2. The terms Indigenous and Aboriginal are used almost synonymously at this time in Canada to refer to people who identify themselves as descendents of the original inhabitants of the land now called Canada. Section 35 of the Canadian Constitution recognizes First Nations, Inuit, and Métis as Aboriginal people of Canada. The term Aboriginal was coined in the 1980s by the Canadian colonial government. The term Indigenous (as used here) is inclusive of First Peoples internationally. Many prefer the term Indigenous as a resistance against imposed colonial naming and because the term Indigenous is more widely used in global advocacy movements and donor agencies to promote Indigenous Peoples' rights, development, and equity.

CHAPTER 6

What We Learned about Early Identification and Screening

Hillel Goelman, Laurie Ford, Mari Pighini, Susan Dabinten, Anne Synnes, Lillian Tse, Jessica Ball, and Virginia E. Hayes

This chapter focuses on The Developmental Pathways, Infant Neuromotor, Community-Based Screening, and The Indigenous Child studies. We have chosen to focus on these four studies for two particular reasons. First, issues around early identification and screening have been identified as priority areas in those disciplines represented in the CHILD Project. These include pediatrics (AAP, 2001; Drotar, Stancin, & Dworkin, 2008; Sand et al., 2007; Synnes, Lisonkova, Houbé, Klassen, & Lee, 2004; Synnes et al., 2006); rehabilitation sciences (Lee & Harris, 2006); nursing (Pinto-Martin, Dunkle, Erels, Fliedner, & Landes, 2005); school psychology (Carlton & Winsler, 1999; Pianta & McCoy, 1997); and First Nations Studies (Ball, 2004; Panagiotopoulos, Rozmus, Gagnon, & Macnab, 2007). Second, precisely because each of these studies arises from particular disciplinary contexts, they present different but complementary perspectives on efforts to determine the health and developmental status of young children. This chapter briefly provides the context, content, and main findings of each of these studies. It also discusses the ways in which these studies both contributed to and were informed by the other studies in CHILD, and the implications for early intervention practice and for further research.

All four of these studies arose out of the recognition that in any population there are children who need extra support. The research has
shown that the early identification of these children and their subsequent participation in high-quality early intervention programs can have positive developmental outcomes. All four studies discussed in this chapter, in different ways, speak to the importance of the two-part strategy presented by Coleman, Buié, and Neitze (2006) of recognizing young children with special needs with accuracy, sensitivity, and cultural fairness and responding to these children and their families with appropriate services. In the following section we provide some background on the history and current practices related to the recognition of and response to the early identification of young children who need extra support.

**A Brief Overview of Screening and Early Identification in Early Childhood**

The terms “assessment,” “screening,” and “early identification” can have a variety of meanings to those in different disciplines or professions and for this reason we define the meanings we are using in this chapter. We have adopted Meisels’ and Atkins-Burnett’s definition of assessment as the broadest of these possible terms in that, “the goal of early childhood assessment is to acquire information and understanding that will facilitate the child’s development and functional abilities within the family and community” (2001, p. 232). The assessment process can provide insights into a child’s developmental strengths and limitations and can identify children who may be at risk for developmental challenges and who may need extra support. Early identification could include the process of screening a population of children to uncover preliminary concerns about a child’s development and/or subsequent diagnostic procedures designed to provide more detailed information about a specific developmental disorder or delay.

For some, the term assessment is synonymous with “formal, standardized testing” and for others, it includes a wide range of formal and informal, quantitative and qualitative techniques, which draw on, for example, observations of children’s play; descriptions and observations of children’s art, music, and puzzle play; developmental checklists; and children’s participation in formal, standardized testing. At their core, all such efforts are interested in assessment as a systematic process for understanding child development, and as part of this systematic process, those collecting assessment data must ask themselves four key questions:

1. What do we want to know about this child?
2. Why do we want to know this?
3. How will we gather the necessary information?
4. What will we do with this information once we gather it?

Brofenbrenner’s (1977) observation on the limitations of experimental procedures with young children can apply to screening and early identification procedures as well: “The science of strange behavior of children in strange situations with strange adults for the briefest possible period of time” (p. 513). As Meisels and Atkins-Burnett (2000) have acknowledged, “early childhood assessment is a field in transition” (p. 231), and the psychometric view is no longer as dominant. This transition continues with new approaches, techniques, measures, and tools uniquely suited to the developmental needs of children in the early years from different disciplinary perspectives. With changes in policies, procedures, and in some cases laws, the need for a wide range of assessment procedures that address the unique needs of children in early childhood continues.

