referred to as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (World Health Organisation, 1976). The word handicap, a term not in common use now, refers to a disadvantage for a given individual, resulting from an impairment or a disability, that prevents the fulfillment of a role that is considered normal (depending on age, sex, and social and cultural factors) for that individual. Thus, developmental disability is another broad term of chronic conditions including intellectual disability, learning disability, emotional disturbance, hearing impairment, deafness, and visual impairment (Marfo et al., 1988; Sonnander, 2000). These impairments manifest themselves in significant functional limitation in academic skills, receptive and expressive language skills, social skills, mobility, self-care, and capacity for independent living. Down's syndrome, cerebral palsy, autism and spina bifida are among the well recognized conditions under this definition.

Disability has also been redefined by the International Classification of Functioning, Disabilities and Health (ICF), a new framework for measuring health and disability at both individual and population levels developed by the World Health Organisation[3]. ICF defines disability as the outcome of the interaction between a person with an impairment

[3]ICF at WHO website: http://www.who.int/classifications/icf/en/. Accessed on September 7, 2007

of body function and/or body structure and the environmental and/or attitudinal barriers a person faces. The outcome of the interaction includes limitations of activities and/or restriction of participation.

Developmental delay is a term used to describe children presenting signs of a slower rate of meeting development milestones in one or more areas of development (Marfo et al., 1988; Petersen et al., 1998). Children with developmental delay usually exhibit no clear signs of associated physical or biological impairments. The delay usually can be identified at any time between the age of birth and five.

Historical Perspectives of Early Childhood Intervention

Prior to the mid 1960s, the common practice of caring for children with developmental disabilities was mostly in hospitals or in a similar institutionally based program with the hope that these children could undertake some learning and skill development. If families chose to care for their children at their own home, they however received little support from government or society. Similarly, children living in extreme poverty and lacking appropriate stimulation did not have any form of intervention prior to entering school (Erickson & Kurz-Riemer, 2002; Panitch, 1993)

Early childhood intervention programs began as research projects and as part of the parent advocacy movement. In Canada, the development and implementation of early childhood intervention programs were largely influenced by the changes of attitude towards people with developmental disabilities and by parent advocacy movements for

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community-based programs for children with developmental disabilities (Panitch, 1993). The concepts and theories of early intervention are rooted in the belief that intervening in the early years will have a significant impact on development later in life. Most early childhood intervention programs emerging in the early 1970s in Canada were based on the service modalities designed for environmentally at risk or culturally disadvantaged children (Marfo & Cook, 1991). One of the most influential educational programs relating to the development of early childhood intervention programs was the experimental project Head Start in the United States. Head Start began in 1965 as a special education program aiming to prepare socially and economically disadvantaged young children (generally African American children) early in their life in order for them to succeed in school (Zigler & Berman, 1983).

In the 1970s, substantial changes occurred in policy and program delivery in Canada and the United States. In Canada, parents and service providers were able to advise how resources were allocated for non-institutional care for children with developmental disabilities through the Canada Assistance Plan which was based on a 50% cost sharing program between federal and provincial governments (Panitch, 1993). In the United States, a series of legislative changes emerged regarding education for all children with or without developmental disabilities such as the Public Law 94-142 (Education for All Handicapped Children Act) mandating that all children with disabilities be guaranteed a free and appropriate public education (Erickson & Kurz-Riemer, 2002). These initiatives arose from the broad concept of normalization. This act was later renamed as Individuals with Disabilities Education Act (IDEA) in 1990. In 1997 the act mandated all states to

serve children with developmentally delay or with a diagnosed condition that would

likely lead to developmental delay. During this period of policy change, early childhood

intervention programs began taking shape. Similar legislation, however, remained absent

in Canada, and many programs emerging in the 1970s had little funding or involvement

from all levels of government (Goelman et al., 2005; Marfo, 1991; Panitch, 1993). In

British Columbia (BC), the Cerebral Palsy Association of BC (CPABC) was first

established in late 1948 by a group of concerned parents who advocated for better

supports for their children living with Cerebral Palsy. Community based child

development centres across the province began to emerge in the 1960s and became

members of CPABC in the 1970s[4]. The Ministry of Health (MOH) funded CPABC,

which in turn, distributed funding to child development centres. However, the majority of

funding sources came from donations. In 1982, child development centres began

receiving funding directly from the MOH for therapy programs. With the creation of the

Ministry of Children and Family Development (MCFD), funding for early childhood

intervention services, for the most part (except for specialized and subspecialized services

such as new born hearing screening, and autism assessment), moved from the MOH to

MCFD.

1.2 EFFECTIVENESS OF EARLY CHILDHOOD INTERVENTION

Human development is described as a life course with a pattern of changes that begins at

conception and continues through adulthood (Hertzman, 1999; Hertzman & Wiens,

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[4] BC Association of Child Development and Intervention webpage:
http://www.bcacdi.org/history.html Accessed on May 24, 2007

1996). The continued interaction between the central nervous system and its environments determine the health and condition at each stage of development. Animal studies (Hubel, 1979) and advances in neuro-imaging (Nelson & Bloom, 1997) have supported the conceptualization of neural plasticity of the human brain. It has also provided substantial empirical evidence to support the view that environments and early year experiences are able to shape human developmental processes. The importance of development in early years, thus, forms the basis of early childhood intervention. The following sections will provide an overview of the theoretical rationale for early childhood intervention, and the effectiveness of early childhood intervention.

Theoretical Basis of Early Childhood Intervention

The theoretical basis of intervening at the earliest age came from developmental science and neuroscience which stress the importance of early years for a developing child. This approach was based on the key and related concepts of neural plasticity and critical periods (Bailey et al., 2001; Nelson & Bloom, 1997). It is now generally agreed that the process of neural plasticity is bounded by time; that is, several critical (sensitive) periods exist during which certain neural functions can be altered. Children who are at risk of developmental delay or who are living with a disability have differences in their neural-functional development. Interventions are designed to bring their functional development back to the normal or close to a normal developmental trajectory.

The view of neural plasticity signifies that a developing brain possesses overproduction of neuronal connections (synapses); these are later pruned according to the experiences

and environments to which a child is exposed (Greenough & Black, 1992). Thus, early intervention takes the advantage of neural plasticity (Nelson, 1999; Nelson & Bloom, 1997). The concept of sensitive periods states that in order to achieve the maximum potential, experiences must occur during a certain window of time according to the child's developmental milestones (Farran, 2001). During the course of early human development, several critical periods exist. Some of these critical periods are within a short time after birth. For example, sensory developments such as vision, hearing, and language for which external stimuli are needed, appear to occur within a narrow window of time during the early years. Beyond this window, more effort and more intense stimuli are required for the development of senses or learning new and complex skills. The general consensus has concluded that different windows of development open at different times. The developmental milestones for each child should be considered individually when designing intervention, and it should target the affected areas according to the developmental stages as soon as possible.

Despite the concept of sensitive periods of development, the exact timing of intervention has been a subject of heated disagreement, even though literature suggested that intervening at the earliest time is a critical factor of optimal developmental outcomes (Majnemer, 1998; Marfo & Cook, 1991). However, studies specifically evaluating the effects of specific ages at enrolment in intervention and, thus, demonstrating the effectiveness of early intervention at various ages have been inconsistent (Casto & Mastropieri, 1986). Moreover, even the concept of "early" in early childhood intervention has been questioned. For example, a meta-analysis conducted by Casto and

Mastropieri (1986) on studies involving children with diagnosed developmental disabilities and delays from birth to age five did not support the notion that earlier is better. The results of this meta-analysis indicated that later enrolment in some interventions was actually associated with better outcomes. The results were in stark contrast to the then common (and contemporary) belief that earlier is better. However, children in the studies under review by Casto and Mastropieri (1986) were mostly diagnosed with intellectual disability (44% of children), and the majority of outcome measures involved IQ. As a result, generalization from these studies to other conditions requires considerable caution. Another analysis of a subset of the same data focusing only on the birth-to-3-year-old group by Shonkoff and Hauser-Cram (1987) revealed a different conclusion. For the more mildly delayed children, better outcomes were observed if they were enrolled at an earlier age (Shonkoff & Hauser-Cram, 1987).

Sharkey et al in 1990 examined the age of referral and the effect of early childhood intervention for children with primarily physical disabilities due to cerebral palsy. This study compared developmental competences (such as fine/gross motor function, self-care, language, and cognition) of children referred before 9 months of age with those of children referred after 9 months of age. The results showed that children enrolled earlier did benefit more from the intervention (Sharkey et al., 1990).

In a more recent study, Moeller (2000) examined the relationship between the age of enrolment in an intervention program and language outcomes at 5 years of age in a group of deaf and hard-of-hearing children. Significantly better language scores were associated with early enrolment especially with high levels of family involvement (Moeller, 2000).

Although family involvement might be a confounder in this study, the finding suggested the importance of starting intervention early for language development.

A paucity of research exists focusing on the optimal timing of intervention for specific diagnoses or target populations. Most suggest that the exact timing needs to be considered in the context of the specific disability group as well as types of intervention (Guralnick, 1991; Moeller, 2000). Once a developmental deficit is identified or is known to likely emerge in the future, age appropriate early intervention should be provided as soon as possible. For example, an infant, diagnosed with Down's syndrome at birth, is referred to a child development centre at 3 months of age. Direct speech therapy, however, would not be appropriate at this age, although indirect speech services such as consultation with parents regarding language stimulation could begin when the child reaches about 6 months of age.

Evidence of Effectiveness and Efficacy

In order to make sound decisions about intervention practices, clinicians and decision makers need to distinguish between the efficacy and effectiveness of an intervention. Efficacy refers to the impact of an intervention in a clinical trial or other ideal conditions while effectiveness refers to the impact of an intervention in real world situations (Gartlehner et al., 2006). Efficacy is high on internal validity. That is a measure of what a treatment intervention is supposed to do for a given illness or health condition in a vigorously controlled study environment. High internal validity is usually achieved at the

expense of generalizability (external validity). Effectiveness, on the other hand, is high on external validity but at some expense with some loss of internal validity. Generalizability is often difficult to achieve when intervention involves long and complex causal pathways because responses to intervention can be affected by the characteristics of the target population, service delivery systems, and environment as well as timing of intervention- consistent with the critical period theory (Eayrs & Jones, 1992). This is especially true when evaluating early childhood intervention programs.

For years, evidence on the effectiveness of early childhood intervention services for children with developmental disabilities was based largely on the findings extrapolated from the literature of early intervention programs designed for environmentally at risk or culturally disadvantaged children (Marfo & Cook, 1991). Numerous reviews on the effectiveness of early childhood intervention programs have generally concluded that children participating in these programs consistently performed better in all developmental domains (Currie, 2000; Guralnick, 1998; Majnemer, 1998; Ramey & Ramey, 1998; Campbell & Ramey, 1994; Guralnick & Bennett 1987; Shonkoff & Hauser-Cram, 1987). This finding is especially true for educational based intervention programs such as the Head Start.

However, children requiring early childhood intervention services generally are (i) those who are at risk of developmental delay due to social and environmental factors, (ii) who are at risk due to medical and biological factors, and/or (iii) who have well recognized disabilities (Guralnick & Bennett, 1987; Majnemer, 1998; Marfo & Cook, 1991). The

following overview of evidence on the efficacy and effectiveness of early childhood interventions are organized by the types of target populations.

Children at Risk of Developmental Delay Due to Social and Environmental Factors

Children who are at environmental risk do not usually exhibit significant developmental delays at the time of entry to early childhood intervention programs; rather, they are referred because their social and/or economic circumstances are associated with a higher probability for developmental delay. Children who are living in disadvantaged environments have an increasing risk of developing learning difficulty and social problems later in life (Ramey & Ramey, 1998). Children in this group might be those born to parents with substance abuse issues and those whose parents are mentally disabled (Meisels & Shonkoff, 2000). Poverty alone can also lead to poor school performance, cognitive functional delay, and poor behaviour and social skills (Eayrs & Jones, 1992; Ramey & Ramey, 1998). Early childhood intervention for this group of children is usually based on preschool educational programs with a developmental focus. The aim is to prevent placement in special education and/or grade retention. Although interventions aimed at children in poverty and disadvantaged families have a long history, not all intervention programs produced the same effects (Currie, 2000).

In a review of early childhood intervention programs with an emphasis on school readiness, Currie (2000) concluded that intervention in the form of educational programs for at risk (environmental risk factors) children have a long term positive impact

especially for children enrolled in the experimental or model programs. Short term

benefits were also found in children enrolled in public-funded programs such as Head

Start. The greater the economical disadvantage, the greater the gains made through these

types of early childhood intervention although the effect of regression to the mean has not

been discussed in these studies.

A systematic review of intervention effectiveness conducted by Anderson et al. (2003)

also provided a strong body of evidence suggesting that centre-based early childhood

intervention programs can prevent developmental delay for children at risk due to

environmental factors. The benefits were seen primarily in children's cognitive

development. In general, children enrolled in these preschool special programs are less

likely to repeat a grade or need special education (Anderson et al., 2003). One of the best

examples is the Abecedarian Project, a carefully randomized control study. Four cohorts

of families were enrolled between 1972 and 1977. Fifty seven infants from low-income

families were randomly assigned to receive intervention in a high quality child care

setting, and 54 were in a non-treatment control group. All children were without any

apparent health issues and were recruited at early infancy from low-income families. The

project followed these children over 20 years. Assessments were conducted when they

turned 12 and 21 (Campbell et al., 2001; Campbell & Ramey, 1994). At age 12, children

in the intervention group showed a non significant trend of reduced placement in special

education. At age 21, the cognitive functioning, academic skills, educational attainment,

employment, parenthood, and social adjustment were assessed for 104 of the original 111

infants (53 from the intervention group and 51 controls). Those who received

intervention scored significantly higher on tests of reading and mathematics from the primary grades through middle adolescence. Effect sizes for reading (d=1.40) were large while those for mathematics (d = 0.86) were moderate to large according to the Cohen's Standard when pooled sample standard deviations were used to estimate the effect sizes (Cohen, 1988).

Children at Risk of Developmental Delays Due to Medical and Biological Factors

Children with biological risk factors for developmental delays include children who are born prematurely and/or with low birthweight. These children are usually at an increased risk of co-morbidities due to complications such as respiratory distress and intraventricular haemorrhage. They are more likely to have delays in motor, communication and cognitive development at the time of school entry (Campbell & Ramey, 1994; Marlow et al., 2005). Intervention for this group of children usually has a focus of mitigation which involves helping children acquire necessary skills to minimize long term effects of specific risk factors (Majnemer, 1998). Early childhood intervention should be initiated before impairments become fully manifest. Results from a number of randomized control studies of various programs for children at risk of developmental delay due to biological factors revealed only modest effects from these interventions especially for the motor development (Brooks-Gunn et al., 1993; Johnson et al., 2005; Rauh et al., 1988).

Intervention in the form of mother-infant interaction for low birthweight infants (below 2250 grams) was studied in a randomized control trial (Rauh et al., 1988). Seventy-eight mothers of low birthweight (LBW) infants were recruited and randomly allocated to intervention (n=38) and control (n= 40) groups. The intervention consisted of 11 sessions, beginning during the final week of hospitalization and extending into the home over a 3-month period. The intervention program aimed to facilitate maternal adjustment to the care of a low birthweight infant through mother-infant interaction exercise. Follow-up information was available for 54 LBW children (25 LBW experimental children, and 29 LBW control children). When assessed at aged 4 with the McCarthy Scales of Children's Abilities, children of families receiving intervention had significantly improved cognitive development. Mean McCarthy cognitive scores obtained by the LWB control group were significantly lower than those of the experimental group children (control= 98.7 vs experimental= 111.6, F=8.82, p< 0.05). Similar trends were also observed when assessed with Bayley Scales of Infant Development-Mental Developmental Indices at 6, 12, and 24 months of age although the differences were not significant. The study also illustrated that mothers of the experimental group were also better adjusted to care for their low birthweight children. The experimental group mothers reported significantly greater self-confidence and satisfaction with parenting.

The Portage Intervention Model is a parent-mediated early childhood intervention program for children with special developmental and/or educational needs. It aims to prepare parents with skills and confidence to care for their children (Cameron, 1997). Each family is visited weekly by a variety of professional groups, including early child

educators, health nurses, family service workers, and therapists. Parents are taught how to use a variety of instructional techniques on their child by the professional home visitors. The program, originated in Portage, Wisconsin in 1969, is now widely available as a coherent educational program specifically designed for children at risk of developmental delay. The first randomized control study of Portage was conducted by the Avon Premature Infant Project in the UK in 1998. A total of 328 preterm infants (<33 weeks) were recruited from Bristol, UK to participate in a 2-year randomized controlled study. Infants were randomly allocated to a Portage group (n=116), parent adviser group (n=106), or non treatment control group (n=106). The parent adviser group received seminars, and individual and group counselling from research nurses to control for effect of the family support aspect of Portage intervention. The non treatment control received standard care from neonatal follow-up. These children were assessed using the Griffiths Mental Development Quotients at age 2 and 5 (Avon Premature Infant Project, 1998; Johnson et al., 2005).

At age two, the Portage intervention showed only a modest increase in the Griffiths Mental Development Quotients (96.8 $\pm$ 1.6 for Portage group, 95.9 $\pm$ 1.6 for parent adviser group, and 92.9 $\pm$ 2.0 for control). However, these modest positive effects on cognitive, behavioural, and motor functions observed at age 2 were no longer seen at age 5 (Johnson et al., 2005). It was suggested that this form of intervention might be more efficacious if provided beyond the 2 years of age and extended to school entry.

The Infant Health and Development Program (IHDP) was a multi-site randomized clinical trial in the US for testing the efficacy of a program providing health information and family support services for low birthweight, premature infants, and their families (Brooks-Gunn et al., 1993). Infants < 2,500 grams at birth were screened for eligibility if they were 37 weeks or less gestational age and were born in one of the participating medical centres in eight cities (Little Rock, Bronx, Cambridge, Miami, Philadelphia, Dallas, Seattle, and New Haven). The trial recruited 985 low birthweight infants in a 3-year trial program. The infants were stratified by site and birthweight ($\leq$ 2000 g and 2001- 2500 g) and were randomly assigned to either IHDP group or follow-up control group. Both groups of infants (and their families) received post-discharge follow-up services such as health assessments and referrals for medical and therapy services. Infants and their families in the IHDP group also received regular home visits by an infant health professional, attended a child development centre and participated in a parent group. The aim of IHDP was to enhance at risk children's competence by working directly with the children and their parents. It also aimed at helping parents improve their parent-child interaction and teaching skills. The program involved home visiting that began shortly after discharge from hospital. During the home visits, parents were provided with information on their child's health and development. They were also taught a series of educational activities that could be used to promote their child's cognitive, language and social development. At age 12 months, the IHDP group children attended child development centre daily for activities that parents learned to carry out with their children from the home visiting professionals. Parents of different families also met every 2

months in parent group meetings for information on parenting, health and safety. The program continued until the child reached the age of 3.

A significant beneficial effect was seen for the IHDP intervention group at age 2 (mean difference in cognitive test score= 9.75; effect size = .59) and age 3 (mean difference in cognitive test score= 9.31; effect size = .59). Although a general decline occurred in cognitive test scores for both groups of children over the 3 years study period, children in the intervention group experienced smaller declines. When these children were assessed at age 5, the beneficial effects of the intervention remained for those with heavier low birthweight group (2000 – 2500 g) but not those with lower birthweight ($\leq$2000 g) (Brooks-Gunn et al., 1994). At age 8 years, only modest benefits emerged in cognitive measures and academic skills seen in the heavier low birthweight (2000 – 2500g) IHDP group children (McCarton et al., 1997). The differences in cognitive test score between the intervention group and follow-up control group of this birthweight stratum were very small (for example, an average of 4 IQ point difference in favour of the intervention group). On the other hand, no differences in any developmental measures between the intervention group and follow-up control group of the lighter low birthweight ($\leq$ 2000g) children were observed. The results suggested that IHDP intervention favoured heavier low birthweight children.

Thus, it appears that IHDP intervention is more effective for some children and families than others. It has been consistently shown that intervention effects interact with a number of child and family risk factors or confounding factors (Berlin et al., 1998). For

example, children of less affluent families in terms of maternal education and poverty benefited more from IHDP intervention (Brooks-Gunn et al., 1992). The findings of IHDP trial and other follow-up studies suggest that different early intervention strategies are needed to target certain sub-populations (Berlin et al., 1998; Brooks-Gunn et al., 1992; Brooks-Gunn et al., 1994; McCarton et al., 1997).

Infant stimulation is another common strategy of early childhood intervention approaches that targets preterm infants during their stay at neonatal intensive care units (NICU) and their immediate post discharge period. This form of intervention is generally used to target the motor development of preterm infants. A systematic review of 34 studies of various early childhood interventions and motor development for NICU and post NICU children indicated that not all intervention programs are efficacious (Blauw-Hospers & Hadders-Algra, 2005). Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and Neurodevelopmental Treatment (NDT) are two of the most commonly used interventions for preterm infants. The NIDCAP intervention is based on a structured assessment tool for establishing infants' developmental goals and providing information on infants' needs to caregivers and professionals. It aims at mimicking the intrauterine environment by observing the infants' reaction to their care environment and adapting individual recommendations according to the infants' behavioural responses during a care procedure in order to support their overall development and self regulation[5]. The NDT intervention is based on the belief that inhibitory control of abnormal movement and stimulation of automatic postural reactions will facilitate motor development (Velickovic & Perat, 2005).

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[5] NIDCAP Federation International (NFI) website: http://www.nidcap.org/. Accessed on September 6, 2004

Eight high quality studies showed that the NIDCAP intervention had only a temporary positive effect on motor abilities for infants at preterm age. At term age, this type of intervention did not show a beneficial effect (Blauw-Hospers & Hadders-Algra, 2005). After term age, certain specific developmental programs such as NDT are usually employed to aid motor development of preterm infants. The NDT type treatment and other developmental programs were evaluated by 12 well-executed post-NICU studies, but the results indicated that NDT did not seem to have a beneficial effect on motor outcome for the post-NICU children.

Spittle et al. (2006) conducted a more recent systematic review of sixteen randomized or quasi-randomized controlled trials of various forms of early childhood intervention that aimed at improving cognitive or motor outcome of children at biological risk of developmental delays. The types of interventions in the studies include physiotherapy, occupational therapy, neurodevelopmental treatment (NDT), parent-infant relationship enhancement programs, infant stimulation, and infant development programs. Interventions were carried out by professionals such as physiotherapists, physicians, nurses, or psychologists. The primary outcomes were the efficacy of these early childhood intervention programs for preterm infants on cognitive and motor developments. The control groups consisted of children who received only standard medical follow-up at 0-2 years' old, preschool age (3-5 years), and school age. Meta-analysis of available data from these studies indicated that these forms of intervention have a positive outcome for cognitive development up to the preschool period. Intervention that focuses on the parent-infant relationship, along with infant development,

has the greatest impact on cognitive development in the short to medium term. By school age, the effects were no longer present and for motor development there was little evidence to indicate any beneficial effect of these interventions (Spittle et al., 2006).

Children with Identified Developmental Delays and Disabilities

Systematic reviews with or without meta-analyses of efficacy studies of interventions for children with established disabilities have suggested moderate but inconsistent positive outcomes (Casto & Mastropieri, 1986; Shonkoff & Hauser-Cram, 1987; Simeonsson et al., 1982). The typical reasons for children with diagnosed developmental delays or disabilities to receive early childhood intervention are delays in mental, communication, and physical development. The primary purpose of early childhood intervention is to enhance early development in order to reach the maximal intellectual and adaptive functioning (Spiker & Hopmann, 1997). The large body of literature for this population came from research on interventions for children with Down's syndrome and cerebral palsy. The evidence of effectiveness and efficacy to date is mostly conflicting because of the large variation in the forms of interventions, experimental designs (outcome measures and frequency of intervention) and age at enrolment. This makes evaluating effectiveness and efficacy of intervention difficult.

Spiker and Hopmann (1997) reviewed studies on the effectiveness of early childhood intervention for children with Down's syndrome, and they concluded that the evidence is only marginal and is limited to short term benefit. For example, moderate positive

developmental advantages in speech and motor development were observed in children with Down's syndrome who received early childhood intervention (Hines & Bennett, 1996). However, these positive outcomes were actually due to a slower rate of decline in cognitive function as a result of intervention rather than improvement from baseline level. It has been suggested that early childhood intervention can prevent the gradual decline in intelligence among children with intellectual disabilities (Guralnick, 1998; Guralnick, 2005). Interventions that are centre based programs (child development centre and infant programs) with a systematic developmental curriculum emphasizing social and intellectual development were found to be most effective.

For children with cerebral palsy, efficacy studies have largely focused on whether interventions could compensate for underlying motor impairments (Harris, 1997). Two randomized control trials and one cohort follow-up study evaluating the effects of NDT (neurodevelopment treatment) on motor developments did not lend much support to the efficacy of this form of intervention for children with cerebral palsy (Bower & McLellan, 1994; Law et al., 1997; Palmer et al., 1990). A more recently completed randomized controlled trial in 2004 did provide some evidence to support the efficacy of therapeutic exercise for children with cerebral palsy. Improvement in gross motor function was observed in children with spastic cerebral palsy after receiving 16 weeks of NDT treatment (Tsorlakis et al., 2004). Children who received treatment 5 times a week also showed significantly better improvement in gross motor function measures (GMFM-66) compared to children receiving only twice a week treatment. However, a systematic review earlier by Butler and Darrah (2001) on the effects of NDT for cerebral palsy did

not provide clear evidence that the treatment produced any non- motor benefits such as enhancement of social-emotional language or cognitive development, and improved parent-child interaction. Furthermore, although NDT might immediately improve range of motion, no consistent evidence indicated that the treatment could slow or prevent contractures or that it improve any functional motor activities (Butler & Darrah, 2001).

Without early childhood intervention, children with developmental speech and language delays/disorders may have severe behavioural, learning, and social difficulties later in life. These problems manifest further when children enter school because they cannot communicate with their peers and become isolated and/or frustrated. Moreover, it has been demonstrated that early childhood intervention for all types of communicative disorders can be highly effective and is more efficient than intervention provided at later ages (Mclean & Woods-Cripe, 1997). A meta-analysis of efficacy studies of speech therapy for children with primary developmental speech-language disorders revealed that speech-language therapy is effective for children with phonological and expressive vocabulary difficulties (Law et al., 2004). However, evidence is less clear for children with expressive syntax difficulties (sentence structure) and receptive language difficulties (understanding of language).

Summary

Studies of early childhood intervention are heterogeneous in design and results. Considerable variation is seen in children's diagnoses and age ranges, the types and

intensity of intervention provided, and the experimental designs (Bailey et al., 1999; Guralnick, 1998; Majnemer, 1998; Shonkoff et al., 1988). This makes systematic reviews and meta-analyses of efficacy research exceedingly difficult to assess contributing to inconsistent conclusions. Thus, challenges remain for some early childhood interventions to prove their efficacy and effectiveness. Nevertheless, interventions focusing on the parent-infant relationship, along with the direct service to children appear to have the greatest impact on cognitive development in the short to medium term, although it is also generally agreed that not all interventions are efficacious or effective. Evidence of the efficacy of motor development intervention for children with physical disabilities in particular, and perhaps surprisingly, remains inconclusive. It seems that intervention may not be able to alter the physical outcome of a motor disorder, such as cerebral palsy; however, it may change the way an affected child functions and participates in society (Harris, 1997). As a result, intervention efforts should not be merely directed toward the elimination of impairments but also toward the promotion of positive adaptation as suggested by some authors (Harris, 1997; Luthar & Cicchett, 2000). Furthermore, an increasing number of studies have emerged evaluating the family's role in early childhood intervention and the beneficial effects of intervention on family's functioning and their well-being. A number of studies investigated the effects of early childhood intervention on families, and most suggested that parents are able to cope or function better at the end of intervention (Bailey et al., 2005; Shonkoff et al., 2001). These programs are able to provide the help and information that families need to care for their special needs children. In a longitudinal follow-up study of children and families one year

after receiving early childhood intervention, it was demonstrated that parents were more positive and better adapted to their special needs children (Shonkoff et al., 2001).

1.3 OVERVIEW OF EARLY CHILDHOOD INTERVENTION SERVICES IN BRITISH COLUMBIA

Almost all early childhood intervention program delivery in Canada is the responsibility of the provincial or territorial governments (Goelman et al., 2005). In late 1999, the federal government instituted a series of initiatives to address early childhood development and parenting issues for communities that are at risk. However, these initiatives are mostly primary prevention programs and not specific secondary or tertiary early childhood intervention programs for infants and young children at risk for developmental delays or having identified disabilities. Early childhood intervention in the provinces and territories consists of different forms of intervention programs targeting different populations. For example, British Columbia, Alberta, Saskatchewan, Newfoundland and Labrador, Ontario, and Prince Edward Island have established infant development programs for children aged birth to 3 or 5. The programs and services in British Columbia are mostly operated by non-profit community groups or societies. In the provinces of Alberta and Newfoundland and Labrador, early childhood intervention programs and services are delivered more directly under the auspices of governmental public health authorities.

In order to put a perspective and context to this study, a more detailed description of early childhood intervention services in British Columbia is described here. As services to children with special needs moved away from an institutionalized model of care (normalization) to community-based care at children's own home, family-centred early childhood intervention programs emerged in British Columbia. The Early Childhood Development division and the Children and Youth with Special Needs division of the Ministry of Children and Family Development[6] provide the majority of early childhood development and intervention services through contracts with community child development centres and non-profit society sponsored programs. The range of early childhood intervention services that seek to improve the outcomes for vulnerable children aged birth to six and their families includes specialized preschool/daycare programs, health surveillance, home visitation programs, parent education, therapeutic services, and specialized programs for children with developmental delays and disabilities. In particular, the early childhood intervention programs include Infant Development Programs (IDP), Supported Child Development Programs (SCDP), and early intervention therapies (Occupational Therapy (OT), Physical therapy (PT) and Speech-Language Pathology (SLP) services). Public health centres under the auspices of regional health authorities also provide speech-language pathology and audiology services to preschool children.

The Ministry of Health also provides funding to regional Health Authorities for preschool speech therapy services at public health centres across the province. Although public health speech therapy services are under the auspice of the Ministry of Health, some

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[6] MCFD webpage : http://www.mcf.gov.bc.ca/early_childhood/index.htm. Accessed on March 23, 2003

MCFD regions purchase speech therapy services from public health to complement their service delivery if the regions require more speech-language pathology services. For school age children, most intervention therapy services are the responsibility of Ministry of Education in conjunction with Ministry of Children and Family Development.

Referral to these early childhood intervention services can be made by a family physician, paediatrician, community or public heath nurse, and any other community professional as well as a family member. The participation of families having a child with developmental delay or disability, between birth and school entry, diagnosed or not is completely voluntary. Families have the choice to enrol their child to the referred services or to seek other programs that better suit their needs. Early childhood intervention services are provided at no cost to families. Some families may seek private therapy services when there is a long waitlist.

Individual agencies providing early childhood intervention programs operate independently and have their own boards of directors, executive directors and staff. The majority of these programs receive funding contracts from MCFD. Additional operational funding for the agencies is sometimes obtained through fundraising, donation and grants within their communities. Most infant development programs and supported child development programs operate as stand alone programs within their sponsoring agencies. These agencies are largely local associations of community living, home support, and family resource centres, or childcare centres. These programs often have access to intervention therapy services within their communities to augment their services. Most

child development centres offer a multidisciplinary or transdisciplinary approach to early childhood intervention and provide a broad spectrum of coordinated services including infant development program, supported child development program, and early intervention therapy services as well family support services.

Infant Development Program

The Infant Development Program (IDP) provides services to families with children, from birth to 3 years, who are at risk for developmental delay or have an identified developmental disability[7]. This program is funded by the Ministry of Children and Family Development (MCFD) and is currently provided by 52 separate non-profit societies including child development centres and associations of community living agencies coordinated by the Office of Provincial Advisor of Infant Development Programs of BC. The primary goal of IDP is to provide home-based services for infants who require extra help to optimize their development. With the emphasis on identifying individual needs, the program specifically works with families to enhance a child's overall development and learning opportunity and to build relationships with their child. The focus of IDP is to provide families with support and resources that enable them to problem solve. Typically, IDP consultants facilitate family access to other local programs and to various resources, and they assist families with transition to new programs such as preschool programs. Stemming from the framework and practices of BC Infant Development Program, the Aboriginal Infant Development Program (AIDP) provides the same or similar services but also incorporates culturally appropriate practices. AIDP

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[7] Infant Development Programs of BC webpage: http://www.idpofbc.ca/. Accessed on March 23, 2003

works with exclusively Aboriginal children and their families, age birth to 3 (or up to 6 years in some communities).

Supported Child Development Program

Supported Child Development Program (SCDP) is intended for children with established disabilities and their families who require extra support to participate in community preschools or inclusive daycare programs. The program primarily serves children from birth to 12 years of age, with some serving children up to 19 in some communities. Over 6000 children every year are served by this program through approximately 60 community agencies in British Columbia[8]. The primary focus of the program is to assist families in locating extra support for their child with developmental delay or disability to enable them to fully participate in regulated childcare settings (or preschool and school settings). The SCDP consultants also provide families with information on typical and atypical child development strategies, community resources related to child developmental needs and quality childcare services. The Aboriginal Supported Child Development Program provides similar services to on reserve Aboriginal families.

Early Intervention Therapy Services

Early intervention therapy (EIT) services are aimed to address the specific functional impairments and/or developmental needs of children with specific developmental challenges. These services include the physiotherapy, occupational therapy and speech-language pathology (or speech therapy) provided in preschool, home and other community settings (MCFD website). Intervention therapies focus on the prevention,

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[8] Supported Child Development Program webpage: http://www.scdp.bc.ca/. Accesses on April 3, 2004

diagnosis and remediation based on children's specific developmental needs. This can be in the form of direct therapy or in the form of caregiver consultation. Preschool intervention therapy services are mostly provided by community child development centres (BCACCS, 2004).

Physiotherapy

Paediatric physiotherapy aims at promoting the gross motor development of young children who are at risk of or having physical disabilities to develop better mobility, independence and physical fitness allowing them to adapt, play, and learn at both home and childcare settings. Gross motor skills including strength, movement, balance, co-ordination, and endurance are evaluated so that families and caregivers can be advised about specialized activities, motility aids, and toys.

Occupational Therapy

Occupational therapy helps children develop skills in self-care and community living such as dressing themselves, toileting, eating, and personal hygiene. Most occupational therapists who work with children have particular interest in the areas of fine motor development and hand-eye coordination; sensory information processing; positioning, splinting, and seating; augmentative communication/computer access; and cognitive, behavioural, and interpersonal skill development. The goal of intervention is to find ways of assisting children with developmental delays or physical disabilities to be as independent as possible with the activities of their daily lives.

Speech-language Pathology (Speech Therapy)

Paediatric Speech-Language Pathologist (SLP) helps children develop the communication ability of both pre-language skills (such as eye contact and body language) and language development (both expressive and receptive language skills). Speech-language pathologists work with children in areas of articulation (speech sound production), fluency, as well as oral motor skills for speech and feeding.

Other Early Childhood Development and Intervention Services in BC

The other MCFD services for children with special needs include the Aboriginal Early Childhood Development, At Home Programs, Autism funding and services, community brain injury program for children and youth, children and youth mental health programs, hearing and vision loss programs, nursing support services, foetal alcohol syndrome services, and general family supports. These are part of the broader early childhood developmental services in British Columbia.

Other provincially based programs also exist to provide highly specialized diagnostic services for children who require specialized wheel-chair seating, feeding, and swallowing evaluation, autism diagnostic assessment, and brain injury assessment. Funded by the Ministry of Health, these services are provided through the province's two tertiary centers: the BC Children's Hospital and Sunny Hill Health Centre for Children.

1.4 RATIONALE OF STUDYING WAITING LISTS AND WAITING TIMES FOR

    EARLY CHILDHOOD INTERVENTION SERVICES

Although a large body of research on waiting list and waiting time has increased our general knowledge of the nature and characteristics of waiting list and waiting time for hospital-based services, the same intensity of attention has been lacking toward the waiting time for early childhood intervention services. In Canada, no federal legislation exists specifically mandating the provision of early childhood intervention services for children with special needs and their families or the timely access to these services (Goelman et al., 2005; Marfo, 1991).

> *Canada's proximity to the United States is both a blessing and a*
>
> *curse to the Canadian special education scene. It is a blessing*
>
> *because progressive legislation and other developments and*
>
> *practices have a potentially beneficial impact on Canadian*
>
> *education. It is a curse because this assimilation process tends to*
>
> *breed a false sense of complacency and security.*
>
>   Marfo, 1991, p. 235

This observation remains true 18 years later. Literature regarding early childhood intervention services has largely come from American studies. Waiting lists for early childhood intervention has not been a major policy concern in the United States. It is evidenced by the paucity of research studies in this area. Similarly, research on waiting lists and waiting times for early childhood intervention services have not been a priority

in Canada despite concerns from both service providers and families regarding the waitlists for these services.

In a recent health care access survey, waitlists remain a primary concern to most Canadians (Statistics Canada, 2005). The report indicated waiting too long for care was cited as the number one barrier among Canadians who have experienced difficulties accessing health care services. At the 2003 First Ministers' Meeting, health ministers of each province agreed to work towards ensuring that all Canadians have timely access to health services (Health Canada, 2003). The series of reports titled Taming the Queue Colloquium also provided a forum for discussions around waiting list management, including the development of medically acceptable benchmarks, innovations and best practices in waiting list management (McIntosh, 2006). However, waiting list issues for early childhood intervention services were not mentioned in any of these initiatives. Information on both the number of children waiting for early childhood intervention services and the length of time waiting is generally unknown because there is a lack of standard databases for these services at both the federal and provincial as well as regional levels.

In British Columbia, the population of children aged six and below was estimated to be 298,000 in 2004. It is estimated that about 25% of all children in BC are developmentally vulnerable when they enter school (MCFD, 2005). In both 2001 and 2005, the British Columbia Association of Child Development & Intervention (BCACDI) expressed concerns over the increasing number of special needs children on waiting lists

for early childhood intervention services in British Columbia. The primary recommendations to the provincial government, particularly to the Ministry of Children and Family Development of British Columbia (MCFD), were increases in funding to reduce the waiting time for early childhood intervention services (The British Columbia Association for Child Development and Intervention, 2005; The British Columbia Association for Child Development and Rehabilitation, 2001). Although calls have been made to address the waiting list issues in the field of early childhood intervention, relatively few studies have focused on this area of research.

1.5 STUDY OBJECTIVES AND ORGANIZATION

The overarching aim of this study is to examine the nature of waiting list and waiting time for early childhood intervention services by exploring the available information and administrative data provided by community agencies in BC. The primary objectives of this study include:

1. To describe the current state of knowledge about waiting lists and wait times for selected early childhood intervention services in British Columbia,

2. To examine the variations in waiting times for selected early childhood intervention services and factors associated with the variations, and

3. To develop a common framework of reporting waiting times for early childhood intervention services.

A large body of literature focusing on hospital-based (or acute care) services has provided valuable insight in conceptualizing the waiting list and wait time measures. In particular, it has contributed to the current understanding of the appropriate methods and indicators to measure waiting lists and wait times, the distinct waiting periods along a patient's care trajectory, and the significant factors associated with waiting list and waiting time variations. This study begins with a literature review of waiting lists and waiting times (Chapter 2). A synthesis of information from published and unpublished literature regarding the key concepts and issues of waiting lists and waiting times in the context of early childhood intervention services will then be described.

Chapter 3 will examine the data that are available as well as the methodological and analytic issues relevant to waiting lists and waiting times with regard to early childhood intervention services. Chapter 4 will highlight the results of both qualitative and quantitative data analyses. It will first provide a general descriptive summary of the current state of knowledge regarding waiting lists and waiting times for early childhood intervention services in BC. This information was obtained from a postal questionnaire survey of public health centres, child development centres and community agencies that provide infant development program (IDP), supported child development program (SCDP), and/or early intervention therapy services (EIT) to special needs children aged birth to 6 in BC.

Currently, information on waiting lists and waiting times for early childhood intervention services is sometimes available from individual agencies and programs but in aggregated form through surveys rather than individual case-based data. A key issue is that waiting lists and waiting times are often not defined, measured, or reported consistently across time and disciplines. The lack of a central waitlist registry does not allow any analysis of the reliability and validity of these wait time and waitlist statistics. This study will explore what administrative data there are with regard to intake and referral information supplied by participating agencies and public health centres, beginning with a descriptive statistic analysis of the waiting times for each service. Multivariate time-to-event regression analysis (Cox regression model) will be used to examine the potential factors associated with wait time variation.

From the acute care waitlist literature, a general agreement exists on what constitutes a wait, although different potential wait periods have been identified in hospital-based services. Chapter 5 will propose the development of a common framework to measure wait times for early childhood intervention services by applying the approach of "Pathway to Service" (Sanmartin & the Steering Committee of the Western Canada Waiting List Project, 2003). This common framework will help define the distinct wait time periods for early childhood intervention services in British Columbia. It is followed by a discussion of the key findings and the implications for future development in research, and policy implications regarding waiting list and waiting time in the field of early childhood intervention services.

CHAPTER 2

WAITING LISTS AND WAITING TIMES
LITERATURE REVIEW

Information on waiting lists and on waiting times is often viewed as an important indicator for assessing the state of a publicly funded health care system. Long waiting lists and waiting times are commonly believed to be simply a result of inadequate resources. Some truth exists about this view since an increase in funding did reduce the wait time for some medical services in the past. For example, because of long waiting lists for coronary artery bypass grafting (CABG) operations in the mid 1990's, the BC government decided to increase funding for this surgical procedure. Levy and his colleagues demonstrated a reduction in wait time for patients requiring a CABG operation after extra funding was provided (Levy et al., 2005). However, significant reduction in waiting time was only seen in patients with the highest urgency. Increasing funding alone did not seem to be the most efficient way of reducing waiting time because most systems were operating at near capacity. Thus, extra funding coupled with better waitlist management would seem to be a better strategy to reduce waiting time ((Lewis et al., 2000). For example, many people on the CABG waiting lists in the 1990s should have not been on them because they were dead, had surgery somewhere else, or did not want surgery.

Initiatives involving a review or audit of waiting lists can sometimes lead to a significant reduction in the number of patients on waiting lists. This reduction can be as high as 30% to 50% (Elwyn et al., 1996; Parmar, 1993; Tomlinson & Cullem, 1992). The strategy of reducing waiting time without additional resources has been demonstrated by Clow et al. in 2002. This initiative of reducing waiting time for child health services in East London began with a review of the accuracy of the waiting lists. The review of the number of children waiting to be seen by specialists resulted in the removal of 47 cases (19% of the original number of 207 children on waiting lists) because these patients had either gone somewhere else for services or because some patients no longer needed the services. The families of children who remained on waiting lists were offered options of either continuing to wait or being given an appointment at a rapid response clinic with a condensed consultation time with a multidisciplinary context (Clow et al., 2002). Sustained reduction of waiting times continued to occur two years after the beginning of the initiative. The majority of surveyed parents using the new system were satisfied with it.

It is now clear that a host of factors may influence waiting list size and waiting time for health care services. A conceptual framework for studying waiting lists and waiting times for hospital-based services has been developed (Sanmartin, 2000). This framework has provided insights into a range of factors that might influence the waiting times for elective surgical interventions. The extensive review of the evidence on waiting lists and waiting times for hospital based services by McDonald and colleagues (1998) also provided a valuable understanding of the nature and characteristics of waiting lists and

waiting times. Considerable variations exist in definitions and in methods of measuring waiting lists and waiting times (McDonald et al., 1998). Waiting list and waiting time research in the context of early childhood intervention services to date, however, has been very limited due to the absence of such a framework and the paucity of waitlist literature in this field. The following sections describe a conceptual overview of waiting list and waiting time definitions and discuss a conceptual framework to identify factors that are relevant to waiting lists and waiting times for early childhood intervention services.

2.1 METHODOLOGY

Relevant studies were first identified by a thorough search of databases including MEDLINE, HealthSTAR, CINAHL, PsycInfo, EBM (Evidence-based Medicine) Review, and Cochrane Database of Systematic Reviews with database specific strategies and search terms. A thorough search of non-peer reviewed publications was also performed through Google and Google Scholar search engines for published books, reports and relevant documents.

Information on waiting lists and waiting times was searched for in both published and unpublished literature. The search strategy was developed to match specific information such as waiting times and waiting lists in the context of early childhood interventions. Search terms and key words included "waiting list," "waiting time," "early (childhood) intervention," "physiotherapy (early intervention)," occupational therapy (early intervention)," and "speech-language therapy (early intervention)." Information was

sought with a focus on early childhood intervention services and around the key themes of conceptualization of waiting lists and waiting times, definitional and measurement issues, characteristics and nature of waiting times, and factors associated with waiting times.

2.2 CONCEPTUALIZATION OF WAITING LISTS

The potentially infinite demand for health care and a finite supply of services make waiting lists an unavoidable phenomenon in many publicly and privately funded health care systems (Blake, 2005). Operating a system of services without waiting lists requires a huge capacity of resources because technical and human resources are not fully utilized during periods of decreased demand. Thus, waiting lists are often used as tools to ensure efficient use of scarce resources through rationing services and prioritizing demands (Iversen, 1993).

Waiting lists for health services have been conceptualized as indicators of unmet health care need, inadequate resources, misallocated resources, and health care access as well as tools for rationing constrained resources (Sanmartin et al., 1998). In their review of waitlist literature, Sanmartin et al. (1998) noted that a simple theory of supply and demand through the lens of economics may not adequately explain the variations in waiting list sizes because consumers' ability or willingness to pay cannot correct the mismatch of excess demand over supply in a publicly funded health care system. Thus, in a non-pricing system, willingness to pay and price of service would not generally play a significant role in resource allocation (Blake, 2005). Furthermore, the meaning of

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demand is often blurred with the terms such as "need," "excess demand," or "unmet need," and a true demand of services is rarely measured in the waitlist literature (Sanmartin et al., 1998; Silvester et al., 2004).

