

# **Interdisciplinary Studies of Childhood Ethics**

*Introducing a new McGill-based research initiative*

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**VOICE: Views On Interdisciplinary Childhood Ethics**



**VOICE**

# VOICE: Views On Interdisciplinary Childhood Ethics Interdisciplinary & Inter-perspective Collaboration

Children  
& Society



CHILDREN & SOCIETY (2013)

DOI:10.1111/chso.12063

## Interdisciplinary Studies of Childhood Ethics: Developing a New Field of Inquiry

Franco A. Carnevale\*, Angela Campbell†, Delphine Collin-Vézina<sup>§</sup> and Mary Ellen Macdonald<sup>¶</sup>



CIHR IRSC

Canadian Institutes of Health Research  
Institut de recherche en santé du Canada



Social Sciences and Humanities  
Research Council of Canada



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VOICE

# Principlism: Dominant bioethical framework

Beauchamp, T. L. & Childress, J. F. (2001)

*Principles of Biomedical Ethics*. (5th ed). Oxford: Oxford University Press

- Autonomy
- Beneficence
- Nonmaleficence
- Justice



## Renée Fox: Sociologist of medicine

Bioethics tends to delimit problems as moral, without consideration of the social, cultural, and political spheres of the issue:

- “Bioethical attention has been riveted on the justifiability of nontreatment decisions. Relatively little attention has been paid to the fact that a disproportionately high number of extremely premature, very low birth weight infants, many with severe congenital abnormalities, cared for in NICUs are babies born to poor, disadvantaged mothers, many of whom are single nonwhite teenagers” (Fox, 1989, p.231).

# Working and Learning with vulnerable populations

## Childhood Ethics



## Childhood and vulnerability

Particularly vulnerable children

- *Disabled*
- *Newborns*
- *Migrant newcomers*
- *Low income/Poverty*
- *Aboriginal*



# Understanding and confronting vulnerability

## *An equity framework*



# EQUITY (World Health Organization)

<http://www.who.int/healthsystems/topics/equity/en/>

- *Equity* is the absence of avoidable or remediable differences among groups of people.
- Reducing health inequities is important because health is a fundamental human right and its progressive realization will eliminate inequalities that result from differences in health status in the opportunity to enjoy life
- Common characteristic of groups that experience health inequities is lack of political, social or economic power.
  - Interventions must go beyond addressing health problems and also help empower the group in question through systemic changes (e.g., policy or practice changes)



# Social Justice

- All peoples, without discrimination, “have the right to live in dignity and freedom and to enjoy the fruits of social progress and should, on their part, contribute to it”

United Nations [UN] High Commissioner for Human Rights, 1969, Part 1, Article 1.

- **10 Defining Attributes of Social Justice**

Canadian Nurses Association; SOCIAL JUSTICE, 2nd Edition 2010

- Equity (including health equity)
- Human rights (including right to health)
- Democracy and civil rights
- Capacity building
- Just institutions
- Enabling environments
- Poverty reduction
- Ethical practice
- Advocacy
- Partnerships

# Structural violence

Farmer et al. 2006 Structural violence and clinical medicine. PLoS Med 3(10): e449

## Defining Structural Violence

- Social arrangements that put individuals and populations in harm's way.
  - The arrangements are structural because they are embedded in the political and economic organization of our social world;
  - They are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities).

# Health Equity

Braveman & Gruskin (2003).

*J Epidemiol Community Health.* 57:254–258.

## Equity is not the same as equality

The concept of equity is normative

The concept of equality can be considered descriptive



**Health equity is the absence of systematic disparities in health (or its social determinants) between more and less advantaged social groups.**

- *Social advantage* means wealth, power, and/or prestige - the attributes defining how people are grouped in social hierarchies.
- Health inequities put disadvantaged groups at further disadvantage with respect to health, diminishing opportunities to be healthy.
- Health equity, an ethical concept based on the principle of distributive justice; linked to human rights.

# Moral agency & moral experience in childhood

*Listening to the voice of young people*



# The voice of the child

Listening authentically to youthful voices: A conception of the moral agency of children

Carnevale, F.A. (2012). In J.L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon*. Pearson Education: Canada.

