Final Report

THE SOCIAL INCLUSION PROJECT FOR AT-RISK CHILDREN AND FAMILIES

SUBMITTED TO THE SOCIAL DEVELOPMENT PARTNERSHIPS PROGRAM, SOCIAL DEVELOPMENT CANADA
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SUMMARY

This report describes in-depth The Social Inclusion Project for At-Risk Children and Families, a project funded by the Social Development Partnerships Program, Social Development Canada, Government of Canada. The project was completed between 2005 and 2008 through the Human Early Learning Partnership, working in partnership and collaboration with the Infant Development Program of British Columbia. The project aimed to identify the barriers to full inclusion for families with young children who are at risk for developmental delays or with special needs. The project created materials and resources to help document the ways in which families experience such barriers within their communities in British Columbia’s Lower Mainland.¹

The report includes a description of the objectives of the project and the project outputs with detailed information and examples for both the research and deliverables components. The final sections of the report consist of the follow-up to the research and deliverables components of the project based on the findings of the research studies and on the feedback provided by members of the Lower Mainland communities targeted in this project. Recommendations to government and non-governmental agencies in terms of the support required by families and their service providers derived from the information drawn from these sources.

¹ www.earlylearning.ubc.ca/sdpp.htm
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SCHEDULE A
MEETING OBJECTIVES AND ACHIEVING RESULTS: RESEARCH AND DELIVERABLES COMPONENTS

The primary goal of the Social Inclusion Project was to identify barriers for social inclusion for children (birth to 6 years old) who are at risk for developmental delays and/or diagnosed with special needs, and for their families, living in British Columbia’s (BC) Lower Mainland. This is a twofold project consisting of a research and deliverables component.

The first component consisted of two research studies that provided the context and structure from which the deliverables component was developed and implemented. Subsequently, the products within the deliverables component derived from the findings of the two studies of the research component.

In order to coordinate both the research and deliverables components, the project was conceived in two phases, including a Phase 1, or “Identification of barriers to social inclusion – Research Component (Two Studies)”, and Phase 2, entitled “Creation and Dissemination of Information (Knowledge translation/ from Phase 1)”. 

The project has successfully met the majority of the objectives listed and described in Schedule A of the Contributions Agreement. It is important to note that while most of the objectives have been fully met, a few specific objectives pertaining to one stage of the research, and to the dissemination phase have only been partially met to-date. Section 3 of this document, regarding follow-up plans, includes an outline explaining how some of the objectives that were only partially met will continue to be pursued between 2009 and 2010.
OBJECTIVE 1: BUILDING COMMUNITY CAPACITY
PHASE 1: IDENTIFICATION OF BARRIERS TO SOCIAL INCLUSION

Barriers to social inclusion were described as those factors preventing developmentally at-risk children in BC’s Lower Mainland, and their families, to fully access the educational, social, developmental/therapeutic, health/mental health, medical and or recreational services they need in order for children to develop to their fullest capacity.

The research component of this project encompassed two different methodologies for each one of the two studies. The first methodology was quantitative and pertains to the population-based study entitled “An Interdisciplinary Study of the Trajectories of At-Risk Infants and Children.” This study first examined the health services accessed and medical treatments sought by BC children since birth (the selected cohort examined children between birth and age nine years). This investigation is ongoing and aims at following these children’s developmental and educational trajectories by linking their health and educational records since Kindergarten and examining the types of early intervention services they have received (see Section 3 in this report).

Data analyses conducted to-date using the BC Linked Health Database (BCLHD) reveal important trends in the health/medical services utilization patterns of young children in BC when comparing children living in urban and rural areas in BC who were treated in Neonatal Intensive Care Units (NICUs), or “at-risk” children, with children who were never admitted or treated in NICUs, or “non-risk” children. It is relevant to note that at-risk vs. non-risk and rural/urban differences were observed for children living in communities within the Health Authorities corresponding to the Lower Mainland (Vancouver Coastal and Fraser regions) where the Social Inclusion Project was defined. Results to date using hospitalization files suggest that the frequency in the number of hospitalizations are related to “risk” status, and particularly to premature, low birth-weight and to the presence of one or more congenital anomalies, in contrast to reasons associated with “health system” access for children and families. At-risk children between birth and age five were hospitalized more often and for a longer time the first five years of life, and especially between birth and age three.

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3 Goelman, Synnes, Hoube, Lisonkova, Pighini & Li (2008)
These results are not yet final, as further investigation utilizing other health files, including the children’s Medical Service Premium files, need to be conducted. Nevertheless, considering the specific health needs of at-risk children, accessible, timely and continuous services to address their specific conditions (health and developmentally wise) are of extreme importance. The population-based study provided the project with the direction it needed to identify health as a primary factor determining the nature of both current and future needs of developmentally at-risk children. Therefore, a major barrier for full inclusion was identified in limited levels of accessibility and service provision of medical and health related services for young, at-risk children. This information is particularly relevant for communities in the Lower Mainland where two out of the three Level III Provincial Neonatal Intensive Care Units are housed.

The second methodology was qualitative and consisted of an ethnography entitled “A Multiple Case Study of the Children and Families in the Infant Development Program of British Columbia.” This study examined experiences of parents with developmentally at-risk children or with special needs identified by age five years old. This study complemented the quantitative population-based study in its seeking to identify the barriers for full social inclusion through the analyses of the information shared by parents through focus groups and interviews, and through the examination of children’s files in the Infant Development Program (IDP) of BC. Not only did the findings of the multiple case study concur with the population-based study in terms of the recurrent medical treatments and health needs of developmentally at-risk children through the years, but it pointed out how systemic issues in early intervention service provision that eventually lead to the social exclusion of young children and their families (e.g., inconsistent or inaccurate professional information for parents about their child’s condition and treatment; lack of referrals for assessment and therapy services; limited accessibility to support programs; limited availability of recreational activities, among others) are exacerbated through professional models of service inspired in “medical models,” and that, although presenting themselves as child focused, they depart

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4 The study was this project research coordinator’s dissertation, defended on September 11, 2008 (Reference: Pighini, 2008).
from family-centred approaches. On the contrary, early intervention models like the one presented through IDP of BC supported parents in readily identifying their children’s needs and their needs as a family and to actively reach out for the treatments, programs and activities they required. In sum, parents were ready to advocate for their children and demand the services needed when given the opportunity. Moreover, the study identified that parents with children who do not receive diagnoses associated with special needs health and/or educational categories, termed in this study as children in the “grey area,” continue to live under stress and pressure in anticipation of unexpected difficulties their children may encounter as they grow older and enter the school system.

Understanding the long-term health and medical needs of at-risk children confirmed by the preliminary findings of the population-based study, and incorporating the powerful message relayed by the parents who participated in the multiple case study, provided the necessary elements to develop the framework for the deliverables component of the Social Inclusion Project. Using a similar model of consultation to that of the case study, the “deliverables” project coordinator worked in consultation and in collaboration with parents, professionals, practitioners and academics representing a variety of agencies and institutions in 15 communities of BC’s Lower Mainland. This work received the joint guidance of the project director and of the community partner agency, and ongoing collaboration and support of the “research” project coordinator and administrative assistant. The series of tools and materials that were compiled and integrated were the result of these multiple collaborations and associations.

The main goal in this process of “building community capacity” was to ensure that the materials being developed would be representative of the needs of the parents and service providers in the BC Lower Mainland communities. Maintaining this purpose and rationale in mind gave way to the conception of a framework that paid attention to both the needs and the assets of children, families and communities. Bronfenbrenner’s ecological model, represented in concentric circles that indicate how each “layer” is embedded into the next one, provided such framework represented in the “microsystem” (child); “mesosystem”

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5 Bronfenbrenner (1979, 1986, 2005)
(family” and “exosystem” (community). This process is further explained in the following section entitled “Phase 2: Creation and dissemination of information from Phase 1.”
PHASE 2: CREATION AND DISSEMINATION OF INFORMATION FROM PHASE 1
Materials and resources included the following:

1) A set of questionnaires for parents of developmentally at-risk children with and without
identified special needs. These questionnaires aimed to support parents in their
identification of the specific needs of their children from a developmental and a
relational perspective; that is, the child in the context of their family and of their
community. Three different sets of questionnaires were compiled, following
Bronfenbrenner’s ecological model:
   a. The “microsystem” questionnaires were entitled “You and Your Child.” In
      addition to helping parents understand where their child is throughout the
different birth-to-age 6 stages in the developmental domains (e.g., physical,
      motor, language, cognition, social and emotional and self-help), the
      questionnaires include items that supported parents in reflecting upon the
      unique gifts and talents of their children. A final section includes one sheet set of
      questions for doctors and other professionals. Parents may use these questions
      as ‘springboards’ in formulating their doubts and concerns when consulting with
      health and medical professionals.
   b. The “mesosystem” questionnaires were entitled “You and Your Family.” Items in
      these questionnaires invite parents to reflect upon, identify and select home and
      other family-related issues (with their partners, with the child’s siblings) that they
      find challenging and that contribute to daily stress in raising a child who
      experienced risks at birth, who may have developmental challenges or with
      special needs.
   c. The “exosystem” questionnaires were entitled “You and Your Community.”
      These questionnaires support parents in the identification of resources,
      programs and activities in their particular community that promote full social
      inclusion for their children, and find out what levels of programs, activities or
      resources they are missing or have less access.

