McKay, Jean

From: McKay, Jean
To: Lori Andrews
Cc: Hudson, Kathy; wexler, nancy; Jordan, Elke; duster, troy; nelkin, dorothy; Drell, Dan; holtzman, tony; Collins, Francis <fc23a>
Subject: RE: status of WG statements
Date: Friday, February 16, 1996 10:05AM

I will FAX a copy of The Bell Curve statement to Nancy. There is a statement at the beginning of The Bell Curve statement that reads: "This statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group). This statement is endorsed by the National Society of Genetic Counselors."

Per information from you, Jeff Murray, who agreed to have his name listed, and Becky, while not agreeing/disagreeing with the position (she had not read the book) both felt comfortable sending out the statement that it was approved by the ELSI Working Group. This also avoided the awkwardness of listing the "signers" at the beginning of the document.

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Jean

From: Lori Andrews
To: jeanm
Subject: RE: status of WG statements
Date: Wednesday, February 14, 1996 4:24PM

Could you please send Nancy Wexler by fax the latest version of the Bell Curve statement? She's at [redacted]. She particularly wants to know who signed on to the statement. Are Jeff Murray and Rebecca Eisenberg ultimately listed as having signed on?

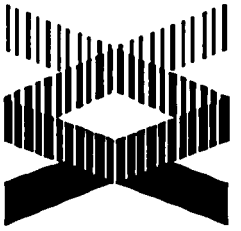
****
*** TX REPORT ***
****

TRANSMISSION OK

TX/RX NO	0232
CONNECTION TEL	913104583937
SUBADDRESS	
CONNECTION ID	
ST. TIME	02/16 10:19
USAGE T	01'42
PGS.	4
RESULT	OK

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH



National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955 FAX: (301) 402-0837

DATE: February 16, 1996

TO: Nancy Wexler

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 4

****

Nancy,

Attached is the ELSI Working Group statement on The Bell Curve, per Lori Andrews's request. I have also included an e-mail that I sent to Lori, and cc'd you.

Jean

McKay, Jean

From: McKay, Jean
To: eisenberg, rebecca
Cc: McKay, Jean; Hudson, Kathy
Subject: The Bell Curve statement
Date: Friday, February 16, 1996 10:10AM

Becky,

The American Journal of Human Genetics is interested in publishing the ELSI WG statement on The Bell Curve, and they have asked for a list of the members of the ELSI WG. As I recall, you were ok with the statement as being "from the ELSI WG," but did not feel comfortable being listed individually. When I prepare the list for the AJHG, how would you like to be noted, as abstaining?

Thanks.

Jean

PS I enjoyed the recent IOM workshop on intellecutual property. Are ther plans to publish a summary of this meeting?

McKay, Jean

From: McKay, Jean
To: Francis Collins/DIR/NCHGR
Cc: McKay, Jean; kathyh
Subject: RE: Bell curve
Date: Tuesday, January 16, 1996 8:17AM

The cover letter that accompanied the statement stated explicitly that it was being sent to a "variety of journals, newsletters, and other publications..." AJHG is interested in publishing the statement as a letter to the editor.

Thanks for the note re: Science. I had not received anything from Science that indicated that they were going to publish this statement, but recall that Lori made a passing reference to it during our conference call on December 19 (and have not yet received my Science at home). I also saw in the back of the Post Book World an adverstisement for The Bell Curve...

Jean

From: Francis Collins/DIR/NCHGR
To: jeanm
Cc: kathyh
Subject: Bell curve
Date: Monday, January 15, 1996 5:05PM

I was pleased to see that Science published the Bell Curve statement in the Jan. 5 issue. Maybe I was unduly pessimistic about this being too out of date
to be of interest to anyone.
I was concemed, however, to see that you received a FAX from Peter Byers of AJHG indicating some interest in publishing the statement there. I had not realized that it was submitted simultaneously to more than one journal. In general, this is a real no-no. Was AJHG told up front that this had gone to other journals? If not, our faces are going to be very red, and we will need to do some major apologizing.
Please advise.
FC

McKay, Jean

From: McKay, Jean
To: andrews, lori
Cc: McKay, Jean; Hudson, Kathy
Subject: FW: FWD: ELSI Working Group statement on stored tissue samples
Date: Wednesday, December 13, 1995 8:29AM

LOri,

The NCHGR address is:

National Institutes of Health
National Center for Human Genome Research
31 Center Drive, Rm. 4B09
Bethesda, MD 20892-2152

Tel: [redacted]

For your information, the FAX number for Mr. Whitaker is [redacted]

Jean

From: McKay, Jean
To: Lori Andrews
Cc: McKay, Jean; kathyh
Subject: RE: FWD: ELSI Working Group statement on stored tissue samples
Date: Tuesday, December 12, 1995 4:20PM

Lori,

We are trying to FAX to Mr. Whitaker, but there is no answer. We'll keep trying. I'll be out of the office Dec. 18-22. If you have time to discuss the statements this week, that would be great.

Thanks.

Jean

From: Lori Andrews
To: jeanm
Cc: kathyh
Subject: RE: FWD: ELSI Working Group statement on stored tissue samples
Date: Tuesday, December 12, 1995 11:37AM

Hi, Jean,

A BBC reporter just called me and asked me to fax him the Bell Curve statement. I don't have a clean copy here. Will you have time to fax it to him today? He's Mark Whitaker at [redacted]. Let me know if you can't get it to him today.

There are a few WG members I need to touch base with on the employment statement, so I will get final statements on the tissue sample background section while I'm at it. Why don't you and I talk next week about future plans on the various statements? I'm waiting for a few faxes

McKay, Jean

From: Lori Andrews
To: jeanm
Cc: kathyh
Subject: RE: FWD: ELSI Working Group statement on stored tissue samples
Date: Tuesday, December 12, 1995 11:37AM

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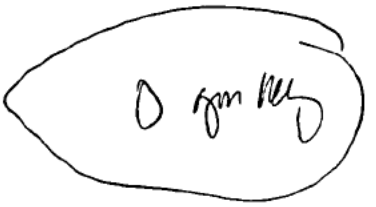
There are a few WG members I need to touch base with on the employment statement, so I will get final statements on the tissue sample background section while I'm at it. Why don't you and I talk next week about future plans on the various statements? I'm waiting for a few faxes from Congress right now, but as soon as they are in I will be expressing you, Francis, and Kathy copies of the Privacy Policy Options for delivery tomorrow as we discussed. Could you please E-mail me the best street address for express deliveries for the NCHGR?

Thanks!
Lori



McKay, Jean

From: Fink, Leslie
To: McKay, Jean
Cc: Jordan, Elke; Hudson, Kathy; Thomson, Elizabeth
Subject: RE: Ideas for articles for next HGN issue?
Date: Friday, November 24, 1995 11:34AM

Yikes. I thought we were kind of embarrassed about that. Can I get a copy? Where else is it going,etc.?--LF

From: McKay, Jean
To: Fink, Leslie
Cc: Jordan, Elke; McKay, Jean; Hudson, Kathy; Thomson, Elizabeth
Subject: RE: Ideas for articles for next HGN issue?
Date: Friday, November 24, 1995 11:20AM

I have sent Betty The Bell Curve statement...

I can check if there is anything from the Task Force on Genetic Testing meeting.

Jean

From: Fink, Leslie
To: Extramural; OD
Subject: FW: Ideas for articles for next HGN issue?
Date: Friday, November 24, 1995 11:12AM

Think real hard folks.--LF

From: bkq
To: LeslieF; daniel.drell
Subject: Ideas for articles for next HGN issue?
Date: Wednesday, November 8, 1995 3:45PM

Leslie and Dan,

Please give me your ideas for articles for the Jan/Feb HGN. We need to get that roster developed so we can get articles in here by mid-December. Please pulse your respective staffs for input!

