

Banked Tissue and Child Protection

A report by the University of Miami Ethics Programs

to

The Florida Department of Children and Families'
Blue Ribbon Panel on Child Protection

September 20, 2002

University of Miami Ethics Programs
Miami, Florida



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Executive Summary

Florida Department of Child and Families assembled a Task Group to examine the feasibility of collecting and maintaining biological materials in service of its child protection mission, as directed by the Governor's Blue Ribbon Panel on Child Protection. The University of Miami Ethics Programs prepared background material for, hosted and facilitated a meeting of the Task Group on Sept. 13, 2002, at the university's School of Medicine. Nearly two dozen individuals with diverse backgrounds in law enforcement, criminal forensics, law, pediatric medicine, genetics, pathology, and ethics met at length with DCF Task Group members, child services providers and local representatives of foster parents to consider the many issues that bear on the question.

This document is a synthesis of and report on the Task Group's deliberations. The recommendations are offered by the UM Ethics Programs as a synthesis of those deliberations.

It is recommended that while genetic identification is a valuable forensic tool for law enforcement, the case for its utility in child protection is unconvincing, in part because the same law enforcement ends can be realized by already available and often less expensive means. Moreover, given technological, resource, and social/ethical concerns associated with tissue banking and genetic databases, a strong consensus arose and held that available resources would be more productively devoted to (a) improving the usefulness of less invasive and less controversial technologies, (b) improving the provision and management of child services. Additionally, Task Group members were keen to ensure that law enforcement agencies had adequate resources to carry out their duties and that the issues raised by the Task Group should be revisited periodically to take note of evolving technology.

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1. Introduction and background

In the United States in general and Florida in particular (in part because of noteworthy cases involving the whereabouts of children in the State's custody), the need to protect the health and welfare of our most vulnerable citizens has become a top priority. Florida Governor Jeb Bush's Blue Ribbon Panel on Child Protection called for an exploration of the feasibility of collecting biological materials from children in the care and custody of the Florida Department of Children and Families (DCF). These materials would serve as a source of genetic information that could be used for identification of missing children.

The Department called on the University of Miami Ethics Programs to provide a review of ethical issues related to the banking of biological material, to facilitate a task group meeting on these and related issues and to provide a synthesis and report of the review and meeting. This document is the result.

Only one-tenth of 1 percent of DNA (about 3 million bases) differs from one person to the next. Scientists can use these variable regions to generate a DNA profile of an individual, using samples from buccal swabs, blood, bone, hair and other body tissues and products. There are many ethical issues to consider when considering the collection of genetic samples from a particular group of children in the population. These questions include the following:

Context

"On April 25, 2002, the Florida Department of Children and Families (DCF) revealed that one of its Miami wards, 5-year-old Rilya Wilson, had disappeared 15 months earlier from her custodial home and had not been seen since... In response, Gov. Jeb Bush on May 6 appointed a four-member Governor's Blue-Ribbon Panel on Child Protection to investigate and report back to him." The panel recommended under "Immediate Priorities" that the governor "Require that DCF and provider files contain a current photograph, fingerprints and birth verification (or evidence of a diligent effort to obtain) of every dependent child [and] make recommendations about the feasibility of a DNA swab for every dependent child."

Source: "The Governor's Blue Ribbon Panel on Child Protection," available at <http://www.myflorida.com/myflorida/government/otherinfo/blueribbon.html>

1. Is it feasible to use banked biological material to improve child protection in Florida?
2. Should human tissue samples be stored at all? If so, how should they be stored?
Where should they be stored? For how long should they be stored?
3. Who owns stored tissue samples?
4. What constitutes permissible uses of human tissue samples?
5. What constitutes free and informed consent in tissue banking practices?
6. Who should have access to human tissue samples?
7. Are mandatory tissue banks morally permissible? If so, what are the justifications?
8. Who should regulate human tissue banks and what should the regulations be?

Although the task of implementing such a program would require the considered input of many disciplines, the primary concern is likely to be privacy. DNA profiles are different from fingerprints, which are useful only for identification. DNA can provide

insights into many intimate aspects of a person and their families including susceptibility to particular diseases, legitimacy of birth, and perhaps predispositions to certain behaviors. This increases the potential for genetic discrimination by government, insurers, employers, school, banks and others.