As long as services are "free" to patients, an excess of demand for services will exist. However, there should be a clear distinction between need and demand (or desire) for services. According to the Western Canada Waiting List steering committee, "need" for services can reasonably be equated with "urgency" when effective treatments actually exist. That is, a patient truly needs the intervention for his/her health condition in a timely manner. If rationing of health care is based on price, those who are most able to pay will be able to meet their "demand" even though they may not be the most in "need" (Blake, 2005). In non-pricing rationing such as that in state funded health care systems, allocation is often based on a first come first served basis, although those who are most in need are allowed to jump queues through prioritization (if the queue is based on some explicit priority process). For those waiting in a long queue for appropriate interventions, their needs are considered unmet according to the definitions of needs and demand.

Waiting lists have also been suggested as an indicator of inadequate resources or lack of capacity (Sanmartin et al., 1998). According to this view, the level of funding would be the most influential factor on waiting list sizes. A general correlation between levels of resources and waiting list sizes, however, has not been established in the literature (Silvester et al., 2004; Stoop et al., 2005; Yates, 2001). Therefore, lack of capacity is typically not the major issue most people believe it to be. For example, in an evaluation

of excessive backlog of patients waiting for services provided by the UK's National Health Services in 2004, it was found that the primary cause of waiting was due to a mismatch between the variation in demand and the variation in capacity. Lack of capacity such as not enough beds, inadequate staffing level of doctors and nurses, or insufficient diagnostic equipment was rarely the major reason for most queues in the UK (Silvester et al., 2004). It was, however, the variability in the system that created waiting lists because of the random nature of the fluctuations in both demand and capacity. The authors also noted that many waiting list initiatives, through an increase in resources attempting to clear waiting lists, often failed because they did not address the underlying causes - the demand and capacity "variation" mismatches.

The existence of waiting lists does not seem to be a universal problem in health care systems but rather an issue of waiting lists usually being restricted to a few elective surgical procedures as noted by Sanmartin et al (1998). Those procedures with very long waiting lists represent conditions that, relative to other conditions, are not a high priority for many physicians, not of interest to the general public, and/or not requiring urgent care such as hip and knee replacement surgery. Similarly, in the field of early childhood intervention, not all programs and services have a waiting list problem. Thus, long waiting lists may also be limited to a few areas of services. For example, some therapy services for young children with special needs are considered of low priority in the UK. Developmental co-ordination disorders are typically not considered a high priority for physical therapy services by the UK's National Health Services (Peters et al., 2004).

However, parents were frustrated because of the exceedingly long waiting times for these services.

Waiting lists are often used as tools to prioritize health care services and allocate scarce resources to areas offering the greatest potential benefit. Thus, waiting lists can be considered an indicator of misallocation of resources when costly services with demonstrated effectiveness are given priority based on public pressure and political desire.

The general concept of access to health care consists of specific dimensions describing relationships between patients and the health care system. These dimensions include availability, accessibility, accommodation, and affordability (Penchansky & Thomas, 1981). The waiting time for an appointment with a doctor is found to be predictive of patient satisfaction under the "accommodation" dimension of access. The concept of health care access has been linked to waiting lists and waiting times in earlier literature (Aday & Andersen, 1974; Penchansky & Thomas, 1981; Torgerson et al., 2006). One of the major components of accessibility in health care systems is the measure of time-based availability (Torgerson et al., 2006). The number of patients waiting for services and the number of weeks or months patients were waiting are examples of time-based availability measures.

Building on this conceptualization, the following sections will examine some definitional and measurement issues as well as factors associated with waiting lists and waiting times

identified by waitlist literature in the context of both hospital based services and early

childhood intervention services. A common framework of tracking waiting times will

then be discussed.

2.3 DEFINITIONS OF WAITING LISTS AND WAITING TIMES

In simplest terms, a "waitlist" for health care is a list of patients awaiting a service such

as surgery or an appointment with a specialist, and "waiting time" is defined as the

amount of time a patient spends on a "waitlist" before receiving the intended service or

procedure (Barer & Lewis, 2000). If information regarding waiting list and waiting time

data is to be meaningful and useful, definitions for these two measures require much

more careful consideration.

2.3.1 Defining Waiting Lists

Hadorn and colleagues (2000) defined a waiting list in a health care system as "a queue

of patients who are deemed to need a health service that is in short supply relative to

demand" (Hadorn & the Steering Committee of the Western Canada Waiting List Project,

2000). With this definition, it is important to distinguish the "wait" for receiving services

as a delay due to normal administrative work (for example, legitimate scheduling and

paper work) and a wait due to excess demand relative to capacity for services.

A waiting list is like a roster of patients awaiting a particular health service (Shortt,

2000). Patients' names are usually added to the lists chronologically, and they receive

their services in the order in which they join the queue. These lists often refer to the waitlists for elective services such as cataract extraction and hip/knee replacement surgeries although some more urgent services may have a waiting list as well, for example, CABG in BC in the 1990's though the wait is much reduced now.

Currently, two types of waiting lists are most frequently recognized: the first is a list of patients waiting to be seen by specialists who control access to the referred intervention, and the second list is for those waiting to receive the actual service once the need for intervention has been verified by specialists and agreed to by patients. The second list is generally what is referred to as a "waiting list" in most waitlist reports (Hadorn & the Steering Committee of the Western Canada Waiting List Project, 2000). Thus, almost all the existing waitlist data have focused on the wait for actual medical interventions, not for initial consultation with specialists.

Intuitively, the two types of waiting lists can also be identified in the field of early childhood intervention. Children/families may be on waiting lists for assessment (the wait between referral and assessment) which determines their eligibility or appropriateness for the intervention; that is, the appropriateness of the referral. Once deemed eligible, children/families may then be placed on a waiting list to receive the intervention.

The validity of waiting list size has rarely been discussed in the waitlist literature (Sanmartin et al, 1998). In general, the validity of a measure is whether the measurement is actually measuring what it is intended to measure (Carmines & Zeller, 1979). Thus, a

valid measure of waiting list size requires careful consideration of inclusion and exclusion criteria. Sanmartin and her colleagues (1998) in their review of the waitlist literature identified only a single study by the UK investigators during the 1980's that had specifically addressed the validity of waiting list size. In that study, information on 1094 patients under the care of 10 surgeons of different specialties awaiting admission to a hospital was analyzed (Sykes, 1986). The analysis indicated that the official hospital waitlist statistics were misleading because they excluded information on 325 (30%) patients waiting for day surgery and 314 (28.7%) patients who were deferred because of medical reasons that made surgery inadvisable. The total number of patients waiting to be admitted for surgery was estimated 79.9% greater than the official figure. The size of an unaudited waiting list would therefore seem to be a poor indicator of service performance or a sign of a capacity problem without considering what constitutes a true waiting list. Also a risk of rewarding the wrong service providers may occur if a long waiting list size is perceived as indication of extra funding needs, certain special expertise or popularity of a particular surgeon.

It is now generally known that waiting lists have been described inconsistently. The variation in waiting list size may mean a true difference in the number of patients waiting for any given service or simply a discrepancy in reporting methods. This is the reliability issue. Reliability refers to the extent to which an experiment, test, or any measuring procedure yields the same results on repeated trials (Carmines & Zeller, 1979). That is whether the result is replicable. In a survey conducted by the Office of the Provincial Advisor of Supported Child Development Programs (SCDP), it was reported that 28

(52%) of the 54 responding programs across BC indicated that they had a waiting list for their services, and a total of 580 children were reported on waiting lists (510 children waiting for extra staff support and 70 waiting for SCDP consultant support) in June 2002 (Bortoletto, 2002). The number of children waiting for SCDP services ranged from 1 to 193. The survey noted discrepancies among agencies in terms of how waiting lists and caseload status were defined. There were also differences in the nature and level of services available to children while they were on waiting lists. Some SCDP programs may place children on waiting lists to obtain extra staff support at daycare or preschool when resources are limited. However, some programs may provide interim services to waitlisted children usually by way of monitoring their development, and thus may not count them in their waiting list reports. Furthermore, it is not unusual that some families do not want or need to use the intervention services immediately but want to keep their options open in case circumstances change or when the need becomes clearer. These parents may not want to risk having to go to the bottom of a waiting list if they need services in the future. Some agencies may keep the files open for these families and include them in the waiting list reporting while other agencies do not.

In hospital based services, it is generally known that some patients may be waiting because they choose to delay admission for non medical reasons, or because they are not ready for a planned intervention. There may need to be a separate account of patients who defer admission because of non-health reasons and such patients should not therefore be included in a "true" waiting list as suggested by the sub-committee on Economics and

Planning of the Hospitals of the European Union (HOPE, 1998). A true waitlist has been

suggested to comprise of:

1. Patients with demonstrated need who have to wait because of hospital resource
   constraints,

2. Patients given a date of admission (except those appearing on a planned repeat
   admission list or deferred admission list),

3. Patients sent home at the time of admission (or not admitted) because of lack of
   beds or other resources, and

4. Patients awaiting transfer to another specialty (except in an emergency).

A similar question of "Who should be counted on a waiting list?" is also relevant to the

field of early childhood intervention. For example, the issue of high caseloads and

particularly long waiting lists are major concerns of the majority of stakeholders

including service providers, agencies and MCFD because they believe early intervention

is time sensitive if desired results are to be achieved (Simces & Ross, 2006). The report

by Simces and Ross (2006) indicated that a number of infant development programs did

not consider themselves as having a waitlist because consultants and their sponsoring

agencies have carried a larger caseload than is recommended in the IDP Policy and

Procedures Manual (IDP-BC, 2004). The IDP Policy and Procedures Manual

recommends a caseload range of 15-25 families per 1 full time equivalent (FTE) IDP

consultant depending on types of cases and the consultant's experience. In the review, a

half-time FTE position may have a caseload of 27 families. Furthermore, some programs

may turn away referrals instead of continuing to add families onto the waiting lists when

all of their consultants have exceeded the caseload limits. In this case, the list size would underestimate need, and illustrate overwhelmed capacity.

A number of programs have offered the option of utilizing group programs to families while they wait for scheduled individualized intervention. No general consensus exists as to whether families are considered on or off the waitlist when they receive such interim services.

The wide variety of options for early childhood intervention available through both health and/or education sectors has also exacerbated the problem of obtaining valid and reliable information regarding the true number of children on waiting lists. For example, some of the therapeutic services are provided through public health clinics, schools or community child development agencies. Thus, it is not uncommon for children to be put on multiple lists in the hope that they may get some service sooner.

2.3.2 Defining Waiting Times

Waiting time can be measured as the number of days or weeks or months between the time patients are placed on a list to the time they receive the service. It is now generally agreed that patient waiting time is more important than simply waiting list sizes. Waiting time is determined by complex interrelated factors such as system capacity, waiting list size and the number of emergent cases trumping those on a waiting list of elective procedures (Hadorn & the Steering Committee of the Western Canada Waiting List Project, 2000). The waiting time period can be thought of as a continuum that starts from

the decision of care seeking to the time when treatment or admission is received. However, not all wait time measures are practical and useful in wait time monitoring because of data availability. Most studies have focused only on a single segment along this continuum (for example, the time between the date when surgeon and patient agree that there is a need for surgery and the date of surgery) and there is no consensus as to which segment should be the true waiting time (Smith, 1994). Furthermore, most waitlist studies in the UK have focused more on the time to in-patient admission than the specialist appointment waiting time or the post referral wait (Pope, 1993). In general, waiting time refers to the length of time required for a patient on the waiting list to receive the desired service (Shortt, 2000) but how a waiting list is constructed (date on and date off waiting) is critical.

To date, information regarding the definitions of waiting times has been all derived from studies of waiting lists and waiting times for hospital based services. In general, three distinct types of waiting time periods have been identified in the literature (Sanmartin & the Steering Committee of the Western Canada Waiting List Project, 2003):

1. Waits for a referred visit to receive a consultation with a specialist (Specialist wait),

2. Waits for actual procedure (Intervention wait) after patient and surgeon agree that surgery is needed, and

3. The total waiting time (Specialist wait + Intervention wait).

Waiting for specialist consultation is defined as the time between a referral from primary care physician to the first consultation appointment with the specialist. For most hospital based services, the intervention wait time is defined as time spent between when the patient is booked for surgery (or placement on the hospital waitlist) and the receipt of the procedure. The total waiting time is, thus, the sum of specialist wait and intervention wait.

For hospital based services, a variety of definitions have been proposed to describe additional segments for waiting time periods that a patient may experience. For example, the British Columbia Medical Association (BCMA) proposed four distinct waiting periods in their 1998 waitlist report: (1) the wait for a GP appointment; (2) the wait for a specialist appointment; (3) the wait for diagnostic tests; and (4) the wait between booking for surgical procedure and the receipt of care (BCMA, 1998). In the United Kingdom, three distinct wait periods were identified as well: (1) waiting for first outpatient consultation (wait between GP referral to first consultation); (2) waiting for placement on a list (wait between application for admission and placement on the hospital waitlist); (3) waiting for treatment intervention or procedure (wait between placement on hospital waiting list and receipt of service or procedure) (Smith, 1994). The beginning of surgical waiting time was also defined as the time when patient and surgeon decided that treatment was necessary and desirable (decision to treat) (Hanning, 1996). The decision to treat is often assumed to take place during the last pre-surgical consultation with the specialist when administrative data are used.

Some argue that the true meaningful measure of waiting is the "total waiting time" for care. One of the earliest definitions that emerged from the UK defined the total wait time as time spent between the date when patients first sought care, often marked by the first visit to the primary care physicians, and the date when the treatment was finally provided (Bloom & Fendrick, 1987). As noted about, a similar definition has also been proposed in Canada by the British Columbia Medical Association (BCMA, 2006).

While most studies agree that waiting ends when a patient receives the referred service, there are differences regarding specifically when the wait begins. In order to determine the waiting time for a hospital-based service that has a waiting list, two reference dates are needed to mark the beginning of a wait or the "Date On" and the end of the wait or the "Date Off" (Sanmartin et al., 1998). According to Sanmartin and colleagues, the definition of "date on" is somewhat problematic because there are different ways that patients can be placed on waiting lists as discussed above. For example, Jacobs and Hart (1990) defined the "date on" as the time when a request for admission to hospital was made. When they conducted a national survey of admission wait time, the placement on the waitlist was assumed to be on the date when a request for a booking date was sent to hospitals (Jacobs & Hart, 1990). Another example came from a provincial health report of Nova Scotia in 1996 in which "date on" the waiting list was defined as the time of the last surgical consult prior to surgery (Nova Scotia Department of Health, 1996). In this report, the placement on a waitlist started from the date of last contact with a specialist. This was 'assumed' to be the point at which a treatment decision was made. However, whether or not this assumption is valid has not been evaluated. The challenge of using

this definition is that patients may have multiple contacts with their surgeons prior to surgery. It is not uncommon that the decision for treatment is made on the first or second visit, not necessarily at the last consultation, and some of the visits entail referral for diagnostic services to confirm the need for surgery or to determine the exact procedure that needs to be done.

In the field of early childhood intervention services, both "Date on" and "Date off" are also problematic and there has been limited discussion of these issues. In a study of the timing of diagnosis and entry into the early childhood intervention system, Bailey and colleagues reported an average delay of 5.2 months between initial diagnosis and a referral (Bailey et al., 2004). This delay was substantial and should not be ignored since "early" is the premise of early childhood intervention. As a result, some may argue that waiting time should start from a diagnosis or screening by a primary care provider or public health nurse before the child is actually in the early intervention system. Therefore, "Date on" is no less controversial in the field of early childhood intervention. The range of possible definitions for "Date on" waiting lists includes referral date, the date decided on intervention strategy, or the date of service request. The date of service request may be defined as the date of formal intake; that is, the date when the family's priority and the child's needs are determined, or it can simply be the date when a family completes the agency service application. Intuitively, "date on" could also be defined as the first date of contact with a family physician or a paediatrician, a public (or community) health nurse or other community professional, or the first date of contact by parents/ caregivers (or other family members) with the community programs or public

health units that provide early childhood intervention services. It could also be defined as the intake date, the program admission date, or the date when a recommendation of service is made or the date when the course of action is agreed upon by both the parent and the service provider.

In a study of waiting for children rehabilitation services, wait times were determined from the date of referral for physiotherapy and occupational therapy and the date of first appointment at four rehabilitation centres in Montreal (Ehrmann-Feldman et al., 2002). Date off would seem reasonable to be defined as the first appointment at each facility for services. This assumption will hold if each rehabilitation facility has the same in-take process and if therapy treatment begins soon after the first appointment.

Further illustration of the variability of 'date off' definition provides some sense of the ongoing problem of determining wait time for early childhood intervention services. For example, the Infant Development Programs of British Columbia (IDP of BC) produces a comprehensive report every two years on their service provision and waitlist information (IDP of BC, 2006). The source of information is based on self-reported aggregated data through a postal questionnaire survey of over 50 individual programs across the province. Waiting time for this report was defined as the time between the receipt of a referral and the time a child is on their active caseload (IDP-BC, 2004). Since waiting list and waiting time statistics in the biennial reports relied on self-reported information from agencies, it will need to be assumed that, for comparison purposes, all agencies were using the same definition of active caseload, that is, home visits at least once per month. However, in

fact, the way of recording the date when a child is considered to be on an active caseload may vary greatly; for example, the date when the IDP consultant decides to take the child on caseload, or the date of first home visit by a consultant. Thus, the first appointment for active intervention is difficult to determine consistently.

"Date off" for the field of early childhood intervention services appears to be more difficult to define. In theory, a child is off waitlist when he/she begins receiving the recommended interventions (or the referred intervention services). Early childhood intervention is a continuum of services within a single program or child development centre. Children and their families usually receive a range of services, and the wait for each of these services varies greatly. For example, waiting for a caregiver consultation is presumably much shorter than waiting for one-on-one therapy. In reality, the "intervention" is usually a combination of consultation, intake screening or assessment, group therapy, parent education, or one-on-one intervention. The points at which children are considered off waiting (date off) could, thus, vary across programs, interventions, agencies, and children.

2.4 BASIC CHARACTERISTICS OF WAITING LISTS AND WAITING TIMES

In their comprehensive review, Sanmartin et al. (1998) highlighted some of the basic characteristics of waiting lists and waiting times. The most noticeable characteristic is the tendency of most elective interventions showing some degree of positive skewed distributions of waiting times. This may occur for a variety of reasons including actual long waits for some patients and/or some degree of unreliable data such as when cases

are not removed after treatment is received. Also, evidence exists suggesting some degree of variation in waiting times is often found across individual service providers, organizations, and geographic locations.

2.4.1 Skewed Distributions

A right skewed (or positive skewed) distribution has a long tail to the right when the number of people (or proportion) waiting at each time interval is plotted against the waiting times. For example, the waiting times for general and orthopaedic surgeries in a London hospital studied by Pope et al. in 1991 were shown to be highly skewed to the right. The analysis illustrated that the majority waited only 1-3 months before receiving surgeries, and a few others waited for considerably longer periods with some waiting over 5 years (Pope et al., 1991).

Another example comes from a caseload study of speech-language therapy services in the UK by van der Gaag et al. in 1999. The waiting times from referral to assessment and from referral to intervention for speech therapy, among the seven districts in the UK have also been demonstrated as highly skewed (van der Gaag et al., 1999). Of the seven centres, one was located within a children's hospital and 4 were community-based and hospital mix organizations[9] that primarily provide services to children. The other two were hospital based with mostly adult patients. The ranges of proportions for those waiting less than a week from referral to assessment and from referral to intervention were 34 - 49% and 22 - 50% respectively for the five centres providing speech and

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[9] These hospitals provide both acute care and community based health services for children.

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language services to mostly children clients. For those who waited 1- 4 weeks from referral to assessment and from referral to intervention, the proportions ranged from 14 - 38% and 10 - 28% respectively. For those who waited for more than 6 months, the proportion of clients ranged from only 0 - 2% and 0 - 15% for assessment and active intervention respectively.

Although evidence suggests that most waiting times in health care tend to be right skewed, and it is especially true for most elective procedures (Sanmartin, 2001), waiting times can also be left skewed (or negative skewed). The distribution is said to be left skewed when it has a long tail at the left of a distribution curve. In a prospective cohort study, Ehrmann-Feldman et al. (2002) examined the waiting times for physiotherapy and occupational therapy services at four rehabilitation centres for children in Montreal. No children received services within 30 days of referral. Only 12.2% of children referred to occupational therapy and 18.7% of children referred to physiotherapy waited 60 to 90 days for their first appointment. However, the majority of children in this cohort were still waiting at the end of the study period with 54% waiting for occupational therapy and 36% waiting for physiotherapy: waiting more than 180 days since referral. This illustrates a left skewed distribution of waiting times.

Therefore, it is important to assess the degree of skewness in waiting times in order to choose a proper statistical reporting method. Pope et al. (1991) reported an average waiting time of 10 months for general surgery in their analysis. This could be significantly misleading since the majority of patients actually waited for only 1-3

months. The authors chose to use the "mean" despite a highly skewed distribution. In this case, the use of "median" would be more appropriate since most patients receive service in less time than the reported mean.

2.4.2 Variations in Waiting List Sizes and Waiting Times

Both studies by Pope et al. (1991) and van der Gaag et al. (1999) discussed above also illustrated high degrees of variations in waiting times. Variation in waiting times can be observed at various levels of service providers (inter-consultant variation), organizations (inter-agency variation), and regions (geographic variation) as well as inter-procedure variation.

One of the objectives in the study conducted by Pope et al. (1991) was to determine the variation in composition and waiting time between surgeons working in the same hospital. It was noted that even within a hospital, surgeons of the same specialty had different waiting times and waiting list sizes. For example, between two orthopaedic surgeons, the proportions of patients waiting less than 1 year were 51.7% and 22.3%, with average waiting times of 15 and 8 months respectively. The waiting list sizes for these two surgeons were 238 and 265 patients respectively (Pope et al., 1991). No simple association appeared to exist between waiting list sizes and waiting times. The reasons for this inter-consultant variation in waiting times were not addressed in this study.

Waiting times are not usually homogenous across geographic regions. The study conducted by van der Gaag et al. in 1999 showed a high degree of regional variations.

Both districts 4 and 5 provided services to a similar client group mix (71-72% children). District 4 is a rural community with about 9.38 FTE speech therapists per 100,000 and District 5 is an urban community with 16.78 FTE speech therapists per 100,000. The percentages of clients waiting less than a week from referral to intervention were 22% and 45% in district 4 and 5 respectively. It appeared that children in the urban area tended to wait shorter periods of time because of a higher therapist-population ratio (i.e. greater capacity). However, other factors such as population of children, case mix, and travel distance by therapists were not investigated. A similar trend was also found in Montreal, Quebec, by Ehrmann-Feldman et al. (2002). Waiting times tended to be shorter for children living in the urban areas of Montreal. Although the variation may be attributed to differences in human resources, the variation can also be influenced by the models of service delivery and the existing policy of maximum waiting times among organizations (Pope et al., 1991). For example, some agencies have set a maximum of one week from referral to assessment.

Evidence exists indicating that substantial numbers of patients with prolonged waiting times were usually limited to a small number of hospitals and regions (Martin et al., 2003). In this study, waitlist information on 718,284 patients waiting for day surgery or in-patient elective procedures in England during the quarter ending December 1999 was examined. The results demonstrated wide inter-procedure and regional variations. For day surgery, 18-28% of patients had waited longer than six months compared to 29-40% for inpatient cases. Inter-specialty waits vary substantially as well. It was noted 28% of ophthalmic day surgery patients had waited longer than 6 months while the

corresponding figure of ear-nose-throat day surgery was only 18%. Between 52% and

83% of patients with prolonged waiting times were concentrated in 25% of the hospitals

clustering along the south coast and northwest of England as well as in London.

Consistent variation in waiting list sizes and waiting times among communities within a

geographic region (intra-regional variation) is also evident in early childhood intervention

in BC. Table 2.1 illustrates the waiting list information for infant development programs

of the Lower Mainland region (a major urban region of British Columbia). No clear

association between waiting list sizes and waiting times is present.

Table 2.1: Waitlist Information for Lower Mainland Infant Development Program

Lower Mainland Region*		
Community	Number of children on waitlist as of March 31, 2004	Average Waiting time (weeks)
North Shore	**	1
Coquitlam	**	3
Burnaby/New West	118	8
Vancouver	128	8
Upper Fraser Valley	133	14
Sea-to-Sky	15	6
Langley	16	2
Richmond	31	4
Delta	32	16
Ridge Meadows	34	2
Surrey/White Rock	47	16.5

Source: Infant Development Programs of BC Biennial Statistics 2003-2004
** North Shore and Coquitlam indicate that their agencies did not have a waiting list for service

2.4.3 Urgency and Prioritization

Not all waiting lists strictly follow the "first come first served" queuing method. In fact,

most waiting lists in health care systems incorporate some forms of prioritization

according to the urgency rating scales. One of the major challenges in deciding who

should have priority is by determining what urgency means; it can include clinical (e.g. pain) or other factors (e.g. employment) (McCormick et al., 2003). Furthermore, determining medically safe waiting periods can be rather complex. In general, waiting times were lower among urgent cases. In fact, emergent cardiac surgery does not have a waiting list. Most prioritizations use urgency scoring systems to assess the impact of anxiety, pain and suffering, function, loss of employment opportunity, and other factors. However, evidence-based protocols informing the prioritization process may not be routinely applied. For example, although significant association was found between urgency rating and waiting time, some anomalies existed. A few patients with higher urgency scores in fact waited longer (Pope et al., 1991).

In a recent Canadian study, Conner-Spady et al. (2005) assessed the relationship between the priority criteria scores developed by the Western Canada Waiting List project and the actual waiting times for hip and knee surgery. The study included 202 patients who were placed on waiting list for hip and knee antroplasty at two Alberta hospitals between December 2000 and June 2001.The correlation between actual waiting times and priority criteria scores was found to be weak although significant (R= -0.25. p<0.0001). In fact, no clear pattern of actual waiting time emerged across all levels of urgency score except at score 80 and above when actual median wait times were plotted against priority scores. Nevertheless, those patients with urgency scores 80 and above still appeared to have the lowest waiting time for surgery (Conner-Spady et al., 2005).

Sound waitlist management through prioritization can be one of the effective strategies in reducing the size of waiting lists. In the UK, the Darlington Children and Adolescents Mental Health Service (CAMHS), a specialist Tier 3 multidisciplinary centre, was faced with a substantial waiting list issue. The waitlist consisted of 99 families, and 39 had been waiting for over 13 weeks in April 2003. A pilot study of waiting list initiatives to ease waiting list problems was reported by Hayes and Caygill (2004). The initiative involved a review of all waitlisted families and assigned a priority based on information received in the initial referral. The code has three levels of priority: urgent, routine, and low. The solution to the waitlist and wait time problem was system re-design, involving a screening clinic which offered "low" priority families a short appointment. The review allocated a low priority classification to 46% of the waitlisted families. A quick appointment was offered to these families to assess whether they could be served by other services such as the Tier 1 and Tier 2 services which typically have shorter waiting times. This initiative reduced the waiting list by 85% in about 6 months with no families waiting more than 13 weeks (Hayes & Caygill, 2004).

2.4.4 Case Mix and Waiting Times

Case mix differences can account for some of the hospital-to-hospital variations in waiting lists and waiting times. In general, hospitals with more elective cases generally report longer waiting lists because elective cases tend to wait longer than urgent or emergent cases. Hospitals with a higher volume of complex cases also tend to have longer waiting lists and waiting times because more resources are required even though

the higher proportion of urgent/emergent cases might tend to decrease hospital specific waits.

A paucity of information exists regarding case mix and waiting time in early childhood intervention services. In the UK, child mental health services are provided by the Child and Adolescent Mental Health Services (CAMHS). CAMHS, as noted above, employs a tiered service framework to reflect the case mix according to the complexity of disorders and the requirement of specialists. Tier 1 consists of primary level care with service providers who do not necessarily possess specific skills of mental health care for children but are likely the first contact between a child and health care agencies. Tier 2 agencies are staffed by child mental health specialists who offer direct services to children and consultation to Tier 1 service providers. Tier 3 agencies offer specialized multidisciplinary services for more severe, complex, or persistent disorders. Tier 4 agencies are essentially tertiary level centres with highly specialized in-patient and out-patient units. Like most other NHS services in the UK, the CAMHS has been facing the problem of increasing demand and long waiting lists. Tier 1 and Tier 2 services usually have shorter waiting times than Tiers 3 and 4 services (Hayes & Caygill, 2004).

Information about the case mix needs to be considered when interpreting waiting time reports. Similarly, a tiered service framework has not been discussed widely in the field of early childhood intervention, and characteristics of waiting times relating to the tiered service framework are relatively unknown.

2.4.5 Queuing Theory

The arrival of patients to a health care organization appears random in nature, and many have suggested using queuing theory (which assumes random arrival at a queue) to study waiting times. Queuing theory, a mathematical model, has been applied to many aspects of health care services including the emergency department, the critical care unit, and the pharmacy (McManus et al., 2004; Nosek & Wilson, 2001; Scott et al., 1978). Queuing theory is used to study the phenomenon and the relationship of standing, waiting and serving. The average total waiting time may be modeled using queuing theory with some basic assumptions. In general, a simple queuing model is used to describe the processes of patients' arrival, patients' waiting for prescribed intervention, the receipt of service, and their departure from the system (Singh, 2006). Most classic queuing models have been based on a Poisson distribution of patient arrival and the exponential probability distribution of service times. This exceedingly simple relationship may help explain the demand and service delivery. For example, McManus et al. (2004) were able to use a queuing model to predict admission and turn-away rates for critical beds with available resources. By using real data and simulation, the authors were able to use queuing theory to demonstrate an exponential increase in the number of turn-away admissions (since critically ill patients could not wait for beds, they were rejected or diverted to other facilities) when capacity utilization exceeded 80-85% (McManus et al., 2004). Although McManus et al. (2004) were able to validate the model using real-world data, limitations remained in using such a model to analyze the real-world queuing processes. Most queuing models require the assumption of a queuing method of "first come first served" as well as the assumption of a constant patient arrival rate and unchanged service time.

However, it is now clear that most waiting lists allow urgent case patients to jump queues and seasonal fluctuations of demand and supply are usually present in most health care settings.

2.5 METHODS OF MEASURING WAITING TIMES

2.5.1 Study Designs

Different methods have been used in waitlist and waiting time research literature (Sanmartin et al., 1998), and each answers a slightly different question. The more commonly discussed and used methods include:

1. **Retrospective**: This method answers the question of how long did patients who recently received their treatment have to wait for their service or procedure. This method does not provide information on patients who are still on a waiting list and those who are removed from the list for reasons other than getting treated.

2. **Prospective**: This method answers the question of how long do patients placed on a list (after a certain date of interest such as the beginning of the study period) have to wait for their service or procedure. This is sometimes referred to as the "cohort method" which follows patients from the time they are on a waitlist until they are removed from the list.

3. **Cross-sectional**: This method answers the question of how long do patients

    currently on a waitlist have to wait. This reflects the times between the date when

    patients are placed on the waitlist and some arbitrary cut-off date (date of interest

    such as last date of the month, or last date of a study period).

A cross-sectional method is commonly employed when an administrative database is

used to report patient waiting times. It provides a snapshot of current waiting time

information. The inherent bias of this method was identified by Don and Goldacre

(1987). Waiting time information derived by this method could be easily dominated by

the longer waiting times. Patients who are experiencing longer waiting times would have

a higher probability of being counted in the cross-sectional data (Don & Goldacre, 1987).

Retrospective and prospective approaches do not usually yield quite the same information

because not all patients on a waitlist will eventually receive the intervention. Sobolev et

al. (2000) demonstrated the differences in waiting time determination using both

retrospective and prospective methods. They followed 1084 consecutive cases for

vascular surgery intervention between 1994 and 1998. Among these patients, 985

received surgery, and 14 were still waiting at the end of the follow-up period (i.e.

censored). Furthermore, 85 (7.8%) were removed from the list without surgery. The

median waiting time for admission was 6 (95%CI, 5 - 6) weeks for a retrospective design

and 7 (95%CI, 6-7) weeks for a prospective design (Sobolev et al., 2000). The differences

in mean waiting time were even greater.

In the retrospective method, only patients who received care will be sampled, and those who are removed from the list because of other reasons are not included in the wait time evaluation. In the prospective method, waiting time is determined for each patient as she/he is added to the list. Waiting times are followed forward in time. If a patient is removed from a list without receiving service, the observation of this patient is considered "right censored." This censored information provides some indication that the waiting time was less than it would have been. If the censored observations are not accounted for, estimated probabilities of receiving the services may be biased toward a higher rate. Both the median and mean waiting time may be underestimated (Don & Goldacre, 1987). This bias could be substantial if the drop out (off waitlist for reasons other than receipt of surgery) rate is high.

Patients' dropping out from a waiting list before receipt of care is not unique in hospital based services. In the field of early childhood intervention, it is also not uncommon to observe that families and children leave the early intervention waiting list before services are provided. To date, the extent and impact of the dropping out on waiting times have not been studied.

2.5.2 Summary Measures

Descriptive studies on in-patient and out-patient hospital waiting times reviewed by Sanmartin et al. (1998) have provided some basic information regarding the frequency distribution of waiting times. A number of summary measures for waiting times have also been identified in the literature.

The central tendency measures such as mean and median are commonly used to report waiting times. It is now well recognized that waiting times for most elective procedures are short and tend to have a right skewed distribution. The mean waiting time tends to reflect the wait experiences by patients at the bulky part of a distribution curve (Pope et al., 1991). Although mean waiting times have been used widely, and "mean" is usually statistically powerful when making adjusted statistical comparisons, it is highly sensitive to outliers. Reporting the mean waiting time alone will not be very informative since it does not reveal the wait experience of those who fall outside the clustering of wait times for most people. Thus, reporting the median waiting times is often used in conjunction with average waiting times.

The median waiting time reflects the 50% value of a list of waiting time experienced by a group of patients in a cohort (i.e. 50% of patients are above and below the median). Differences between means and medians are usually minimal when the frequency distribution is close to normal. However, in some circumstances, the differences can be enormous when the average waiting times are significantly skewed by even a small number of cases with unusually long waits. Median waiting times are often reported in the literature because the values are not influenced by outliers but could be problematic if there are a lot of them relative to the total number of patients.

 The use of percentiles (e.g. 90% patients waited less than 3 months) and other aggregated methods such as pre-determined waiting time categories of waits (e.g. less

than 30 days, 31- 90 days, 91 – 180 days, etc) are also commonly used because they are not affected by the outliers. However, the use of these methods using data group by time period renders some loss of information. For example, central tendency and variability of observations cannot be determined.

2.6 WAITING LISTS AND WAITING TIMES IN THE CONTEXT OF EARLY CHILDHOOD INTERVENTION

In the field of early childhood intervention services, a general theoretical framework outlining a comprehensive range of factors associated with waiting list size and time is currently lacking. Factors related to the nature and characteristics of waiting list and waiting time to date come mostly from surgical and acute care literature. For example, a host of non clinical factors may influence the length of waiting times in the health care system. De Coster (2005) investigated the relationship between waiting times for cataract surgery and a variety of non clinical characteristics such as sex, age, region of residence, and surgeons. In a cohort of 6114 patients who had their first eye cataract surgery performed between November, 1998 and March, 2000 in Manitoba, it was found that the most influential factor was the choice of surgeons (De Coster, 2005). The median waiting times varied widely by surgeons ranging from 61 days to 399 days. Multiple regression analysis indicated that the choice of surgeons alone could explain 29.5% of variance. Age and sex were also found to be significant factors associated with waiting times in this study with a retrospective design. Female patients and older individuals tend to wait longer. It was hypothesized that surgeons might have given the employable individuals (generally males) higher priority for surgery. The threat of lost productivity might have

given an advantage to younger male patients in terms of waiting times. In this cohort, 85% of patients were 65 and older, and oddly enough the surgeons appeared to think that female patients were less likely to drive or were employed in that age range.

There are still gaps in the information regarding a whole range of patients, physician, and hospital factors that may affect waiting lists and waiting times. A number of factors have been hypothesized to affect waiting lists and times for various health services including a lack of resources (Shorrt & Ford, 1998). However, studies have shown that an increase in funding will often only reduce waiting lists temporarily (Hanning, 1996). Other potential factors have also been implicated to affect waiting lists and waiting times for services in a publicly funded healthcare system. This includes patients' clinical burdens and the physicians' association with the hospital facilities (Atler et al., 1999) as well as organizational characteristics such as global budgets of a healthcare system or institution and the level of physicians' functional autonomy (Baker, 1994). For example, a tightly capped global budget is thought to be associated with long waiting lists. Moreover, given a choice, physicians typically will choose to make patients wait, rather than deny patients clinically effective services through rationing (Baker, 1994).

Access theory has been identified as one of the key frameworks used by various researchers to facilitate their understanding of waiting times and waiting lists (Aday & Andersen, 1974; Donabedian, 1973; Sanmartin, 2000). These key concepts will be used for the following discussion of waiting list and waiting time for early childhood intervention services.

The Lesson Learned from Hospital Based Services

Sanmartin (2000) illustrated a conceptual model to study the waiting time for 3 elective surgical procedures (hip replacement, cataract extraction and knee replacement) based on the "access to care" framework. Hypothesized factors considered in the model development include hospital, physician, and patient factors. Among these, patient characteristics were found, reasonably, to be the most significant group of factors affecting waiting times. Specifically, the patient's clinical status and waitlist placement were consistently found to be highly significantly associated with waiting times. Shorter waiting times seemed to be associated with more urgent clinical status in most cases. A similar model for the field of early childhood intervention services is lacking. The following sections will describe some of the relevant variables that can be considered to develop a similar conceptual framework for studying waiting time for early childhood intervention services.

 According to Donabedian (1973) and Aday and Andensen (1974), access-to-care can be classified as socio-organizational accessibility and geographical accessibility. Socio-organizational accessibility signifies the concept of how all the characteristics of a community and health organizations affect the consumption of health care resources. These characteristics include service provider characteristics, family characteristics, and local community factors. On the other hand, geographical accessibility relates to the spatial characteristics of the health organizations to the location of the consumer's residence and traveling time. For early childhood intervention services, Donabedian's approach to access-to-care can be modified to conceptualize the factors that explain the

variation in waiting time across time and communities. These factors include the service

provider and health care organization's characteristics, the child's characteristics, and

family characteristics considered in the development of the conceptual framework are

outlined in Figure 2.1.

Figure 2.1: Factors Affecting Waiting Lists and Waiting Times for Early Intervention Services

Child factors
- Age
- Diagnosis
- Age first diagnosed
- number of services

Family factors
- Age/gender
- Education/income
- Knowledge of system

Provider factors:
- Area of training
- Years of training
- Referral practice
- Caseload
- Waitlist management

Organizational factors:
- Staffing level
- Budget
- Caseload
- Waitlist management

Community factors:
Resources
Economy

Geographical factors:
- Urban: Rural
- Location of services
- Traveling distance/time

Socio-organization Accessibility

Geographical Accessibility

Waiting time

Explanatory variables

Dependent variable

Child Factors

In hospital based services, it has been demonstrated that patient factors (except demographics variables) explain most of the variations in wait time (Sanmartin, 2000). For example, patients with an urgent or emergent status have a much shorter wait. Patients' gender, age, and type of residence appear to have less effect on their wait time for elective surgeries in British Columbia. Given that the premise of early intervention is to intervene as soon as possible when a developmental concern is identified, the child's age is expected to be a significant factor affecting the waiting time for intervention. Ehrmann-Feldman et al. (2002) found that age is inversely related to waiting time for the first appointment at children rehabilitation centres. Moreover, the nature of developmental delay and disability may sometimes reflect the urgency of intervention. Waiting time is expected to vary according to the child's developmental needs. Early childhood intervention services provided in certain child development centres often consist of multidisciplinary teams; thus, waiting time may vary depending on the service disciplines that the child needs. It is not uncommon that a child is referred to more than one discipline. The number of different disciplines or types of services within the organization required may also affect the waiting time, and each discipline may have its own waitlist and waiting time.

Family Factors

Parental help-seeking behaviour can be an important factor affecting waiting time. It has been demonstrated that empowering parents has been associated with a decrease in their child's waiting time for health care and therapy services (Ehrmann-Feldman et al., 2002;

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Fox et al., 1993). Parents who can articulate their needs and manoeuvre within the health system may access services more quickly for their children. Parental empowerment and help-seeking behaviour have also been shown to be associated with socio-demographic factors such as parental education level, occupation, and household income (Cooper et al., 1998; Sexena et al., 1999).

Service Provider Factors

It is known that physicians' high surgical workload significantly increased their patients' waiting time (Sanmartin, 2000). Similarly, a service provider's high workload is expected to be positively associated with waiting time for early childhood intervention. The amount of time and the frequency that a service provider spends with the clients will also affect the waitlist size and waiting time. It is not uncommon that a service provider is the sole therapist or intervention consultant in some agencies. Waiting time can be longer if the sole service provider needs to take a leave. The years of experience of service providers and their service (therapy) styles can also directly influence the waiting time. Presumably, clinicians with extensive experience are more efficient in managing the waitlist because of higher output. Similarly, the clinician's preference of practice style (group therapy versus one-on-one therapy) can greatly affect the waiting time. Thus, service provider characteristics including training and experiences, practice style, sole charge, and workload can be considered as relevant variables that affect waiting time.

The Health Care Organization Factors

In British Columbia, early childhood intervention services are provided mostly through community agencies which operate independently of each other. Thus, the practice and management of waiting lists by individual organizations can directly affect the waiting time. Characteristics of a health care organization including case mix, global budget, staffing level, caseload, and method of waitlist management have all been implicated to be closely associated with waiting lists and waiting time. An indirect organization level factor, hospital slow down, has also been identified to be significantly associated with waiting time (Sanmartin, 2000). Patients who are placed on a waitlist just prior to or during a slow period (e.g. holidays) are likely to wait longer. In the field of early childhood intervention, periods of "slow down" also exist. Seasonal variation may occur in referral rate and waiting time. For example, summer months are considered "slow down" periods because many service providers are likely to take breaks (SCDP survey report, 2002). It is important to note that waitlists fluctuate throughout the year; thus, the time frame for which data are requested may reflect an increase or decrease in referrals and waitlists. For example, the months of June and July are considered a slow time of the year for new referrals and typically reflect a period of reduced waitlists in some agencies. This is reflected in the month-to-month variability in waiting times within an organization.

The Community and Geographic Factors

Access to early childhood intervention services clearly depends largely on the availability of services. Thus, geographic factors such as urban and rural settings can be critical. This

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is also related to the characteristics of organization. Some agencies provide solely centre-based programs while others offer mostly outreach based services. If services are needed to cover a vast geographic area, likely the case for agencies serving rural communities, service providers, or families may need to travel a great distance to provide or receive services. It is hypothesized that waiting times for these agencies tend to be longer.

Waiting times have generally been hypothesized to be associated with the demand of services. If a region is experiencing an increase in children identified (e.g. due to newly implemented screening programs) with developmental concerns or disabilities, waiting times for this region will likely increase as well. Other community characteristics that can potentially affect waiting time include population distribution of age (such as proportion of young families and young children living in the region), and prevalence of children with special needs.

2.7 COMMON FRAMEWORK OF DEFINING WAITING TIMES FOR EARLY CHILDHOOD INTERVENTION SERVICES

One of the major obstacles to understanding the true state and extent of waiting for care in Canada's health care system is the absence of accurate and comparable waiting list information.

(Western Canada Waiting List Project, 2001)

In the final report of *From Chaos to Order: Making Sense of Waiting Lists in Canada* by the Western Canada Waiting List Project (2001), the project working group has made this observation. This has highlighted the importance and urgency of establishing a common framework for defining the waiting times in the field of early childhood intervention services as well.

In Canada, after the release of the ten years plan of reducing waiting times, regional governments struck a committee to identify comparable indicators of access for the five priority areas listed by First Ministers. The five priority areas are cancer, heart, diagnostic imaging, joint replacement, and sight restoration. The committee members agreed on establishing common definitions and measures of wait times across jurisdictions as the starting point (Health Canada, 2004).

In order to have a consistent definition of waiting time, Sanmartin and colleagues (2003) proposed several standard paths to care for selected diagnostic and surgical procedures. A standard path-to-care would help identify all the potential wait periods faced by patients. For the surgical wait times, the waits were identified as (Sanmartin & the Steering Committee of the Western Canada Waiting List Project, 2003):

1. **Wait# 1**: Waiting for the first consultation with a primary care provider (family physician),

2. **Wait# 2**: Waiting for the initial consultation with a specialist.

3. **Wait# 3**: Waiting for a treatment decision. There may be waits for diagnostic procedures (wait# 3a) and a subsequent surgical consultation (wait# 3b).

4. **Wait# 4**: Waiting for surgery. This may be defined as the time between the date of decision to treatment and the date when surgery is done (wait# 4a). Alternatively, this may be defined as the time between the dates of booking and the receipt of surgery (wait# 4b).

Similar discussions about the definitions of waiting times for early childhood intervention services are completely lacking. Understanding the characteristics of waiting time for early childhood intervention requires an evaluation of the service delivery process. This process provides a pragmatic way of identifying all potential wait periods and guides a design for a wait time data collection system. The Developmental Systems Model of early childhood intervention is a framework of describing a pathway of service delivery for community-based early childhood intervention services (Guralnick, 2001). This model helps visualize each potential waiting period faced by children and their families in a similar way to that of the acute care setting as described by Sanmartin and the WCWL group (2003). The service delivery pathway described by Guralnick's Developmental Systems Model for early childhood intervention can be outlined by the following simplified steps, and the potential wait periods can be identified in the following way:

1. The entry into the early childhood intervention system starts from a screening process (or a referral from health professionals directly to child development centres or agencies when a child's disability is established before).

Wait#1: Waiting for a screening process when the parent or community professional raises concern about the child's development.

2. If a concern is raised from the screening program, the child will be referred to the appropriate child development centres for a comprehensive assessment to determine the eligibility for early childhood intervention.
Wait # 2: Waiting for a comprehensive assessment. It might be defined as the time between referral to a child development centre and the date of assessment.