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Betty K. Mansfield
Managing editor, Human Genome News
Oak Ridge National Laboratory
1060 Commerce Park, MS 6480
Oak Ridge, TN 37830
[redacted]
HGMIS World Wide Web URL:
http://www.ornl.gov/TechResources/Human_Genome/home.html
<><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><><>

McKay, Jean

From: Lori Andrews
To: jeanm
Subject: RE: status of WG statements
Date: Friday, February 16, 1996 10:42AM

FORWARDED MESSAGE from McKay, Jean (JEANM @ SMTP {JeanM@od.nchgr.nih.gov}) at 2/16/96 9:06a

>
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>
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>———
>From: Lori Andrews
>To: jeanm
>Subject: RE: status of WG statements
>Date: Wednesday, February 14, 1996 4:24PM
>
>Could you please send Nancy Wexler by fax the latest version of the Bell
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>who signed on to the statement. Are Jeff Murray and Rebecca Eisenberg
>ultimately listed as having signed on?
***** NOTES from Lori Andrews ([redacted]) at 2/16/96 10:42a
Thanks for your prompt attention to this.

McKay, Jean

From: Hudson, Kathy
To: Fink, Leslie
Cc: McKay, Jean
Subject: FW: Bell Curve Statement for HGN?
Date: Thursday, February 22, 1996 3:08PM

Fink-see Jean's note. The statement should be published and Dot listed as contact. Entire WG listed as authors (I think, check with Jean). Geez. How does betty know so much so fast? The gyrations of the working group are irrelevant to the publication of the statement. The letters to science were fine and appropriate. Print the damn thing!

From: McKay, Jean
To: Hudson, Kathy
Cc: Fink, Leslie
Subject: RE: Bell Curve Statement for HGN?
Date: Thursday, February 22, 1996 2:49PM

Because, so far, this is the only place where the statement will be published in its entirety, and the WG continutes to have an expressed interest in the broadest dissemination possible, and would likely be unhappy if we in any way interfered with its publication.

Jean

From: Hudson, Kathy
To: McKay, Jean
Subject: FW: Bell Curve Statement for HGN?
Date: Thursday, February 22, 1996 2:35PM

please advise as soon as possible on why we want this published again???

From: Fink, Leslie
To: bkq
Cc: Hudson, Kathy
Subject: RE: Bell Curve Statement for HGN?
Date: Thursday, February 22, 1996 12:44PM

Thanks, Betty. I think your judgment is right on. It's not exactly timely and I suspect most of the HGN readers have already seen the Science thing. I would vote not to include it, but final decision should probably come from Kathy and Dan.--LF

From: bkq
To: lsf
Subject: Bell Curve Statement for HGN?
Date: Thursday, February 22, 1996 12:24PM

Leslie,

While the anniversary issue of HGN was in press, we received a copy of the Bell Curve Statement from the ELSI working group with a cover letter signed by Lori Andrews and Dorothy Nelkin. The letter asked us to publish the statement and said if we and presumably anyone had questions about the statement to contact them.

With Andrews' resignation and the letter sent out two days ago by 3 members of the group (including Nelkin), it appears that the group is in extreme flux.

Our current draft contains a notice asking readers to address any comments to Lori Andrews or Dorothy Nelkin of the working group.

We need to list a contact person or persons to be associated with this statement. In light of the recent developments, how do you think we should handle this? Ask people to contact you and Hudson and Drell?

It seems that including the statement at this time in HGN will not only help bring an old book into the limelight again, but will draw attention to the working group whose status is currently uncertain. It could also draw attention to the reasons (concerning autonomy of the group) for that uncertainty which could be an embarrassment for NIH.

We also saw some critical letters to the Science editor about the statement which appeared in an earlier issue of letters to the editor of Science.

I understand Dan is meeting with Kathy for lunch, hopefully they discuss this and approve of our not printing the statement in HGN.

FYI that issue of HGN is laid out and we're awaiting some GDB text. You should get it on Monday.

Betty K. Mansfield
Managing editor, Human Genome News
Oak Ridge National Laboratory
1060 Commerce Park, MS 6480
Oak Ridge, TN 37830
[redacted]
* Note the area code for Oak Ridge has changed from "615" to "423" for most callers.

HGMIS World Wide Web URL:
http://www.ornl.gov/TechResources/Human_Genome/home.html

McKay, Jean

From: McKay, Jean
To: Jackson, Laird; kaback, michael; vivian
Cc: McKay, Jean; Hudson, Kathy
Subject: RE: bell curve statement
Date: Tuesday, September 19, 1995 4:56PM

Vivian,

Yes, I did receive the letter of endorsement from the NSGC. To date, I have not heard anything from the other professional societies regarding their support of The Bell Curve statement.

Thank you again for your efforts in submitting it to the NSGC board, and following-up on the outcome.

Jean

From: vivian
To: JEANM
Subject: bell curve statement
Date: Tuesday, September 19, 1995 4:36PM

Hi Jean--I'm assuming that you've all had notification that NSGC will sign on to the ELSI Bell Curve Statement. If you have not been notified officially, please let me know and I will investigate to see what the hold-up is. I was wondering if you have heard whether or not the other professional societies have also decided to endorse the statement--some of the Board members have wondered, as well, and I'd appreciate an update if you have one. Thanks.
Vivian

McKay, Jean

From: McKay, Jean
To: vivian
Cc: McKay, Jean
Subject: RE: 10/95 ELSI meeting
Date: Wednesday, September 13, 1995 4:27PM

Vivian,

Thanks much for your response. We are very pleased that the NSGC has agreed to sign on to The Bell Curve statement.

There will not be a nominating committee meeting at the October meeting, and I still need to clarify the nominating committee membership. I will let you know as soon as possible.

Regarding travel, Lori suggested that if folks wanted to take advantage of the lower fares, that if for some reason the WG meeting was not held Octobe 9-10, (now looking a little less likely, but who knows??) that there is only a small fee ($30) to change a ticket and use it for some other travel. This may be a reasonable option.

Tomorrow, I will be FAXing the agenda to WG for comments.

Thank you again for your help!

Jean

From: vivian
To: JeanM
Subject: 10/95 ELSI meeting
Date: Wednesday, September 13, 1995 1:48PM

Jean--I thought I'd e-mail you to respond to your message! I actually thought there would *not* be a nominating committee meeting at the upcoming meeting, but when I spoke with Bonnie, the NSGC president, she just wanted to be sure that I attended the meeting regardless of cost **if** the nominating committee was meeting and **if** I was the liason member on the committee this rotation. I suspected that this was not the case, but I told her I would clarify this with you. As it stands, I can still obtain a reasonably priced flight if I can give the airline a 7 day advance reservation(depending, of course, on availability). This being the case, I think it is most likely that I will be there if the meeting takes place.
Additionally, I have just had official notification that NSGC **will** sign on to the ELSI statement on "The Bell Curve"!!! Lori should receive official notification of this by FedEx tomorrow. I hope our fellow professional organizations follow suit... Thanks for your help, Vivian

national society
of genetic
counselors, inc.
nsgc

September 12, 1995

Lori Andrews, J.D.
Chair, ELSI Working Group
Chicago - Kent College of Law
Illinois Institute of Technology
565 West Adams Street
Chicago, IL 60661

Dear Ms. Andrews,

The National Society of Genetic Counselors extends our strong support for The Bell Curve statement developed by the NIH-DOE Joint Working Group on the Ethical, Legal and Social Implications of the Human Genome Project.

