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## Exploring the Knowledge Transfer Process for Childhood Autism Spectrum Disorders

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## Outline

- Background
  - Knowledge transfer (KT)
  - Autism spectrum disorders (ASD)
- Study objectives
- Qualitative methods
- Analytic approach
- Preliminary findings
  - Parents' perspectives
  - Researchers' perspectives
  - Policy-makers' perspectives
- Further questions

## Background – KT

- Knowledge transfer (KT):
  - Originally conceived as means to increase research use
  - Increasingly viewed as an interactive process involving researchers, policy-makers and others
- How to increase research use in policy-making?
  - Better *products* (e.g., timely and relevant syntheses)
  - Better *processes* (e.g., engaging policy-makers in research)
- Ideal outcomes of the KT process:
  - Evidence-informed policy
  - Policy-relevant research

## Background – ASD

- Symptoms of autism:
  - Impairments in reciprocal social interaction
  - Impairments in verbal and non-verbal communication
  - Restricted and repetitive interests and activities
- Autism spectrum disorders (ASD):
  - Children with autism have difficulty in all three areas
  - Children with Asperger's have fewer language difficulties
- ASD typically diagnosed in children aged 2–4 years

## Background – ASD

- Research on childhood ASD is often contentious:
  - Prevalence, causation, diagnosis, treatment
- Policy-making for childhood ASD is often adversarial:
  - Auton case in BC, Supreme Court of Canada: medical necessity of behavioural interventions for preschool children
  - Wynberg case in Ontario: public funding for behavioural interventions for school-aged children
  - Senate of Canada: national strategy for intervention funding

## Study Objectives

- How can parents, researchers and policy-makers work together more effectively to improve outcomes for children with ASD?
  - To make better collective decisions on behalf of children, we need to understand the perspectives of everyone involved
- Qualitative study of interaction between:
  - Parents who belong to community groups for ASD
  - University-based researchers who specialize in ASD
  - Provincial policy-makers who are responsible for ASD

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## Study Objectives

	BC	AB	ON	QC	NS	Total
Parents	2-3	2-3	2-3	2-3	2-3	10-15
Researchers	2-3	2-3	2-3	2-3	2-3	10-15
Policy-Makers	2-3	2-3	2-3	2-3	2-3	10-15
	6-9	6-9	6-9	6-9	6-9	30-45

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## Qualitative Methods

- 30-45 participants will be included
- 25 participants have been interviewed:
  - 8 parents – 11 researchers – 6 policy-makers
  - 8 BC – 3 AB – 6 ON – 2 QC – 6 NS
- Semi-structured interview protocol:
  - Interviews range from 1 to 2 hours, average 90 minutes



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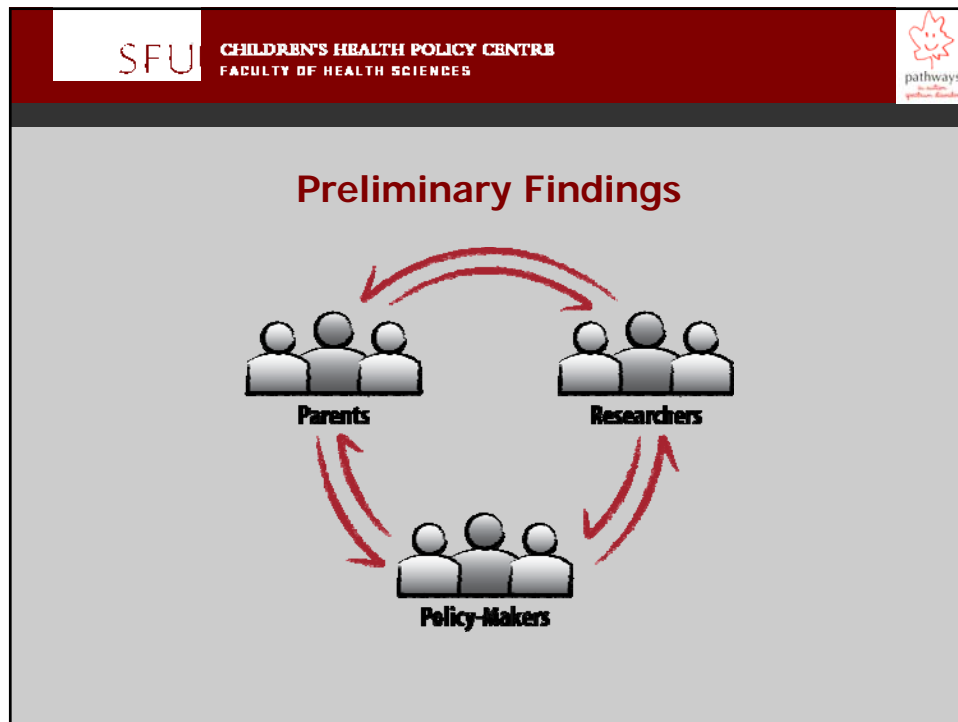
## Analytic Approach