Major national organizations in the United States and Canada including the Council on Children with Disabilities (CCD; 2006), the American Academy of Pediatrics (AAP; 2001) and the Canadian Paediatric Society (CPS; 2010) have all endorsed screening procedures for young children as matters of public policy. The CPS has stated two major objectives for their policy:

1. To identify populations that are at risk, and to obtain important ecological and epidemiological data on their circumstances; and
2. To evaluate the success of public health interventions by tracking their effectiveness (CPS, 2010).

The expansion of early childhood special education programs, school readiness initiatives, and other early intervention programs has contributed to the growth and need for reliable, valid, and culturally fair assessment of children in early childhood. The expansion of programs, policies, and procedures has also been accompanied by the articulation of basic principles that should guide the early screening and identification of young children in need of extra support. Meisels and Atkins-Burnett (2000) have proposed that the assessment of young children be based on a number of key principles including the following: assessment should be a collaborative process drawing on parents, family members, and professionals; assessment should draw upon parental information and feedback; assessment should draw on multiple sources of information; assessment should address children’s
current levels of strength as well as anticipated growth areas in the future; assessment should be seen as a step in the process of intervention and continued feedback; and the assessment process should be nonthreatening, safe, and nonjudgmental for children and parents.

Assessment, screening, and early identification processes are not without their critics (e.g., Bloch, 1990; Canella, 1997). Dahlberg, Moss, and Pence (1999), for example, have criticized the historical hegemony of developmental psychology in the field of early childhood. They have also rightly pointed out that developmental psychology has long argued for a universal approach to understanding the ages and stages of child development and how this view has influenced curricula, programs, and the assessment of young children. Scholars writing from a reconceptualist orientation have identified the ways in which this traditional hegemony has been used as means to marginalize, control, and oppress specific populations of young children and their families. Their appeals for more holistic and culturally fair screening and assessment procedures have invited a number of constructive additions to the growing repertoire of such procedures. New Zealand’s integrated curriculum framework known as Te Whariki includes approaches and techniques, which allow classroom teachers in early childhood classrooms to understand the learning and development of children (Carr, Hatherly, Lee, & Ramsey, 2003). These include the systematic collection of portfolios, which document the children’s development through photographs, the children’s art, and emergent writing. Perhaps most exciting is their creation of “learning stories” that generate narratives around the ways in which young children discover, build, and organize their learning experiences in the classroom. Similar approaches have been developed in the Reggio Emilia learning centers in Italy (Edwards, 1993) where portfolios, anecdotal record keeping, and ongoing parent-teacher conferences form the basis for ongoing consultations on the children’s progress. Both the Reggio Emilia and Te Whariki programs, it should be pointed out, are approaches used with all of the children in the classrooms and are not designed specifically to identify children with developmental challenges. The other encouraging news about these approaches is that they demonstrate the potential for collecting information on children’s health and development in ways that are multidisciplinary and respectful of the children, their parents, and families.

In summary, all of these formal and informal approaches to monitoring children’s growth and development should be consistent with the principles articulated by Meisels and Atkins-Burnett (2000) and to help determine the kinds of information which are needed and the ways in which the information will be obtained.

**Overview of Early Screening and Identification Programs in British Columbia**

Screening and early identification practices in British Columbia include a combination of universal and targeted approaches for children of different ages, for different purposes, with different instruments and conducted by different medical, health, educational, and social service professionals. As indicated in table 6.1, some procedures are routine and nearly universal; others are intended for all children but parents are not mandated to participate; and others are recommended for children who appear to be at risk for developmental challenges.

All children receive Apgar scores at birth and although this is not actually a screening measure per se, the Apgar score assists the medical staff in attending to the vital aspects of the newborn child. Recently, British Columbia has also instituted newborn hearing screening. Most infants are discharged directly from the hospital to their homes, but at-risk infants are instead transferred to a Neonatal Intensive Care Unit (NICU) where they are given a detailed medical assessment. Upon their discharge from the hospital, these infants who had been treated in the NICU undergo a systematic assessment process. The most vulnerable babies, including those with birth weights under 800 grams, have their development monitored through the hospital’s Neonatal Follow-Up Program (NFUP).

