Including All Children and Families Expanding Partnerships Project

Final Report

The University of British Columbia
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Prepared by
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Available at *http://includingallchildren.educ.ubc.ca/work-research/publications/*

Canada

Dedication

We dedicate this project to...

All families in British Columbia, and especially to families raising children with additional needs in rural and remote communities

The professionals and staff working with parents and children with additional needs

Our Advisory Committee representing community agencies and provincial organizations throughout BC

Thank you for your participation, insights and contributions that made this project possible and took it to its completion!

In memoriam

Karen Brough
Coordinator Infant Development Program with the Boys
and Girls Club (Penticton, BC) who died on November 2,
2010

Clive Sykes
Boundary Individual and Services Society, Grand Forks,
BC, who died on August 22, 2012

Your work, presence and commitment to the lives of
children and families will always be remembered.

Content

Acknowledgments

Listing of Proposal (Signatory members)

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Diana Elliott (Provincial Advisor, AIDP)

Tanya Brown (former Provincial Advisor, SCDP) and

Clyde Hertzman, HELP (2008-2009)

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With the talent and expertise for our Final Project Report of

Adriana Briseño

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Andrea Lemire – Society for Children and youth of BC, Executive Director

Angela Clancy – Family Support Institute of BC

Annie Wolverton – Fraser Health Infant and Child Mental Health, Burnaby Infant Development Program

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Clive Sykes – Boundary Family and Individual Services Society BFISS (+August 22, 2012)

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1   Project Overview

1.1   Summary

The Including all Children and Families-Expanding Partnerships Project took place from February 1, 2010 to December 31, 2012 with the funding and support of the Social Development Partnerships Program, Social Development Canada, Government of Canada. Our main goal was to build community capacity and to conduct field-based research focused on children with special needs and their families. These families face both gaps and obstacles in their search for appropriate child- and family-supportive programs and these problems are compounded by poverty, race and geographical distribution. This project created materials, approaches and processes designed to bridge gaps in services for children and families with diagnosed disabilities, developmental delays, or who are at risk for developmental delays, in order to address a prevalent need for family-supportive programs in rural and urban communities in British Columbia.

1.2   Project Description

Children with special needs and their families face significant obstacles in their search for appropriate child and family-supportive programs and experience gaps in services that affect child outcomes. These problems are further compounded by poverty, race, and geographical distribution. The University of British Columbia project, Including all Children and Families: Expanding Partnerships, will address the need for family-supportive programs by creating materials, approaches and processes designed to bridge gaps in services for at-risk children and families and eliminate obstacles to their participation in community life.

Project funding will enable the University of British Columbia to develop a database with information on children's and families' participation in intervention programs. The data collected through surveys, questionnaires, focus groups and interviews will be used to assist agencies in revising service delivery plans. Project funding will also allow The CHILD Project in the Human Early Learning Partnership at UBC-Pt Grey to expand an online professional development course to include information on children from birth to 12 years of age.

1.3   Our Research Team of Experts

- Dr. Hillel Goelman (Project Director)
- Dr. Mari Pighini (Research Coordinator)
- Dr. Lara El-Khatib (Project Coordinator)
- Dr. Herb Chan (LINKED-DISC Coordinator)
- Dr. Anat Zaidman Zait (Post-Doctoral Fellow and Co-Investigator)
- Mary Stewart, M.A. (Research Assistant)
- Maya Goldstein, M.A. (Research Assistant)
- Dr Bozena Zdaniuk (Statistician)

This report includes a description of the objectives of the project and the project's final outputs with detailed information and examples for both the research and deliverables components. Recommendations to government and non-governmental agencies derived from the outcomes of this project are also provided.

1.4   Beneficiaries of this Project

The main beneficiaries of this project are children with diagnosed disabilities, developmental delays, or who are at risk for developmental delays, their families and their service providers. Aboriginal and non-Aboriginal families living in urban and rural communities were targeted as the direct beneficiaries of this project.

Concretely, our estimate is that over 400,000 children ages birth to12 years and their families could potentially benefit from the outcomes of this Project. Additionally, organizations and partner agencies such as IDP, AIDP, SCDP and ASCDP, together with collaborators (approximately 25 local health areas within the Provincial Health Service Authority – Fraser, Interior, and Northern Regions), teachers, counselors and resource/special need teacher and support workers in school districts (Ministry of Education) in the Interior and Fraser Regions (approximately 25), ECEBC members (Early Childhood Educators of BC), community centers, family places, and neighborhood houses, could also benefit from our efforts. As a particular case, we anticipate benefits for rural and reserve communities surrounding 25 urban communities/hubs in the Fraser and Interior regions.

2   Need for the Project: Priority N° 1 Supporting Children/Youth and Families

"Overall I think the greatest achievement of this project is that we have started (and I use the term started because I truly believe work needs to continue) an amazing early intervention network to share and disseminate information. This research has true significance and when written up and shared, will have impact for families and children."

Mary Stewart, MA
Research Assistant for the Project, UBC.

Findings derived from reports and studies conducted in BC with families with children who are at-risk for developmental delays (Goelman, Pighini, El Khatib, Brynelsen & Hertzman, 2009; Goelman, Synnes, Houbé, Pighini, Li et al., 2007; Pighini, 2008; & Pivik, 2007) describe the many challenges these families confront on an ongoing basis, and that are specific to the communities they reside BC Children First (2005). Needs may vary for families whose children are identified with specific risks and needs, and for families with children with suspected risks. Two themes identified in this research include "cycle of disability" and "parenting over a lifetime" Pighini (2008). The "cycle of disability" can be seen, for example, when children with identified needs are connected with necessary services soon after birth; however, funding for these services is often unstable and gaps exist between such services. Children's health, developmental and educational issues become even more complex as children grow older but the fragmentation and limitations of services in the preschool years continues into the school years. The "parenting over a lifetime" becomes a major issue as the cycle of disability places a heavy burden on the child's parents, especially when no other relatives are available to support the family. These issues may be exacerbated for the more vulnerable families that are identified in this project who face additional social, economic and cultural challenges; e.g., families living in poverty, families who self-identify as Aboriginal, and immigrant and refugee families. For families with children with suspected risks the situation is more complex due to the difficulty

of obtaining accurate diagnoses and prescriptions for remediation for these "grey area" children until later in their elementary school years. These children receive limited remedial support, in contrast to comprehensive, and more effective, early intervention services (Hebbeler, Spiker, Scarborough, Mallik, Simeonsson, et al., 2007; Meisels, 1999). The objectives and methods represent and expansion and enhancements of the sampling, methodology and deliverables of our successful, recently completed previous SDPP project. This project intends to address the challenges faced by vulnerable families.

3 Objectives

The objectives are based on the rationale that integrated systems service delivery enhances the implementation of both universal and targeted based deliverables for children at-risk and for their families (Pighini, 2008; Pivik, 2007).

In order to achieve the overarching goal of supporting at-risk children and families to overcome the obstacles for their participation in community life, seven general objectives were established. The objectives were met through the implementation of a number of research studies and the development of practical instruments and tools.

> **Objective 1:** To improve information systems for parents and agencies in order to document children's development and early intervention history.
>
> **Objective 2:** To create effective collaborations between university-based researchers and community-based Aboriginal and non-Aboriginal intervention services for children from birth to age 12.
>
> **Objective 3:** To create effective collaborations between university-based researchers and urban and rural communities in three of British Columbia's five health authorities.
>
> **Objective 4:** To increase our understanding of children's, parents' and service providers' experiences, challenges and successes in families with children with identified and suspected risks.
>
> **Objective 5:** To use the information gained in Objectives 2, 3 and 4 by service providers in order to address identified needs in their communities.
>
> **Objective 6:** To provide service providers with more opportunities for staff professional development.
>
> **Objective 7:** To increase knowledge on the longitudinal development of children who are identified with special needs at birth

To date, we have successfully met these objectives due to the support received from the different partner agencies, centres, and programs that collaborated with the research team. The Project's objectives and results were achieved through the implementation of six research studies (Figure

1) which provided the background and foundations for the development of the deliverable elements.
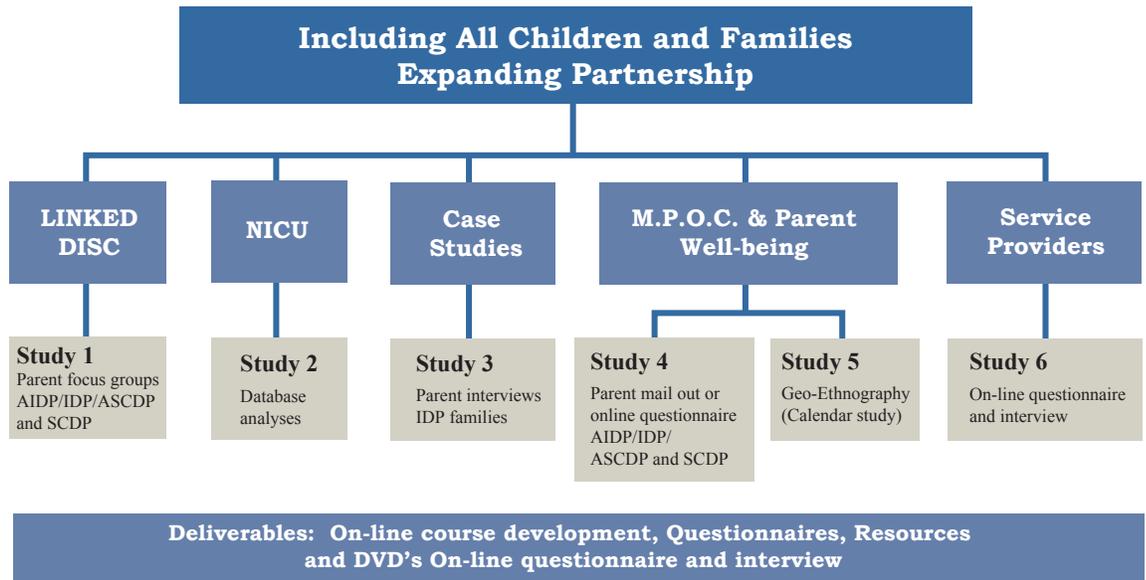

