Infant Development Program of British Columbia

UBC

“From here to there I need a hand”:

The Experiences of Parents with Young Children Diagnosed with Autism Spectrum Disorder (ASD)

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Today

- Introduction to multiple case study
- Family 3: The Journey
- Findings (all participants)
- Recommendations for early intervention and support practices in child development
- Questions, comments and feedback

Introduction

A Multiple Case Study on the Experiences of Parents in the Infant Development Program of British Columbia*

Pighini (2008); Pighini, Goelman, Buchanan,Schonert-Reichl, and Brynelsen. Under Review.

Their reality

- What happens for parents when “life” re-shapes the path they (thought they) were set to go?
- How do they manage as they approach new milestones, and as they encounter roadblocks along the way?

Daly; Klassen; Poston; Santos; Turnbull ; and others

The Objective:

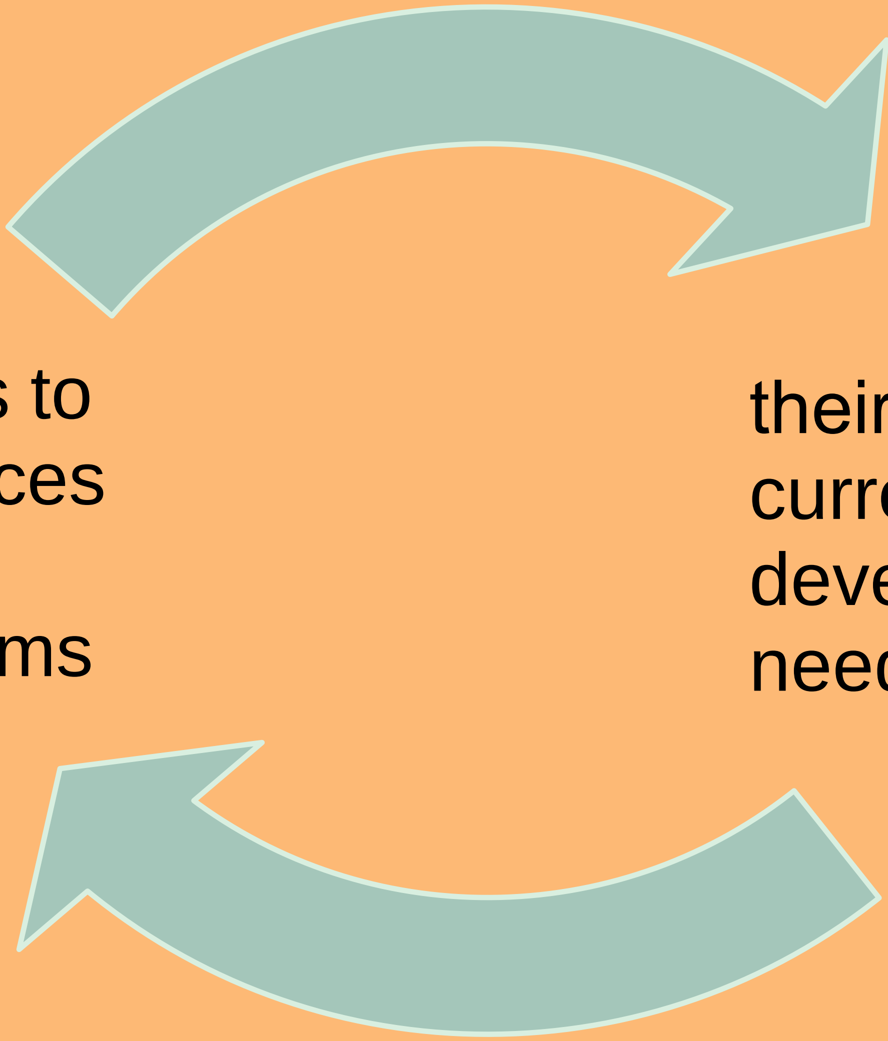
To learn about the experiences of parents with children identified as at-risk for *developmental delays* or with *developmental disabilities* as they transitioned from early intervention into school programs

Dunst; Glascoe; King; Meisels; Olds; and many others

The Question(s):

What are the individual experiences of parents of developmentally at-risk children and their families who participated in the Infant Development Program of British Columbia (IDP of BC) in terms of. . .