The National Society of Genetic Counselors condemns any use of genetic information to set social policy which establishes discrimination. Members of the National Society of Genetic Counselors adopted a code of ethics in August of 1991 that clearly states "genetic counselors strive to prevent discrimination on the basis of race, sex , sexual orientation, age, Genetic Status or socio-economic status."

Genetic counselors are health care professionals with specialized education and experience in medical genetics and counseling. Also clearly stated in our code of ethics; "The counselor - client relationship is based on values of care and respect for the for the client's autonomy, individuality, welfare, and freedom. The primary concern of genetic counselors is the interests of their clients."

The conclusions stated by the authors in "The Bell Curve" are in direct conflict with the adopted values of the members of the National Society of Genetic Counselors. Therefore, we uphold the response statement of the ELSI working group with no reservations.

Sincerely,

Bonnie S. LeRoy

Bonnie S. LeRoy, M.S., President
National Society of Genetic Counselors

cc: Ms. Vivian Weinblatt, M.S.
NSGC liaison to the ELSI working group

EXECUTIVE OFFICE MAILING ADDRESS:
233 CANTERBURY DRIVE
WALLINGFORD PA 19086-6617

PHONE: 610-872-7608
FAX#: 610-872-1192
E-MAIL: BEANSGC@aol.com

McKay, Jean

From: Lori Andrews
To: jeanm
Subject: RE: status of WG statements
Date: Friday, February 16, 1996 10:42AM

FORWARDED MESSAGE from McKay, Jean (JEANM @ SMTP {J[redacted]) at 2/16/96 9:06a

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***** NOTES from Lori Andrews ([redacted]) at 2/16/96 10:42a
Thanks for your prompt attention to this.

McKay, Jean

From: McKay, Jean
To: eisenberg, rebecca
Cc: McKay, Jean; Hudson, Kathy
Subject: The Bell Curve statement
Date: Friday, February 16, 1996 10:10AM

Becky,

The American Journal of Human Genetics is interested in publishing the ELSI WG statement on The Bell Curve, and they have asked for a list of the members of the ELSI WG. As I recall, you were ok with the statement as being "from the ELSI WG," but did not feel comfortable being listed individually. When I prepare the list for the AJHG, how would you like to be noted, as abstaining?

Thanks.

Jean

PS I enjoyed the recent IOM workshop on intellecutual property. Are ther plans to publish a summary of this meeting?

McKay, Jean

From: Lori Andrews
To: jeanm
Cc: kathyh; thomsone
Subject: Bell Curve statement
Date: Tuesday, September 12, 1995 11:05AM

Good news about the Bell Curve statement. We can drop the awkward list of signers at the beginning. I talked to Becky and Jeff and they are both comfortable with sending it out with the tag line that it was approved by the ELSI WG. Jeff said that in its current form, he is even willing to have his name listed. Becky still says she doesn't want her name listed since she will then feel obliged to read the book if she is listed in her individual capacity, but she is perfectly comfortable being listed in an institutional capacity.
So, you can tell Joan Weiss that she can print it without the awkward listing and when you and others at the NCHGR send it out, it can be sent as the ELSI WG's statement on The Bell Curve.

9/12 called Joan W - 2 ↑

[redacted]

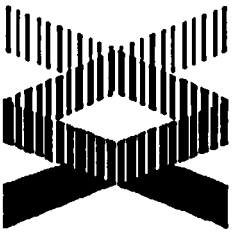
Date: Fri, 1 Sep 95 16:34:00 -0500
From: Lori Andrews [redacted]>
Sender: Lori Andrews [redacted]u>
Organization: Chicago-Kent College of Law
To: [redacted] Hi
MIME-Version: 1.0
Content-type: text/plain; charset="US-ASCII"
Content-transfer-encoding: 7BIT
X-mailer: Connect2-SMTP 4.00 MHS to SMTP Gateway

Thanks for the Joan Weiss query. Who all has not signed on to the Bell Curve statement at this time. Has the old WG all signed on? Is anyone besides Botkin and Eisenberg not included at this point? If they are the only two I'm tempted to call them and just ask how they would feel if it went into the newsletter with a line that said it was adopted by the WG (since that is very common language even in situations in which there is not a total consensus. Certainly laws are "adopted" all the time even though not all legislators agree.) When we talk on Tuesday morning, we can resolve this and go over your helpful draft agenda. Have a nice weekend.
Lori

Jeff Murray 9/5 AX L.A. will call Murray & Eisenberg to see have problems on Franchiss stmts..

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH



National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: September 1, 1995

TO: Lori Andrews

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 3

****

Lori,

Attached is a note from Joan Weiss. She would like to include The Bell Curve statement in the Alliance's newsletter, but, rather than include the list of WG members, she would like state "and endorsed by the majority of its members." (See item 1 in her memo to me.) In addition, Joan would like to send a letter to Social Work that summarizes the viewpoint expressed in The Bell Curve statement (item #2).

Please advise.

Thank you.

Jean

ALLIANCE of Genetic Support Groups
A Coalition of Voluntary Organizations and Professionals

35 Wisconsin Circle, Suite 440 • Chevy Chase, MD 20815-7015
(800) 336-GENE • (301) 652-5553 • Fax (301) 654-0171

Memorandum

From: Joan O. Weiss

To: Jean McKay

Date: September 1, 1995

Subject: The Bell Curve statement

1. Suggested revision of the introduction of the statement, as is, for an enclosure of the statement with the September Alliance *Alert*, as we discussed by phone:

This statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group), February 1995, and endorsed by the majority of its members.

2. For submission to:

Letters, Social Work, NASW Press, and to *Practice updates*, NASW Press, 750 First Street, NE, Suite 700 Washington, DC 20002-4241:

Social workers who questioned Hernnstein's and Murray's claim in The Bell Curve for genetic determinism of behavioral traits may be interested in a recent protest. The National Institute of Health-Department of Energy Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group) has issued a statement expressing caution and serious reservations about misrepresenting the state of genetic knowledge in the area of behavioral genetics and misusing this information to inform social policy. "We are only beginning to explore the intricate relationship between genes and environment. . . If anything, the lack of

predictability from genetic information has become the rule rather than the exception."

If you are interested in receiving a copy of the ELSI Working Group statement, please contact me at 1-800-336-GENE.

Joan O. Weiss, LICSW, LCSW
Director, Alliance of Genetic Support Groups

Liaison member of ELSI WORKING GROUP

Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815
(800) 336-GENE
(301) 652-5553
Fax No. (301) 654-0171

Date: 9/1/95

To: Jean McKay [redacted]

From: Joan Weiss

Total number of pages (including this page): 3

Remarks: Please let me know what Lori Andrevs says, as soon as possible. Thank you.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Center for Human
Genome Research
Bethesda, Maryland 20892

Building 31, Room 4B09
Phone (301) 402-0955
FAX (301) 402-0837

DATE: August 23, 1995

TO: Members
ELSI Working Group

FROM: Jean McKay

SUBJECT: The Bell Curve statement

For your information, attached are the final draft of the ELSI Working Group statement on The Bell Curve and the letter that will accompany this statement when it is submitted to a variety of journals, newsletters, etc. for publication.

Suggested publications and organizations include Journal of NIH Research, Human Genome News, Journal of Clinical Ethics, Journal of Medical Ethics, Science, American Journal of Human Genetics, American Journal of Medical Genetics, European Journal of Human Genetics, Medical Genetics, Journal of Behavioral Genetics, New Scientist, Nature, Nature Genetics, American Psychological Association, American Psychiatric Association, and the National Society of Genetic Counselors.

Please let me know by Friday, September 8, the names of other journals or organizations to which you would like the statement submitted.

Thank you.

Attachments

The National Institutes of Health-Department of Energy Working Group on the Ethical, Legal, and Social Implications of Human Genome Research

August 14, 1995

Dear....