3. If the child is eligible for an intervention program, a needs assessment of the child and his/her family will be conducted. An intervention strategy begins to be formulated.
Wait# 3: Waiting for the needs assessment (wait# 3a) and waiting for Individualized Family Service Plan (wait# 3b) which outlines the intervention goals and strategies for the child and family.

4. If the intervention has a waiting list. The child will be placed on the waitlist and wait for the intervention (wait#4).

The Developmental Systems Model provides a general framework for community-based early childhood intervention services and supports for vulnerable children and their families. The infant development program (IDP) of BC is an example of one of the many ways in which the framework can be implemented. Using processes similar to the Developmental Systems Model, the infant development program holds that early assessment and intervention should follow a specific sequence, involve multiple sources of information, include observations of the child with his/her caregiver, and be seen as a first step in designing an appropriate intervention process (Goelman et al., 2005).

The general service delivery process in which waiting times can be identified at various stages for infant development programs is illustrated in Figure 2.2. The process begins when an infant development program (IDP) in the community receives a referral from a family member or from a community professional. Following a telephone contact, an IDP

Figure 2.2: Model of Service for Infant Development Program of BC
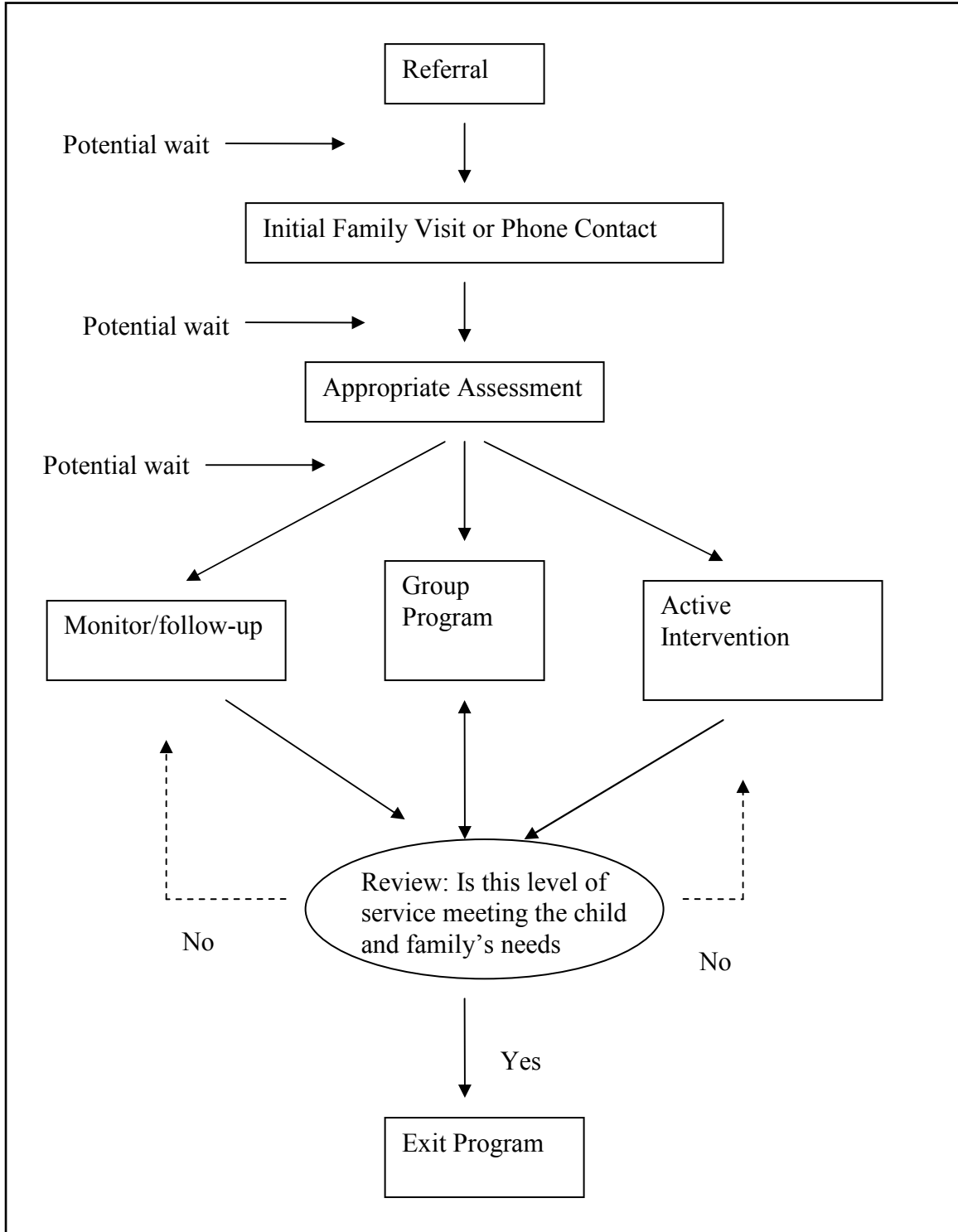
Redrawn from IDP-BC Policy and Procedures, 2004 with permission given by The Office of Provincial Advisor of Infant Development Programs of British Columbia

consultant may also arrange a family visit to explain the program. If the family decides

that it wishes to work with the IDP consultant, the assessment process begins with a

family needs assessment. The family and the infant development consultant will then

decide whether it is appropriate to proceed with a developmental assessment of the child

and/or whether they wish to consult with other health care and/or intervention

professionals. If the family decides to work with IDP, then they may choose from among

three levels of service:

1. Monitoring the child's development and/or periodic follow-up assessments.
2. Enrolling the child in appropriate group programs and activities.
3. Conducting active one-on-one intervention with the child and family involving
   regular home visits.

These services differ in terms of intensity and frequency of contact with the family and

also in the extent to which the services are provided to individual children at home or in a

group program in the community. With the active one-on-one intervention, an

individualized family service plan will be developed based on child and family goals. The

family receives regular home visits from an infant development consultant, as well as

ongoing consultation with other health and therapy professionals. Group program

activities involve the family's participation in playgroups, parent groups, and more

specific groups such as the Parent-Child Mother Goose Programs, or a therapy group for

monitoring the child's development.

The infant development program approach differs from the Developmental Systems Model in the degree of linearity in the service delivery process. The infant development consultant and the family periodically evaluate whether the level of service chosen is meeting the child and family's needs. As the child's condition changes, the levels of service may be adjusted through a review consultation. This provides a more flexible (non-linear) movement along the service delivery pathway and between the various levels of service.

Some factors may alter this model in terms of sequence of events or the nature and/or level of services (Goelman et al., 2005):

1. Long waiting lists may exist for other specific services (e.g. speech and hearing assessment) which often result in delays in decisions and referrals.

2. Financial, staffing, or administrative difficulties within specific agencies can affect service delivery.

3. Some parents may be reluctant to participate in an intervention program or to receive suggestions for specific assessments and/or interventions.

4. A professional in a specific community may have made an inappropriate referral.

5. Some agencies sponsoring IDPs may not be fully practicing family-centred care and may have separate intakes and assessments or multidisciplinary procedures that affect the capacity of IDP to implement this model.

The Developmental Systems Model includes many steps and decision points between the initial referral and the child's actual receipt of active intervention. On the other hand, early childhood intervention programs in most BC communities tend to have a simpler referral and intake process (Figure 2.2).

The Community Child Development Centre

Most community child development centres in BC offer a variety of early childhood intervention programs including intervention therapy services, infant development, and/or supported child development. Most have similar referral and service delivery processes as outlined below:

1. The referral can be received from a family, physician or other community professionals by fax, letter, phone call, or walk-in by the family.

2. The preliminary intake assessment determines eligibility for service.

3. The initial consultation represents the first significant encounter between family and agency personnel for additional information and medical history.

4. The formal assessment or comprehensive assessment to (i) confirms eligibility and/or (ii) formulates Individualized Family Service Plan.

5. The intervention received by children.

6. The discharge from program (child may be transferred to another programs within agency).

7. The complete discharge from agency.

By constructing a pathway-to-care, Sanmartin and colleagues (2003) identified various wait periods for surgical and diagnostic services through a consensus process involving stakeholders from various medical communities. Borrowing from this approach and using the Developmental Systems Model, potential wait periods in the field of early childhood intervention can be identified. Figure 2.3 illustrates such a service delivery pathway in the context of early childhood intervention services as well as the respective potential waits along the service pathway. The construction of this pathway is largely based on both Guralnick's Developmental Systems Model, the Infant Development Program and service delivery models of community child development centres in BC. The general stages of service delivery for which children and families are likely to experience some wait include:

1. Waiting for the initial consultation with family (or intake orientation),

2. Waiting for the comprehensive assessment for formulating the individualized family service plan,

3. Waiting for the intervention, which can be caregiver consultation, group activity or one-on-one intervention, and

4. Waiting for the review consultation, which may lead to a change of intervention strategy or to exit from the intervention program.

Figure 2.3: Preliminary Model of Service Delivery Pathway
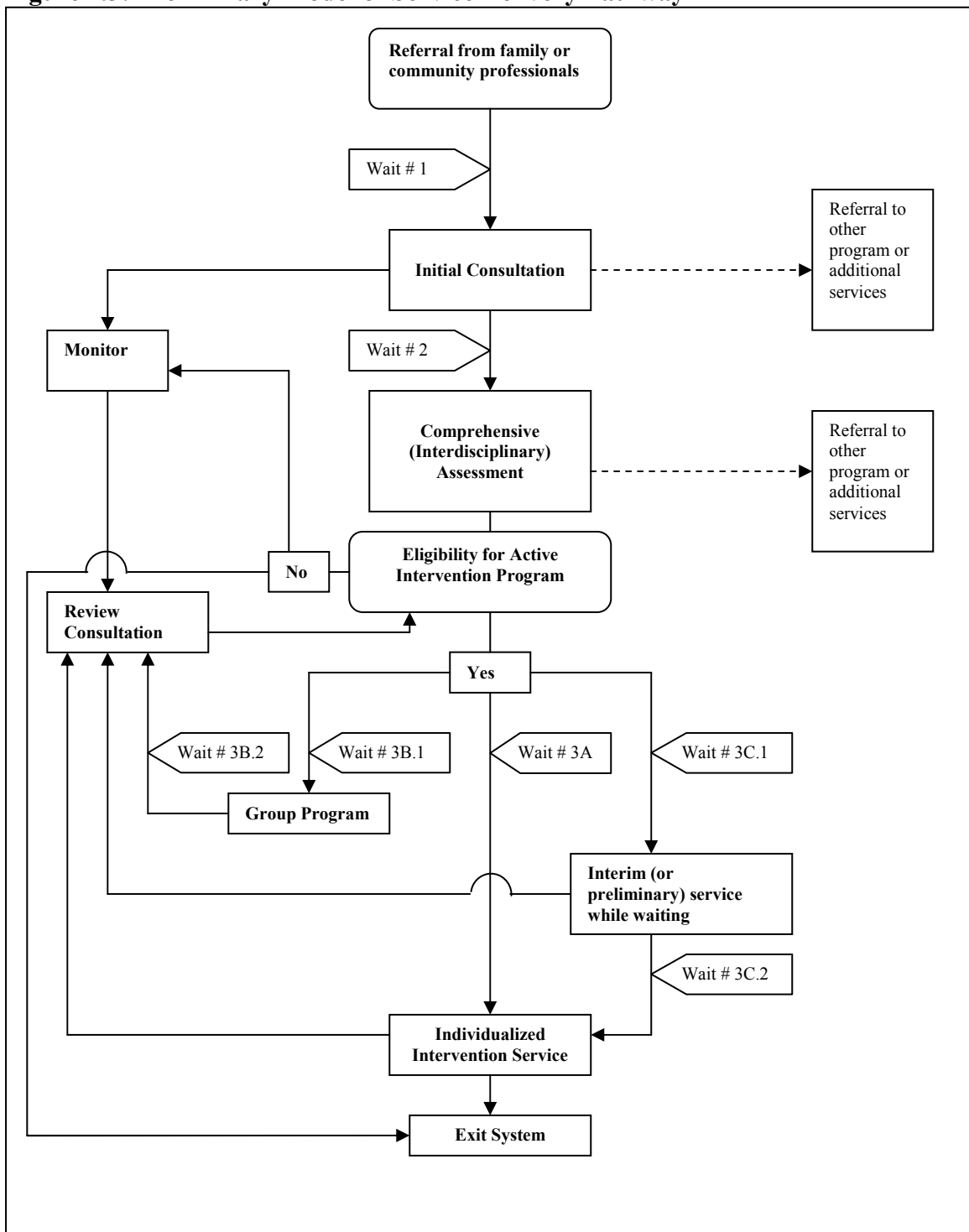
*Possible Wait Periods can be identified for early childhood intervention services. This preliminary model was presented to focus group participants for discussion.

This preliminary model (Figure 2.3) was presented to focus groups for discussion on common wait time measures which will be described in Chapter 5.

The Referral

The process starts when parents/caregivers or community healthcare professionals raise concerns about the children's developmental progress or parents/caregivers seek help to promote the development of their children who are at risk of or living with physical or developmental disabilities. The entry into the early childhood intervention program usually begins with a referral made by the parents themselves, a hospital, or community professional such as family physician, paediatrician, social worker, family support worker, public health nurse, or paediatric therapist.

The Initial Consultation

Most agencies will normally respond to a new referral by providing an initial (or intake) consultation. The waiting between referral and the appointment for an initial consultation is likely the first wait that most families will experience (Wait #1). The initial consultation represents the "first point of access" in which families obtain information about the intervention programs, the available services, and the service eligibility criteria. During this session, agencies may gather additional information about the children and families that is not recorded in referral letters. At this point, families may decide whether they will participate and work with the agencies or seek other services that are more suitable to their needs. From these first encounters, service providers may be able to obtain enough information to determine the nature of risk (whether it is biological,

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developmental or, environmental), to identify the child's developmental needs and to understand the family's priorities. This information is important for making initial service plans and providing interim services to families if needed. A comprehensive assessment and/or referrals to additional services or other programs outside the agencies may be arranged at this point if needed.

The Comprehensive Assessment

After the initial consultation, service providers may organize one or more comprehensive assessments (or comprehensive *interdisciplinary* assessment if a multi-program agency is involved). This formal assessment is an essential step for establishing or confirming diagnosis and severity of delays or disabilities, guiding an individualized service plan and making intervention recommendation. The wait between initial consultation and the comprehensive assessment appointment is defined as the second wait that children and their families may experience in the early childhood intervention system (Wait #2).

Although most children are usually eligible for the intervention services at this point, a comprehensive assessment is sometimes required to determine the eligibility because clinical judgment at the initial consultation without a formal assessment can only represent the best guess of what the child's real needs are. If a child does not meet the immediate intervention criteria, he/she may be put on a monitoring program or referred to other services.

Following the comprehensive assessment, families may receive immediate feedback regarding their child's performance, eligibility, and recommendation of intervention strategies. Depending on the needs and severity of delays or disabilities, children may be recommended to an individualized (one-on-one) intervention program or group program. In some cases children may be referred to other additional programs within the agency.

The Individualized Intervention Program

If families and the service provider agree that an individualized (one-on-one) intervention program is required, they will then wait for their first appointment for the recommended intervention program. The first appointment for the recommended intervention service represents the end of the last wait in the early childhood intervention system (Wait #3A). At this point, referred children will begin receiving regular therapy sessions with a paediatric therapist for a therapy intervention program, regular home visit program by an infant development consultant, or a support consultation by a supported child development consultant.

The Group Program

A number of agencies provide group activities or programs to children and their families. These can be drop-in or scheduled (by appointment) group programs in which a few children with similar needs can be seen by service providers in a group setting. Some group programs are in a form of an educational session in which intervention service providers teach parents or primary caregivers to work with their children at home. Families are sometimes offered group programs as interim services while they are

waiting for either further assessment or active intervention. Families may decide to enrol

their children in a group program if it meets their needs. It is not uncommon for service

providers to refer children to a group program as the primary form of intervention

because it is the most appropriate form of intervention for their developmental needs

which may be still evolving. Generally, it is hypothesized that the wait (wait #3B) for a

prescribed group program is minimal.

The Monitor Program

After the Initial Consultation or Comprehensive Assessment, some children may enter

into a monitor program because the initial observation or assessment may suggest that

monitoring is sufficient for the child's developmental needs. Monitoring represents

infrequent contacts with the families for updates on their child's developmental progress.

One of the primary functions of monitoring is to provide a safety net for children whose

developmental concerns may not meet the criteria of immediate attention, as well as for

children who are on a long waitlist for services and who may have functional

deterioration while waiting.

The Review Consultation

The function of the Review Consultation is to re-evaluate service levels and the

child/family's needs and priority after some services have been provided. Children under

the monitoring program may be recommended for a review consultation when subsequent

developmental issues emerge. Similarly, children receiving interim services while

waiting for active intervention may be recommended for a review consultation if their developmental patterns change.

Interim Services

At any point along the service pathway, a child can be referred to additional services or other community programs. Some waiting families may begin to receive interim (preliminary) services including playgroups, consultative or educational sessions, and/or referrals to other community services. An example of interim services can be found from an information pamphlet:

> *We have policies that all departments will see the*
>
> *child/family up to 5 times in the first few months even if there*
>
> *is a waiting list for their individualized therapy. The purpose*
>
> *of the quick response is to meet the immediate needs, provide*
>
> *parent training and education, and begin any needed*
>
> *external referrals.*
>
> Ridge Meadows Child Development Centre

2.8 SUMMARY AND INFORMATION GAPS REGARDING WAITING LISTS

AND WAITING TIMES FOR EARLY CHILDHOOD INTERVENTION

Waiting list size and waiting time are two primary measures of waiting list data. It is now

clear that the length of waiting times for any given health care services can be affected by

many factors. In the acute care setting, these include changes of patient health

conditions, types of medical interventions, human resources, referral patterns, patient

preferences, other resources, organization management practices, and other non clinical

factors. Very few studies have addressed waiting list and waiting time information for

children needing early childhood intervention services.

Waiting times vary significantly at various levels of service provider and region. There

appears no simple causal-relationship between the size of waiting lists and waiting times.

Furthermore, variations in waiting time can be due to true differences or the lack of

universally accepted definitions.

Little is known about the acceptable waiting time for early childhood intervention and

how waiting can affect outcomes in the short and long terms. Many agree that they

should be based on clinical evidence to ensure that patients do not suffer adverse clinical

effects due to waiting (McDonald et al., 1998).

In summary, waiting lists and waiting times for health care services have been an issue

for many publicly funded health care systems. To date, the majority initiatives of

studying and reducing waiting lists and waiting times have been primarily focused on

hospital based services and most services are provided to the adult population. Very few have focused on child health services. The literature review has confirmed that research on the nature and characteristics of waiting lists and waiting times in the context of early childhood intervention is very limited. The following chapters will describe an exploratory study on the current waiting list and waiting time information for early childhood intervention services in British Columbia.

CHAPTER 3

DATA AND METHODS

As discussed in Chapter 2, limited research has specifically investigated waiting lists and waiting times for early childhood intervention services. In order to gain a broader perspective of the current state of information, this study utilized both quantitative and qualitative methodologies. Quantitative methods are more suitable to theory testing and prevalence determination while qualitative methods may be used when relatively little information is available about the research subject area (Morgan, 1993; Sandelowski, 2000; Thorne, 2000). Data for this study were obtained from a questionnaire survey of agencies, follow-up interviews, individual agencies' administrative data, and focus groups. The study was reviewed by the University of British Columbia's Behavioural Research Ethics Board. Ethics approval for this study was obtained on December 9th, 2004 (UBC BREB # B04-0797, Appendix A). This chapter will first provide an overview of the utilization of administrative data and the analytical methodologies commonly used in waiting list and waiting time research. It is then followed by an outline of the project design and analytical approaches for this study.

3.1 DATA AVAILABILITY

Information derived from hospital medical charts is considered the 'gold standard' of obtaining reliable waiting time data by most researchers (Shorrt et al., 2004) . The hospital health records often maintain information such as the date of admission, the date of decision to treat, the diagnosis, the physician identifier, the first and last dates of consultation visits, surgery date (usually from surgical dictation notes), and the procedures performed. The date when a patient is placed on a waiting list can also be reliably abstracted from a surgeon's or specialist's letter to a referring family physician.

Most community programs and child development centres also maintain fairly comprehensive information about their clients. The information includes the date of referral, the date when specific services were provided, the program admission date, reasons for referral or diagnosis, the type of intervention program, detailed consultation notes, and basic client demographics in their paper files. Waiting times for various appointments including initial contact, assessment, and treatment appointments within agencies may also be derived by chart abstraction from consultation notes and intake forms. However, chart abstraction is time consuming and is not an efficient way of assessing information on waiting lists and waiting times involving multi agencies and/or large sample size studies.

An alternative to chart abstraction is the use of electronic administrative databases. Administrative data have been widely used to examine waiting lists and waiting times for a number of elective hospital based services. Although administrative data are generally

not designed to report on waiting list and waiting time information, it has been

demonstrated that waiting times can be reliably derived from various administrative

databases. Therefore, when a central data repository is available, and the validity of

measures has been assessed, the use of administrative data can be an effective and

economical way of monitoring waiting lists and waiting times (Sanmartin, 2000; Shorrt et

al., 2004).

A number of Canadian studies have used a variety of administrative databases to examine

waiting times for elective medical services (De Coster, 2005; De Coster et al., 2007;

Levy et al., 2005; Sanmartin, 2000; Shorrt et al., 2004; Sobolev et al., 2000; Sobolev et

al., 2001). The most commonly used databases are the surgical waitlist registry in

combination with the provincial physician billing data and hospital separation data. In

BC, the medical service plan (MSP) billing database keeps all records of payment by the

Ministry of Health Services for all physician services on a fee-for-service basis. The MSP

billing database maintains a record of patient MSP numbers, physician encounter dates,

physician identification numbers, service and procedure codes, diagnostic codes, and

basic demographic information on patients such as sex, date of birth, and postal code[10].

The hospital separation database maintains a record of all hospital separation in the

province. The database includes information on all services provided to patients and

information regarding diagnosis, services and procedures, physician identifier, basic

patient demographics, relevant appointment dates such as hospital admission dates and

surgery dates, and discharge dates. The hospital separation data and MSP data are part of

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[10] BC Health Linked Database, Medical Service Plan Masterfile, Website:
http://www.chspr.ubc.ca/files/data/tables/msp.htm. Accessed on March 2, 2007

the BC Linked Health Database jointly established by the Ministry of Health of British Columbia and the Center for Health Services and Policy Research (CHSPR) at the University of British Columbia.

The Ministry of Health Services has also been maintaining a Surgical Waitlist (SWL) Registry since 1994 to track waiting times and waiting list sizes for a wide range of surgical procedures. Currently, waitlist information is collected from individual hospitals through the regional health authorities. The Ministry, then, records and aggregates the reported data into the Wait List Registry. The information is intended to provide information on every single patient currently waiting for selected surgical interventions as well as historical cases. The Wait List Registry covers about 95% of the total scheduled surgeries in BC, from about 1,100 doctors at 41 of BC's largest hospitals[11]. Waitlist for cancer services such as radiotherapy and chemotherapy is monitored by the BC Cancer Agency while waitlist for heart surgery is monitored through the BC Cardiac Services.

Sanmartin (2000) assessed the validity of waiting time measures by linking SWL data, hospital separation data, and MSP data for four elective surgical procedures. Probabilistic linkages were able to identify about 70% of patients. The proportion of patients who were placed on waiting lists according to the SWL data after the last surgical consultation visit were found to be 63%, 67% , 77%, and 54% for knee replacement, hip replacement, cardiac, and cataract surgery respectively. The proportion of patients taken off of waiting

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[11] BC's Ministry of Health Services, website: http://www.health.gov.bc.ca/waitlist/ Accessed on June 23, 2007

lists upon receipt of treatment were found to be 90%, 89%, 92%, and 98% for knee replacement, hip replacement, cardiac, and cataract surgeries respectively. Thus, the date on waiting lists was less consistently defined while the date off waiting lists was reliably recorded.

The length of waiting time will depend on the choices of tracking methods. With the SWL data, waiting time can be calculated by taking the difference between the date when a patient is placed on a waiting list and the date when treatment is received. With MSP data and hospital separation data, the date on a waiting list can be marked either by the last surgical consultation visit or the first surgical consultation visit as discussed in Chapter 2. By assessing the extent of discrepancy using these methods, Sanmartin (2000) found that using the last consultation dates as a proxy of dates on a waiting list closely approximated the waiting time determined with the SWL data.

One of the major challenges of studying waiting lists and waiting times for early childhood intervention services is the lack of such central data repository. The majority of early childhood intervention services are not covered by the BC's Medical Service Plan and thus the ability to find relevant data in other provincial databases is non existent. Nevertheless, some community agencies use electronic databases to manage their client information in addition to paper systems. However, all information is kept locally at individual agencies and no integration of information exists between agencies within and among organizations across regions. Therefore, information about waiting lists and waiting times has not been reliably determined at regional and provincial levels. Children

can be on multiple program waitlists within agencies or within regions. Thus, it is difficult to determine the reliability of wait time measures and the exact number of children waiting for different types of services. Moreover, the validity and utility of these administrative data with regard to waitlist and wait time research have not been systematically assessed.

Given the situation described above, various data sources were used to assess the currently available information on waiting lists and waiting times for early childhood intervention services in British Columbia. Data in this study were obtained by a questionnaire survey and follow-up interviews with community agencies' administrators, and by electronic administrative data from participating agencies (where available). Specifically, administrative data of referral and intake information were requested. This information would be used to assess the validity, reliability, and compatibility of wait time determination.

Community programs and child development centres that provide infant development programs, supported child development programs, physiotherapy, occupational therapy, and/or speech-language pathology services were invited to participate in a postal questionnaire survey. The questionnaire asked about the typical waiting times for both assessment and treatment appointments, waitlist management methods, staffing, caseloads, and available services and programs. Telephone follow-up interviews with agency management were conducted upon receiving their completed questionnaire for clarification about their data system and perceived issues regarding waiting times.

Focus group interviews with various stakeholders from the communities including service providers, program managers, and agency executive directors were then conducted. Focus group is, in general, used to find the range of experiences and opinions from participants across various groups on subjects that interest the researcher (Krueger & Casey, 2000). In this study, the goal of the focus group is to seek the opinions from various stakeholders about how a common framework of measuring waiting times for early childhood interventions services could be developed using the model outlined in Chapter 2.

3.2 ANALYTICAL ISSUES

Data for this study consist of both quantitative data and qualitative data. This section will provide a brief overview of analytical issues for quantitative and qualitative data.

3.2.1 Quantitative Data Analysis

Multivariate Analysis

It is now clear that waiting times tend to have either positively or negatively skewed distributions. Both mean and median waiting times as well as percentile have been used in the waitlist literature. Reporting of median waiting times in addition to mean waiting times was preferred by most researchers as the median is less likely to be influenced by the unusually short and/or excessively long waiting times. Since the underlying distribution of most waiting times is rarely normal, the assumption of normality and

homogeneity of variance is often not satisfied when mean waiting times are compared. Therefore, normalization of waiting time data through natural log transformation is commonly used in multi-variable regression analysis.

A number of analytical strategies have been used in the waitlist literature to examine the potential factors associated with the length of waiting times (De Coster, 2005; Ehrmann-Feldman et al., 2002; Sanmartin, 2000; Shorrt et al., 2004; Sobolev et al., 2000). De Coster (2005), for example, employed a stepwise linear regression to explore the relationship between waiting times for cataract surgery in Manitoba and a variety of non-clinical factors such as age and sex. The explanatory variables included the surgeon, the surgeons' caseload, the prioritization score, and patient demographic information. Data sources were from the Manitoba Cataract Surgery Waiting List Registry and hospital separation information (Population Health Research Data Repository). The dependent variable was the natural log of waiting time.

In order to justify the use of a linear regression model for the purpose of prediction, four underlying assumptions need to be satisfied (Bewick et al., 2003). These are (1) a linear relationship between dependent variable and independent variable, (2) an independent relationship between observations (i.e. successive observations of the dependent variable are uncorrelated), (3) a constant variance, and (4) a normal distribution of dependent variable. Thus, the classic linear regression models may not be the most appropriate approach to study waiting times because individual observations are not completely independent. Autocorrelation might be present because waiting times of any individual might be affected by the waiting times of patients immediately ahead of them within an

individual surgeon's waitlist or within that of individual hospitals. Thus, it is unlikely that the assumptions required for linear regression, even if log transformed data are used, can be met to assess waiting times.

The autoregressive (AR) model has been used by Sanmartin (2000) to address the issues of the violation of observation independency or autocorrelation. Autocorrelation can be corrected if a time variable (or variables) that changes over time is available for statistical model development. The rationale of using the autoregressive model is that the lack of a time dependent variable is often not the cause of autocorrelation (Sanmartin, 2000). One of the shortcomings of using autoregressive modeling is that the only patients included in this study were those who had received interventions; i.e. a retrospective design. Information on waiting times of those still waiting and those removed from waitlists due to other reasons is not included in the analysis.

A number of authors have used survival analysis (time-to-event analysis) to study waiting times (Ehrmann-Feldman et al., 2002; Levy et al., 2005; Sobolev et al., 2000; Sobolev et al., 2001). The Kaplan-Meier approach (or Product-limit method) of survival analysis is a non-parametric statistical method for analyzing time-to-event (or survival time) data with censored observations. It has also been used to estimate waiting times for admission or for the receipt of medical interventions. If all patients received their medical intervention at the end of a study period, the mean and median waiting times are essentially the same as those obtained from ordinary descriptive analyses. That is because no extra information from censored observations is used (Chan, 2004). In this case, the prospective design and retrospective design will yield similar mean and median waiting

times. When censored observations are included, it is expected that some degree of discrepancy between the two sampling approaches exists because a retrospective design includes only data of patients who have received the intervention. In a prospective design, censored information is also included in the analysis.

The Kaplan-Meier technique is equivalent to a univariate analysis of a parametric statistical method. Log rank test is generally performed to assess whether a difference of mean or median waiting times occur between different groups of patients. Cox regression is required when more than one explanatory variable is considered in the analysis in order to take into account the effects of confounders.

In the children's rehabilitation services study, Ehrmann-Feldman et al. (2002) used Cox regression analysis to determine whether factors such as age, region of residence, language, and diagnosis were associated with delays for physical therapy and occupational therapy appointments for children with physical disabilities. The waiting times were analyzed as prospectively collected observations. The information on children who were still waiting for services by the cut off date (end date of study period) was censored. The estimated probability of admission is expressed as a hazard rate. The expression hazard ratio (HR) is the estimate of the ratio of the hazard rate in one group to the hazard rate in the reference group (or comparison group) within a covariate. The ratio indicates the odds of an event occurring faster or slower, not how much faster or slower an event may occur, given some covariates (Garson, 2006). The interpretation of a hazard ratio (HR) for categorical variables is similar to that of the odds ratio in logistic

regression and is used to indicate the likelihood of a patient receiving interventions at

some point in time:

HR = 1 means no differences exist between groups in having a "shorter time to
admission."

HR > 1 means that the group of interest likely has a "shorter time to admission"
compared to the reference group (i.e. shorter wait).

HR < 1 means that the group of interest is less likely to have a "shorter time to
admission" compared to the reference group (i.e. longer wait).

For example, Ehrmann-Feldman et al. (2000) found that a chid living in the city has 1.77

times the chances as a child living outside the city in the next time increment (HR$_{(city)}$ =

1.77, 95%CI = 0.92 – 3.41) for receiving a physical therapy appointment although it is

not a significant factor. That is, children who lived within Montreal's city boundary

tended to wait less in this study. For a continuous variable, the hazard ratio is the hazard

associated with each unit increase in the predictor variable. In this example, increasing

age is associated with a less likelihood of having a "shorter time to event" (i.e. PT

appointment) since HR is less than 1 (HR $_{(age)}$ = 0.46, 95%CI = 0.34 - 0.62). Thus, older

children tended to wait longer for physical therapy appointments.

One of the major advantages of Cox regression analysis is that no assumption is made

about the probability distribution of the hazard (Bewick et al., 2004). The method

assumes that the hazard ratio does not change with time, thus, the assumption of

proportional hazard. This assumption may be checked by plotting the "log-minus-log"

plot (LML plot). The assumption is satisfied when the LML plots of different groups of

interest do not cross each other. When this assumption is not satisfied, a time dependent variable is required in the analysis.

3.2.2 Qualitative Data Analysis

Qualitative data consist of non-numeric information such as words and observations. It relies on the inductive reasoning processes to interpret the meanings derived from data (Thorne, 2000). A number of formal methods are used for analyzing qualitative data depending on the research questions and the context of a study (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). In general, qualitative methodologies involve reading all data repeatedly to obtain a sense of the whole context. The data are, then, read word by word to derive codes or meaning units by highlighting the exact words or phrases capturing the key concepts. Impression and thoughts on the text emerge. Codes or meaning units are, then, sorted and categorized based on how they are related and linked. Furthermore, categories are used to identify themes and findings.

Qualitative data in this study came from follow-up interviews with agencies' management who completed the agency questionnaire survey as well as the focus group interviews with various stakeholders in the field. The specific information sought from the qualitative data includes the following points for the questionnaire follow-up interviews:

1. Waitlist and waiting time issues for early childhood intervention services in BC,

2. Reasons for an increase or decrease in waiting lists and waiting times in recent years for these services, and

3. Reasons for the variation in waiting times,

For the focus group interviews, the topics included:

1. Challenges in monitoring waiting list and waiting time information, and

2. Framework of service delivery pathway and definition of waiting time.

A qualitative content analysis approach was considered in this research-because the current study is primarily exploratory in nature (Graneheim & Lundman, 2004; Morgan, 1993). Therefore, the analysis was less structured since it is a description of the qualitative data in order to gain insight to a subject area about which relatively little is known. This approach is well suited to data obtained from interviews and focus groups. The general process of qualitative content analysis is illustrated in Table 3.1 (Graneheim & Lundman, 2004). For this study, coding and analysis were done by one person (i.e. the author). The procedure for data analysis was conducted in the following manner:

1. Data were read through several times to identify the focus of questions and topic of interest posed by the author.

2. The text about the participants' experiences and opinions was extracted and brought together into one text, which constituted the unit of analysis.

3. Text was then read for general impressions and divided into meaning units

4. Meaning units were condensed into a description close to the text (manifest content) or into an interpretation of the underlying meaning (latent content).

5. The condensed meaning units were abstracted into sub-themes.

6. Findings were then interpreted by bringing the sub-themes together and by attaching

   meanings and significance to the connections of all sub-themes.

Table 3.1: Qualitative Data, Organization and Categorization of Themes

Meaning units	Condensed meaning	Interpretation of meaning units	Sub-theme	Theme
For our organization, it is not the terms [*the definition of terms*]. It is the term usage. Whether everyone uses the same term is more important	Not everyone uses the same definitions	Lack of common definition is not the sole problem	Inconsistent use of definition	Inconsistency in service delivery, definition, and use of terminology remains a major challenge to wait time reporting
The speech's got a good picture. Yes, you need therapy and put you on a list. Or no, you're fine developmentally, then move on. They are quite clear. …The occupational therapy department will say "we can't just do a screening" We can't do it in one meeting", "We can't do it with one tool". So they wait until therapy is allowable to initial service period. So they do not do initial screening. They have longer wait. But when they do get on, then service is full service.	OT and SLP differ in model of service delivery even within agency	Different disciplines have different views in service delivery	Inconsistency in service delivery	

3.3 METHODS AND ANALYTICAL APPROACH

3.3.1 Questionnaire Survey of Community Agencies

A cross-sectional survey of agencies providing early childhood intervention services to children aged 0 to 6 in British Columbia was conducted. Executive directors and program managers were asked to complete a postal questionnaire regarding the waiting list and waiting time information for their organizations. Agencies were identified through the BC Association of Child Development and Intervention (BCACDI), the offices of Provincial Advisors of Infant Development Programs and Supported Child Development Programs, public health units of regional health authorities, and the Ministry of Children and Family Development website.

A total of 89 agencies were identified. Postal questionnaires were mailed to the executive directors or program managers of these agencies in April 2005. An email reminder was sent to non-respondents three weeks after the first mailing. A second reminder with a copy of the questionnaire was also sent to non-respondents three weeks after the email reminders. Telephone follow-up interviews for clarification and additional information relevant to local communities were conducted after the receipt of completed questionnaires.

Originally, Aboriginal Infant Development Programs (AIDP) across BC were also included in this study. The Office of the Provincial Advisor of AIDP preferred that questionnaires were mailed from their office, and they would contact individual programs directly. However, because most AIDP were established recently, and, therefore, only

limited information might be available, it was decided that AIDP was to be excluded from the main body of analysis.

The survey questionnaire (Appendix B) took approximately 30 minutes to fill out depending on the number of services available at the agencies. The survey was developed to elicit general information about the following areas:

- General characteristics of the agency such as staffing level, program type, and caseload (questions 1 - 6),

- Program/discipline specific waitlist and waiting time information (questions 7 – 8),

- Waitlist management (questions 9 - 17),

- Client profiles (questions 16 - 18), and

- Issues and concerns of waiting times (questions 20 - 21 and telephone interview).

During the development of the questionnaire, a small number of service providers and program managers from child development centres were consulted regarding the questions about waitlist and waiting times. A total of 21 questions consisting of closed and open ended questions were developed. The final draft of the questionnaire was sent to two agencies for comment before it was sent to other agencies. Since most questions sought factual information about the responding organizations, a formal assessment of validity and reliability was not performed. Moreover, it was logistically difficult to ask agencies to test and re-test the questionnaire given the small number of agencies willing to participate and because of time constraint. Respondents were offered the opportunity

to provide additional information, opinion, and issues regarding waiting lists and waiting times for early childhood intervention services that were not covered by the questionnaire. The telephone follow-up interviews were conducted as soon as the completed questionnaire was received. The telephone interview was specifically geared toward the following questions:

1. If your agency is experiencing an increase (or decrease) in waiting times for services in recent years, what are the probable reasons that are relevant to your local community?

2. What are the strategies your agency is using to manage waiting lists?

3. If waiting lists are not a problem in your agency, what would be the reasons?

4. What are the general issues regarding waiting lists and waiting times for early childhood interventions your agency might have?

3.3.2 Administrative Data

Agencies completing the questionnaire survey were also asked to provide their electronic administrative data of referral and intake information. Specifically, the requested data elements included are described in Table 3.2. The administrative data received from participating agencies were assessed for compatibility, comprehensiveness, and data quality including completeness and accuracy. The inclusion criteria for this study included the following:

1. Children aged birth to 6 years at the time of referral

2. Children who were referred to IDP, SCDP, OT, PT, and/or SLP services in BC

3. Children who were referred between January 01, 2003 and September 30, 2004

In British Columbia, children usually enter the school system at about age 5, and most early childhood intervention services provide a transition plan when children are entering Kindergarten. The first inclusion criterion ensured that children who were referred slightly beyond age 5 would be included. The third inclusion criterion was suggested by various service providers because the longest waiting times for some services typically range from 40 to 80 weeks (280 – 560 days). Data submission from participating agencies was expected to begin in the summer of 2005. Therefore, excessively long waiting times could be captured in this study within the defined timeframe.

Table 3.2: Administrative Data Elements Requested from Participating Agencies

Date of referral	All relevant referral dates including agency referral date and program referral date.
Date of birth	Child's date of birth
Referral source	Referral agency and referral professional (discipline) is included
Gender	Child's gender
Reason of referral	Referral reasons include information recorded in referral form such as child's needs for intervention, developmental goals, etc
Diagnosis	Established diagnosis or biological risks such as low birth weight
Language	Family's primary Language
Service Dates	All relevant appointment dates corresponding to the types of services such as assessment appointment, consultation appointment, treatment appointment, group program session, etc
Discharge date	File closing date and last date of service
Reason of discharge	Reasons for leaving the program

3.3.3 Statistical Analysis

The first set of administrative data was received on May 23rd, 2005, and the last set came in March, 2006. Thus, the cut-off date (censoring date) of this study was set as May 31, 2005 because agencies that submitted data before the cut-off date might not have complete information for some clients beyond May 31, 2005. Information on children who had not received services by May 31, 2005 and children who were discharged from agencies before receiving services was censored. A descriptive statistical analysis with Kaplan-Meier estimates of mean and median waiting times for IDP, SCDP, PT, OT, and SLP was conducted. Log rank test was used to test the differences between groups.

Cox regression for time-to-event analysis was used to examine the variation in waiting times across agencies and adjusted for child factors such as age at referral, and referral source. The initial assessment of the electronic administrative data provided by participating agencies indicated a wide variation in terms of availability and consistency of certain data elements. In particular, the referral reasons and established diagnoses were not consistently recorded across agencies and programs, thus, making comparison impossible. Therefore, this information was not used for multivariate analysis. The explanatory variables outlined in Table 3.3 represent the data elements that could be reliably obtained from agencies' administrative data and the questionnaire survey.

Table 3.3 Explanatory Variables for Cox Regression

Explanatory Variables	Types and Categories	Description	Sources
AGENCY	Categorical	Agency Code	Questionnaire data
REFAGE	Continuous or Categorical	Age at referral	Administrative data
SEX	Categorical: M = male F= Female	Gender	Administrative data
AGTYPE	Categorical: CDC=child development centre (multi-program agency), PH=public health unit (SLP service only), Program=single community program	Type of agency	Questionnaire data
LOCATION	Categorical: Aglocat1=major and small urban community, AgLocat2=rural community, AgLocat3=both urban and rural communities	Service location	Questionnaire data
PROGFTE	Categorical: ProgFTE1 $\leq$ 1 FTE, ProgFTE2 = 2 – 3 FTE, ProgFTE3 $\geq$ 4 FTE	Program staff level	Questionnaire data
FTE	Categorical: FTE1 $\leq$ 10 FTE, FTE2 = 11 – 20 FTE, FTE3 $\geq$ 21 FTE.	Agency staff level (total agency staff)	Questionnaire data
CASELOAD	Categorical: e.g. CASELOAD1 $\leq$ 400 clients, CASELOAD2 = 401 – 1000 clients, CASELOAD3 $\geq$ 1000 clients	Number of clients served annually. Grouping differs in different programs	Questionnaire data
LANG	Categorical: LANG1 = English, LANG2 = non-English	Family's primary language	Administrative data
REFSO	Categorical: e.g. family referral, Physician, Health Nurse, therapist, and other	Referral Source	Administrative data

All statistical analyses were conducted with SPSS for Windows v.15.0 (SPSS Inc., Chicago, IL). Descriptive analyses, Kaplan-Meier survival estimations, and Cox regression modeling were performed with 2-sided statistical testing at $\alpha = 0.05$. All confidence intervals presented were at 95% level. In this study, Cox regression analysis was used to investigate factors associated with the wait time variations for IDP and SLP services because these two interventions have better data availability.

3.3.4 Variables

The dependent variable is the waiting time in days for the first appointment with agencies or the first appointment for active intervention from date of referral. Explanatory variables considered for Cox regression analysis included:

Agency Code (AGENCY)

As agencies are coded with unique identifiers, the agency code was used as a categorical variable to illustrate the inter-agency variation in waiting times. For ease of comparison, the agency with the median waiting times closest to the provincial value estimated by Kaplan-Meier analysis was used as the reference group so that the hazard ratio (HR) of other agencies could be compared to this agency in Cox regression analysis.

Age at referral (REFAGE)

The child's age in months at the time of referral was determined based on the child's date of birth and the date when the referral was received by agencies. Age at referral was categorized into groups for better visualization when comparing waiting times across

different age groups. For IDP, four age groups are categorized as Refage1 $\leq$ 6 months old, Refage2 = 6 - 18 months old, Refage3 = 19 – 30 months old and Refage4 > 30 months old. For SLP, four age groups are categorized as Refage1 $\leq$ 18 months old, Refage2 = 19 - 30 months old, Refage3 = 31 – 42 months old and Refage4 > 42 months old.

Gender (SEX)

The child's gender coded as M for male and F for female. Male was the reference group in the Cox regression analysis.

Type of agency (AGTYPE)

Speech and language pathology (SLP) services are provided by public health units and child development centres. Children who are referred to child development centres (multi-program agencies, CDC)) tend to have a more complex diagnosis or condition. It is known that waiting time is associated with the case-mix characteristics of organizations. Similarly, infant development programs (IDP) and supported child development programs (SCDP) are provided by single community programs or child development centres (multi-program agencies). The type of agency is coded as CDC = child development centre, PH= public health unit (SLP only), and Program = single community program. The category of child development centre is used as the reference group in Cox regression analysis.

Service location (LOCATION)

The service location was self identified by agencies as urban or rural communities when they submitted information to various provincial reports such as the biennial statistical reports of Infant Development Programs. The service delivery areas do not have the same defined boundary as the Local Health Area and, thus, could not be grouped based on their population per square kilometre. Many agencies provide services to several communities of different population sizes. In general, a community with a population of 100,000 is considered urban, and a community with a population less than 10,000 is defined as rural. In this study, the variable LOCATION is coded as: AgLocat1 = Agency provides services in a major urban or small urban community, AgLocat2 = Agency offers services in a rural community only, and AgLocat3 = Agency makes available services in both urban and rural communities.

Program staff level (PROGFTE)

This variable reflects the staffing level of service providers in terms of the full-time equivalent (FTE) employed for each program within agencies. It is often assumed that waiting time for each program may be affected by the number of service providers available. The program staff level variable was used as a categorical variable coded as ProgFTE1 $\leq$ 1 FTE, ProgFTE2 = 2 – 3 FTE, and Prog3FTE > 3 FTE.

Total agency staff level (FTE)

This variable reflects the size of agencies which is also likely associated with waiting times. It is often assumed that larger agencies may be able to shift resources in response

to increasing waiting lists. Information on staff level including administrative staff and program staff in full-time equivalent (FTE) was obtained from the questionnaire survey. Agency staff level was used as the categorical variable and was coded as FTE1 ≤ 10 FTE, FTE2 = 11 – 20 FTE, and FTE3 > 20 FTE.