Figure 1. The six studies that constitute the Including all Children and Families – Expanding Partnerships Project, and the deliverables or resources and materials from this

3.1 Meeting the Objectives of the Project through Research and Deliverables

Objective 1: Three research studies inform this objective (Parents Survey Study – MPOC, Calendar Study, and Parents Focus Groups – Linked-Disc). Parents Survey Study – MPOC and Calendar Study allowed us to develop a deeper understanding of parents' perceptions about the actual state of the information systems available, and the challenges family face in the process of accessing services and information around their disabled child. We were also able to collect data on what parents find helpful about the current information systems. The Parents Focus Groups – Linked-Disc project allowed us to directly explore the perceived utility and potential acceptance of such a database, and based on the positive outcomes of these consultations, the database was developed and tested. We successfully completed feasibility studies regarding family access to information on an existing centralized database (Linked-Disc), which contains all pertinent information on children's and families' participation in intervention programs. These consultations contributed to the development of the software which has been professionally developed by a Vancouver based IT company (LinuSoft). The full implementation, distribution and use of the software at the agency level is still pending (see Section 2D for flow up plans). The software includes: data on availability of health and developmental services for young children and families; geographical information, or healthcare locators, connected to those services; and information on current/expected waiting times for families, referral and diagnosis information. It is designed to be used as a client information management system with built-in capacity for future population-based research. Service providers as well as parents and community members have expressed their deep interest in such development and its potential benefits to their overall experience with information access.

Objective 2: Effective collaborations were created with representatives from Aboriginal and non-Aboriginal intervention services.

Aboriginal programs

We specifically established a fruitful professional relationship with Cindy Jamieson who is the Provincial Coordinator for Aboriginal Supported Child Development Program of BC and who also served as a member of the Advisory Committee for this Project. Because of provincial government re-structuring of the Provincial Advisors for the IDP, SCDP/ASCDP and AIDP, Diana Elliot (Provincial Advisor for Aboriginal Infant Development Program of BC and community signatory for the Including All Children and Families-Expanding Partnerships Project Contribution Agreement) and Cindy Jamieson, newly appointed ASCDP coordinator, re-defined their roles within their programs. Cindy Jamieson took over the research component for AIDP and ASCDP Diana Elliott continued to participate as a member of the Steering Committee for the Assessment Workshop, a yearly professional/academic collaborative event that began in 2003 and that was supported through this project. Their insights and input were very useful in the development and implementation of the following deliverable elements that represent practical tools for Aboriginal and non-Aboriginal parents, service providers and agencies: series of pre-screening questionnaires; online course, website, and healthcare services locator (an online tool that allows users to look for health care providers in any area of British Columbia on an interactive map, http:// includingallchildren.educ.ubc.ca/work-research/social-inclusion-project/healthcare-services-locator/). Through Cindy Jamieson, we learned how the power of stories in our research reaches their communities in a way that the messages are meaningful for them. Both Cindy and Diana were instrumental in supporting the research teams in their advertising and helping with recruitment of families and service providers through the programs they serve.

Non-Aboriginal Programs

Infant Development Program of BC (IDP): The then Provincial Advisor for the Infant Development Program of BC, Dana Brynelsen was a signatory for the original proposal for this project, in conjunction with the regional advisors for the North, Interior, Fraser and Vancouver regions. The Provincial government terminated the Provincial Advisor's Office in 2008 and the Ministry for Children and Family Development took over the regional advisors' roles and positions. This resulted in the IDP programs no longer having a centralized office which would provide province-wide training and support. New connections, relationships and structures had to be recreated in order to provide support for the individual IDP programs under the supervision of the Ministry of Children and Family Development. This restructuring process has continued over the past four years, as reported by numerous agencies have reported. The impact of this restructuring process was also reported to us through the preliminary findings from the Service Providers' study.

In her new capacity as a community member, Dana Brynelsen volunteered her time over the past three years bringing her leadership and vision throughout the project. Drawing from over 30 years of experience in the field of early intervention, and her work with parents, professionals and the vast research network she developed over

decades, Dana Brynelsen continued to contribute to the development of the study proposals, requests for ethical approvals, the creation of materials and resources so that important points that relate to family centred practices with parents, and contextual aspects that relate to the work of service providers would not be missed. Dana has travelled BC extensively over the past 30 years, and she understands some of the geographical challenges families with children with disabilities experience in rural and remote BC. Her knowledge and intuition on the need for research in rural areas prompted her to fully support **_Mary Stewart's MA thesis_**, "Parents' Perceptions in Raising a Child with a Developmental Delay or a Disability", the first study completed through this project. Mary Stewart, former regional IDP advisor for the North region in BC, contributed to this project as a graduate research assistant. It was because of Mary's extensive networks and solid relationships built over years of work with the Provincial Advisors' office that this project successfully embarked in action and participatory research with community agency representatives throughout BC, in spite of the radical organizational changes that IDP (and Supported Child Development Programs) had experienced.

An interview with Dana Brynelsen with Adriana Briseno (co-author in this report) highlights aspects of the creation and development and vision of the IDP of BC and the programs that evolved in early intervention after the creation of the IDP (you can listen to a interview audio-recording **_here_**).

The Supported Child Development Program of BC (SCDP): The then Provincial advisor for the SCDP, Tanya Brown was also a signatory to the original proposal for this project. The structural changes at the provincial advisor's office level described earlier for the IDP of BC impacted on the organization of SCDP in very similar ways, with no provincial advisor office remaining by the end of 2009. Tanya Brown, former provincial advisor, gradually established contacts with two regional advisors for SCDP and under the BC Ministry for Children and Families, Juanita Hagman (North) and Wendy Kenward (Interior). Both regional advisors became invaluable members of this project's community advisory team between 2010-2012 and acted as informants and contacts for recruitment and participation for the different studies in this project.

Objective 3: An essential component of this project was the establishment of successful collaborations with representatives of urban, rural, and remote communities, reaching out to all five health authorities and not only to the three intended ones. In this way, we worked closely with five of British Columbia's health authorities: Northern Health, Interior Health, Vancouver Coastal Health, and Fraser Health, as well as Vancouver Island Health Authority for the Service Providers' study, and the second stage of the MPOC parent study (online data collection). Delegates of agencies representing urban, rural, and remote communities served as active members of our advisory committee and worked closely with the research team in the development and implementation of a series of pre-screening questionnaires, online course, website, and in the organization and delivery of presentations and workshops throughout the province. These resources and materials are being used already by parents and service providers from rural and remote communities in British Columbia.

Users of the data base included consultants and their families in the early intervention/supported child development programs including **_IDP_**, **_SCDP_**, **_AIDP_** and **_ASCDP_**, as well as early

childhood educators with the Early Childhood Educators of British Columbia (*ECEBC*), and those working for the Developmental Disabilities Association (*DDA*). Diploma and master's students in the *MED* programs at UBC in early childhood education, both *off campus* and *online cohorts* who work in pre-school and school-age settings throughout BC and Canada, have also accessed these resources

Objective 4: The implementation of five of our research studies allowed us to achieve this objective (Case Study, Parents Survey Study – MPOC, Calendar Study, Parents Focus Groups – Linked-disc, and Service Providers). The first of these four studies provided us with a deeper knowledge of parents' perspectives and experiences in taking care of a child with an identified disability and in accessing services for their children. A diversity of methodological approaches permitted the research team to grasp the issue under analysis from different perspectives and to gain extended understandings of parents' challenges and successes across urban, rural, and remote settings (click *here* for an example of a reflection on these issues). The fifth study, Service Providers, focused on eliciting service providers' professional and personal experiences, and on examining what they perceive as successes and challenges in working with families with a disabled child. It was not possible for us to directly measure children's perspectives; we were only able to explore children's views and experiences through the voices and perspectives of their parents. The goal of learning about children's perspectives from the children themselves remains as a task for future research.

Objective 5: Learning about parents' perspectives and experiences through Case Study, Parents Survey Study – MPOC, Calendar Study, Parents Focus Groups – Linked-disc, was an important component for the identification of challenges that service providers face in their everyday practice. The outcomes of these studies assisted agencies in revising service delivery plans, resources and types of services available vs. services needed. The Serve Providers study was the research component that provided the most information about what service providers perceive as challenging and/or advantageous factors and situations in their interaction with families, communities and agencies. This study allowed us to identify and deeply explore service providers' needs across the province and to learn about their experiences and opinions. In integrating this information with data gathered on families' reported experiences, it was possible to assist service providers in identifying and addressing the needs of families in their communities. Moreover, the findings of the Service Providers study are of particular use to administrators and provincial administrators of early intervention programs at local, regional and provincial levels when planning for their programs, in terms of allocation of funds for staff to continue with their training and in the implementation of working strategies for their families. Research outcomes have been made more accessible and useful for practitioners through workshops, seminars, and materials that helped us achieve this objective (see Section 4B)

Objective 6: In order to provide service providers with alternative opportunities for professional development, several deliverable resources have been designed and implemented. We have developed a comprehensive set of learning modules that are offered online as a free "online course" on child development, early intervention and connecting the different components that living and/or working with a child at risk for developmental delays or with disabilities entails. These modules are currently available through our website (*http://includingallchildren.educ.ubc.ca/course/*). Revisions following academic/expert review are in progress to ensure contents are as accurate and professional as they can possibly be. We continued to implement a series of yearly events on the topic of assessment in early childhood entitled "*Assessment Workshops*" guided by expert presentations on diverse topics relevant to

early intervention, child development and early childhood education, as well as multiple local presentations and seminars in which the research team has presented the results of our research efforts. A publication by Dr. Hillel Goelman on the Assessment Workshop initiative by ***Zero to Three*** describes and summarizes the first ten years of this initiative led by ***Dr. Goelman***. Our website brings together the stories and successes of our project in a user-friendly virtual environment so that interested students, parents and community professionals may access them (***http://includingallchildren.educ.ubc.ca/***). All of these tools and materials have been made accessible to service providers with the purpose of attaining Objective 6.