2. Discussion and recommendations

Based on the extensive Working Group discussions, the following findings and recommendations are offered in support of these conclusions:

1. DNA is immensely productive in the identification of deceased persons and in matching persons to crime-scene evidence. While the latter has some potential in tracing abducted juveniles who are also victims of other crimes, it does not appear to be productive in abductions where the juvenile is not in physical danger, as in the more typical cases of children seized by non-custodial parents.
2. Deceased persons are, in most cases, successfully identified via detailed physical descriptions, blood group analysis, fingerprints, dental and medical records, and by persons who recognize them. It is recommended that more extensive use of dental records be explored; indeed, better dental care is itself among the goals of improved child protection. Although DNA is regarded as the gold standard of identification, it is unlikely to be necessary except in extraordinary circumstances. Even then, DNA can be obtained in most cases from samples collected on Guthrie cards, from personal items, or from close family members. Given technological, resource and social/ethical concerns discussed below, the very small number of instances in which DNA is necessary does not justify wholesale collection and maintenance of biomaterials from every child under DCF care (totaling approximately 48,000 receiving in-home and out-of-home services), or even the subgroup of children whose parents' rights have been terminated (approximately 5,000).¹

Note that DCF has some experience in arranging for the collection and analysis of biological material to obtain genetic information to determine paternity. The department has processed nearly 500 cases in the past two years.

3. Based on reports from DCF and law enforcement, children are determined to be "missing" if they are not in their DCF-designated custodial residence.² More than half of those are missing of their own accord, that is, older teenage runaways who have voluntarily forsaken state supervision. The Task Group understands

1. Parental rights have been terminated by court order in fewer than 5,000 cases out of 48,200 as of March 31, 2002. Of those remaining with intact parental rights, approximately 15,000 children receive services while they remain in the parental home, another 16,000 have been placed with approved relatives, and slightly over 12,000 have been placed in licensed care (foster homes, group homes).

2 Operation SafeKids 9-17-02 press release at

http://www.fdle.state.fl.us/press_releases/20020917_safekids_findings.html.

that DNA, were it available, might be used to implicate juveniles in criminal activities, both now and after they reach their majority, but DNA does not otherwise appear to be an aid in locating them or successfully resuming protective custody. While even a single “profoundly missing” child is unacceptable, large scale tissue banking and DNA databasing do not address the failures that account for missing children’s untraceability.

4. The Working Group addressed the issue of community impact of DNA technologies. Members reported resistance among child service providers to the directive that all children in DCF custody be fingerprinted. Attention is warranted to the concerns that technologies such as fingerprinting and DNA banking – because of their association with criminal prosecution – may be perceived as stigmatizing, further traumatizing vulnerable children and denigrating communities. The wider community needs to be included in debates and discussions regarding the moral and social hazards posed by the technologies under consideration.
5. The Working Group noted the tendency technological “creep.” For example, criminal DNA registries were initially created for convicted sex offenders; registration of violent felons followed, and now movements are underway to register all convicted felons. The worry is that while it might make sense to create a database for a limited subset of children, it may well be impossible to restrict its expansion. Moreover, information obtained for specified purposes bleeds into other domains, say from child protection to law enforcement, or from health care to employment or insurance, and so forth. It is the strong recommendation of the Working Group that a truly independent oversight body, analogous to an ethics committee, be established in order to prevent inappropriate and secondary uses of biological materials and/or database information.
6. It appears likely that advances in genome technology will render significant investment in the current state of the art inadvisable, somewhat like buying last year’s computer. Although reference samples can be stored for reasonably long periods of time under proper conditions, experience with the genetic database for convicted felons suggests that samples will have to be retested and recoded at intervals – perhaps as often as every five years – as testing technology, knowledge about significant markers, and database capability advance.
7. The Working Group did not attempt a formal cost-benefit analysis, but arrived at an initial cost of perhaps \$7.5 million to obtain, process and digitize DNA for 48,000 children. This does not include infrastructure (secure storage and maintenance of reference samples, including storage device and personnel costs), annual additions, database management such as security protection and monitoring, deleting emancipated juveniles, and so forth.