2) A set of “mesosystem” and “exosystem” questionnaires for service providers
   supporting them in the identification and recognition of their assets and needs when
working with specific families (You and Your Family) and with the communities they are assigned (You and Your Community). The purpose for this set of tools was to empower service providers in their work with families by (a) providing them with tools to individualized services for families, (b) providing them with information on what are the resources, programs and activities they count on in their community; and, (c) identifying those resources, programs and activities that are not accessible or available so that they can fully meet the information and service needs of their families.

a. The “exosystem” questionnaires for parents and for service providers include an “online” submission tool with an entry to the users’ three-digit postal code. This will allow for future tracking of individual (anonymized) responses relating to parents and service providers’ level of accessibility to services in their individual communities (please refer to section 3, “Follow-Up Plans.”)

3) Information about the 15 different communities representing the first point of access for help for parents and service providers where they may communicate the challenges and difficulties they experience with their children.

4) Lists of professionals and agencies and the services they provide for specific issues, conditions and diagnoses related to developmental risks and special needs, and

5) Lists of resources and materials expanding on information on these specific issues, conditions, and diagnoses.

6) A free, not-for credit, online course with in-depth information on the following topics related to early child typical and atypical development and early intervention, written in lay terms for parents and early child/special needs/early intervention service providers. The course includes:

a. Background and description of developmental risks associated with biological, hereditary, environmental and social and emotional factors.

b. Early intervention strategies and programs related to specific conditions and situations/experiences of developmentally at-risk children and of children with special needs.

c. Information for parents and service providers on the rights of children and of legal aspects related with service provision for children with special needs.
The materials and resources described in this section have undergone a rigorous process of consultation, editing and multiple revisions following the feedback and comments of all the individuals and agencies involved in their creation and compilation. This process has taken almost two years and has included numerous one-to-one consultation sessions (in person; through email; over telephone conferences), as well as group and community presentations, workshops and paper and poster sessions in local, national and international conferences.⁶

Public and/or academic presentations have been conducted since the very beginning of the project. These have included local, provincial and International presentations that have been individually listed in the quarterly reports (2006-2008). Academic presentations continued to be scheduled as this final report is completed. At the same time, manuscripts are in process with individual papers reporting the preliminary findings of the population-based study, of the qualitative case study and of the overall project.

⁶ See Appendix B for the SDPP quarterly reports dated April 15, 2006 to December 15, 2008
1) PRODUCTS OR OUTPUTS FOR OBJECTIVE 2: KNOWLEDGE CREATION AND DISSEMINATION

The products or outputs followed the originally proposed format, in that they represented a combination of online and printed materials developed and introduced to the communities as follows:

1) A series of preliminary presentations/group discussions were conducted with community members who were participating in The CHILD Project (one of the partner projects for this project) and with agency umbrella organizations including the Developmental Disabilities Association. The proposed project was outlined in these discussions and invitations were extended to these group’s participants to collaborate, brainstorm and provide feedback to the research and deliverables team members.\(^7\) Handouts and flyers were distributed in these sessions that (a) described the Social Inclusion Project; (b) invited those attending the session to leave their name and contact information to either obtain further information on the project or to be contacted to provide their feedback throughout the process of creating and compiling the deliverables. The list of contact names was gradually entered into a database that was later on used throughout the different dissemination stages of the project.

2) The research coordinators consulted with community health representatives and Infant Development Program of British Columbia regional program coordinators, as well as with staff from other early child development programs in different communities in the Lower Mainland, for example, Supported Child Development Programs and Child Development Centres, about the primary additional language needs.

3) Considering the needs of immigrant and dual-language families in the selected communities in BC’s Lower Mainland, five languages were identified for translation. The first three languages selected included Traditional and Simplified Chinese, Punjabi and Farsi. Vietnamese and Spanish were identified as the next two languages for questionnaire translation.\(^8\) (Note: In follow-up meetings with representatives of other communities representing the Fraser Health Authority, Korean, Japanese and Arabic were brought up as suggestions for future translation.)

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\(^7\) See Appendix B for SDPP quarterly reports dated April 15, 2006 to October 15, 2007
\(^8\) Source: BC Statistics Community Profiles (2008)
4) Under the guidance of the IDP Provincial Advisor and the IDP Regional Coordinators, the project’s research coordinators targeted three pilot communities in the Lower Mainland (the city of Vancouver’s North Health Unit area, the cities of North and West Vancouver, and the city of Richmond). The rationale behind this selection was that these three communities have implemented early intervention/early child development hubs and have regular meetings or “roundtables” that would facilitate the dissemination of this pilot phase of the project. The program coordinators in these communities volunteered to try out the resources and assist the project coordinators in contacting other agencies and programs working with early child development and early intervention between birth and age 6 years. These included representatives from Aboriginal Infant Development Programs, Supported Child Development Programs, Child Development Centres and the corresponding Community Health Unit (Ministry of Health), and representatives from the Ministry of Child and Family Services (MCFD), among others.

Local community health units were identified as the first point of online access for users of the web-based resource, following the BC Ministry of Health’s mandate, and considering that offices are locally staffed to address the needs of the residents in each community. This decision was taken upon the recommendation of the IDP Provincial Advisor, and in consultation with representatives from the community health units in both the Vancouver Coastal and Fraser Health Authorities. A healthcare interactive locator was created for users to click in according to their postal code and access information corresponding to their geographical area. This feature has enhanced the value of the project deliverables in that it facilitates users in their search for early child development, early intervention, and other family-related resources. At the same time, access to the healthcare locator is expected to streamline referrals requested by parents and service providers; health unit offices will forward their calls and inquiries to the most appropriate resource, agency or program according to the ages and/or needs of their child/children. In the absence of a similar contacting mechanism, contacts would be mainly directed to the IDP program(s), therefore adding an unnecessary burden for these local programs. This information has been also made available in printed form (please refer to point # 7).

Josh Beailieu, RedFive Marketing (Consulting for HELP)
5) Revised versions of the questionnaires (including translations into Chinese (Traditional and Simplified), Punjabi and Farsi) were uploaded to HELP’s website under a provisional URL that was active, but not yet populated for public use. \(^{10}\) A contact email for the project coordinators and administrative assistant helped maintain ongoing communication with the pilot users of the website. (Note: technical difficulties with the first server utilized slowed down this process for the first three months. The server has since been changed and communication with users is ongoing through the current email addresses: Mari.Lara.Ginny@ubc.ca and sdpp@help.ubc.ca.

6) The project delivery coordinator established contact and/or scheduled presentations with IDP program coordinators, other early child development representatives and health units in these communities between September 2006 and April 2007. These presentations focused on the deliverables of the project and guided pilot users in the navigation of the URL. The research coordinators invited pilot users to send in their feedback and comments about: the final presentation, wording (targeting grade 4 to grade 6 reading level) of resources; the setting, format and layout of the website, and corrections/edits to contact information and resources. \(^{11}\)

7) Following a successful pilot stage with the three identified communities, and having completed the revisions that users indicated, the URL was populated. The project director and coordinators announced the official launching of the SDPP website in late spring of 2007. \(^{12}\) Twenty-five presentations to the remaining communities followed through 2007 and 2008. \(^{13}\) These presentations followed a similar format to the previous ones. They included the following: (1) sessions at specific agencies (like IDP and AIDP Programs); (2) roundtable meetings (with early childhood educators, Special Needs and Early Intervention representatives from health units, child development centres, Supported Child Development Programs; Ministry of Child and Family Services); and (3) coalitions or larger organizations (e.g. First Call BC; BC Council for Families; Board of Directors of the Child

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\(^{10}\) URL: www.earlylearning.ubc.ca/sdpp

\(^{11}\) See Appendix B for SDPP Quarterly Reports dated January 15, 2007 and April 15, 2007

\(^{12}\) See Appendix B for SDPP Quarterly Report dated July 15, 2007

\(^{13}\) Burnaby, Delta, Surrey/White Rock; Langley; Abbotsford, Ladner, Maple Ridge, Tri-Cities (Coquitlam, Port-Coquitlam, Port-Moody), and Chilliwack
Development Centres Association and Representative for Child and Youth; Developmental Disabilities Association).  

8) A separate set of presentations were scheduled with the network of public Libraries, following an initial, brainstorming meeting with representatives of the Vancouver Public Library (Main) Public Relations and Child Division departments. Suggestions for dissemination from the VPL included their adding an online link to their website, including samples of printed material (in binder format) to their collection and adding brochures introducing the project to the public.