Objective 7: This objective was addressed mainly through one specific research study: NICU. In this study, the longitudinal educational development and school performance of children admitted to neonatal intensive care units (NICU) was investigated through the examination of large databases. Also, the Parents Focus Groups – Linked-Disc study helped us meet this objective by means of providing a systematized approach to collecting and archiving longitudinal data on clinical and early intervention records of children identified with or at risk of special needs.

While most of the seven general objectives have been fully met, a few specific goals have only been partially met to-date. This report includes follow-up plans as well as a detailed description of the remaining work.

4 — Results and Deliverables

"The insight and intelligence of these Advisory Committee members is an inspiration to me to continue to try to do my best to help children and families. The curiosity of the committee members to ask for feedback and to remain open to receive the feedback is a healthy way to lead life and pursue change. The outcomes of this committee have spread amongst families and given them more autonomy in learning and understanding their own children. From this, families feel more confident about asking questions about their children

▼

The intended collaboration with partner agencies was fully achieved and has exceeded our expectations in terms of additional agencies that currently collaborate with us (including the Society for Children and Youth) and researchers who are interested in following up with our research and/or publications (including ***Dr. Silvia Vilches*** at SFU, ***Dr. Linda Farr-Darling***, ***Dr. Helen Brown*** and ***Dr. Gladys Mcpherson*** at UBC, ***Dr. Veronica Smith***, at the University of Alberta, and ***Dr. Judith Duncan***, at the University of Canterbury, Christ Church, New Zealand). The connections with ***Dr. Marilyn Chapman*** and ***Dr. Mark Edwards*** from the on campus, off-campus and online ***M.Ed. program in Early Childhood Education (UBC)*** has resulted in more professionals around the Province, especially in the Interior and North of BC, having expressed their interest in furthering their professional training as a result of the work we have accomplished. An added achievement that has given rise of promising future joint projects has been the successful collaboration with the Institute of Early Childhood Education and Research (***IECER***) –Dr. Marilynn Chapman, Director; Iris Berger, Early Years Coordinator; and Dr. Jodi Streelasky, M.Ed. on campus coordinator, and with the Professional Development & Community Engagement unit (***PDCE***) –Dr. Mark Edwards, Assistant Dean.

Members of our advisory committee and agencies collaborating with our research team have shared how our results and outcomes have informed agencies' revisions of service delivery plans in urban, rural and remote aboriginal and non-aboriginal communities. This has been helpful in order to meet the specific needs of the families with disabled children they serve. We also obtained a high level of staff engagement of over 50% both as part of agency and community involvement with the project and the creation and implementation of parent surveys,

course materials and the database. Over 60 service providers took part filled in the service providers' surveys, thus exceeding our initial expectations in this regard. Parental participation also exceeded our intended enrolment goal. Almost 40 parents took part in interviews and focus groups, whereas 64 parents filled in the parent questionnaires (29 mailed, 35 online). Moreover, our online course (online learning modules) is now completed to include information on children aged birth to 12, and is currently under review to include the feedback provided by members of our advisory committee. On the other hand, the valuable participation and input from the staff of our *partner agencies* was crucial in the development of the series of the pre-screening questionnaires, also available through our website (*http://includingallchildren.educ. ubc.ca/questionnaire-series/*).

4.1   Research Studies

Each of the six research studies and deliverable components was designed to help us achieve one or more of the intended objectives and results, in a coordinated and focused manner, and through ongoing consultation with university and community partners. In what follows we provide a description for each research study's objectives and methods, and we describe the deliverable components individually.

4.1.1   "Experiences of parents in rural and remote British Columbia who have a child with a disability or developmental delay (*Case Study*)"

Parental voices regarding issues of disability and developmental delay in rural and remote communities have not been adequately studied and most of what we know about parents with children with disabilities is drawn from families living in urban centres. As a result, there is a lack of understanding of the needs of rural and isolated families, and interventions and policies for young children with disabilities and their families may not be truly responsive to their actual needs and realities. Moreover, families living in rural and remote communities are considered to be highly vulnerable because of a lack or limitation in accessibility to specialized resources.

This study aimed at gaining a deeper understanding of parents' experiences through an ethnographic case study methodology. A total of eight parents living in rural and remote communities in Northern and the Interior regions of British Columbia, with a developmentally at-risk infant or child under the age of three who was on the Infant Development Program., took part in this study. Click *here* for a summary of the outcomes of this research study.

4.1.2   "Measure of process of care (*Parents Survey Study: MPOC*)"

To get a more detailed understanding of parents' experiences with early intervention service delivery in rural areas, the quantitative study "Parents' perceptions of family-centred services" was implemented. This study also looked at how early intervention services relate to parents' sense of hope and well-being, life satisfaction and levels of stress. In order to achieve these goals, families from the North and Interior regions of British Columbia, with children with additional needs of age birth to 12 years old and who have been referred to early intervention/ child development support programs, were asked to complete a mailed-out survey. A total of 64 of parents took part in this study.

The data collection packet included: a demographic questionnaire; questions about their

perceptions and experiences with family-centred models of service delivery; the Measure of Process of Care instrument; the Satisfaction with Life Scale; the Family Context-Specific Stress tool; and questions about the social support families receive and about perceived parental competence. Also, participants were invited to provide comments at the end of the survey in order to add a qualitative component to this study. Data analysis included descriptive and non-parametric (correlational/chi-square association) analyses of the quantitative data, as well as a content analysis of parents' comments. Click *here* for a summary of this research study.

4.1.3 "Geo-ethnography – Parents access to services (*Calendar Study*)"

This study was conceived as an extension to the "Parents' perceptions of family-centred services" (MPOC-Parents' Survey Study) first stage of data collection, where parents were asked whether they were willing to participate in this follow up study in order to further our understandings and views about participants' perceptions and experiences of accessing services for their disabled child and themselves. In this second stage, participants took part in a telephone interview as well as in a calendar filling activity through which we aimed at learning more about families' interactions and relationships with different service providers. Particularly, we were interested in learning more about what parents had found helpful or not helpful in this process within their own daily contexts. A total of 11 of participants out of the 29 participants from the first stage of data collection took part in this follow-up study.

The telephone interview was a guided conversation that invited parents to discuss the topics and issues raised in the original survey. Also, parents were asked to list the services they received during one calendar month (e.g., speech therapy; doctor; home visits), and to state the time, place, and purpose of the appointment. Data analysis consisted of critical incident methodology where examples of events or situations that helped or hindered family centred services were examined, in addition to the visual analyses of distances and number/places of visits for parents. Click *here* for an exemplary case illustrating the Geo-Ethnography analyses. Data analysis for this study is still in progress and community summaries and publications are forthcoming.

4.1.4 "Parents' experiences in accessing their child's early intervention data (*Parents Focus Groups - Linked-Disc*)"

Families of children with special needs may have access to their child's health and/or intervention therapy service records at most health clinics and child development centers. However, this information may be provided in loosely organized and unarticulated files which can be problematic since poor communication between families and service providers often leads to misunderstandings and extra burden for families. The study "Parents' experiences in accessing their child's early intervention data" examined the accessibility of service records of early intervention programs through a series of focus group discussions with parents whose children have received these services both in urban and rural communities. It also investigated the feasibility of the construction and implementation of a database with information on children's and families' participation in intervention programs.

In this study, parents of children from birth to 12 years old and who were involved in one of the four early intervention/supported child development programs of BC, met with researchers to discuss their experiences in accessing their children's developmental information and or records in early intervention or child development services. A total of five focus groups were held in Vancouver, North and Interior regions of British Columbia, and were particularly designed to

engage parents in a discussion about the information they currently have and the information they would like to have access, as well as to elicit parents' ideas and feelings about an electronic and centralized online database, identified as "LINKED-DISC" and which would represent a significant improvement to the ways in which current information systems operate in British Columbia. Nineteen people took part in these focus groups (3 in Vancouver, 1 in Enderby, 3 in Salmon Arm, 5 in Grand Forks 5, 3 in Fort Nelson, and 4 in Dawson Creek). Conversations were analyzed through qualitative content analysis methods.

Qualitative content analyses of the conversations allowed the identification of the following salient themes: Parent knowledge; Information; Lifestyle; Challenges; Communication, and Systemic Challenges. This study revealed how much parents rely on their service providers to obtain information that integrates their children's health, development and progress. This study has contributed to better serve families receiving early intervention and special needs support services throughout British Columbia. Click *here* for a summary of this research.

4.1.5 "Service providers' experiences in providing family-centred services (*Service Providers Study*)"

Building awareness around the experiences and perspectives of early intervention service providers is essential to bridge gaps in services for families with children with identified and suspected risks, since service providers deliver home visit and family-centred services to children and their parents' right from the intake process when they enter the program and up to the case discharge when they exit the program. Previous research with service providers working with at-risk children focused on hospital or clinical settings and has been conducted primarily in urban areas. The mixed-methods study "Service providers' experiences with early intervention family-centred services" examined the experiences of early intervention and supported child development service providers who work with families in rural and urban communities. Participant practitioners work with one of the following family-centred programs of British Columbia, where parents collaborate and consult with them towards identifying their children's needs: the Infant Development Program, Aboriginal Infant Development Program, Supported Child Development Program, and Aboriginal Supported Child Development Program.