Number of clients served annually (CASELOAD)

Caseload levels of organizations are also used to reflect the size of agencies. The typical number of clients served annually was obtained from the agency questionnaire. This variable was categorized in groups such as CASELOAD1 ≤ 400 clients, CASELOAD2 = 401 – 1000 clients, and CASELOAD2 ≥ 1000 clients.

Family's primary language (LANG)

The primary language of family is derived from administrative data. As discussed in Chapter 2, family's primary language was found to be associated with waiting times for rehabilitation services. For example, it is assumed that non-English speaking families may experience longer delays because extra time may be required to arrange interpreter services. In this research, bilingual families with English as one of the primary languages spoken at home were coded as English speaking families. Primary language was coded as LANG1 = English and LANG2 = non-English. This variable was not used for analysis because very few families were coded as non-English group.

Referral source (REFSO)

The majority of referrals to early childhood intervention services were made either by family physicians and paediatricians or by family members. The referral source is categorized as Family = self referred by a family member, MD=physician (or hospital), PHN=public health nurse (and health unit), and Other =other referral sources including therapists, child care workers, social worker, etc. Family referral was used as the reference group.

3.3.5 Model Development

The first set of the Cox regression model development was to investigate inter-agency variations adjusted for child factors including the child's age at referral, gender, and referral source. Model variables were entered into the regression model in blocks:

    Block 1: Agency

    Block 2: Age at referral, gender, and referral source (Child factors)

Model development 1:

    Model 1: Waiting time = Block 1 (Agency)

    Model 2: Waiting time = Block 1 (Agency) + Block 2 (Child factors)

The second set of the Cox regression model development was used to explain the variation in waiting times in terms of agency factors such as service location, agency

type, staffing level, caseload, etc. adjusted for the child factors. Variables were entered into the regression model in 2 blocks:

Block 1: Service location, agency type, staff level, and caseload (agency characteristic)

Block 2: Referral age, gender, and referral source (child characteristic)

Model development 2:

Model 1: Waiting time = Block 1 (agency characteristics)

Model 2: Waiting time = Block 1 (agency characteristics) + Block 2 (child characteristics)

3.4 FOCUS GROUP INTERVIEWS

The focus group participants including intervention service providers, intake coordinators, program directors, and agencies' executive directors were invited to participate in one of the four focus group sessions. The final invitation was sent to all service providers and managers of the responding agencies in March 2006. The four focus groups were then held in June and July 2006. At each session, focus group participants were given the opportunity to discuss the reporting indicators set out by the Ministry of Children and Family Development, definitions and terms currently used in the field, and challenges in monitoring waiting times. Participants were, then, presented with the preliminary model of the service delivery pathway (Figure 2.3, Page 91) as discussed in Chapter 2 and the proposed wait time periods along the service pathway. The general discussion at each session focused on the following questions.

Question#1: What are your thoughts about the service terminology that is currently used in the field such as "Initial Services," "Initial Consultation," "Assessment Waitlist," and "Direct Therapy or Direct Service Waitlist"? What are the challenges in using these terms to monitor waiting times?

Question#2: Please comment on the proposed service delivery pathway and the three different WAIT periods along the pathway. What will you do to improve this?

Question #3: What waitlist and wait time indicators should be collected for caseload management and for informing families and the public or government?

Each group session was taped, transcribed, and analysed according to the method outlined by Graneheim and Lundman (2004). The analysis is transcript based. Each focus group interview was transcribed verbatim. The results of focus group interviews will be described in Chapter 4.

CHAPTER 4

RESULTS

4.1 CURRENT STATE OF INFORMATION OF WAITING LISTS AND WAITING TIMES FOR EARLY CHILDHOOD INTERVENTION SERVICES IN BRITISH COLUMBIA

4.1.1 Results of Agency Questionnaire Survey

Response Rate: A total of 53 agencies (60%) responded to the survey. Of the 53 agencies, 36 provide infant development programs (IDP), 16 provide occupational therapy (OT), 17 provide physiotherapy (PT), 29 provide supported child development programs (SCDP) and 25 provide speech-language pathology (SLP) services. Tables 4.1A and 4.1B outline the service profiles of the 53 responding agencies. Some agencies provide single programs while some provide a broad spectrum of services. The geographic distribution of responding agencies by available services and programs is given in Table 4.1B. It will be seen from Table 4.1B that agencies in major urban centres are underrepresented in this study. A number of child development centres in the Metro Vancouver region either explicitly refused to participate or just did not respond to the request for participation. Table 4.1B shows that a larger number of responding agencies provide services to both small urban and rural communities. Some of these agencies often deliver services over a large geographic area.

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Table 4.1A: Response Rate – Agency Questionnaire Survey

Agency with programs of	Total sent	Refused	Non Responder	Responded
EIT only	5	1	2	2 (40%)
EIT+ IDP	6	3	0	3 (50%)
EIT+IDP+SCDP	11	0	2	9 (82%)
EIT+ SCDP	4	2	1	1 (25%)
IDP only	19	0	6	13 (68%)
IDP+SCDP	17	0	6	11 (65%)
SCDP only	16	2	8	6 (38%)
PH (SLP)	11	0	3	8 (73%)
Total	89	8	28	53 (60%)

EIT = Early Intervention Therapy services include Occupational therapy (OT),
     Physiotherapy (PT), and/or Speech-language pathology (SLP) services
IDP = Infant Development Programs
SCDP = Supported Child Development Programs
PH = Public Health Units (for preschool SLP services only)

Table 4.1B: Geographic Distributions of Intervention Disciplines

	Location of Service*			
Intervention	Urban	Rural	Urban & Rural	Total**
IDP	5	13	18	36
SCDP	3	7	19	29
OT	3	3	10	16
PT	3	3	11	17
SLP	5	5	15	25

* The location of service was self-identified by responding agencies.
  - "Urban" reflects both major and small urban centres.
  - "Urban & Rural" indicates that agencies provide services to both small urban centres and rural communities.
** The total number of agencies is based on disciplines. For example, 36 agencies provide IDP and 29 provide SCDP. Many agencies provide multiple programs and services as indicated in Table 4.1A; thus, the total is greater than 53 responding agencies.

4.1.2 Regional Differences in Self-Reported Waiting Lists and Waiting Times

Each agency was asked to indicate whether there was a wait for each of the available intervention services. It is clear that not all intervention disciplines had a waiting list in this survey (Figure 4.1.1). For physiotherapy (PT), infant development program (IDP) and supported child development program (SCDP), about 50% of responding agencies indicated that they usually have a waiting list for the services during the time of survey. Fewer agencies with IDPs in rural communities tended to have a waiting list. PT and SCDP in the urban areas seemed to have fewer waiting lists as well but these results might be biased because the number of responding agencies from the urban communities was unfortunately low. Children who required SLP and OT services were more likely to be put on a waiting list. Of all the agencies providing SLP and OT interventions, 96% indicated a waitlist for the SLP services and 80% reported a waitlist for OT services.

Figure 4.1.1: Regional Variation* in Waiting Lists for Services
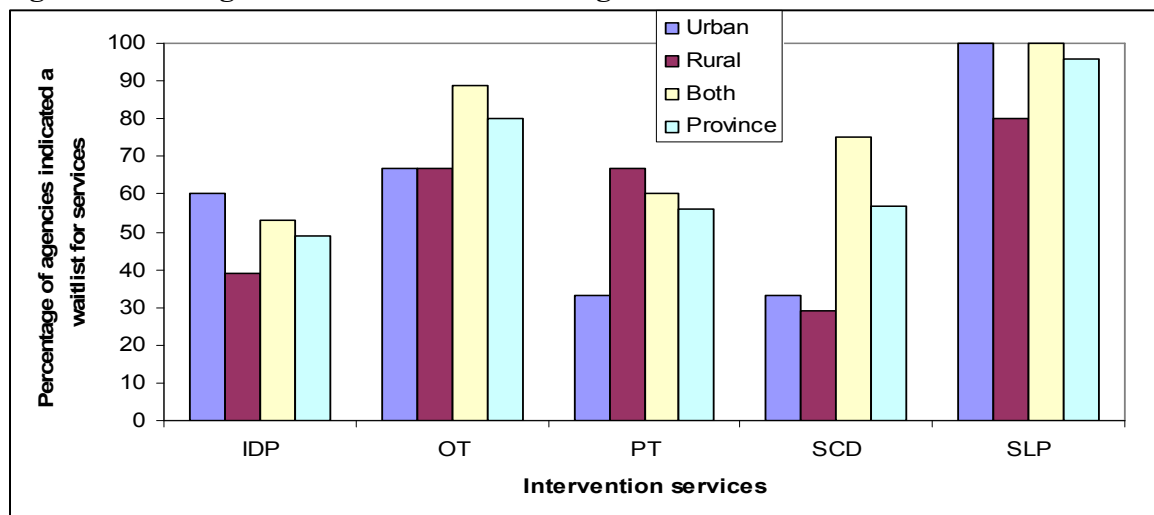
IDP= Infant Development Program; OT= Occupational Therapy; PT= Physiotherapy;
SCD= Supported Child Development Program; SLP= Speech & Language Pathology
* Percentage of agencies indicated a waitlist for services

The self-reported waiting times for each intervention are given in Table 4.1C. The survey was intended to obtain typical waiting times, for each type of intervention, agencies had at the time of the survey. It would take enormous effort for most agencies to provide more precise information on waiting times since most agency administrative data were not designed to track waiting time. Moreover, waiting list and waiting time for these services have not been defined consistently.

Table 4.1C: Typical Assessment and Treatment Waiting Times (Weeks) of Agencies Indicated with a Waitlist for Services

Intervention Service	Number of agencies indicated a waitlist for **Assessment**	Number of agencies indicating a waitlist but did not know the average wait times	Mean Wait Times (Median)*	Range
OT	11	2	13.67 (6.0) wks	4 - 40 wks
PT	9	2	9.86 (6.0) wks	2 – 36 wks
SLP	21	3	27.23 (22.0) wks	2 - 104 wks
IDP	17	2	9.53 (4.0) wks	2 - 52 wks
SCDP	10	2	3.13 (3.50) wks	1 - 5 wks

Intervention Service	Number of agencies indicated a waitlist for **Treatment**	Number of agencies indicating a waitlist but did not know the average wait times	Mean Wait Time (Median)*	Range
OT	11	5	15.33 (13.0) wks	2 - 36 wks
PT	8	3	9.60 (4.0) wks	2 – 36 wks
SLP	23	7	30.63 (24.0) wks	2 - 105 wks
IDP	17	2	12.20 (4.0) wks	2 - 52 wks
SCDP	13	3	7.50 (4.0) wks	2 - 36 wks

* Waiting time between referral and receipt of first services

Table 4.1C shows that waiting times for SLP services seemed to be the longest among all the early childhood intervention services in this survey. The average waiting times for SLP assessment ranged from 2 to 105 weeks depending on location. The combined provincial averages were 27.23 weeks for assessment appointment and 30.63 weeks for treatment appointment. The median waiting times for SLP assessment and treatment appointments were 22 weeks and 24 weeks respectively indicating that only a few agencies reported excessively long waiting times for their services.

The waiting times for supported child development Program (SCDP) seemed to be the shortest. The combined averages were 3.13 weeks for assessment wait and 7.50 weeks for intervention wait. Agencies with SCDP services indicated that the waiting times reported here reflected mostly only the wait for receiving consultation from a SCDP consultant. Children who have received SCDP consultation would still need to wait for extra staffing support at childcare facilities.

Regional differences of self-reported waiting times for each intervention discipline are given in Figures 4.1.2A to 4.1.2J. Longer waiting times were typically associated with agencies providing services to both urban and rural communities. It is especially apparent for occupational therapy and speech-language pathology services (Figures 4.1.2C. 4.1.2D, 4.1.2 I and 4.1.2J)

Figure 4.1.2A: Regional Variation of Typical Assessment Waiting Times for Infant Development Program
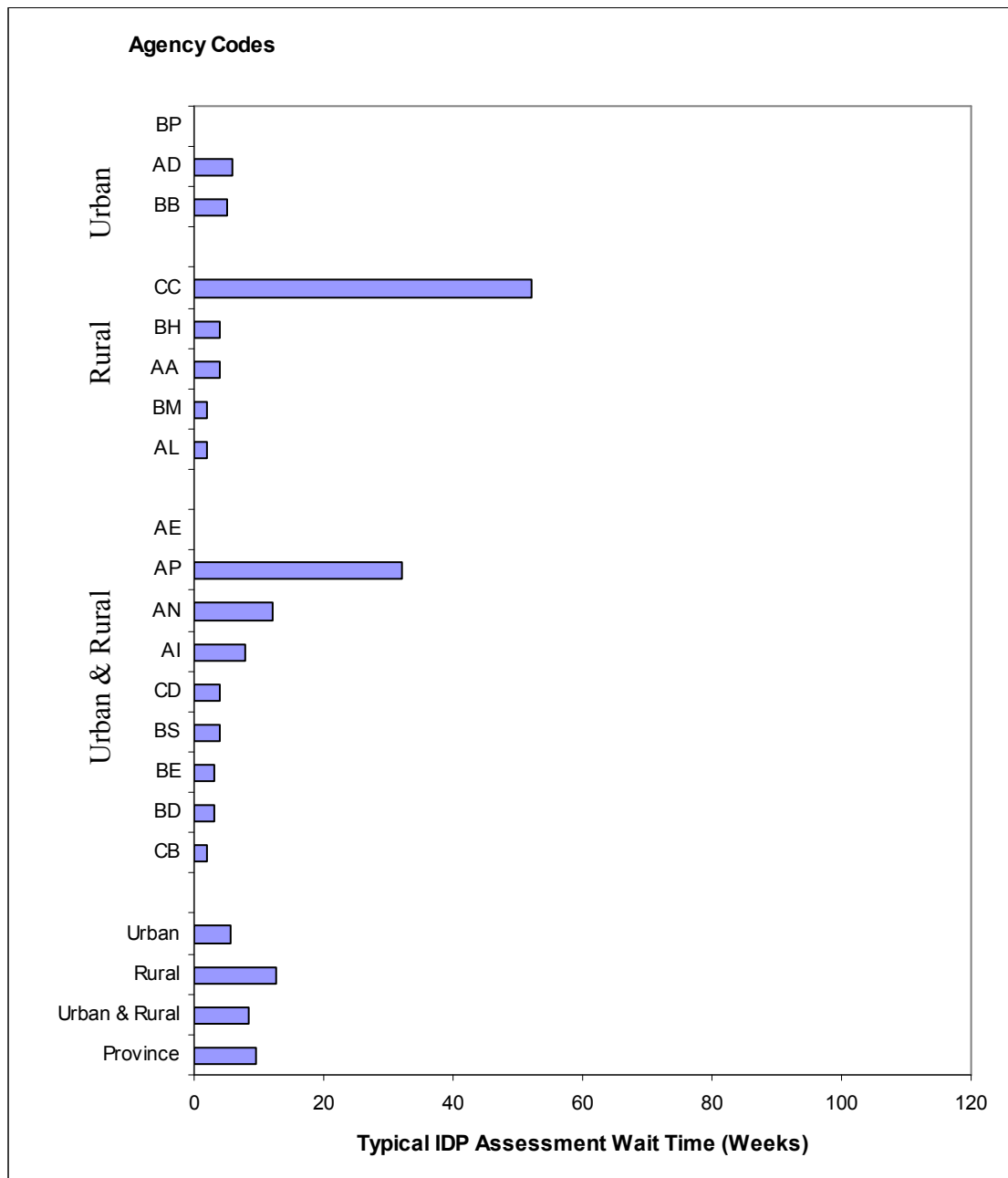
Agencies BP and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2B: Regional Variation of Typical Intervention Waiting Times for Infant Development Program
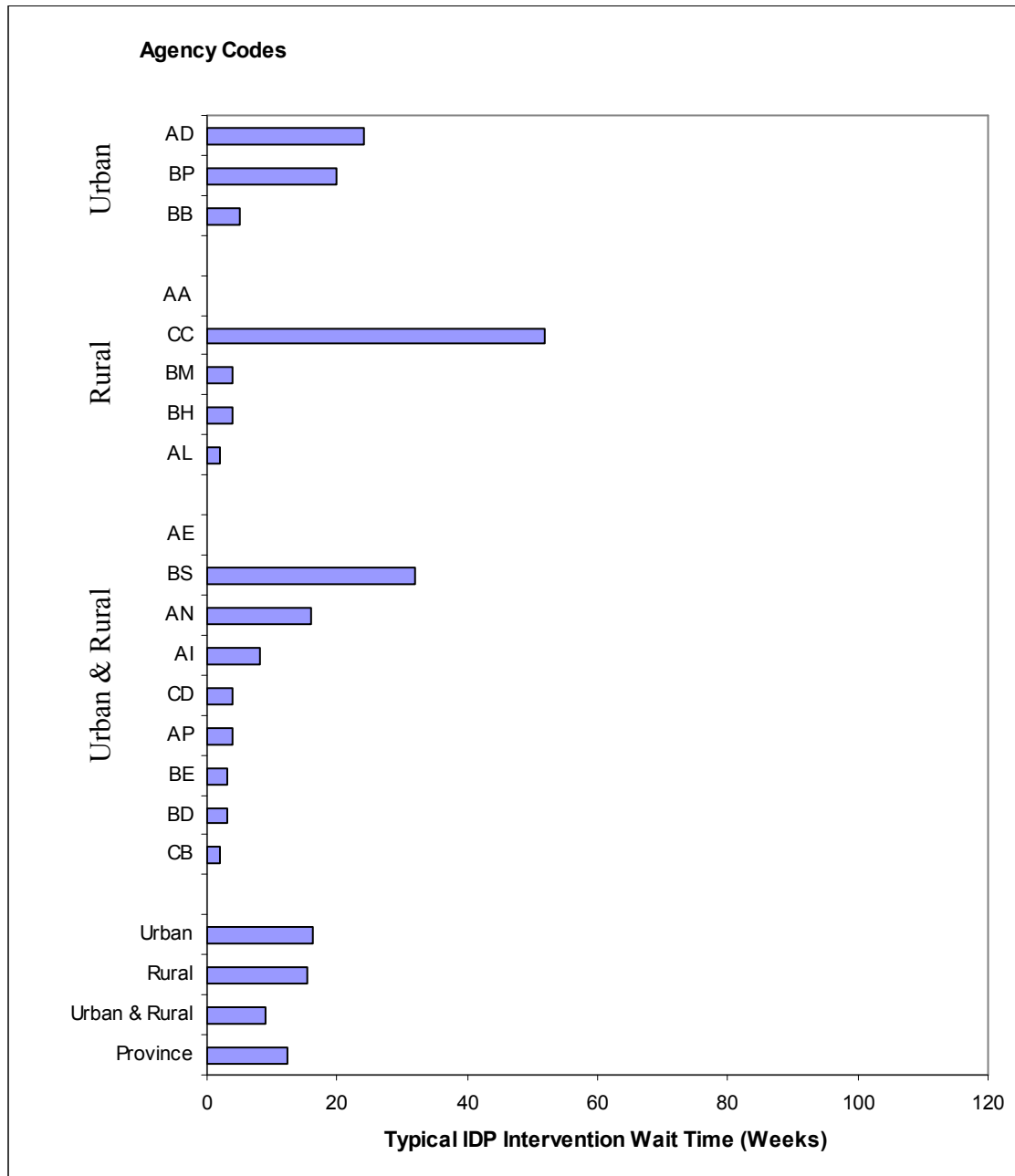
Agencies AA and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2C: Regional Variation of Typical Assessment Waiting Times for Occupational Therapy
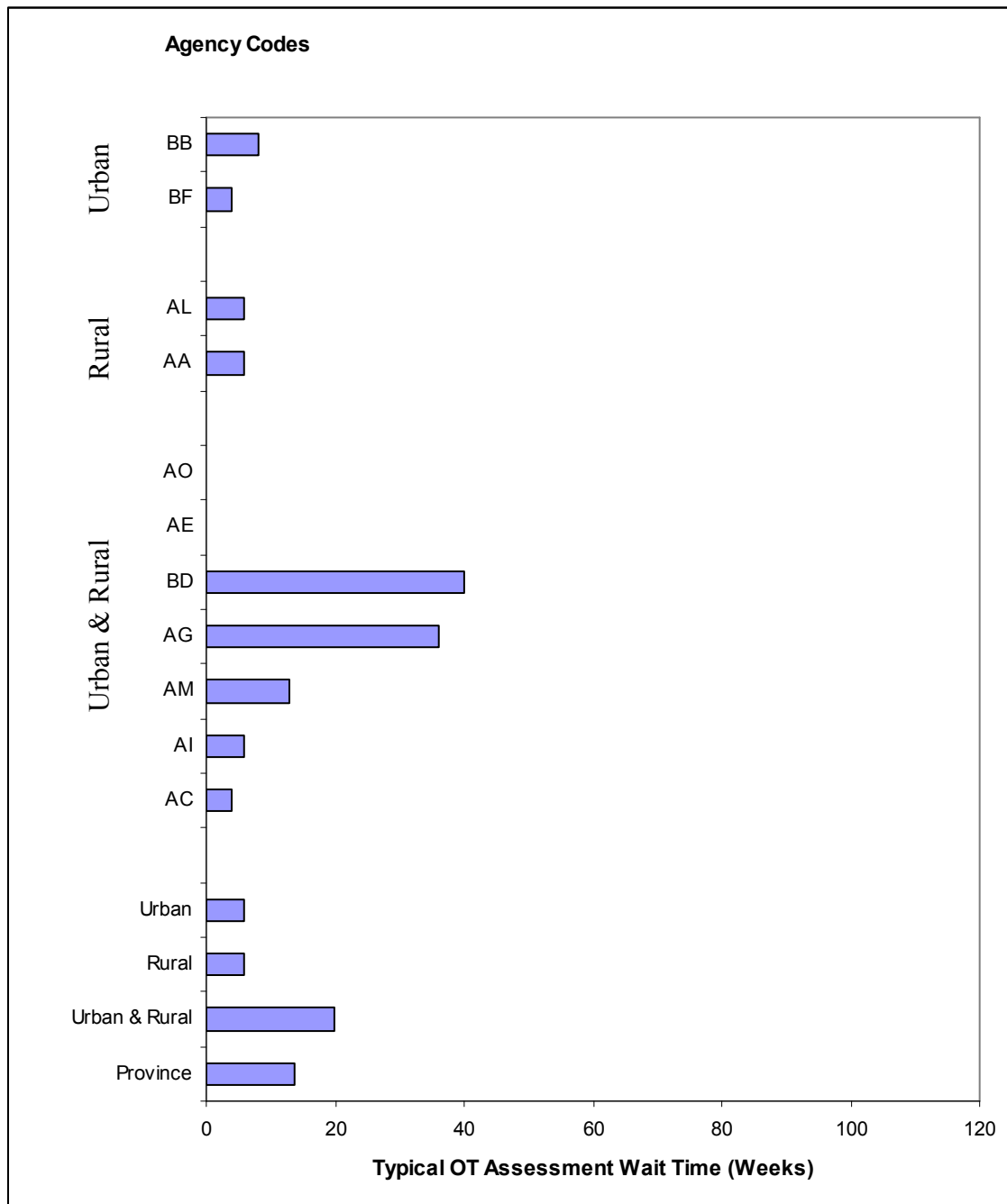
Agencies AO and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2D: Regional Variation of Typical Intervention Waiting Times for Occupational Therapy
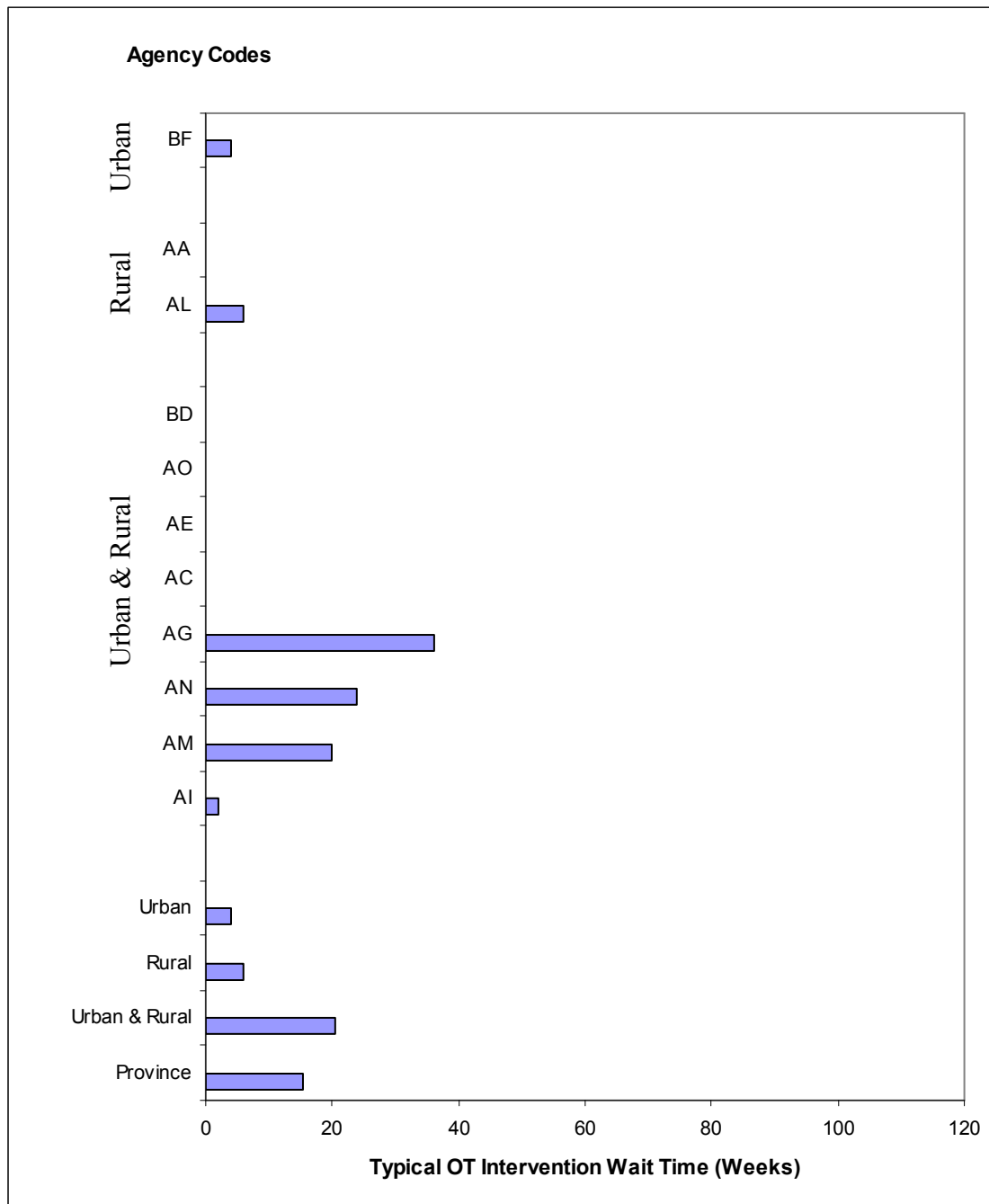
Agencies AA, BD, AO, AC and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2E: Regional Variation of Typical Assessment Waiting Times for Physiotherapy
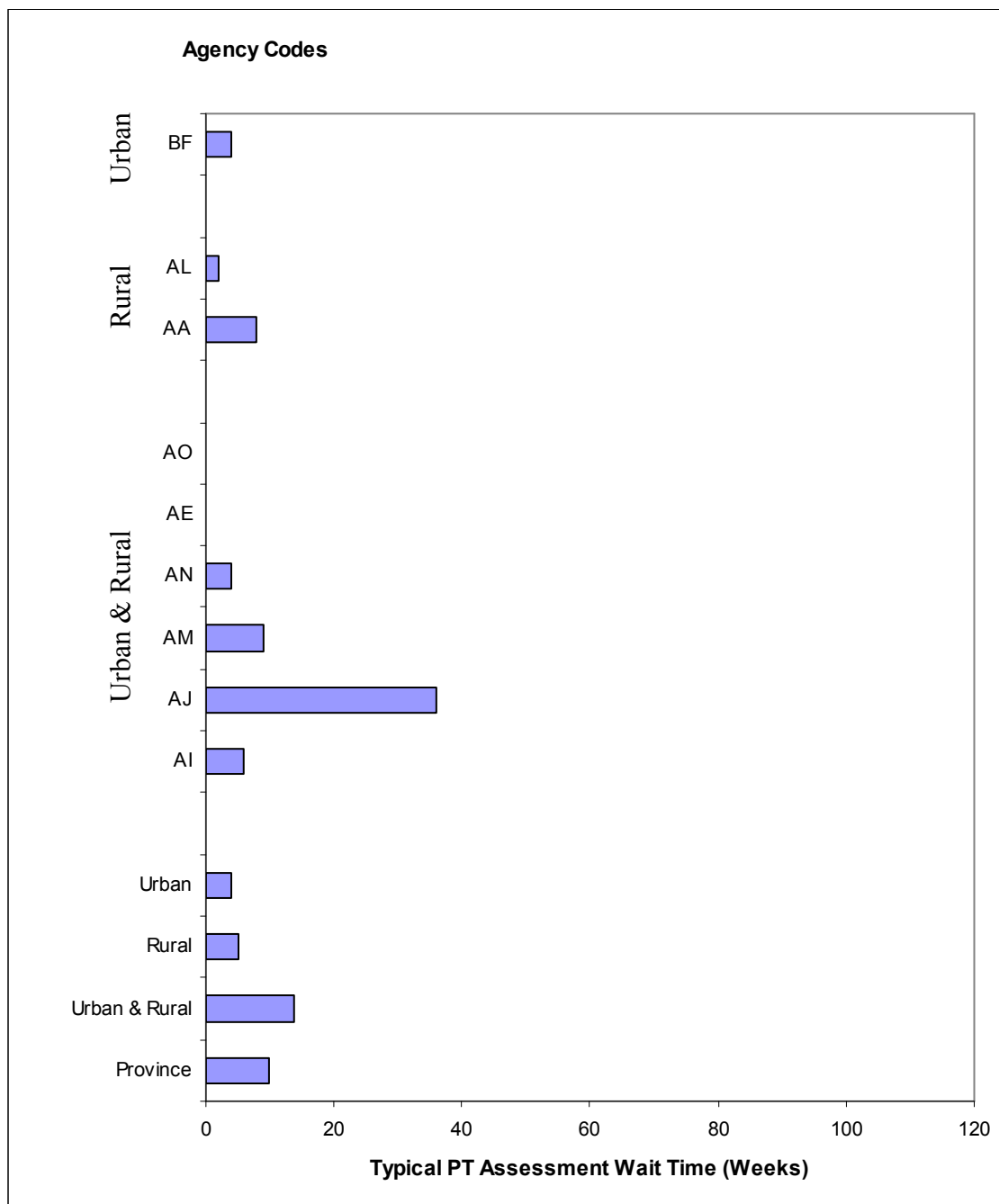
Agencies AO and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2F: Regional Variation of Typical Intervention Waiting Times for Physiotherapy
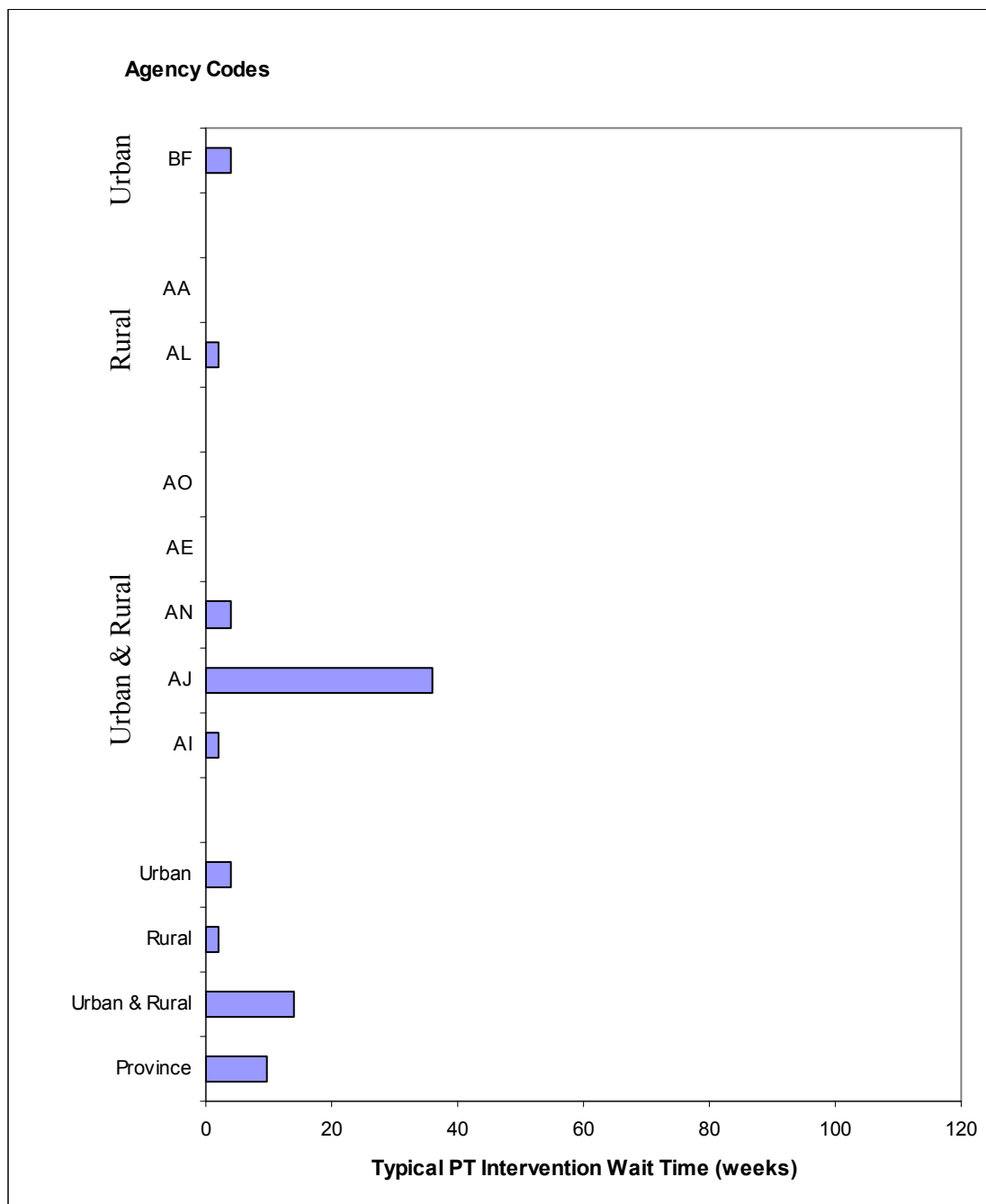
Agencies AA, AO and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2G: Regional Variation of Typical Assessment Waiting Times for Supported Child Development Program
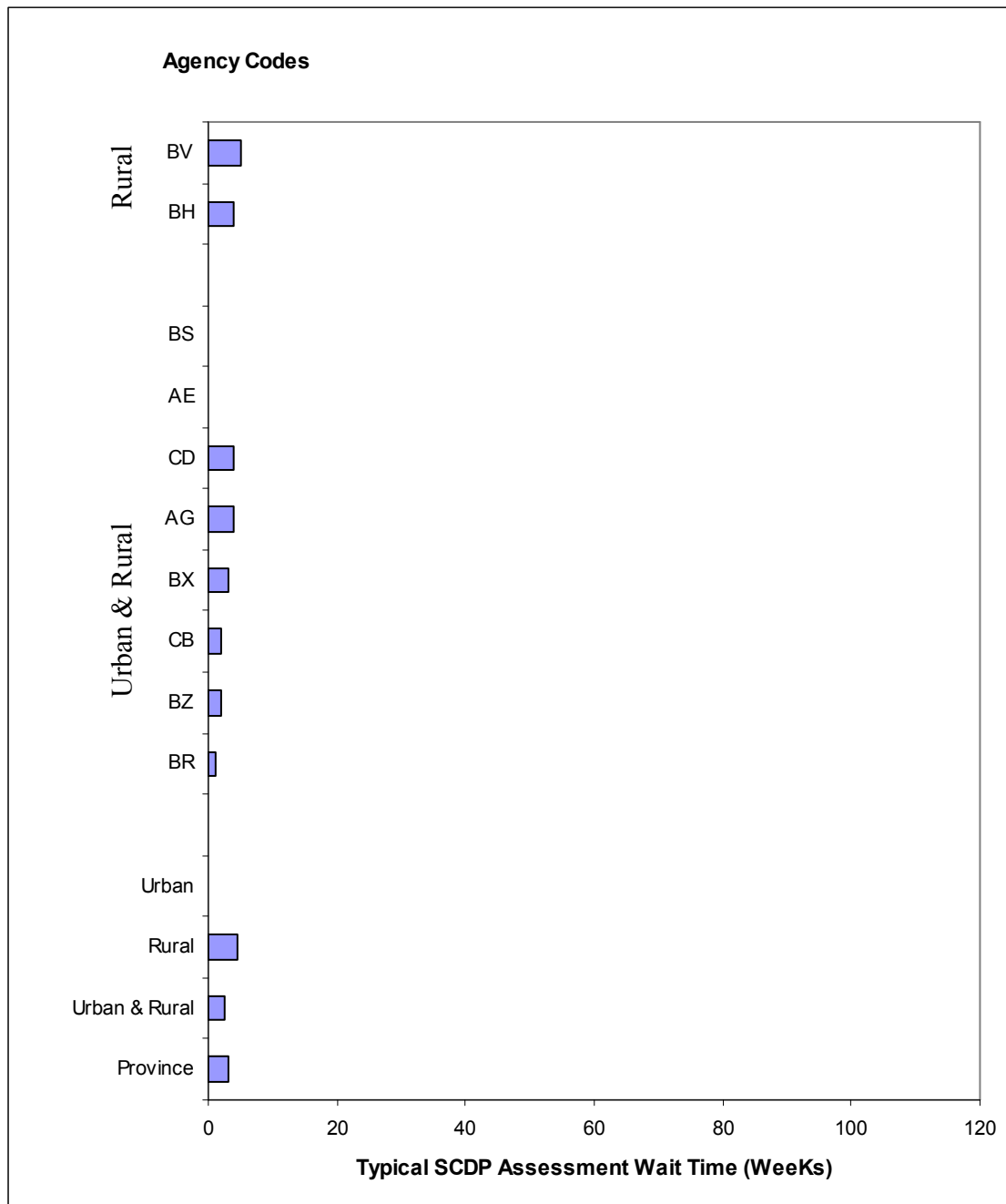
Agencies BS and AE indicated there was a waitlist for the services but did not provide the typical waiting time. No agencies in urban setting reported a waiting list.

Figure 4.1.2H: Regional Variation of Typical Intervention Waiting Times for Supported Child Development Program
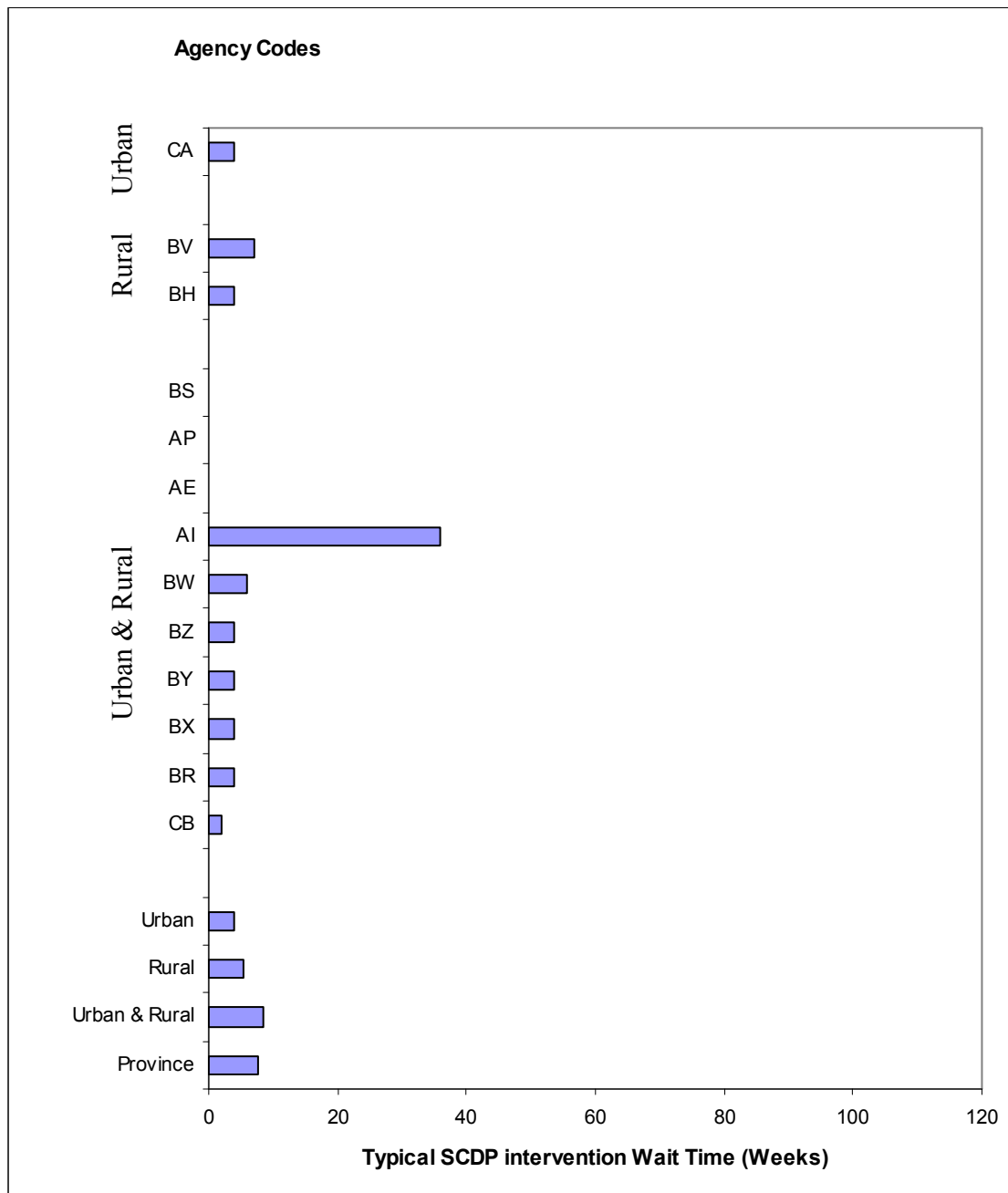
Agencies BS, AP and AE indicated there was a waitlist for the services but did not provide the typical waiting time. No agencies in urban setting reported a waiting list.