9) A printed version of the online material was developed soon after the population of the website, and with the assistance of a graphic designer. The printed version was assembled into a three-ring binder format with a similar format to the online material (see attached). The printed material underwent a consultation and revision process similar to the online material uploaded on the website. A first printed version was available for the pilot communities and larger agencies/organizations in October 2008; a revised and updated version has been available as of December 2008. At the same time, updates and revisions to the online and printed materials have been uploaded to the website for easy access and download by users. This revised printed version has been made available to the programs and agencies listed in this report (numbers # 3, 4 and 6 in this section); copies will be also available for agencies listed in number # 7 of this section.

10) Following suggestions and recommendations of our partner programs in the IDP, and of other early child development and early intervention professionals in the health and social work professions, the last group of contacts and presentations have targeted the following programs, agencies and communities (via electronic and/or personal contact):
   a. The 15 school boards in the Lower Mainland communities (contacting Counsellors and Special Needs or Resource Teachers);
   b. Strong Start Programs
   c. Early Childhood Educators of BC (ECEBC)
   d. BC’s College of Physicians and Surgeons

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14 See Appendix B for SDPP Quarterly Reports dated July 15, 2007; October 15, 2007 and December 15, 2007
15 Juan Carlos Partidas Graphics Design
e. BC Pediatric Association
f. BC Child Healthy Alliance
g. Affiliation of Multicultural Societies and Service Agencies of BC
h. Family Services of Greater Vancouver

11) Promoting and support materials for presentations have included the following (see attached):
   a. A one page flyer, sent electronically and with print copies available
   b. A PowerPoint presentation with hyperlinks to illustrate the online materials
   c. A brochure to be distributed in agencies and offices including libraries, neighbourhood houses, doctor’s offices
   d. A sample copy of the binder containing the printed information uploaded on the website
   e. Samples of books (for parents, children and service providers) listed in the Resources section of the online/printed materials

12) The framework for the early intervention online course (# 6, section 1) has been developed in consultation and collaboration with a consultative committee. The course consists of four separate modules that introduce parents and service providers to the topic of early intervention for children from birth to age 6 years old. The modules provide an overview of typical and atypical development and introduce essential concepts in child development such as bonding and attachment. The notions of risk and resiliency are introduced from a multi-risk perspective (biological, hereditary, environmental, social and emotional). The section covering early intervention strategies and resources is consistent with the holistic perspective of the introductory modules, and includes models of intervention addressing conditions of biological and/or hereditary, environmental, social and emotional, and the inter-connections and inter-dependability among them. An important component of the course is a detailed section on children’s rights in reference to treatment and services provided to address their unique developmental needs. This component provides parents and service providers with important and up to date

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16 El Khatib, L. & Stewart, M., manuscript in progress
17 T. Brown, Supported Child Development Program; D. Brynelsen, IDP of BC, H. Goelman and M. Pighini, HELP/UBC.
information that is presented in lay terms. The contents in the modules of this course are consistent with the information uploaded on the website for parents and service providers. In this way, course users may navigate through the modules and connect with links that are common for the website and course when exploring specific child development issues, particular developmental conditions or relevant resources (please see attached document).

1. Outcomes of the Project/ Examples

The project’s multiple outcomes will be described in its separate research and deliverables components.

Research Component: The preliminary findings of the population-based study entitled “An Interdisciplinary Study of the Trajectories of At-Risk Children and Their Families” have alerted academics in research units/universities, professionals and community agencies working with at-risk children and their families of the long-term consequences observed for BC children in terms of their frequency of access to hospitals for treatments, especially flagging the high number of premature and very- to severely- low birth weight children living in rural areas. These findings are compelling and reiterate the need for further exploration of these children’s trajectories, and especially looking into the impact of such health trajectories in their developmental and educational performances. Such findings make a strong case for the need to complete data linkages between the children’s health and education files through anonymized procedures. This study is one of the first of its kind and has been identified as a “Case” or “Model” study among a group of data-linkage studies that await permission to proceed with data linkage. The study has received the overwhelming support of academics and professionals in Canada and internationally, in local presentations and conferences (e.g. Edudata Forum; HELP May Research Days; CCHR Research Day; Early Years Conference), and in international meetings; for example, Zero to Three Communities Building and the International Society of Early Intervention Conference.

18 These data linkages were already approved by the BC Ministry of Education; however, they await the permission of the BC Ministry of Health.
The findings from the qualitative study entitled “A Multiple Case Study of the Children and Families in the Infant Development Program of British Columbia” have promoted further discussion and brainstorming sessions among program coordinators in the IDP of BC. Interactive presentations sessions have been scheduled with the author21 in order to re-examine their programs’ practices, following the recommendations of the study to enhance and solidify their family-centred approaches as a means to empower parents participating in their programs. The findings of the study support ongoing funding of family-centred programs providing a seamless continuum of services for families with children with special developmental needs. Two agencies who are currently involved with their yearly funding process through grant proposal writings have included the findings of this study in their references. Likewise, the population-based study has been shared with audiences attending the national and international sessions listed earlier.

Deliverables Component:

1) Online and printed resources: Since it’s piloting in 2007, the online resource has been welcome among community professionals working with parents during home-visits and has been utilized it as a reference point within their agencies. The resources for parents (microsystem, “You and Your Child” and mesosystem, “You and Your Family”) contain confidential information and have been uploaded in printable formats for parents to consult with their family doctor and/or any other professional working with the family. However, the exosystem component (e.g. “You and Your Community”) of the online resources allows for online submissions that are tracked down by 3 digit postal code so that the responses can be analyzed by topic and subtopic. Community members attending the presentations on the Social Inclusion Project are gradually incorporating the use of this tool in their practice, as they navigate through the website and better understand the information available. To-date, there have been a total of 465,760 visits to the website out of 1,913,709 (100%

20 See Appendix B for SDPP quarterly report on October 2007 and in April 2008.
21 Pighini (2008)
successful) hits. The average number of visits per day is 692, with users accessing the “physical development” section of the “You and Your Child” (microsystem) questionnaire the most; e.g. “most popular page”. An indicator of the success of the website is the substantial number of repeat users (27%, with an average of 4.57 visit times for each one of them) and the average time spent being 15 minutes per visit. A total of 331 emails from professionals in community agencies seeking additional information have been sent to either the contact address on the website, or to the project coordinators’ contact email following presentations and introductory letters. Other responses providing feedback about users’ experiences have been provided following presentations or in personal communication; for example, “I am really interested in this resource, could you please provide me with more information about the ‘exo’ questionnaire?” (email from a physiotherapist working in a Child Development Centre in Abbotsford, BC).

The printed resources in a binder format have recently been released to the public. As cited in number 7) of the previous section, the first release was in October 2008 with approximately 50 binders shared among IDP program coordinators, AIDP/SCDP Program Advisors and other contact professionals and staff who were part of the pilot stage during the dissemination stage of this resource. These included the Children’s Division at the Main Vancouver Public Library and the Community Nurse acting as the central contact for Community Health Unit distribution, among others. Having incorporated two additional languages (Vietnamese and Spanish) and edits generated through a feedback process with users of the binder in its pilot phase, an additional 105 copies of the revised binder were printed in December and are currently in the process of distribution to the agencies listed above. Approximately 800 brochures with basic information about the project have been distributed in public libraries, neighbourhood houses and health units. The printed version (binder format) is already generating a similar type of response; for example:

“I am really enjoying this resource when conducting home visits with parents; if they have a developmental concern about one of

their children, we can go over the child development questionnaires and fill it with them; later on, in my office I can navigate the website and find more information that is relevant for this family” (Family Counsellor, Family Services in Vancouver). “

And,

“My sister did find the binder useful; she found information (about autism for her child) that was not in another resource that the (staff at hospital) had given her” (sibling of parent in Vancouver, BC).

The staff in different Infant Development Programs have welcomed the online and printed materials as a central or “one-stop” resource that supports their work with families in home-visit and centre settings. In addition, IDP Program coordinators in other BC regions (e.g., North, Interior and Vancouver Island) have reported about their staff are accessing and using some of the online resources when working with families, and finding these materials “incredibly helpful”.

2) Early Intervention (EI) Online Course: The EI course was conceived as resource for parents and professionals (including infant consultants, preschool and Early Primary teachers, social workers, community nurses, and child and family counselors), and includes two levels of training. The first level corresponds to a summary of essential information for each one of the topics and subtopics covered in each module. Each sub-topic allows users to expand on information and level of depth according to their interest level and needs. The second level in the online course will also contain links to other references and to examples of the original sources of documentation and research for the corresponding topic (e.g. online articles and reports) for those users who utilize this course as a component of their professional training. The IDP, AIDP and SCDP Provincial Advisors and program coordinators have identified the EI course as a priority among the deliverables of the project in the following capacities:

a. As a training tool for beginning consultants

23 Personal communication, Mary Stewart, IDP Regional Advisor, January 19, 2008
24 Personal communication, Dana Brynelsen, IDP Provincial Advisor, January 19, 2008
b. As a professional development tool for consultants at any level

c. As a source of information and development for parents of children receiving their services, and for any parents in the Lower Mainland (or any region) in BC in terms of issues in typical and atypical child development, children’s rights, and instruction on early intervention strategies, resources and professionals delivering these services.

