

Dear Ms. Thompson, Manager of UBC Behavioural Research Ethics Board,

As we discussed earlier this week, I am writing regarding the activities of the Human Early Learning Partnership (HELP) based at UBC, HELP Director Dr. Clyde Hertzman, Dr Paul Kershaw, and others at HELP.

There are numerous complaints about the ethics of HELP's activities.

Due to time constraints, parts of the complaint will be sent later. At this time the first item listed below is included as it is an urgent concern due to the proposed February 2011 'EDI' and the January distribution of EDI letters from HELP to parents.

I - violation of privacy and informed consent

II - misrepresentation of research and researchers, false and misleading claims

III – lack of peer-review for HELP claims which HELP widely disseminates.

IV - failure and refusal to disclose methods and definitions

V – public attacks on other academics and researchers

VI - excessively close ties to and influence on government

VII – widespread dissemination by and through HELP of false, misleading, and unexplained statements presented as research findings

VIII – HELP's adverse effect on public policy, democratic process, and lives the of children, women, and parents

I - Violation of privacy and informed consent

1 - The Early Development Instrument (EDI) is a long questionnaire filled in by kindergarten teachers. It is promoted, provided, administered, and interpreted by the Human Early Learning Partnership (HELP) under the leadership of HELP Director Dr Clyde Hertzman. HELP states that it is funded by 3 ministries in the BC government to do the EDI.

2 - The current version of the EDI and the EDI Teachers' Guide can be found at

http://www.offordcentre.com/readiness/EDI_viewonly.html

<http://www.offordcentre.com/readiness/teachers.html>

3 - According to HELP, the EDI has been conducted on almost all kindergarten children in BC in the years 2003, 2006, 2009, and 2010. It was conducted on Vancouver children in 2000. Dr Hertzman requested and was granted funds and permission to conduct it annually as of 2010.

4 - HELP states that it "links" the "person specific" EDI data with other personal data on "all children in BC" "from pre-conception to young adulthood" (also: "from conception to high school leaving") including: medical, hospital, perinatal, pharmaceutical, mental health school performance, child care, child in gov't care, Workers' Compensation, child care, death, census, etc.

see

documents no longer on HELP website

<http://www.kidsfirstcanada.org/HELP-personal-records.pdf>

<http://www.kidsfirstcanada.org/HELP-preconception-adulthood.pdf>

5 - Judging from the types of data being collected - ie perinatal records, hospital records, census, etc - parents' and/or mothers' personal records are also linked.

6 - HELP people including Dr Hertzman have recommended in a paper for Statistics Canada that personal income tax data should be "linked".

see p. 19

<http://www.statcan.ca/english/research/11F0019MIE/11F0019MIE2006284.pdf>

7 - No 'end date' for the data collection and linkage, or storage, is indicated.

8 - Nor is there any clearly stated extent/limit to the records to be eventually or possibly included in the "linkage" process. HELP's data-collection and linkage aspirations are open-ended and ever-expanding.

See

<http://www.earlylearning.ubc.ca/research/initiatives/developmental-trajectories/research/>

see also

<http://www.earlylearning.ubc.ca/research/initiatives/developmental-trajectories/linked-databases/>

9 - HELP has stated in media and elsewhere that names and addresses are not used. However, given that HELP obtains Personal Education Numbers, medical numbers and postal codes, etc, names and addresses would not be needed to individually identify a person or a family.

See

Burnaby Now article- <http://www.burnabynow.com/Does+data+collection+privacy+risk/2531109/story.html>

10 - The properly informed consent of the children and parents is not obtained. So-called "PASSIVE CONSENT" is NOT GOOD ENOUGH. It violates the right of the parents and children to privacy and informed consent forever or until & unless the data is destroyed.

11 - It is impossible to provide informed consent to an on-going unknown process such as HELP's data linkage.

12 - Letters from HELP and schools to kindergarten parents about the EDI do not fully disclose the data collection and linkage aspect; that is, the letters have never listed all the records HELP is now - or may be in the unknowable future - linking or planning or hoping to link.

13 - There is no effort to ensure that the parents even receive the letter and read it, or are able to read, and understand it. No translations are sent out, no parental signature confirming receipt of the letter is required, no signature confirming that a parent has 'read and understood' the content is required.

14 - This especially discriminates against the rights of parents and children who do not read English well enough to understand the letter due for language, cultural, educational, intellectual, or other constraints.

15 - It also discriminates against parents who for cultural, experiential, political, or other reasons are reluctant to question or challenge school or governmental authority - authority which HELP is relying on to obtain the data it seeks.