<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Universal (routine): All infants after birth, Apgar screening</td>
</tr>
<tr>
<td>2. Universal (routine): All infants after birth, newborn hearing</td>
</tr>
<tr>
<td>3. At-risk infants, up to 72 hours after birth—more detailed medical diagnoses</td>
</tr>
<tr>
<td>4. Universal (routine): All infants, birth to one year, public health nurse visits, general screen</td>
</tr>
<tr>
<td>5. Vision screening at three years (Not yet universal although this is being planned.)</td>
</tr>
<tr>
<td>6. Family physicians and pediatric visits, birth to five years general screen (as needed, requested, referred)</td>
</tr>
<tr>
<td>7. Suspected deficits, diagnostic testing, birth to five years (as needed, requested, referred)</td>
</tr>
<tr>
<td>8. Universal vision screening at kindergarten</td>
</tr>
</tbody>
</table>
After discharge from the hospital both NICU and non-NICU infants usually receive at least one follow-up home visit by a Public Health Nurse that includes an overall health check-up. Should specific concerns arise following the administration of any of the checklists used by the PHNs, such as the Ages and Stages Questionnaire (Bricker, Squires, & Mounts, 1999), follow-up assessment and early intervention, support referrals are generally in place. Throughout their preschool years, children may participate in the voluntary screening and early identification programs that are offered to the entire population. The population-based newborn hearing screening occurs soon after birth (prior to hospital discharge). It is not only a screening program but is a coordinated Early Hearing Detection and Intervention program (BC Early Hearing Program) with services across multidisciplinary service providers and involves multiple ministries. There is a dental (caries) risk assessment conducted by public health staff, which typically occurs when the child is 12 months old. The caries risk assessment is not an in-the-mouth assessment; public health staff pose questions to parents and assign a risk level. Vision screening is also not yet available province-wide (although universal three-year-old vision screening is the goal). These regularly scheduled voluntary screening and early identification programs may or may not result in referrals for more diagnostic testing and/or intervention programs.

There are many different assessment and intervention pathways, which may be used in the zero-to-five age period. Children with identified or suspected developmental challenges may be assessed at any point in the early years as a result of parent concerns and/or professional referrals. Some children are referred by family physicians, nurses, Infant Development Consultants, or Aboriginal Infant Development Consultants. They may be referred to medical subspecialists such as pediatricians or to other health care professionals such as optometrists, audiologists, psychologists, or physical or occupational therapists. In some cases, children may be referred directly by their parents. Developmental assessment practices will in many cases be linked to recommendations (by these various professionals) to parents to enrol their children in early intervention programs. This support may be provided through home-based or in-center consultation and/or therapy services for babies and young children with “suspected” risks, as in the case of those identified during the Public Health Nurse’s home visit (BC Centre for Ability, 2010). Assessment and intervention may be provided by the same agency or may be conducted through different auspices. There is no one systematized pattern to these various services, referrals, assessments, and interventions. There is no one entry point or exit point and parents must be their children’s best advocates in order to best negotiate these multiple options.

Despite the existence of these various pieces of the early identification puzzle, there is no one, integrated universal program for the screening of children’s developmental status in all domains throughout the early years for all children from birth to school entry. For the most part, the efforts to provide screening, identification, and intervention in British Columbia try to meet the needs for those children who are most medically and developmentally fragile. As a result, it is the children in the “grey area” who are frequently missed by established screening and early identification processes. They may be in the “grey area” because their developmental difficulties are so subtle or because the assessment devices are not sensitive enough to identify their particular condition. Alternatively, a child may not be identified with a specific diagnosis because he or she has fallen through the cracks of the system for routine monitoring, screening, and assessment. This can happen for a number of reasons. For example, the child and her family perhaps do not speak English; may change address frequently; or may have a lapse in insurance coverage. Another reason is that the child may be in foster care. Assessment and intervention services may be limited in remote and isolated communities, and/or the child’s caregiver(s) may choose not to have their child monitored, screened, or assessed by developmental health personnel. The identification of children with diagnoses as well as children in the grey area continues to be an ongoing issue across the medical, educational, and social service sectors in the province. One essential element in all of British Columbia’s developmental screening practices is the close connection between the assessment/identification process and the funding provided for services for children assigned to specific labelled categories. Assignment to these categories is strictly dependent on a medical or developmental diagnosis (Pighini, 2008; Pivik, 2008). This labelling/funding process is also used to provide educational support for children ages five and older as they enter the school system (British Columbia Ministry of Education, 2000b). However, for children without labelled diagnoses, funding is discontinued once they enter the school system (Committee on Children with Disabilities, 2005; Pighini, 2008). Only through “special needs” labelling will these children have access to more individualized resources and program adaptations outlined in their Individualized Educational Programs (British Columbia Ministry of Education, 2000a; Learning Assistance Teaching Association of British Columbia, 2002).
**Brief Summary of the Design and Findings of the Four Studies in the CHILD Project**