8. More than one third of Florida hospitals participate in the Child Identification Program (Ch*I*P) sponsored by the Florida Department of Law Enforcement.³ Ch*I*P is designed for use by individual parents or guardians on a voluntary basis. Blood is drawn from the heel of a baby upon birth, or from school children by needle stick, and placed on a specially treated paper (called an FTA card) which is placed into a foil envelope and given directly to the parent or guardian. Neither the schools, county health departments, hospitals, nor the Florida Department of Law Enforcement or any other law enforcement agencies keep any records or samples. Only the parent or guardian has access to the blood sample. The DNA does not need to be analyzed unless it is necessary for investigative purposes, at which point, law enforcement will analyze it free of charge. Discrete, voluntary programs such as Ch*I*P, properly administered and resourced, are valuable aids to law enforcement. It should also be noted that while Ch*I*P type programs they may avoid some of the more worrisome aspects of state registries, they are not a substitute for recent pictures and detailed physical descriptions, the two most important items associated with successfully locating missing children alive.

While it acknowledges that “technology, done well, can be a most vital tool for progress,” the Blue Ribbon Panel Report correctly cautions, “Technology is not the answer to the future – human beings are.”⁴

3. Biological samples

Newborn screening laboratories may have archives of newborn screening cards from the early 1960’s that represent an enormous source of banked DNA. As biomedical techniques advance, scientists are performing more and more tests on smaller and smaller sample sizes.

A study in Iowa successfully developed an efficient procedure for extracting DNA from large numbers of blood spotted filter paper cards collected from newborns in the mid-1980’s. Therefore, these Guthrie cards are a potential source of genetic material without additional, invasive, procedures.

There is, however, the problem of consent. One study revealed that only 13 states required or specified that parents should be informed that neonatal tests were even going to be performed on their newborns. Only four of those states required that parents be given an opportunity to object. It appears that most states today use informed refusal (although it may be allowed only on religious grounds), but written documentation of consent is not required.

For reference files, buccal, or mouth or cheek, swabs generally provide sufficient DNA to develop a profile, although there can be wide variability in the use of brushes to

3. <http://www.fdle.state.fl.us/Chip/>

4. <http://www.myflorida.com/myflorida/government/otherinfo/blueribbon.html>

obtain buccal samples. Additionally, cells collected on buccal brushes and frozen are thought to provide useful DNA for only a limited time after freezing. Blood can be frozen for at least 10 years and still reliably provide DNA. There is great uncertainty about the long-term stability of any biological material, although the technology is improving steadily.

For samples from the missing subject, teeth and hairs may be adequate for DNA profiling. For samples from unidentified subjects, blood, tissue and bones may be submitted for testing.

3.1 Forensic DNA banks

The DNA Identification Act of 1994 (Pub. L. No. 103-322, 1994 HR 3355, 108 Stat. 1796, *210304), a federal law enacted in fall 1994 as part of the Omnibus Crime Control Law, created a national oversight committee to develop guidelines for DNA forensics and established a five-year, \$40 million grant for state and local crime laboratories in developing or improving forensic DNA testing capabilities. The Act also formally authorized the FBI to establish the Combined DNA Index System (CODIS) for law enforcement identification purposes.

Using CODIS, federal, state and local law enforcement agencies can compare DNA profiles from crime scenes to DNA profiles of felons in the CODIS database.

4. Precedents

4.1 What are others doing?

States have a patchwork of genetic-information nondiscrimination laws, none of them comprehensive. Existing state laws differ in coverage, protections afforded, and enforcement schemes. Some of the first state laws enacted to address this issue prohibited discrimination against individuals with specific genetic traits or disorders. Other state laws regulate both the use of genetic testing in employment decisions and the disclosure of genetic test results. These state laws generally prohibit employers from requiring workers and applicants to undergo genetic testing as a condition of employment. Some states permit genetic testing when it is requested by the worker or applicant for the purpose of investigating a compensation claim or determining the worker's susceptibility to potentially toxic chemicals in the workplace. These statutes often require the worker to provide informed written consent for such testing, contain specific restrictions governing disclosure, and prevent the employer from taking adverse action against the employee.

California has maintained a statewide-centralized repository of information about missing persons at the California Attorney General's Department of Justice since the 1950's. The year 2000 saw the passage of Senate Bill 1818, sponsored by The Amber Foundation for Missing Children and the California State Coroners Association. Codified as Title 12.5, Section 14250 & 14251 in the California Penal Code on January 1, 2001, it made California the first state in the nation to formalize a statewide process to use DNA to solve crimes involving missing persons, identify previously unidentified deceased persons.