- Underestimated children's capacities
- Children's moral experience
- Conflicting adult interests
- Promote *assent*



# The voice of the child

A broad conception of **assent**

To attend to children`s voices while recognizing potential limits to the responsibility they can assume?

Assent implies:

1. *Optimizing the child`s understanding of his/her condition and proposed tests and treatments.*
2. *Seeking the child`s voluntary cooperation to the proposed care.*



# Moral Experience

## Moral experience: a framework for bioethics research

Matthew R Hunt,<sup>1,2</sup> Franco A Carnevale<sup>3,4</sup>

## Charles Taylor, hermeneutics and *Social Imaginaries*: a framework for ethics research

Franco A. Carnevale RN PhD



# Moral experience & disability

## Exploring disability through the lens of moral experience

Matthew R. Hunt<sup>1,2</sup>, Franco A. Carnevale<sup>2,3,4</sup>

PERSPECTIVES ON REHABILITATION

**“This is my way”**: reimagining disability, in/dependence and interconnectedness of persons and assistive technologies

Barbara E. Gibson, PhD, PT<sup>1</sup>, Franco A. Carnevale, RN, PhD<sup>2</sup> & Gillian King, PhD<sup>3</sup>

**UNE PERSPECTIVE ÉTHIQUE SUR LE SOUTIEN  
AUX FAMILLES D'ENFANTS ATTEINTS  
DE CONDITIONS CHRONIQUES COMPLEXES<sup>1</sup>**

Franco A. Carnevale



# Childhood Disability and Moral Experience

## Daily Living With Distress and Enrichment: The Moral Experience of Families With Ventilator-Assisted Children at Home

Franco A. Carnevale, RN, PhD<sup>a</sup>, Eren Alexander, RN, MSc(A)<sup>a</sup>, Michael Davis, MD<sup>a,b</sup>, Janet Rennick, RN, PhD<sup>a</sup>, Rita Troini, RRT, MA<sup>b</sup>



# Working and Learning with vulnerable populations

## Childhood Disability: Community actions



# Daily Living With Distress and Enrichment: The Moral Experience of Families With Ventilator-Assisted Children at Home

Franco A. Comevale, RN, PhD<sup>a</sup>, Eren Alexander, RN, MSc(A)<sup>a</sup>, Michael Davis, MD<sup>a,b</sup>, Janet Rennick, RN, PhD<sup>a</sup>, Rita Troini, RRT, MA<sup>b</sup>

*Pediatrics*, 117(1),  
e48-60, 2006



# Community Centres (respite & other supports)

## The Lighthouse: Children and families (Montreal)

<http://www.phare-lighthouse.com/en/Videos-photos>



**Le soutien aux familles  
d'enfants gravement  
malades**  
*Regards sur des  
pratiques novatrices*  
**Champagne et al.  
(2014)**