- Using the constant comparative approach from grounded theory
  - “One criterion for qualitative research is that the researcher tries to describe and conceptualise the variety that exists within the subject under study...looking for commonalities and differences in behaviour, reasons, attitudes, perspectives and so on.” — Boeije 2002
  - “The method of comparing and contrasting is used for practically all intellectual tasks during analysis: forming categories, establishing the boundaries of the categories, assigning the segments to categories, summarizing the content of each category, finding negative evidence, etc.” — Tesch 1990

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## Analytic Approach

- Comparative approach is built into study design, sample frame, interview protocol, etc.
- Essential comparisons:
  - Within groups — e.g., parent A vs. parent B
  - Between groups — e.g., parents vs. policy-makers
  - Between provinces — e.g., BC parents vs. NS parents
- Additional comparisons:
  - Interviews vs. feedback (participants)
  - Interviews vs. documents (non-participants)



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## Parents' Perspectives

- Parents spoke passionately about the impact of ASD:  
 "You're fighting these different systems that are supposed to help you. You're working all these extra hours to do some type of intervention. You never go to bed at night — ever — thinking, I did enough today."
- Parents were forced to become advocates: "Speak for your child until they can speak for themselves"  
 "When I first got involved, there was very little government support in our province. So families were rallying together, and that has brought about some change. We now have funding for an intensive program for kids six and under."

## Parents' Perspectives

- Parents were acutely aware of the window of opportunity for early intervention in ASD:
  - “I know, from first-hand experience, that children continue to grow, continue to learn, but there is a recognized panic that I have between the time my child is 2 and 6 to really make an effective change.”
- Possibility of “recovery” increased sense of urgency:
  - “When parents know that they have 4 or 5 years to make a significant impact, and you tell them they have to wait for 3 years? Can you think of any diagnosis where we would say that to a parent? If your child had cancer or diabetes?”

## Parents' Perspectives

- Parents' concerns depended on child's age, stage:
  - “Many policy-makers seem to be addressing the time of diagnosis and early intervention, not recognizing how lonely the adolescent years are...once my son graduates, I'm quite frightened to think how little there'll be for him.”
- Autism societies and family advocacy groups are not necessarily “representative of parents”:
  - “There's such a limited amount of money. You have parents of 2-year-olds saying, my child will never get any funding, and you have parents of 9-year-olds saying, what are you doing for me? And then they start to fight with each other.”

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## Researchers' Perspectives

- Many ASD researchers empathized with parents:  
 "You really get close to some of them. It's really hard. It's just so frustrating, to see the distress of the families..."
- Many were sympathetic to parents' concerns:  
 "As if we have a right to decide what's important. We walk into these people's lives for a year. They've got these kids forever."

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## Researchers' Perspectives

- Researchers acknowledged parents' expectations:  
 "That's the one thing every parent knows about early interventions...they're told they have to do it as soon as possible. They're also told all sorts of miracle stories about how it's changed kids' lives."
- Therefore, many researchers were highly motivated to develop interventions, improve services for ASD:  
 "How can we give parents a diagnosis and say the evidence is that they need these interventions and then have nowhere to send them? That's completely unethical."