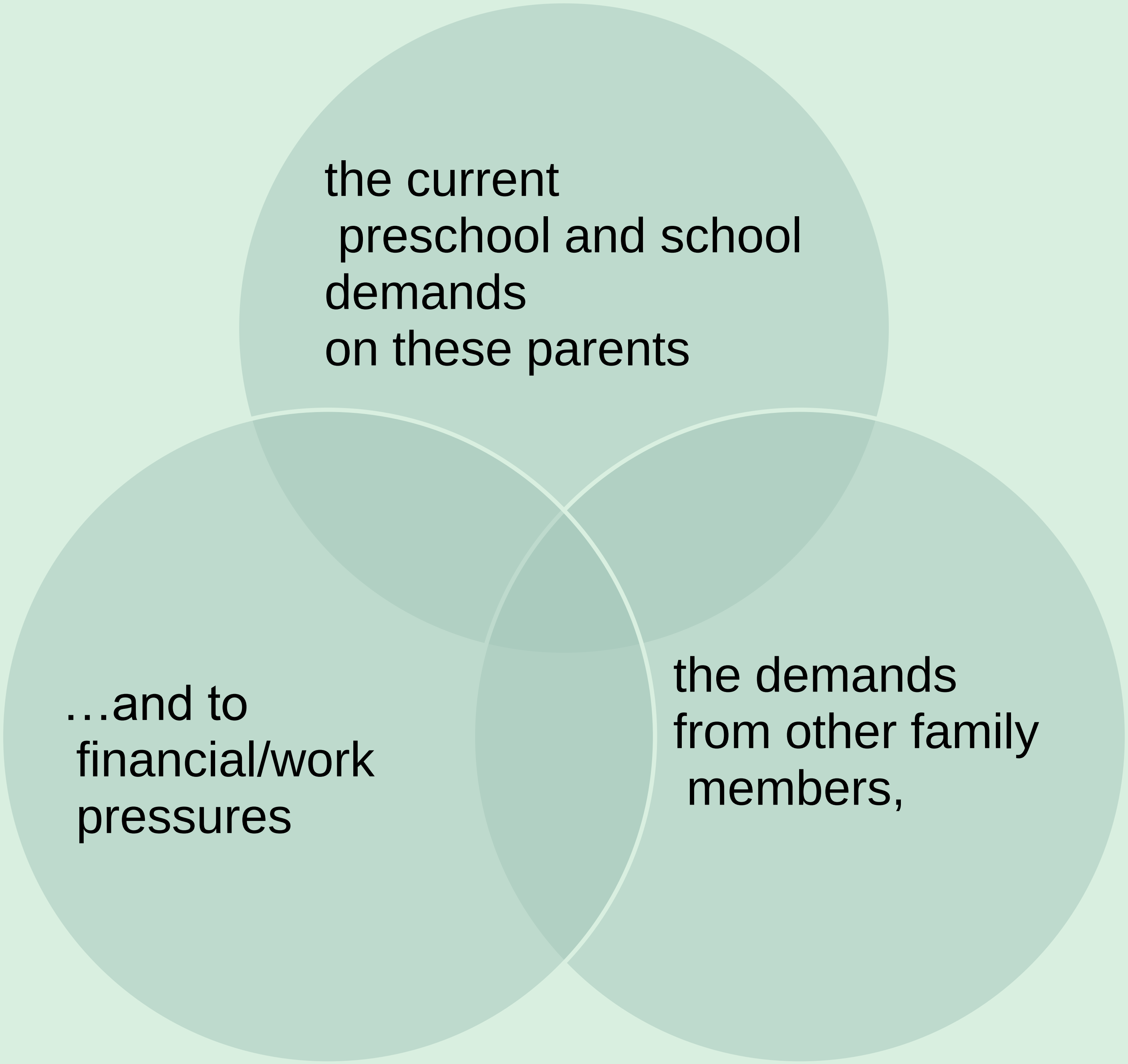
McCollum (2002) "What is it that works in EI?"



access to resources and programs

their child’s current developmental needs

And how do these relate to…



the current
preschool and school
demands
on these parents

…and to
financial/work
pressures

the demands
from other family
members,

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 since 1965*:

- Based on family-centred principles**
- Open referral process, including self-referral
- *Home based*, *in-centre* and *drop-in groups* types and levels of services
- Over 100 IDP Programs throughout BC's four regions; these include the Aboriginal Infant Development Program (AIDP) since 2000.