Figure 4.1.2I: Regional Variation of Typical Assessment Waiting Times for Speech and Language Pathology Services
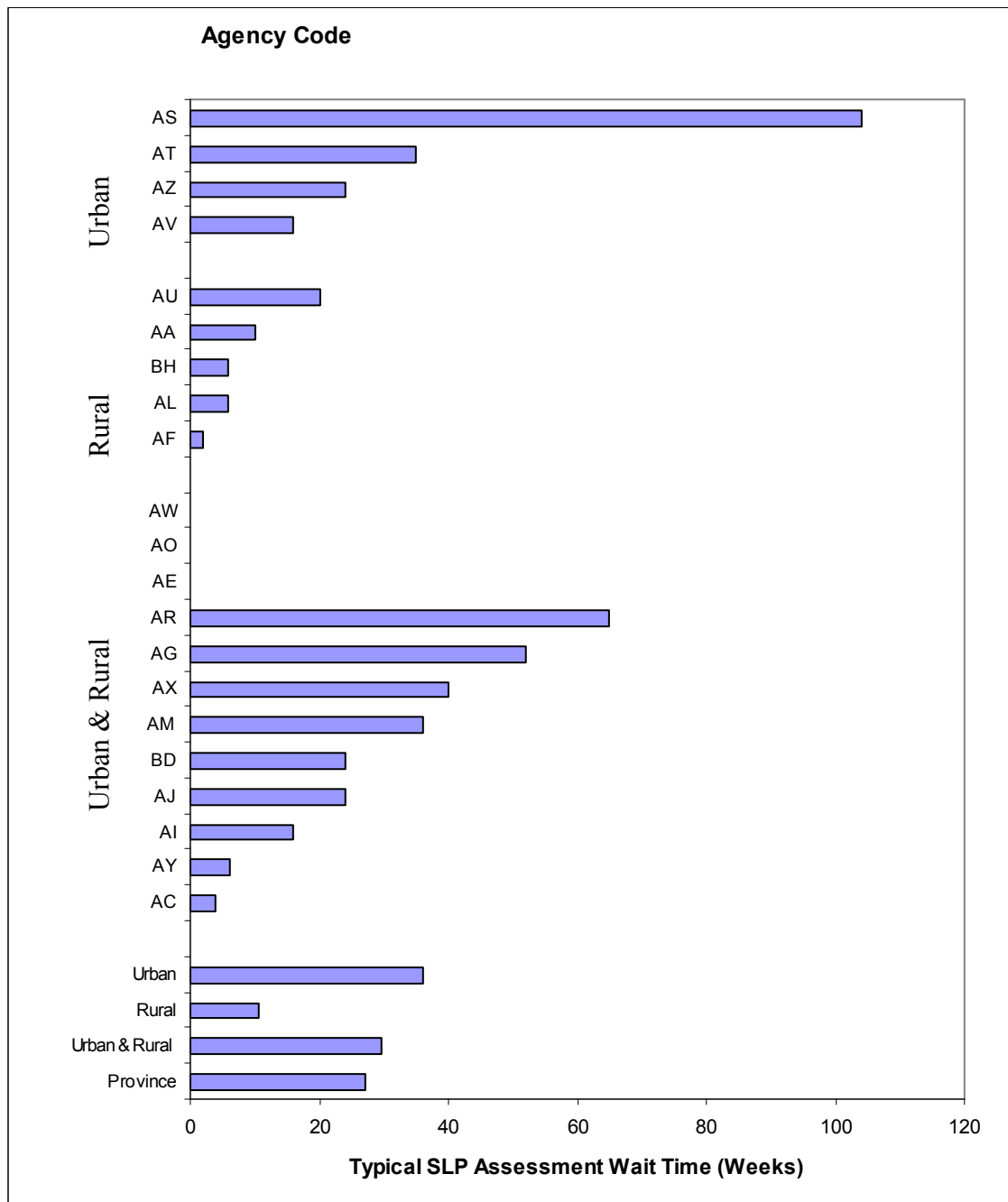
Agencies AW, AO and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

Figure 4.1.2J: Regional Variation of Typical Intervention Waiting Times for Speech and Language Pathology Services
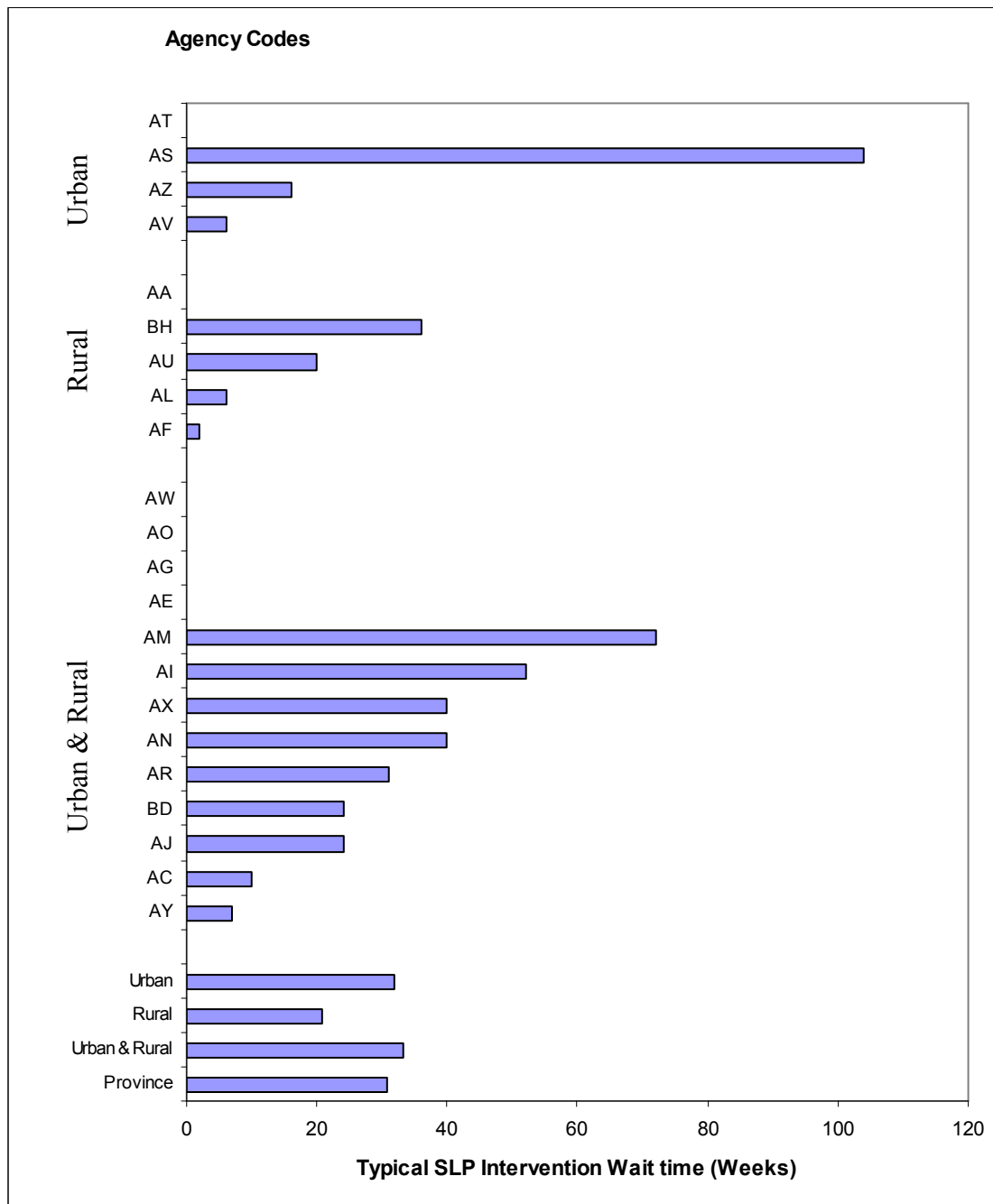
Agencies AW, AO, AG and AE indicated there was a waitlist for the services but did not provide the typical waiting time.

4.1.3 Waitlist Management

Of the 53 responding agencies, only 21 (40%) currently used an electronic database

system for client information (Table 4.1.3). This information was obtained through

telephone follow-up interviews. The majority of remaining agencies were using either

simple spreadsheet programs or paper charting methods. Furthermore, some agencies

were not using the data systems consistently even within organizations. This is especially

true for agencies with multiple satellite offices located in different communities.

Moreover, the type of information entered into database systems for monitoring waiting

lists and waiting times varied widely across agencies in terms of comprehensiveness and

completeness.

Table 4.1.3: Waitlist Management

	Number of agencies (%)
Use a Database System to manage client information	21 (40%)
With Established Methods to prioritize clients	39 (74%)
Routinely update and audit waitlist	38 (72%)
Routinely survey impact of wait times on families	17 (32%)
Routinely survey family satisfaction on wait times	20 (38%)

About 74% of responding agencies indicated that they prioritized their clients with some

specific guidelines. Referral date and child's specific needs appeared to be the most

common determining factors of how children were placed on service queues. For

example, children with feeding issues are usually considered urgent for OT and SLP

services. Infants who are referred to IDP because of prematurity are often prioritized to

be seen more quickly. The commonly used criteria for prioritization include:

- Referral date

- Referral date + child/family specific needs

- Referral date + urgency and need

- Child's age

- Child's health and Safety

However, these criteria are operationalized differently across agencies. For example,

some IDP and SCDP of different agencies only follow the provincial service guidelines[12]

loosely. It is clear that a standardized prioritization system is currently lacking in the field

of early childhood intervention services.

Approximately, 72% of responding agencies routinely updated and audited information

on their clients still waiting for services. This means that some agencies might bring

cases forward for review if children were on a waiting list for a significant of time. Some

files would be closed since children either no longer needed the services or had moved.

Thus most agencies were aware of which children were waiting unusually long or who

should be taken off from waiting lists. Only 32% of responding agencies routinely

collected information regarding the impact of waiting on children and families and 38%

conducted surveys on the family's satisfaction with regard to waiting times.

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[12] For example, SCDP Policy and Procedures Manual (working draft 2005): Waitlist management
guidelines for SCDP (page 109) state that requests for service are to be prioritized based first on the service
request date, and second on the urgency of needs of the child and family. The urgency of needs takes into
account of child's age, nature of support needs, childcare space and external supports available to families.

4.1.4 Concerns about Waiting Times

Agencies were asked to provide their perception of the problem with respect to waiting times for each intervention discipline. Waiting for speech-language pathology (SLP) and occupational therapy (OT) seemed to be of greatest consistent concerns to most agencies (Table 4.1.4A). Fifteen SLP agencies (60% of those responding) and 8 OT agencies (50% responding) indicated that waiting times were "always" a problem in recent years. On the other hand, the majority of responding IDP and SCDP agencies indicated that waiting times did not seem to be an issue. For PT services however, about half of the responding agencies indicated children did not usually wait long before getting a PT appointment while the other half stating waiting time was usually or always a problem.

Table 4.1.4A: Respondents' Perception of Waiting Time Problem

To what extent is the waiting time a problem?	IDP	SCDP	OT	PT	SLP
Not a problem	15 (41.7%)	7 (24.1%)	3 (18.8%)	7 (41.2%)	0 (0.0%)
Occasionally a problem	9 (25.0%)	11 (37.9%)	1 (6.3%)	0 (0.0%)	4 (16.0%)
Usually a problem	3 (8.3%)	5 (17.2%)	4 (25%)	4 (23.5%)	6 (24%)
Always a problem	7 (19.4%)	5 (17.2%)	8 (50%)	6 (35.3%)	15 (60%)
Total number of agencies	36	29	16	17	25

While waiting times were increasing for most interventions in most communities at the time of the survey, some were actually experiencing a decrease in waiting times (Table 4.1.4B). For example, 5 agencies (20% of responding agencies) providing SLP indicated that waiting times had decreased compared to 2 years ago, and 3 agencies (12% of

responding agencies) have indicated that their waiting times have greatly decreased over the last 2 years.

Table 4.1.4B: The Upward and Downward Trends in Waiting Times

	INTERVENTIONS				
Compared to 2 years ago, waiting time has:	IDP	SCDP	OT	PT	SLP
Greatly increased	6 (16.7%)	2 (6.9%)	5 (31.3%)	3 (17.6%)	5 (20.0%)
Increased	11 (31.4%)	13 (44.8%)	7 (43.8%)	7 (41.2%)	9 (36.0%)
No Change	13 (37.1%)	8 (27.6%)	2 (12.5%)	6 (35.3%)	1 (4.0%)
Decreased	2 (5.7%)	3 (10.3%)	0 (0.0%)	0 (0.0%)	5 (20.0%)
Greatly decreased	0 (0.0%)	0 (0.0%)	1 (6.3%)	1 (5.9%)	3 (12.0%)
Total number of agencies	36	29	16	17	25

Follow-up telephone interviews provided some insights regarding the reasons why waiting times were in an upward trend or downward trend for some communities and intervention disciplines. While the reasons for increase or decrease in waiting times were specific to local communities, many agencies had the similar concerns. These reasons could be grouped into two broad categories: Demand in services and staffing issues (Table 4.1.4C).

Table 4.1.4C: Reasons for Recent Increase or Decrease in Waiting Times

Demand for Services	Awareness of services	• Family doctors and community professionals are increasingly aware of the services. • Families are better educated in identifying their child's developmental problems.
	Population Changes	• Affordable housing • Job opportunity • Birth rate
Staffing Issues	Recruitment	• Ability to recruit service providers when funding is available. • Recruiting new staff can be a major challenge for some communities.
	Resource	• Funding availability for additional staff

4.1.5 Reasons for a Downward Trend in Waiting Times

Decrease in Demand

A number of agencies, particularly in rural communities, are experiencing a decrease in demand for services. Because of the economic down turn, one agency was seeing families moving out of the community for better job opportunities. This would probably apply to other communities with resource-based economies such as mining and logging where one or two companies are the primary employers.

Lack of affordable housing and a decrease in birth rate were also suggested as reasons for the decreasing in demand for services. One agency (in an urban community) noted that

the waiting list had not been an issue in recent years because owning or renting a home in that community is becoming relatively unaffordable. Many young low income families are moving to neighbouring communities with more affordable housing. One agency specifically stated that their area does not have a big waitlist for SLP services because of low birth rate. However, another agency in this same community expressed concern regarding waiting time for IDP service because they are carrying a higher caseload than they should. Thus, even within a community different intervention disciplines have different perspectives on the waiting time problems.

Staffing issues

A number of agencies indicated that their waiting time improved recently simply because more service providers were on staff. With recent funding for extra staff, some agencies had reduced their average waiting time. For example, the waiting times for a number of IDP programs in Metro Vancouver area actually improved because of extra resources were available.

4.1.6 Reasons for an Upward Trend in Waiting Times

Increase in Demand

One agency in the Northern Health Authority region stated increasing demand in service was the primary reason for increasing waiting times for service in their community. This community has a high level of teenage pregnancy. The lack of prenatal care and primary care to teenage mothers and their children have increased referrals to agencies for a variety of services particularly IDP and SLP.

A number of agencies thought that the increase in service demand was due to the fact that their communities are more aware of their services. These agencies have been raising their profiles in the communities by providing workshops to parents and community professionals. Thus, children with developmental challenges are identified earlier. More families are better educated to identify their child's developmental problems and self-referred to access various services. Moreover, in some communities, more families are referred by their family physicians and community professionals when they are made aware of available services.

As discussed above, some communities are experiencing an influx of young families from neighbouring communities for more affordable housing or job opportunities. For example, the populations of a number of cities in the Fraser Health region increased rapidly in recent years and so did the waiting times for various early childhood intervention services.

Staffing issues

In some communities, staff shortage was thought to be the primary reason for the recent increase in waiting times. The majority of service providers in the field of early childhood intervention are female practitioners. In some cases, therapists can be on leave or the positions are vacated for significant periods of time. When waiting times are exceedingly long, some agencies will not take referrals. Sometimes, therapists are brought in from neighbouring communities or children are sent to other communities for

service. Thus, lack of funding is not always the only issue of waiting time problem. For some communities such as those in small urban or remote areas, hiring new therapists and consultants, as with many healthcare staff, is expected to be a major challenge.

4.1.7 Other Reasons for Longer Waiting Times

There are also other reasons why some communities have longer waiting time. In some communities, outreach based services are the primary model of service delivery with services being provided to a large geographic area. Service providers need to spend considerable time on travelling to children's homes. As a result, children in these communities tend to have a much longer waiting time, and agencies in these communities generally serve fewer families. This might explain why waiting times of agencies providing services to both small urban and rural communities tend to be longer. However, outreach based services do not have to mean longer waiting time. This is especially true if the communities have a small population of children and the services do not involve long distance travel. A few rural agencies with IDPs indicated that they do not receive a large volume of referrals simply because they have a small number of births. However, waiting times for OT, PT and SLP are still a problem because it is more difficult to access these therapists.

Thus, both staff shortage (due to lack of funding and/or recruitment difficulty) and increase in demand for services seem to undermine some agencies' ability to provide timely services. A number of strategies in managing the waiting time were identified from the follow-up interviews. These strategies include implementing block therapy or

group consultation so that as many children can be seen as possible. However, many agencies also indicated that children and families are often receiving sub-optimal services in order to reduce waiting time. Thus, the reported waiting lists and waiting times for optimal services may appear shorter than they actually are.

4.1.8 Strategies to Cope with Long Waiting Times

Agencies reported that generally they have spread their services thin to meet the increasing demand. They often see children less frequently than they should. For example, one IDP noted that they are funded to provide services to 125 families monthly but they routinely see over 200 families each month. Thus, to reduce waiting time, services are routinely offered to groups of children instead of the traditional one-on-one interaction. Group services have become increasingly common for many agencies when waiting times become a problem. Some agencies considered group programs a better alterative than waiting for a long period of time without any service. Although it is an efficient way to provide services when resources are limited, some argue that group programs may not provide much benefit at all for some children.

For one agency, waiting time for speech and language services has always been a problem because of difficulty in recruiting staff. One strategy of managing the waiting lists is by providing therapy services to children and their parents extensively for a few months and then easing off so that parents can work with their child at home. Another strategy mentioned by another agency was to equalize the intensity of intervention services. Thus, all children receive the same level of services despite differences in level

of need. This way, all children referred to the agency would receive some (therapy service) although some should be receiving more.

Consultation based services are also becoming a common practice for early intervention therapies. For example, a physiotherapist would see every child referred to an agency on a "consultation basis" so that families, child care workers or other child aides can work with the children themselves. Some agencies provide block therapy (block consultation). At certain time of the year, children on waiting lists are offered regular sessions of consultation in a set number of weeks followed by a monitoring program.

Streamlining the operational and administrative processes as a strategy in reducing waiting times was mentioned by some responding agencies. A few agencies indicated that sometimes longer waiting is associated with problems connecting with families, scheduling, children being transferred to foster homes, parents out of town, and parents deferring services. One agency suggested that a mechanism is needed to exclude the waiting times of these cases from the general waiting list and waiting time reporting. The issue of missing appointment (or no shows) by families was also suggested as contributing longer waiting times in some cases. However, detailed information about the extent of waiting time problem attributable to "no shows" is limited.

4.2 RESULTS FROM FOCUS GROUP INTERVIEWS

A total of 25 stakeholders participated in 4 focus group sessions. The focus group participants included service providers, intake coordinators, program directors and agencies' executive directors from four of the five regional health authorities (Fraser, Vancouver Island, Interior and Northern Health Authorities). Most participants play dual roles as program managers and service providers.

Service terminologies that are currently used in the field

Participants were asked to comment on the current service terminologies used by agencies and the Ministry. Discussions were mostly focused on the waiting times for initial services.

Summary of comments:

1. There is a need for consistency in the definition of terms used in the field of early childhood intervention services. Most participants recognized the urgent need of common understanding of waiting times. However, many also recognized the difficulty of implementing standard definitions because individual organizations have different service delivery models which affect the information tracking methods and the use of all service terminologies.

   Example of quotes from focus group participants:

   ❖ *For our organization, it is not the terms [the definition of terms]. It is the term usage. Whether everyone uses the same terms is more important.*

   ❖ *One good thing about the [service] indicators and definitions [from MCFD] is that we're stepping into the right direction to get into consistency.*

❖ *The speech has got a good picture. Yes, you need therapy and put you on a list. Or no, you're fine developmentally, then move on [discharge]. They are quite clear. …The OT department will say: we can't just do a screening, we can't do it in one meeting…… we can't do it with one tool. So they [children] wait until therapy is available. So they [occupational therapists] do not do initial screening. They have longer wait. But when they do get on, then it is full service.*

2. The term "Initial Services" was used as one of the service indictors for contract reporting by the Ministry. It was also used as an indictor for measuring waiting time for first services. However, most participants agreed that the term "Initial Services" is too broad to be useful for wait time determination. Similarly, the term "Initial Consultation" or "Intake Consultation" has been used loosely in the field and cannot sufficiently signify initial services. The term "First Contact" was suggested by a few participants to indicate the first significant service encounter with families in the system. "First Contact" may be a better term to identify the first substantial interaction between a family and a service provider.

Example of quotes from focus group participants:

❖ *The way I see initial consultation is not the way I usually see the initial consultation. To me, it is the initial contact or first contact…..*

❖ *Consultation in initial consultation is a big word. It makes me think that you have seen the child, you are giving advices, intervention strategy … But what it is, is just fishing for information ……*

❖ *We use too often "Initial" like initial contact, initial consultation, initial service…..You just want the "first contact".*

❖ *The definition of initial services that includes consultation and group program is too broad to be useful.*

❖ *Initial services should be first contact or appointment with service provider. The first service is when family gets that service requested or when family is getting their needs met by seeing the profession they (parents) wanted to see.*

❖ *The initial consultation is some sort of initial appointment. There is an intake process that is associated with it to see whether referral is appropriate or not [determining eligibility]. If other services are needed, referrals to these services may be made at this point.*

❖ *Some of the things written here about initial consultation are actually things that our intake person [family resource consultant] does.*

Service delivery pathway

Participants were presented with the proposed service delivery pathway (Figure 2.3, Page 91) for the development of a common framework of wait time measures. Although the general discussion surrounded the wide variation in client flow along the service pathway, participants were able to offer their opinions on wait time tracking at each milestone along the pathway.

Summary of comments

1. Not all referred children require one-on-one therapy (or intervention) service. Waiting times and waiting lists should be defined according to the types of intervention (group therapy/program, caregiver consultation, and direct therapy/one-on-one service) and disciplines children require.

Example of quotes from focus group participants:

❖ *Therapy is often consultation… Many children did not get direct therapy from the therapist.*

❖ *When looking at the wait time to treatment, you need to consider the amount of services [the amount of resources needed for each form of intervention: group program versus individual therapy] that a child will be receiving.*

❖ *It seems like individual therapy is the gold standard, everyone is try to get it but that is not the case.*

2. The agency referral date (the date when a referral is made to an agency) should be used to mark the beginning of wait ("date on" waiting) in the early intervention system. However, for multi-program agencies, recording agency referral date alone may not be sufficient because some children may be referred to specific programs sometime later after the initial agency referral. In many cases, there may be a significant time lag between the agency referral and the program referral. Therefore some participants suggested that the program referral date need to be taken into consideration.

Example of quotes from focus group participants:

- ❖ *For a multi-program agency……..usually only one program [discipline] will make that initial contact. Therefore, on the surface the other referred programs may seem unresponsive.*

- ❖ *Because of long waitlist, sometimes children are referred very early. This may skew the data if using original referral date.*

- ❖ *We distinguish the original referral date and admit date for calculating the wait time. For children referred from another program, the date would be admit date.*

- ❖ *We know the original date of referral or original date of referral for some other programs. We also know that when they [children] are referred to PT, OT, Speech or family support worker. It does not look like,... they are referred to all services on the same day.*

3. "Assessment Wait" or "Waiting for comprehensive Assessment" is not a useful indicator to reflect how much time a child needs to wait for that service. Although assessment relating to eligibility to receive service may seem to be important and logical, assessment is not generally used to determine eligibility to service. For most agencies, eligibility is determined from referral information or by intake meeting within agencies. Moreover, some assessments are considered part of an

on-going intervention. For example, some assessment sessions are used to guide intervention treatment strategies by determining and/or monitoring the developmental progress and clinical need. For example, Ages and Stages Questionnaires are used to monitor developmental progress while a child is on active caseload of intervention. Therefore, waiting for "First or Intake" assessment appointment is an important indicator. This is similar to that of surgical consultation for determining whether surgery is necessary. Some patients may have more than one consultation before surgery. Thus, waiting for first assessment (intake assessment) would be equivalent to waiting for first surgical consultation appointment.

Example of quotes from focus group participants:

- ❖ *I do not think there is anything you need to go in and screen for acceptability [eligibility]. Referral has enough information for the intake.*

- ❖ *Because of waitlist, children would not receive any therapeutic assessment until therapist is ready to provide therapy. It is difficult for therapists to let children wait when they know children needed the services*

- ❖ *I don't think we would ever wait for that many steps [comprehensive assessment] to be happened before we decide whether they are eligible for the intervention. If they are not eligible, we are not going to be doing all these [assessment] .... We decided at the referral or at the initial consultation.*

- ❖ *One problem with the framework: The comprehensive interdisciplinary assessment comes up too early. And not all children require the comprehensive assessment.*

- ❖ *We can determine for most of our families from the referral that they are eligible for the program based on our provincial eligibility criterion for IDP.*

- ❖ *Assessment can be part of the therapy……Not an in-depth assessment… It is used to establish whether there is a problem, the nature of problem, and what they can do in the short term.*

- ❖ *Initial service does not usually include assessment. Children will be on caseload [begin intervention] when assessment is preformed.*

- ❖ *I like to see, after eligibility for intervention program, something like recommended services and under recommendation services are individual and group programs.*

- ❖ *Assessment, diagnosis and therapy are in block together. They don't occur independently. We are not going to assess unless we have the intention to provide the therapy services as a result of the assessment.*

- ❖ *They do not do comprehensive interdisciplinary assessment to determine eligibility. Eligibility is determined by each specific program/service*

4. Traditional one-on-one service should not be perceived as the gold standard of early intervention. Many children do not need one-on-one services, thus group intervention program and caregiver consultation should be treated as legitimate forms of early intervention. If children do not require one-on-one intervention, their wait times for other forms of intervention should be specified.

Example of quotes from focus group participants:

- ❖ *We should not blend all services together as the end point because children get to be seen quicker if it is for consultation only…….Consider consultation as another form of intervention.*

- ❖ *Your solid line into the individual therapy… those [group programs] will be the side bars and makes it less legitimate.*

- ❖ *The only difference between a group program and individual therapy. They are both therapy. They are waiting for therapy. Why some children get in sooner? That is because they fit into a group.*

- ❖ *As long as families are receiving services [although these are subservice], caseload begins as soon as service begins. If they are waiting for the group to start, they are on waitlist.*

Waiting time indicators

Participants were asked to suggest what they thought would be valid and useful indicators for reporting wait times according to the perspectives of families, service providers and government.

Summary of comments

1. Waiting (from referral date) for first contact and individualized family service plan are important indicators for both parents and service providers. Many agreed that families need to know when there is someone available to speak to them after the initial referral is made and what the next course of action is. The first contact often eases the anxiety and worry of families. Receiving individualized family service plan is another important milestone. The expectation of intervention outcome and recommendation of services are usually discussed between the family and the service provider at the service plan appointment. This appears important to most families because this provides information on the developmental state of the child, the course of action and the availability of resources.

Example of quotes from focus group participants:

❖ *The initial service is kind of nice to know….. the family is getting something, how long it takes to get even that first visit or initial contact with the family. But the really important one [indicator] is on caseload.*

❖ *The most important thing is: I got the referral, when does someone come in would have an impact on the family and child. Those are the gaps. It is important as a way of building on the relationship. "I hear you" those kinds of things.*

❖ *How long families will wait to speak to somebody. They might say: it is nice to be able to see the intake worker.*

2. Children/Families are not waiting for preliminary or interim services. Although, services and resources provided to waitlisted families should be accounted for, these should not be part of the waiting time calculations.

Example of quotes from focus group participants:

   ❖ *The time from the referral to the time families get the services they are actually referred to get.*

   ❖ *They are not waiting for initial consultation [interim services]. They are getting the initial consultation because they are waiting to go on the caseload.*

3. For the government, waiting times of all wait periods should be reported. It is also important to monitor waiting times according to the level of resource (and time) requirements. This will give a fairer comparison given that there is a wide range of practice models and philosophies across agencies.

Example of quotes from focus group participants:

   ❖ *Better to have indicators to indicate whether children are getting appropriate services within certain time.*

   ❖ *How long children wait for treatment after initial services? That is a more crucial benchmark to be monitored. That is the Wait time to Treatment.*

   ❖ *Amount of treatment time required can be a determining factor.*

   ❖ *That's why I think the crucial one [indicator] is how long you wait to get to [intake] assessment and screening, and how long you wait to get the treatment. There are 3 types of treatment. You must also relate to the amount of services [resources].*

4.3 ADMINISTRATIVE DATA

While 30 agencies were willing to provide their administrative data, only 21 were able to send in their data at the end of the study period. Four of the 21 agencies did not have a database system to manage client information but were able to provide data. The most common reason for not being able to provide data was that their existing database systems were not designed to provide case based information easily. Their database systems are designed to be used as an information management system. In order to extract the requested data in a usable form, agencies would need to modify their systems. Thus, time and resource restrictions might have prevented some agencies from supplying the requested data. Furthermore, some agencies also indicated that information had not been consistently entered into their database because their existing data systems were outdated and being phased out. The administrative data received from participating agencies were assessed for quality and comparability. Data from 3 agencies were not used because of incomplete data elements but data from the remaining 18 agencies were used for the waiting time analysis. The profile of the18 agencies is outlined in Table 4.3A.

The waiting times in this study represent the time delays between the *Referral Date* and either the first *Appointment Date* or "*Service Delivery*" *Start Date* at the participating individual agencies, because not all services had a waiting list. Table 4.3B outlines the data elements and terms currently used by various community based agencies for managing their own client intake and referral information.

Table 4.3A: Profile of the 18 Participating Agencies

Agency	Type *	Programs	Service Location**	Average annual caseload	Staffing (FTE)
AB	CDC	IDP, SCDP, OT, PT, SLP	Urban + Rural	822	16.0
AE	CDC	IDP, OT, PT, SLP	Urban + Rural	1100	45.0
AF	CDC	IDP, SCDP, OT, PT, SLP	Rural	190	8.0
AI	CDC	IDP, SCDP, OT, PT, SLP	Urban + Rural	337	14.0
AM	CDC	IDP, SCDP, OT, PT, SLP	Urban + Rural	476	12.0
AR	PH	SLP	Urban + Rural	1800	26.0
AS	PH	SLP	Urban	350	7.8
AT	PH	SLP	Urban	250	5.0
AU	PH	SLP	Rural	250	5.0
AV	PH	SLP	Urban + Rural	1250	17.8
AW	PH	SLP	Urban + Rural	740	8.2
AX	PH	SLP	Urban + Rural	870	12.5
AZ	CDC	SLP	Urban	220	3.0
BA	Program	IDP	Rural	190	3.0
BE	Program	IDP	Rural	50	1.5
BN	Program	IDP	Urban + Rural	105	3.5
CC	Program	IDP	Rural	136	3.0
CD	Program	IDP	Urban + Rural	35	2

*CDC = Child Development Centre (multi-program agencies); PH = Public Health Unit; Program = Single program community agency; **Urban = agency provided services primarily in an urban community (small or large urban centre), Some agencies provide services to both small urban and rural communities.

Table 4.3B demonstrates the nomenclature issues and possible common terms that would be used to set up a standard set of definitions. The first column lists the important dates that can be used to determine waiting times for various services at each stage of the early intervention service system. The second column indicates the service terms different agencies use that correspond to the dates on which services are provided. It is evident that no consistency exists across agencies. For example, there are 6 different terms that can be used to represent the beginning of a service request found in the different data systems.

These include the "Referral date," "Initial referral date," "Original referral date," "File open date," "Admission date," and "Program admission date". For a single program agency, there may be just one type of referral information recorded. On the other hand, for a multi-program agency, several types of referral date information may be recorded in their databases.

Table 4.3B: Commonly Used Terms in Administrative Data for Intake and Referral Information.

Important Dates	Services
Referral • Referral date • Initial referral date • Original referral date • File open date • Admission date • Program admission date	**Service Request** • Referral received by agency • Internal referral for additional program(s) • Child's file created by administrative staff
Intake • First contact date • Accepted date • Intake date • Initial contact date	**Initial responses to referral** • Initial Consultation • Intake Consultation • Intake Visit • First Contact • Initial Contact (Some initial appointments may also include formal intake assessment or multidisciplinary assessment)
Service Recommendation • Recommendation date • Program recommendation date	**Decision/Recommendation on Program and intervention streams** • Program recommendation • Service recommendation • Individualized Service Plan
Service Delivery • Home visit date • Program admission date • Active service date • Service delivered date	**Type of intervention streams** • Therapy • Consultation therapy • Group therapy • Home visit • Monitoring • Review Consultation • Parent education • Consultation to other professional

The *Referral Date* usually means the date when a referral is received by agencies. The *Initial Referral Date* however may mean the previous referral date for a returning child who had been previously discharged. It may also mean the original referral date in the case of a child being referred from one program to another service or program within that agency, or the referral date from a different agency in the case of a child being transferred to the current agency.

In this study, it is reasonable to consider *Referral Date* (or *Program Referral Date* if it differs from *Agency Referral Date*) as *Date On* waiting and *First Appointment Date* (First date of *Initial Consultation* or date of *First Contact*) as Date Off waiting. For example, agency AF is a multi-program child development centre providing a full spectrum of early childhood intervention services including IDP, SCDP, PT, OT and SLP in a rural community. For the *Date On*, agency AF recorded the *Agency Referral Date*, and both the *Program Referral Date* and the *Program Recommendation Date*. Each child had a single *Agency Referral Date* but several different *Program Referral Dates* or *Program Recommendation Dates* for different programs. The *Agency Referral Date* in this case represented the date when a referral was received by the agency. The *Program Referral Date* represented the date when recommendation for a specific program was made (or the internal program referral). Some children were referred to more than one program at the same time while others were referred to different programs at different times as they progressed within the agency. In this case, it is reasonable to suggest that the *Program Referral Date* instead of the *Agency Referral Date* should be used as the *Date On* (for a

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specific service request) for determining waiting time for each referred program. Using the *Agency Referral Date* as the *Date On* regardless of when a program referral was made would make the waiting time appear exceedingly long in some cases.

The first appointment for each program was generally reflected by either an intake date or an admission date. Some agencies also used the "admission date" (or the "Program admission date") to represent the date when a referral was filed or added to their data system. Others, however, used the "admission date" to represent the date of first formal assessment (or intake assessment) for eligibility and needs determination. Moreover, for some organizations as noted in focus group interview, it may also represent the date of the first therapy session or the date of first interim service session signifying the clients' entry to caseload.

For the D*ate Off*, agency AF used either the "Program intake date," the "Program admission date," or the 'File open date". However, both *Intake Date* and *Admission Date* actually represented the first date of service delivery for each specific program at that agency. The 'file open date' represented the date of first contact with the family by the agency in general.

Some agencies only provided an *Admission Date* or an *Accepted Date* as the intake information. These dates might or might not necessarily represent the first date of services. Thus, there is a wide range of service delivery dates that correspond to a wide range of different services. The range of possible different start dates and end dates within and between agencies makes self-reported waiting list and waiting time

information prone to bias because of the inconsistent service definitions specifically, and more generally inconsistent use of these terms. The following sections attempted to assess the compatibility of the available administrative data to guide the choice of *Date On* and *Date Off* waiting for the five early childhood intervention services in BC.

4.3.1 Infant Development Program (IDP)

The administrative data sets from the 10 IDP agencies yielded 1326 infant-based referral records and their intake information (Table 4.3.1.A). Five of these agencies were single-program agencies. For the referral information, the single program agencies use only the *Agency Referral Date* as *Date On*. The multi-program agencies recorded both the *Agency Referral Date* and the *Program Referral Date* as the *Date On* waiting.

Agency AF, a multi-program child development centre, recorded the *File Open Date* and the *Intake Date*. The *File Open Date* represented first contact with the family by the agency in general, while the *Program Admission Date* represented the first service date for each specific program. The *Intake Date* was mostly recorded as the *Program Admission Date*. Agencies AE, BA, and BN provided only the *Program Admission Date* while agencies AB, AF, AI, BE, CC and CD recorded both the *Initial Contact Date* or the *First Contact Date* and the *Admission Date* or the *Accepted Date* as the potential *Date Off* indicators (Table 4.3.1A).

Table 4.3.1A: Administrative Data: Infant Development Program

Agency	Date On (Number of records)	Date Off (Number of records)	Notes
AB[#]	Agency Referral Date (70), Program Referral Date (70)	Intake Date (22), Admission Date (59)	Intake date and admission date were on the same dates. Most referrals (84%) had a record of "admission date" but not "intake date". Intake date was not consistently recorded.
AE[#]	Agency Referral Date (550), Program Referral Date (550)	Program Admission Date (339)	This agency only provided record of Program admission dates to mark beginning of services.
AF[#]	Agency Referral Date (37), Program Referral Date (37)	Program Admission Date (35), File Open Date (36), Intake Date (33)	File open date represented first contact by agency in general. Intake date and program admission date were on the same date
AI[#]	Agency Referral Date (115), Program Referral Date (115)	Initial Contact Date (101) Active Service Date (47)	The "Active Service Date" is equivalent to the program admission date.
AM[#]	Referral Date (151), Program Recommendation Date (151)	Intake Consultation (IC) Dates (131)	Most referrals had an IC date as first appointment (86%). Other records were coded as monitor or missing information. Thus IC date is used as "date on" for this agency. The admitted date and Referral date were on the same date for this agency. It represents the agency referral date
BA[##]	Referral Date (144)	Accepted Date (144)	Only recorded accepted dates
BE[##]	Referral Date (48)	First Contact Date (14) Accepted Date (48)	All have accepted date, only 14 recorded first contact dates
BN[##]	Referral Date (80)	First Visit Date (78)	First home visit date represented accepted date.
CC[##]	Referral Date (85)	First Contact Date (82) Accepted Date (59)	Most accepted date occurred at a later date after first contact
CD[##]	Referral Date (66)	First Contact Date (64) Accepted Date (66)	Most accepted dates occurred at a later date after first contact

Multi-program agencies (Community Child Development Centres)
Single-program agencies

Table 4.3.1B shows the mean and median wait time in days between the first contact and program admission for those accepted to IDP and first contacted on or before May 31, 2005. In most cases, program admission occurred after the first contact and in some cases there was a lengthy wait between the two dates.

Table 4.3.1B: Time Delay between First Contact and Program Admission for Infant Development Program

Agency *	Number of Cases	Mean (in days)	Median (in days)
AB	59	0.0	0.0
AF	35	2.14	0.0
AI	47	38.9	16
BE	14	52.7	46.5
CC	58	28.3	6.5
CD	63	8.2	1

* Information is for agencies recording both *First Contact Date* and *Program Admission Date*.

The *First Contact Date* and the *Program Admission Date* for agency AB were on the same date since the mean and median time delays were 0 days (Table 4.3.1B). For agencies AI, BE, and CC, program admission occurred at a significantly later time in most cases especially for agency BE.

Agency AM, another multi-program centre, employed a data system using different service delivery codes such as "Intake Consultation," "Assessment," "Therapy," "Monitor," "Review," etc. There were 151 referrals during the study period and 288 service delivery records. Of the 151 referrals, 131 (86%) received an initial consultation as the first appointment to IDP on or before May 31, 2005. The other 20 referrals had a "Monitor" or "Unknown" coded as the only service dates for IDP. These cases were excluded from the analysis because monitoring was not considered by agencies as initial contact or program admission. The date for the "Intake Consultation" is assumed to be

the *Program Admission Date* (thus the *Date off*) for IDP at agency AM because "Intake Consultation" and "Monitor" were the only service delivery codes found in the 288 service delivery records. Therefore, for IDP the *Program Admission Date* (or *Accepted Date*) from each agency's administrative data set was used as the indictor for the *Date Off* waiting for IDP services.

4.3.1.1 Descriptive Statistical Analysis, IDP

There were 1326 referrals with complete referral and intake information. However 29 cases were excluded because program admission occurred earlier than the referral date or the referral occurred earlier than the date of birth. Although rare, referral could be made even before birth when prenatal diagnosis such as Down's syndrome was established. However, this information could not be verified. Data entry error could not be ruled out for these cases.

The program admission status of the remaining 1297 referrals is shown in Table 4.3.1.1A. In general 75.0% of all referrals were admitted to IDP on or before May 31, 2005 (the study end date). Agencies AI and AE appeared to have lower admission rates: 40.7% and 61.5% respectively. A small number of children (50; 3.9% of all referrals) were still waiting for program admission on May 31, 2005.

A significant number of children (274; 21% of all referrals) were discharged from IDP before receiving any services on or before May 31, 2005. The reasons for leaving the program for this group of children are outlined in Table 4.3.1.1B. A significant number of

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families either withdrew their service request voluntarily (81 families)) or left the

program because service providers felt that services were no longer needed (76 cases)

before they were even admitted. Families who moved or failed to make contact after

making referrals also represented a significant number of cases leaving the program

without receiving services. The high number of families leaving the IDP before receiving

services makes a retrospective design of waiting time analysis inappropriate because of

the inherent bias as discussed in Chapter 3.

Table 4.3.1.1A: Number of Referrals and Program Admission Status for Infant Development Program

| Agency | Program Admission Status | | | Number of referrals |
	Admitted*	Left	Waiting	
AB	59 (84.3%)	11 (15.7%)	0 (0%)	70
AE	337 (61.5%)	188 (34.3%)	23 (4.2%)	548
AF	35 (94.6%)	2 (5.4%)	0 (0%)	37
AI	46 (40.7%)	66 (58.4%)	1 (.9%)	114
AM	125 (95.4%)	6 (4.6%)	0 (0%)	131
BA	131 (100.0%)	0 (0%)	0 (0%)	131
BE	48 (100.0%)	0 (0%)	0 (0%)	48
BN	72 (97.3%)	1 (1.4%)	1 (1.4%)	74
CC	58 (69.9%)	0 (0%)	25 (30.1%)	83
CD	62 (100.0%)	0 (0%)	0 (0%)	62
Total	973 (75.0%)	274 (21.0%)	50 (3.9%)	1297

* Admitted = Admitted to program on or before May 31, 2005
  Left = Discharged without receiving services on or before May 31, 2005
  Waiting = Still waiting for program admission on May 31, 2005

Table 4.3.1.1B: Discharge Reasons for Those Left IDP without Services

Reasons	Number of cases	%
Not stated	11	4.0
Died	1	0.4
Inappropriate Referral	10	3.6
Moved	27	9.9
Failed to Make Contact	31	11.4
No Longer Eligible	37	13.6
No Longer Need Services	75	27.5
Family Withdrew	81	29.7
Total	274	100.0

The inter-agency and intra-agency variations in waiting times for admission to IDP are illustrated in Figure 4.3.1.1A using box-plots and Table 4.3.1.1C. The degree of dispersion within each agency is depicted by the inter-quartile range indicated by the lower and upper limits of the box. Intra-agency variation appeared to be higher for agencies CC and AE with a range of 175.8 and 150 days respectively (Table 4.3.1.1C). The lowest ranges were found to be 6 and 8 days for agencies AF and BA. The median waiting time is represented by the horizontal line inside the box which is more useful for comparing waiting time among agencies because it is less sensitive to outliers. Median waiting time also appeared to be highest for agency AE (157 days) and lowest for agency AB (0 days).

Figure 4.3.1.1A: Variation in Waiting Times for Admission to Infant Development Program
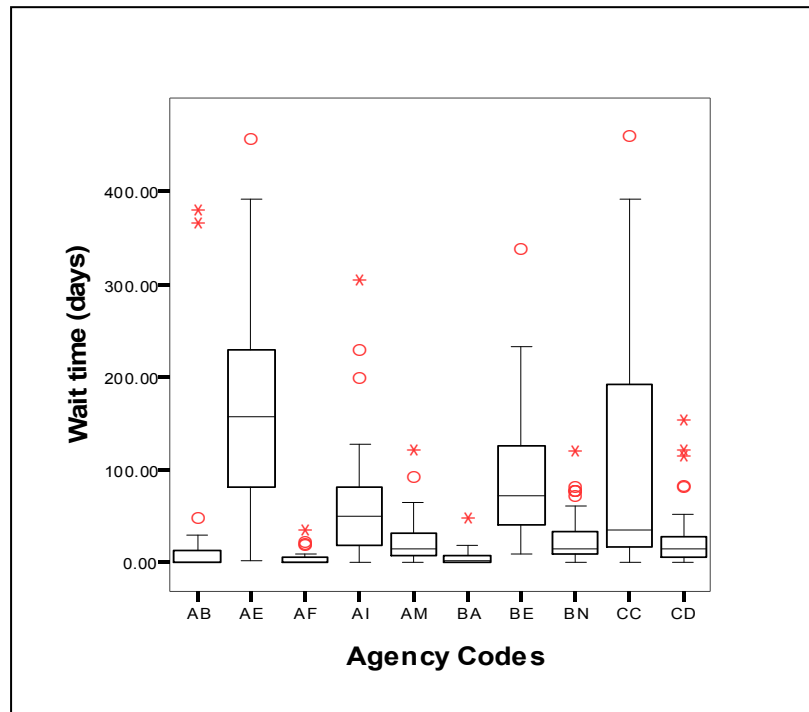
Table 4.3.1.1C: Inter-Quartile Range, IDP Admission

Agency	Number admitted	Mean wait time (days)**	Median wait time (days)**	IQR (days)*
AB	59	18.9	0	14
AE	337	159.5	157	150
AF	35	4.5	1	6
AI	46	60.9	50	64.25
AM	125	21.1	16	24
BA	131	4.9	3	8
BE	48	88.4	72	85.5
BN	72	24.4	15	25.5
CC	58	106.7	36.5	175.75
CD	62	24.2	14.5	22.75
Total	973	76.9	30	116

*IQR = Inter-quartile range

** Waiting time for IDP admission for those admitted on or before May 31, 2005

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Waiting time information with censored cases is presented in Table 4.3.1.1D. The overall mean and median times spent waiting for censored cases appeared higher than that of non censored cases in some agencies. Agency AI had only one case still waiting on May 31, 2005. The time spent waiting was 764 days. A close examination of this single case revealed that the child was referred at 1.2 months of age. Thus, the exceedingly long waiting time could be due to the fact that some children were not ready for any intervention (e.g. child was in the hospital for a long period of time) or some should have been removed from the list.

The mean and median waiting times for IDP admission by agency estimated by Kaplan-Meier method, taking censored events into consideration, is presented in Table 4.3.1.1E. The overall comparison by the Log Rank Test indicated that differences in waiting time among agencies are highly significant. The median waiting times range from the longest, 229 (95%CI, 31.67, 426.33) days in agency AI to the shortest, 1 (95%CI, 0.02, 1.98) day in agency AF.

Table 4.3.1.1D: Waiting for Infant Development Program Admission with Censored Cases

	Admitted*		Left Program**		Still waiting ***	
Agency	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)
AB[#]	18.93	0	136.00	138	n/a	n/a
AE[#]	159.45	157	148.84	124	329.26	270
AF[#]	4.54	1	170.50	170.50	n/a	n/a
AI[#]	60.96	50	145.95	120	764.00	764
AM[#]	21.10	16	74.33	56	n/a	n/a
BA[##]	4.89	3	n/a	n/a	n/a	n/a
BE[##]	88.44	72	n/a	n/a	n/a	n/a
BN[##]	24.36	15	322.00	322	673.00	673
CC[##]	106.74	36	n/a	n/a	436.36	405
CD[##]	24.19	14	n/a	n/a	n/a	n/a
All Agencies	76.86	30	146.78	120	398.38	335

* Waiting time for IDP admission for those admitted on or before May 31, 2005

** Time spent waiting before leaving the program for those did not receive services on or before May 31, 2005

*** Time spent waiting since referral for those still waiting program admission on May 31, 2005

Multi-program agencies; ## Single program agencies

Table 4.3.1.1E: Variation in Waiting Times by Agency, Infant Development Program

Agency[#]	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
AB	67.12	34.07	100.17	7	0.00	15.88
AE	231.94	208.49	255.39	213	201.06	224.94
AF	14.44	0.00	33.32	1	0.02	1.98
AI	385.54	302.28	468.80	229	31.67	426.33
AM	25.18	19.89	30.48	19	14.88	23.12
BA	4.89	3.83	5.95	3	1.48	4.52
BE	88.44	69.50	107.38	70	51.89	88.11
BN	41.89	17.36	66.43	15	11.99	18.01
CC	272.03	209.32	334.74	147	0.00	300.75
CD	24.19	16.87	31.52	14	11.11	16.89
Overall	161.29	146.49	176.10	70	55.61	84.39

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =1360.52, df =9, P <0.001
AB, AE, AF, AI, AM are multi-program agencies; BA, BE, BN, CC, CD are single program agencies.

Variation in waiting time for IDP admission by child's characteristics is illustrated in Tables 4.3.1.1F – H. The mean and median ages at referral for IDP are 11.6 months and 7.4 months of age respectively. The majority were referred before 6 months of age. Table 4.3.1.1F presents the waiting time for IDP admission by age at referral.

