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FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

Alberta **LAW**  
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**Moving on:**

***Offspring health and wellbeing,  
record disclosure and  
legislative policy***

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# Objectives

- To recollect the paramount concern of the *Assisted Human Reproduction Act*.
- To present briefly some recently commissioned health science research.
- To describe categories of current provincial and territorial adoption disclosure provisions.
- To recommend provincial and territorial legislative policy.

# Preliminary matter: “Offspring” definition

Noun

“A person created by the use of gametes, which were provided for human procreation by a person who does not intend to rear the resulting child.”

*Plural:* Offspring

# Plan for today

- 1. Assisted Human Reproduction Act**
2. Two Problems: Secrecy, Anonymity
3. Recent Health Science Research
4. Adoption Disclosure Legislative Models
5. Recommendations

# Assisted Human Reproduction Act

Section 2: Parliament recognized and

1. Health and well-being of children  
declared that:

2. must be given priority

3. in all usage decisions.

(a) The health and well-being of children  
born through the application of assisted  
human reproductive technologies must be  
given priority in all the decisions  
respecting their use.

# *Assisted Human Reproduction Act* then stated

- That gamete providers could be anonymous to Offspring. s. 18(2)
- That gamete providers may require the destruction of records about themselves. s. 16(2)
- Those sections no longer valid but anonymity still practiced.



# Question: Was the Act internally inconsistent?

Is it in the health and wellbeing interest of Offspring to have a progenitor who is anonymous to the Offspring?

Related question: should the state participate in the creation of birth certificates that are inaccurate with respect to genetic lineage?

**Research Project: What are the health and well-being interests of Offspring with respect to records?**  
Guichon, Mitchell, Giroux eds.



1. Assisted Human Reproduction Act
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# Secrecy: definition

- Where truth about unusual conception kept from Offspring.
- “Secrecy” entails absence of the telling of the whole truth.
- Includes passive lying.

# One reaction to secrecy ending

“I nodded and walked far enough ahead that you wouldn’t think I was with them. I’M ARTIFICIALLY INSEMINATED??? ONE PART OF ME IS WORTH 20 BUCKS? THAT’S ALL?? THIS “DAD” OF MINE IS NOT ACTUALLY HIM. WELL WHO IS HE? SOME RANDOM GUY THAT JUST MOVED IN THE FAMILY! WHO IS HE? GET OUT OF MY LIFE! WHERE’S MY REAL DAD? WHERE IS HE? I CAN’T MEET HIM.... I can’t meet him... I can’t know him... [...] We got back to the hotel and I hid under my covers, tears streaming down my cheeks.” - J.S. aged 13

# Anonymity: definition

- Where the gamete provider is anonymous to his or her offspring.
- Anonymity can be accompanied by the absence of medical, social and cultural information.

# One reaction to anonymity justification

How could this man – if he is still alive - feel threatened by the curiosity of his own son? [...] our genetic connection is a private matter we share together, something I feel I should be able to pass to my own children and grandchildren as their birthright. My legitimate demands upon him are clearly limited. But his duty must be acknowledged. All men have a moral obligation to meet the children they create and to answer their questions about their paternal heritage. No doctor can absolve anyone of this duty.

- Bill Cordray

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# Recently commissioned health science research regarding Offspring health and well-being

- Two types.
  1. Systematic reviews of cohort studies regarding psychosocial outcome.
  2. Research regarding clinical practice.
- Outcomes vary.

# Systematic Reviews

Review of studies concerning secrecy

Review of studies concerning anonymity

# Systematic review 1

## Secrecy: Gibbard 2010

### QUESTION:

Is it in the best interests of Offsprings' psycho-social health to know about their conception?

(Does secrecy have negative psycho-social effects?)

# Secrecy: Gibbard (con't)

- Most parents do not tell.  
Berger (1986); Brewaeys (1996); Braverman (1998);  
Gottlieb (2000) ; Brewaeys (2001); Colpin (2002);  
Lycett (2005); Jadvá (2009); Owen (2009).
- Same sex rearing parents more likely to tell.  
Jadvá (2009).
- Arguments for non-disclosure: protection against stigma (Nachtigall 1998); feared disruption of parental bond (Cook 1995); parental privacy (Shenfield 1997).
- In one study, of those who have not told the child, 53% had told another person. Gottlieb (2000)

# Secrecy: Gibbard (con't)

## CONCLUSION

- Existing research is insufficient.
- Current psychosocial outcome research is preliminary (e.g. small samples; low response rates; studies used unknown measures of psychosocial outcome)
- Not known if those who know about their conception differ from those who do not know.
- Not known if disclosure has benefits that depend on age of disclosure.

# Systematic review 2

## Anonymity: Page 2010

### QUESTION:

What are psychosocial outcomes for children conceived by gamete provision and raised in heterosexual families?

### CONCLUSION:

We cannot answer this question yet.

