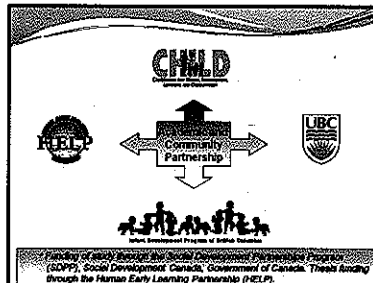


Children and Families in an Infant Development Program: A Multiple Case Study

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Rationale

Limited qualitative, retrospective research in early child development:

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this creates a gap in our understanding of the experiences of children who are developmentally at risk and of their families*.

* e.g. pre-eclampsia birth, congenital anomalies and clefts

Background

The Infant Development Program of British Columbia (IDP of BC):

- British Columbia's Provincial early intervention (EI) program for developmentally at-risk children (birth to age 3 years) and their families:
- Provincial funding and community-based sponsorship
- Home Based, In-centre and Drop-In Groups Levels of services
- Over 100 IDP Programs in BC, including the Aboriginal Infant Development Program (AIDP).

Source: www.idpbc.ca

- The IDP of BC has collected, but not analyzed, medical, developmental and family information on more than 79 000 children in BC since 1972 (Office of the Provincial Advisor, 2006).
- The IDP of BC has never participated in this kind of research study before.

Objective of the Study

- To examine the experiences of parents with developmentally at-risk children.

Purpose and Meaning of the Study

To:

- add parents' perspectives and voices to special needs research; this is a missing component in extant research literature;
- begin tracing children's developmental paths within their family contexts.

"Topic" Research Question

What are the parents' perceptions of the impact of early intervention on:

- early childhood development,
- parenting, and/or
- family dynamics,

In families with a child at-risk for developmental delays or diagnosed with developmental disabilities?

Four Specific Research Questions

- What are the experiences of parents of developmentally at risk children and their families who participated in the IDP in terms of their child current developmental needs?
- What are the experiences of parents of developmentally at risk children who participated in the IDP in terms of access to resources and programs?
- In what ways do the experiences described in 1) and 2) relate to the current preschool/school demands on these parents?
- In what ways do the experiences described in 1) and 2) relate to the demands from other family members, and to financial/work pressures?

Methods

- Epistemological Stance: Post Positivism
 - Approximation to reality
 - Multiple methods of data collection
- Tradition of Inquiry: Ethnography
 - The case of parents in the IDP
- Naturalistic Research Design
 - Multiple case study approach (Creswell, 1998, 2003)
- Participatory research (Tedlock, 2000)

Two Stages for Data Collection

Stage One: Families 1, 2, 3, and 4 – Home visited.

By age 3 years:
 • four children diagnosed with disabilities*;
 • special needs designations and support services in place since preschool;
 • one child with developmental delays; no diagnosis;
 • attended inclusive preschool with therapy services;
 • diagnosis and special needs designation only at age 5 years.

Stage Two: Families 5 and 6 – Attended waitlist/monitoring group.

At birth:
 • two children identified as "at-risk" for developmental delays*;
 • attended preschool;
 • received no diagnoses, special needs designations, follow-up consultation services, or therapy services after IDP discharge.

* children in the "grey area"

Characteristics of Final Sample

- Purposefully targeted sample:
 - Parents whose children were born between 1999 – 2003; children's ages ranged between 3 and 7 years old;
 - in preschool or school stages during the data collection.
- The final sample included 11 parents, in six families with seven children;
 - all met criteria for inclusion.

Family Demographics

- Five two-parent families; one lone parent family.
- Adult participant parents/guardians (e.g., older than 21 years old).
- Parents had at least some post-secondary education.
- Parents received no income assistance; most parents worked part-time.
- All parents spoke English; at the same time, families represented a range of five languages and countries of origin, and seven cultures.