Children younger than 6 months of age or older than 30 months tended to have shorter waiting time. As discussed in previous section, age is one of the prioritizing criteria. Older children waited a shorter period because IDP only provides intervention to children up to age 36 months. A quick one-time transition service might be provided to children who are near 3 years old. Younger infants waited a shorter time because they were generally considered in urgent need of intervention, or because they were likely to have

an established or well recognised diagnosis such as significant feeding problems or

Down's syndrome. Gender did not play a significant role in waiting time variation as

expected (Table 4.3.1.1G).

Table 4.3.1.1F: Variation in Waiting Times by Referral Age, Infant Development Program

| Referral Age (months) | Number (%) | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 6	609 (47.0%)	143.47	124.76	162.17	50	34.03	65.97
6 – 18	261 (20.1%)	195.96	158.10	233.83	78	38.54	117.46
19 – 30	357 (27.5%)	145.33	130.47	160.20	109	83.55	134.45
> 30	70 (5.4%)	120.99	81.51	160.46	42	29.36	54.64

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =12.181, df =3, P =0.007

Table 4.3.1.1G: Variation in Waiting Times by Sex, Infant Development Program

| Sex | Number (%) | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
F	528 (40.7%)	155.75	133.57	177.93	61	41.52	80.48
M	769 (59.3%)	159.99	141.91	178.07	76	55.23	96.77

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =1.296, df =1, P =0.255

Children who were referred by their parents or other family members also tended to wait

a shorter time than those referred by either physician or public health nurse (Table

4.3.1.1H). This finding is somewhat surprising. It is unclear whether or not parents who

self-referred were also more empowered. It is known that empowerment might have

some influence on the waiting times for some services as discussed in Chapter 2.

Table 4.3.1.1H: Variation in Waiting Times by Referral Source, Infant Development Program

Referral source**	Number (%)	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
FM	251 (19.4%)	115.85	93.60	138.09	24.00	11.17	36.83
MD	177 (13.6%)	227.66	171.21	284.10	121.00	74.47	167.53
PHN	449 (34.6%)	183.20	155.96	210.43	104.00	64.38	143.62
Other	420 (32.4%)	132.95	114.95	150.96	65.00	47.82	82.18

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =26.582, df =3, P <0.0001
** FM= family member, MD=physician/hospital, PHN= Public health nurse, and Other includes therapist, social worker, early child educators, etc

Variations in waiting times for IDP admission by agency factors are presented in Tables 4.3.1.1I –N. Agencies in rural communities tended to have shorter waiting times for admission (Table 4.3.1.1I). The median wait time for IDP admission was 7 days in rural community agencies whereas the median wait time was 106 days for agencies serving both rural and small urban communities. Single IDP program agencies also appeared to have shorter wait time for admission compared to IDP program within multi-program agencies (Table 4.3.1.1J). The median wait time was 14 days in single program agencies while it is 146 days in multi-program agencies.

Table 4.3.1.1I: Variation in Waiting Times by Urban-Rural Location, Infant Development Program

Location**	Number (%)	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
Rural	251 (19.4%)	96.16	69.71	122.62	7	5.33	8.67
Both	1046 (80.6%)	166.88	150.00	183.76	106	90.48	121.52

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =85.721, df =1, P <0.0001
** Rural= Primarily rural communities, Both= Urban and rural communities

Table 4.3.1.1J: Variation in Waiting Times by Agency Type, Infant Development Program

| Agency type** | Number (%) | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
Multi-program	899 (69.3%)	186.54	166.75	206.34	146	122.13	169.87
Single Program	398 (30.7%)	80.41	63.15	97.67	14	12.18	15.82

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =163.025, df =1, P <0.0001
** Multi-program agencies are mostly community chid development centre; Single
program agencies= IDP as stand alone program within agencies

Annual caseload from agency survey represents the average number of children on
agency's active caseload in each year. This information together with program staff size
and total agency staff size was used to reflect the size of an agency. Agencies with fewer
staff members and smaller annual caseload appeared to have shorter waiting time (Tables
4.3.1.1K - M). Overall, the results from Kaplan-Meier analysis suggested that smaller
agencies in rural communities tended to admit children earlier.

Table 4.3.1.1K: Variation in Waiting Times by Annual Caseload, Infant Development Program

| Annual Average Caseload** | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 150	117.46	92.93	142.00	30	23.14	36.86
150 -500	116.07	88.18	143.95	12	9.39	14.61
> 500	211.35	190.12	232.58	203	187.03	218.97

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =313.550, df =2, P <0.0001
** Average number of clients served per year by agencies. Information obtained from
agency questionnaire

Table 4.3.1.1L: Variation in Waiting Times by Agency Staffing, Infant Development Program

Agency Staff (FTE)**	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 10	75.59	59.40	91.78	14	11.78	16.22
10 – 20	139.06	92.63	185.50	28	22.34	33.66
> 20	231.94	208.49	255.39	213	201.06	224.94

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =315.095, df =2, P =0.001
** Agency staff level (Full Time Equivalence). Information obtained from agency questionnaire

Table 4.3.1.1M: Variation in Waiting Times by Program Staffing, Infant Development Program

Program Staff (FTE)**	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 2.5	110.35	91.27	129.44	16	13.48	18.52
2.5 – 5.5	41.89	17.36	66.43	15	11.99	18.01
> 5.5	231.94	208.49	255.39	213	201.06	224.94

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =307.584, df =2, P <0.0001
** IDP Program staff level (Full Time Equivalence). Information obtained from agency questionnaire

Waiting time was also closely associated with the percent of children admitted over the study period. The total percent of admission between January 2003 and May 2005 for each agency was determined from the administrative data. Waiting times appeared significantly shorter in agencies with more than 75% admission (Table 4.3.1N).

Table 4.3.1N: Variation in Waiting Times by Admission Rate, Infant Development Program

Percent Admission	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
≤ 75%	258.81	235.91	281.70	212	198.18	225.92
> 75%	32.34	25.13	39.55	11	9.55	84.39

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =883.831, df =1, P <0.0001
** Percent Admission = overall admission rate between January 1, 2003 and May 30, 2005 (Total admitted/ Total referral * 100%)

The variations in the number of referrals for IDP and in mean and median waiting times by calendar month for the year of 2003 are presented in Table 4.3.1O and Table 4.3.1P. No particular seasonal trend in terms of referral was noted. Nevertheless, the number of referrals was lower in December and highest in September. The information for 2004 is not presented because referrals were only included up to September of 2004. Waiting times appeared to be shorter when referrals were made in particular months (February, June, and October) and, not surprisingly, longer in the months of July and August. Thus, waiting time tends to be longer in summer months when service providers take vacation break. This analysis included the non-censored cases only because the month when admission occurred for the censored cases could not be ascertained. This variable however will not be used in Cox regression analysis because censored information is not available.

Table 4.3.1O: Number of IDP Referrals by Calendar Month

Months of 2003	Number of referrals	Percentage
January	52	7.6
February	47	6.8
March	56	8.1
April	54	7.8
May	71	10.3
June	65	9.4
July	60	8.7
August	51	7.4
September	77	11.2
October	63	9.2
November	55	8.0
December	37	5.4
Total	688	100.0

Table 4.3.1P: Variation in Waiting Times by Calendar Month of Referral, IDP

Referral month	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
January	61.64	37.94	85.35	26	5.13	46.87
February	78.29	45.58	110.99	17	0.44	33.56
March	73.87	51.31	96.42	37	18.60	55.40
April	85.58	56.65	114.50	50	0.00	102.06
May	71.45	49.71	93.19	38	15.61	60.39
June	48.63	29.70	67.55	14	7.00	21.00
July	105.48	74.04	136.92	61	0.00	125.99
August	83.20	59.02	107.37	57	23.54	90.46
September	70.87	49.15	92.58	32	11.76	52.24
October	54.62	31.35	77.88	15	0.22	29.78
November	86.91	53.89	119.93	36	28.50	43.50
December	87.41	49.76	125.07	42	17.39	66.61

The sizes of referral rate and admission rate reflect demand and capacity of service provision. Together, the above results provide some empirical data to support the conceptual framework (Figure 2.1) of how waiting times are related to child's age, referral source admission rate, agency type, size and geographical location.

4.3.1.2 Cox Regression Analysis, IDP

The first regression model was used to investigate inter-agency variation in wait time adjusted for child factors such as child's age at referral and referral source. The crude hazard ratios (HR) for individual agencies was obtained by entering variable "Agency" to the model as block 1 variable. The reference agency was BE because the mean and median wait times (mean= 88.4 days, median =70 days) of this agency for IDP admission were closest to the provincial values (mean= 161.29 days, median=70 days) as determined by Kaplan-Meier analysis. Adjusted hazard ratios were then obtained by entering child factors, "Referral Age" and "Referral Source", to the model as block 2 variables. The variables "Referral Age" and "Referral sources" were selected because they were found to be significant factors by Kaplan-Meier analysis. The final model depicting the inter-agency variation adjusted for child factors is expressed as:

$$\ln [h(t)/ h_0(t)] = b_{agency1}.AGENCY1 + \ldots + b_{agencyn}.AGENCYn + b_{refage1}.REFAGE1 + \ldots$$
$$b_{refagen}.REFAGEn + b_{refso1}.REFSO1 + \ldots + b_{refson}.REFSOn$$

where
$$REFAGE = \text{referral age (categorical)}$$
$$REFSO = \text{referral source (categorical)}$$

Table 4.3.1.2A shows the crude and adjusted standardized hazard ratios (HR) of agencies. HR greater than 1 means a higher probability of receiving service in the next time increment, that is, shorter waiting time compared to reference agency (BE). The results indicated that inter-agency variation persisted after adjusting for child factors. Waiting time for IDP admission in agencies AE, AI, and CC were likely longer than that of agency BE and provincial average, whereas agencies AB, AF, AM, BA, BN and CD tended to have shorter waiting times compared with agency BE and provincial average.

Agency BA (a single program agency) appeared to have the shortest waiting times

$(HR_{BA}=10.68, 95\%CI: 7.42, 15.37)$.

Table 4.3.1.2A: Cox Regression Model 1, IDP

	Block1	Block 1 + Block 2
Variable	Hazard ratio (95% CI)	Hazard ratio (95% CI)
Agency		
BE	Reference	Reference
AB	1.86 (1.27, 2.73)*	1.81 (1.20, 2.74)*
AE	0.35 (0.26, 0.48)**	0.36 (0.26, 0.50)**
AF	4.80 (3.08, 7.42)*	5.55 (3.42, 9.00)*
AI	0.32 (0.21, 0.48)*	0.35 (0.23, 0.52)*
AM	2.84. (2.02, 3.99)*	2.95 (2.08, 4.17)*
BA	10.32 (7.24, 14.79)*	10.68 (7.42, 15.37)*
BN	2.15 (1.49, 3.11)*	2.13 (1.46, 3.09)*
CC	0.33 (0.22, 0.48)*	0.35 (0.23, 0.52)*
CD	3.01 (2.06, 4.42)*	3.12 (2.11, 4.61)*
Age at Referral (months)		
< 6		Reference
6 -18		0.92 (0.77, 1.1)
19 – 30		1.00 (0.85, 1.18)
> 30		0.74 (0.53, 1.05)
Referral source		
Family member (FM)		Reference
Medical (MD)		0.74 (0.58, 0.95)***
Public Health Nurse (PHN)		0.83 (0.68, 1.01)
Other		0.96 (0.79, 1.16)
-2 Log Likelihood	11564.099	11551.805[#]

* P<0.0001, **P<0.01, ***P<0.05
[#]Change from block1 is not significant by Chi-Square test, P=0.056

The inclusion of "referral age" and "referral source" did not improve the model

significantly as shown by the small changes in the -2 Log Likelihood ratio statistics and

Chi Square statistics. This indicated that one or both covariates (referral age or referral

source) were not contributing significantly to the prediction of time to event. In this case,

child's age at referral was not found to be a significant variable. No differences in waiting time among different referral age groups were observed in the final model. On the other hand, children who were referred by medical professionals (for example, physician or hospital referral) were more likely to wait longer compared with children who were self-referred by their parents (HR_{MD}=0.70, 95%CI (0.54, 0.89)). The wait time of children who were referred by public health nurses or other professionals did not differ significantly from that of children who were self-referred by their parents.

The second set of model development was used to explain the wait time variations by modeling agency characteristics such as location, agency type, annual caseload, and staffing level adjusted for child factors. Agency location, type, caseload, and admission rate were included in the final model adjusted for child factors (referral age and referral source). Multicollinearity among groups of predictor variables was detected during the initial model development. Collinearity implies that two or more categories of the interaction terms and/or variables were highly correlated. If these variables were included, the effects of changes in any one variable on the dependent variable (wait time) became more difficult to interpret. The variable "Agency staff size" was dropped from the analysis because significant correlation between "Agency staff size" and "Program staff size" was found. It was decided to exclude agency staff size (number of service providers plus clerical and administrative staff) because program staff size was conceptually more closely associated with waiting time. The final model is expressed by the equation:

$$\ln [h(t)/ h_0(t)] = b_{location}.LOCATION + b_{casload}.CASELOAD + b_{type}.TYPE +$$
$$b_{Admitrate}.ADMITRATE + b_{progFTE}.PROGFTE + b_{refage}.REFAGE + b_{refso}.REFSO$$

where

LOCATION = agency location (categorical)

CASELOAD = agency annual caseload (categorical)

Type = agency type (categorical)

ADMITRATE = admission rate (categorical)

PROGFTE = program FTE (categorical)

REFAGE = referral age (categorical)

REFSO = referral source (categorical)

Table 4.3.1.2B shows the standardized hazard ratios (HR) of agency characteristics adjusted for child factors. In comparison, single-program agencies tended to have shorter waiting time than multi-program agencies ($HR_{Program}$ =1.99, 95% CI (1.36, 2.91)). The waiting time was also likely to be shorter in agencies with more than 75% admission rate ($HR_{>75\%}$ = 8.31, 95% CI (6.32, 10.92). Agencies serving both rural and urban communities were more likely to have longer waiting time for IDP admission compared with agencies serving only rural communities (HR_{both} = 0.56, 95% CI (0.42, 0.75))

It appeared that the size of an agency was also significantly associated with the waiting time for IDP admission. Larger agencies in terms of annual caseload and program staffing level were more likely to have shorter waiting times (Table 4.3.1.2B). This is a stark contrast to the results of Kaplan-Meier analysis (Tables 4.3.1K and M). Agencies with the largest caseload group (500 children or more) had significantly longer mean and median waiting times than agencies of the smallest caseload group (150 children or less), whereas agencies with a caseload of between 150 and 500 had the shortest median waiting time among the 3 groups. Agencies with the highest program FTE also had the

longest median waiting times. Thus, the effects of caseload size and program staff size on waiting times appeared to be influenced by agency type and location.

Similar to the first set of model development, child's age at referral and referral source did not appear to improve the overall fit of the model. Nevertheless, Referral source still appeared to play a role in explaining the variation in waiting time after adjusting for agency factors. The adjusted hazard ratios of referral sources indicated that compared to any professional referral, self-referral by parent or family member was more likely to have shorter waiting time for IDP admission.

Interaction between agency type and agency service location was included to investigate the interaction effect of agency service location and agency type in the final model. The interaction term was insignificant in the model indicated that regardless the type of agency (single program versus multi-program agencies), agencies serving only rural communities tended to have shorter waiting times for IDP. The insignificant interaction term also indicated that regardless the service location (rural versus urban + rural), single program agencies tended to have shorter waiting time compared with multi-program agencies.

Table 4.3.1.2B: Cox Regression Model 2, IDP

	Block1	Blocks 1 + 2	Blocks 1 + 2 +3
Variable	Hazard ratio (95% CI)	Hazard ratio (95% CI)	
Location			
Rural	Reference	Reference	
Rural + urban	0.58 (0.44, 0.76)*	0.56 (0.42, 0.75)*	0.54 (0.36, 0.83)**
Caseload Size			
< 150	Reference	Reference	
150 -500	3.55 (2.53, 4.98)*	3.54 (2.47, 5.08)*	3.67 (2.28, 5.91)*
> 500	2.40 (1.54, 3.73)*	2.15 (1.34, 3.43)***	2.25 (1.21, 4.17)***
Program FTE			
< 2.5	Reference	Reference	
2.5 -5.5	1.33 (0.99, 1.78)	1.30 (0.97, 1.75)	1.29 (0.96, 1.75)
> 5.5	1.62 (1.11, 2.37)***	1.71 (1.15, 2.54)***	1.67 (1.07, 2.62)***
Agency type			
Child development centre	Reference		
Single-Program	2.06 (1.46, 2.91)*	1.99 (1.36, 2.91)**	1.95 (1.27, 2.99)**
Admission Rate			
< 75% admitted	Reference	Reference	
≥ 75% admitted	8.48. (6.54, 11.00)*	8.31 (6.32, 10.92)*	8.1 (5.70, 11.52)*
Age at Referral (months)			
<6		Reference	
6 – 18		0.95 (0.79, 1.13)	0.95 (0.79, 1.13)
19 - 30		1.05 (0.89, 1.23)	1.05 (0.89, 1.23)
> 30		0.83 (0.59, 1.15)	0.82 (0.58, 1.15)
Referral source			
Family (FM)		Reference	
Medical (MD)		0.70 (0.54, 0.89)***	0.70 (0.54, 0.89)**
Public Health Nurse (PHN)		0.85 (0.70, 1.03)	0.85 (0.70, 1.03)
Other		0.91 (0.75, 1.10)	0.90 (0.75, 1.10)
Interaction			
Location x CDC			1.08 (0.55, 2.11)
-2 Log Likelihood	11596.146	11584.090[#]	11584.041[##]

* P<0.0001, **P<0.01, ***P<0.05

[#]Change from block1 is not significant by Chi-Square test, P=0.061

[##]Change from block 1+2 is not significant by Chi-Square test, P=827

4.3.2 Supported Child Development Program (SCDP)

Referral and intake information were obtained from 4 community child development

centres (AB, AF, AI and AM). A total of 248 individual based referral records with

complete information are outlined in Table 4.3.2.

Table 4.3.2: Administrative Data, Supported Child Development Program

Agency[#]	Date On (number of records)	Date Off (number of records)	Notes
AB	Program Referral Date (31)	Intake Date (26), Admission Date (29)	Intake date and admission date were on the same date for this agency. Most referrals had a record of admission dates which reflected the first appointments for SCDP.
AF	Program Referral Date (13)	Program Admission Date (10), File Open Date (13), Intake Date (7)	Program admission date reflected the first appointment as noted previous for IDP services of this agency.
AI	Program Referral Date (72)	Initial Contact Date (65), Active Service Date (39)	The "Active Service Date" is equivalent to the "Program Admission Date".
AM	Program Recommendation Date (132)	Service codes were not recorded.	124 referrals received at least one SCDP appointments but most cases did not have a service code.

AB, AF, AI and AM are all multi-program agencies

Agency AF and AB did not have a waiting list for SCDP services as indicated by the

questionnaire survey. Program admission date for SCDP services represented the first

consultation appointment. For agency AM, 124 referrals received at least one SCDP

appointment; however, service delivery codes such as the "Intake Consultation" or the

"Consultation" were not recorded for these appointments. Thus, the first SCDP

appointment for agency AM is assumed to be the first consultation appointment for

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SCDP services. Agency AI recorded both the *Initial Consultation Date* and the *Program Active Date*. 65 referrals received initial consultation by the SCDP consultants and 39 of these 65 cases also became "active" on the SCDP caseload.

As discussed in Chapter 1, SCDP provides services mainly consisting of consultation in the form of linking families with other services and resources for their children with special needs. Some children may require extra staffing support arranged at a special daycare facility and may wait an additional length of time while many others require only consultation services provided by a SCDP consultant. The administrative data provided information primarily on the SCDP consultation services. Therefore, the first appointment for SCDP services recorded on these administrative data sets may be used as the *Date Off* indicator for determining the time delays for these services at these agencies.

4.3.2.1 Descriptive Statistical Analysis, SCDP

A total of 248 referrals to the 4 agencies were available for analysis. Table 4.3.2.1A shows that 18 (7.3%) referrals were discharged before receiving the first SCDP appointment and 2 (0.8%) referrals were still waiting as of May 31, 2005. The reasons for leaving the program without receiving any SCDP services are outlined in Table 4.3.2.1C. Families that moved or withdrew represented the most common reasons for not receiving SCDP consultation services after referrals were made. The 2 cases that were still waiting on May 31, 2005 had waited 61 days and 337 days (Table 4.3.2.1B). The 18 cases left SCDP without services had also waited on average 143 days (median=65.5 days).

Table 4.3.2.1A: Referral and Intake Information for Supported Child Development Program

| Agency# | First Consultation Status | | | Number of Referrals |
	Consultation*	Left	Waiting	
AB	29 (93.5%)	2 (6.5%)	0 (0.0%)	31
AF	10 (76.9%)	2 (15.4%)	1 (7.7%)	13
AI	65 (90.3%)	6 (8.3%)	1 (1.4%)	72
AM	124 (93.9%)	8 (6.1%)	0 (0.0%)	132
Total	228 (91.9%)	18 (7.3%)	2 (0.8%)	248

* Consultation = Received first consultation appointment on or before May 31, 2005
  Left = Discharged without receiving any services on or before May 31, 2005
  Waiting = Still waiting for first consultation appointment on May 31, 2005
# AB, AF, AI and AM are all multi-program agencies

Table 4.3.2.1B: Waiting for First Consultation, Supported Child Development Program with Censored Cases

| | Consultation* | | Left Program** | | Still waiting *** | |
Agency	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)
AB	4.86	0	321.00	321	n/a	n/a
AF	79.70	44	135.00	135	61.00	61
AI	74.58	42	223.67	230	337.00	337
AM	16.44	0	40.13	24.5	n/a	n/a
All Agencies	34.32	8	143.06	69.5	199.00	199

* Consultation = Received first consultation appointment on or before May 31, 2005
** Left = Discharged without receiving any services on or before May 31, 2005
***Still Waiting = Still waiting for first consultation appointment on May 31, 2005

Table 4.3.2.1C: Reasons for Leaving SCDP without Receiving Services

Reason for discharge	Frequency	%
Withdrew	3	16.7
Died	1	5.6
Duplicate Referral	1	5.6
Inappropriate Referral	2	11.1
Moved	5	27.8
No longer need services	2	11.1
No Contact	1	5.6
Not stated	3	16.7
Total	18	100

The degree of dispersion in waiting times for SCDP is shown in Figure 4.3.2.1A and

Table 4.3.2.1D. The intra-agency variation in agency AF appeared high with the IQR of

169 days. The overall dispersion in waiting times otherwise appeared to be reasonably

small for SCDP.

Figure 4.3.2.1A: Variation in Waiting Times for First Consultation, Supported Child Development Program
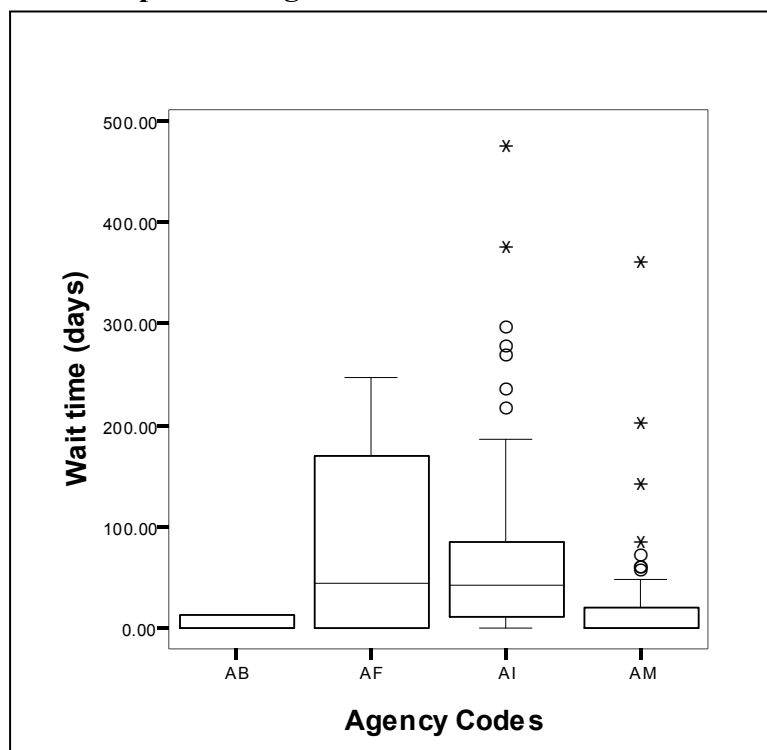
Table 4.3.2.1D: Inter-Quartile Range, SCDP Consultation

Agency[#]	Number admitted	Mean wait time (days)	Median wait time (days)	IQR (days)*
AB	29	4.9	0	14
AF	10	79.7	44	169.75
AI	65	74.6	42	87
AM	124	16.4	0	20.75
Total	228	34.3	8	14

*IQR =Inter-quartile range
AB, AF, AI and AM are all multi-program agencies

The Kaplan-Meier estimated mean and median waiting times for the first consultation appointment with a SCDP consultant is presented in Table 4.3.2.1E. The overall comparison between agencies by Log-Rank Test indicated that differences in waiting times between agencies are statistically significant. The median waiting time ranged from 0 day in agencies AB and AM to 121 days in agency AF.

Table 4.3.2.1E Variation in Waiting Times by Agency, Supported Child Development Program

Agency	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
AB	36.23	0.00	78.33	0	.	.
AF	107.10	52.64	161.57	121	0.00	288.68
AI	101.94	70.25	133.62	44	35.80	52.20
AM	22.47	12.08	32.86	0	.	.
Overall	52.93	39.18	66.69	12	7.31	16.69

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =46.735, df =3, P <0.0001

Variations in waiting time for SCDP consultation by child's age at referral, gender and referral source are displayed in Table 4.3.2.1F – H. The mean and median ages at referral

for SCDP of the 248 cases were both 38.4 months. It is known that children referred to

SCDP are usually older with an average age of 36 months (SCDP, Policy and Procedures

Manual 2005). Information from the 4 agencies indicated that the younger a child the

longer he/she would need to wait although the overall differences are not statistically

significant (Table 4.3.2.1F). As expected, gender did not seem to play a role in waiting

time variation. Referral source on the other hand was a significant factor in explaining

waiting time variation (Table 4.3.2.1H). Family member referral and early child educator

referral (by preschool or childcare worker) tended be associated with shorter waiting time

as compared to that of a medical referral (for example, family doctor).

Table 4.3.2.1F: Variation in Waiting Times by Referral Age, Supported Child Development Program

Referral Age (months)	Number (%)	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 18	26(10.5%)	71.01	24.84	117.18	31.00	7.75	54.25
18 – 30	42 (16.9%)	81.49	34.35	128.63	17.00	2.94	31.06
31 – 42	80 (32.3%)	41.35	25.29	57.41	12.00	6.74	17.26
> 42	100 (40.3%)	46.24	25.32	67.16	3.00	.	.

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =3.697, df =3, P =0.296

Table 4.3.2.1G: Variation in Waiting Times by Sex, Supported Child Development Program

Sex	Number (%)	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
F	85 (34.3%)	46.32	22.51	70.14	8.00	0.00	16.13
M	163 (65.7%)	55.74	39.32	72.16	14.00	9.66	18.34

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =1.551, df =1, P =0.213

Table 4.3.2.1H: Variation in Waiting Times by Referral Source, Supported Child Development Program

Referral source**	Number (%)	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
FM	64 (25.8%)	28.39	6.84	49.94	1	.	.
ECE	32 (12.9%)	24.33	5.42	43.23	0	.	.
MD	25 (10.1%)	52.00	15.48	88.53	15	0.00	30.24
TH	53 (21.4%)	59.20	27.89	90.51	15	5.19	24.81
Other	74 (29.8%)	76.36	48.81	103.91	31	12.69	49.31

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =16.206, df =4, P =0.003
** FM= family member, ECE= early child educator, MD=physician, TH=therapist, Other= unspecified sources

Variations in waiting time by agency variables are presented in Tables 4.3.2.1I –K. The 4 agencies that provided SCDP information are small to median size child development centres. Longer waiting time for SCDP consultation appeared to be associated with small agencies in terms of annual caseload size and staffing level. Agencies in the rural communities also tended to have longer wait times. However, interpretation of these results needs some caution because of small number of agencies included in the analysis and there was only one small rural community agency for the comparison. Cox regression analysis for SCDP waiting time variation was not performed due to the imbalance of observation in agency size and location groupings. For example, there were only 13 observations for the "rural" location while there were 235 observations for "rural + urban" location.

Table 4.3.2.1I: Variation in Waiting Times by Urban-Rural Location, Supported Child Development Program

| Location** | Number (%) | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
Rural	13 (5.2%)	107.10	52.64	161.57	121	0.00	288.68
Both	235 (94.8%)	49.38	35.65	63.11	11	6.05	15.95

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =4.070, df =1 P =0.044
**Rural= Primarily rural communities, Both= Rural + small urban communities

Table 4.3.2.1J: Variation in Waiting Times by Annual Caseload, Supported Child Development Program

| Annual Average Caseload** | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 400	104.47	75.05	133.89	44	30.79	57.21
400 -1000	25.97	13.10	38.85	0	.	.

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =46.586, df =1, P <0.0001
** Average number of clients served per year by agencies. Information obtained from agency questionnaire

Table 4.3.2.1K: Variation in Waiting Times by Agency Staffing, Supported Child Development Program

| Agency Staff (FTE)** | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 10	107.10	52.64	161.57	121	0.00	288.68
10 – 20	49.38	35.65	63.11	11	6.05	15.95

*Mean and Median are estimated by Kaplan-Meier method with censored information, comparison by Log Rank Test: Chi-Square =4.070, df =1 P =0.044
** Agency staff level (Full Time Equivalence). Information obtained from agency questionnaire

The mean and median waiting times by calendar month when referral was made are

presented in Table 4.3.2.1M- N. The month of February tended to be associated with

longer mean and median waits, whereas the month of August appeared to have shorter

mean and median waits. The exact reason for this variation is unclear at present.

However, it is plausible to think that the shorter wait in the month of August may be due

to the fact that quick consultation is required for school transitioning for some children.

Table 4.3.2.1M: Number of SCDP Referrals by Calendar Month

Month of 2003	Number of referrals	Percentage
January	14	14.43
February	7	7.22
March	9	9.28
April	11	11.34
May	10	10.31
June	10	10.31
July	4	4.12
August	1	1.03
September	4	4.12
October	11	11.34
November	11	11.34
December	5	5.15
Total	97	100.00

Table 4.3.2.1N: Variation in Waiting Times by Calendar Month of Referral, SCDP

Referral month	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
January	45.07	0.00	111.67	0	.	.
February	113.57	8.15	219.00	55	39.60	70.40
March	36.00	0.00	74.03	4	0.00	15.69
April	45.91	6.03	85.79	0	.	.
May	50.20	0.00	110.67	0	.	.
June	70.80	1.57	140.03	22	0.00	76.23
July	5.50	0.00	12.50	0	.	.
August	0.00	0.00	0.00	0	.	.
September	12.50	0.00	33.27	0	.	.
October	80.64	10.51	150.77	0	.	.
November	11.91	5.58	18.24	14	0.00	28.59
December	53.80	0.00	143.95	0	.	.

4.3.3 Physiotherapy and Occupational Therapy (PT and OT)

Physiotherapy (PT) and Occupational therapy (OT) services as a form of early intervention therapy are provided primarily by community child development centres (multi-program agencies). In this study, 5 child development centres were able to provide the referral and intake information for their PT and OT services. These are agencies AB, AE, AF, AI and AM.

As discussed above, agencies AB, AE and AF provided *Program Admission Dates* to represent the first appointments for the therapy programs. On the other hand, agencies AI and AM recorded both the *Initial Contact Date* (or the *Intake Consultation Date*) and the *Active Service Date* (or the *Therapy Consultation Date*) respectively (Table 4.3.3.A). Therefore, assessment of administrative data of agencies AB, AE and AF, and agencies AI and AM are discussed separately.

For agency AB, an intake coordinator was available to make contact with families immediately, often on the same date when a referral was received. Families were admitted to the program within a few days. There were 54 and 68 children referred to PT and OT respectively during the study period and all were admitted in Agency AB.

For agency AE, 321 referrals to PT and 249 referrals to OT were recorded. Among these referrals, 125 (38.9%) and 43 (17.3%) children were admitted to PT and OT programs respectively on or before May 31, 2005. A significant number of children left the therapy programs before being admitted (Tables 4.3.3.A and 4.3.3.B). Agency AF had a

relatively small number of referrals for both PT and OT. Most referrals were admitted to

the agency's programs on or before May 31, 2005.

Table 4.3.3A: Referral and Intake Information on Physiotherapy Intervention for Agencies AB, AE and AF

Agency	Referral	Admitted*	Left**	Waiting***
AB	54	54	0	0
AE	321	125 (38.9%)	145 (45.2%)	51 (15.9%)
AF	6	2 (33.3%)	2 (33.3%)	2 (33.3%)

*Admitted = Children were admitted to the physiotherapy program
** Left = Discharged without receiving any services on or before May 31, 2005
*** Waiting = Still waiting for admission to physiotherapy program on May 31, 2005

Table 4.3.3B: Referral and Intake Information on Occupational Therapy Intervention for Agencies AB, AE and AF

Agency	Referral	Admitted*	Left**	Waiting ***
AB	68	68 (100%)	0	0
AE	249	43 (17.3%)	108 (43.4%)	98 (39.4%)
AF	22	22 (100%)	0	0

*Admitted = Children were admitted to the occupational therapy program
** Left = Discharged without receiving any services on or before May 31, 2005
*** Waiting = Still waiting for admission to occupational therapy program on May 31, 2005

For agency AI, the date of initial contact was the date for which a program service

provider first contacted with the family after the referral was made. The *Active Service*

Date represented the date that services began. During the study period, 124 referrals to

PT and 16 referrals to OT were recorded for this agency.

Among the 114 cases who received the first appointment by a physiotherapist, 82 received active services on or before May 31, 2005 (Figure 4.3.3A). Of the 82 active cases, the mean and median time delays between the initial contact and becoming active status were 13.7 days and 7 days respectively. Since most cases became active within two weeks of the initial contact, the initial contact date by a physiotherapist for agency AI was used to represent *Program Admission Date (*or *Date Off* waiting).

Figure 4.3.3A: Referral and Intake Information on Physiotherapy for Agency AI

```
                            124 referrals
                                 |
         _____|_____
        |                        |                        |
       IC                      Left                    Waiting
       114                       6                         4
        |                        |                         |
   _____|_____              _____|_____               _____|_____
  |     |     |            |           |             |           |
Active Left Waiting      Active      Left          Active     Waiting
  82   20    12            1           5             1           3
```

*IC = Initial contact by therapist, Active = Receiving active service, Left = discharged from program before receiving services, Waiting = Still waiting for services on May 31, 2005

Regarding OT, 16 referrals were recorded at agency AI (Figure 4.3.3B). Of these 16 referrals, 11 received the initial contact appointment and 6 became active. The time delay between the initial contact and becoming active for the 3 cases were found to be 2, 7 and 12 days. For the remaining 3 cases, the time delay was found to be 0 days. A total of 10

children remained waiting to become active on and before May 31, 2005. Thus, the *First Contact Date* can also be assumed to be the *Program Admission Date* (*Date off*) for OT services in agency AI.

Figure 4.3.3B: Referral and Intake Information on Occupational Therapy for Agency AI
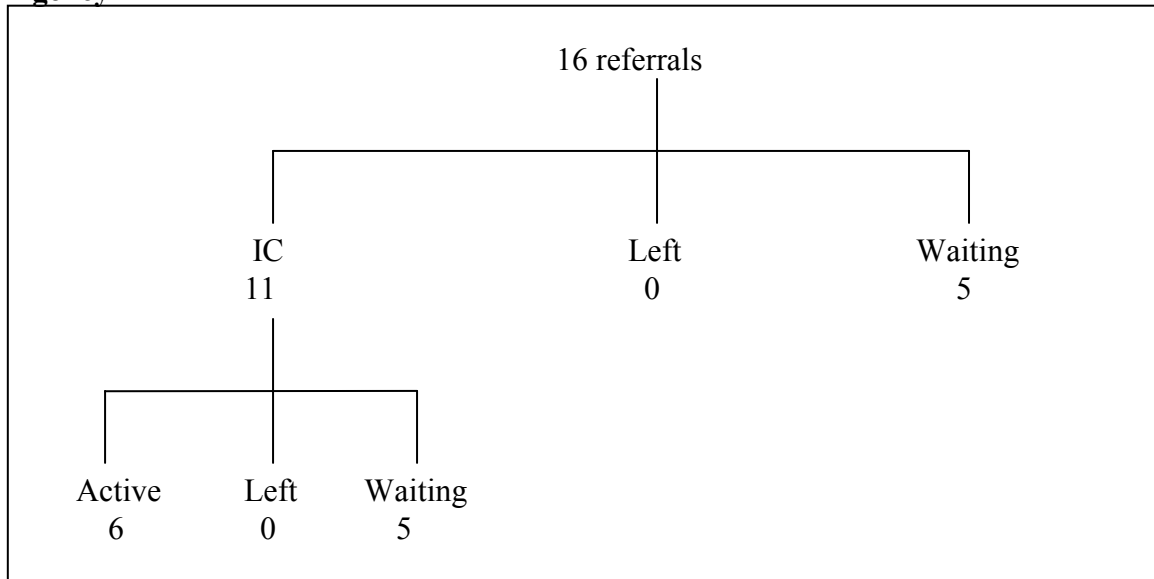
IC = Initial contact by therapist, Active = Receiving active service, Left = discharged from program before receiving services, Waiting = Still waiting for services on May 31, 2005

Agency AM recorded both the intake consultation date and the therapy consultation dates instead of the program admission date or the active service date. Of the 94 referrals received by agency AM, 90 received initial consultation services on or before May 31, 2005 (Figure 4.3.3C) and 41 received therapy consultation appointments.

Figure 4.3.3C: Referral and Intake Information on Physiotherapy for Agency AM

```
                            94 referrals
                                 |
         _____
         |                       |                         |
        IC                      Left                    Waiting
        90                        4                         0
         |
     _____
     |                |
    TH              No TH
    41               49
```
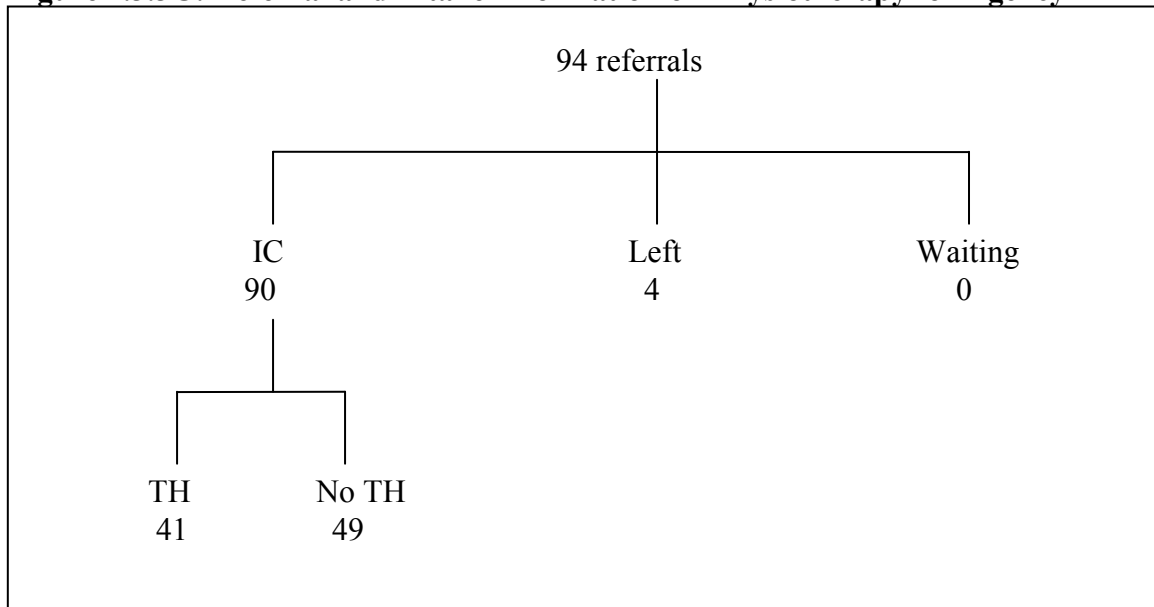
IC = Intake consultation, TH = Therapy consultation

All of the 41 cases with a recommendation for therapy consultation received the recommended services. The 49 cases who did not receive therapy consultation service could be because services might not be required at all given that no recommendation for therapy was noted for these 49 cases. The mean and median time delays between intake consultation and therapy consultation for the 41 cases were found to be 2.14 days and 0 days respectively. It was evident that the time delay between the intake consultation and the therapy consultation for physiotherapy was minimal at agency AM. Thus, the *Initial Consultation Date* for PT services at this agency can be assumed to represent the *Program Admission Date*.

The referral and intake information on OT services for agency AM is shown in Figure 4.3.3D. Among the 47 cases who received both the intake consultation and the therapy

consultation, the mean and median time delays between the intake and the therapy

consultations were found to be 44.6 days and 16 days respectively. Thus, this delay is

significant if the "Intake consultation" for OT is considered to be the "Program

admission" in order to compare with information of other agencies. It is important to

note that not all referrals actually require therapy services. However, an indicator to

signify that a child was indeed waiting for therapy services was not available within the

current database structure. Thus, the waiting time for therapy consultation could only be

analysed by a retrospective design. The intake consultation date for occupational therapy

services for agency AM will be considered as the program admission date for the wait

time analysis.

Figure 4.3.3D: Referral and Intake Information on Occupational Therapy for Agency AM
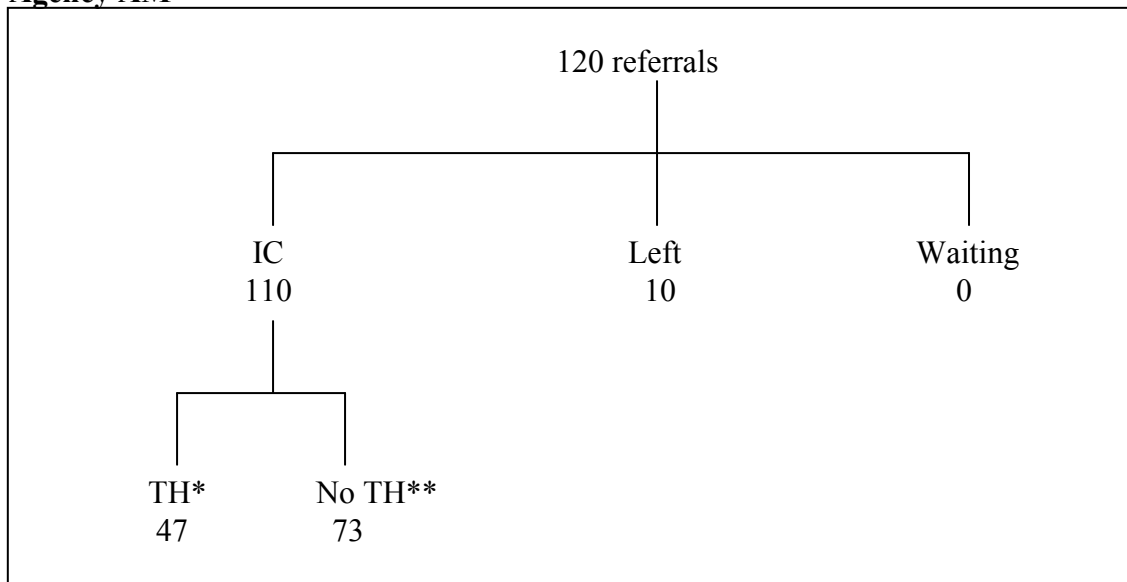
* All of 47 cases that received therapy consultation (TH) were recommended to receive therapy consultation. ** 73 of the 110 cases that received intake consultation (IC) did not have an indicator whether or not therapy consultation was needed.

4.3.3.1 Descriptive Statistical Analysis, PT and OT

The referral and intake information on physiotherapy (PT) and occupational therapy (OT) services is summarized in Tables 4.3.3.1A. A total of 599 referrals for PT and 474 referrals for OT were received by the 5 agencies. Of these, 385 (64.3%) PT referrals and 254 (53.6%) OT referrals received first intake consultation appointment on or before May 31, 2005. The mean and median waiting times for intake consultation were 52.04 days and 20 days for PT, and 77.24 days and 30.5 days for OT respectively (Table 4.3.3.1B). The referrals that were still waiting on the "cut-off" date had spent the longest time in waiting (PT, mean = 413.32 days and median = 391 days; OT, mean =479.87 days and median=440 days).