The enclosed statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group). Its purpose is to express our caution and serious reservations about the claims for genetic determinism of behavioral traits that appeared in The Bell Curve. We believe that this publication is inappropriately drawing legitimacy from the success of the Human Genome Project, misrepresenting the state of genetic knowledge in the area of behavioral genetics and misusing this information to inform social policy.

In order to disseminate our statement as broadly as possible, we are submitting it to a variety of journals, newsletters, and other publications of professional and community organizations. Therefore, we would greatly appreciate your publishing the ELSI Working Group statement in [journal, newsletter, etc].

Please contact Dorothy Nelkin if you have any questions or need additional information about the statement. Ms. Nelkin can be reached at (212) 998-8347.

Thank you for your consideration.

Sincerely,

Lori B. Andrews
Chair, ELSI Working Group

Dorothy Nelkin
Member, ELSI Working Group

Enclosure

FROM: McKay, Jean

TO: duster, troy
nelkin, dorothy

CC: McKay, Jean
Thomson, Elizabeth
andrews, lori

SUBJECT: RE: ELSI Working Group
PRIORITY:
ATTACHMENTS:

Dorothy and Troy -- FYI The Bell Curve part of Joe's e-mail.

Jean

FORWARDED FROM: McKay, Jean
Return-Path: [redacted]
[redacted]05
MST
Date: Tue, 29 Aug 1995 16:36:04 MST
To: [redacted]v
Message-ID: [redacted]>
Subject: RE: ELSI Working Group
Hi Jean. Thanks for the recent packet of informtion about the Stanford WG meeting. My schedule for October is changing as I write, but it still ooks doubtful that I can make the meeting.

Re the Bell Curve statement: I'm happy it's finally been accepted; I'll be citing it in a lengthy article I'm doing for the Quarterly Review of Biology. Please consider the following publications as you think about distribution of the statement: American Biology Teacher, The Science Teacher, The Journal of College Science Teaching, Education Week, BioScience, Chronicle of Higher Education, Phi Delta Kappan, Science and Children, Educational Leadership. Thanks for soliciting our input on this matter. Best -- Joe

JMCINERNEY@cc.colorado.edu

Return-Path: <[redacted]

[redacted] Wed, 30 Aug 1995 07:55:44 MST
Date: Wed, 30 Aug 1995 07:55:43 MST
To: JeanM@od.nchgr.nih.gov
Message-ID: [redacted]u>
Subject: RE: ELSI Working Group

Hi Jean. One more suggestion for the statement: you might send it to The New York Review of Books. They published a lengthy review and numerous letters about the book. The New Republic and National Review also had lengthy special sections devoted to the book. Best -- Joe

[redacted]

FROM: McKay, Jean

TO: [redacted]

DATE: 09-01-95
TIME: 10:47

CC: McKay, Jean

SUBJECT: bell curve statement
PRIORITY:
ATTACHMENTS:

Vivian,

Thanks for the update! This is good news. The statement has not yet been submitted for publication, and I appreciate your recommendations for where to publish, especially the lay press.

Thanks.

Have a good weekend.

Jean

REPLY FROM: [redacted]

Subject: bell curve statement
To: [redacted]
[redacted]33 -0400 (EDT)
X-Mailer: ELM [version 2.4 PL20]
MIME-Version: 1.0
Content-Type: text/plain; charset=US-ASCII
Content-Transfer-Encoding: 7bit
Content-Length: 678

Jean--
I am beginning to get responses from NSGC's board of directors, and so far they
are all positive towards supporting the statement! I still must hear from several more poeple, but I am hopeful that this will fly! One of the Board members wondered if an attempt was to be made to have this published in the New York Times or Washington Post either as an editorial or even as a 1/4 page ad. It is possible that NSGC or even individual members might offer financial support to that end. Please let me know if there has been any discussion about this. I know it was raised back in December, but I haven't heard anything
about the lay press since then.

Thanks--

Return-Path: [redacted]
Subject: Re: The Bell Curve statement
To: [redacted]
[redacted] Tue, 29 Aug 1995 18:29:46 -0400 (EDT)
In-Reply-To: [redacted] from "McKay, Jean" at Aug 29, 95
04:26:00 pm
X-Mailer: ELM [version 2.4 PL20]
MIME-Version: 1.0
Content-Type: text/plain; charset=US-ASCII
Content-Transfer-Encoding: 7bit
Content-Length: 302

Jean,

The nsgc board next meets in october, but I think they will do their best to comply with the september deadline. If they are unable to decide by then, either I or Bonnie LeRoy, the nsgc president will let you know. Thanks for your
quick response to my query. I'll keep you informed. Vivian

FROM: McKay, Jean

TO: weinblatt, vivian

DATE: 08-29-95
TIME: 16:28

CC: McKay, Jean

SUBJECT: The Bell Curve statement
PRIORITY:
ATTACHMENTS:

Vivian,

Thanks for your phone call re: finalizing The Bell Curve statement. The plan is to send the statement to various journals, etc. the second/third week of September. Does this fit in with the timeframe for your Board? If not, please let me know what your timeframe is and we will try to accomodate it.

Thanks.

Jean

National Research Council
National Academy of Sciences
National Academy of Engineering
Institute of Medicine

To: Jean McKay Date: 9-5-95

From: Robert Cook-Deegan at NOIES Page 1 of 2

Sending Fax number: Use Originator's FAX

Receiving Fax number: ,9, [redacted]

Subject: Bell Curve statement

9/5/95 8:55AM

From : Robert Cook-Deegan at NOTES
To : Jean McKay [redacted] at FAX
Subject : Bell Curve statement

Item Summary

Text item : Bell Curve statement

Message Contents

Distance has given this statement a stronger appeal. I now like it, and hope others agree. There may be a bit of chortling and some "and now a year later..." comments, but so be it.

Thank you for sending it.

BCD
==========
Robert Mullan Cook-Deegan, MD
National Academy of Sciences, NAS-285
2101 Constitution Avenue, NW
Washington, DC 20418

[redacted]simile

To: Please send revised letter to Jeff Murray + those others. Thanks who may not have signed.

DRAFT

The National Institutes of Health-Department of Energy
Working Group on the Ethical, Legal, and Social Implications
of Human Genome Research

Please send me letters ASAP and Nancy Wexler!

Statement

The Bell Curve

This statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group), February 1995: Anita Allen, Lori Andrews, Jonathan Beckwith, Robert Cook-Deegan, David Cox, Troy Duster, Neil Holtzman, Joseph McInerney, Victor McKusick, Robert Murray, Thomas Murray, Dorothy Nelkin, [redacted] Marsha Saxton. The following new members of the ELSI Working Group support the statement: Betsy Anderson, James Bowman, Beth Fiac, Philip Kitcher, John Mulvihill, and Rayna Rapp.

In 1994, a highly publicized book, Richard Herrnstein and Charles Murray's The Bell Curve, claimed that IQ is largely genetically determined and that the differences in IQ between ethnic groups are substantially explained by genetic factors. We are especially concerned about the impact of The Bell Curve, and a series of subsequent "bell-curve" books developing similar themes, because [redacted] the legitimate successes of the Human Genome Project in identifying genes associated with [redacted] human diseases should not be used to foster an environment in which mistaken claims for genetic determination of other human traits gain undeserved credibility.

too cute

Herrnstein and Murray suggest that fundamental IQ differences between people explain social problems such as crime, welfare dependence, and single parenting. Now that socio-cultural barriers to personal advancement have largely been removed, they say, social success and high IQ are highly correlated. Programs to eliminate inequalities are [redacted] doomed to failure. Herrnstein and Murray are especially concerned that high birth rates among the poor and the 'dysgenic' behavior of women with high IQs, who are not bearing enough children, are threatening the population with genetic decline. According to them, these trends are "exerting downward pressure on the distribution of cognitive ability in the United States."