**Le soutien  
aux familles  
d'enfants  
gravement malades**

Regards sur des pratiques novatrices

Sous la direction de  
Manon Champagne  
Suzanne Mongeau  
Lyse Lussier

COLLECTION

PROBLÈMES SOCIAUX  
ET INTERVENTIONS SOCIALES

 Presses  
de l'Université  
du Québec



**McGill**

Long-term Mechanical  
Ventilation in the Home

# A QUESTION OF CHOICE

Clinician Information Booklet

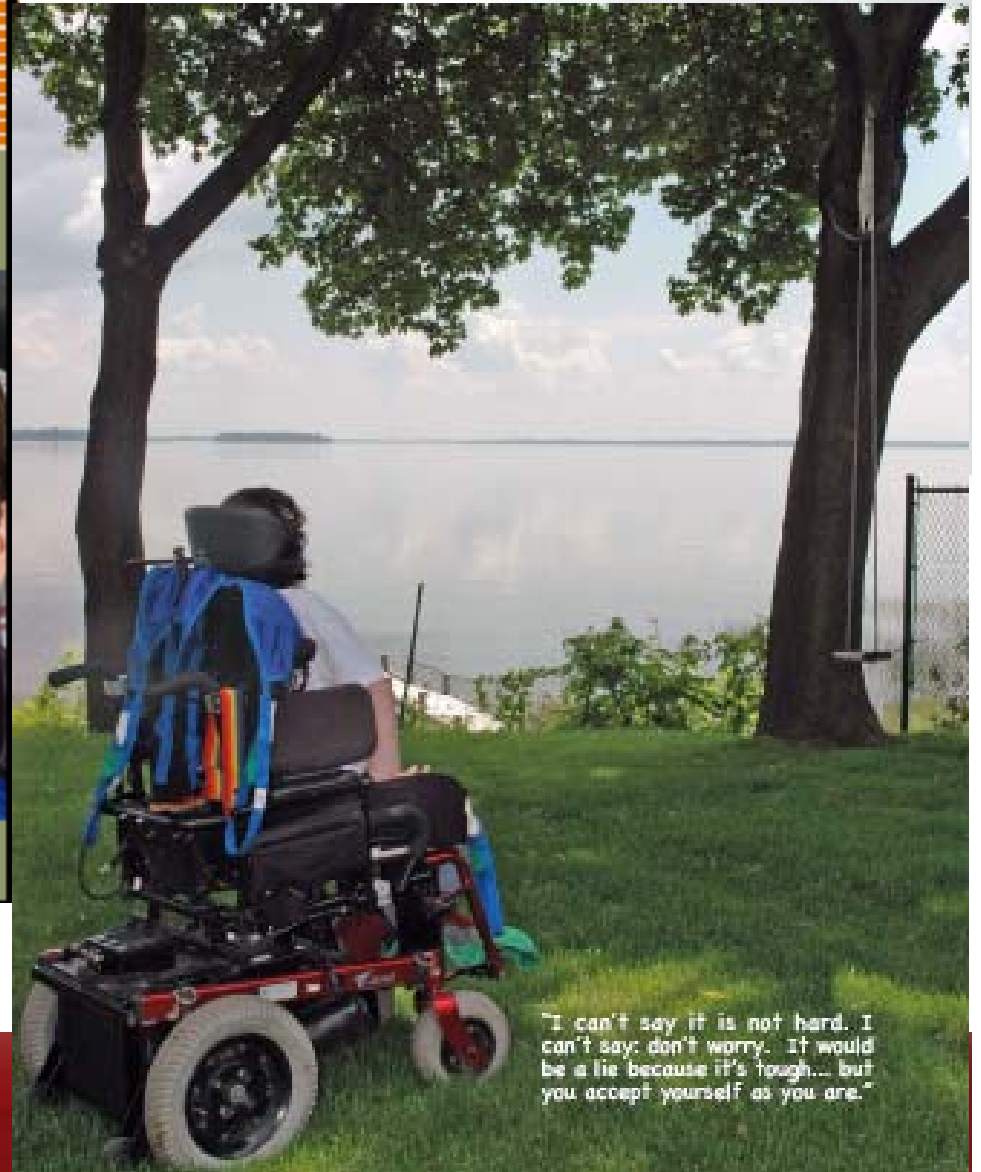


Information/Sensitization Booklets  
*Parents & Clinicians*



McGill

## Rethinking Disability



"I can't say it is not hard. I can't say: don't worry. It would be a lie because it's tough... but you accept yourself as you are."

# Participatory Documentary

*Interdisciplinary Capacity Enhancement Grant, HCTP CIHR Strategic Research and Training*



***Living with Miracles*** introduces three unforgettable children dealing with complex medical needs while living at home. Through their insights into disability, autonomy and quality of life, the children create a powerful tool for promoting public awareness and battling discrimination.