16 - We have spoken to kindergarten parents who did not even receive the EDI letter when it was conducted in their school. HELP does not insure that parents receive the letter.

17 - We have letters from 2006, 2009, 2010. They have been changed over the years to increase the information somewhat and now offer so-called "passive consent" consisting of a vague 'negative opt out' (ie speak to the teacher a few weeks before the EDI takes place).

see

2010 EDI full letter http://www.kidsfirstcanada.org/HELP_Full_Parent_Letter_English.pdf

2010 EDI short letter <http://www.kidsfirstcanada.org/HELPExecutive-Summary-Parent-Letter-English.pdf>
2009 and 2006 EDI letters <http://www.kidsfirstcanada.org/letterstoparents.htm>

18 - Never have parents been asked to sign and return a form providing HELP with their informed consent as they are required to do if child participates in eg a field trip or hot dog day. Children who do not return the properly signed consent forms do not participate.

19 - HELP claims to be obtaining and linking data not only from students subjected to the EDI but also from students in other grades: "**all children of school age**".

20 - In 2004 HELP stated that it had linked the personal medical and personal education numbers of 97% of BC children. There is no information provided to these parents and children at all, no effort to do so.

See
HELP documents linked above

21 - The EDI asks questions that only parents could answer reliably such as details of prior non-parental care arrangements, Sunday school attendance, etc.

22- It is obvious that HELP in collaboration with or on behalf of the government of BC is going to great lengths to avoid parent-citizens by repeatedly circumventing standard research ethics, due process, and democratic rights to informed consent in these endeavours. This effort should not be condoned by a university "ethics review".

23- We have spoken to kindergarten teachers and school administrators involved in the EDI who were not informed about or did not understand the data-linkage aspect of the project and expressed shock at the extent of it.

24 – The EDI is invasive, asking questions of a private nature about the children, and about the family, such as the above questions (22), toilet habits, eating habits, energy level, temperament, “problems at home”, etc.

25 – With the increased use of electronic testing in school, children’s personal beliefs, plans, opinions and experiences expressed in writing could potentially be linked.

26 – HELP was instrumental in getting ‘Strong Start’ (drop-in programs for 0-5 year olds accompanied by a parent or other care-provider), run by the Ministry of Education. However, these ‘drop-in’ programs unlike all other drop-in programs, require children to register and obtain a Personal Education Number (PEN) in order to participate. Legislation was changed to allow PENS for children under school age:

from BC government website

http://www.bced.gov.bc.ca/early_learning/strongstart_bc/qa_pen_reporting.htm#background

“On July 1, 2007, the provisions of the Student Achievement Enabling Act, Bill 20 came into effect. This Bill introduced a number of changes, including assigning personal education numbers or PENs to children participating in StrongStart BC Early Learning Programs.

”The Ministry already assigns every school-age child with a personal education number (PEN). **This personal education number forms the basis of the student’s educational record, from kindergarten to graduation, and on to post secondary programs.**

”**With the new legislation, information may now be collected about children participating in StrongStart BC programs.**”

27 - Therefore, the personal records of these children age 0-5 and their families may also be subject to collection and linkage with no form of consent.

28 – These tactics by HELP and the BC government have the effect of furthering the political marginalization of parents –and particularly women as mothers who most often take primary responsibility for their children’s school communications. This avoidance and marginalization/dis-empowerment calls into question HELP’s claims to be concerned with improving “gender equity” and “supporting” parents.

29 – HELP’s secretive non-consensual, undemocratic data-mining and linkage activities treat the lives of children and their families as resources to be used by themselves and others in paid and privileged positions. That this is done using the language of justice - in the name of “supporting” parents, “gender equity”, and helping children - adds insult to injury.

30 – HELP’s has ties to and funding from the Canadian Institutes for Health Research and the Michael Smith Foundation for Health Research. Both of these bodies emphasize “commercial potential” and “commercialization” of activities they fund. HELP is also closely tied to the World Bank with Dr Hertzman as a long time staff/consultant, though this fact is omitted in his current biographies and PR. HELP and Dr Hertzman have long cultivated so-called “partnerships” with the business sector including the BC Business Council, chambers of commerce and the Vancouver Board of Trade, etc. These connections raise concerns about the possibility of commercial exploitation of the data collected.

31 – These connections further raise concerns about the need for protection of the interests of children, women, parents, families, voters, and taxpayers affected by HELP research and policy making activities. At present, there is little protecting these interests vis a vis the interests of HELP’s leadership and the interests it represents.