Data Sources and Data Analyses

- Data Sources:**
 - children's IDP file reviews;
 - interviews (participant parents only);
 - focus groups (Stage One only);
 - memos and theoretical notes/annotations (Strauss, 1987).
- Data Collection:**
 - number of interactions during main data collection activities, file revision and member-check sessions
- Data Analyses:**
 - mostly qualitative content analysis for data analyses of interviews/focus groups (e.g., Berg, 2007).

Findings: Time, Timing and Timely

Thematic Analyses*

- Themes Across Participants
 - thirteen main themes combined into seven revised themes and categories
- Themes Within Participants
 - six themes were identified

*e.g., Krippendorff, 2004

"Topic" Research Question: Perceptions on Impact of Early Intervention

Two important aspects in the effectiveness of early intervention programs:

Theme 1: Family Centred Approach and Home Visitation Services

- parents' knowledge of their children's needs leads EI family-centred practices;
- asking parents "what works" is key for the success of EI program;
- ignoring parents' needs reduces chances for parents accessing EI services.

Specific Research Question 1: Child's Current Developmental Needs

Theme 2: One to one relationship with consultant or therapist; and,

Theme 3: Inclusion of family members

Consultants' unique role and relationship support parents in:

- their awareness of their children's developmental needs;
- timely referrals for EI services;
- these may not continue after IDP discharge;
- parents confronted with medically-based criteria for referrals that do not support children in the "grey area."*

*refers to children at-risk, but with no identified diagnosis

Specific Research Question 2: Access to Resources and Programs

Theme 4: Collaborative Consultation;

and,

Theme 5: Effective Knowledge Translation in Sharing Information/ Resources

A family centred approach is needed to ensure the following:

- collaborative practices between professionals and families, that in turn support empowerment and joint decision making; and,
- effective two-way knowledge translation in sharing clear and meaningful information with parents.

Specific Research Question 3: Current Preschool/School Demands

Theme 6: Case Managing and Service Coordination

Implementation of joint parent-professional collaboration and knowledge translation:

- ensures centralized ECE/EI services and case managing coordination;
- This is not in place following IDP discharge.

Absence of coordination following IDP discharge:

- accessing ECE/EI program and services becomes stressful;
- ineffective for parents.

Specific Research Question 4
Needs of Family (i.e., logistics, job, financial)

Parents' ongoing confrontation with stressors that become barriers:

- "cycles of disability and anticipation;"
- parenting over a lifetime;
- different family stressors on fathers, mothers, and siblings;
- less explicit: family dynamics including couples and family-related issues.

Theme 7: Stressors that Become Barriers

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Six Themes and Quotes by Family (Within Participants)

Family 1: Conflict of Values: prefer to use public, rather than private services.
Mother 1: "We are all planetary citizens." Father 1: "The problem is all with what I can pay for [in town], as a matter of fact, I am glad with what I am now."

Family 2: Support and Networking to gain on a daily basis and anticipate needs of child
Mother 2: "When your child is 3, you are still in a denial that your child has special needs. You are still vulnerable. What do I do next?"... "My child can not use a stroller at school!"

Family 3: Alliances, Information (e.g., knowledge translation) during transition times, and Advocacy.
Mother 3: "From here to there, I cannot jump like that...I need to be hand held during the transition."

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Family 4: Inclusion of --and Listening to-- all family members throughout EI program services.
Mother 4: "Siblings are teachers, too!...Consultant was like our protector, checking on all of us" Father 4: "We went into survival mode."

Family 5: Integrity of Information and Communication (e.g., two-way since birth, ongoing).
Father 5: [re Hospital staff providing information] "...it could be this, it could be that"... Now we could do evolutions ourselves [at the IDP waitlist group]. Mother 5 [her recommendation]: "Have an IDP Office at the ITCR -- or is it technology?"