Data collection took place in two phases. First, participants completed three online or mailed-out questionnaires in order to identify service providers' needs and perceptions about their relationships with families, their program, and the community. A total of 62 of participants completed the quantitative questionnaires that included a demographic section, online surveys inquiring about service providers' ratings of their work, and the Measure of Process and Care questionnaires (MPOC). Second, a sub-set of practitioners participated in a follow-up telephone interview that was designed to investigate issues and factors that help or hinder service providers' capability to meet the needs of the families they serve throughout different communities in rural and urban locations of British Columbia. Fourteen participants took part in the interviews. A qualitative content-analysis was employed to identify salient themes and sub-themes across interviews, and critical incident analysis was used to identify elements that promote or hinder service provision. For details on preliminary findings and conclusions of this research study please click *here*.

4.1.6 "An interdisciplinary study of the trajectories of at-risk infants and children (*NICU*)"

Neonatal Intensive Care Units (NICUs) provide care for high risk pregnancies and intensive care for severely ill infants. These children are considered to be at risk for developmental problems because of anomalies they are born with, complications during the newborn period, and/or concomitant risk elements. However, most research on NICUs survivors is limited to sub-populations. It has been shown for instance, that approximately 50% of extremely low birth weight children have a learning disability, but is not yet clear how other children admitted to the NICUs perform longitudinally despite the fact that data collected on at-risk children in BC are stored in several provincial databases including BC Health Linked Database (BCHLD) and Edudata Canada.

The study "An interdisciplinary study of the developmental trajectories of at-risk children" aimed at investigating the performance at school and longitudinal educational development of children admitted to a NICU at birth through a quantitative analysis of existing records and large data sets. A case cohort of children admitted to NICUs, born between 1996 and 1997, and a matched comparison group of low-risk children not treated in NICUs, were identified in BCHLD. Also, Foundations Skills Assessment and Early Development Instrument data files for such individuals were accessed in the Edudata Canada Student Longitudinal Database. Descriptive and statistical analyses were performed in order to cross-link health and education data for the case cohort and comparison group. We developed maps representing where families with children in the NICU access these services in urban and rural areas in BC (click *here*). Future applications will aim to meet the intended objectives to expand Phase 2 so that it includes all NICUs children who were born after 1997.

The current findings in this study have contributed to gain a better understanding of the interplay between child development in the multiple contexts of family, neighbourhood, community, and education policy by providing a longitudinal and interdisciplinary perspective to the issues under analysis. So far, the outcomes of this study point at invaluable information that will advise professionals and senior administrators in terms of advancing on practices and on formulating policies at the provincial level. For a summary of this research, please click *here*.

4.2 Deliverable Components

4.2.1 Series of *Pre-screening Questionnaires*

"Results are practical tools for parents and children"

Annie Wolverton
Fraser Health Infant and Child Mental Health/Burnaby Infant Development Program.

A series of pre-screening questionnaires to be used by families of children with and without identifiable special needs, as well as by professionals who work with them, was developed as a result of university-community collaboration. The questionnaires are classified as birth to 6 years of age, and six to twelve years of age, and encompass three main sections: development (motor, social/emotional, intellectual (cognitive), language, and adaptive); emotional well-being and coping strategies; and availability of resources and funds in the community. Given the cultural diversity of British Columbia, the questionnaires are available on the project's website (*http://includingallchildren.educ.ubc.ca/*) in English, Chinese (traditional and simplified), Farsi, Punjabi, Spanish and Vietnamese. A PDF version of the English questionnaires has been created to facilitate use by all community members.

The questionnaires were employed to help users (parents, service providers, any professionals, students, and/or researchers) get a general idea about how well a child is doing, in all developmental areas, and will also guide them to the public health unit that is closest to the child's place of residence. Parents and practitioners can fill out and print the development and well-being questionnaires. No identifying information is requested. In the community questionnaire, however, users are asked to submit their answers, along with the first three digits of their postal code, in order to help us determine the services that are available in the area. It is important to highlight that these questionnaires were designed as pre-screening tools only, and are not meant to be used as an alternative to a thorough assessment by a professional.

4.2.2   Learning Modules or "*Online Course*"

In collaboration with a team of professionals (plain language editor, website developer and graphic artist) and with the ongoing support from the team's advisory committee, an online course about the development of children who are between the ages of birth and 12 years was developed. These learning modules consist of two main sections: Section 1 - Early Childhood, birth to 6 years of age; and Section 2 - Middle Childhood, six to twelve years of age. Each Section comprises four modules: Module 1: typical and atypical development; Module 2: disorders and conditions; Module 3: professionals in the fields of early intervention and special education; and Module 4: how parents and professionals can use this course and where can parents go from here. The complete online course can be accessed through the project's website (*http://includingallchildren.educ.ubc.ca/course/*).

The course has been designed to benefit parents of children with special needs and for any professional who works with these parents and their children. It assist parents and professionals in putting a child's development (or developmental delay) in perspective, as it delineates the typical developmental stages that most children go through, and how and why some children do not develop typically. It further describes the most common types of developmental disorders and mental illnesses that are likely to be identified between the ages of birth to twelve years, as well as prenatally. The course also lists some of professionals who usually work with children with special needs, both in therapeutic, educational, and medical settings.

This course is a powerful resource for a range of different family situations, including: parents concerned with their child's development despite the absence of a formal diagnosis; parents of a child with an identified special need, foster parents of a child in their care; and professionals working with young children in any capacity.

4.2.3   Linked-Disc Database Program

Linked-Disc is used by three community agencies including three IDP, one SCDP and one foster care program. Currently, the database is used as a web-based client information management system only. The user survey has provided information for modification and upgrade.

4.2.4   *Assessment Workshops*

Since 2003, Assessment Workshops have been held annually in preparation for the annual conference of the Early Childhood Educators of British Columbia (ECEBC). These events, held at the campus of the University of British Columbia, were offered in the past years with the collaboration of ECEBC and the Human Early Learning Partnership (HELP). More recently,

these activities have received support from The Psychoeducational Research Training Centre at UBC (PRTC), the Institute for Research in Early Childhood Education at UBC (IECER), the Infant Development Program of British Columbia (IDP of BC), the Aboriginal Infant Development Program of BC, and the Supported Child Development Program of BC. Each year`s theme has had a particular focus in one aspect of early childhood education.

The annual Assessment Workshops consist on several expert presentations given by teams of early childhood educators, elementary school teachers, professionals in the health and mental health fields and university professors, who share their visions on the many different formal and informal ways of assessing children's cognitive, physical, motor, language, and social-emotional development. The average attendance has had an average of over 150 delegates per year.

Past PowerPoint and PDF presentations, research slides, workshop materials and streaming video content have been compiled in our website and are free and public resources (***http://includingallchildren.educ.ubc.ca/work-research/assessmentworkshops/***).

4.2.5   **Website (*http://includingallchildren.educ.ubc.ca/*)**

The project's website is an ongoing development that holds a vast amount of information based on our goals, mission, deliverables and research findings. . The website, hosted by the University of British Columbia's Faculty of Education, contains information, materials, and resources geared toward caregivers, healthcare professionals, students, and educators of children who have been identified as vulnerable due to developmental delays, identified disabilities, or other challenges.

In accordance with the project's objectives, the resources posted on the website focus on assisting and providing resources children from birth to age 12 years throughout British Columbia, with special emphasis on families living in rural, interior, and northern communities. Our courses, questionnaires, research studies, materials (e.g., recommended books, upcoming events, news in the field, etc.), service locator tool, and other online resources are public and free. It is our intent to maintain the website updated and active since we consider it is a very valuable outcome that concentrates the work we have done during the past years. This tool also allows users to post comments and questions in several pages, and this initiate a conversation with other community members who may be going through similar personal or professional challenges. Users' posts are directed to a designated email address operated by the research team, who then accepts the publication of the post or not, depending on its appropriateness in the context of our study (i.e., comments that advertise or publicise products or programs will not be made public in our website). Once comments are made public, other users can reply/add another comment; the goal is to open a space for interested people, where they can share experiences and perspectives around raising/assisting children with special needs. Public interest has started and some comments have been already received and questions have been answered.

5   Partnerships and Collaborations

The project was completed through the Human Early Learning Partnership (2009-2010) and through The University of British Columbia's Faculty of Education (2011-2012). The project built and expanded on a strong network of university-community alliances and collaborations that have been developed over the past ten years through projects including ***The CHILD Project*** (e.g., Goelman & The CHILD Collaborative, 2007), the previous SDPP ***Social Inclusion Project*** (Goelman, Brynelsen, Hertzman, Pighini & El Khatib, 2008), and the current ***EDI*** mapping project (Human Early Learning Partnership).

The committed partnership and collaboration from the Infant Development Program of BC, Aboriginal Infant Development Program of BC, Supported Child Development Program of BC, and Aboriginal Supported Child Development Program of BC, and their active participation in the brainstorming, planning, evaluation, implementation and follow up of the project's research and output component was crucial for this Project. Agencies' representatives' familiarity with the scope of the Project and their integral awareness and knowledge of the needs of the families and communities they service also proved invaluable in the completion of the Project.

Another instrumental component of this project was the creation of a ***Community Advisory Committee***, and the establishment of research partnerships with diverse ***Research Collaborators***. We also established a solid network of ***Community Research Partners***, whose work informed our own decisions and proceedings in a number of different areas.

6   Knowledge Transfer and Sustainability of Outcomes

Our initial knowledge transfer strategy was based in part on the Human Early Learning Partnership's "tool kit" approach and the use of community researchers in the CHILD Project. This approach to knowledge translation draws upon evidence-based resources that are created to assist communities in developing policies and programs that can inform community decision-making and priority-setting. By developing materials such as questionnaires, websites, and courses, and by presenting the outcomes of our research work in diverse forums, we strove to reach to parents and service providers across the province through our four partnering agencies. Besides resources and tools, we projected a wide media exposure. Moreover, the development and implementation of a database on child development and involvement in early intervention programs would provide a major improvement to the ability to monitor child growth and development during the critical early years of life. Our four partnering agencies were also committed to extending and enhancing their service delivery and to making use of the information and materials developed as result of this Project, in their ongoing activities to support of children and families. The project then would contribute to the continuing process of collaboration and interaction among community-based agencies and university-based researchers in an effort to better understand and respond to the needs within specific communities, and beyond materials, courses and databases. This collaborative process is essential to agencies committed to providing high levels of service to their communities

and also to researchers committed to collecting and disseminating evidence-based practice, programs and policies.