The four studies we discuss in the chapter offer a range of different approaches and methodologies. As shown in table 6.2, which was constructed on the basis of the studies' respective CHILDTalk papers (see Chapter 3), each of the studies identified the information they needed, their reasons for needing that information, and the very different methodologies each used. On the fourth question—what the information they collected would be used for—there was much greater similarity than difference in their responses. All of the studies wanted to use their data to help improve the system of screening, identification, and early intervention in the province.

The lead academic researchers in *The Developmental Pathways Study* were a neonatologist and a developmental paediatrician and their community partner was a provincial early intervention program, the Infant Development Program of British Columbia. *The Developmental Pathways Study* examined the mortality, morbidity, development, and hospital utilization rates of children who were treated in NICUs at birth (Schiariti et al., 2008; Synnes et al., 2004, 2006). One analysis revealed that infant mortality rates among extremely low-birth weight NICU-treated infants from 1983 to 2002 decreased significantly compared to previous years. However, the disability rates for these children during the same time period were unchanged. A second analysis examined the medical and social determinants of hospital utilization rates of NICU infants born in 1996–1997 with a broader range of birth weights. The medical factors that were statistically associated with the rates of hospital utilization were congenital anomaly, gestational age, severity of illness, and health status; the social determinants were the larger number of children in the family, lower levels of family income, and the involvement of early intervention services. Based on their years of doing assessments on at-risk infants, the team members concluded that the classification system that was used was reliable in identifying moderate to severe disabilities but was not sensitive enough to pick up “softer” or “milder” forms of disabilities of children in the so-called grey area.

During the life of the CHILD Project two important spin-off programs of research were developed. In one, a population health study was initiated by using Ministry of Health administrative databases to collect (anonymized) data on over 70,000 children of whom approximately 10 percent had been treated in NICUs for at least 24 hours. The administrative set allowed the researchers to develop full medical

<table>
<thead>
<tr>
<th>Table 6.2</th>
<th>Four Questions about Screening in the Four Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The Developmental Pathways Study</strong></td>
<td><strong>What do we want to know?</strong></td>
</tr>
<tr>
<td><strong>The Infant Neuromotor Study</strong></td>
<td>To determine whether or not early screening for at-risk and healthy infants for motor development has positive outcomes for infants and their families by age three, and to compare two methods of training child professionals to use two different assessment measures.</td>
</tr>
<tr>
<td><strong>The Community-based Screening Study</strong></td>
<td>To help the CHILD Project the local community, and the broader community to understand the effectiveness of screening young children with the Nipissing District Developmental Screen.</td>
</tr>
</tbody>
</table>
Table 6.2 Continued

<table>
<thead>
<tr>
<th>What do we want to know?</th>
<th>Why do we want to know this?</th>
<th>How will we gather information?</th>
<th>What will we do with the information?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Indigenous Child Project</td>
<td>The overall goal of the project is to explore new approaches for gathering information and designing assessment strategies that ensure the cultural and community relevance, or ecocultural validity, of procedures used for determining service needs and impacts in early childhood learning and development.</td>
<td>It is important to hear from community members about &quot;assessment&quot;—what it means to them, whether or how it has been useful within the broad agenda of Aboriginal peoples' recovery from the residential school era and a desire for postcolonial / antiracist relationships with non-Aboriginal peoples and agencies.</td>
<td>Interviews in communities, conducted by community-based teams primarily with parents about goals for children's development, cultural practices, desired and actual supports for young children and views about assessment. To identify local requirements for research, possible research strategies, data collection opportunities, and interpretations of the context and meanings of data obtained.</td>
</tr>
</tbody>
</table>

Histories for these at-risk children from birth to age nine. Permission has been requested to link these medical files to the children's files in the Ministry of Education in order to examine the children's developmental and educational outcomes (Goelman, 2008). The second study also addressed questions of developmental trajectories of at-risk children but did so through a multiple case-study approach. Using qualitative methods including interviews and focus groups, this study examined families' experiences and their perspectives on the assessment and intervention processes that they lived through (Pighini, 2008).