**Dec. 2008:BC Prov. government closed Office of the Provincial Advisor: critical organizational changes*

Study description

- Ethnography; participatory research
- Retrospective multiple case study
- Examined the experiences of 11 parents in six families with infants and young children flagged as at-risk for developmental delays, or identified with developmental disabilities(ages 3 – 8 at time of data collection)
- Approached study from a post-positivist stance: trying to approximate *their* reality

Creswell; Stake; Tedlock and others

Seven participant children:
(IDP)File Reviews*

♀ **Child 1:**
pre-natal diagnosis, severe

Child 2:
diagnosis at birth, profound ♀

♂ **Child A:**
Mom suspected delays, moderate

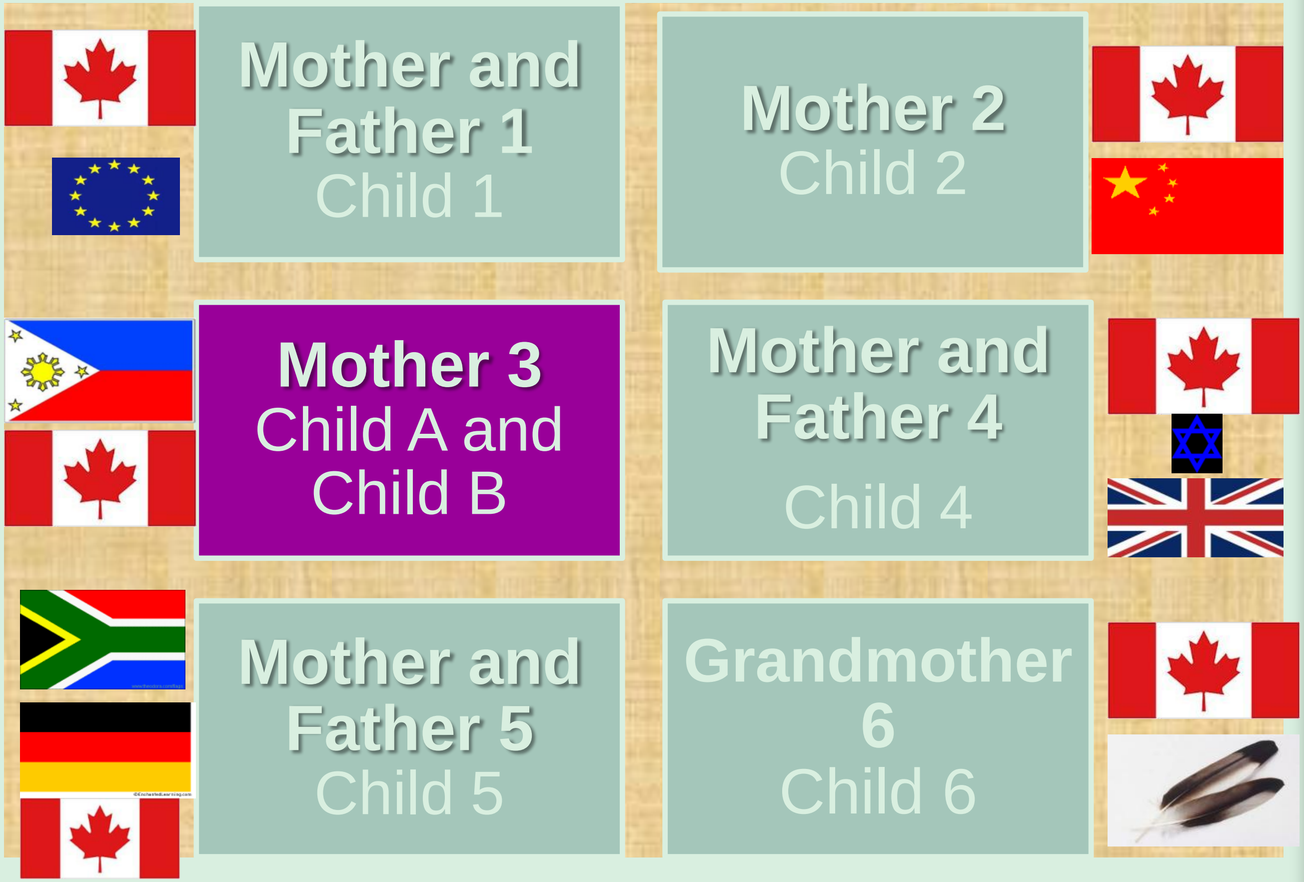
Child B:
At-risk identified at birth, severe ♂