The knowledge transfer strategy as stated has been fully attained. We have developed many different kinds of materials and resources (described in detail in section 4B), which are already being used extensively by parents and service providers throughout British Columbia's urban and rural regions. The partnering agencies have been actively involved in the collaborative development of every tool and material, and have also been active in the use of such resources to inform their practice and services. Besides the resources described in section 4B, the outcomes of this Project are also informing current Master of Education and Diploma program courses at the University of British Columbia's Early Childhood Education Program.

6.1 Publications, Presentations and Tools Developed

Many different tools, events and resources have been developed and made public as part of this project. In this section we provide a comprehensive list of the activities we carried out in order to disseminate the objectives and outcomes of the project.

6.1.1 Academic Presentations

- Goelman, H. (2012). Longitudinal Community-Based Research on Children with Developmental Disabilities. Early Years Conference. Vancouver, BC, February 3-4, 2012.

- Goelman, H., Pighini, M., Synnes, A., Li, Z. and Lisonkova, S. (2010). Understanding the Health, Developmental and Educational Needs of At-Risk Children in BC. Early Years Conference. Victoria, BC, February 5, 2010.

- Goldstein, M. (2012). Play and Development in a Multicultural Context. The Early Years Conference. Vancouver, BC, February 3-4, 2012.

- Pighini, M. (2012). "From here to there I need a hand": The experiences of parents of young children March 6, 2012.

- Pighini, M., Goelman, H. and Brynelsen, D. (2009). A Multiple Case Study of Children and Families in the Infant Development Program of British Columbia. Society for Research in Child Development Biennial Meeting. Denver, CO, April 2-4, 2009.

- Pighini, M., Goelman, H. and Brynelsen, D. (2009). Children and Families in an Infant Development Program: A Multiple Case Study. Division of Early Childhood Conference. Albuquerque New Mexico, October 17, 2009.

- Pighini, M., Lisonkova, S. and Li, Z. (2009). An Interdisciplinary Study of the Trajectories of At-Risk Infants and Children Phase 1: Examining the Children's Health Records in the BC Linked Health Database. Canadian Council for Health Research Student Forum. Vancouver, BC, June 18, 2009.

- Pighini, M.J. (2012). "From here to there I need a hand." The Experiences of Parents with Young Children Diagnosed with ASD. CIRCA-The University of British Columbia, Vancouver, BC, March 6, 2012. Available at *http://circa.educ. ubc.ca/sites/circa.educ.ubc.ca/files/CIRCA_Pighini_Mar6_2012.mov* Slides: *http://*

circa.educ.ubc.ca/sites/circa.educ.ubc.ca/files/Pighini_CIRCA_March-6-2012.pdf

- Stewart, M. (2011). Experiences of families living in rural and remote British Columbia with a child with a disability or developmental delay. Canadian Rural Health Research Society Conference. Richmond, BC, October 20-22, 2011.

- Stewart, M. (2012). The challenges and benefits for families living in rural and remote British Columbia with a child with a disability or developmental delay. Canadian Rural Health Research Society Conference. Levis, Quebec, October 26-27, 2012.

- Stewart, M. (2012). The challenges and benefits for families living in rural and remote British Columbia with a child with a disability or developmental delay. Ontario Association of Infant and Child Development Conference. Vaughan, ON, October 25, 2012.

- Vilches, S., Stewart, M., Goldstein, M., and Pighini, M. (2012). Revealing an Urbanist Policy Bias: Mapping a Social Index of Rurality. Canadian Rural Health Research Society Conference. Lévis, Quebec, October 26-27, 2012.

- Zdaniuk, B. and Pighini, M.J. (2012). Differences in Mental Health Service Utilization between NICU and Non-NICU Children Years 1 to 8. Early Years Conference. Vancouver, BC, February 3-4, 2012.

6.1.2   Community Presentations

- Goelman, H. and Project Team (2012). Learning from Parents and Consultants: Practice to research to practice. DDA Conference. Vancouver, BC, November 9, 2012.

- Goelman, H., Zdaniuk, B., El Khatib, L., Pighini, M., Stewart, M., and Goldstein, M. (2012). Summary of Research and Resources for Berwick Centre (Including all Children Families – Expanding Partnerships Project). DDA, Berwick Child Development Center staff. Vancouver, BC, November 30, 2012.

- Goldstein, M. (2012). Parent-Child Play Interactions in Immigrant South Asian Families. Family Resource Program staff. Surrey, BC, January 25, 2012.

- Goldstein, M. and Pighini, M. (2012). Cross-Cultural Lens on Play and Accessing Child Development Online Resources. Circles of Caring Conference. Richmond, BC, November 3, 2012.

- Pighini, M. and Stewart, M. (2012). Building Connectivity: Developing Online Resources for Parents. DDA Conference. Vancouver, BC, November 10, 2012.

- Pighini, M. and Stewart, M. (2012). Including all Children and Families, Active Listening and Reflective Practices. Infant Development Program staff. Vancouver, BC, June 12, 2012.

- Pighini, M., Stewart, M. and Goldstein, M. (2012). Including all Children and Families-Expanding Partnerships. AIDP, SCDP, IDP staff. Merritt, BC, October 22, 2012.

6.1.3 Government/Board/Inter-sectorial Presentations

- Goelman, H. (2012). In-camera briefing presentations to the Deputy Minister and Assistant Deputy Ministers in the BC Ministry of Children and Family Development. Victoria, BC, October, 2012 and December, 2012.

- Goelman, H. Pighini, M., and Stewart, M. (2011). The Including all Children Research Project. DDA Board Meeting, 2011.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). Boundary Family Individual Services Society. Grand Forks, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). DDA Board Presentation. Richmond, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). Early Intervention Service Providers (AIDP,IDP,ASCDP, SCDP). Prince George, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). Fraser Lake Infant Development Program. Fraser Lake, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). Merritt Infant Development Program. Merritt, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). Nechako Valley Association for Community Living. Vanderhoof, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2010). Yellowhead Community Services. Clearwater, BC, 2010.

- Pighini, M., Stewart, M., and Goldstein, M. (2011). Dawson Creek Child Development Center. Dawson Creek, BC, 2011.

- Pighini, M., Stewart, M., and Goldstein, M. (2011). Enderby Community Resources Centre. Enderby, BC, 2011.

- Pighini, M., Stewart, M., and Goldstein, M. (2011). Fort Nelson Family Development Society. Fort Nelson, BC, 2011.

- Pighini, M., Stewart, M., and Goldstein, M. (2011). Golden Family Services. Golden, BC, 2011.

- Pighini, M., Stewart, M., and Goldstein, M. (2011). Secwepemc Child & Family Services. Kamloops, BC, 2011.

6.1.4 Research Reports

- Goelman, H. Pighini, M., and Stewart, M. (2011). BC Kids not all Born Equal. Policy brief and full academic report. Population Data BC (*UBC*), 2011.

- Goelman, H., Houbé, J., Klassen, A., Li, Z., Lisonkova, S., Pighini, M., Synnes, A., and Zdaniuk, B. (2011). Using Linked Administrative Data Bases to Study the Longitudinal Outcomes of Children Treated in NICU Settings: Technical Report. Population Data BC, 2011.

6.1.5 Scholarly Articles

- Goelman, H., Ford, L., Pighini, M., Dahinten, S., Synnes, A., Tse, L., Ball, J., et al. (2011). What we have learned from early identification and screening. In H. Goelman, J. Pivik, & M. Guhn (Eds.), New approaches to early child development. Rules, rituals and realities, pp. 95-116. New York, NY: Palgrave Macmillan.

- Goelman, H., Zdaniuk, B. and Pighini, M. The Educational Outcomes of a Population of NICU Survivors and non-NICU Children in Kindergarten and Grade 4 Using Linked Administrative Data Bases (Manuscript in preparation).

- Guhn, M., Swart, S., Pighini, M. and Vilches, S. (2011). Graduate student experiences in the CHILD project: The invaluable contribution of interdisciplinary, collaborative research to young academics and professionals. In: H. Goelman, J. Pivik & M. Guhn (Eds.) New approaches to early child development. Rules, rituals and realities, pp. 179-200. New York: Palgrave.

- Pighini, M., Goelman , H., Buchanan, M. Schonert-Reichl, K. and Brynelsen, D. (2012). Learning from Parents' Stories about What Works in Early Intervention. (Manuscript submitted for publication).

- Stewart, M. The Challenges and Benefits for Families Living in Rural and Remote British Columbia with a Child with a Disability or Developmental Delay. (working title) (Manuscript in preparation).

- Vilches, S., Stewart, M., Pighini, M., Goldstein, M., Chan, H., and Goelman, H. Rural Index Revealing an Urbanist Policy Bias: Mapping a Social Index of Rurality (working title) (Manuscript in preparation).

- Zaidman-Zait, A., Pighini, M., Stewart, M., and Zdaniuk, B. Early Intervention Service Providers' Experiences with Family Centered Practices (working title) (Manuscript in preparation).

6.1.6 Theses

- Stewart, M. (2012). Experiences of families living in rural and remote British Columbia with a child with a disability or developmental delay. Master of Arts Thesis, University of British Columbia, Canada. Available at *https://circle.ubc.ca/ bitstream/handle/2429/42144/ubc_2012_spring_stewart_mary.pdf?sequence=1*

6.1.7 Community-Professional/Online Publications

- Collective-Advisory Committee (2011). Snow. Compiled by Mari Pighini.