Where disclosure of genetic origins is not prevalent, it is difficult to know about effects of anonymity.

# Page: Anonymity (con't)

Secrecy limits scope and validity of research

Other limitations:

- small sample sizes
- repeated observation of the same groups
- selection bias
  - only those willing to participate, did participate
  - participants had chosen this method of procreation
  - existing studies focused on rearing parents' perspectives

# Policy Suggestions

- Gibbard and Page make recommendations for future research regarding psychosocial outcomes
- Conduct quantitative and qualitative research
  - Larger samples, attempting to control for selection bias
- Consider all variables that affect psychosocial development
- Review details of risk and adaptation with respect to individual, family, community and cultural variables
- Explore family therapy and adoption literature regarding secrecy and anonymity from **both** family dynamic and child psycho-social and medical outcome perspectives.



# Clinical Practice Research

Social Work

Medical Genetics

# Clinical Practice: Social Work

## Benward 2010

Question:

Is identity development impeded by secrecy and anonymity?

Conclusion:

Yes.

# Clinical Social Work (con't)

- Identity formation is central to well-being
- Definition: the universal, vital and continuous task of human development.
  - “Who am I?”
  - “How am I like or different from others in appearance, traits, personality and talents?”

## Concluded:

- Secrecy can be harmful to well-being because it can end in discovery.
- Discovery can cause painful deconstruction and reconstruction of identity.

# Clinical Social Work (con't)

Anonymity is also harmful to well-being.

- Individuals form identities best when they can:
  - See genetic resemblance
  - Hear people engage in resemblance talk
  - Understand where they fit in past and future generations
- Anonymity deprives Offspring of these benefits

# Clinical Medical Genetics: Lauzon 2010

Question:

From the perspective of clinical medical genetics, are secrecy and anonymity harmful to Offspring health and well-being?

Answer:

Yes.

# Clinical Medical Genetics: Lauzon 2010

Secrecy can harm offspring and provider.

False family history can lead to:

- misdiagnosis of genetic condition
- unnecessary and potentially invasive screening
- omission of screening and consequent loss of opportunity to take preventative measures

# Clinical Medical Genetics: Lauzon 2010

Anonymity deprives Offspring of medical benefits of a family history.

Family history helps geneticist in:

- Recognizing that a condition may be genetic.

- Guiding diagnostic testing and treatment.

- Identifying at-risk relatives & offering genetic testing.

- Implementing screening strategies in affected or at-risk family individuals.

- Providing education, understanding and support.

- Discussing reproductive options.

# Policy Suggestions

Benward and Lauzon do not recommend secrecy and anonymity.

Benward specifically states to all parties:

- Disclose truth early to children: no secrecy.
- Recognize emotional losses created by lack of progenitor information.
- Provide social and emotional support to Offspring.
- Create, preserve, disclose progenitor information.
- Enable and encourage access to the progenitor.



# What to do when health science research is inconclusive?

- Do more and better research regarding health and well-being interests of those people conceived using provider gametes.
- But fill the gaps pending outcomes of better research.
- “Gap” is a suspected detriment to off-spring health and well-being associated with secrecy, anonymity or both.
- Litigation puts burden (and enmity) on one person or class. Legislate.

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# Pratten First Instance Decision Held:

Offspring and adoptees are similarly situated regarding need to know origins.

- *Pratten v. A.G.B.C. and College of Physicians and Surgeons of British Columbia*, 2011 BCSC 656  
per Adair, J. at paragraph 234

# Canadian adoptees have significant rights

Legislation varies, and can be categorized:

A. Non-identifying medical, social and cultural information

B. Identifying information

1. Consent

2. No consent

a. Past adoption

b. Future adoption

# 1. Non-identifying information

- All Canadian provinces and territories provide disclosure at least at majority.
- Adoption Act, R. S. B. C. 1996, c. 5, s. 65(4), 66(7); Child, Youth and Family Enhancement Act, R. S. A. 2000, c. C-12, s. 74.2(2) qualified by s. 74.2(9); Adoption Act, S. S. 1998, c. A-5.2, s. 26(1) (c) and (e); Adoption Act, C. C. S. M. c. F20, s. 112(4) and 113(4); Adoption Information Disclosure, O. Reg. 464/07, s. 11(2); Family Services Act, S. N. B. 1980, c. F-2.2, 92(1); Adoption Information Act, S.N.S. 1996, c. 3s. 11(1); Adoption Act, R. S. P. E. I. 1988, c. A-4. 1, s. 48(1); Adoption Act, S. N. L. 1999, c. A-2. 1, s. 48; Child and Family Services Act, S.Y. 2008, c. 1, s. 143(4) and (6); Adoption Act, S. N. W. T. 1998, c. 9, ss. 63 – 64; Adoption Act, S. N. W. T. (Nu.) 1998, c. 9, ss. 63 – 64.