Table 4.3.3.1A: Referral and Intake Information for Occupational Therapy and Physiotherapy

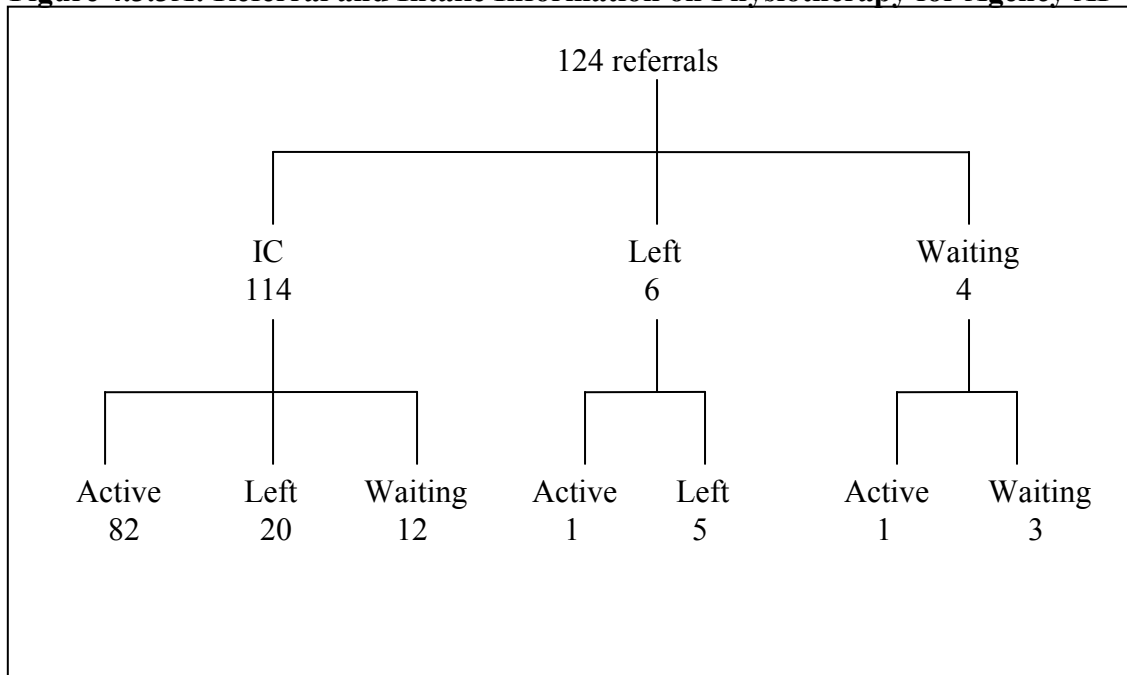| Agency[#]	Intake Consultation			Number of referrals
PT	IC*	Left**	Waiting***	
AB	54 (100.0%)	0 (0.0%)	0 (0.0%)	54
AE	125 (38.9%)	145 (45.2%)	51(15.9%)	321
AF	2 (33.3%)	2 (33.3%)	2 (33.3%)	6
AI	114 (91.9%)	6 (4.8%)	4 (3.2%)	124
AM	90 (95.7%)	4 (4.3%)	0 (0.0%)	94
Total	385 (64.3%)	157 (26.2%)	57 (9.5%)	599
OT	IC*	Left**	Waiting***	
AB	68 (100.0%)	0 (0.0%)	0 (0.0%)	68
AE	43 (17.3%)	108 (43.5%)	97 (39.1%)	248
AF	22 (100.0%)	0 (0.0%)	0 (0.0%)	22
AI	11 (68.8%)	0 (0.0%)	5 (31.3%)	16
AM	110 (91.7%)	10 (8.3%)	0 (0.0%)	120
Total	254 (53.6%)	118 (24.9%)	102 (21.5%)	474

* IC = Received intake consultation on or before May 31, 2005
**Left = Discharged without receiving services on or before May 31, 2005
***Waiting = Still waiting for program admission on May 31, 2005
All agencies are multi-program child development centres

Of all referrals, 157 (26.2%) of PT and 118 (24.9%) of OT left the therapy programs without receiving services while 102 (21.5%) OT referrals and 57 (9.5%) PT referrals were still waiting on May 31, 2005. Agencies AE had relatively low admission rate of 17% for OT and 38.9% for PT. The admission rate for PT in agency AF was low, but only 6 referrals were received in agency AF. Because of data availability, analysis for PT and OT will be limited to a few descriptive statistical analyses.

Table 4.3.3.1B: Waiting for Intake Consultation of Physiotherapy and Occupational Therapy with Censored Cases

PT	Received IC*		Left Program**		Still waiting ***	
Agency	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)
AB	5.87	0	n/a	n/a	n/a	n/a
AE	114.57	69	188.20	173	417.94	392
AF	174.5	174.5	49.50	49.5	434.5	434.5
AI	25.08	13	43.83	37	343.76	315.5
AM	24.34	14.5	69.5	68.5	26.27	15.5
All Agencies	52.04	20	177.89	149	413.32	391
OT	Received IC*		Left Program**		Still waiting ***	
Agency	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)
AB	12.36	6	n/a	n/a	n/a	n/a
AE	248.30	161	205.85	162	484.49	441
AF	30.32	14	n/a	n/a	n/a	n/a
AI	32.73	16	n/a	n/a	390.20	413
AM	64.30	59	42.50	30	62.49	57.50
All Agencies	77.24	30.50	192.00	150	479.87	440

* Waiting time to receive intake consultation for those received services on or before May 31, 2005,
** Time spent waiting before leaving the program for those did not receive services on or before May 31, 2005,
*** Time spent waiting since referral for those still waiting for service on May 31, 2005

The box plot analysis of these 2 therapy services showed a lesser degree of intra-agency variation except for agency AE (Figure 4.3.3.1A). The lowest IQR's for PT and OT were found in agency AB: 14 days for program admission (Table 4.3.3.1C). Agency AB indicated during the follow-up interview that admission to their programs usually occurred quickly after the referral.

The mean and median waiting times for intake consultation by agency as estimated by the Kaplan-Meier method were outlined in Table 4.3.3.1D. The overall comparison by the Log Rank Test indicated significant inter-agency differences in both mean and median waiting times for PT and OT. The overall mean and median waiting times were estimated to be 263.87 days and 57 days for PT, and 384 days and 180 days for OT. The estimated median wait times were much lower than the mean wait times for both PT and OT indicating that a few referrals had waited a significantly long time.

Figure 4.3.3.1A Variation in Waiting Times for Intake Consultation of PT and OT
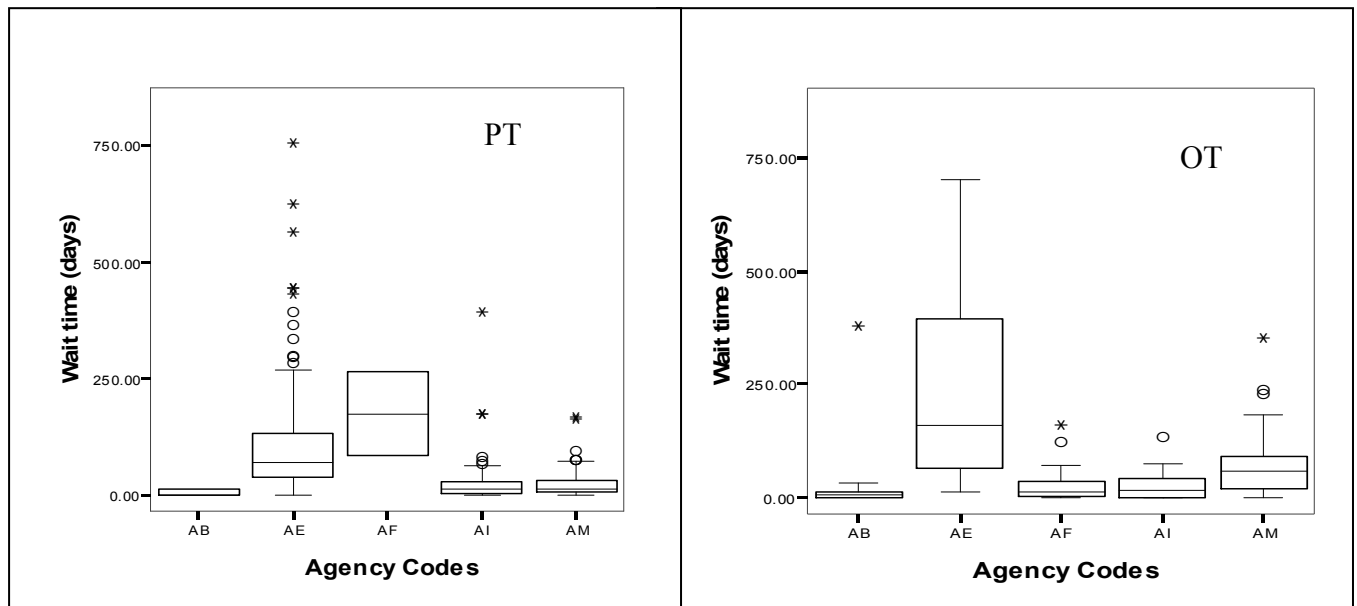
Table 4.3.3.1C: Inter-Quartile Range, Occupational Therapy and Physiotherapy

PT	Number admitted	Mean wait time (days)	Median wait time (days)	IQR (days)*
AB	54	5.87	0	14
AE	125	114.57	69	95
AF	2	174.50	174.5	.
AI	114	25.08	13	24.25
AM	90	24.34	14.5	26
Total	385	52.04	20	49.5
OT	Number admitted	Mean wait time (days)	Median wait time (days)	IQR (days)*
AB	68	12.35	6	14
AE	43	248.30	161	335
AF	22	30.32	14	35.5
AI	11	32.73	16	51
AM	110	64.31	59	71.5
Total	254	77.24	30.5	78.75

*IQR = Inter quartile range

Table 4.3.3.1D: Variation in Waiting Times by Agency, Physiotherapy and Occupational Therapy

PT	Mean* (days)	95% CI of the mean Lower Bound	Upper Bound	Median* (days)	95% CI of the median Lower Bound	Upper Bound
AB	5.87	4.11	7.63	0	.	.
AE	451.06	398.05	504.06	444	274.99	613.01
AF	369.40	137.38	601.42	264	3.81	524.19
AI	45.67	27.78	63.56	15	10.50	19.50
AM	28.48	20.92	36.04	15	10.93	19.07
Overall	263.87	229.85	297.89	57	41.97	72.03
OT	Mean* (days)	95% CI of the mean Lower Bound	Upper Bound	Median* (days)	95% CI of the median Lower Bound	Upper Bound
AB	12.35	1.45	23.25	6	.	.
AE	683.63	635.62	731.64	.	.	.
AF	30.32	12.86	47.77	13	8.40	17.60
AI	169.38	68.78	269.97	37	.000	86.00
AM	67.71	56.83	78.58	61	53.41	68.59
Overall	384.30	345.05	423.56	180	62.84	297.16

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test:
  Chi-Square =615.172, df =4, P <0.001 (OT)
  Chi-Square =575.054, df =4, P <0.001 (PT)

Table 4.3.3.1E: Variation in Waiting Times by Sex, Physiotherapy and Occupational Therapy

PT	Number (%)	Mean* (days)	95% CI of the mean Lower Bound	Upper Bound	Median* (days)	95% CI of the median Lower Bound	Upper Bound
F	250 (41.7%)	247.80	196.58	299.01	49	35.11	62.89
M	349 (58.3%)	272.80	228.57	317.04	69	46.835	91.17
OT	Number (%)	Mean* (days)	95% CI of the mean Lower Bound	Upper Bound	Median* (days)	95% CI of the median Lower Bound	Upper Bound
F	164 (34.6%)	357.36	296.12	418.61	131.00	0.00	308.86
M	310 (65.4%)	388.83	340.90	436.77	182.00	29.51	334.49

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =0.698, df =1, P =0.403 (PT);
 Chi-Square =0.057, df =1, P =0.812 (OT)

Age at referral, but not gender, appeared to play a significant role in waiting time for occupational therapy but not for physiotherapy (Tables 4.3.3.1E and F). Children less one year old seemed to wait less for OT services. Feeding issues could be one of the reasons why very young infants did not wait long for OT services.

Table 4.3.3.1F: Variation in Waiting Times by Referral Age, Physiotherapy and Occupational Therapy

PT			95% CI of the mean			95% CI of the median	
Referral Age [#] (months)	Number (%)	Mean* (days)	Lower Bound	Upper Bound	Median* (days)	Lower Bound	Upper Bound
< 6	205 (34.2%)	233.75	180.39	287.12	59	35.00	83.00
6 – 18	110 (18.4%)	279.99	213.22	346.75	55	30.89	79.11
19 – 30	148 (24.7%)	215.08	168.94	261.22	53	24.73	81.27
> 30	136 (22.7%)	331.56	257.68	405.44	76	24.79	127.21
OT			95% CI of the mean			95% CI of the median	
Referral Age [#] (months)	Number (%)	Mean* (days)	Lower Bound	Upper Bound	Median* (days)	Lower Bound	Upper Bound
< 12	75 (15.82%)	90.05	60.36	119.74	38	13.86	62.14
12 – 24	60 (12.66%)	342.21	263.81	420.60	358	119.31	596.69
23 – 36	95 (20.04%)	401.99	316.94	487.03	182	0.00	467.75
37 – 48	103 (21.73%)	329.20	260.89	397.50	131	0.00	325.63
> 48	141 (29.75%)	471.82	401.72	541.92	651	236.56	1065.45

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =1.598, df =3, P =0.660 (PT); Chi-Square =36.059, df =4, P < 0.001 (OT)
[#] Mean and median age at referrals were 18 and 10 months for PT, and 36 and 38 months for OT

Referral source was also associated with waiting time variations for both therapy services (Table 4.3.3.1G). Self-referral seemed to have shortest mean and median wait times for both PT and OT. The median waiting times are 14 and 28 days respectively. Medical

referral source (physician or hospital) was also associated with a shorter waiting time for

PT (median=33 days) but not for OT (median=566 days).

Table 4.3.3.1G: Variation in Waiting Times by Referral Source, Occupational Therapy and Physiotherapy

PT			95% CI of the mean			95% CI of the median	
Referral source**	Number (%)	Mean* (days)	Lower Bound	Upper Bound	Median* (days)	Lower Bound	Upper Bound
FM	118 (19.7%)	123.12	75.05	171.20	14	9.75	18.25
IDP	133 (22.2%)	401.43	315.84	487.01	259	83.12	434.88
MD	153 (25.6%)	148.99	111.05	186.94	33	21.86	44.14
PHN	107 (17.9%)	321.49	234.14	408.83	133	84.03	181.97
Other	88 (14.7%)	334.93	250.67	419.20	104	0.63	207.37
OT			95% CI of the mean			95% CI of the median	
Referral source**	Number (%)	Mean* (days)	Lower Bound	Upper Bound	Median* (days)	Lower Bound	Upper Bound
FM	103 (21.7%)	125.50	90.19	160.81	28.00	17.34	38.66
IDP	109 (23.0%)	637.83	562.14	713.52	.	.	.
TH	59 (12.4%)	274.65	188.36	360.94	77.00	38.63	115.37
MD	42 (8.9%)	471.72	345.85	597.59	566.00	278.73	853.27
PHN	56 (11.8%)	388.33	275.93	500.74	131.00	0.00	303.60
Other	105 (22.2%)	297.32	226.06	368.58	98.00	56.01	140.00

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test:
Chi-Square =92.563, df =5, P > 0.0001 (OT), Chi-Square =26.582, df =4, P <0.0001 (PT)
**FM= family member, MD=physician or hospital, PHN= Public health nurse or health unit, TH= therapist and "Other" includes social worker, early child educators, etc

Analysis of waiting time variation by agency factors such as location, caseload, and

staffing level was not done because of the small number of agencies and imbalance in

observations among the 5 agencies. For example, only one of the 5 agencies is

considered to be a rural agency with only a small number of referrals received during the

study period. There were only 6 PT referrals (1% of total referrals) and 22 OT referrals

(4.6% of total referrals) for this rural community agency. Thus, caution is required with

regard to the interpretation of the effect of agency size and location on waiting time.

4.3.4 Speech-Language Pathology (SLP)

In this study speech-language pathology (SLP) services were provided by 7 public health units and 6 community child development centres. A total of 5593 case-based referrals were recorded from the 13 agencies between January 1, 2003 and September 30, 2004. Six of the 7 public health units (AR, AS, AU, AV, AW and AZ) recorded intake consultation as the first service appointment. The one remaining health unit (AT) recorded only the *Program Active Date*.

As discussed in previous sections, the *Program Admission Date* for agencies AB, AE, AF can be assumed to approximate the *Intake Consultation Date* for the ease of comparison. On the other hand, agencies AM and AZ recorded both *Intake Consultation Date* and *Therapy Service Date*. Intake consultation for agencies AM and AZ will be used as indicator of first service appointment.

Agency AI, a child development centre, recorded both *Initial Contact Date* and *Active Service Date*. As discussed in previous sections for physiotherapy and occupational therapy, the *Initial Contact Date* represents the first date of contact with a program service provider. In this study, 67 referrals in agency AI had a first contact and 23 of these became active. The mean and median time delays between initial contact and active status for these 23 cases were 138.9 days and 105 days respectively. The *Initial Contact Date* approximates the *Program Admission* or *Intake Consultation Date* whereas the *Service Active Date* is used to represent the beginning of active therapy intervention.

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Thus, *Intake Consultation Date* is used as the indicator for "*date off*" waiting for the first speech-language pathology appointment. For agencies recording *Program Admission Date* only, this date will be treated as first program appointment or the *Intake Consultation Date* (i.e. *Date Off* waiting).

4.3.4.1 Descriptive Statistical Analysis, SLP

The referral and intake information of speech-language pathology services is summarized in Table 4.3.4.1A**.** Of the 5593 referrals received between January 1, 2003 and September 30, 2004, 4450 (79.5%) received intake consultation appointments, 705 (12.6%) left the program without receiving any services, and 438 (7.9%) were still waiting for intake appointments on May 31, 2005.

The proportion of referrals still waiting on May 31, 2005 varied across agencies with the highest percentage found in agency AX (17.1%), followed by agency AT (15.6%). The proportion of referrals that left the program without services also varied widely across agencies. The percentage of children left the program in Agencies AB and AM before receiving intake appointment were found to be 41% and 36% respectively. The findings for these 2 agencies appear high compared with that of other agencies.

Table 4.3.4.1A Referral and Intake Information for Speech-Language Pathology Services

Agency	Intake Consultation						Number of referrals
	IC*		Left		Waiting		
AB[#]	27	(58.7%)	19	(41.3%)	0	(0.0%)	46
AE[#]	171	(70.8%)	41	(17.6%)	21	(11.6%)	233
AF[#]	32	(97.0%)	0	(0.0%)	1	(3.0%)	33
AI[#]	67	(87.0%)	6	(7.8%)	4	(5.2%)	77
AM[#]	53	(57.6%)	33	(35.9%)	6	(6.5%)	92
AR[##]	1014	(75.5%)	169	(12.6%)	160	(11.9%)	1343
AS[##]	196	(76.3%)	56	(21.8%)	5	(1.9%)	257
AT[##]	282	(66.8%)	74	(17.5%)	66	(15.6%)	422
AU[##]	173	(74.6%)	39	(16.8%)	20	(8.6%)	232
AV[##]	1233	(99.1%)	6	(0.5%)	5	(0.4%)	1244
AW[##]	493	(74.5%)	150	(22.7%)	19	(2.9%)	662
AX[##]	553	(74.4%)	63	(8.5%)	127	(17.1%)	743
AZ[#]	156	(74.6%)	49	(23.4%)	4	(1.9%)	209
Total	4450	(79.5%)	705	(12.6%)	438	(7.9%)	5593

* IC = Received intake consultation on or before May 31, 2005
   Left = Discharged without receiving services on or before May 31, 2005
   Waiting = Still waiting for Program admission on May 31, 2005
# Multi-program agencies (child development centres)
Public Health Units

The reasons for discharge before receiving SLP services are displayed in Table 4.3.4.1B**.**

Information was missing for 293 cases (41.6% of all cases that left the program without

services). Agency AR did not provide any information on the reasons for discharge and

it accounted for almost the majority of cases with missing information. For agency AM,

25 of the 33 cases left without services also did not state a reason. A closer examination

of agency AB's data, the reasons for discharge before intake consultation did not show

any particular pattern. Overall, failure to make contact with the families appeared to be

one of the most common reasons for not receiving services followed by "Services are no

longer needed" (Table 4.3.4.1B**)**.

Table 4.3.4.1B Discharge Reasons for Those Left the Speech-Language Pathology Program without Services

Reasons	Number of cases	%
Not stated	293	41.6
Inappropriate referral	6	.9
Moved	56	7.9
No contact*	124	17.6
No longer needed	81	11.5
No show**	9	1.3
Private#	2	.3
School##	49	7.0
Transferred	62	8.8
Withdrew	23	3.3
Total	705	100.0

* No contact = agencies could not make contact with the families due to a variety of reasons

** No show = families failed to attend scheduled appointments and did respond to agencies' rescheduling.

Private = families sought private SLP services

School = Child reached school age

The inter-agency and intra-agency variations in waiting time for intake consultation are illustrated by box plot in Figure 4.3.4.1A and Table 4.3.4.1C. The results for Figure 4.3.4.1A and Table 4.3.4.1C included only those received intake services on or before the study cut- off date (May 31, 2005); that is, censored cases were not included in the analysis. The overall mean and median waiting times for intake consultation for the 4450 referrals were found to be 114.49 days and 84.5 days respectively. Waiting time appeared to vary widely across and within agencies as shown by the box plot and the inter-quartile ranges for individual agencies. Intra-agency variation appeared to be higher for agencies AB, AE and AX. The IQR for these agencies were 237 days, 220 days and 208 days

respectively. The median waiting times ranged from 20 days in agency AF to 189.5 days

in agency AT (Table 4.3.4.1C).

Figure 4.3.4.1A: Variation in Waiting Times for Intake Consultation, Speech-Language Pathology
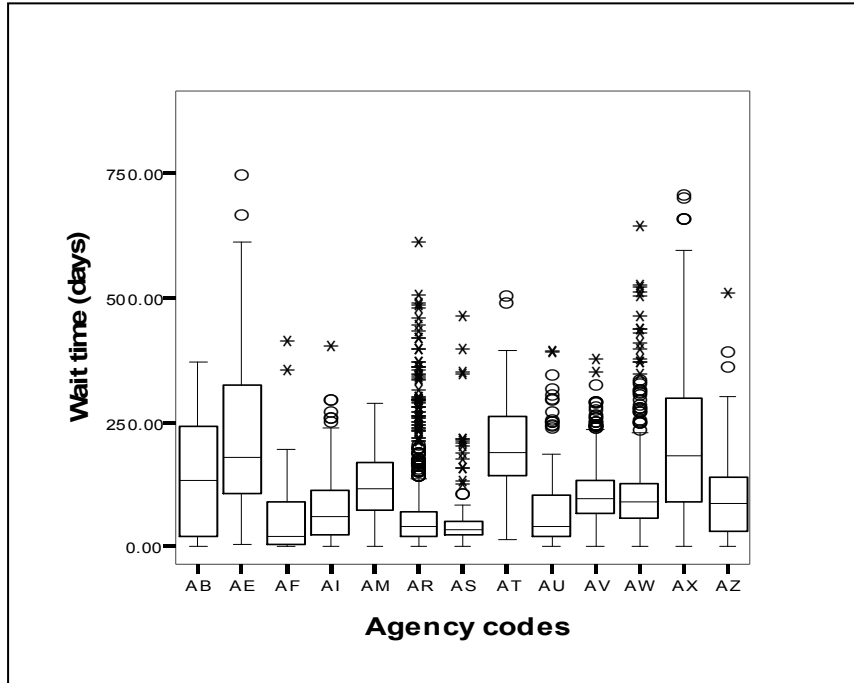
Table 4.3.4.1C: Inter-Quartile Range, Speech-language Pathology

Agency	Number received IC	Mean (days)	Median (days)	IQR*
AB	27	139.63	132	237
AE	171	219.04	181	220
AF	32	67.34	20	91.25
AI	67	86.99	59	91
AM	53	126.70	118	98.5
AR	1014	63.34	42	47
AS	196	50.82	35	25.5
AT	282	204.41	189.5	119.5
AU	173	74.24	41	83.5
AV	1233	103.03	96	68
AW	493	107.95	89	70.5
AX	553	205.45	181	208
AZ	156	96.33	86.5	108.75
Total	4450	114.49	84.5	111

* IQR = Interquartile range

Waiting time information with censored cases is presented in Table 4.3.4.1D. The overall

mean and median times spent waiting for the censored cases appeared significantly

higher than that of non censored cases. The 438 referrals (7.9% of all referrals) that were

still waiting on the "cut-off" date had spent the longest time in waiting (mean = 457.70

days and median = 411 days). Those left without services (705 cases, 12.6% of all

referrals) spent on average 207.05 days (median = 168 days) waiting before their files

were closed and discharged from the program.

Table 4.3.4.1D: Waiting for Intake Consultation of Speech-Language Pathology Services with Censored Cases

Agency	Received IC*		Left Program**		Still waiting ***	
	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)	Mean wait time (days)	Median wait time (days)
AB	139.63	132.00	231.32	266.00	n/a	n/a
AE	219.04	181.00	135.54	118.00	423.57	391.00
AF	67.34	20.00	n/a	n/a	300.00	300.00
AI	86.99	59.00	134.17	131.00	388.50	403.00
AM	126.70	118.00	203.85	166.00	500.67	518.00
AR	63.34	42.00	232.09	196.00	486.91	461.50
AS	50.82	35.00	386.18	412.00	377.00	369.00
AT	204.41	189.50	159.30	170.00	310.47	301.00
AU	74.24	41.00	212.69	194.00	595.15	632.00
AV	103.03	96.00	131.67	116.50	386.00	295.00
AW	107.95	89.00	166.15	123.50	449.79	440.00
AX	205.45	181.00	221.17	162.00	484.84	454.00
AZ	96.33	86.50	161.31	146.00	620.75	582.50
All Agencies	114.49	84.50	207.05	168.00	457.70	411.00

* Waiting time to receive intake consultation for those received services on or before
May 31, 2005,
** Time spent waiting before leaving the program for those did not receive services on or
before May 31, 2005,
*** Time spent waiting since referral for those still waiting for service on May 31, 2005

The mean and median SLP waiting times by agency estimated by Kaplan-Meier method is presented in Table 4.3.4.1E. The overall comparison by Log Rank Test indicated that the mean and median waiting times were significantly different among some of the agencies. The overall mean and median waiting times were found to be 211.29 days (95% CI, 203.71, 218.86) and 112 days (95% CI, 108.04, 115.96) respectively.   The longest waiting time was in agency AB with a median of 257 days (95% CI, 201, 312), and the shortest median waiting time was 22 days (95% CI, 7.37, 87.34) in agency AF.

Table 4.3.4.1E: Variation in Waiting Times by Agency, Speech-Language Pathology

		95% CI of the mean			95% CI of the median	
Agency	Mean* (days)	Lower Bound	Upper Bound	Median* (days)	Lower Bound	Upper Bound
AB	224.14	180.61	267.66	257	201.50	312.50
AE	274.36	246.84	301.88	230	175.30	284.70
AF	76.89	37.75	116.04	22	7.37	36.63
AI	117.43	89.39	145.47	65	42.66	87.34
AM	267.18	216.69	317.67	173	135.13	210.87
AR	232.59	213.67	251.52	57	53.21	60.79
AS	187.92	154.60	221.24	41	37.36	44.64
AT	259.00	239.93	278.07	248	232.44	263.56
AU	232.08	187.98	276.18	77	54.99	99.01
AV	104.96	101.55	108.37	97	93.34	100.66
AW	182.32	164.89	199.75	106	99.01	112.99
AX	317.04	296.40	337.68	248	226.29	269.71
AZ	180.80	144.32	217.27	112	100.81	123.19
Overall	211.29	203.71	218.86	112	108.04	115.96

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square = 663.87, df =12, P <0.0001

Variations in waiting time for SLP services by child's factors are displayed in Tables 4.3.4.1F – H. The mean and median age at referral for SLP services were 2.83 and 2.76 years old. Age at referral and referral source were found to be associated with wait time

variations for SLP services. Older children tended to wait less for SLP services. Children

who were referred before the age of 18 months waited the longest time. On average they

waited for 232 days (median = 129 days) for intake consultation. Self-referral by family

member to SLP tended to be associated with shorter waiting time than referrals that came

from physicians or public health units. As expected gender did not play a role in waiting

time variation.

Table 4.3.4.1F: Variation in Waiting Times by Referral Age, Speech-Language Pathology

Referral Age (months)	Number (%)	Mean* (days)	95% CI of the mean Lower Bound	95% CI of the mean Upper Bound	Median* (days)	95% CI of the median Lower Bound	95% CI of the median Upper Bound
< 18	596 (10.7%)	232.00	209.54	254.46	129	111.14	146.86
18 – 30	1886 (33.7%)	208.75	196.37	221.13	113	106.61	119.39
31 – 42	1482 (26.5%)	212.65	198.41	226.90	117	109.51	124.49
> 42	1629 (29.1%)	210.96	195.61	226.32	103	95.07	110.93

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =13.826, df =3, P =0.003

Table 4.3.4.1G: Variation in Waiting Times by Sex, Speech-Language Pathology

Sex	Number (%)	Mean* (days)	95% CI of the mean Lower Bound	95% CI of the mean Upper Bound	Median* (days)	95% CI of the median Lower Bound	95% CI of the median Upper Bound
F	1798 (32.2%)	201.40	188.66	214.13	108	100.46	115.54
M	3795 (67.8%)	215.97	206.61	225.34	115	110.05	119.95

*Mean and Median are estimated by Kaplan-Meier method with censored information,
Overall comparison by Log Rank Test: Chi-Square =2.018, df =1, P =0.155

Table 4.3.4.1H: Variation in Waiting Times by Referral Source, Speech-Language Pathology

Referral source**	Number (%)	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
FM	1565 (28.0%)	190.55	176.80	204.30	96	88.24	103.76
MD	1565 (28.0%)	205.45	192.53	218.37	125	118.10	131.90
PH	1440 (25.7%)	208.61	193.16	224.07	102	93.98	110.02
Agency	680 (12.2%)	280.83	255.76	305.90	143	125.75	160.25
Other	343 (6.1%)	192.89	166.14	219.64	114	100.37	127.63

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =59.252, df =4, P <0.0001
**FM= family member, MD=physician and Hospital, PH= public health and public health nurse, Agency = community child development centre, and Other includes therapist, social worker, early child educators, etc

Variations in waiting times for SLP service by agency variables are presented in Tables 4.3.4.1 I – N. Agencies providing services to both urban and rural communities tended to have longer waiting time. Child development centres tended to have longer waiting time for SLP services than public health units as expected because children with more complex needs are generally referred to child development centre. Agencies with higher admission rate, higher annual caseload, higher agency staff level and program staff level also tended to have shorter waiting times.

The variations in the number of referrals and in the mean and median waiting times did not appear random by calendar month. For the year 2003, the number of referrals tended to be lower in the months of August and December which might be expected because

most take holidays in those 2 months (Table 4.3.4.1O). The mean and median waiting times by calendar month when referral was made are illustrated in Table 4.3.4.1P. This analysis included the non-censored cases only because the date when intake consultation occurred could not be ascertained for the censored cases. This variable will not be used in Cox regression. The overall mean and median waiting times for those receiving service were 114 days and 84 days (Table 4.3.4.1D). Waiting times tended to be shorter when referrals were made in the summer months of July, August and September (median waits = 79 days, 76 days, and 72 days respectively).

Table 4.3.4.1I: Variation in Waiting Times by Urban-Rural Location, Speech-Language Pathology

| Location** | Number (%) | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
Urban	2132 (38.1%)	158.59	150.33	166.84	112	107.86	116.14
Rural	265 (4.7%)	211.34	172.05	250.64	62	39.81	84.19
Both	3196 (57.1%)	246.57	235.37	257.78	119	110.35	127.65

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =101.845, df =2, P <0.0001
** Urban= Primarily major or small urban communities, Rural= Primarily rural communities, Both= Urban and rural communities

Table 4.3.4.1J: Variation in Waiting Times by Agency Type, Speech-Language Pathology

| Agency type** | Number (%) | Mean* (days) | 95% CI of the mean | | Median* (days) | 95% CI of the median | |
			Lower Bound	Upper Bound		Lower Bound	Upper Bound
CDC	690 (12.3%)	222.21	203.07	241.34	153	138.77	167.23
PH	4903 (87.7%)	209.43	201.35	217.52	107	102.63	111.37

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =17.951, df =1, P <0.0001
** CDC = community chid development centre, PH = public health unit

Table 4.3.4.1K: Variation in Waiting Times by Annual Caseload, Speech-Language Pathology

Annual Average Caseload**	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 400	239.57	221.54	257.61	141	129.21	152.79
400 -1000	264.42	249.65	279.18	168	156.57	179.43
> 1000	172.77	163.13	182.41	86	82.29	89.71

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =251.905, df =2, P <0.0001
** Average number of clients served per year by agencies. Information obtained from agency questionnaire

Table 4.3.4.1L: Variation in Waiting Times by Agency Staffing, Speech-Language Pathology

Agency Staff (FTE)**	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 10	227.78	213.15	242.40	127	119.59	134.41
10 – 20	187.99	178.80	197.18	121	116.33	125.67
> 20	235.18	218.07	252.29	68	62.87	73.13

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =13.235, df =2, P =0.001
** Agency staff level (Full Time Equivalence). Information obtained from agency questionnaire

Table 4.3.4.1M: Variation in Waiting Times by Program Staffing, Speech-Language Pathology

Program Staff (FTE)**	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
< 2.5	205.12	178.66	231.58	118	104.93	131.07
2.5 – 5.5	265.47	243.72	287.22	166	151.09	180.91
> 5.5	201.06	192.80	209.31	105	100.99	109.01

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =39.760, df =2, P <0.0001
** SLP program staff level (Full Time Equivalence). Information obtained from agency questionnaire

Table 4.3.4.1N: Variation in Waiting Times by Admission Rate, Speech-Language Pathology

		95% CI of the mean			95% CI of the median	
Percent Admission **	Mean* (days)	Lower Bound	Upper Bound	Median* (days)	Lower Bound	Upper Bound
≤ 75%	259.74	248.54	270.95	175	166.84	183.16
> 75%	169.29	159.66	178.91	76	72.89	79.11

*Mean and Median are estimated by Kaplan-Meier method with censored information, Overall comparison by Log Rank Test: Chi-Square =443.915, df =1, P <0.0001
** Percent Admission = overall admission rate between January 1, 2003 and May 30, 2005

Table 4.3.4.1O: Number of SLP Referrals by Calendar Month

Month of 2003	Number of referrals	Percentage
January	284	9.0
February	274	8.6
March	277	8.7
April	258	8.1
May	245	7.7
June	265	8.4
July	245	7.7
August	174	5.5
September	321	10.1
October	333	10.5
November	269	8.5
December	225	7.1
Total	3170	100.0

Table 4.3.4.1P: Variation in Waiting Time by Calendar Month of Referral, SLP

Referral month	Mean* (days)	95% CI of the mean		Median* (days)	95% CI of the median	
		Lower Bound	Upper Bound		Lower Bound	Upper Bound
January	117.84	107.82	127.86	78	70.23	85.77
February	125.77	115.21	136.34	84	72.48	95.52
March	123.41	114.49	132.34	103	94.39	111.61
April	115.64	105.57	125.72	88	79.18	96.82
May	109.06	100.30	117.81	90	78.30	101.70
June	102.30	93.37	111.23	80	71.76	88.24
July	106.05	96.59	115.51	79	70.40	87.60
August	98.75	88.73	108.76	76	69.03	82.97
September	103.42	94.13	112.72	72	64.09	79.91
October	131.06	117.94	144.18	103	84.95	121.05
November	118.74	104.54	132.93	89	74.96	103.04
December	127.38	111.44	143.32	93	87.09	98.91

4.3.4.2 Cox Regression Analysis, SLP

The model depicting the inter-agency variation in waiting time for speech-language

pathology services is expressed with the following equation:

$$\ln [h(t)/ h_0(t)] = b_{agency1}.AGENCY1 + \ldots + b_{agencyn}.AGENCYn + b_{refage1}.REFAGE1 + \ldots$$
$$b_{refagen}.REFAGEn + b_{refso1}.REFSO1 + \ldots + b_{refson}.REFSOn$$

where
$$REFAGE = \text{referral age (categorical)}$$
$$REFSO = \text{referral source (categorical)}$$

Agency AZ had mean and median waiting times closer to the provincial mean and

median determined by Kaplan-Meier method and was used as the reference agency for

comparison. The results of Cox Regression model showing the crude and adjusted hazard

ratios for variable "Agency" are presented in Table 4.3.4.2A.

Inter-agency variation remained highly significant after adjusted for child's age at referral and referral source. The results showed that compared with agency AZ and provincial average, agencies AB, AE, AM, AT and AX were likely to have a longer waiting time for SLP intake consultation, whereas agencies AF, AI, AS and AV were likely to have shorter waiting time than agency AZ.

Agency characteristics played a significant role in explaining the differences in waiting time as shown in Table 4.3.4.2B. The second model depicting wait time variations in terms of agency characteristics is expressed with the following equation:

$$\ln [h(t)/ h_0(t)] = b_{location.}.LOCATION + b_{casload}.CASELOAD + b_{Admitrate}.ADMITRATE + b_{progFTE}.PROGFTE + b_{type}.TYPE + b_{refso}.REFSO + b_{refage}.REFAGE$$

where
    LOCATION = agency service location (categorical)
                                CASELOAD = agency annual caseload (categorical)
    ADMITRATE = admission rate (categorical)
    Type = agency type (categorical)
    PROGFTE = program FTE (categorical)
    REFSO = referral source (categorical)
    REFAGE = referral age (categorical)

The adjusted hazard ratios of agency factors indicated that rural community agencies were more likely to have shorter waiting time than agencies serving urban communities (HR_{rural}=1.66, 95%CI (1.41, 1.94)). On the other hand, agencies providing services to both rural and urban communities tended to have longer waiting time (HR_{both}=0.73, 95%CI (0.67, 0.80)). Agencies with a larger caseload size (>1000 children annually) and fewer program staff were also likely to have longer waiting time ($HR_{caseload>1000}$=0.65, 95%CI (0.50, 0.86), $HR_{progstaff>5.5}$=1.79, 95%CI (1.30, 2.48)). Agencies with more than

total 75% admission rate during the study period were consistently associated shorter waiting times ($HR_{>75\%}$=2.30, 95%CI (1.97, 2.69)) as well.

Referral source appeared to play a significant role in explaining wait time variation for SLP services as indicated in both Cox regression models. Children who were self-referred by their parents (or other family members) tended to receive services earlier compared with children who were referred by a professional such as family doctor or by an agency. This trend was similar to that of IDP waiting time.

Children older than 3.5 years old also tended to have shorter waiting time for SLP services as showed in both models (Tables 4.3.4.2A and 4.3.4.2B) although not significantly. Shorter waiting time for this group of children might be due to the fact that some of these children were about to enter school. A one time consultation might be provided for these children in order to assist them for school entry.

In a previous section, it was shown that public health units tended to have significantly shorter median waiting times for SLP services compared with multi-program child development centres determined by the Kaplan-Meier analyses. It was hypothesized that public health units tended to serve children with less complex conditions thus shorter waiting time. However, the difference in wait time between the two agency types was no longer significant (HR_{PH}=0.97, 95%CI (0.78, 1.21)) when other agency factors such as admission rate, caseload size and staff size were controlled for (Table 4.3.4.2B, Block 1 model). This trend was even reversed after it was adjusted for other child factors.

Comparing to child development centres, public health units were more likely to have longer waiting times (HR_{PH}=0.70, 95% CI (0.56, 0.89)).

Interaction between agency service location and agency type was included in the final model to investigate the influence of these agency characteristics further (Table 4.3.4.2B). Wait time of rural agencies no longer differed from that of urban agencies when interaction was included. Agencies providing services to both rural and urban communities, however, consistently had longer waiting time (HR_{both}=0.59, 95%CI (0.43, 0.84). Wait time for public health SLP services remained to be longer as well (HR_{PH}=0.49, 95%CI (0.29, 0.80). However, the significant interaction indicated that public health SLP services tended to have shorter wait time if the public health unit is in a rural location (HR=2.28, 95%CI (1.39, 3.74)).

Table 4.3.4.2A: Cox Regression Model 1, SLP

	Block1	Block 1 + Block 2
Variable	Hazard ratio (95% CI)	Hazard ratio (95% CI)
Agency		
AW	Reference	Reference
AB	0.57 (0.38, 0.84)*	0.52 (0.35, 0.76)*
AE	0.60 (0.49, 0.7)*	0.74 (0.6, 0.86)*
AF	2.25 (1.57, 3.22)*	2.51 (1.75, 3.6)*
AI	1.42 (1.1, 1.83)**	1.73 (1.33, 2.24)*
AM	0.58 (0.43, 0.76)*	0.57 (0.43, 0.76)*
AR	1.11 (0.99, 1.24)	1.16 (1.04, 1.29)**
AS	1.2 (1.01, 1.41)***	1.42 (1.2, 1.69)*
AT	0.53 (0.46, 0.61)*	0.52 (0.45, 0.6)*
AU	1.04 (0.87, 1.24)	1.03 (0.87, 1.23)
AV	1.57 (1.41, 1.74)*	1.6 (1.44, 1.78)*
AX	0.56 (0.5, 0.63)*	0.55 (0.49, 0.62)*
AZ	1.07 (0.89, 1.28)	1.05 (0.88, 1.26)
Referral source		
Family (/FM)		Reference
Medical (MD)		0.87 (0.8, 0.94)*
Health Unit (HU)		0.83 (0.77, 0.9)*
Agency (CDC)		0.58 (0.52, 0.65)*
Other		0.78 (0.68, 0.89)*
Age at referral (months)		
< 18		Reference
18- 30		1.1 (0.99, 1.22)
31 – 42		1.07 (0.96, 1.2)
> 42		1.14 (1.02, 1.28)***
-2 Log Likelihood	69515.100	69407.251[#]

*P<0.0001, **P<0.01, ***P<0.05
[#]Change from Block 1 is significant by Chi-Square test, P< 0.0001

Table 4.3.4.2B: Cox Regression Model 2, SLP

	Block1	Blocks 1 + 2	Blocks 1 + 2 + 3
Variable	Hazard ratio (95% CI)	Hazard ratio (95% CI)	Hazard ratio (95% CI)
Location			
Urban	Reference	Reference	Reference
Rural	1.66 (1.42, 1.95)*	1.65 (1.41, 1.94)*	0.87 (0.57, 1.33)
Both	0.72 (0.66, 0.78)*	0.73 (0.67, 0.80)*	0.59 (0.42, 0.84)*
Caseload Size			
< 400	Reference	Reference	
400 -1000	0.81 (0.62, 1.06)	0.79 (0.60, 1.03)	0.89 (0.61, 1.29)
> 1000	0.65 (0.50, 0.86)**	0.56 (0.43, 0.74)*	0.54 (0.38, 0.75)*
Admission Rate			
$\leq$ 75%	Reference	Reference	
> 75%	1.95 (1.69, 2.25)*	2.31 (2.00, 2.68)*	2.73 (2.26, 3.29)*
Program staff level (FTE)			
< 2.5	Reference	Reference	
2.5 – 5.5	0.60 (0.46, 0.79)*	0.84 (0.63, 1.13)	1.02 (0.66, 1.56)
> 5.5	1.27 (0.93, 1.74)	1.79 (1.30, 2.48)*	2.13 (1.51, 3.00)*
Agency type			
Child Development Centre (CDC)	Reference	Reference	
Public Health Unit (PH)	0.97 (0.78, 1.21)	0.70 (0.56, 0.89)**	0.49 (0.29, 0.80)**
Referral source			
Family (FM)		Reference	
Medical (MD)		0.86 (0.79, 0.93)*	0.86 (0.79, 0.93)*
Health Unit (HU)		0.86 (0.79, 0.93)*	0.85 (0.79, 0.93)*
Agency (CDC)		0.59 (0.53, 0.66)*	0.59 (0.53, 0.66)*
Other		0.79 (0.69, 0.90)*	0.79 (0.69, 0.90)*
Age at Referral (months)			
< 18		Reference	
18 – 30		1.07 (0.96, 1.19)	1.07 (0.97, 1.19)
31 – 42		1.04 (0.93, 1.16)	1.05 (0.94, 1.18)
> 42		1.14 (1.00, 1.24)	1.12 (1.00, 1.25)
Agency Type x Location Interaction			
PHxUrban			Reference
PHxRural			2.28 (1.39, 3.74)**
PHxBoth			1.23 (0.86, 1.74)
-2 Log Likelihood	70092.404	69418.288[#]	69406.735[##]

*P<0.0001, **P<0.01, ***P<0.05

[#]Change from Block 1 is significant by Chi-Square test, P< 0.0001

[##]Change from Block is significant by Chi-Square test, P=0.003

4.4 CONCLUSION

4.4.1 Agency Survey

The intention of the survey was to gain an understanding of the current state of waiting list and waiting time information in the absence of any formal data source. The definitions of waiting list and waiting time in this survey were adapted from the hospital waiting list literature because standard definitions were lacking when the survey was launched. As a result, this study can only present the approximate figures of the waiting times for assessment and treatment, though agencies prepared their estimates as accurately as they could.

One limitation of the questionnaire survey in this study is the under representation of agencies serving families and children in major urban centres. Some of the non respondent agencies expressed that the primary reasons for not participating were shortage of resources and time. One agency refused to participate based on a concern about issues of privacy and confidentiality. The missing information from a few larger centres may lead to misleading provincial trends and estimates of waitlist and waiting times. Nevertheless, the results of this study can still provide some insight to issues of waiting lists and waiting times for early childhood intervention services.

Data availability was a major barrier for waiting time assessment for early childhood intervention services. Waiting time measures for early childhood intervention services have yet to be clearly defined. This study provided a snapshot of current waitlist and

waiting time information for these services in British Columbia. As expected not all programs had a waiting list for services. However, waiting for SLP and OT services appeared to be consistently a challenge to all service providers in the province at the time of survey. For physiotherapy, some therapists have shifted their service delivery from providing direct therapy to consultation and training of others (e.g. family and childcare staff) to provide therapy. This may explain why waitlist for physiotherapy did not appear to be a problem in some areas.

Because of the inconsistent description of waitlist, the term "waitlist" in the field of early childhood intervention service can be baffling. All families and their children need to wait even just for a few days because of scheduling and administration processes. Not having a waitlist does not mean families and children wait 0 day for services. Some children may wait up to one month before getting their first service but they are still not considered on a waiting list by the agency. No waitlist can also mean that an agency is not accepting new referrals because no more staff are available, thus the agency has reached its capacity. As a result, research should focus more on the waiting time as the delay of services from referral.