The online course provides information presented in text, audio and video clips, and hyperlinks. The content includes a combination of short descriptions with headings, case scenarios and “test your knowledge” formats. The final version of the online course is still in production, pending the final write-up in a language that it is both professional and friendly to users. (Note: The section of this project describing future plans includes statements about the follow-up plans for this course.)

2. Number of Individuals Impacted/Examples

**Background:** Current research based on health population statistics has determined that approximately one in five individuals (or approximately 20%) of any given population will require additional physical/mental health support over their life course; that the onset of conditions precluding these needs manifest during their early years; and that this proportion of the population will access up to 60% of their society’s resource (in this case, health and mental health).  

Disability indexes in North America report approximately 5-10% of children (birth to 18) being limited with at least one developmental/physical disability. In Canada, survey reports cite 2% of children age five and under with established disabilities, with numbers increasing to almost 5% between age 5 and age 9 years old. These statistics do not include children with mental health issues requiring mental health services, which, according to Waddell, Ewan, Shepherd, Offord, & Hua (2005), approximate to 14% of children who “at any given time experience significant mental disorders.”

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25 Boyce (2007)
26 Wenger, LaPlante & Kaye (1996)
28 As cited in Children’s Mental Health Research Quarterly Vol. 3, No. 1, p.3
Findings from the two research studies comprising this project confirm the reality of children and families requiring ongoing health, developmental and educational, social and recreational services, with approximately 11% of Canadian children experiencing developmental delays in one or more domains between the ages of birth and 3 years. In particular, findings from the multiple case study revealed parents’ immediate need to obtain information about their child’s condition(s) and their expected developmental patterns that is both current and accurate; that is linked to resources they can access within their areas of residence; and that provides them with tools that empower them to identify their needs within their families and in their communities.

BC and Lower Mainland statistics: The target audience and users of this project are parents with infants and children birth to age six years who are at risk for developmental delays or identified with developmental disabilities, and service providers working with them. Census information in BC and IDP/AIDP and SCDP programs’ statistics reveal the following information about the total number of children and families targeted through this project. As progress continues in the dissemination process, these are families and service providers who are impacted through both the findings of the research involved in this project and the deliverables above described:

a. Over 2,200,000 residents live in the 15 communities/areas that were identified in the Lower Mainland for the Social Inclusion Project.

b. Of these 2,200,000 residents, approximately 700,000 residents are identified as families, with an average of 3.1 members per family.

i. The number of children under age 6 years in these communities corresponded to 130,229, with 125,375 under age five, and 4854 children entering Kindergarten at age 5. (Note: Approximately 200,000 children in BC are under age five, with children birth to age four years comprising approximately 5% of BC’s population)

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29 Goelman, Synnes, Hoube, Lisonkova, Pighini & Li (2008)
30 Pighini, (2008)
c. Based on these regional statistics, 10 - 15% of 130,000 children (approximately 20,000) and their families living in the 15 communities within the Vancouver Coastal and Fraser (North and South) regions in BC will be considered to be at risk (with established or suspected risk) in one or more developmental areas, including physical, motor, cognitive, language, social and emotional. The project aims to reach all of these children’s parents.

d. More specifically, the IDP of BC program statistics report their program staff having contact with over 3500 infants and young children ages birth to three years old who are residents in these 15 communities, and are referred to their program because of established (or identified) and/or suspected risks (biological, social and/or environmental)\(^34\). These infants correspond to approximately .3% of the population of children under age five years in these selected communities.

i. The Aboriginal Infant Development Program AIDP houses 12 programs in the area that corresponds to these communities within the Vancouver Coastal and Fraser regions (Health Authorities); the AIDP program statistics include data on Aboriginal children and families.\(^35\)

e. The number of staff in IDP programs serving families with children ages birth to three range between 8 and 10 consultants per program in the 15 selected communities. The range of reach of IDP consultants varies between 1:30,000 and 1-70:000 to the total number of residents in their community. The current caseload for IDP consultants in the Vancouver Coastal Region is 1600 children/families; for the Fraser Region, the caseload is up to 2385 children/families, with a total of 3985 children/families served through the IDP programs in these two regions. Presently, the online and printed resources have been made available to regional and program coordinators in these areas, and continue to be distributed among program consultants. At the same time, IDP consultants work in collaboration with AIDP and SCDP consultants serving these regions and who have also made available the online and printed resources.


\(35\) Source: Office of the Provincial Advisor, Infant Development Program of BC (2005-2006)
f. The Supported Child Development Program (SCDP) latest statistics report having served 8,994 children in 2007/08 in BC, with 68% of these children between the ages of birth and 6 years, and with 1,239 families waiting for services. At least 11% of families identify themselves as Aboriginal. The regional advisor for the SCDP Vancouver Coastal region oversees consultants working in 8 centres and the regional advisor in the Fraser region oversees consultants working in 8 centres.\(^{36}\) The total number of consultants in these areas totals 111 at the time of this report.\(^{37}\) (Note: No specific information was available with regards to the number of children in the specific communities where this project is based).\(^{38}\)

i. Approximately 60% of the children followed by SCDP would have also been previously serviced through the IDP/AIDP between birth and age 3 years. Almost 30% of these children would have had an established developmental condition at the time of referral to IDP; whereas the remaining 30% would have received a medical/developmental diagnosis --or a referral for diagnosis by age 3 years, at the time of discharge.\(^{39}\)

g. The total number of agencies and programs identified per community serving young children and their families exceeds 200 \(^{40}\) including the following:

i. Health units (at least 2 per community)

ii. IDP/AIDP/SCDP (at least one program per community of each program)

iii. Public library systems (one per community; with several branches in each community)

iv. School district systems (one per community; targeting Elementary school and Strong Start Programs)

v. Neighbourhood houses/community centres in each community

\(^{36}\) Source: Suported Child Development Program, December 2005 Statistics

\(^{37}\) Personal communication, Tanya Brown, SCD Provincial Advisor, January 22, 2009

\(^{38}\) Personal communication, Tanya Brown, SCD Provincial Advisor, January 22, 2009

\(^{39}\) IDP Program Statistics, 2005-2006

\(^{40}\) Please see Appendix C for the SDPP Project Database
vi. Provincial Agencies and Associations including Early Childhood Educators of BC, Family Services agencies and the Affiliation of Multicultural Service Societies of BC, among others.

3. Summary: Overall Impact of Project and Follow-up

The Social Inclusion Project will be reaching parents of approximately 200,000 children under age six years living in the 15 Lower Mainland communities and service providers for young children and families in over 200 local, regional and/or provincial agencies. The open definition of “at-risk” utilized in this project in terms of the child development and child characteristics information (microsystem) available for parents and service providers will translate on these resources being of interest and benefit for the following users:

1) At the family level (mesosystem): Any parent of children between birth and age six years who has concerns about their child/children’s development throughout these ages and stages, with an estimated 15-20% children with either established or suspected developmental risks requiring some type of intervention or special needs shortly after school entry.

2) At the service provider level (exosystem):

   a. Early child development consultants and teachers, primary teachers, child and family counsellors, child care and family workers, social workers, physicians including family practitioners, pediatricians and child psychiatrists, as well as other mental health professionals and community health nurses involved with families with young children who have expressed their concerns about risk factors impacting on their development; and,

   b. Program advisors, program coordinators, school administrators and agency managers interested in the following: (i) expanding their knowledge, information and professional training in the areas of child development (typical and atypical); and, (ii) utilizing the information derived from users’ responses in advocating to their local, regional and provincial government representatives in improving the access to- and upgrading the resources available for- their programs/agencies in their specific communities (macrosystem). By including parents and service providers, the impact of
this project expands its interventionist mission related to early intervention and follow-up with a preventative component. The inclusion of such preventative component represents a response to the findings and recommendations of both the population-based study\textsuperscript{41} and of the multiple case studies\textsuperscript{42} conforming the research component of this project. The preliminary findings of the population-based study point at a significantly higher proportion of at-risk children who have been admitted to Neonatal Intensive Care Units, with or without established diagnoses at birth or soon after, requiring hospitalization more often and for longer periods of times than their non-risk counterparts. The findings of the multiple case study included the experiences of parents of children with suspected risks, or in the “grey area” who do not have a diagnoses or specific “special needs” label; these findings revealed how information about services and resources was limited or inconsistent for the parents of these children, and that without a specific diagnoses available, they have limited accessibility to the existing programs.