- Collective-Advisory Committee (2012). The Ride. Published in the Newsletter of the Family Suppport Institute: *http://gallery.mailchimp.com/ 48e9946677c3ab7e869897041/files/Fall_2012_Newsletter.pdf* (page: 19-20) Compiled by Mari Pighini.

- Goldstein, M. (2012). Including all Children and Families Trips (Audiovisual). Unlisted video available at *http://www.youtube.com/watch?v=7IpEyBgeELg* (pending approval)

- Goldstein, M. (2012). Play in a Multicultural World. "Family Connections" the

BC Council for Families Magazine. 16(1), 9-1. *http://issuu.com/bcfamilies/docs/familyconnections_spring_2012*

6.1.8 Assessment Workshops

- Brynelsen, D., Chan, H., Pighini, M., Stewart, M., and Zaidman-Zait, A. (2012). Implementing Fair and Family-Centred Assessment Practices: Ask Parents First! 10th Annual Early Assessment Workshop, Faculty of Education, UBC, May 3, 2012.

- Goelman, H. (2012). Keynote: The Dangers of "High Stakes Assessment". 10th Annual Early Assessment Workshop, Faculty of Education, UBC, May 3, 2012.

- Goldstein, M. and Mazabel, S. (2012). Cultural and Linguistic Diversity in Play and Literacy Assessments - 10th Annual Early Assessment Workshop, Faculty of Education, UBC, May 3, 2012.

- Goldstein, M. and Negreiros, J. (2011). Play and Drawings: Expressions of Child Development - 9th Annual Early Assessment Workshop, Faculty of Education, UBC, May 12, 2011.

- Stewart, M. and Brown, T. (2011). ASQ-SE: Using the Ages and Stages Social Emotional Questionnaire in Community Practice - 9th Annual Early Assessment Workshop, Faculty of Education, UBC, May 12, 2011.

6.1.9 Tools/Materials

A. **Healthcare locator.** We have developed a free interactive map that shows the exact location of healthcare providers throughout BC. (*http://includingallchildren.educ.ubc.ca/work-research/social-inclusion-project/healthcare-services-locator/*). Users can browse the page by region and locate the centres in that geographical area. This tool will potentially benefit parents of children with special needs and the professionals who work with them.

B. **Linked Disc.** An electronic and centralized online database with information on children's and families' participation in intervention programs. The database has been tested at the pilot level. The Linked Disc is to be used by parents of children with special needs.

C. **Questionnaires.** Getting some information about how a child is developing. These questionnaires are pre-screening tools. They are not meant to replace assessment or screening tools, and they are not meant to monitor a child's development. They offer parents and professionals informal information about what typically developing children can do at different stages of development. These materials will potentially be useful for parents of children with special needs and the professionals who work with them.

D. **Online learning modules.** The purpose of the course is to introduce those who are exceptionally interested in the field of early intervention. The course has four modules that briefly describe typical and atypical child development, what the major developmental disabilities and conditions are, what intervention options are available for these conditions, and who the professionals are working in the early intervention field. The learning modules are geared towards Parents of children with special needs and the professionals who work with them. The course could possibly be used by ECE, early intervention and child development students.

E.   *Website*.   The website has practical information that can help parents of children with special needs and the professionals who work with them find resources both in their communities and elsewhere. Resources found here will be particularly useful to parents of children with special needs and the professionals who work with them.

6.2   Sustainability Plan

An essential element of our sustainability plan is our website (*http://includingallchildren.educ.ubc.ca/*). This site serves as repository of a very important fraction of our research team's work, and is also a place where users can post comments or questions. The continuation and maintenance of the website and an accurate response to users' comments is critical for the future impact that the Project could have on parents, service providers, community members and professionals of any discipline. The website is currently hosted at UBC's Faculty of Education's servers where it will remain in the future years, also linked to the Institute of Early Childhood Education and Research (IECER-Research Links) where the research coordinator of the project holds a cohort advisor/instructor role. We are in the process of looking for funds to hire a webmaster that would update the website regularly, respond to users' comments and attend to any issues that may relate to the proper functioning of our website.

Also central to our sustainability plan is the preservation and continuation of the partnerships and network connections that were created and enhanced as part of this Project. Towards this end, we will continue to enhance our collaborative practices for example, with the Berwick Child Development Centre, DDA, and through ongoing research collaboration with faculty and post-doctoral fellows in BC, Canada and abroad, including UBC, SFU, University of Alberta, University of Canterbury (New Zealand) and Tel-Aviv University (Israel).

One more element in our sustainability plan is the creation of a "Centre for Collaborative Research and Training in Intervention and Developmental Disability." To date, we have found a physical space for this resource centre at Berwick Child Development Centre facility located at the University of British Columbia. The centre will integrate academic, professional, and family expertise and resources and will hold a unique collection of books, reports, DVDs, and other resources for early intervention professionals and early childhood educators. Its main objective will be to support those working, and living with, children who experience additional developmental needs, or who are at risk for developmental delays or disabilities and their families in their current practices, and in the planning, implementation and follow up of the different programs with which they are involved. We are currently looking for means to hire part time staff that would maintain the resource centre in working order and potentially deliver workshops for interested community members.

7   Main Achievements and Lessons Learned

In the course of this project several challenges were overcome and numerous successes were achieved. We will briefly describe our experiences in working with the different actors that formed part of this journey.

7.1   Main Achievements

The project has positively connected to the different participant agencies and the families they serve in different meaningful ways. The establishment of collaborative partnerships and networks with the different agencies has certai nly been a highlight of this project. This has been acknowledged by Marilee Peters (BC Council for Families) and Beth Hutchinson (Mother Goose of BC), who have reported that the networking and information sharing provided great advantages for them and their agencies. They also claimed that their participation and involvement with the research allowed them to disseminate information among staff thus enhancing current membership and allowed them to reach to a broader community of supporters and followers. The research team concurs in that one of the main achievements of the project was in fact the scope of connections that were made across the province and the engagement from community in the research process.

One of the main achievements of this project was that it facilitated dialogue between families and professionals living in remote and rural communities. A second related achievement, was the ability to learn about and to document the rural experience. This has been corroborated by different advisory committee members. From the research team's perspective, the connections made with rural communities was a very valuable outcome. It was an enormous project with many layers and levels, which encompassed the voice of families and service providers working with some of the most vulnerable children in the province in many geographic areas (communities) that had not previously been involved in research to this degree before or may have never been involved in research at all. During the course of this project researchers visited many rural communities in the interior and Northern BC and in every place they encountered warm hearted people who welcomed them into their homes and communities. The research team members interviewed parents, did focus group interviews with parents and presented to a group of service providers in each community we visited. So one of the main successes of this project was to provide the opportunity for people to share their own experiences and stories. The feedback received was always very important and taken into serious consideration, and researchers agree in that we learned from the people just as much, if not more, of that what they have learned from us. Going on these trips and visiting those communities was the highlight of the project, and what really made it unique and different since we were not just a group of well-intentioned researches but a devoted group that actually went and visited the communities. We drove the roads as the parents and service providers did, and we had first-hand experiences about how these people live.

Other achievements included the development of online learning modules and other online resources that can help parents learn about the special need that their child has. Further, the project succeeded in the development of questionnaires that can help parents and professionals learn about normative child development. These questionnaires are available in several languages and this means they can be reached by more people and specifically more parents. Advisory committee members have indicated that the online parenting course on child development, along with the other vast online resources developed throughout the project, is indeed a huge accomplishment and something that originally got the representatives interested in the project. These resources will be tremendously helpful for parents in understanding their child's development.

Overall, the relevance of the project is the powerful way in which it has helped bring various resources, information, and support together for BC families with disabled children from 0-12.

In effect, according to Dr. Linda Farr Darling (UBC), it has shone light on what is available for parents and guardians in rural communities, and has also brought attention to where and what the gaps might be in terms of service provision, education, and guidance.

7.2 **Lessons Learned**

As a research team, we learned that different individuals view child development and early intervention through different lenses, and it was not always easy to address comments/edits from different members of the team, especially when they had opposing positions about the same topic. This has also been noted by some of our advisory committee members, who have shared that one of the challenges of the committee was feeling that things were somewhat political, and that at times, it seemed difficult to achieve consensus or a shared vision.

Also, one lesson learned is that it is very hard to stay connected and informed on a project this size, and that having face to face meetings from time-to-time would help connect the advisory group.

According to our advisory committee members, the challenges of partnering for this project involved the development of an increased capacity to act and respond to informational requests related to access to healthcare. As a result, representatives from the Society for Children and Youth of BC have expressed their interest in continuing to focus on issues of access and health through different health advocacy projects that promote capacity building for health professionals to be health advocates.

On the research implementation side, there were many lessons learned and challenges overcame. For instance, while the scope of the project was one of its major achievements, it was also one of the main challenges and provided the research team with many lessons learned. Initial contact was sometimes hard as researchers did not have established relationships in community earlier, with the closure of the IDP/SCDP provincial offices, previously established networks for communication were dissolved. While research team members utilized formal and informal networks, which certainly can work well, sometimes people and connection were inadvertently missed.

On the methodological side, due to the extensive work load, sometimes the timing of the distribution of materials was not as researchers would have liked, i.e,. sending out surveys close to holiday season or summer. Another challenge was the part-time nature of some of the staff so that not everyone was able to or chose to participate in provincial meetings and travel when required. This did not allow those staff the full experience of understanding the great diversity and distance and challenges of the families and service providers included in the studies.

If the absence of the IDP Provincial Advisor's role (and the office of the Provincial Advisor) impacted on our recruitment and data collection process for the research component of this project, the presence of Mary Stewart in our team mitigated some of the initial challenges we experienced. Mary's active presence ensured that the connections that could have been lost were instead re-gained and maintained with former project coordinators and new provincial contacts including those from the Ministry of Children and Families. Mary Stewart was the Regional Advisor for IDP for the North Region for more than a decade, and previously worked as an Infant Development Consultant for these communities. Her solid contributions and integrity in her work made it possible for this project to secure the support of many of the agencies with the different programs. Her work, in conjunction with the supportive roles played by Diana Elliott, Provincial Advisor for the AIDP, and Cindy Jamieson, Provincial Advisor for the ASCDP, enabled the project to overcome its challenges.