♂ **Child 4:**
Diagnosis at birth, severe

♂ **Child 5**
peri- and post-natal risk, mild

♂ **Child 6**
Pre- natal risk, mild

Nine parents took part in interviews and focus groups*



Mother and Father 1
Child 1

Mother 2
Child 2

Mother 3
Child A and Child B

Mother and Father 4
Child 4

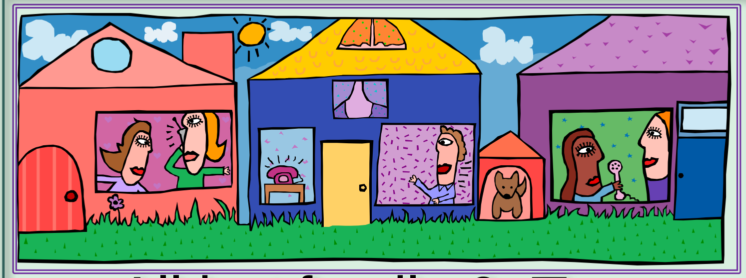
Mother and Father 5
Child 5

Grandmother 6
Child 6

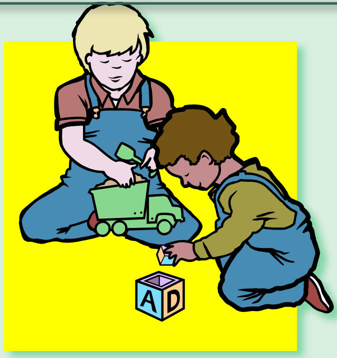
**Triangulation of data collection (Krippendorf)*

Only parents in Family 2 hold full-time jobs

All parents have **post-secondary** education



All but family 6: **Two-parent** family living in one household



Child 1: has older brother
Children A&B : A is older brother
Child 4: has older sister
Child 6: has younger sibling (not living together)

Apartment
Duplex
All but family 6 own home

Home-based

- **Families 1, 2, 3, and 4 ~ Home visited**

Identified disabilities= referrals

- By age 3: four children diagnosed with disabilities
- special needs designations and support services in place since preschool for Children in Families 1, 2, child B in Family 3 and Child 4.

One child: grey area

- Child A in Family 3 with developmental delays; no diagnosis
  - attended inclusive preschool with therapy services
  - diagnosis and special needs designation only at age 5 years.

In-centre

- **Families 5 and 6 ~ Attended waitlist and monitoring group**

Suspected

- Child 5 and Child 6 deemed “at-risk” for developmental delays
- Discharged by age 3 – “caught up”

No further referrals

- Attended preschool;
- No other services required (e.g., therapy); no diagnoses received

Family 3: The Journey

DESTINATION: ACCESS TO SERVICES

3. Rosario
Mother 3
Age range:
30-40 years

- Bi-lingual, immigrant, professional
- Works part-time with husband in at-home business
- In-laws and sister help out
- Rest of family away in country of origin

1. Logan
Child B
Age: 4 years

- Younger sibling, born premature, very low birthweight and severe medical complications; in NICU for weeks
- Following discharge Community Health Nurse contacted parents and initiated referral to the IDP at age 2 mos.

2.Peter
Child A
Age: 6 years

- Older sibling ; term baby; no pre- or post-natal medical complications on file
- Family doctor did not address Rosario's developmental concerns since age 6 mo.
- CHN supported Rosario to express concerns to IDP consultant following up on Logan at age 2 years.

File Reviews
~ *Information Fields*

- Referral source
- Identified condition
- Medical history
- IDP intake
- Wait time
- Developmental status
- IDP services:
    - ✓ home visitation or
    - ✓ monitoring
    - ✓ frequency
- (Additional) therapy/ies
- Other programs accessed)
- Other referrals
- Other services provided
- Assessment
- Transition
- Discharge
- Excerpts: Consultant’s comments
- Family feedback:
    - ✓ Comments
    - ✓ Artifacts

Logan (1)

File Reviews

Healthy pregnancy; born at 37 weeks, cusp between low and very low BW–almost 1500 gr.- with Intrauterine Growth Retardation; intracranial bleeding

Prone to ear infections – tubes inserted; seizures –MRI - Neurologist consultation
Also torticolli and scoliosis – Orthopedist consultation; metabolic condition – Genetics consultation.

File Revisions

Also attended Parent Child Mother Goose and enjoyed program; mother confirmed consultant's comments

Member checks

Placement to preschool changed PT to FT; juggling with logistics

Logan (1)

File Reviews

IDP services between 4 and 36 mos.; consultations for language, play, eating & drinking skills, and physiotherapy – on target until 24 mos.; deterioration afterwards; fine motor skills -difficulties

Referral to Centre– PT and OT; Assessment (S. Hill): sensory integration difficulties - ASD diagnosis – age 3 years; ABA support; referral to preschool with special needs support

File Revisions

OT was private;
Private psychological assessment confirmed ASD

Member checks

Transition to K in process had special needs placement confirmed, same school as Peter.