The Infant Neuromotor Study was led by an interdisciplinary team of academic researchers from nursing, occupational and physical therapy, and community partners from two provincial early intervention programs, the IDP, and the British Columbia Centre for Ability. The Infant Neuromotor Study set out to determine the concurrent validity of two specific tools designed to identify infants under one year of age with neuromotor difficulties: the Alberta Infant Motor Scales (AIMS) (Tse et al., 2008) and the Harris Infant Motor Test (HINT) (Mayson, Hayes, Harris, & Backman, 2009). The AIMS was designed for children from birth to 18 months while the HINT was designed for children from 2.5 to 12.5 months of age. There was a high level of convergent validity between the two measures at Time 1 (4–6.5 months) and at Time 2 (10–12.5 months) with a sample of 72 children who were referred to the study because of suspected neuromotor delays/disorders and 49 children where neuromotor delays/disorders were not suspected. The study also established the predictive validity of the HINT by using the Bayley Scales of Infant Development II at 24 months and the Bayley Scales of Infant and Toddler Development at 36 months (Bayley, 1993, 2006).

In order to expand the training opportunities for interdisciplinary early child development professionals in both urban and rural settings to reliably screen for neuromotor delays/disorders, The Infant Neuromotor Study team developed and piloted both face-to-face and online formats to deliver course material to learn to administer the AIMS. The online version was used and tested with professionals mostly in remote communities, thereby offering them and their clientele services that would otherwise not have been possible due to a lack of training opportunities. In addition to occupational and physical therapists, the courses also enrolled nurses, early childhood educators, and other early interventionists. The researchers concluded that both course delivery formats could help in early screening and cettion of infants with delays and, therefore, lead to increased early referral to intervention services.

The Community-Based Screening Study evaluated a population-based developmental surveillance program that had been implemented in the community 18 months prior. The two previously discussed studies dealt with diagnostic assessment conducted by professionals, while The Community-Based Screening Study explored the use of a parent-completed measure—the Nipissing District Developmental Screen (NDDS)—to screen a nonrisk population for children who might require subsequent diagnostic assessment and perhaps intervention. The children in this study included infants, toddlers, preschoolers, and kindergarten students. Although the children were initially recruited through nonrandom sampling, an effort was made to obtain a sample that was representative of the diversity in the general population. Recruitment of the younger children was conducted at a public health immunization clinic, a family support center, child health fairs, and through advertising in the community (e.g., newspapers, posters). Recruitment of kindergarten students took place.
through selected classrooms within selected schools. The study also made use of the Bayley Scales of Infant Development for the 193 children aged 4, 18, and 24 months and of the Stanford-Binet for the 90 36-month-old children and 89 kindergarten students.

The Community-Based Developmental Screening Study found that the NDDS was able to correctly identify children with major developmental concerns or with no major developmental concerns (i.e., high test specificity for major concerns). However, the measure was much less reliable in its ability to identify children with mild or moderate disabilities. The screening program also yielded a number of positive benefits at the family and community levels. The screening provided a framework for public health nurses to discuss child growth and development with parents and other community professionals from the health, medical, social service, and education sectors (Ball, 2005; Canam, Dahinten, & Ford, 2007; Dahinten, Ford, & Lapointe, 2004; Dahinten, Ford, Canam, Lapointe, & Merkel, 2007). In fact, this study was launched as part of the CHILD Project at the initiative of the community public health nurses who were interested in exploring the effectiveness and usefulness of a program of community-based developmental screening (Anstett, 2003; Dahinten et al., 2004).

As discussed in Chapter 5, The Indigenous Child Project addressed the perceptions of and beliefs about child development among parents, professionals, and Elders in Indigenous communities. In particular, this study examined the participants' experiences with previous early childhood assessment practices in their communities and their recommendations for assessment practices in the future. Through focus groups and interviews, the participants described their personal experiences with previous child assessments as depersonalized and "high-handed" due to a number of factors. Parents were often not asked to give informed consent to the assessments, which were frequently conducted by professionals behind closed doors. Typically, these assessments were conducted with no or little input from parents or others who knew the children well. Further, parents received little in the way of feedback, discussion, or consultation based on the assessments, and written copies of reports were rarely provided to the parents. Parents felt that many of the measures were not culturally fair or sensitive to Indigenous children and did not acknowledge or respect local knowledge, history, custom, and language. Parents reported situations in which assessment results were often used to place children into remedial educational streams from which it was extremely difficult to have them removed.