8.1   **Reaching Communities throughout BC**

For geographically isolated communities of BC, this project has represented an opportunity for their members to participate in a province wide project giving voice to such commonly overlooked communities and consequently, the regions where they are located. The relevance of this project and what makes it unique is its focus on reaching families in rural and remote communities. Families living in isolated areas are hard to reach and therefore they are often isolated from research and services. We tried to break this pattern and by involving rural families and communities in a new and creative initiative that had never before been offered to them and which they can replicate in the future. What is more, the connections formed at every juncture of the project will be useful future initiatives that will illustrate and describe experiences of parents in raising children with disabilities, and sharing their perceptions of the ways in which they access information about their children, and receive services for their children).

In order to reach different communities in BC, we *travelled* and connected with community members in different early intervention agencies; when we met with them, we shared with them the goals and deliverables of our project and asked them for ideas on how to go about recruiting participants for our studies. Our first trips (Spring and Summer 2010) provided us with initial contacts and informants, who shared their current professional experiences, and invited parents in their communities to share their interests and feed in their ideas. Informant communities through IDP and AIDP program agencies included Kelowna, Merritt and Clearwater in the Interior, and Prince George, Vanderhoof and Fraser Lake in the North. During the Fall of 2010 and throughout 2011, the trips continued to other communities. This stage of the project included data collection for the Multiple Case Study and initial recruitment steps for the MPOC Parent and Linked Disc studies. At the same time, we planned to meet with community agency representatives in one or more of the early intervention programs, and for them to connect, at their own discretion with any other early childhood education programs, schools, families, social services, health and/or therapy agency programs. During these meetings, we shared goals and deliverables of the project and from the very beginning provided highlights of preliminary findings that would be of interest for communities. We used power point presentations that were individually edited depending on the interests of the particular audience. We also provided

handouts, and sometimes meetings consisted more of an informal conversation, trying to engage the different community professional and agency staff members wherever they were at the time and depending on the available setting of the meeting.

For example, program coordinators representing several early intervention programs in the North region had comments on and questions about the way we would recruit for the focus groups (Linked Disc) study, and how to find out about parents accessing information about their children. These were some of the comments:

> On practice: **"I** [coordinator] **give them** [parents] **a blank book and they keep their records…**[the coordinator] **has created a whole system, then they** [parents] **don't need to tell it every time.**
>
> Sharing achievements/ideas: **"The Canadian Prenatal Society - have a lot of successes with focus groups, do it around once a month."**

And,

> **"Sometimes go to existing groups, we invite ourselves and we go."**
>
> On support: **"That's a great way to recruit people."**
>
> Queries/concerns: **"What about sensitive information on the Linked-Disc? Would you put things like FASD?"**

In a similar meeting in the Interior with representatives of ECE, school and family services agencies in the Interior, a suggestion to find out about the Spectrum Solution program was shared in order to find out how this program was working in terms of collecting and sharing information on assessment and follow-up children and families. Spectrum Solution is a database project connecting parents with children with autism which includes the I-CAN Assessment. This is funded through the Kootenay Boundary Community Services Cooperative (http://www.thekoop.ca/services/).

Agency representatives in this meeting also commented on the recruitment and data collection process for the "Multiple Case Study" and "Focus Groups." They valued the following characteristics:

> **"Face to face interaction, link with someone in the community, communication with the people, telling them that someone will come especially to interview them."**
>
> They added: **"It's very different than getting something in the mail."**

And,

> **"It is important to have within a trusted relationship"**

We followed similar steps with informant groups in the communities of Salmon Arm, Enderby, Kelowna, Kamloops, Grand Forks, Castlegar, Golden, in the Interior region, and Smithers, Houston, Fort Nelson and Dawson Creek in the North (click *here* for a detailed chronological list of events of informant, data collection trips, and the creation of resources and materials).

Issues of rurality and remotedness were brought up when reading the main topic research question for the "Multiple Case Study" (Stewart, 2011) "What are the experiences of parents raising a child with a disability and living in rural/remote communities". These comments and insights from the research team travelling experiences in different rural and remote communities throughout the 2010-2011 trips are captured in the document entitled "SNOW" (click _here_ to read this document).

Several of these sites were also places where we conducted data collection for the Case Studies, Linked Disc and MPOC Parents (and Geo-Ethnography) studies. For all of these sites, an important component of our presentations was the resources or "deliverables" with the website, online questionnaires and learning modules (online course). Agency representatives did not only comment then on the data collection and tools we planned to use for our studies with critical feedback, but they also provided us with insights and feedback on the internet and printed resources – including our brochure—that were in the making at the time (click _here_).

Informants and collaborators in these community meetings also cautioned the research team on what are elements that may limit our participant recruitment, including the wording used in the ethics contact letter and form:

> **"Reading the first two paragraphs people will not want to continue. We need to have sense of trust/ confidence built first – put it in more "friendly" voice than the one from UBC ethics."**

The length and literacy level of the parent survey (MPOC-Parents) were questioned. The feedback provided allowed the research team to conduct extensive edits to the material to be sent to prospective participant parents:

> Concerns about parents filling surveys: **"…difficult to read; headings on each page are needed** (formatting)**"** and later **"not sure they will be comfortable to answer it with them, some questions are very personal"**

And,

> **"Finding the time to do it is problematic. When you have the time to sit down you don't want to fill in a survey."**

> Concerns about time spent with service providers: **"Some questions will open other issues that the parents will want to talk about if the service provider will do it with them, and the service providers are very busy."**

> Anticipation/ predictions: **"Some parents will do it, but not a lot." … "I think it will be very interesting but the response rate will be low."**

And,

> **"The families here sometimes have too many surveys. If they knew that there is an outcome, if it will benefit their child development they will want to do it, not it an**

economic way, not a gift card, but information. Otherwise it's problematic. "

Suggestion: **"The families would do it if someone would sit down to do it with them."**

Predictions about low return rates for the MPOC Parent mailed study were accurate. Even after over 250 envelopes were sent out, with approximately 100 delivered in person to agencies, and the rest mailed to the identified contacts in the selected agencies, only 29 parents living in smaller urban and rural and remote communities in the North and Interior region completed the mailed survey. Almost a year later, we decided to try a second data collection phase and convert the MPOC survey to an online format through a secure system (Enterprise Management System) at UBC. This time, recruitment was conducted with the help of provincial agencies and organizations that sat on our advisory committee by posting a link with an invitation to participate in the study directly posed to parents receiving early intervention services for their children. The results were quite different as in less than 21 days we received completed online surveys from 35 participants throughout BC (mostly Vancouver-Coastal, Fraser and Vancouver Island). At the time of the writing of this final report, we are completing analyses of the data collected with all participants. Therefore, only preliminary analyses including descriptive information for stage 1 of the data collection, and some hints of emerging trends are available (click *here*). Updated community summaries and academic publications are forthcoming during 2013 and 2014.

In reference to the Service Providers study that was only completed in the late Fall of 2012, all informants and collaborators attending the group meetings agreed that it would be an important study and one where service providers would readily take part. Their predictions were accurate as the study recruited over 60 participants in a 2-week online data collection process from all regions (Vancouver-Coastal, Fraser, Vancouver Island, Interior and North). Moreover, 14 participants participated in follow-up interviews expanding on their experiences as early intervention service providers in IDP, AIDP, SCDP and/or ASCDP. A summary of preliminary findings is available *here*, with more updated summaries and a forthcoming academic publication in progress.

An important value added to this project was the contribution from Maya Goldstein's graduate study on the parents' perceptions of play and child development from the perspective of South-East Asian parents. Maya's research was independent from this project; however, the topic explored for the master's thesis soon proved to be a relevant one for this project in that it acknowledged the unique realities experienced by immigrant families with individual notions of what is play, how and when to play and what is the purpose of play. The study highlighted the roles extended families play in supporting child development and the non-traditional ways in which played is viewed by these parents. Maya's work is featured on this online publication of the BC Council for Families (*http://issuu.com/bcfamilies/docs/familyconnections_spring_2012*). Through this publication, an additional shorter version for the BBCF newsletter (*http://www.bccf.ca/professionals/blog/2011-11/children-play-how-does-culture-fit*) and Maya's community presentations, the Including All Children and Families Project was also featured, together with our materials. Several invitations for community presentations came along thanks to Maya Goldstein's work. Establishing different paths and connections for diverse aspects of this project proved fruitful in the knowledge translation and dissemination of our project.

8.2 **Online Resources**

The availability of a series of online learning modules where the family can learn about the special need that a child has, and what intervention options are available to them will hopefully help these families make informed decisions for their children about who to consult and how to proceed with intervention options. The fact that these modules are free of charge is another added benefit. Parents and professionals can reach these modules anytime they want, without having to pay anything. According to our advisory committee members, the creation of the online resources will add value to the project for as long as they are maintained, since these are fabulous resources for families of children with disabling conditions or with developmental challenges. They have also expressed that they see the value of continuing to inform families about the project and its resources, and researchers concur with this perspective.

> **"The on-line parenting course on child development is a huge accomplishment and what originally got me interested in the project." Lorraine Gerwing** – ECD Northern Rockies.

> **"The on-line course that has been developed (with many people's expertise) for parents and service providers is a much-needed addition to resources that are available to educate families about child development, developmental delays, special needs, etc. This was also an inspirational model of course development for me. I am presently co-developing, with rural researchers and educators, an interactive online course for rural teachers and teacher candidates that addresses the economic, socio-cultural, and political contexts in which rural schools are nested." Linda Farr Darling,** PhD – Faculty of Education, UBC.