<http://www.skyworksfoundation.org/documentaries/productions/lwm/index.html>

# Community Organization *Blogs*



## 'Burden' of complex kids not whole picture, ethicist says

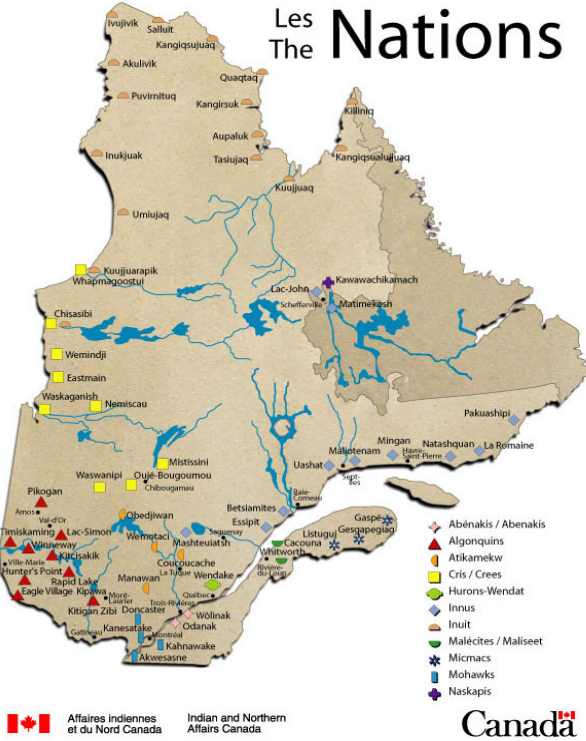
Uploaded on Dec 2, 2011

- In this BLOOM clip, Dr. Franco Carnevale, clinical ethicist, nurse, psychologist from Montreal Children's Hospital, talks about how a devaluing of children with disabilities can impact care.



# Working and Learning with vulnerable populations

## Aboriginal Health



# Partnership: Community-Health Canada-University

**Kiwabigonem: Barriers and Facilitators to Fostering Community Involvement in a Prenatal Program in an Algonquin Community.** Lang C, Macdonald ME Carnevale FA, Lévesque MJ, Decoursay A (2010) *Kadiminekak Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 8(1), 55-81.

**The development and implementation of a Type 2 diabetes prevention program for youth in Algonquin community of Rapid Lake, Quebec.** Sherman J, Macdonald ME, Carnevale FA, Vignola S (2011) *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 9(1), 219-244.

**Minododazin: Translating an Algonquin tradition of respect into youth well-being in Rapid Lake, Quebec.** Kooiman H, Macdonald ME, Carnevale FA, Pineda C, Nottaway W, Vignola S (2012) *Pimatisiwin, A Journal of Indigenous and Aboriginal Community Health*, 10(1), 1-15.

**Diabetes Bingo! Using Participatory Research to Tackle Diabetes with the Algonquin of Barriere Lake.** Wakani L, Macdonald ME, Carnevale FA, Bernier I, Wawatie J (2013) *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 11(3), 361-376.

**Exploring oral health and hygiene practices in the Algonquin community of Rapid Lake.** Naidu A, Macdonald ME, Carnevale FA, Nottaway W, Thivierge C, Vignola S. (2015) Quebec. *Rural and Remote Health*.

# Working and Learning with vulnerable populations

## Poverty



# Homelessness

## Welcome Hall Mission

- Men's services
- Women's services
- **Children's services**
- Youth services
- Food bank
- WHM Transitional Housing
- Education & employability
- La Boutique
- Jim Lund Dental Clinic
- Nursing



Welcome Hall  
**MISSION**

# Working and Learning with vulnerable populations

## Childhood Ethics

### *Developing International Research*



# Recent PICU research

## *International pediatric critical care ethics*

### The moral experience of parents regarding life-support decisions for their critically-ill children: a preliminary study in France

FRANCO A. CARNEVALE, RN,  
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PIERRE CANOÛT, MD  
Hôpital Necker-Enfants Malades, Paris, France

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Hôpital Ste-Justine, Montreal, Canada

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AMÉLIE DOUSSAU, RN  
Montreal Children's Hospital, McGill  
University Health Centre, Montreal, Canada

MARIE-JOSÉE SEGUIN, RN, BScN  
Montreal Children's Hospital, McGill  
University Health Centre, Montreal, Canada

JACQUES LACROIX, MD  
Hôpital Ste-Justine, Montreal, Canada

### Tracheotomy and children with spinal muscular atrophy type I: Ethical considerations in the French context

**Brigitte Rul**

Raymond Poincaré Hospital, France;

**Franco Carnevale**

Montreal Children's Hospital, Canada

**Brigitte Estournet**

Raymond Poincaré Hospital, France;

**Michèle Rudler**

Paris-Descartes University, France

**Christian Hervé**

Paris-Descartes University, France

### Which Child Will Live or Die in France: Examining Physician Responsibility for Critically Ill Children

Franco A. Carnevale and Gilles Bibeau

*Anthropology & Medicine*

*Vol. 14, No. 2, August 2007, pp. 125–137*

### Understanding the private worlds of physicians, nurses, and parents: A study of life-sustaining treatment decisions in Italian paediatric critical care