Peter (1)

File Reviews

Born at 39 weeks, 3500 g BW; hospitalized with respiratory infections twice; motor development – no concerns; physiotherapy by age 1 (torticolli)

Speech/language delays by year 1; behaviour concerns - overactive and perseverative play - Hearing tests in preschool and school years: “grossly within normal limits”

File Revisions

Peter experienced fetal distress during labour; required heart monitoring; c-section; was susceptible to colds as an infant

Member checks

Peter to Grade 2; Rosario was happy to keep same SSW for Peter;

Peter (2)

File Reviews

IDP home visit s: 25 – 46 mos. Independent from Logan's
Attended Parent Child Mother Goose Program; imitated songs and rhymes; referred to Speech Language therapy

SLP/IDP in collaboration*;
no diagnosis by time of IDP discharge; referrals completed for assessment (Sunny Hill) and preschool with focus on language/special needs

File Revisions

Peter highly enjoyed PCMG, also with grandmother and aunt

Member checks

Peter enjoyed attending preschool

Assessment conducted prior to K entry – diagnosis: ASD – high functioning

Summary

In addition to working with their IDP consultant twice each week (once for each child) this family had ongoing consultations with:

- At least 5 medical specialists
- At least 3 therapists
- Psychologist

during their children’s first three years of life

The rest of the participant parents reported similar experiences of multiple consultations during this period of time

Connections:

- Findings connect with reports from population-based study on the health trajectories of children deemed at-risk at birth when compared to non-risk counterparts (Phase I)
- More about children’s developmental and educational trajectories “to be revealed” in Phase II

An Interdisciplinary Study of the Trajectories of At-Risk Children
Goelman et al. (Under Review)

Questions during interviews

- Tell me about the early years, the early experiences with your child and with IDP
- Tell me about the transition after IDP discharge, whap happened then (preschool years)
- Tell me about the transition to school
- Do you have anything to add about other things happening in your family at these times?

Rosario’s life events and perceptions

Prior to data collection

Came as a student, married and stayed, worked full time

Had Peter and 2 years later had Logan here in BC, Canada

During data collection

Part-time stay-at home mom; received services with IDP; relationship with consultant

Became empowered to advocate for Peter’s needs

Member Checks*

Accepted transcripts and interpretation; transition Logan to K; Peter to Grade 2

In shock following death of her father

Wants other parents to know:

- Other parents should access services early enough — as opposed to being asked to “wait and see” from physician
- Frustrated: only because second child (Logan) met risk criteria for developmental disabilities she was able to flash older child’s (Peter’s) needs – not met obvious risk criteria

Memory, memories:

“I guess I’ll start on by talking what’s the IDP all about, when my son was four (months), **I was so worried something was not right with my son**, he was not, you know, talking... I didn’t know who to go to, I **know** something is **not right**, well, the doctor would say *“oh, he’s fine”,* he would say that, you know?, and it didn’t happen until when my other son was born. . . well, I **already** had a concern with my older son. . .

Referral to the IDP:

. . .and then my younger son, he was born really, really, really, small, like almost 3 lbs., and I guess because it was with the community nurse, and part of what the community nurse was doing was to ask about the sibling; and then we told her we had concern with the older sibling, and they said "*Why don't the two of you, you have got the two kids, why don't you bring them to the IDP…*"

. . .Because my son was low birth weight he was asthmatic, then he. . . he met the "criteria,"* and my older son, he is healthy, over 8 lbs, and nobody referred him to the IDP…"

**used this term in focus group*

Help is on its way:

“ My husband and I went to the IDP, and told them that my baby, he is the younger one, [Logan] we don’t know if there is anything wrong with him by now, he is only 6 months, but we have a concerns about our older child [Peter]. Everything got rolling and then IDP did the referrals, and we got assigned for therapy, and we got play therapy. After that the ball got started and IDP helped us a lot and [our consultant] was so good with our son, [Peter]. . .