> **"One of the greatest achievements of this project is the establishment of vast online resource of information and questionnaires for parents to use in understanding their child's development"**. **Beth Hutchinson** – Mother Goose of BC.

Agency representatives in the Interior region expressed their views following a presentation of the online resources, not only for professional training but also for parent information.

> **"It will be helpful for families that we contact with, they could check online too, because our time with them is limited and not everyone is home when we are there to explain."**

> **"The question is if parents will think that they can get all the information online and won't want the service providers anymore?"**

> **"The online course is the most exciting part."**

> **"Language is not a barrier in the work we do here in Kelowna. Punjabi is the only language we come across with…"**

"…Many times cultural [issues] **and development come across. We try to tell the parents what to do with their children when they are very young, but according to some parents, in their culture, children should rest for their first 40 days and not been seen by anyone** (an example)**."**

Additionally, the online resources, in particular the learning modules, are not only perceived as a much-needed addition to resources already available to families and practitioners, but also as an inspirational model of course development. Dr. Linda Farr Darling (UBC), a member of our research and collaborator with our advisory committee has indicated that she is presently co-developing, with rural researchers and educators, an interactive online course for rural teachers and teacher candidates that addresses the economic, socio-cultural, and political contexts in which rural schools are nested, and that our work has served as a model and inspiration (www.ruralteachers.com).

Therefore, the maintenance of the website and all its contents is a crucial element of our sustainability plan.

8.3   Policy Making

In the view of the research team, this project contributes a great deal to the existing literature on best practice for children/youth with special needs and their families. This brings together the voice of families and practitioners, and can provide some clear guidelines and direction for policy at government, community, agency, and practice levels regarding what is working for families and what is not. Agencies' representatives have also acknowledged the potential of this research into the needs of families, to influence policy.

For instance, the different research studies in this project have highlighted that parents appreciate the importance of a well informed and local service provider and the importance of a strong working relationship with the service providers ("Case Study"). Service providers, on the other hand, value connecting within their community as well as any training and access to information and networks, both within community and within the larger province and early intervention field ("Service Providers Study"). We have also identified concrete behaviors that enhance family centered service delivery so programs and service providers can use this information to enhance their practice ("Parents Survey Study: MPOC"). Further analyses of all the projects will be needed to further "connect the dots" and create stronger service delivery for families and children. This research is meaningful and applied and that has been noted as a value added component for community by researchers. Parental or service provider participation in the study increases their sense of self-worth and value. For instance, parents have expressed "I just so appreciated someone hearing my story" or "Telling my story over again made me realize what we have been through and how far we have come." As these quotes illustrate, this project can have huge implications in terms of parental feelings of competence. Service providers also expressed that they appreciated being heard and or that they appreciated the project being interested in their work. These individuals may go on to participate in further research and or may view research generally very differently because it has meaning and is relevant to them.

"As a researcher working in social policy, I find the array of the linked projects provides a comprehensive set of vantage points on social issues. The mix of quantitative and qualitative data, plus the variety of methods, provides data for a very robust assessment of how social policies are affecting families, children and service providers. Research tends to be focused on either clinical issues or structural issues due to lack of time or budget, so the amount that was done with little resources is a testament to the vision of the team leads. The community advisor committee provides a strong check on external validity, as well."

Silvia Vilches, PhD
Postdoctoral Fellow, Department of Sociology, Simon Fraser University

8.4   **Methodological Value**

Members of the research team have highlighted the value of the project also in terms of its methods and theoretical approach. The variety of methodologies and methods for data collection and data analysis resulted in a mix of quantitative and qualitative data that allow for a sturdy evaluation of the different issues that affect families, children and service providers. This project also allowed for a deeper appreciation of the multiple points of intersection between education, social and health services in small BC communities, and the potential there is to integrate research data with other resources in order to promote the well-being of children living with disabilities.

Research team members have also acknowledged the incredible opportunity this project presented in terms of learning and training. Having the chance to learn from such a diverse group of researchers and to be given the opportunity to actively and meaningfully facilitate the link between community practice/experience and research work was another positive outcome of this project. Members of the research team agree in that having been part of this incredible and diverse experience was an expansive professional learning opportunity.

9   Recommendations and Final Comments

"The diverse sources of information and methodologies reinforced each other, making a very strong foundation for future research. It is generally difficult to obtain data which matches personal experiences to statistical population descriptors especially at a single moment in policy time. This study was an opportunity to provide a benchmark for future work as well as an extraordinary opportunity to learn about the unique strengths and needs of rural families."

Silvia Vilches, PhD
Postdoctoral Fellow, Department of Sociology, Simon Fraser University.

Research collaborators as well as advisory committee members have expressed their interest and hope that the project can continue in some way, and that the resources we have developed are maintained available to the public. Bringing researchers, practitioners and service providers together enriches all our efforts to help children realize their potential no matter the challenges they face. A project like this highlights the power of collaboration and communication across sectors in order to provide support and education to families and children.

Some examples include:

- Having obtained space at Berwick Centre through DDA with the possibility of developing a resource centre

- Being close to ECE professional staff and children and parents, that in turns allow for ongoing communication and opportunities to provide additional training (also for other centres, face to face or online)

- Working in conjunction with organizations like the Family Support Institute, the BC Council for Families and Parent Child Mother Goose and the Society for Children and Youth (the latter also located at Berwick Centre)

- Ongoing collaboration and continuation of learning and training through post-secondary education programs (*IECER* and *PDCE* at UBC) that increase the possibilities of knowledge translation and dissemination of information with diploma and graduate level students who are leaders in their communities in BC and throughout Canada.

We are aware of the huge amount of responsibility we have as holders of such vast and rich information. We also acknowledge we can continue to make a change in families' and service providers' lives. For this reason, we will seek means to ensure that the outcomes of this project are communicated broadly to different audiences.

An important aspect of this project referred to working in collaboration with Aboriginal programs and learning from Aboriginal parents' experiences in raising their children with additional needs (especially in rural and remote communities), and also learning from early intervention service providers working with these families. Feedback on the impact of the project included the following statement from Cindy Jamieson, Community Advisory member, in her role as Provincial Advisor of the Aboriginal Supported Child Development Program: "This project could have relevance for supporting children, youth and families by generating the following information: evidence for service gaps to inform advocacy efforts for increase resources; examples of best practices in BC ECD programs toward inspiring future program development for better quality services; and opportunities for information sharing among service providers, thereby promoting enhanced service integration and collaboration." At the same time, the team was cautioned of the burden that staff in Aboriginal early intervention programs had experienced between 2010-2012 with different surveys coming their way. Our efforts to support the data collection through narratives (stories) were commended; and yet, the fact that we did not represent (as team members) Aboriginal voices was noted, with an invitation from Cindy Jamieson to allow for "communities and programs [to] . . . lead these projects, according to their stated needs, instead of relying on 'expert' or academic insights."

While we acknowledge that our project was not exclusively framed by an aboriginal research approach and philosophy, we do believe our project captures the voices of several Aboriginal parents in the North, as well as service providers in Aboriginal early intervention programs throughout British Columbia. We would like to express that we concur with Cindy Jamieson in that it would be most beneficial for families and service providers if future research studies would address early intervention from an indigenous education perspective. For now, we present and make available to all this final report that includes resources and materials informed by aboriginal voices as well. As we progress with the data analyses, interpretation, and writing of our findings we will be able to further share these with Aboriginal and non-Aboriginal programs and communities in BC. We are grateful of all the interest, support, commitment and dedication of each one of the staff members, parents, and agency representatives who contributed to this project.

As a research team, we are very proud of what we accomplished despite all the challenges and adversities.

BC Children First (2005). Early Childhood Development in the Fraser Region. Retrieved April 27, 2008 from http://www.bcchildrenfirst.ca/newwest/ECDintheFraserRegion.pdf

Goelman, H. & The CHILD Collaborative (2010). Three complementary community-based approaches to the early identification of young children at risk for developmental delays/disorders. Infants and Young Children, Journal of the International Society for Early Intervention.

Goelman, H. & The CHILD Collaborative (in press). Three complementary community-based approaches to the early identification of young children at risk for developmental delays/disorders. Infants and Young Children, Journal of the International Society for Early Intervention.

Goelman, H., Synnes, A., Houbé, J., Klassen, A., Lisonkova, S., & Pighini, M.J, (2008). Follow-up of children at-risk for developmental disabilities and their families. Paper presented at the Early Years Conference, February 1, 2008, Vancouver, BC.

Goelman, H., Synnes, A., Houbé, J., Klassen, A., Lisonkova, S., & Pighini, M.J, (2008). Follow-up of children at-risk for developmental disabilities and their families. Paper presented at the Early Years Conference, February 1, 2008, Vancouver, BC.

Hebbeler, K.; Spiker, D.; Bailey, D.; Scarborough, A.; Mallik, S.; Simeonsson, R., et al. (2007). Early intervention for infants & toddlers with disabilities and their families: Participants, services, and outcomes. Final Report of the National Early Intervention Longitudinal Study (NEILS). Retrieved July 31, 2007 from http://www.sri.com/neils/pdfs/NEILS_Report_02_07_Final2.pdf.

Meisels, S. J. (1999). Can Developmental Screening Tests Identify Children Who Are Developmentally at Risk? Pediatrics, 83, 578-585.

Pighini, MJ (2008) A multiple case study of the children and families in the Infant Development Program of British Columbia. Unpublished doctoral dissertation, The University of British Columbia, Vancouver, Canada. Available online at https://circle.ubc.ca/handle/2429/5308

Pivik, J. (2008). Principles, Policy and Practice: Supporting Children with Special Needs in British Columbia, BC Healthy Development Alliance –Special Needs (BCHDA-SN), Vancouver, British Columbia

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Welcome Baby!

We welcome baby Essy (Esme), born October 2011 and daughter of Chanelle and Shaun Sweeney - and also the newest addition to our team

January 2013