To remedy these problems, the communities recommended that all assessments be guided by respect for Indigenous peoples and their culture and traditions—a perspective that is being reported increasingly in research on screening in Indigenous communities (e.g., Panagiotopoulos et al., 2007). The process of conducting child assessments must be built upon meaningful relationships with the members of the Indigenous communities; these relationships must be expressed through reciprocity between the professional assessors and the child, the child's family, the child's community, and the community Elders. Parents expressed interest in learning more about standardized assessment instruments in order to determine whether there were ways in which these instruments could be modified or customized to be used with First Nations communities. Overall, community participants were in favor of activities that could help parents, teachers, and other professionals to gain a better understanding of their children's development and to use the results of different forms of assessments to continue to develop programs that could respond to the unique needs of each child.

The Benefits and Challenges of Interdisciplinary Research in Early Identification and Screening

The benefits and challenges of conducting these four complementary studies under one project umbrella fall into three general categories: shared and complementary methodologies; implications for complementary levels of practice; the uses, misuses, and possible abuses of language in the assessment and diagnosis of young children.

Shared and Complementary Methodologies

The sharing of research methodologies, instruments, and training procedures can save time and money and can certainly facilitate cross-disciplinary discourse. The Developmental Pathways Study (at 18 months), The Infant Neuromotor Study (24 and 36 months), and The Community-Based Screening Study (4, 18, and 36 months) all used the Bayley Scales of Infant Development, resulting in cost-savings to the CHILD Project as a whole. Further, the school psychologist involved in The Community-Based Screening Study also trained the research assistants in The Infant Neuromotor Study. The CHILD Project provided a shared context for discussing the advantages and disadvantages of developmental assessment measures across these four studies.
The success of the interdisciplinary training program for use of the HINT in The Infant Neuromotor Study reveals the potential and importance of shared preservice and in-service training for health and early intervention professionals and how this kind of training can serve as a basis for further collaboration and interaction across existing professional boundaries. With a broader range of professionals (e.g., nurses, child care workers, IDP consultants) trained to administer a broader range of assessment measures, a province-wide system of early screening and identification would be much more flexible and responsive (see also Browning & Solomon, 2005; Strennich, Bateman, & Jones, 1988).

The four studies demonstrated that what is often presented as a dichotomy—universal versus targeted approaches in early identification—can actually be viewed as a continuum of complementary and mutually reinforcing approaches to both research and practice. The inclusion of all four studies allowed the CHILD Project as a whole to explore issues relating to broad community-based universal screening practices at one end of the continuum and to the use of diagnostic assessments to identify individual children with specific atypical developmental profiles at the other end of the continuum (figure 6.1). A major contribution of The Indigenous Child Project was the emphasis placed on the child’s culture and history and on the importance of respectful and ongoing communication with the child’s parents. We recommend including these concerns as integral to assessment procedures across the entire continuum.

![Figure 6.1 Continuum of Screening Models in the CHILD Project](image-url)

**Table 6.3 Current and Proposed Early Screening and Identification Procedures in British Columbia**

<table>
<thead>
<tr>
<th>Screening of all children, routine administration</th>
<th>Screening available to all children, voluntary</th>
<th>Screening for children with suspected or diagnosed conditions</th>
<th>Diagnostic follow-up for children with suspected or diagnosed conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>All infants right after birth, routine medical screening</td>
<td>At-risk infants, referral to NICU</td>
<td>Suspected deficits, identified disabilities</td>
<td>Continued follow-up for most vulnerable infants (&lt;800 grams) through early and middle childhood referral for intervention</td>
</tr>
<tr>
<td>All infants, universal newborn hearing soon after birth</td>
<td>Neuroumotor screening with HINT at six months.</td>
<td>Suspected deficits, identified disabilities</td>
<td>• Referral to early intervention program.</td>
</tr>
<tr>
<td>As needed between zero–five years</td>
<td>Consultations with assessments, and referrals by</td>
<td>Literature review, and referrals by</td>
<td>• Continued follow-up and monitoring.</td>
</tr>
<tr>
<td></td>
<td>• Parents;</td>
<td></td>
<td>• Continued consultation, involvement with parents.</td>
</tr>
<tr>
<td></td>
<td>• Public health nurses;</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Pediatricians;</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Infant Development consultants;</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Occupational, physical therapists;</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Elders.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