## Researchers' Perspectives

- Some ASD researchers also felt they had a duty to contribute to policy-making:
  - “I thought my responsibility ended at publishing the evidence. I realize now that isn't good enough. You have to listen to policy-makers' questions and formulate the answers very carefully. My evidence-based language is not necessarily the language that they would speak.”
- Others had difficult experiences with policy-makers:
  - “I was afraid that if I didn't work with them, who were they going to ask? But I was thrilled when it was all over with.”

## Policy-Makers' Perspectives

- ASD is “a particularly volatile area” for policy-makers:
  - “It is different from other social services. For example, in child protection or youth justice, I hate to say it, but you're dealing with poor people — less able to advocate for themselves. In special needs, the level of advocacy in general is quite remarkable. But particularly around autism, there is a level of passion that exceeds other areas.”

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## Policy-Makers' Perspectives

- Policy-makers saw themselves as child advocates, often based on "grassroots" experience:
  - "All of our effort was spent trying to convince government to take actions in the best interests of children and families."
- But found themselves opposite parents in court:
  - "It was the first time in my career that I have been chastised by families. We were ordered to provide behavioural programs. It was the first time I've ever done social policy as dictated by litigation."

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## Policy-Makers' Perspectives

- Policy-makers were very conscious of competing demands for limited resources:
  - "Speaking very candidly, there is a resentment in the province — from service providers, from other families, from some academics — that autism has taken up too much government time and too much government money. At a meeting yesterday, somebody said, we're burnt by autism, autism kids get so much and other kids don't."
- Policy-makers hope research can reduce "tension":
  - "...to marry that diversity of wants to something that is solidly based on research, with the resources available."




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The diagram, titled "Further Questions – KT", contains a bulleted list of points. The SFU logo and "CHILDREN'S HEALTH POLICY CENTRE FACULTY OF HEALTH SCIENCES" are in the top left, and the "pathways" logo is in the top right.


### Further Questions – KT

- Conventional approach to KT assumes that "evidence" is unambiguous and incontrovertible
- Whether ASD policy is "evidence-based" depends on where you're located in the university
  - Health services researchers might question public funding for behavioural interventions, given the mixed evidence
  - Many ASD researchers believe that public investment is inadequate, given the potential benefits for children

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## Further Questions – ASD

- Policy-makers hope that researchers can help them to address parents' concerns, advocates' demands
- But ASD researchers often share parents' concerns:  
    "The parents are right. There's nothing for kids with autism in this province. Zero. That's criminal."

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## Further Questions – ASD

- Parents' perspectives:  
    "Autism is different because it's felt to be treatable. You can lose your autism. I know people say you can't, but my child did. Because of the potential for treatment, money and time should be spent over other childhood illnesses."
- Policy-makers' perspectives:  
    "It would take a bottomless pit of resources...government has never done this for any condition."

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## Further Questions – ASD

- Reconciling the differences:
  - “Keep your eye on the prize. People have their eye on their own political agenda or theoretical agenda. The kids are the ones who can bring everyone together. To really understand what it means to make a difference in a kid’s life.”

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## Pathways in ASD – Study Overview

- Pathways in ASD
  - Longitudinal study of children’s developmental trajectories
  - Involves 400 children and families from 5 provinces
  - Includes intervention RCT and qualitative study of KT
- Funders
  - Canadian Institutes of Health Research
  - Autism Speaks Canada
  - BC Ministry of Children and Family Development
  - Alberta Heritage Foundation for Medical Research

## Pathways in ASD – Investigators

- Peter Szatmari, McMaster University
- Susan Bryson, Dalhousie University
- Eric Fombonne, Montreal Children's Hospital
- Pat Mirenda, University of British Columbia
- Wendy Roberts, Hospital for Sick Children
- Isabel Smith, Dalhousie University
- Tracy Vaillancourt, University of Ottawa
- Joanne Volden, University of Alberta
- Charlotte Waddell, Simon Fraser University
- Lonnie Zwaigenbaum, University of Alberta

## Pathways in ASD – Research Team

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