Family 6: (a) (Multiple) Stressors (e.g., childcare issues); and, (b) Engagement through Information.
Grandmother 6: (a) "I don't think that he... that they [biological parents] get it [re childcare needs]; in the end...there's no one else [to count on]"; (b) "but I think they [consultants] are professionals and they know what to look for in children... and I WOULD ask..."

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Time, timely and timing

- Three words that emerged throughout interviews, for all participants, across themes and contexts:
- **Time:** parenting and intervention
 - Over a lifetime -- a long notion of time
 - Change over time, time needed to learn to appreciate the "quality of change"
- **Timely** means that it cannot be any time: the right time for the child and family
- **Timing** refers to the synchronicity of events (visits, scheduling professionals, referrals, activities, other interventions)... or else the time might be lost...for a long time, forever.

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Implications for Professionals

Medical/health professionals:

- Specialized training in typical and atypical development to ensure timely referrals to appropriate services;
- Professional awareness that timing of referrals is crucial for infants and young children
- To expand referral criteria beyond medical model of diagnosis;
 - for example, refer to WHO's IFCDH criteria when applicable;
 - listen to parents' developmental concerns and requests, and to immediately follow-up with referrals.

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- Academic and professional training for all Early Intervention professionals to enhance parents' strategies in making informed decisions;
- support parental knowledge of child development and health literacies:
 - importance of family-needs assessments in establishing collaborative relationships
- acknowledgment of implicit vs. explicit concerns: consultants to encourage parents questions and comments about child development during screening and assessments;
- promote home visitation services: nurturing parent/consultant and/or parent/therapist long-term relationships.

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Implications for Future Research

- Unique methodology: parents as EI "program users".
- Follow-up studies on effectiveness of EI services in the IDP and other EI programs, considering specific issues that may impact on the experiences of participating families, including:
 - different geographical contexts;
 - gender issues in parenting; and,
 - family structure and family dynamics,
 - English as an additional language for immigrant and refugee families,
 - wider ethno-cultural diversity, educational background, employment and income conditions, among others.

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- Additional research to consider other perspectives in EI; for example:
 - asking consultants and other EI professionals about their experiences with parents and families;
 - looking into EI program practices from the perspectives of consultants, and other EI program professionals;
 - documenting children's experiences; and,
 - examining the combined experiences of parents/children, and professionals in EI, and how they mutually influence each others' practices.

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Implications for Policy

- A universal system of early childhood identification, monitoring, assessment; and follow-up is needed in BC;
- System to address the needs of individual children and families; for example, the *Response to Intervention (RTI)* model.
- Benefits include increased possibilities to identifying children beginning at birth, and working in consultation with family members and EI/other professionals.

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- Additional policy considerations to support families' ability to cope with ongoing family and job/financial stressors regarding:
 - **child care services;**
 - **funding for therapy and support; and,**
 - **clear financial guidelines for parents**

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Recommendations include:

- A centralized case managing system; e.g. through the Provincial health system.
- Moving away from current BC criteria for referrals to intervention and services practices.

Infants

- One alternative: The World Health Organization's International Classification of Functioning, Disability and Health for Children and Youth (ICFDH).
- Establish funded programs to provide continuous follow-up for children from birth to their school-age years.

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Limitations of the Study

- Families' location of residence.
- Only English speaking participants recruited.
- Children not included as participants in study.
 - Children's files as data sources.
- Limited father participation (two fathers in interviews, one father in second focus group).
- Participants chose not to elaborate on family issues; e.g., couple relationship during interviews.

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The "Social Inclusion for At-Risk Children" Project:


Comprises "research" and "deliverables" components:

- research component: multiple case study informs and provides context to a population-based study of developmentally at-risk children in BC.
- deliverables component: preliminary findings of studies contributed to the creation of multimedia and multi-lingual resources and materials for parents and ECE/EI professionals;
 - currently in final stages of dissemination in the Lower Mainland.
 - presentation this afternoon (El Khalil & Pighini)

Source: www.earlylearning.ubc.ca/idpp.htm

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References available upon request.

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