Consultations with IDP:

. . .She told us what to do, where to go, and then we found out about the Parent-Child Mother Goose (program) and then you found that you were not . . .in a. . .situation where you . . . were not alone all by yourself. . . Then [we] would get together and kids would do their thing. . . Later on we found out that our younger son has also problems* and, IDP took over again, and we got help …”

Rosario’s is talking about the referrals for Logan’s assessment*

Referral for diagnosis:

“My older son (Peter) and I we went to the doctor and Peter didn’t smile, you know he is still in the [autism] spectrum; we wouldn’t have known anything about that, without IDP, because our consultant helped us a lot; she asked us to see the doctor, and the doctor would say *“Wait”* and our consultant said *“Why don’t you go and see to this doctor”* as she recommended us a different doctor; this doctor she knows that would help. I go to my doctor and say: *“Can you recommend me to this doctor?”* and she says: *“How do you know that doctor? . . .*

:Consultant’s role as advocate and liaison:

“For Peter, do this, tell your doctor to make referral to the Provincial Centre. ” I didn’t even know about [this centre] at this time, and then we got there for (the assessment) and our consultant came to the meeting. If not for her, my son would not be diagnosed, and then nothing would have happened, we’ve not have any help, because they said . . .*“I think it’s just language delay”* but consultant said: *“Wait a minute, you forgot this, this, and that,”* . . . Cuz you know, one would go to Hospital, and they (doctor) would look at our son (Peter), and it’s only for him (doctor), a few hours; but our consultant worked with my son for two years, forever, so she is more an expert.”

Navigating the medical system

“So because our consultant is more a professional, the doctor said *“Peter, maybe we give him a [provisional] diagnosis”* and that got me the funding; and our consultant said to me *“It’s just a label;”* if they say ‘your child is autistic’, even better here, because you can get help. . . You know, you have child who has delay, you don’t get help... unfortunately help depends on the label... So there we go, we got the label; and now if you see my son, he’s night and day* if you compare him... Our consultant helped him to do that, and of course with my other son, our consultant helped him too . . .”

Rosario’s recommendations:

. . . And because of the experience for other families **especially** for some families who can hardly speak English, maybe they have children, maybe like my children, and don’t know what to do; they go and get a diagnosis, but then they wouldn’t know what to do after that, because Provincial Centre just said “Peter, your son, has autistic disorder,” but, **Who do you go to next?** Perhaps they could talk to the parents and tell them what to do next...”

Rosario (Mother 3)

Overarching topic: Perceptions on the Impact of Early Intervention

Across- and within-family analyses: seven themes

Berg; Krippendorf; Silverman; and others

What is it that works in early intervention?

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

Ingrid, mother 5: "I am not going anywhere where they tell me that my kid 'is this and that"

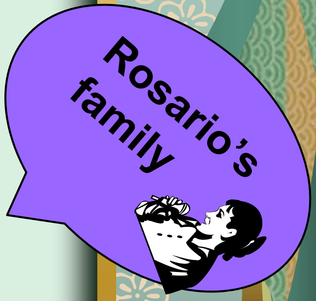
Learning from Rosario and from the rest of the participants. .

Hand holding looks like this:

Themes 2 and 3: One to One Relationship with Consultant or Therapist;
and,
Inclusion of Other Family Members

Consultants' play **unique** role and develop a special relationship as they support parents in:

- their **awareness** of their children's developmental needs;
- **timely** referrals for EI services;
- Working in ways that **allow** siblings, aunties, and grandparents to take part in the consultation process



This may be lost later on:

- Following IDP discharge
- At the time of school entry (Kindergarten or Grade 1)

- When parents confront the system that utilizes strict medically-based criteria
- Referrals at this time did not support children in the “**grey area**”*

Peter’s case

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

Journey towards destination: How to access services?

Themes 4 and 5: Collaborative Consultation and, Effective Knowledge Translation in Sharing Information/ Resources

The family centred approach to early intervention services **ensures** these take place:

- collaborative practices between professionals and families in turn support empowerment and **joint** decision making; and,
- effective **two-way** knowledge translation in sharing clear and meaningful information with parents – make it explicit!