In terms of dissemination of the project’s research findings and deliverables, this project has utilized the support from the Provincial Advisor, Regional Advisors and program coordinators from the IDP of BC, in collaboration with community-based Provincial Advisors of the AIDP and SCDP of BC and their staff working. The dissemination has consisted of a combination of community and academic presentations, flyers, brochures, telephone conversations and teleconferences and electronic correspondence. Community agency presentations have included the introduction and explanation on how to use the binder that replicates the online materials. A copy of the binder has been made available to each of the programs/agencies. Approximately 50 presentations have been held to date. Many of these presentations included delegates representing several partner or networking agencies. As previously mentioned, given the high demand for these materials an additional 105 binders were made available for these and other agencies that were contacted for this program. They were distributed throughout January 2009.

\textsuperscript{41} Goelman, Brynelsen, & Pighini (2007); Goelman et al., (2007, 2008)
\textsuperscript{42} Pighini & Goelman (2007); Pighini (2008)
4. Follow-up Plans

1. Summarized reports deriving from this final report have been --and will continue to be-- made available to the community agencies listed. The reports will describe and offer the following:
   a. Updated descriptions of the project deliverables
   b. Research findings and statistics that can be quoted in their reports to the government agencies that have provided supervision and/or funding
   c. Principle Investigator and Research Coordinator contact information (telephone, email, mail) in case clarification or additional information is needed by the agency.

2. Academic reports, presentations and publications continue to be presented to local, national and international conferences and journals

3. Follow up includes future research and expansion of project deliverables (which will require additional funding):
   a. Considering the warm reception the findings of this project’s research studies and deliverables received, three follow-up activities have been outlined:
      i. An invitation to participate in subsequent research will be extended to the members of the community agencies previously listed. This research will consist in the examination of the electronic records showing online tallying of the responses to the “exosystem” or “You and Your Community” questionnaires. For example, identifying and comparing the presence of and access to resources, activities and programs among the different communities according to the number of responses (“Yes,” “No” or “Not Applicable”).
      ii. A proposal submission (already in process) to develop an academic version of the online Early Intervention Course that it is offered for

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43 IDP Programs, Simon Fraser Society for Community Living (Tri-Cities, BC), Human Early Learning Partnership
44 See Appendix D for the SDPP Seminal Publications
45 This will require applications for additional funding from non-governmental organizations and/or from Provincial/Federal grant sources
credit through diploma and graduate studies (master's level) programs through a post-secondary institution in British Columbia.

iii. An invitation to community government and non-government operated agencies in other BC regions to participate in documenting their access to services, so that the online and printed materials may include the following:

1. An expansion of the services and resources in every BC region, including the Fraser, Interior, Vancouver Island and Northern regions.

2. An interactive healthcare locator for communities in each region.

3. Materials and information that are particularly relevant to service providers and families residing in these regions. For example, based on the preliminary findings of the population-based study on the trajectories of at-risk infants and children, health needs of at-risk children and their families living in rural communities appear to be different than those of children living in rural areas in BC, with a proportion of almost 2:1 rural vs. urban at-risk children hospitalized over time (between birth and age nine years).

4. Considering the availability of data deriving from the findings of both studies where children are followed up to their primary school years (between the ages of eight and nine years old), and the importance of research documenting the crucial stages of development after the “early intervention” stages, develop and compile resources for parents of children in two additional age categories, including 6-9 years old and 9-12 years old, also referred to as the “middle” years.46

46 Schonert-Reichl and collaborators (2007)
5. Effecting Change for Canadians

The social inclusion of at-risk children and families is an issue that continues to require the attention of government and of society in general, both nationally and internationally. The individual characteristics of the Social Inclusion Project are such that this project can effect change for Canadians living in BC’s Lower Mainland, and, as described in the follow-up plans, throughout the whole of British Columbia. The ways in which this project effects change will translate into beneficial outcomes for Canadians include the following:

1) The project’s early identification/intervention approach; its conception through multi-methodological and interdisciplinary research; and, its structuring through multi-stage deliverables. The integration of these three aspects allows Canadians including parents, service providers, administrators and government representatives, to identify concrete strategies and find solutions to bridge the obstacles preventing the full inclusion of children who are developmentally at-risk and/or with special needs within their communities.

2) The value and the importance of such strategies leading to solutions lay in the fact that these are not externally imposed. These solutions are being self-generated through the voices and the opinions of parents (child or microsystem and family, or mesosystem) and service providers (community and administrative levels or mesosystem). Hence, they are the product of a consumer-oriented model of services --a model that has proven highly effective within the social services.

3) Moreover, the deliverables of this project were informed through cutting-edge research at a population-based level and through rigorous qualitative, participatory research. It is the integrity of this research and the importance of the current findings that invite the ongoing examination of the barriers for social inclusion and how to aim for the full social inclusion of all Canadian children who are developmentally at risk and their families, for the benefit of Canadian society.

47 e.g. Glass (2006); Micklewright (2002)
48 e.g., Collins, Lemon. & Street (2000)
6. Opportunities for Work with Different Levels of Government

Given the project’s participatory and collaborative characteristics throughout the different stages, and as a result of both the research and deliverables components, the Social Inclusion Project represents an informing tool of inherent democratic value for government officials in BC’s Lower Mainland. More specifically, the information collected in the project’s deliverables translates for users—and transmits to government officials and representatives—the actual and current needs, characteristics, assets, challenges and obstacles that community residents in BC’s Lower Mainland face on a daily basis as they take care of their own children, in the case of parents and relatives of developmentally at-risk children, or the children and families they work with, for service providers. The two-fold nature of this project, i.e., research to practice, allows for representatives of different government levels to make use of this information at the municipal, regional and provincial levels in the following ways:

1) The findings on the studies comprising the research component of the project reveal precise information on the health and developmental paths of at-risk children from birth and into their primary school years, and especially when compared to their non-risk counterparts. The preliminary results of the population-based study already point to the need for ongoing provincial funding that supports a system that can ensure the continuous provision of regional health services, particularly those require hospital treatments, and especially for rural areas in BC where the proportion of medical services use by at-risk children is significantly higher than in urban areas. These data was consistent through all provincial regions, including the Fraser and Vancouver Coastal where this project was focused. The findings from the multiple case studies reaffirm parents’ rights to advocate for seamless services at the municipal and regional levels that meet the individual needs of their children in terms of health, development and education requirements.

2) The information collected during the development of the deliverables component of this project confirms the needs of community agency representatives for—and intentions of—utilizing both the research findings and the resources within the deliverables’ component as part of their ongoing documentation within their agencies and/or programs. The objective for
this documentation aims to draw on the information for planning, implementation and advocacy purposes in one or more of the following scenarios: (a) when renewing contract agreements between non-governmental and governmental agencies (municipal, regional and/or provincial); (b) when seeking additional funding for specific programs, as identified through questionnaire responses of users (micro, meso or exosystem levels); (c) when disputing budget cuts to specific programs, using the research findings and the information from users as evidence-based supporting information for their request.
REFERENCES


Research Network (DHRN) International Graduate Student Conference, December 6, 2007, Vancouver, BC.


APPENDICES
Appendix A: Early Childhood Intervention Four Module Course Outline

For children ages birth to six years, their families and service providers

1. **MODULE ONE**: Early intervention and child development

   1.1. Rationale, goals and objectives for the course
   
   This is a gentle introduction to the course. It briefly describes child development (e.g. infant mental health, the nature/nurture interplay), special education and early childhood intervention. It will also be stated, in this section, that the entire spectrum of disorders is covered, from severe and profound delays to children who fall in the gray area. It will also be made clear, in this section, that there are no quick fixes and easy solutions to any of the disorders that some children may have.
   
   This section allows the user to know what he/she can learn from the course.

   1.2. What is early intervention and why is it important?

      1.2.1. Introduction
      
      1.2.1.1. Charter of the rights of the child: this is a brief description of the charter of the rights of the child, including Canadian and U. N. laws.
      
      1.2.1.2. Inclusion laws: this is a brief description of inclusion laws as they pertain to early childhood, in Canada.
      
      1.2.1.3. Early childhood education laws: this is a brief description of early childhood education laws and what these laws mean to parents of young children.

      1.2.2. Overview of disability and its impact on Canadian culture
      
      This is a brief description of how disability is viewed in Canada and what barriers some children with special needs still experience, in certain settings.

      1.2.3. Definition of early childhood intervention
      
      This is a detailed description of early childhood intervention and what it means, to both parents and children. It will be clearly stated that intervention includes helping the child overcome certain developmental conditions AND changing and
modifying the environment in order to minimize the effect of a disability on a child.

1.2.4. Importance and necessity of early childhood intervention

This section covers the importance of early childhood intervention, especially in developmental areas where intervention is known to work. This specifically includes infant mental health and fostering children’s social/emotional development.