**Franco A Carnevale**

McGill University, Montreal, Canada

**Monica Benedetti, Amabile Bonaldi, Elena Bravi, Gaetano Trabucco and Paolo Biban**

Major City Hospital, Azienda Ospedaliera Universitaria Integrata di Verona, Italy



# International research

## Sondaggio sulle scelte di trattamenti di supporto vitale nelle Terapie Intensive Pediatriche Italiane

**Paolo Biban** (rianimatore-pediatria, Verona)

**Amabile Bonaldi** (infermiera, Verona)

**Elena Bravi** (psicologa, Verona)

**Franco A. Carnevale** (consulente di etica, infermiere, psicologo; Canada)

**Alberto Giannini** (rianimatore-pediatria, Milano)



# Republic of Georgia

*Georgian Medical News, 2013 December (225), 87-93.*

## **PEDIATRIC BIOETHICS IN GEORGIA: A PROPOSED ETHICAL FRAMEWORK**

**Manjavidze I., Franco A. Carnevale**

*Tbilisi State Medical University, Clinical Skills Center Georgia;  
McGill University Clinical Ethicist, Montreal Children's Hospital Montreal, Canada*

რეზიუმე

პედიატრიული ბიოეთიკა საქართველოში-წარმოდ-  
გენილი ეთიკური ჩარჩო

ი. მანჯავიძე, ფ. კარნევალე







Revista da SORBI, 2014; 2(1), p. 35-55.

ANÁLISE NORMATIVA DOS PADRÕES ÉTICOS PARA CRIANÇAS NO BRASIL  
NORMATIVE ANALYSIS OF ETHICAL STANDARDS FOR CHILDREN IN BRAZIL

Franco Carnevale<sup>1</sup>

Renata de Moura Bubadué<sup>2</sup>

Eneida Simões da Fonseca<sup>3</sup>

Anelise Espírito Santo<sup>4</sup>

Ivone Evangelista Cabral<sup>5</sup>

**Objetivo:** conduzir uma análise das normas brasileiras sobre padrões éticos e os aspectos significativos das mesmas para a infância brasileira.

**Métodos:** análise normativa de 22 documentos relevantes do Brasil em dois quadros teóricos interrelacionados: ético e interdisciplinar.

**Resultados:** Emergiram nove categorias: Princípios Gerais, Cidadania, Saúde, Direito do Nascituro, Pesquisa, Educação, Assistência Social, Trabalho Infantil e Crianças com Necessidades Especiais de Saúde. Cada uma teve de uma a cinco subcategorias, discutidas conforme relevância ética e prioridades para pesquisas futuras.

**Conclusão:** apesar do curto espaço de tempo que o Brasil teve para desenvolver seus sistemas normativos e legais atuais, o país desenvolveu um quadro conceitual ético rico e compreensivo para vários domínios da vida da criança. Destaca-se a necessidade de investir no desenvolvimento científico para investigar como as normas de ética pediátrica estão sendo respeitadas nas práticas diárias.



# Mauritius Ministry of Health



# VOICE: Views On Interdisciplinary Childhood Ethics Interdisciplinary & Inter-perspective Collaboration

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McGill

VOICE

# VOICE: Views On Interdisciplinary Childhood Ethics

## Interdisciplinary & Inter-perspective Collaboration

- McGill-based research and practice development initiative conducted by an interdisciplinary research team in collaboration with a network of community partners and stakeholders.
- Principal aim: identify, investigate, and develop strategies for addressing ethical concerns relating to young people.
- Committed to ACTION!