![Image](image-url)
complementary model: assessment based upon parent involvement and collaboration; assessment based upon the use of multiple sources of information; an assessment of child strengths and challenges. To these principles we would add those recommended by The Indigenous Child Project: That all assessment be conducted with dignity and respect; and that all assessments be conducted in ways that are culturally fair and culturally safe. The framework is intended to address the needs of children from birth to age five across the entire spectrum of typically and atypically developing children and is based in part on similar models developed by Miller and McNulty (1997), Guralnick (2004), and Goelman et al. (2004).

At the broadest level, the framework recognizes the need for screening procedures that are delivered almost universally and are performed routinely at specific times and places (e.g., at birth, at kindergarten entry). The next level would be screening programs, which are offered universally to all children and families who are strongly encouraged to participate but not mandated to participate. In this category we are proposing neuromotor screening (HINT) at 6 months and a complete developmental assessment at 18, 36, and 54 months across all domains with a valid screening tool. If the results indicate the presence of a developmental concern, further referrals for diagnostic assessment would be recommended.

At a more targeted and specific level, children cared for in the NICU at very high risk of neurodevelopmental disabilities would continue to be monitored through Neonatal Follow-up Programs. Woven throughout these timelines for regular developmental assessment would be numerous opportunities for parents to initiate assessments of their children through, for example, home visits by community nurses, Infant Development Consultants, or during visits to pediatric offices. The framework would allow for multiple points of entry and would strongly encourage a high degree of information sharing and collaboration among parents and various health, educational, and social service professionals. Figure 6.2 provides an overview of the various offices and agencies, which would be expected to play a role to facilitate this essential coordination.

**Figure 6.2** Proposed Integration of Screening and Intervention Services in British Columbia Based on the CHILD Project

*Source: Adapted from N. Halton, 2004.*

**Language: The power of words and words of power**

The CHILD Project included qualitative and quantitative researchers from the health and social sciences and community professionals from different professions. In some ways, and at certain times, the members of the CHILD Project found themselves speaking different dialects of the same language and sometimes even different languages. As one of the principal investigators on The Income Assistance Study put it, child development research has used “the power of words” to describe how professionals describe the children they have assessed. Conversely, “words of power” have been used to label, diagnose, or to control children and their families. We have learned from our experiences that the languages of assessment can have both positive and negative effects.

One such issue discussed at length in Chapter 5 on the Indigenous studies was the use of the terms “screening” and “surveillance” that were used by The Community-Based Screening Study, The Developmental Pathways Study, and The Infant Neuromotor Study to describe an approach to monitoring children’s health and development in a universal, consistent, and systematic fashion. Developmental surveillance is a technique more commonly used by health professionals including physicians and public health nurses. One of the more widely cited definitions of surveillance is put forth by Dworkin (1993) who
defined developmental surveillance as “a flexible, continuous process in which knowledgeable professionals perform skilled observations of children during the provision of health care” (p. 531). In its most basic form it is the process undertaken by a health care provider in their day-to-day work with young children, observing their development. It includes the provider’s attendance to the concerns of the parents, coupled with their obtaining relevant developmental history. Checklists are often completed to help track milestones. Many view surveillance and screening, particularly universal screening, as similar processes. “Screening” is a brief procedure with the goal of working to determine those in need of more in-depth follow-up for possible diagnosis. The spirit of both is to identify those in need of further follow up or monitoring. While surveillance is thought to be a longitudinal process occurring as a part of effective day-to-day practice (Dworkin & Glascoe, 2005), screening, in contrast, involves a more summative snapshot of the child at a given point in time. Its purpose is to identify those children in need of further in-depth assessment. Screening is often considered a part of effective developmental surveillance or ongoing systematic review of the child’s development.

The term “surveillance,” however, carried ominous overtones in particular to some members of other study teams within the CHILD Project. For researchers and community partners in The Indigenous Child Project, the term “surveillance” had connotations of the kinds of governmental control and manipulation of First Nations people for centuries. Similarly, The Income Assistance Study of families living in poverty also had strong negative reactions to “surveillance.” Many of the families living in poverty who participated in interviews and focus groups reported that the governmental regulations that framed and monitored their eligibility to receive income assistance relied upon different forms of government reporting and “surveillance” of, for example, their incomes, expenditures, family status, and marital status.