The authors follow this analysis with policy recommendations. They propose eliminating welfare, which they feel subsidizes birth among poor women, thus lowering the average intelligence of the population. They suggest ending remedial education programs because the results are not worth the cost, given the

8/14 To: Jean McKay From: Nancy Wexler

DRAFT

claimed significant genetic determination of IQ differences. They urge the development of programs of social support that would encourage women from the higher socio-economic classes to have more children.

Neither Herrnstein nor Murray are geneticists nor have they carried out studies themselves on the genetic basis of behavior. Their lack of training and experience in genetics does not disqualify them from evaluating genetic research nor from drawing their own conclusions. However, as geneticists and ethicists associated with the Human Genome Project, we deplore The Bell Curve's misrepresentation of the state of genetic knowledge in this area and the misuse of genetics to inform social policy.

We urge consideration of the following three points:

First, Herrnstein and Murray invoke the authority of genetics to argue that "it is beyond significant technical dispute that cognitive ability is substantially heritable." Research in this field is still evolving, studies cited by Herrnstein and Murray face significant methodological difficulties, and the validity of results quoted are disputed. Many geneticists have pointed out the enormous scientific and methodological problems in attempting to separate genetic components from environmental contributors, particularly given the intricate interplay between genes and the environment that may affect such a complex human trait as intelligence.

Second, even if there were consensus on the heritability of cognitive ability, lessons from genetics are misrepresented. The authors argue that it is not possible to ~~alter differential cognitive ability~~ change it and that remedial education is not worth the effort or cost. This is neither an accurate message from genetics nor a necessary lesson from efforts at remedial education. Heritability estimates are relevant only for the specific environment in which they are measured. Change the environment and the heritability of traits can change remarkably. Saying a trait has high heritability has never implied that the trait is fated to be. Height is both genetically determined and dependent on nutrition. Common conditions in which genetics plays a role, such as diabetes or heart disease, can be corrected with insulin or cholesterol-lowering drugs and diet. Common gene-influenced conditions such as myopia or allergic rhinitis can be corrected with eyeglasses or behavior modification (avoidance of allergens). The disabilities associated with single-gene conditions, such as phenylketonuria or Wilson disease, can also be prevented or significantly ameliorated by medical or nutritional therapy.

DRAFT

Third, the more ~~[illegible]~~ scientists learn about human genes the more complexity is revealed. This complexity has become apparent as more genes correlated with human genetic diseases are discovered. We are only beginning to explore the intricate relationship between genes and environment and between individual genes and the rest of the human genome. If anything, the lack of predictability from genetic information has become the rule rather than the exception. Simplistic claims about the inheritance and malleability of such a complex trait as cognitive ability are unjustifiable. Moreover, as the history of eugenics shows, it ~~may be dangerous~~ is Dangerous.

Genetic arguments cannot and should not be used to determine or inform social policy in the areas cited by Herrnstein and Murray. Since the lessons of genetics are not deterministic, they do not provide useful information on deciding whether or not to pursue various programs to enhance the capabilities of different members of society. Those decisions are moral, social, and political ones.

8/9/95

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH

National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: August 15, 1995

TO: Nancy Wexler

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 2

****

Attached is a copy of Jeff Murray's comments on The Bell Curve statement. Jeff's number is [redacted]. I'll check with Elizabeth re: David Smith abstract.

Return-Path: [redacted]
Date: Fri, 14 Jul 1995 11:04:24 -0500 (CDT)
From: Jeff Murray <[redacted]u>
To: "McKay, Jean" [redacted]>
Subject: Re: Statement on The Bell Curve
In-Reply-To: [redacted]v>
Message-Id: [redacted]d
    u>
Mime-Version: 1.0
Content-Type: TEXT/PLAIN; charset=US-ASCII

---

jean
  in the spirit of getting out a statement on this which is important please do so if the others are happy with it but i have a couple of concerns about it so please leave my name off

if there is thought to still change things then a couple of minor points are that in second papra pg2 at end myopia is not yet defined as being any more "genetic" than cognitive ability is and is equally controversial in the field so it is a bad example that wil be used against this statement and this sent could be left out or changed
next i dont think the next papra really helps suppoert the argument all that well

finally from a global perspective i think the point should be that genetics should not drive social ppolicy this is the error they make, the argument about the genetic comp to cognitive ability is not relevant and indeed and group of 50 very respected behavioral geneti have signed a letter in the wall street journal agreeing with herr and murray that there is a genetic component to cog ability and since this could be shown someday if we argue this is wrong if it turns out to be correct we lose the force of the argument which again is that it is not the way to make policy

jeff

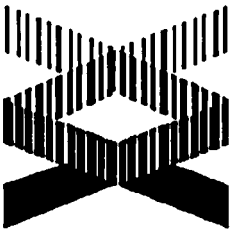
****
*** ACTIVITY REPORT ***
****

TRANSMISSION OK

TX/RX NO.	1438
CONNECTION TEL	912127812661
CONNECTION ID	
START TIME	08/15 13:28
USAGE TIME	01'32
PAGES	2
RESULT	OK

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH



National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: August 3, 1995

TO: Nancy Wexler

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 2

****

Attached is a copy of Jeff Murray's comments on The Bell Curve statement.

****
*** ACTIVITY REPORT ***
****

TRANSMISSION OK

TX/RX NO.	1153
CONNECTION TEL	[redacted]
CONNECTION ID	
START TIME	08/03 13:14
USAGE TIME	01'27
PAGES	2
RESULT	OK

FROM: McKay, Jean

TO: [redacted]

DATE: 08-14-95
TIME: 10:38

CC: McKay, Jean

SUBJECT:
PRIORITY:
ATTACHMENTS:

I will be happy to incorporate the edits. Thanks for the additional journal names.

Jean

REPLY FROM: McKay, Jean
Return-Path: [redacted]

CC: NEIL A HOLTZMAN [redacted]

Mime-Version: 1.0
Content-Type: TEXT/PLAIN; charset=US-ASCII
Content-Length: 1027

Jean,

I'm a bit embarassed to say that a careful reading of the "final draft" of The Bell Curve statement leads me to suggest a few minor changes. These remove superfluous words. My insert makes our points clearer. Can you see what the other members of the Exec. Comm. think?

Par. 2, Sent. 1: Delete the words "fundamental" and "differences between people". Add "s" to "explain." Thus the sentence would read: "Herrnstein and Murray suggest that IQ explains social problems such as crime, welfare dependence, and single parenting." [They're not saying its IQ differences that explains this but IQ per se. The word "fundamental" is unnecessary.]

Par 3, Sent. 2: Change "feel" to "believe"

P. 3, par. 1, next to last sentence. Delete "and malleability". Herrnstein and Murray don't think it's malleable.

Could you also add the Journal of Clinical Ethics and the Journal of

Medical Ethics to the list. The Hastings Center Report should be added, too, if it's not on it.

Talk to you Wednesday.

Tony

FROM: McKay, Jean

TO: landrews@kentlaw.edu

DATE: 08-10-95
TIME: 16:29

CC: McKay, Jean

SUBJECT: RE: drafts
PRIORITY:
ATTACHMENTS:

Thanks for your feedback.

REPLY FROM: McKay, Jean
Return-Path: [redacted]
[redacted]>
Date: Thu, 10 Aug 95 14:50:00 -0500
From: Lori Andrews [redacted]u>
Sender: Lori Andrews <[redacted]>
Organization: Chicago-Kent College of Law
To: [redacted]ov
Subject: RE: drafts
MIME-Version: 1.0
Content-type: text/plain; charset="US-ASCII"
Content-transfer-encoding: 7BIT
X-mailer: Connect2-SMTP 4.00 MHS to SMTP Gateway
The Bell Curve statement looks fine to me; thanks for all your work on it. I have some changes on the health insurance recommendations, which I am faxing to Wanda as requested today.