# Advancing interdisciplinary research in childhood ethics

## An ethnographic examination of best interests and moral agency

### **Principal Investigator**

Franco Carnevale (nursing, psychology, bioethics)

### **Co- Investigators**

Delphine Collin-Vézina (child welfare, psychology)

Mary Ellen Macdonald (anthropology)

Shaheen Shariff (childhood education)

Victoria Talwar (childhood education, psychology)

Shauna Van Praagh (law)

### **Collaborators**

Myra Bluebond-Langner (anthropology)

Jean-Frédéric Menard (law)

Kathleen Glass (bioethics, law)

Patricia McKeever (disability studies, nursing, sociology)

Nico Trocmé (child welfare)

Daniel Weinstock (ethics, law, philosophy)

### **Stakeholder advisors**

(others to be added)

Youth representatives, The Students Commission of Canada, The Centre of Excellence for Youth Engagement Youth Advisory Committee, Holland Bloorview Kids Rehabilitation (disabled children participants)

Parent representatives, Canadian Family Advisory Network

Ontario Provincial Advocate for Children and Youth (Irwin Elman, Toronto)

Laura Sky (documentary filmmaker with focus on childhood concerns)

### **Collaborator (In Memoriam)**

Kathleen Glass (bioethics, law)

# VOICE: Views On Interdisciplinary Childhood Ethics

**VOICE** arranges educational and consultation activities (in addition to conducting research):

- Diverse formats conducted in various settings to promote community engagement
- Suggestions for themes or activities are welcome!

## **Affiliated with**

McGill Centre for Research on Children and Families

McGill Institute for Health and Social Policy

## **Funded by**

Canadian Institutes of Health Research and

Social Sciences and Humanities Research Council

## **For information contact**

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VOICE

# VOICE: Views On Interdisciplinary Childhood Ethics

## Interdisciplinary & Inter-perspective Collaboration

### Integrated knowledge & action

#### Knowledge synthesis

##### *Scoping reviews*

- Moral agency in childhood
- Childhood ethics and aboriginal health
- Intersection of pediatric medicine, child welfare, and ethics
- Intersection of moral agency, best interests, and childhood
- Ethical issues relating to newborns
- Confidentiality in pediatric health care

#### Knowledge production

- Ethnography of moral agency in childhood
- School research (including children with chronic illnesses)
- ‘Working poor’ population (Welcome Hall Mission Children’s Services)
- Aboriginal community
- Child welfare
- Childhood disability

#### *Legal analyses*

- Intersection of pediatric medicine & child welfare
- Legal issues relating to newborns

#### **Knowledge translation & utilization**

- Policy development
- Educational program development

# Advancing interdisciplinary research in childhood ethics

An ethnographic examination of best interests and  
moral agency





# Advancing interdisciplinary research in childhood ethics

An ethnographic examination of best interests and  
moral agency

## Background Research



# Interdisciplinary Studies of Childhood Ethics: Developing a New Field of Inquiry

Franco A. Carnevale\*, Angela Campbell†, Delphine Collin-Vézina<sup>§</sup> and Mary Ellen Macdonald<sup>¶</sup>

The principal aim of this investigation was to help develop 'Interdisciplinary Studies of Childhood Ethics' as a new field of inquiry

We identified

- (i) current intra-disciplinary and interdisciplinary knowledge gaps in childhood ethics
- (ii) priorities for future research and development.

# Interdisciplinary Studies of Childhood Ethics

## Methods (Scoping Review)

- Examination of childhood ethics knowledge relating childhood to matters of right/wrong, good/bad or just/unjust. Included:
  - i) normative sources (e.g. legislation, case law, ethics codes)
  - ii) empirical evidence describing moral phenomena and how these are affected by social/cultural contexts
  - iii) theoretical and methodological frameworks; and
  - iv) policies and guidelines that define practices relating to childhood ethical matters.

# Child citizenship and agency in law

Campbell A, Carnevale M, Jackson S, Carnevale FA, Collin-Vezina D, Macdonald ME. 2011. Child citizenship and agency as shaped by legal obligations. *Child and Family Law Quarterly* 23: 489–512

Legal recognition of obligations for children facilitates their recognition as citizens and agents when such obligations are understood from contextual and relational perspectives. Study of three separate settings:

- Part I examines **child as student** and studies children's obligations within schools
- Part II considers **street child** and obligations and challenges children encounter when they live away from their families & communities
- Part III contemplates **child as bargainer** and focuses on obligations children assume when accessing, negotiating for, and acquiring services in their communities

# Interdisciplinary Studies of Childhood Ethics

## Findings

- Child Law
- Child Psychology
- Childhood Education
- Pediatric Medicine
- Child Welfare
- Social Studies of Childhood

## **Interdisciplinary transversal problem:**

How should the best interests standard should be reconciled with the recognition of children as agents?