What they said:

- Information sharing and knowledge translation within a collaborative model of services:

Jon, Father 5: "*It was very different once we were there (IDP)...it was pretty comfortable and pretty casual.*"

Ingrid, Mother 5: "*(At the hospital) we did not understand...it could be this, it could be that...; now (with IDP) we could do our own assessment*"

Age 3 years: IDP discharge*

Themes 6 and 7: Case Managing and Service Coordination, and Stressors that Become Barriers

- Transition planned following a joint parent-professional collaboration and knowledge translation model.
  - If followed throughout other programs and agencies, this would ensure **centralized** ECE/EI services and case managing coordination
- Parents' **ongoing** confrontation with stressors; these become barriers

**first transition; child may attend preschool or daycare*

Theme 6: The sense of loss continues; anxiety perpetuated:

- This is not in place following IDP discharge
- Insufficient coordination between preschool and school services

Rosario, Mother 3: *"From here to there, I cannot jump like that…I need to be hand held during the transition."*

- In the absence of long-term coordination following IDP discharge:
  - accessing ECE/EI program and services becomes stressful and **ineffective** for parents, and they lose precious time

Anna, Mother 1: *"You have a feeling you have been dropped".*

Rosario's comments resonate with other participant parents who also mention their desire to be helped during transitions:

May, Mother 2: *"We need a chart showing how system and services work"*

Jim, Father 1: *"One gets tired of being told, you have to work with less...this means writing letters, accessing people. . . tiring, frustrating."*

Susan, Grandmother 6: *"I just want to make sure that there is nothing else because when they are little like this it is the time to catch things."**

*Child 6 was 5 years old at the time**

Theme 7: Juggling family, work, and finances – life goes on:

- Complexity of issues and logistics in participant families:

Health risks and disability, child care availability, and the impact on participant families' job and financial conditions

May, Mother 2: *"Once she goes to school, they are not going to carry her around !Yes, This is reality and we've got to think into the future. . ."*

Mother 4: "*He was just tiny. He was very sick with pneumonia, and being on oxygen. They kept checking on us. They (IDP) protected me from panicking ."*

Ira, Father 4: *For 3 months I only slept for an average of 3 – 4 hours a night. . . by February, it creeps on you... I went to my director and said, "I can't keep this up". . .I took time off for seven months and that's what changed everything."*

Cycles of *disability* and *anticipation*, *parenting over a lifetime*

Rosario, Mother 3: “*I’d like for Peter to speak my language; it’ s so hard* ”

May, Mother 2: “*. . .We did not know at this stage she would not be walking”*

Susan, Grandmother 6*:* “*One does not know what comes up at the turn of the bend . . .”*

Jim, Father 1: *“This kid has the potential for 10000 conditions”*

- Fathers and Mothers report **different** family stressors, also on other family members, like siblings
- **Less explicit**: family dynamics_including couples and family-related issues.

Father 4:”*The way I look at our schedule, there is a three-hour break for each person each day. . .Right now no one can do “time on your own,”* (but with this system) *I think the pressure is off . . . Well, talk to me in a few weeks.”*

Research: Multiple case study approach – with expanded criteria

- Different geographic contexts, including rural and remote communities*
- Wider ethno-cultural and educational background, employment and income conditions
- Immigrant and refugee families with little or no spoken English
- Different family structures – focusing on dynamics of families

*Stewart, MA thesis TBD; Including All Children and Families Project

Practice: Implications for medical and other health professionals:

- Specialized training in typical and atypical development to ensure timely referrals to appropriate services:
  - Waste no time! Awareness that timing of referrals does make a difference for infants and young children's developmental outcomes
- Expanding referral criteria outside of the medical model of diagnosis:
  - E.g.: refer to World Health Organization's International Functional Classification for Disability and Handicap criteria whenever possible*
  - Pay attention to - and follow up - parents' developmental concerns and requests for referrals

*Simeonsson and others**

Early Intervention Professionals and Family Centred Practices:

a. Support parental knowledge: health and developmental literacies

b. Acknowledge implicit concerns; work on articulating explicit concerns

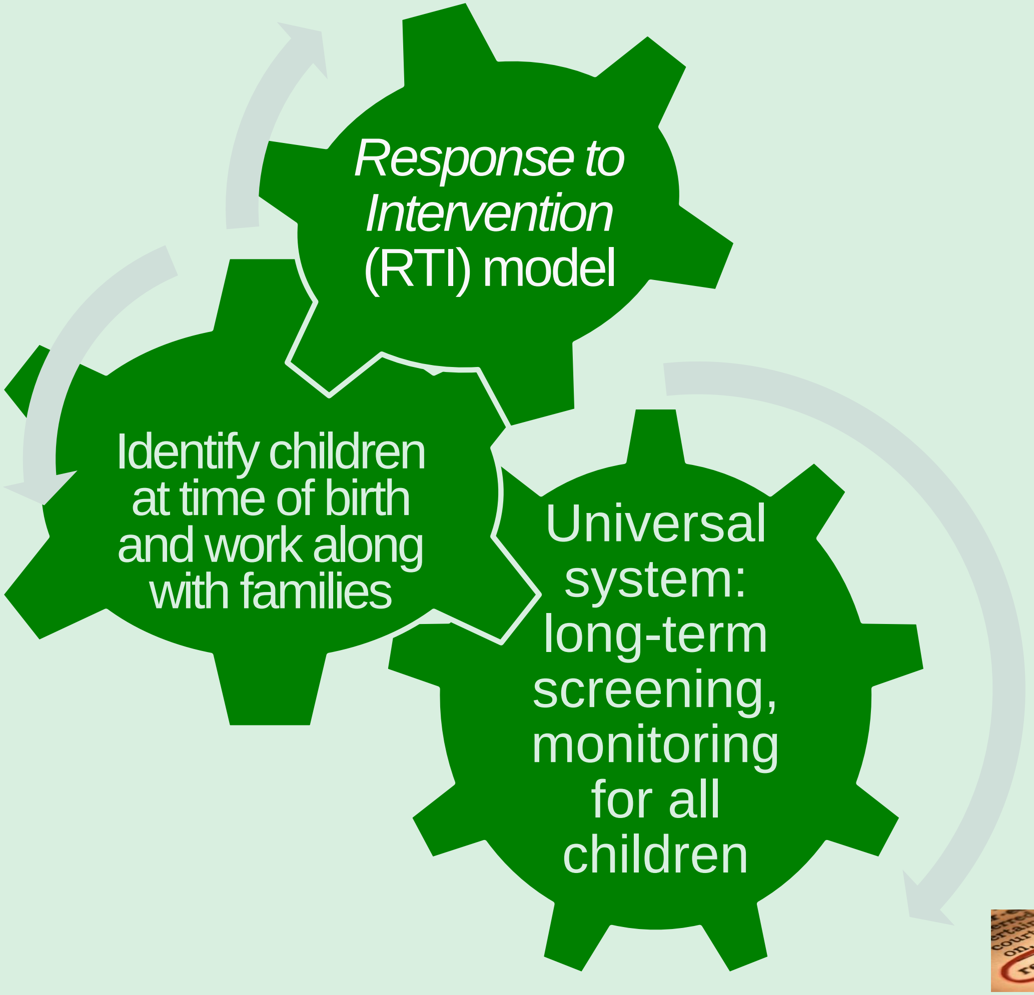
Academic, professional training for early intervention professionals: develop skills; enhance parents’ strategies in making informed decisions

c. Promote home visitation services

What are early intervention consultants experiences of family centred-services?*

*Including All Children and Families-Expanding Partnerships project

At the policy* level:



Response to Intervention (RTI) model

Identify children at time of birth and work along with families

Universal system: long-term screening, monitoring for all children

*Hebbeler report; Pivik report

Thank-you(s) and Acknowledgments

- Participant children and parents
- Dana Brynelsen
- IDP program coordinators and staff
- To Pat Mirenda for inviting me today!

Including all Children
and Families
Expanding Partnerships

Canada

http://eci.sites.olt.ubc.ca/ or includingallchildren.ubc.ca
(Materials and resources for families and service providers)

Questions and comments? Please see next couple of slides…

Comments

- *Referral to IDP experiences during presentation resonated with own experiences with son and early intervention process a few decades ago!*
- *Enjoyed presentation and pace of it*
- *Appreciated the mentioning of family centred practices and making information explicit to parents from a consultant's perspective and think it is important to talk more about this for professional training*

Questions

- *Q: Where there examples of how family's experiences with children with ASD were different from those of parents whose children had other conditions?*
- *R: In addition to difficulties with functional language and to not being able to share language of origin with son, Rosario identified struggles with logistics and planning at the recreation and social sphere in addition to other logistics issues shared during presentations. This is because any external stimulus including having too many people, sounds, light or change in schedule would alter the whole day for her children; explaining that children had special needs was hard also because children's conditions were not apparent at first sight*

Questions

- *Where there any examples of things that did not work for parents in terms of early intervention services with the IDP?*
- *Two of the parents who received home visitation services would have liked to have kept the same consultant and not changing consultants (they left and someone else was hired as it happens in different workplaces); parents in-centre monitoring would have liked the same consultant to follow up on their child when they visited. They all appreciated the home visiting records or summary records so that the next consultant would follow up. The personal relationship and fine details of continuity was somewhat missed for these parents*

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REFERENCE LIST AVAILABLE UPON REQUEST