FROM: McKay, Jean

TO: Jordan, Elke

DATE: 08-08-95
TIME: 15:06

CC: Hudson, Kathy
McKay, Jean
Thomson, Elizabeth

SUBJECT: RE: drafts
PRIORITY:
ATTACHMENTS:

Thank you for your response.

I spoke to Dot Nelkin, who is willing to be listed as the contact person and will co-sign the letter, which should be sufficient. I will be sure that Lori and Dot both know that I will be happy to do any additional work on the statement prior to publication(!!).

Jean

f/u is follow-up (sorry).

REPLY FROM: McKay, Jean
Microsoft Mail v3.0 IPM.Microsoft Mail.Note
From: Jordan, Elke
To: McKay, Jean
Subject: RE: drafts
Date: 1995-08-08 14:40
Priority:
Message ID: 14E29287
Conversation ID: 14E29287

What's an f/u? That's a new abbreviation for me. Leslie could certainly handle inquiries by referring people to a WG member or just providing facts such as date and time of meetings or copies of the statement. I do not think she should be listed in the letter as a contact person, though, nor should anyone else from here. If they must have a local name, it would be more appropriate to list Jean, the executive secretary, as someone who can direct inqiries about more information to the right WG member. No one from NCHGR should sign the statement. Lori's signature should be sufficient. How about listing all the members of the WG as a sort of footnote? That would alleviate some of the rush of phone calls Lori may be worried about.

From: McKay, Jean
To: Thomson, Elizabeth; Jordan, Elke; Hudson, Kathy
Cc: McKay, Jean
Subject: drafts
Date: Tuesday, August 08, 1995 1:52PM

Elke, Elizabeth, Kathy,

It is my understanding that it is not appropriate (desirable) to have Leslie's office handle any f/u about this statement (since this is not an official statement from the NCHGR/DOE)? (See Lori's attached e-mail.)

Thanks.

Jean

FORWARDED FROM: McKay, Jean
FROM: McKay, Jean

TO: [redacted] DATE: 08-08-95

TIME: 13:48

CC: Hudson, Kathy
McKay, Jean

SUBJECT: drafts
PRIORITY:
ATTACHMENTS:

Lori,

I appreciate your letting me know how to proceed re: your signature on WG documents. Dot did send me the draft letter; I edited, adding the paragraph

about who to contact and the WG chair as the author of the letter. Your suggestion about including a knowledgeable WG member as the contact person is
a good one, and I will f/u with Dot/Troy (maybe you and WG member contact should co-sign letter?).

Thanks.

Jean

REPLY FROM: McKay, Jean
Return-Path: [redacted], 8 Aug 1995 12:00:31 -0400
Received: [redacted] id MAA07097;
Tue, 8 Aug 1995 12:00:30 -0400
Received: from NetWare MHS (SMF70) [redacted];
Tue,
8 Aug 95 10:56:31 -0500
Message-ID: [redacted]>
Date: Tue, 8 Aug 95 10:55:00 -0500
From: Lori Andrews [redacted]u>
Sender: Lori Andrews [redacted]u>
Organization: Chicago-Kent College of Law
To: [redacted]
Subject: drafts
MIME-Version: 1.0
Content-type: text/plain; charset="US-ASCII"
Content-transfer-encoding: 7BIT

X-mailer: Connect2-SMTP 4.00 MHS to SMTP Gateway
Hi, Jean,
Hope all is going well with you. I wanted to ask you a favor, and I didn't want to do it on the response to Dan. Please do not send out a draft of anything over my signature without sending it to me first for approval. If you need to get something out quickly for approval and I am not reachable (which was not the case today), just leave off my name until I have a chance to read it. In addition to the suggestion I made in the response to Dan, the third paragraph needs to be changed. The contact person should be someone at the Genome Center or on the Working Group who is particularly knowledgable about the criticisms of behavioral genetics (such as Dot or Troy). Perhaps you should include both the press officer at the NCHGR and a WG member as contact people. I realize that this is probably Dot's draft, and the gist of it is fine, but we want to make sure that reporters and editors can get good additional info if they need it.
Lori

FROM: McKay, Jean

TO: andrews, lori

DATE: 08-08-95
TIME: 15:13

CC: McKay, Jean
nelkin, dorothy

SUBJECT: draft letter
PRIORITY:
ATTACHMENTS:

Lori,

Dorothy Nelkin has agreed to be the contact person for "The Bell Curve" statement, and co-sign the letter accompanying the statement. I will modify the letter accordingly.

Jean

FROM: McKay, Jean

TO: Hudson, Kathy
Jordan, Elke
Thomson, Elizabeth

DATE: 08-08-95
TIME: 15:13

CC: McKay, Jean

SUBJECT: draft letter
PRIORITY:
ATTACHMENTS:

FYI

FORWARDED FROM: McKay, Jean
FROM: McKay, Jean

TO: andrews, lori

DATE: 08-08-95
TIME: 15:13

CC: McKay, Jean
nelkin, dorothy

SUBJECT: draft letter
PRIORITY:
ATTACHMENTS:

Lori,

Dorothy Nelkin has agreed to be the contact person for "The Bell Curve" statement, and co-sign the letter accompanying the statement. I will modify the letter accordingly.

Jean

Return-Path: [redacted]
Date: Tue, 8 Aug 95 10:37:00 -0500
From: Lori Andrews <[redacted]>
Sender: Lori Andrews [redacted]
Organization: Chicago-Kent College of Law
To: [redacted]
Subject: RE: draft letter regarding Bell Curve statement
MIME-Version: 1.0
Content-type: text/plain; charset="US-ASCII"
Content-transfer-encoding: 7BIT
X-mailer: Connect2-SMTP 4.00 MHS to SMTP Gateway

FORWARDED MESSAGE from Daniel.Drell ([redacted] at 8/8/95 10:30a

> Lori, Jean:
>
> The draft letter to various journals, etc. submitting the Bell Curve statement from the ELSI WG sounds fine to me, exept I have some concern about the phrase, "...that these books are inappropriately drawing legitimacy from the success of the Human Genome Project..." Is this true? Rather, aren't these books misunderstanding (or, worse, misrepresenting) the purposes of the HGP?
>
> In any event, the draft letter is basically fine.
>
>
> Dan

***** NOTES from Lori Andrews ([redacted]) at 8/8/95 10:33a
Dan--
Your point is very well taken as to the books. But I think many of the articles in the press, etc., do use the HGP as a way to bootstrap the legitimacy of shaky behavioral genetics. How about changing that sentence two to say the Bell Curve and subsequent publications and change books in the next sentence to publications as well? Lori

Return-Path: [redacted]) id
    WT11558.374; Tue, 08 Aug 1995 12:03:48 EDT
Date: 8 Aug 95 12:03:00 -0400
To: [redacted]
Subject: Re[2]: draft letter regarding Bell Curve statement
Message-Id: [redacted]

Sounds fine to me!

Dan

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH

National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: August 8, 1995

TO: ELSI Working Group Executive Committee
Lori Andrews
Troy Duster
Tony Holtzman
Nancy Wexler
Dan Drell
Elizabeth Thomson

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 2

Attached is a draft letter to journal editors, associations, etc. that will accompany The Bell Curve statement. If you have any revisions, please mark them directly on the document and FAX to me at [redacted] I would appreciate receiving any revisions by Friday, August 11.

Thank you.

The National Institutes of Health-Department of Energy Working Group on the Ethical, Legal, and Social Implications of Human Genome Research

August 7, 1995

EJ comments

DRAFT

Dear....