1.2.5. Short term and long term effectiveness of early intervention

The short term and long term effects of early childhood intervention are stated. Short term effects include having a child overcome or compensate for a disability and prevention. Long term effects include prevention and being able to be contributing members of society.

1.2.6. The effects of culture on family and disability

Canada is a multi-cultural society and different disabilities may be viewed differently by members of different cultures. How culture impacts how a family views a disability is discussed in this section.

1.2.7. The nature/nurture debate

This section covers the interplay between biological and environmental factors.

1.2.8. Overview of family adaptation (in relation to stress that may be associated with having a child with a disability):

Different families view disabilities differently. Family factors and dynamics relating to this topic are presented and discussed.

1.2.9. Concerns/special considerations for people of Aboriginal descent

This section covers how having a disability may be viewed by different families of Aboriginal descent.

1.2.10. Why is all this important, both to professionals and parents?

1.2.11. Videos/vignettes

1.2.12. Test your knowledge
1.3. What is development?

This section explains how typical and atypical development exist on a continuum and how there is often an overlap between these two parts of development.

1.3.1. Typical development

1.3.1.1. Social and emotional development

This section covers social and emotional development, how important it is for parents to meet the emotional needs of their children, and how the brain’s development could be largely influenced by how an infant is treated, in the early years.

1.3.1.1.1. A brief overview
1.3.1.1.2. Social skills
1.3.1.1.3. Emotional skills
1.3.1.1.4. Attachment
1.3.1.1.5. Temperament
1.3.1.1.6. Parenting styles (and the goodness of fit theory)
1.3.1.1.7. How development in the early childhood years affects development in the elementary school years
1.3.1.1.8. What brain development research is telling us
1.3.1.1.9. Test your knowledge
1.3.1.1.10. Videos/vignettes

1.3.1.2. Communication development

This section describes how children communicate with others. It describes the different parts of communication and how children start to communicate with those around them, long before they learn how to talk.

1.3.1.2.1. A brief overview
1.3.1.2.2. Expressive language
1.3.1.2.3. Receptive language
1.3.1.2.4. Articulation
1.3.1.2.5. Pragmatics
1.3.1.2.6. How development in the early childhood years affects development in the elementary school years

1.3.1.2.7. What brain development research is telling us

1.3.1.2.8. Videos/vignettes

1.3.1.2.9. Test your knowledge

1.3.1.3. Cognitive development

This section describes what is meant by cognitive development. It goes over basic processing skills that all children need, in order to function well in society. Such skills include reasoning, solving problems and adapting to one’s environment. Such skills also include the use of memory processes in order to learn. This section also dispels what some books may say about “stimulating young children's cognitive development”. For example, this section describes why it is much better to allow a child to learn though play, rather than be taught “how to read or recognize letters”, at extremely low ages.

1.3.1.3.1. A brief overview

1.3.1.3.2. Thinking skills

1.3.1.3.3. Pre-academic/academic skills

1.3.1.3.4. How development in the early childhood years affects development in the elementary school years

1.3.1.3.5. What brain development research is telling us

1.3.1.3.6. Videos/vignettes

1.3.1.3.7. Test your knowledge

1.3.1.4. Adaptive (self-help) development

This section describes the skills that a child needs to acquire in order to function well, in everyday situations.

1.3.1.4.1. General development

1.3.1.4.2. Typical sleep patterns in infants, toddlers and young children
1.3.1.4.3. Typical feeding/nutrition patterns in infants, toddlers and young children
1.3.1.4.4. General toileting for infants, toddlers and young children
1.3.1.4.5. What brain development research is telling us
1.3.1.4.6. How development in the early childhood years affects development in the elementary school years
1.3.1.4.7. Videos/vignettes
1.3.1.4.8. Test your knowledge

1.3.1.5. Motor development

This section describes motor development, and includes a description of the proprioceptive and vestibular systems as well. It describes how motor skills develop and where intervention is most likely to succeed, in the case of delays in the motor area.

1.3.1.5.1. A brief overview
1.3.1.5.2. Gross motor skills
1.3.1.5.3. Fine motor skills
1.3.1.5.4. How development in the early childhood years affects development in the elementary school years
1.3.1.5.5. What brain development research is telling us
1.3.1.5.6. Videos/vignettes
1.3.1.5.7. Test your knowledge
1.3.1.5.8. The development of our five senses
1.3.1.5.9. Vision
1.3.1.5.10. Hearing
1.3.1.5.11. Touch
1.3.1.5.12. Taste
1.3.1.5.13. Smell
1.3.1.5.14. How development in the early childhood years affects development in the elementary school years
1.3.1.5.15. What brain development research is telling us
1.3.1.6. The science of brain development

This section describes what is usually meant by early development and the brain and dispels some of the myths that are related to the plasticity of the brain.

1.3.1.6.1. What is research really telling us?
1.3.1.6.2. The plasticity of the brain
1.3.1.6.3. The nature/nurture debate
1.3.1.6.4. Implications for typical child development
1.3.1.6.5. Videos/vignettes
1.3.1.6.6. Test your knowledge

1.3.2. Atypical development

This section describes atypical development and keeps in line with the typical development section. It will be made clear that typical and atypical development exist on a continuum and what may appear as atypical development in one situation, may be perfectly typical, in another. This section also keeps in mind that each child is unique, each family situation is unique and each child should and can only be viewed accurately, if viewed through the family and environmental system in which he/she lives.

1.3.2.1. Social and emotional development

1.3.2.1.1. A brief overview
1.3.2.1.2. Attachment
1.3.2.1.3. Temperament
1.3.2.1.4. Parenting styles (and the goodness of fit model)
1.3.2.1.5. Discipline styles
1.3.2.1.6. Social skills
1.3.2.1.7. Emotional skills
1.3.2.1.8. How development in the early childhood years affects development in the elementary school years
1.3.2.1.9. What brain development research is telling us
1.3.2.1.10. Videos/vignettes
1.3.2.1.11. Test your knowledge

1.3.2.2. Communication development
  1.3.2.2.1. A brief overview
  1.3.2.2.2. Expressive language
  1.3.2.2.3. Receptive language
  1.3.2.2.4. Articulation
  1.3.2.2.5. Pragmatics
  1.3.2.2.6. How development in the early childhood years affects development in the elementary school years
  1.3.2.2.7. What brain development research is telling us
  1.3.2.2.8. Videos/vignettes
  1.3.2.2.9. Test your knowledge

1.3.2.3. Cognitive development
  1.3.2.3.1. A brief overview
  1.3.2.3.2. Thinking skills
  1.3.2.3.3. Pre-academic/academic skills
  1.3.2.3.4. How development in the early childhood years affects development in the elementary school years
  1.3.2.3.5. What brain development research is telling us
  1.3.2.3.6. Videos/vignettes
  1.3.2.3.7. Test your knowledge

1.3.2.4. Motor development
  1.3.2.4.1. A brief overview
  1.3.2.4.2. Gross motor skills
  1.3.2.4.3. Fine motor skills
1.3.2.4.4. How development in the early childhood years affects development in the elementary school years

1.3.2.4.5. What brain development research is telling us

1.3.2.4.6. Videos/vignettes

1.3.2.4.7. Test your knowledge

1.3.2.5. Adaptive (self-help) development

1.3.2.5.1. Sleep difficulties/concerns in infants, toddlers and young children

1.3.2.5.2. Feeding/nutrition difficulties/concerns in infants, toddlers and young children

1.3.2.5.3. Toileting difficulties/concerns for infants, toddlers and young children

1.3.2.5.4. How development in the early years affects development in the elementary school years

1.3.2.5.5. What brain development research is telling us

1.3.2.5.6. Videos/vignettes

1.3.2.5.7. Test your knowledge

1.3.2.6. The development of our five senses

1.3.2.6.1. Vision

1.3.2.6.1.1. Hypersensitivity to certain visual stimuli

1.3.2.6.1.2. Hyposensitivity to certain visual stimuli

1.3.2.6.2. Hearing

1.3.2.6.2.1. Hypersensitivity to certain auditory stimuli

1.3.2.6.2.2. Hyposensitivity to certain auditory stimuli

1.3.2.6.3. Touch

1.3.2.6.3.1. Hypersensitivity to certain textures

1.3.2.6.3.2. Hyposensitivity to certain textures

1.3.2.6.4. Taste

1.3.2.6.4.1. Hypersensitivity to certain food textures

1.3.2.6.4.2. Hyposensitivity to certain food textures

1.3.2.6.5. Smell

1.3.2.6.5.1. Hypersensitivity to certain smells
1.3.2.5.2. Hyposensitivity to certain smells
1.3.2.6. How development in the early childhood years affects development in the elementary school years
1.3.2.6.7. What brain development research is telling us
1.3.2.6.8. Videos/vignettes
1.3.2.6.9. Test your knowledge
1.3.2.7. The science of brain development
   1.3.2.7.1. What is research really telling us?
   1.3.2.7.2. The elasticity of the brain
   1.3.2.7.3. The nature/nurture debate
   1.3.2.7.4. Implications for atypical child development
   1.3.2.7.5. Implications for early intervention
   1.3.2.7.6. Videos/vignettes
   1.3.2.7.7. Test your knowledge

2. MODULE TWO: Who are the children with special needs?
   Each disorder is described in terms of the developmental areas that are likely to be affected. This section covers the profound to gray area continuum of developmental disorders and conditions. With regards to intervention strategies, this section provides a critical overview of different intervention strategies that may be available for each disorder. Conventional and controversial strategies are covered, with a clear note stating which intervention strategies are conventional and which are controversial.