# Interdisciplinary Studies of Childhood Ethics

## *Synthesis*

Many intra- and inter-disciplinary knowledge and practice gaps in childhood ethics

Gaps within disciplines and divisions between service providers and researchers

Fragmentation is particularly problematic for children within vulnerable populations

### **Examples of problems in childhood ethics**

|   |                                 |
|---|---------------------------------|
| Decisional authority                      | Childhood education             |
| Definitional problems with best interests | Child welfare                   |
| Actions of courts                         | Child as victim and perpetrator |
| Legal rights/responsibilities             | Equity and social justice       |
| Right to be heard                         | Child as economic actor         |
| Moral development                         | Research participation          |
| Social studies of childhood               | Knowledge to action gaps        |

# Interdisciplinary Studies of Childhood Ethics

## *Objectives*

To advance interdisciplinary research and knowledge mobilization to address ethical concerns relating to childhood; with a central focus on best interests and moral agency

- 1) Examine the moral experiences of children in situations involving a determination of their best interests or their engagement in moral agency;
- 2) Investigate how children's best interests and moral agency are conceived by four key social institutions (i.e., child welfare, education, law, psychology);
- 3) Identify significant concerns that emerge within and between children's moral experiences and institutional practices;
- 4) Highlight priorities for the development of norms, policies, practice standards, research, and educational programs for childhood-related professions, and develop materials to respond to these recommendations, based on the findings of this investigation

# Theoretical framework

## Three interrelated frameworks

- 1) Ethical framework: social constructivist
- 2) Disciplinary focus: interdisciplinary framework
- 3) Knowledge to action framework



## Design

### 5-year project with 3 phases

Phases I and II: how childhood ethics “is” understood and practiced

Phase III: how childhood ethics “ought” to be understood and practiced

Overarching methodology: ethnography

### The investigation will examine

- 1) children’s *moral experiences*
- 2) the practices of four *social institutions* (i.e., education, child welfare, the law, child psychology; identified in our previous research)
- 3) the intersections of moral experiences and institutional practices in four *institutional settings* (i.e., school, community, courts, home)

# Design

Three sub-populations identified as particularly vulnerable and priority concern for the study:

- a) children of aboriginal descent
- b) children with disabilities
- b) children of disadvantaged social & economic backgrounds (homeless/working poor)

Stakeholder participation is incorporated into all phases.

## Phase II Data collection and analysis (3.5 years; Months 7-48)

Ethnographic investigation of best interests and moral agency in childhood (i.e., empirical and document analyses), through an examination of moral experiences and institutional practices.

Sampling will ensure

- Diverse childhood perspectives are reflected (e.g., age, gender, cultural, social diversity)
- As well as the three vulnerable populations prioritized for this investigation

Various data collection and analysis methods will be used

## Phase II Data collection and analysis

### **Guiding questions**

Data collection/analysis oriented by guiding questions (adapted throughout study).

***Moral experience***

***Institutional practices***

***Textual analyses***



## **Phase II-A (1 year; Months 7-18)**

### **Key informants (KI)**

- Primary school
- Secondary school

### **Early childhood participant observation**

- Kindergarten
- Pre-school

### **Institutional practices**

Interviews

Institutional documents

### **Textual Analyses**

Legal (e.g., court judgments, legislation) as well as policy and practice standards relating to schooling, child welfare and child law will be examined

Multiple provincial jurisdictions will be sampled



## Phase II-B (1 year; Months 19-30)

### Focus groups to

- a) conduct more structured investigations
- b) further examine themes identified in Phase II-A
- c) identify additional data that should be examined

- Child focus groups
- Adult focus groups

### Participant observation



## Phase II-C (1 year; Months 31-42)

### Quantitative research to examine children's

- Actual experiences
- Moral emotions
- Moral cognitions



## Some Discussion Questions for CRCF

- How to examine childhood ethics relating to:
  - 1) Child welfare
  - 2) Childhood disability
  - 3) Poverty
  - 4) Aboriginal context
- Specific questions or problems to examine
- Groups and/or settings to 'sample'
- Optimal methods to ensure young people's participation

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