The enclosed statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group). Its purpose is to express concern about the claims for genetic determinism of behavioral traits that appeared in The Bell Curve, ~~and subsequent books~~. We believe that ~~these~~ books are inappropriately drawing legitimacy from the success of the Human Genome Project, misrepresenting the state of ~~genetic~~ knowledge in ~~this~~ area and misusing ~~genetics~~ to inform social policy.

behavioral genetics — this information

In order to disseminate our statement as broadly as possible, we are submitting it to a variety of journals, newsletters, and other publications of professional and community organizations. Therefore, we would greatly appreciate your publishing the ELSI Working Group statement in [journal, newsletter, etc].

Please do not hesitate to contact me if you have any questions or need additional information. I can be reached at (312) 906-5359.

Thank you for your consideration.

Sincerely,

Lori B. Andrews, J.D.
Chair, ELSI Working Group

Enclosure

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH

National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: August 8, 1995

TO: Dorothy Nelkin

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 7

****

Dorothy,

Attached is a revised version of the ELSI Working Group statement on The Bell Curve, with suggested revisions from Nancy Wexler and Tony Holtzman (also attached). I understand that the inclusion of any of these revisions is your decision.

In addition, attached is a draft of the letter to go with the statement, which I have FAXed to the other members of the ELSI Working Group Executive Committee.

Please let me know what you decide about the suggested revisions to the statement, as well as send me any comments on the draft letter.

I can be reached at [redacted]

Thank you.

The National Institutes of Health-Department of Energy
Working Group on the Ethical, Legal, and Social Implications
of Human Genome Research

Statement

The Bell Curve

This statement was developed by the NIH-DOE Joint Working Group on the Ethical Legal, and Social Implications of Human Genome Research (ELSI Working Group) February 1995: Anita Allen, Lori B. Andrews, Jonathan Beckwith, Robert Cook-Deegan, David Cox, Troy Duster, Neil Holtzman, Joseph McInerney, Victor McKusick, Thomas Murray, Dorothy Nelkin, and Marsha Saxton. The following new members of the ELSI Working Group support the statement: Betsy Anderson, James Bowman, Beth Fine, Philip Kitcher, John Mulvihill, and Rayna Rapp.

In 1994, a highly publicized book, Richard Herrnstein and Charles Murray's The Bell Curve, claimed that IQ is largely genetically determined and that the differences in IQ between ethnic groups are substantially explained by genetic factors. We are especially concerned about the impact of The Bell Curve, and a series of subsequent "bell curve" clones developing similar themes, because we believe that the legitimate successes of the Human Genome Project in identifying genes associated with various human diseases should not be used to foster an environment in which mistaken claims for genetic determination of other human traits gain undeserved credibility.

Herrnstein and Murray suggest that fundamental IQ differences between people explain social problems such as crime, welfare dependence, and single parenting. Now that socio-cultural barriers to personal advancement have largely been removed, they say, social success and high IQ are highly correlated. Programs to eliminate inequalities are thus doomed to failure. Herrnstein and Murray are especially concerned that high birth rates among the poor and the "dysgenic" behavior of women with high IQs, who are not bearing enough children, are threatening the population with genetic decline. According to them, these trends are "exerting downward pressure on the distribution of cognitive ability in the United States."

The authors follow this analysis with policy recommendations. They propose eliminating welfare, which they feel subsidizes birth among poor women, thus lowering the average intelligence of the population. They suggest ending remedial education programs because the results are not worth the cost, given the

claimed significant genetic determination of IQ differences. They urge the development of programs of social support that would encourage women from the higher socio-economic classes to have more children.

Neither Herrnstein nor Murray are geneticists, nor have they carried out studies themselves on the genetic basis of behavior. Their lack of training and experience in genetics does not disqualify them from evaluating genetic research nor from drawing their own conclusion. However, as geneticists and ethicists associated with the Human Genome Project, we deplore The Bell Curve's misrepresentation of the state of genetic knowledge in this area and the misuse of genetics to inform social policy.

We urge consideration of the following three points:

First, Herrnstein and Murray invoke the authority of genetics to argue that "it is beyond significant technical dispute that cognitive ability is substantially heritable." ~~But, the r~~Research in this field is still evolving, ~~the~~ studies ~~they~~ cited by Herrnstein and Murray face significant methodological difficulties, and the validity of ~~their~~ results quoted are ~~is~~ disputed. ~~Some~~ Many geneticists have pointed out the enormous scientific and methodological problems in attempting to separate genetic components from environmental contributors, particularly given the intricate interplay between genes and the environment ~~for~~ that may affect such a complex human trait as intelligence.

Second, even if there were a consensus on the heritability of cognitive ability, the lessons from genetics are misrepresented. The authors argue that it is not possible to alter differential cognitive ability so that remedial education is not worth the effort or cost. This is neither an accurate message from genetics nor a necessary lesson from efforts at remedial education. Heritability estimates are relevant only for the specific environment in which they are measured. Change the environment and ~~heritable~~ the heritability of traits can change remarkably. Saying a trait has high heritability has never implied that the trait is fated to be. Height is both genetically determined and dependent on nutrition. Common ~~genetic~~ conditions, in which genetics plays a role, such as ~~myopia or allergic rhinitis can be corrected with eyeglasses or behavioral modification (avoidance of allergens).~~ diabetes or heart disease can be corrected with insulin or cholesterol-lowering drugs an diet. [Tony Holtzman suggested: Common gene-influenced conditions such as myopia or allergic rhinitis can be corrected with eyeglasses or behavior modification (avoidance of allergens). The

disabilities associated with rare single-gene conditions, such as phenylketonuria or Wilson disease, can also be prevented by medical therapy.

Third, the more genome scientists learn about human genes, the more complexity is revealed. This complexity has become even clearer as more genes correlated with human genetic diseases are discovered. We are only beginning to explore the intricate relationship between genes and environment and between individual genes and the rest of the human genome. If anything, the lack of predictability from genetic information has become the rule rather than the exception. ~~To make simplistic e~~ Simplistic claims about the inheritance and malleability of such a complex trait as cognitive ability ~~at this stage of genetic research is~~ are unjustifiable. Moreover, as the history of eugenics shows, it may be dangerous.

~~It follows that the arguments from genetics~~ Genetic arguments cannot and should not be used to determine nor inform social policy in the areas cited by Herrnstein and Murray. Since the lessons of genetics are not deterministic, they do not provide useful information on deciding whether or not to pursue various programs to enhance the capabilities of different members of society. Those decisions are moral, social, and political ones.

Post-it™ brand fax transmittal memo 7671 | # of pages ▸ 1
To Jean McKay | From Lori Andrews
Co. | Co.
Dept. | Phone #
Fax # [redacted]

Nancy's comments!

We urge consideration of the following three ;

First, Hernnstein and Murray invoke the authority of genetics to argue that "it is beyond significant technical dispute that cognitive ability is substantially heritable." [redacted] research in this field is still evolving, the studies [redacted] cite face significant methodological difficulties, and the validity of [redacted] results is disputed. [redacted] geneticists have pointed out the enormous problems in attempting to separate genetic components from environmental contributors, particularly given the intricate interplay between genes and the environment [redacted] such a complex human trait as intelligence

Second, even if there were a consensus on the heritability of cognitive ability, the lessons from genetics are misrepresented. The authors argue that it is not possible to alter differential cognitive ability so that remedial education is not worth the effort or cost. But, this is neither an accurate message from genetics nor a necessary lesson from efforts at remedial education. Heritability estimates are relevant only for the specific environment in which they are measured. Change the environment and heritable traits can change remarkably. Saying a trait has high heritability has never implied that the trait is fated to be. Height is both genetically determined and dependent on nutrition. Common ~~genetic~~ conditions ~~such as myopia~~ or ~~allergic rhinitis~~ can be corrected with ~~eyeglasses~~ or ~~behavior modification (avoidance of allergens)~~

Third, the more genome scientists learn about human genes, the more complexity is revealed. This complexity has become even clearer as more genes correlated with human genetic diseases are discovered. We are only beginning to explore the intricate relationship between genes and environment and between individual genes and the rest of the human genome. If anything, the lack of predictability from genetic information has become the rule rather than the exception. ~~[redacted]~~ claims about the inheritance and malleability of such a complex trait as cognitive ability ~~at this stage of genetic research~~ is unjustifiable. Moreover, as the history of eugenics shows, it may be dangerous.