2.1. Children with established risk conditions
   2.1.1. Children with genetic disorders
      2.1.1.1. Children with Down syndrome
         2.1.1.1.1. Description
         2.1.1.1.2. Intervention options
      2.1.1.2. Children with Fragile X syndrome
         2.1.1.2.1. Description
2.1.1.2.2. Intervention options

2.1.1.3. Children with other genetic disorders

2.1.1.3.1. Description

2.1.1.3.2. Intervention options

2.1.2. Children with nervous system disorders

2.1.2.1. Children with cerebral palsy

2.1.2.1.1. Description

2.1.2.1.2. Intervention options

2.1.2.2. Children with epilepsy

2.1.2.2.1. Description

2.1.2.2.2. Intervention options

2.1.2.3. Children with spina bifida

2.1.2.3.1. Description

2.1.2.3.2. Intervention options

2.1.2.4. Children with Tourette syndrome

2.1.2.4.1. Description

2.1.2.4.2. Intervention options

2.1.2.5. Children with Fetal Alcohol Spectrum Disorder (FASD)

2.1.2.5.1. Description

2.1.2.5.2. Intervention options

2.1.2.6. Children with brain injury

2.1.2.6.1. Description

2.1.2.6.2. Intervention options

2.1.2.7. Children with other nervous system disorders

2.1.2.7.1. Description

2.1.2.7.2. Intervention options

2.1.3. Children with pervasive developmental disorders (PDD)

2.1.3.1. Children with autism

2.1.3.1.1. Description

2.1.3.1.2. Intervention options
2.1.3.2. Children with Asperger syndrome
   2.1.3.2.1. Description
   2.1.3.2.2. Intervention options

2.1.3.3. Children with Rett disorder
   2.1.3.3.1. Description
   2.1.3.3.2. Intervention options

2.1.3.4. Children with childhood disintegrative disorder
   2.1.3.4.1. Description
   2.1.3.4.2. Intervention options

2.1.3.5. Children with PDD-NOS
   2.1.3.5.1. Description
   2.1.3.5.2. Intervention options

2.1.4. Case studies/vignettes/videos

2.1.5. Test your knowledge

2.2. Children with biological risk conditions
   In this section, different biological risk factors are described. It will be made clear that many of these risk factors often co-exist and when a child has one, he/she is likely to have others as well.

2.2.1. The biological risk conditions:
   2.2.1.1. Children with low birth weight
   2.2.1.2. Children who are born premature
   2.2.1.3. Children who are born small for gestational age
   2.2.1.4. Children born with low Apgar scores
   2.2.1.5. Children born with brain bleeds
   2.2.1.6. Children with anoxia
   2.2.1.7. Intervention options

2.2.2. Possible intervention strategies/what can be done

2.2.3. Case studies/vignettes/videos

2.2.4. Test your knowledge
2.3. Children with environmental risk conditions

2.3.1. Children living in poverty
   2.3.1.1. Description
   2.3.1.2. What can be done and where can one go for help

2.3.2. Children who are abused
   2.3.2.1. Children who are physically abused
      2.3.2.1.1. Description
      2.3.2.1.2. Intervention options/where can one go for help
   2.3.2.2. Children who are emotionally/psychologically abused
      2.3.2.2.1. Description
      2.3.2.2.2. Intervention options
   2.3.2.3. Children who are sexually abused
      2.3.2.3.1. Description
      2.3.2.3.2. Intervention options/where can one go for help
   2.3.2.4. Children who are neglected
      2.3.2.4.1. Description
      2.3.2.4.2. Intervention options/where can one go for help

2.3.2.5. Children with other environmental risk conditions
   2.3.2.5.1. Description
   2.3.2.5.2. Intervention options/where can one go for help

2.3.3. Case studies/vignettes/videos

2.3.4. Test your knowledge

2.4. Children with sensory impairments

2.4.1. Children with hearing impairments
   2.4.1.1. Description
   2.4.1.2. Intervention options

2.4.2. Children with visual impairments
   2.4.2.1. Description
   2.4.2.2. Intervention options

2.4.3. Children who are deaf/blind
2.4.3.1. Description
2.4.3.2. Intervention options
2.4.4. Case studies/vignettes/videos
2.4.5. Test your knowledge

2.5. Children with other types of disorders
2.5.1. Children with ADHD
   2.5.1.1. Description
   2.5.1.2. Intervention options
2.5.2. Children with learning differences
   2.5.2.1. Description
   2.5.2.2. Intervention options
2.5.3. Case studies/vignettes/videos
2.5.4. Test your knowledge

2.6. Children who are gifted
2.6.1. The many dimensions of giftedness
   2.6.1.1. Description
   2.6.1.2. Intervention options
2.6.2. Talent
2.6.3. Case studies/vignettes/videos
2.6.4. Test your knowledge

2.7. Children who are chronically ill
2.7.1. Children with diabetes
   2.7.1.1. Description
   2.7.1.2. Intervention options
2.7.2. Children with HIV/AIDS
   2.7.2.1. Description
   2.7.2.2. Intervention options
2.7.3. Children with cancer
   2.7.3.1. Description
   2.7.3.2. Intervention options
2.7.4. Children with asthma
  2.7.4.1. Description
  2.7.4.2. Intervention options

2.7.5. Children with other types of chronic illness
  2.7.5.1. Description
  2.7.5.2. Intervention options

2.7.6. Case studies/vignettes/videos

2.7.7. Test your knowledge

2.8. Children with communication disorders
  2.8.1. Children with receptive language difficulties
    2.8.1.1. Description
    2.8.1.2. Intervention options

  2.8.2. Children with expressive language difficulties
    2.8.2.1. Description
    2.8.2.2. Intervention options

  2.8.3. Children with articulation difficulties
    2.8.3.1. Description
    2.8.3.2. Intervention options

  2.8.4. Children with pragmatic difficulties
    2.8.4.1. Description
    2.8.4.2. Intervention options

  2.8.5. Case studies/vignettes/videos

  2.8.6. Test your knowledge

2.9. Children with mental health disorders
  2.9.1. Children with anxiety disorders
    2.9.1.1. Children with general anxiety
      2.9.1.1.1. Description
      2.9.1.1.2. Intervention options

    2.9.1.2. Children with phobias
      2.9.1.2.1. Description
2.9.1.2.2. Intervention options

2.9.1.3. Children with obsessive-compulsive disorder
   2.9.1.3.1. Description
   2.9.1.3.2. Intervention options

2.9.1.4. Children with separation anxiety disorder
   2.9.1.4.1. Description
   2.9.1.4.2. Intervention options

2.9.1.5. Children with attachment disorders
   2.9.1.5.1. Description
   2.9.1.5.2. Intervention options

2.9.2. Children with mood disorders
   2.9.2.1. Description
   2.9.2.2. Intervention options

2.9.3. Children with other types of mental illness
   2.9.3.1. Description
   2.9.3.2. Intervention options

2.9.4. Case studies/vignettes/videos

2.9.5. Test your knowledge

3. MODULE THREE: The early childhood intervention professionals

In this section, most professionals who are likely to be involved in the development and intervention plan of a child who either has special needs or is at risk for developing a special need will be described. It will be stated how each of these professionals can help both the child and the family.