The Missing and Unidentified Persons (MUPS) DNA data bank stores DNA profiles in two different files. One file is made up of either DNA profiles from relatives of reported missing persons or a DNA profile established from a sample from the missing person (reference file). The second file is made up of DNA profiles developed from samples from unidentified persons. An identification will be made if the DNA profile of the sample from the unidentified person matches a DNA profile in the reference file.

The Department of Defense, through the Armed Forces Institute of Pathology, has created a repository of biological samples to be used to identify the remains of fatalities in future conflicts. The specimens, buccal swabs and Guthrie-like cards, are not analyzed for DNA until there is a request to help identify human remains. Policies governing the repository stipulate that samples may not be used for medical, research or other purposes.

4.2 How do others protect individual privacy?

The samples collected for the California program will only be analyzed for genetic markers useful for identification purposes. The MUPS DNA data bank is separate from the Department of Justice's Convicted Felon DNA data bank, meaning profiles from the two data banks will not be routinely cross searched. Additionally, the law specifically provides for punishment of any person who violates the privacy provisions of the law that created the MUPS DNA data bank program.

In Colorado, the Legislature enacted a statute limiting access and use of genetic testing information in a process that illustrated the challenges of negotiating ethical conflict in a pluralistic society (directed principally towards insurance companies).

Four key elements went into negotiating the public policy on the issue and ultimately developing and enacting the final statute:

1. *Access* – Interested participants were given the opportunity to debate. Participants included the State Department of Public Health and Environment, the insurance industry, health lawyers, physicians, patients, those trained in genetics, health policy experts, philosophers and bioethicists, theologians, the media, interest groups and citizens from various walks of life.
2. *Information* – Providing sufficient instruction, counsel and knowledge to participants so that discussion could proceed.
3. *Noncoercion* – Peaceful manipulation undergirds the process of negotiation through which individuals fashion agreements based on respect; this must be distinguished from acts of outright threats or coercion.
4. *Compromise* – Involves adjusting or settling differences by mutual agreement unfortunately, there is apparently no current state statute that specifically covers the collection and use of biomaterials from children to be used at some future date exclusively for identification purposes.

5. Public and cultural acceptance

Primary public concerns are based on two broad sets of fears.

First, the government banking of biological material will seem Orwellian to some – even if the intent is to protect a segment of the population. Government genetic databases for law-enforcement or even quasi-law-enforcement purposes are troubling, although there is growing acceptance of the practice if biological material is obtained from convicts and, to a lesser degree, even suspects. Distrust of the government and medical establishments remains high among certain populations, perhaps especially those disproportionately represented by subgroups under DCF protection.

Second, some contend that insurers will use genetic information to deny, limit, or cancel insurance policies, or employers will use genetic information against existing workers or to screen potential employees. An ongoing fear is samples collected for one, benign, purpose might later be used for another, improper, one. These were among the fears expressed by two Marine Corps enlistees who objected to the DOD's tissue bank and sued the government; an appeals court ruled against them.

Both issues need to be addressed by any proposal to collect samples from DCF wards. Note the difference, and the tradeoffs, between and among

- Use of existing samples (e.g., Guthrie cards)
- Acquiring new samples by invasive means (blood)
- Acquiring new samples by less invasive means (buccal swabs)

These issues are especially acute in cases involving children.

There is also the policy tension between the needs of law enforcement and of child protection. Thus, are public resources best spent on identifying children or improving the state's ability to bring those who harm children to justice, or on providing adequate support for guardian and foster care programs?

Throughout, it is noteworthy how many and varied the ethical issues are. There are a number of precedents for including explicitly ethical issues and expertise at the policy table. In the case of the federal government, a series of distinguished presidential commissions has produced useful advice on a broad array of issues. In Florida, there is a less extensive track record, but the state's ethics community is regularly brought in to provide advice on end-of-life legislation, on Department of Corrections health and policy issues, and so forth.

Note also the opposition in Pinellas and Pasco counties to photographing and fingerprinting of children as part of new DCF policy. Child welfare advocates have alleged the process is perceived by the children and others as stigmatizing and that it evokes interactions with correctional facilities more than child protection.