## 2. Identifying Information: If mutual consent, then disclosure

- Every Canadian jurisdiction provides disclosure to adoptees with consent.
- Adoption Act, R.S.B.C. 1996, c. 5, s. 69; Child, Youth and Family Enhancement Act, R. S. A. 2000, c. C-12, s. 75; Adoption Regulations, 2003, R.R.S. c. A-5.2 Reg. 1, ss. 27-32; Adoption Act, C. C. S. M. c. F20, s. 108, Post-Adoption Registry; Adoption Information Disclosure, O. Reg. 464/07, s. 9-10; Article 583 C.C.Q.; Family Services Act, S.N.B. 1980, c. F-2.2, s. 92(5); Adoption Information Act, S.N.S. 1996, c. 3, s. 9(1); Adoption Act, R. S. P. E. I. 1988, c. A-4. 1, ss.49-50.; Adoption Act, S. N. L. 1999, c. A-2. 1, s.44; Child and Family Services Act, S.Y. 2008, c. 1, s. 146; Adoption Act, S. N. W. T. 1998, c. 9, s. 66; and Adoption Act, S. N. W. T. (Nu.) 1998, c. 9, s. 66.

### 3. Some governments will search and ask for consent.

- BC SK MB QC NB PE NL YT NT NU will all help adoptees
- Adoption Act, R. S. B. C. 1996, c. 5., s. 71(1); Adoption Regulations, 2003, R.R.S. c. A-5.2 Reg. 1, s. 31(1); Post-Adoption Registry Regulation, Man. Reg. 22/99, s. 5; Adoption Council of Canada, About Adoption, Search and Reunion: Quebec, <http://www.adoption.ca/AboutAdoption.html>; Family Services Act, S. N. B. 1980, c. F-2.2, 92(3); Adoption Council of Canada, About Adoption, Search and Reunion: Nova Scotia: <http://www.adoption.ca/AboutAdoption.html>; Adoption Act, R. S. P. E. I. 1988, c. A-4. 1, s. 50(3); Adoption Act, S. N. L. 1999, c. A-2. 1, s. 56; Child and Family Services Act, S.Y. 2008, c. 1, s. 147(1) Adoption Act, S. N. W. T. 1998, c. 9, ss. 66(4); Adoption Act, S. N. W. T. (Nu.) 1998, c. 9, ss. 66(2)

## 4. Some governments permit unlimited disclosure regarding past adoptions provided no Disclosure Veto.

- BC AB ON NL YT
- *Adoption Act*, R.S.B.C. 1996, c. 5; *Child, Youth and Family Enhancement Act*, R. S. A. 2000, c. C-12; *Vital Statistics Act*, R.S.O. 1990, c. V.4; *Adoption Act*, S. N. L. 1999, c. A-2. 1; *Child and Family Services Act*, S.Y. 2008, c., 143.



5. Some governments permit unlimited disclosure if party has been searching for more than one year.

- NT and NU
- *Adoption Act*, SNWT 1998, c 9, 66(4); *Adoption Act*, SNWT (Nu) 1998, c 9, 66(2).

## 6. Some governments make disclosure automatic regarding future adoptions.

- BC ON NL YK
- *Adoption Act*, R.S.B.C. 1996, c. 5; *Vital Statistics Act*, R.S.O. 1990, c. V.4; *Adoption Act*, S. N. L. 1999, c. A-2. 1; *Child and Family Services Act*, S.Y. 2008, c., 143.

# State benefits granted to adoptees, not to Offspring

1. No effective state regulation of field.
2. No state data collection to create non identifying medical, social and cultural information.
3. No state creation of accurate records of parentage.
4. No state method of contact in case of medical necessity.

# State benefits granted to adoptees, not to Offspring

5. No state mutual consent registry.
6. No state search facilities.
7. No ability to know if a proposed sexual partner is genetically related.
8. No opportunity in future gamete provisions for disclosure as of right.

These gaps probably negatively affect Offspring health and well-being

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# Recommendations

## 1. Accept that the field is difficult to regulate in interests of child.

- Suffering attendant upon childlessness can be significant.
- Medical professional focus on adult interest.
- Lack of political appetite to address reproductive issues.

2. Take seriously Parliament's declaration that the health and well-being interests of Offspring are paramount.
3. Conduct more and better research on effects of secrecy and anonymity for Offspring health and well-being.
4. Pending better research, fill legislative gaps regarding legal benefits provided to adoptees and not Offspring.

## 4.1 Provinces and territories: encourage the creation of accurate certificates of genetic lineage

- require independent representation for child in applications to misstate genetic lineage





## 4.2 Create, preserve and disclose identifying and medical, social and cultural information for Offspring under adoption legislation.



## 4.3 Recognize that practices are changing quickly and effective legislation is overdue.



# Thank you



# QUESTIONS?



**Windswept**  
**O.N. Grandmaison**

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