Since in Canada, early intervention services such as infant development programs and preschool intervention therapy services are traditionally the sole responsibility of territorial and provincial governments, the federal government does not have any national mandate to give direction to the development and provision of early childhood intervention services (Goelman et al., 2005). Unlike many hospital based services,

waiting lists for early childhood intervention services have received very little attention. This study highlighted the current state of information about the waiting times and waiting lists in the area of early childhood development and intervention services in British Columbia.

4.4.2 Focus Group Interviews

The service delivery of BC's early childhood intervention programs does not conform to a simplistic framework of Referral –Assessment –Treatment pathway according to the focus group participants. Children may go various directions within programs and/or agencies after referrals are made. Some children may receive a formal assessment before receiving treatment intervention while some may directly go to intervention without a formal assessment. Some children may wait for a group intervention only while some may wait for both group program and one-on-one intervention. Thus, consensus on a common framework of service delivery for each early childhood intervention program is urgently needed. The proposed frameworks of service delivery pathway and wait time tracking emerged from focus group discussion will be discussed in Chapter 5.

4.4.3 Administrative Data

The assessment of the administrative data revealed that locally kept administrative data varied widely in terms of comprehensiveness and quality regarding referral and intake, diagnosis and reason for referral, and information on the decision to treat (service recommendation, assessment date and assessment outcome). With the current data

structure, it is difficult to ascertain whether or not children who are waiting for services do indeed still need the services. This is especially true for direct intervention services (service provider works with the child directly) because not all children who are referred to early intervention therapy services require the high intensity one-on-on direct therapy. On the other hand, it can be assumed that all referrals would require at least the intake consultation as the first service appointment.

With the given data, it was found that occupational therapy has the longest median waiting time (180 days, 95% CI 62.84 – 297.16 days) followed by speech-language pathology services (112 days, 95%CI 108.04 - 115.96 days). Supported child development program has the shortest median waiting time (12 days, 95%CI 7.31 – 16.69 days). The overall median waiting times for infant development program and physiotherapy are 70 days (95%CI 55.61 - 84.39 days) and 57 days (95%CI 41.97 -72.03) respectively.

In general, gender did not play a role in wait time variation although percentage of male children was consistently higher across all intervention disciplines. Age at referral alone explained some of the variation in waiting time but differently for different types of interventions. Younger children tended to have shorter waiting times for infant development programs, occupational therapy and physiotherapy. For supported child development program and speech-language pathology, older children tended to receive services earlier compared to younger children.

Analysis using Kaplan-Meier method indicated that waiting times varied widely across agencies, referral age groups and referral sources. In terms of agency variables, agency location, staffing level, and average caseload size of agency were all found to be significantly associated with waiting time. However, because of limited information for physiotherapy, occupational therapy and supported child development program, firm conclusions cannot be drawn in terms of agency variables for these services. Furthermore, the differences in waiting time observed in those agencies with only the *Program Admission Date* might be due to the incorrect assumption that program admission was in fact the first intake consultation appointment for these agencies.

For infant development program, age at referral became an insignificant factor when the analysis was adjusted for other confounders. Further analysis revealed that age at referral also varied widely across agencies (Table 4.4.3A). For example, the mean and median ages at referral in agency BA were 4.3 months and 1.3 months old while in agency AB, they were 13.9 and 13.6 months respectively. Thus, the variation in waiting time across referral age groups could be due to the variation by agency. Thus, effect of age became insignificant when it is adjusted for agency factors.

For supported child development programs, the results of Kaplan-Meier analysis suggested that longer waiting time was associated with small caseload, low staffing level, and rural location. However, there is only one rural agency with SCDP data available for comparison. Therefore, firm conclusions from these results cannot be drawn.

Table 4.4.3A: Referral Age by Agency, IDP

Agency	Mean age (months)	Median age (months)
AB	13.9	13.6
AE	13.5	12.3
AF	20.2	21.2
AI	8.0	2.9
AM	11.3	5.7
BA	4.3	1.3
BE	7.0	2.5
BN	11.6	8.2
CC	12.6	9.2
CD	14.0	14.4
Overall	11.7	7.5

For speech-language pathology, adjusted hazard ratios suggested that longer waiting times were associated with younger children, professional referral source, smaller program staff sizes, larger caseload size, lower than 75% admission rate and public health units. The results also suggested that demand for public health SLP services might be higher in urban-rural mix communities, thus longer waiting time.

This study demonstrated that for those children having received services, the majority (over 90%) received initial consultations or first contacted by service providers within a year after referrals (Table 4.4.3B). It was, however, also noted that those children who have not yet received services have waited on average 398 days, 119 days, 479 days, 413 days and 457 days for IDP, SCDP, PT, OT and SLP respectively. Longer waiting time for those still waiting might be due to the fact that children were referred too early, or were not perceived to be urgent and they were not ready for intervention. The factors that

influenced the decision of intake to caseload are unclear, however. Some of these

children on waitlist should have been removed from the database because they might no

longer need the services. Data audit might have removed some of these cases.

Table 4.4.3B: Percentile of Children Received Services within 30, 60, 90, 120, and 365 days

Wait time* from referral date	IDP	SCDP	PT	OT	SLP
Within 30 days	50.2%	71.9%	59.0%	50.0%	17.6%
Within 60 days	62.9%	84.6%	77.9%	63.8%	36.3%
Within 90 days	69.8%	89.9%	84.7%	76.4%	52.3%
Within 120 days	74.3%	91.7%	89.6%	84.6%	64.6%
Within 365 days	99.2%	99.1	97.7%	94.9%	96.4%
Number of referrals	973	228	385	254	4450

*Wait time of children who received services on or before May 31, 2005.

Children who left the program without services also spent longer time waiting. The exact

reason is also unclear. It was speculated that for various reasons, sometimes service

providers might need to wait an extended period of time for family's response with

regard to scheduling appointments. Some families might have lost interest in services

without notifying agencies of their intention to leave or might have failed to notify the

agencies of their new contact information when they moved.

Older children tended to wait shorter time for IDP, SCDP and SLP services. Interestingly,

in general, it was found that family referral has a shorter waiting time compared to

referrals from the medical and public health sources for all types of intervention except

for SCDP. Referral from an early child educator (childcare worker) tended to have shorter waiting time than family referral and other sources of referral for SCDP. A key difference between early childhood intervention services and hospital based services is that families can self-refer their child to most early childhood intervention services. Thus, parent care seeking behaviour may influence the appointment rates and waiting times. Agencies may be able to schedule appointments with self-referred families more quickly because these families are already in contact with the agencies. One the other hand, agencies may require time to gather additional information from professional referral sources before they can contact with the families.

Further investigation into the relationship between referral age groups and referral sources revealed a clear referral age differences between family referral and professional referral. For example, Table 4.4.3C showed the proportions of professional and family referrals within each age group for IDP and SLP. It is evident that older children tended to be referred by Parents. Univariate analyses have demonstrated that children older than 30 months and 42 months tended to have the shortest median wait times for IDP and SLP respectively. This might explain why family referrals were consistently shown to be associated with shorter waiting time. The exact reason for shorter waiting times associated with family referral requires further investigation.

Table 4.4.3C: Proportions of Professional and Family Referrals within Each Referral Age Group

IDP	Referral age	MD	PHN	FM
	< 6 months	14.3%	43.7%	10.8%
	6 – 18 months	18.8%	28%	24.1%
	19 – 30 months	9.2%	28.3%	27.7%
	> 30 months	11.4%	12.9%	32.9%
SLP	Referral age	MD	PH	FM
	<18 months	18.6%	18.6%	19.0%
	19 – 30 months	28.6%	28.6%	22..3%
	31 – 42 months	33.6%	33.6%	31.2%
	> 42 months	25%	25%	34.9%

MD= Medical referral, PHN= Public health nurse referral,
PH=Public health referral, and FM= Family referral

One limitation in this study is the lack of comprehensive information regarding the referral reasons and family demographic information. Parent characteristics (age, gender, education, location) were not available to determine whether they could explain some of the variations in waiting times. However, it is speculated that parent's care seeking behaviour may explain the rates of "no show" for appointment, difficulty in scheduling appointment, and difficulty in making contact with service providers. These might all influence the waiting time for services. In the focus group sessions and follow-up interviews, some suggested waiting time should be discounted for situations such as:

1. The time that an agency requires to gather additional documentation from parent or referral source.

2. When parents specifically ask for a later date for an initial appointment.

3. Waiting time that is not due to agency's lack of resources. For example, referral is made when the infant is still in hospital and in some cases, the infant may stay in the hospital for an extended period of time.

4. The time that agencies take to contact families.

The impact of these reasons on waiting time is currently unknown. Moreover, a relatively sophisticated data system is required to differentiate the time associated with these reasons from the true waiting time for services.

In conclusion, this study has confirmed the significant inter-agency and intra-agency variations in waiting times for the 5 community based early childhood intervention services. The overall results from the administrative data agree with that of the questionnaire survey data. Occupational therapy and speech-language pathology seemed to have more challenges in terms of waiting times. The overall results also suggested that factors such as age at referral and referral source may play an important role in determining waiting time within an agency.

CHAPTER 5

DISCUSSION AND POLICY IMPLICATIONS

The primary objective of this study was to investigate the current state of knowledge regarding waiting lists and waiting times for community based early childhood intervention services in British Columbia (BC). Overall, this study revealed that the complexity and the wide variation in service provision as well as the lack of standardized and comprehensive data have posed major challenges in this field. Thus, the relevant implications emerging from this study surround the need of developing policies and programs of research to address the near absence of waitlist data, and inconsistent definitions and terminologies. Bolstering the infrastructure to support a common data system capable of collecting standardized and valid waitlist information is clearly an essential step. The following sections will discuss several policy implications and future research needs. First, however, it is necessary to discuss the limitations of this study.

5.1 STUDY LIMITATIONS

The questionnaire survey and focus group sessions, along with the administrative data, have provided some insights into the waiting list phenomenon in the context of early childhood intervention services. However, this study suffers a number of limitations due to the data availability. In particular, the main limitation relates to the wide variation in the comprehensiveness and compatibility of administrative data provided by participating agencies. This has significantly limited the scope of this study to only a few key relevant

attributes associated with the wait time variations. Nevertheless, this study was able to demonstrate wide variations in waiting times due to agency factors (agency type, location and size) and child factors (referral age and referral source). Although observed patterns might help suggest some hypotheses, the exact reasons for the variations could not be confirmed with the current data.

The literature has identified a number of clinical and non-clinical factors (such as diagnosis, referral reason, and urgency rating) that are potentially associated with wait time variations. However, most of this information was not available for analysis due to non-standardized record keeping across agencies. Moreover, demographic information on parents of children accessing early childhood intervention services was not included in this study. This was due to the logistic difficulty in surveying families. Given this, the results of this study should serve as the baseline information to guide the next stages of research in this area.

Another notable limitation of this study is the generalizability of the results. A number of factors have limited the generalizability in this study. First, not all agencies participated in both the questionnaire survey and the focus group interviews. Agencies from major urban communities were underrepresented in this study. Furthermore, only a small number of agencies were able to provide administrative data. Although the results may be generalized to agencies providing services to small urban and rural communities, it is expected that similar results may apply to agencies in major urban communities. Second, the analysis is based on data only from the province of BC. It is unclear whether similar

results may be seen in other provinces. Third, this study has focused on the five intervention services provided by community agencies for children up to six years of age. Further study is needed for other specialized programs such as the provincial Autism diagnostic and assessment program and other intervention services provided by the tertiary facilities. A different set of research methodologies would probably be required because service delivery and prioritization within these specialized programs are very different from those of community based early childhood intervention services.

Finally, the issue of autocorrelation of data within agencies has not been completely addressed by using time-to-event statistical method (Cox regression). Most Cox regression software packages including SPSS use 'robust variance estimation' as the default to adjust for time dependency of observations (Garson, 2006). This may have resulted in higher standard errors for the parameter (hazard ratio) estimation although parameter estimates usually remain the same. This implies a higher probability of some covariates in the Cox model used here that were found to be non-significant variables. Thus, some insignificant categories of variables indicated in this study might have been deemed significant in explaining wait time variations.

5.2 MONITORING WAITING LISTS AND WAITING TIMES

Little information exists regarding the active monitoring of waiting lists and waiting times for early childhood intervention services in BC or elsewhere in Canada. The Children and Youth with Special Needs Division of the BC's Ministry of Children and Family Development (MCFD) has been developing a service indicator reporting

framework (SIRF) since 2004 (MCFD, 2007). SIRF consists of a set of service indicators for the four intervention services in BC: the Infant Development Program, the Supported Child Development Program, the Early Intervention Therapy (OT, PT and SLP) services, and the School-Age Therapy (OT, PT and SLP) services. All agencies providing one or more of these programs and services with a Ministry funding contract are required to report on the indicators using an Excel spreadsheet template. The primary purpose of SIRF is to provide the Ministry with information on the accessibility and service utilization of children with special needs.

These indicators include some waitlist information such as number of children served within 30 days (or 90 days) from the date of service request and number of children on waiting list in each month. By collecting this information, SIRF also attempts to promote consistent definitions and use of terminologies by establishing a handbook of service terminologies.

Unlike waiting for surgical interventions and diagnostic services, early childhood intervention services do not have a "clear cut" point in time indicating when a service is scheduled and when an intervention has taken place. As discussed in Chapter 2, different forms of intervention can be provided either concurrently or consecutively. The wide variations in waitlist management and monitoring methods used by community agencies have contributed significant challenges to the implementation of the standardized definitions. Thus, continued efforts to engage community service providers to reach a common ground in defining and using the same wait time terminologies are needed.

Initiatives such as SIRF attempting to promote consistency and reliable information collection should be supported. Waitlist information collected in this way can be useful if the "date on" waiting and "date off" waiting are validly defined and used consistently across agencies and regions. However, more general limitations still exist with this approach of data collection. For example, agencies and service providers may face additional burden in generating this aggregated information regularly without a good data system and technical supports. Self-reported information may also be more prone to bias and inconsistency even with a set of common definitions.

Moreover, aggregated waiting time and waiting list information is less useful beyond descriptive analyses. For example, one of the purposes of monitoring waiting lists and waiting times is to ensure that those on waiting lists do, in fact, need and want to receive the referred services. With the current data structure, it is difficult to assess the validity of any waiting lists at both the regional and the provincial levels.

The complexity of service delivery in the field of early childhood intervention implies that different strategies of tracking and reporting waiting lists and waiting times are needed. The first step in monitoring waiting lists and waiting times is to have a common framework for defining the potential waiting periods along the service pathway for each early childhood intervention. A common data system then is needed to track service delivery and waiting time information.

5.3 COMMON FRAMEWORKS FOR DEFINING WAITING TIME PERIODS

Results from focus groups in this study indicated a need of clarity of wait time definitions in the field. A common framework of defining various waiting periods should be recommended through a consensus building process. Designing a wait time framework is influenced by the range and diversity of agency service delivery as discussed in Chapter 2. For a single-program agency, the service delivery pathway can be straightforward. For an agency with multiple programs, referred children might have complex needs and require multiple services simultaneously within the organization. Additional steps may be needed along the pathway such as triage or intake meeting with an interdisciplinary team before or after families are first contacted. Internal referrals to specific disciplines and programs may also be necessary.

Some agencies provide services to a few neighbouring rural communities covering a large geographic area. A number of rural communities will not offer group activities because there may not be enough children to form group programs or because the distance between neighbouring communities is too far for families to travel to the hosting venues. Some services in many rural communities are largely home based programs in which service providers are required to travel a long distance to their clients' homes for services. On the other hand, some urban agencies will mostly utilize group programs to serve many waitlisted families and children. This illustrates a few differences in service delivery among rural and urban agencies.

The presence of a waitlist may also alter the service delivery pathway (Figure 2.3)
outlined in Chapter 2. The stage along the pathway where new referrals are put on a
waitlist varies from agency to agency. Some believe that children cannot wait. It is better
to receive interim services but less intensive intervention when there is a long waiting
list. For these agencies, all new referrals will be contacted and assessed before they are
put on waitlists for active intervention. These agencies tend to provide more interim
services of different forms to waitlisted families. At the other extreme, some agencies
will not do intake assessment until a service provider is available to offer active
intervention immediately after the assessment. These agencies tend to put all children on
waitlists immediately after receiving the referrals. Some agencies may have a process of
monitoring waitlisted children to determine whether immediate attention is required
while they are waiting for services.

Early childhood developmental issues are not always straightforward. Information
collected during the first contact with the family or intake session can only represent the
preliminary assessment of the child's real developmental needs. This is often done
through informal observation of the child's developmental progress. It is not uncommon
that a child requires a different program from the one to which the child was referred or
the child requires other additional programs. Furthermore, intervention can take many
forms which are largely dictated by the natural flow of each child's needs. For some
agencies, a review of service level (review consultation) may take place when services
(interim or active intervention) have been provided.

Defining a set of common wait time measures is, therefore, a multifaceted challenge.

The proposed framework presented in Figure 5.1A and Figure 5.1B emerged largely

from the focus group participants' perspective and suggestion in the present study.

Generally, participants agreed with the three definable wait periods suggested in the
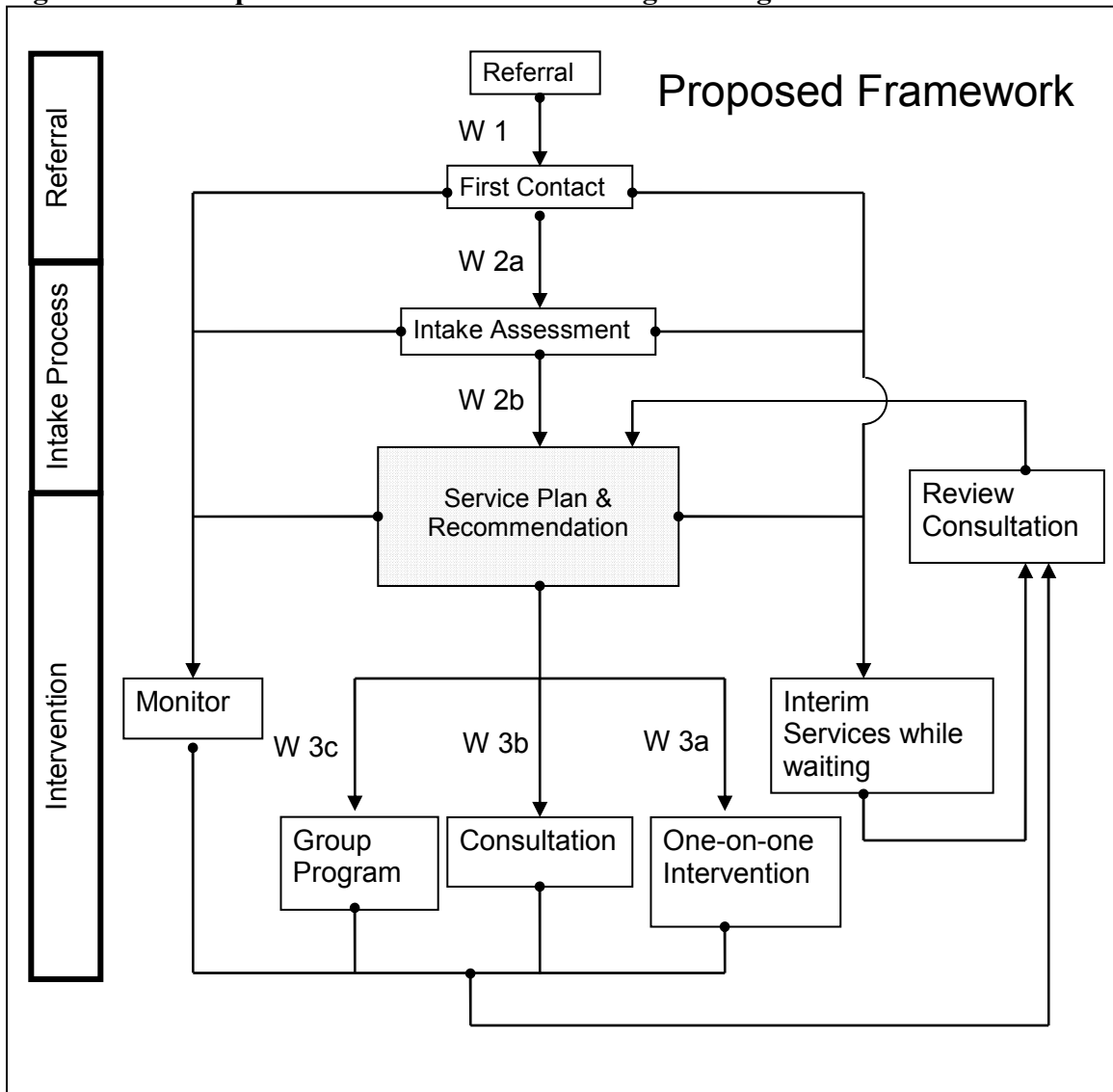
model and described below:

Wait #1: *Waiting for "First Contact" by an intake coordinator or intervention service provider after the referral is received by agency (or program).*

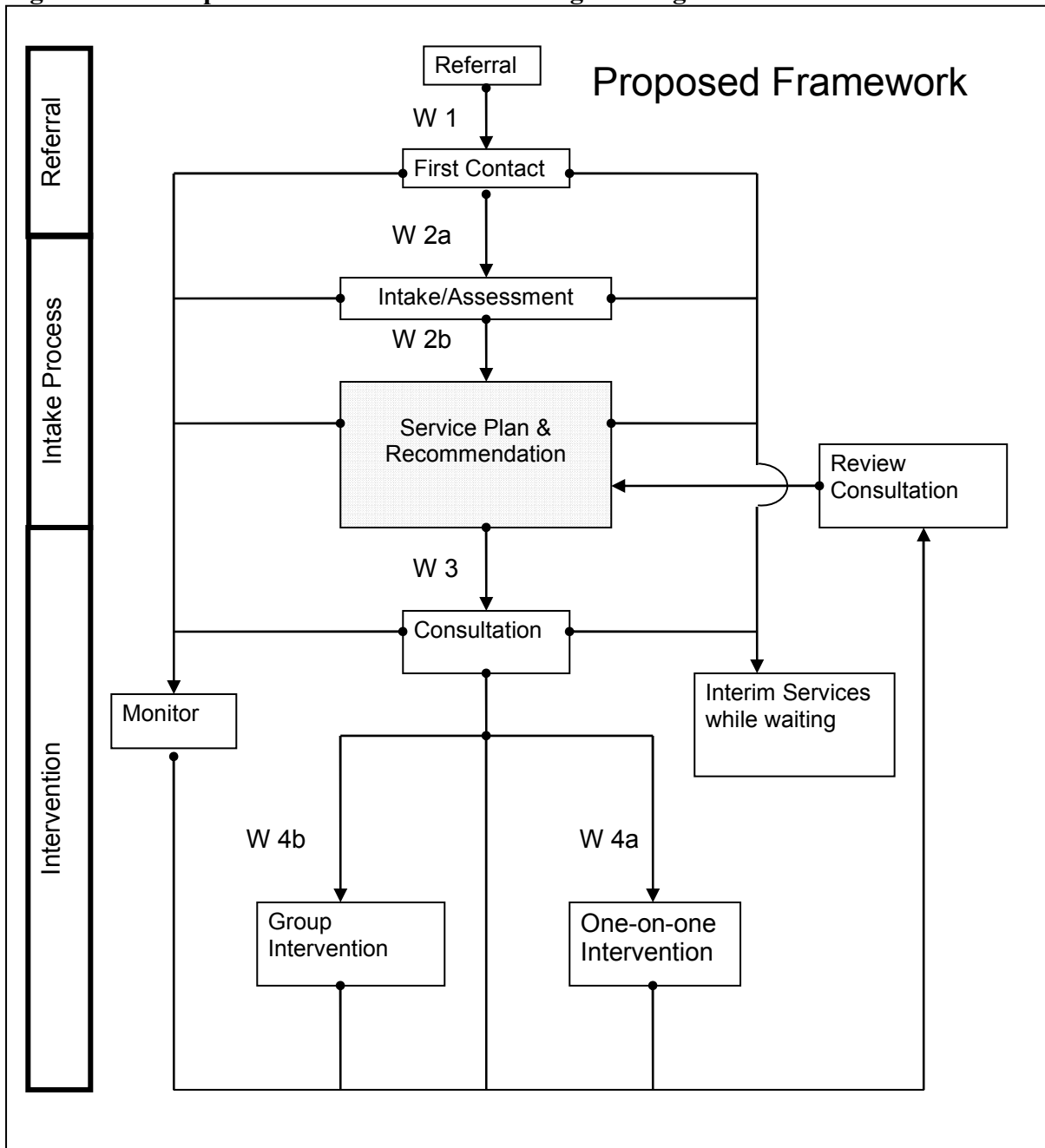*Wait #2*: *Waiting for "Intake Assessment" and "Intervention recommendation" after the first contact has taken place.*

Wait #3: *Waiting for the "Recommended Intervention" after the intake assessment.*

The underlying assumption for this proposed framework is that the referral is appropriate,

and children are waiting for their recommended services. If a child is not eligible for the

referred service, he/she may be discharged from the system after the first contact or

intake assessment. Such discharges, however, need to be officially recorded.

Figure 5.1A: Proposed Framework of Measuring Waiting Times for IDP and EIT.

Proposed Framework

Referral

Intake Process

Intervention

Referral
W 1
First Contact
W 2a
Intake Assessment
W 2b
Service Plan & Recommendation
Monitor
W 3c
W 3b
W 3a
Group Program
Consultation
One-on-one Intervention
Interim Services while waiting
Review Consultation

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Figure 5.1B: Proposed Framework of Measuring Waiting Times for SCDP

Infant Development Program and Early Intervention Therapy

The framework presented in Figure 5.1A may be applied to the Infant Development

Program and Early Intervention Therapy services because the general stages are similar

for these two intervention services.

Wait #1: Waiting for First Contact (Between Date of Referral and Date of First Contact)

First Contact can be defined as the first face-to-face or telephone contact with the family

by a service provider or intake coordinator following the referral. It is designed to obtain

descriptive information about the family and the child. Depending on the agencies' usual

practices, the primary function of "First Contact" is to acknowledge referral, gather

additional information, and identify immediate crises and family needs. For some, the

"First Contact" is an opportunity for agencies to provide information about their

programs, to introduce service providers, and to organize some preliminary support to

families if warranted. This initial contact is valuable to families. Families seem to feel

acknowledged even though they are still waiting for the actual intervention services.

Wait #2: Waiting for Intake Assessment and Service Recommendation (Between Date of First Contact and Date of Intake Assessment and Service Recommendation)

> **Wait # 2a: Waiting to Intake Assessment:** Intake Assessment is defined as the
>
> first formal assessment or observation to determine the type of intervention
>
> required. In multi-program agencies, after first contact, children/families may go
>
> into specific program areas where program/discipline specific assessments occur.
>
> The first contact may be done by an intake coordinator. The next contact will be an
>
> intake assessment by each discipline's service provider.

Wait # 2b: Waiting for Service Plan/Recommendation: Service Plan and/or Recommendations are used to decide on the form of intervention that is most appropriate for the child's developmental or clinical needs. Some agencies may provide additional comprehensive assessment after the intake assessment. The information obtained from this assessment is used to guide the service plan and recommendation. The formation of a service plan and program recommendation represents an important milestone on the service pathway. It is similar to the notion of "Decision to Treat" in the surgical model. The family may need to wait for a service recommendation appointment at which time the family meets with a service provider to discuss a service plan (or recommendation). This includes the decision on the level and nature of intervention.

Wait #3: Waiting for the Recommended Form of Intervention (Between Date of Service Plan/recommendation and Date of First Intervention Appointment)

Wait #3a: Waiting for Individualized Service (One-on-one Intervention): In this study, focus group participants agreed that "individualized (one-on-one) service" should not be perceived as a gold standard of intervention. Although many children do not require individualized intervention services, it is important to monitor the waiting time for this form of intervention. Presumably the most significant waits may be seen in those children who are waiting for individualized services. This form of intervention tends to require more resources, thus longer waiting time is expected.

Wait #3b: Waiting for Consultation: One focus group participant suggested that caregiver consultation should also be seen as one form of intervention. For example, therapists may instruct early childhood development workers or family caregivers to carry out home programs. Waiting time for a caregiver consultation should be referred to the wait for which families will receive caregiver consultation as a form of intervention.

Wait #3c: Waiting for Group Program: Group programs are considered to be a legitimate form of intervention by many service providers. Group program may be the desired type of treatment or it may be part of preliminary services, provided in conjunction with caregiver consultation and/or an individualized intervention program.

Supported Child Development Program

For the Supported Child Development Program, a slightly modified framework is presented in Figure 5.1B. The majority of families only require consultation with a SCDP consultant. As discussed in Chapter 2, a SCDP consultation consists of linking the family to appropriate services and resources for their child in the childcare and preschool setting. Thus, for most families, waiting for a consultation appointment with a SCDP consultant is the only potential intervention wait period (Wait #3) following the intake and service recommendation appointments.

**W#3 = Waiting for first SCDP Consultation (Between Date of Service
Recommendation and First Consultation Appointment)**

A small number of children also need extra staffing support at childcare facilities.

During a service plan meeting, the family and the SCDP consultant will generally

discus a child and family service plan and make a decision on the level of support, for

example:

Level 1 -Training, support, and consultation, no additional staffing required.

Level 2 - Short-term, transitional, intermittent, or shared support requiring

additional support workers at childcare facilities.

Level 3 - Significant, on-going individualized support requiring additional support

workers at childcare facilities.

If a child needs only Level 1 support, the family will normally only receive

consultations by a SCDP consultant. If a child needs Level 2 or 3 services, the SCDP

consultant will assist the family in locating funding and resources for the support of

their child within a childcare setting (SCDP Program Manual, 2005). Thus, a potential

wait period is necessary if the extra support is not available immediately.

**W#4 = Waiting for Extra Staffing Support (Between Date of First Consultation
and First Date extra staffing support at the childcare facility)**

W#4a = Waiting for one-on-one (individualized support)

W#4b = Waiting for shared support (group intervention)

The implementation of this framework will depend on the establishment of standard practices and processes in service delivery. As indicated by SIRF, this has been the most challenging task because of the diverse service delivery approaches across and within regions. Individual agencies often have different perspectives and values in ways of serving children and families.

Most early childhood intervention agencies in BC operate in a 'silo' fashion. Adopting a set of common definitions of service terminology and wait time measures would clearly improve our understanding of waitlist phenomenon. However, in many cases, information from existing individual data systems may not have been collected according to the standard definitions. A provincial data system may help simplify data collection and further improve the consistency in wait time reporting.

5.4 PROVINCIAL DATA NETWORK FOR EARLY CHILDHOOD
   INTERVENTION SERVICES

Limited data availability has led to the suggestion of developing a provincial data network for compiling anonymous administrative data as a strategy of improving the quality and quantity of information on early childhood intervention services not just waitlist information[13]. Policy relevant research on best practices, access, barriers to early childhood intervention services, and longitudinal studies on the effectiveness of early childhood interventions on the long term development of children have not been

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[13] LINKED-DISC project webpage: http://www.idpofbc.ca/linkdisc.html. Accesses on October 15, 2007

undertaken. Interdisciplinary research is needed for knowledge translation and for conceptualizing and understanding the impact of early childhood intervention on children and their family in a Canadian context. This should also include the role of neighbourhood, community and policy initiatives on the developmental progress of children at risk or with disabilities (Goalman et al, 2005).

The long-standing issue of client privacy and confidentiality due to the voluntary nature of service provision is one of the major barriers to the implementation of both a universal data management system and a central data registry. Early childhood interventions differ from medical interventions in their service delivery philosophy. Early childhood interventions often combine health and social services to ensure that children and families will receive a full array of services. Service providers need to respect the privacy and confidentiality of families and their children in order to encourage their participation in the programs. For example, some families may receive income support in addition to services they receive from an intervention program. Thus, some families may not be willing to disclose information worrying that the government may use the information against them by, for example, reducing services. As a result, service providers are often reluctant to share client information with researchers and government. However, service providers are also increasingly recognizing the importance of providing population based data to their funders and the research community. Many are working toward developing policies and guidelines to facilitate information sharing while safeguarding the privacy and confidentiality of families and their children.

Thus, initiatives improving information technology for all community agencies should be supported. This may encourage agencies to participate in such a provincial data network. Anonymous individual based data can be collected to form a single administrative data source. Common data system and data registry have been found in other jurisdictions and programs.

In Washington State, USA, the Infant Toddler Early Intervention Program is provided by community service contractors and agencies. A pilot project of a state wide information management system for tracking program information is being conducted[14]. Monthly state wide program data including referral pattern, service delivery, and child outcome information can be generated by the system for program planning and quality improvement. In BC, the BC Perinatal Database Registry funded by the Ministry of Health is an example of a provincial data network (BCPDR, 2003). The registry began in 1988 with only a small number of hospital sites. To date, the registry maintains data from all hospitals in BC accounting for 99% of births in the province. Participation in the registry is completely voluntary.

Currently, a project in BC is underway to develop a province-wide client information management system (the LINKED-DISC project) to assist in collecting individual level data and for integrating information to track service delivery and waiting list information on early childhood intervention services. One of the project objectives is to bring all agencies to the same standard of information management and to ensure the consistent

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[14] Infant and Toddler Early Intervention Programs webpage:
http://www.dshs.wa.gov/iteip/ Accessed on November 22, 2007

use of high quality waitlist data for monitoring waiting times for various services. Well designed data system and data registry are vital to both research development and decision-making processes. The network data for the early childhood intervention services can be used, for example, to establish, modify, and/or validate exiting urgency rating tools, and maximum acceptable waiting times. The data can also be used to monitor waiting times and waiting lists across regions. MCFD should continue to play a significant role in engaging community agencies in developing mechanisms for effective data capture in this field while ensuring the privacy and confidentiality of families accessing these services.

5.5 EFFECT OF WAITING TIMES

This study revealed that a significant number of children left intervention programs before receiving any services. A number of reasons for leaving programs were identified, in particular non-attendance (failure to attend a scheduled appointment) and failure to be contacted (families did not respond to agencies). Further study is needed to examine whether long waiting time may have affected the decision of families in accessing early childhood intervention services. Some suggested that the likelihood of attendance by clients once an appointment is scheduled may be affected by the long waiting time. Foreman and Hanna (2000) demonstrated the impact of long waiting time on the intention of families to attend the child and adolescent psychiatric clinics. This UK study found that a long delay between referral and first contact with the service is a fundamental reason for non attendance in the clinics (Foreman & Hanna, 2000).

In another UK study, Rona et al. (1991) audited the intake information on the developmental surveillance of vision, hearing, and language referrals in the London inner city areas (Rona et al., 1991). It was noted that the poorest attendance rate was identified for speech therapy. The authors suggested that besides the complex nature of speech therapy and assessment, the existence of long waiting lists was one of the possible reasons explaining the large percentage of non-attendance.

In this study, a significant number of referrals were closed before children/families received services due to failure to contact or non-attendance. With the existing data, it is unclear whether or not waiting too long is the primary cause of failure to attend appointments or withdrawing service request by families. Non-attendance rates are typically high for some services (e.g. 17.6% of those left SLP before receiving services in this study). Efforts are needed to re-contact families periodically who have been waiting for a significantly long period of time. As discussed in Chapter 2, the rate of non-attendance needs to be addressed in order to avoid resource wastage and increase in the waiting list size.

Long waiting lists and waiting times also have a negative influence on referral rate by professionals (Keating et al., 1998). In a survey of paediatricians on their referral practice, Keating et al. (1998) noticed that the existence of long waiting lists for services discouraged paediatricians from making referral. This might also apply to other referral sources. Thus, studies on service accessibility and utilization need to take into account the effect of waiting lists on referral rates. The results of this study also suggested that

professional referrals tended to be associated with longer waiting time for both IDP and SLP compared with family referrals. This may have some adverse effect on the referral rate by professionals. Further study is needed to investigate the underlying reasons for the discrepancy.

5.6 FUTURE RESEARCH

Adding to the growing body of knowledge about waiting lists and waiting times, this study provided a few specific observations of the current state of information regarding the waiting lists and waiting times for early childhood intervention services. This study has also identified a number of significant challenges and information gaps. To date, little research has been done to examine the impact of waiting on families and children's development and the effectiveness of interim services provided to waitlisted children and their families. Early childhood intervention programs vary widely across Canada in terms of service provision, program model, and enrolment eligibility as discussed in Chapter 2. Future research with a focus on increasing our understanding of waiting list and waiting time dynamic in relation to models of intervention and service delivery should be supported.

A program of research is also needed to delineate the reasons for variations in waiting times at both local and regional levels. Reliable information is needed to inform decision makers who continue to face difficult choices about how scarce resources should be used. This study revealed that waiting times vary widely across programs and regions. The reasons for variations can be complex. In the absence of strong evidence, decisions about

the need for more resources may sometimes rely on anecdotal information or less than perfect data. Although this study has identified a few potential factors associated with the waiting time variations, future research should be extended to uncover a wider range of factors and the nature of their associations. Moreover, the proposed conceptual framework of factors affecting waiting lists and waiting times is constructed with a number of assumptions (Figure 2.1). Most empirical data supporting these assumptions, however, are currently not consistently collected. In particular, family characteristics (such as language and socio-economic status), service provider workload, urgency rating, diagnosis, reason for referral, birth rate, private service availability, and local economy should be included in future studies.

Effort is needed to establish common tool of measuring waiting times in order to achieve a better understanding of waiting list and waiting time definitions in this field. A consensus-building process with various stakeholders should be continued. When reliable data are available through, for example, the provincial data network, collected data should be used to examine the construct validity of wait time definitions to ensure that the definitions can accurately reflect the waiting experienced by families and children. Moreover, when collective understanding of waiting list and waiting time definitions is achieved, waitlist research efforts should begin to be based on the standardized clinical and non-clinical information along with the development of urgency rating tools. This will help establish evidence based benchmarks of maximum acceptable waiting times for various intervention services. Qualitative data should be an additional information source

to establish these benchmarks. In particular, the impact of waiting on families and their decision in withdrawing or accessing services should be included.

This study represents the first assessment of waiting list and waiting time information in the context of early childhood intervention services. It has only 'scratched the surface' of a rather complex service delivery system in terms of waiting list research. The wait for specialized habilitative services and mental health services for special needs children has not been included in this study. Future research should also extend to the development of a framework for measuring waiting times for these services as we work toward standardization of both the waiting list and waiting time measures and tracking methods.

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APPENDIX A

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR	DEPARTMENT	NUMBER
Sheps, S.B.	Health Care/Epidemiology	B04-0797

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT

Children's & Women's Health Centre ,

CO-INVESTIGATORS:

Armstrong, Robert, Paediatrics; Chan, Herbert, Health Care/Epidemiology

SPONSORING AGENCIES

Human Early Learning Partnership (HELP)

TITLE:

Waiting Lists and Waiting Time for Early Intervention Services for Preschool Children in BC

APPROVAL DATE	TERM (YEARS)	DOCUMENTS INCLUDED IN THIS APPROVAL
DEC 09 2004	1	Sept. 1, 2004, Consent forms / Questionnaire / Cover letter / May 1, 2004, Contact letter

CERTIFICATION:

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. James Frankish, Chair,
Dr. Cay Holbrook, Associate Chair,
Dr. Susan Rowley, Associate Chair
Dr. Anita Hubley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures

Centre for Community Child Health Research (CCCHR)
L408 - 4480 Oak Street
Vancouver, B.C. Canada V6H 3V4

UBC

Waiting Lists and Waiting Time for Early Intervention Services for Preschool Children in British Columbia

AGENCY QUESTIONNAIRE

Instructions

1. Please check on the box ☑ that best represents your response or fill in the information.
2. There is no right or wrong answer. You may skip over questions that do not apply to you.
3. If you are unsure how to answer a question, please give the best answer you can and write a note to us on the margin.
4. If you have any other comment or issue that is not covered in the questionnaire, please feel free to write on any space of the questionnaire.
5. If you need any assistance to complete this questionnaire, please feel free to contact Herbert Chan at 604-875-2433 or by email (hwpchan@cw.bc.ca)

About your organization

1. **The name of your organization:**

2. Your agency's catchment area is a part of which of the following MCFD regions? (Please check all that apply)

☐ Fraser
☐ Interior
☐ North
☐ Vancouver Costal
☐ Vancouver Island

3. Which of the following best describes the location of your agency's catchment area?

☐ Major Urban
☐ Small Urban
☐ Rural
☐ Both Urban and Rural

4. Which of the following best describes your organization?

☐ Public agency
☐ Private nonprofit organization
☐ Private for-profit organization
☐ Others (specify): _____

About your program staffs

5. How many full-time-equivalent staff (including administration and clerical staff) involved with early intervention programs in your organization?

(Please give your best estimate): _____

6. How many full-time-equivalent staff of the following provide early intervention services directly to children and their families?

Please give your best estimate for the following

Early Intervention services	How many F.T.E.?
Aboriginal Infant Development Consultant	
Infant development Consultant	
Occupational therapist	
Physiotherapist	
Speech/language Pathologist	
Supported Child Care Consultant	

About the Waiting List

7. Currently, is there a waiting list for <u>ASSESSMENT</u> of the following services in your organization?

Please put **DK** if you do not know or **NA** if service is not available.

Assessment waitlist	Yes	No	If yes, what is the average waiting time (in weeks) for these services?	If yes, what is the longest waiting time (in weeks) for these services?
Aboriginal Infant Development Program	☐	☐		
Infant Development Program	☐	☐		
Occupational therapy	☐	☐		
Physiotherapy	☐	☐		
Speech/language therapy	☐	☐		
Supported Child Care Program	☐	☐		

8. Currently, is there a waiting list for <u>TREATMENT</u> of the following services in your organization?

Please put **DK** if you do not know or **NA** if service is not available.

Treatment waitlist	Yes	No	If yes, what is the average waiting time (in weeks) for these services?	If yes, what is the longest waiting time (in weeks) for these services?
Aboriginal Infant Development Program	☐	☐		
Infant Development Program	☐	☐		
Occupational therapy	☐	☐		
Physiotherapy	☐	☐		
Speech/language therapy	☐	☐		
Supported Child Care Program	☐	☐		

9. **Does your organization have a single waitlist for <u>EACH</u> early intervention program listed in questions 8 and 9?**

   ☐Yes
   ☐No
   ☐Don't know
   ☐Other (please specify): _____

10. **Is your organization currently using any methods to prioritize children/families' placement on the waiting lists?**

    ☐Yes   ☐No   ☐Don't know

    If Yes, Please specify the methods: _____
    _____
    _____

11. **Do you or someone in your organization routinely update/audit the waiting lists for each early intervention program?**

    ☐Yes
    ☐No
    ☐Don't know

12. **Please indicate WHEN a child/family is considered to have been placed on a waiting list in your organization for each of the following services.**

    Aboriginal Infant Development Program
    ☐ When referral letter or referral request is received
    ☐ When first review of referral indicates referral appropriate
    ☐ When assessment is done and treatment is deemed appropriate
    ☐ Not Applicable
    ☐ Other (please specify):

    _____

    _____

    Infant Development Program
    ☐ When referral letter or referral request is received
    ☐ When first review of referral indicates referral appropriate
    ☐ When assessment is done and treatment is deemed appropriate
    ☐ Not Applicable
    ☐ Other (please specify): _____

    _____

Occupational therapy
☐ When referral letter or referral request is received
☐ When first review of referral indicates referral appropriate
☐ When assessment is done and treatment is deemed appropriate
☐ Not Applicable
☐ Other (please specify): _____

_____

Physiotherapy
☐ When referral letter or referral request is received
☐ When first review of referral indicates referral appropriate
☐ When assessment is done and treatment is deemed appropriate
☐ Not Applicable
☐ Other (please specify): _____

_____

Speech/language therapy
☐ When referral letter or referral request is received
☐ When first review of referral indicates referral appropriate
☐ When assessment is done and treatment is deemed appropriate
☐ Not Applicable
☐ Other (please specify): _____

_____

Supported Child Care Program
☐ When referral letter or referral request is received
☐ When first review of referral indicates referral appropriate
☐ When assessment is done and treatment is deemed appropriate
☐ Not Applicable
☐ Other (please specify): _____

_____

13. Does your organization routinely collect or review information on the impact of waiting on children and their families?

☐Yes
☐No
☐Don't know

14. Does your organization routinely collect or review information on the impact of waiting on families' satisfaction of services they are receiving or will receive?

☐Yes
☐No
☐Don't know

15. Does your organization have a policy for non-attendants (missed appointment)?

Please describe:

_____

_____

About your clients

16. Approximately how many children and their families does your organization serve in a 1-year period? Please give your best estimate

Number of children/families served in 1 year _____

17. Approximately how many new referrals does your organization receive in a typical month?
Please give your best estimate

	Number of new referrals in a typical month?
Aboriginal Infant Development Program	
Infant Development Program	
Occupational Therapy	
Physiotherapy	
Speech/language Therapy	
Supported Child Care Program	

18. **What percentage of the children/families your organization provides early intervention services to speak a language other than English at home?**

Please give your best estimate _____%

19. **Approximately how many clients are taken off the active caseload in your organization in a typical month?**

	Number of children/families taken off from active caseloads in a typical month?
Aboriginal Infant Development Program	
Infant Development Program	
Occupational Therapy	
Physiotherapy	
Speech/language Therapy	
Supported Child Care Program	

20. **In general to what extent are the waiting times a problem in your organization for each of the following services:**

   1=Not a problem at all
   2=Occasionally a problem
   3=Usually a problem
   4=Always a problem
   5=Don't know
   6=Not applicable

Please use the rating (1-6) from above

_____Aboriginal Infant Development Program
_____Infant Development Program
_____Occupational Therapy
_____Physiotherapy
_____Speech/language Therapy
_____Supported Child Care Program

21. Compared to 2 years ago, the waiting time for children requiring the following services in your agency has

    1=Greatly increased
    2=Increased
    3=Neither increased nor decreased
    4=Decreased
    5=Greatly decreased
    6=Don't know
    7=Not Applicable

Please use the rating (1-6) from above

_____Aboriginal Infant Development Program
_____Infant Development Program
_____Occupational Therapy
_____Physiotherapy
_____Speech/language Therapy
_____Supported Child Care Program

Thank You