The research community itself is apparently beginning to recognize the problematic status of the word “surveillance” and has begun to advocate for stronger parent voices and control in programs of developmental surveillance (Glascoe, 1999, 2006).

The “power of words” was also found to be an issue in the kinds of diagnoses that were distributed to children based on their ethnic or Indigenous identity. One of the researchers on The Income Assistance Study quoted from one of the interviewees: “How come when my kid acts up they call it Fetal Alcohol Syndrome but when my white neighbour’s kid acts up they call it Learning Disability?” Thus, while terms like developmental surveillance, Fetal Alcohol Syndrome, and learning disability may be intended to be used as objective, diagnostic, and value-free words, we learned that depending on the context, they can each carry powerful negative implications for people on the receiving end of the diagnosis.

The terms “delay,” “disorder,” and “disability”—especially when coupled with the adjectives “mild,” “moderate,” and “severe”—all create meanings that do not always travel well beyond the boundaries of one discipline or even beyond the definitions of a specific assessment measure. This issue of the language of diagnosis also arose in discussions of how best to describe children for whom there were developmental concerns but who did not fall into any universally agreed upon definition of disability. In the pediatrics literature, Glascoe, Foster, and Wolraich (1997) described the problem in this way: “Unfortunately, many disabilities are difficult to recognize; they are often subtle, rarely associated with dysmorphology or other obvious characteristics, or incompletely manifested during pediatric encounters” (p. 830).

The CHILD Project studies reviewed in this chapter reported the relative ease of identifying children with “severe” conditions but the great difficulty they had in assigning diagnoses to children with “soft” or “mild” conditions. The prevalence of these hard-to-diagnose children was in fact predicted and confirmed by the community partners on the respective research teams and led some in the CHILD Project to refer to these undiagnosed children as being in the “grey area.” These were children who appeared to perform within the normal range on developmental assessments but for whom there remained concerns caused by some combination of trauma at birth, social behaviors in early childhood, or parental reports of something being “off” or “not right,” which was found in observations and experiences. In other words, the precise language of diagnosis and disability was often found to be inadequate; instead of forcing children into an inappropriate diagnostic category the research teams acknowledged the complexity of the developmental profile of these children and in response, created new language to more accurately reflect that complexity (Goelman et al., 2007).

Conclusions

The CHILD Project represents one attempt to better understand the process, content, and study of child development, especially for children who present with developmental concerns. By bringing together
researchers from different disciplinary and professional perspectives, the CHILD Project created the opportunity for these researchers to articulate and share the meanings of "children," "childhood" and "disability" that had guided their research to date and to invite them to engage in the process of extending and co-constructing new meanings through collaborative discourse, problem-finding, and problem-solving. Similarly, the collaboration of community professionals and university researchers allowed for an ongoing exploration on how the worlds of professional practice and academic research construct meaning and knowledge regarding the conditions, policies, and programs that best support children and their families. The design and implementation of the CHILD Project generated information on the practical needs of parents and health care professionals and real-life applications of the CHILD Project’s findings.

Taken together, the studies reviewed in this chapter can be understood to recommend different types of parent involvement in the screening and early identification process. There are at least two specific recommendations that emerge from an ethic of parental respect. First, it is important even for so-called universal screening programs to obtain informed consent from all parents for data to be collected on their children. The second is that participation rates will increase when there are parent involvement and education programs, which explain the value and importance of early screening and identification programs.

The screening and early identification studies in the CHILD Project have provided valuable information on the health and social development of typical and atypical young children, and have also begun to teach us about both the benefits and challenges of collaborative, interdisciplinary work. As noted throughout the chapter, the screening and identification practices in the province are fragmented with few coherent guidelines. In recent years, however, the new BC Early Hearing Program involving universal early hearing detection and intervention has done a great deal of work to try to address issues of fragmentation. They’ve developed provincial standards and protocols for professionals across sites and disciplines through a coordinated, cross-ministerial approach. Different medical, health, educational, and social service agencies—and different government departments and ministries—are involved with different mandates, protocols, and funding procedures. The research studies have reported data that demonstrate the “best practices” within their own specific disciplines and professions. Taken together, the four studies discussed in this chapter provide guidance for substantive programmatic revision in the area of screening and early identification.

Notes

1. See chapter 5 for a full discussion of the findings of the two studies on child development in First Nations communities.