3.1. The medical field professionals (in alphabetical order)
   3.1.1.1. Audiologist
   3.1.1.2. Child psychiatrist
   3.1.1.3. ENT specialist
   3.1.1.4. General practitioner (GP)
3.1.1.5. geneticist
3.1.1.6. Neurologist
3.1.1.7. Nurse
3.1.1.8. Occupational therapist
3.1.1.9. Ophthalmologist
3.1.1.10. Orthopedic surgeon
3.1.1.11. Pediatrician
3.1.1.12. Physio-therapist
3.1.1.13. Psychiatrist
3.1.1.14. Psycho-therapist
3.1.1.15. Sensory integration specialist
3.1.1.16. Case studies/vignettes/videos
3.1.1.17. Test your knowledge

3.2. The professionals from the allied field (in alphabetical order)

3.2.1.1. Aboriginal Infant Development Consultant
3.2.1.2. Aboriginal Supported Child Development Consultant
3.2.1.3. Behavior consultant
3.2.1.4. Behavior interventionist
3.2.1.5. Child psychiatrist
3.2.1.6. Clinical psychologist
3.2.1.7. Counseling psychologist
3.2.1.8. Deaf/blind specialist/consultant
3.2.1.9. Deaf and hard of hearing consultant
3.2.1.10. Dietician
3.2.1.11. Early childhood educator
3.2.1.12. Early childhood interventionist
3.2.1.13. Family support worker
3.2.1.14. Infant Development Consultant
3.2.1.15. Orientation/mobility specialist
3.2.1.16. Play/music/art/dance and movement therapist
3.2.1.17. Resource teacher
3.2.1.18. School psychologist
3.2.1.19. Special educator
3.2.1.20. Speech and language pathologist
3.2.1.21. School support teacher
3.2.1.22. Social worker
3.2.1.23. Supported Child Development Consultant
3.2.1.24. Vision consultant
3.2.1.25. Case studies/vignettes/videos
3.2.1.26. Test your knowledge

4. **MODULE FOUR**: how does it all tie together and what does it mean for you?

This may very well be the most important part of the course. It clearly outlines how the intervention process works, how referral, assessment and identification are carried out, how, where and by whom intervention plans are carried out, and how it should all tie together to help the child transition from home or preschool to school as smoothly as possible.

4.1. For families
   4.1.1. You and your child
   4.1.2. You and your family
   4.1.3. You and the professionals who work with your child
   4.1.4. The importance of family-centered and collaborative practice
   4.1.5. Where to go for help
   4.1.6. Getting ready for school

4.2. For service providers
   4.2.1. You and the child with whom you are working
   4.2.2. You and your program
   4.2.3. You and your team
4.2.4. The importance of family-centered and collaborative practice

4.2.5. Where to go for help

4.2.6. Helping the child you are working with get ready for school

5. Reference material

5.1. Books

There are recommended and highly recommended books for each section of the course. Each of these books has a brief description that describes what they are about and why they could be useful to whoever might read them.

5.2. Journals

5.2.1. The journal of early intervention

5.2.2. Zero to three

5.2.3. Child development

5.2.4. Topics in early childhood special education

5.2.5. Journal of speech and hearing research

5.2.6. Young children

5.2.7. The exceptional parent

5.2.8. The CEC journal

5.2.9. The Canadian version of the CEC journal

5.2.10. Infants and young children

5.3. DVDs

5.4. University courses

5.4.1. At UBC

5.4.2. At SFU

5.4.3. At U Vic

5.4.4. At Capilano College

5.4.5. At Douglas College

5.4.6. Other
5.5. Web links

5.5.1. Tips regarding using internet sites
5.5.2. Important/recommended websites
5.5.3. Parent support networks

5.6. Appendices

5.6.1. Course overview in table format: Appendix A.1.
5.6.2. Target audience (for the free basic course): Appendix A.2.
5.6.3. Course Advisory Committee (by alphabetical order)

To be invited: Faculty members at UBC-Pt Grey, University of Washington, University of Florida, among others.
## Appendix A.1.: Course Overview (in table format)

<table>
<thead>
<tr>
<th>Course home page</th>
<th>Module 1 (early childhood intervention and child development)</th>
<th>Module 2 (who are the children with special needs?)</th>
<th>Module 3 (the early childhood intervention professionals)</th>
<th>Module 4 (how does it all tie together and what does it mean for you?)</th>
<th>Comments</th>
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<td><strong>Overview of major issues (including the definition of early childhood intervention, the nature/nurture debate, culture, Aboriginal and First Nations considerations and the short term and long term effects of early intervention)</strong></td>
<td>Children with established risk conditions</td>
<td>The medical field professionals</td>
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<td>You and your child</td>
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<tr>
<td><strong>Typical development (the five developmental areas + the development of the senses + the development of the brain)</strong></td>
<td>Children with biological risk conditions</td>
<td>The professionals from the allied field</td>
<td></td>
<td>You and your family</td>
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<tr>
<td><strong>Atypical development (the five developmental areas + the development of the senses + the development of the brain)</strong></td>
<td>Children with environmental risk conditions</td>
<td>The mental health professionals</td>
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<td>You and the professionals who work with your child</td>
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<tr>
<td>Videos and vignettes (available for most sections)</td>
<td>Children with sensory impairments</td>
<td>Professionals who can help (when parents need help)</td>
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<td>The importance of family-centered and collaborative practice</td>
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<td>Short tests (available for most sections)</td>
<td>Children with other types of disorders</td>
<td>Where to go for help</td>
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<td>Children who are gifted</td>
<td>Getting ready for school</td>
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<td>Children who are chronically ill</td>
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<td>Children with communication disorders</td>
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<td>Children with mental illness disorders</td>
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</table>

- **References (books, journals, conferences, poster sessions, websites...)**
  - References
  - References
  - References

- **Goals and objectives for the course**
  - Target audiences
  - Advisory committee for the course

Description of what the module is about and what can be accomplished by its completion
Actual content of the course
References
Appendix A.2.: Target Audience for SDPP online course

1. Parents of children in the birth to age six age range:
   1.1. Parents of children with disabilities
   1.2. Parents of children who are at risk for developmental delays
   1.3. Parents of children in the gray area
   1.4. Parents of typically developing children
   1.5. Parents of children who are gifted
   1.6. Foster parents

2. Service providers:
   2.1. Early childhood education staff
       2.1.1. Teachers
       2.1.2. Aides
       2.1.3. School support workers
   2.2. Early intervention staff
       2.2.1. Infant development consultants
       2.2.2. Aboriginal infant development consultants
       2.2.3. Supported child development consultants
       2.2.4. Aboriginal supported child development consultants
       2.2.5. Behavior interventionists/consultants
   2.3. Special education staff
       2.3.1. Teachers
       2.3.2. Aides
       2.3.3. School support workers
   2.4. General school personnel
       2.4.1. School and out of school care staff
       2.4.2. Child and youth care workers
   2.5. Professionals in the medical field
       2.5.1. General practitioners
       2.5.2. Pediatricians
2.5.3. Geneticists
2.5.4. Neurologists
2.5.5. Ear/nose/throat specialists
2.5.6. Orthopedists
2.5.7. Ophthalmologists
2.5.8. Audiologists
2.5.9. Nurses
2.5.10. Occupational therapists
2.5.11. Physio-therapists
2.5.12. Sensory integration specialists
2.5.13. Child psychiatrists
2.5.14. Psycho-therapists

2.6. Professionals in the allied field
2.6.1. Child and youth mental health professionals
2.6.2. Speech and language pathologists
2.6.3. School psychologists
2.6.4. Clinical psychologists
2.6.5. Counseling psychologists
2.6.6. Social workers
2.6.7. Family workers
2.6.8. Dietitians
2.6.9. Deafblind specialists
2.6.10. Orientation/mobility specialists
2.6.11. Vision consultants
2.6.12. Hearing consultants
2.6.13. Play/music/art/dance and movement therapists

2.7. Other
2.7.1. Recreational workers
2.7.2. Parks and recreation staff
2.7.3. Family resource program staff
Appendix A.3.: Bibliography for Early Intervention Course


Meyer, D. *The sibling slam book: what it’s really like to have a brother or sister with special needs*. Bethesda, Maryland: Woodbine House.


Appendix A.4.: Online Resources

http://www.idpofbc.ca/prof.html

http://pediatrics.aappublications.org/cgi/content/full/102/1/137 (does not mention prenatal exposure to alcohol or drugs under any category)

http://www.idpofbc.ca/prof.html

http://books.google.ca/books?id=fcVGT5CI85sC&pg=PA201&lpg=PA201&dq=definition+of+biological+risk+conditions+in+early+childhood+intervention&source=web&ots=Q9kaBQdudN&sig=pGSAly5ujTbYen8RYDn KgUKymCo&hl=en&sa=X&oi=book_result&resnum=10&ct=result#PPA201,M1

http://pediatrics.aappublications.org/cgi/content/full/102/1/137

http://books.google.ca/books?id=fcVGT5CI85sC&pg=PA201&lpg=PA201&dq=definition+of+biological+risk+conditions+in+early+childhood+intervention&source=web&ots=Q9kaBQdudN&sig=pGSAly5ujTbYen8RYDn KgUKymCo&hl=en&sa=X&oi=book_result&resnum=10&ct=result#PPA201,M1

BC Association of Speech Language Pathologists and Audiologists:

http://www.bcphysio.org/app/index.cfm?fuseaction=pabc.home


http://www.kidsource.com/kidsource/content/early.intervention.html

http://www.earlyinterventioncanada.com/early_intervention.html

http://www.mcf.gov.bc.ca/spec_needs/eits.htm

Publications:


Posters:


Presentations:


Upcoming Publications and Presentations