6. Selected Bibliography

Selected tissue banking issues

Eiseman E, Haga SB. *Handbook of Human Tissue Sources: A National Resource of Human Tissue Samples*. Science and Technology Policy Institute, RAND, 1999 (esp. Chapter 7, “State Screening Laboratories and Forensic DNA Banks”).

Frankel MS, ed. *Exploring Public Policy Issues in Genetics*. Washington, DC: American Association for the Advancement of Science.

Harper PS. Research samples from families with genetic diseases: a proposed code of conduct. *BMJ* 1993;306:1391-4.

Knoppers BM, Laberge C. DNA Sampling and Informed Consent. *CMAJ* 1989;140:1023-1028.

McEwen JE, Reilly PR. State legislative efforts to regulate use and potential misuses of genetic information. *American Journal of Human Genetics* 1992;51:637-647.

McEwen JE, Reilly PR. A review of state legislation on DNA forensic data banking. *American Journal of Human Genetics* 1994;54:941-958.

McEwen JE, Reilly PR. Stored Guthrie cards as DNA “Banks.” *American Journal of Human Genetics* 1994;55:196-200.

Survey of state newborn screening repositories, showing views of lab directors on release of Guthrie cards to various institutions, including employers, insurance companies, law enforcement agencies and researchers.

McEwen JE, Reilly PR.. A survey of DNA diagnostic laboratories regarding DNA banking. *American Journal of Human Genetics* 1995;56:1477-1486.

Weir R, ed. *Stored Tissue Samples: Ethical, Legal and Public Policy Implications*. University of Iowa Press, 1998.

Among other things, contributors discusses newborn screening and the use and development of DNA databanks in law enforcement.

Selected Department of Defense-related issues

Jollenbeck LM, Russell PK, Guse SB, eds. *Strategies to Protect the Health of Deployed U.S. Forces: Medical Surveillance, Record Keeping, and Risk Reduction*. Washington, D.C.: National Academy of Sciences, 1999.

In part emphasizes importance of meticulous record keeping and the accessibility of the information when needed.

Selected forensic issues

Penchaszadeh VB. Genetic identification of children of the disappeared in Argentina. *Journal of the American Medical Women's Association* 1997;52:16-22.

Online sources

ACLU LIST OF STATE GENETIC DISCRIMINATION LEGISLATION

http://www.aclu.org/privacy/genetic_laws99.html

(Note typo in url, i.e., "genetic" is correct)

ANALYTICAL GENETIC TESTING CENTER, INC.

<http://www.geneticid.com/we0300.htm>

AMBER FOUNDATION FOR MISSING CHILDREN

<http://www.missingchild.org/directions/mups.asp>

HUMAN GENOME PROJECT INFORMATION

<http://www.ornl.gov/hgmis/elsi/forensics.html>

HOW DNA WORKS

This site describes how forensic identification works with links to information on the ethical, legal, and social issues associated with DNA banking.

<http://howstuffworks.com/dna-evidence.htm/printable>

RELIABILITY OF FINGERPRINT IDENTIFICATION

<http://www.forensic-evidence.com/site/ID/pollak2002.html>

PERSONAL IDENTIFICATION BY THE IRIS OF THE EYE

http://www.forensic-evidence.com/site/ID/ID_iris_jarvis.html

Appendices

Appendix 1

Agenda for Sept. 13, 2002, Task Group meeting

Florida Department of Children and Families

Task Group for Blue Ribbon Panel on Child Protection
And
University of Miami Ethics Programs

Friday, Sept. 13, 2002
Mailman Center for Child Development
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10 a.m.	Welcome	F. Daniel Armstrong
10:10	Introductions	Attendees
10:15	Statement of task	June Noel
10:20	Ethics and public policy	Kenneth W. Goodman
10:30	Moderated discussion	Attendees
11:30	Forensic issues	Mike Hass
12:00	Moderated discussion	Attendees
1:00	Working lunch: Issues in Genetics	Lisa Baumbach et al.
2:00	Other ethical issues and concluding discussion	Stephanie Anderson, Robin Fiore and attendees
3:00	Adjourn	

Appendix 2

Attendees at Sept. 13, 2002, Task Group Meeting

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