~~Inferences that the capabilities of a person~~ genetics cannot be used to determine nor inform social policy in the areas cited by Hernnstein and Murray. Since the lessons of genetics are not deterministic, they do not provide useful information on deciding whether or not to pursue various programs to enhance the capabilities of different members of the society. Those decisions are moral, social, and political ones.

Return-Path: [redacted]
To: "McKay, Jean" [redacted]
Cc: NEIL A HOLTZMAN [redacted]
Subject: Re: distribution of Bell Curve statement
In-Reply-To: [redacted]
Message-Id: [redacted]
Mime-Version: 1.0
Content-Type: TEXT/PLAIN; charset=US-ASCII
Content-Length: 1187

Hi Jean,

The statement on the development (signers) of the Bell Curve document looks fine. So far as corrections: The fifth sentence in the par. on p. 2 (beginning "Second, efen if there were a consensus...") should read: "Change the environment and the heritability of traits can change remarkably." The last sentence of the same par. should begin: "Common gene-influenced conditions..." You can add diabetes and insulin in parallel with myopia and allergic rhinitis. Even better examples, which deserve a new sentence, are PKU and Wilson disease: "The disabilities associated with rare single-gene conditions, such as phenylketonuria or Wilson disease, can also be prevented by medical therapy." If Lori and Dot agree to that addition, I don't think you have to go further. Even Jeff Murray wouldn't diagree with it.

I think the statement should be sent to the editors of the Am J Hum Genet, Am J Med Genet, Eur J Human Genet, Med Genet, J Behav Genet.

AFter the Exec Comm conf call I called Beth Fine (as I said I would) to bring her up to date on my discussions with the Johnson Foundation on professional education. She and I will keep in touch.

Tony

>

The National Institutes of Health-Department of Energy Working Group on the Ethical, Legal, and Social Implications of Human Genome Research

August 7, 1995

DRAFT

Dear....

The enclosed statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group). Its purpose is to express concern about the claims for genetic determinism of behavioral traits that appeared in The Bell Curve and subsequent books. We believe that these books are inappropriately drawing legitimacy from the success of the Human Genome Project, misrepresenting the state of genetic knowledge in this area and misusing genetics to inform social policy.

In order to disseminate our statement as broadly as possible, we are submitting it to a variety of journals, newsletters, and other publications of professional and community organizations. Therefore, we would greatly appreciate your publishing the ELSI Working Group statement in [journal, newsletter, etc].

Please do not hesitate to contact me if you have any questions or need additional information. I can be reached at (312) 906-5359.

Thank you for your consideration.

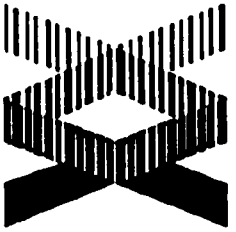
Sincerely,

Lori B. Andrews, J.D.
Chair, ELSI Working Group

Enclosure

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH



National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: August 8, 1995

TO: Dorothy Nelkin

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 4

****

Dorothy,

Attached is a revised version of the ELSI Working Group statement on The Bell Curve. I spoke with Tony Holtzman, who anticipated your concerns about the PKU example and suggested some revisions to that sentence. These revisions are indicated on page 2 of the statement. Tony also suggested that I ask Francis Collins about the PKU example, which I will do. There are a few other minor edits that I made; if inappropriate, please do NOT hesitate to let me know.

After you are satisfied with the statement, I will share with the Exec. Comm., and then with the former and current ELSI Working Group members.

I can be reached at (301) 594-2740.

Thank you very much for your help (and patience).

The National Institutes of Health-Department of Energy
Working Group on the Ethical, Legal, and Social Implications
of Human Genome Research

DRAFT

Statement

The Bell Curve

This statement was developed by the NIH-DOE Joint Working Group on the Ethical Legal, and Social Implications of Human Genome Research (ELSI Working Group) February 1995: Anita Allen, Lori B. Andrews, Jonathan Beckwith, Robert Cook-Deegan, David Cox, Troy Duster, Neil Holtzman, Joseph McInerney, Victor McKusick, Thomas Murray, Dorothy Nelkin, and Marsha Saxton. The following new members of the ELSI Working Group support the statement: Betsy Anderson, James Bowman, Beth Fine, Philip Kitcher, John Mulvihill, and Rayna Rapp.

In 1994, a highly publicized book, Richard Herrnstein and Charles Murray's The Bell Curve, claimed that IQ is largely genetically determined and that the differences in IQ between ethnic groups are substantially explained by genetic factors. We are especially concerned about the impact of The Bell Curve, and a series of subsequent "bell curve" clones developing similar themes, because we believe that the legitimate successes of the Human Genome Project in identifying genes associated with various human diseases should not be used to foster an environment in which mistaken claims for genetic determination of other human traits gain undeserved credibility.

Herrnstein and Murray suggest that fundamental IQ differences between people explain social problems such as crime, welfare dependence, and single parenting. Now that socio-cultural barriers to personal advancement have largely been removed, they say, social success and high IQ are highly correlated. Programs to eliminate inequalities are thus doomed to failure. Herrnstein and Murray are especially concerned that high birth rates among the poor and the "dysgenic" behavior of women with high IQs, who are not bearing enough children, are threatening the population with genetic decline. According to them, these trends are "exerting downward pressure on the distribution of cognitive ability in the United States."

The authors follow this analysis with policy recommendations. They propose eliminating welfare, which they feel subsidizes birth among poor women, thus lowering the average intelligence of the population. They suggest ending remedial education programs because the results are not worth the cost, given the

claimed significant genetic determination of IQ differences. They urge the development of programs of social support that would encourage women from the higher socio-economic classes to have more children.

Neither Herrnstein nor Murray are geneticists, nor have they carried out studies themselves on the genetic basis of behavior. Their lack of training and experience in genetics does not disqualify them from evaluating genetic research nor from drawing their own conclusion. However, as geneticists and ethicists associated with the Human Genome Project, we deplore The Bell Curve's misrepresentation of the state of genetic knowledge in this area and the misuse of genetics to inform social policy.

We urge consideration of the following three points:

First, Herrnstein and Murray invoke the authority of genetics to argue that "it is beyond significant technical dispute that cognitive ability is substantially heritable." Research in this field is still evolving, studies cited by Herrnstein and Murray face significant methodological difficulties, and the validity of results quoted are disputed. Many geneticists have pointed out the enormous scientific and methodological problems in attempting to separate genetic components from environmental contributors, particularly given the intricate interplay between genes and the environment that may affect such a complex human trait as intelligence.

Second, even if there were a consensus on the heritability of cognitive ability, the lessons from genetics are misrepresented. The authors argue that it is not possible to alter differential cognitive ability so that remedial education is not worth the effort or cost. This is neither an accurate message from genetics nor a necessary lesson from efforts at remedial education. Heritability estimates are relevant only for the specific environment in which they are measured. Change the environment and the heritability of traits can change remarkably. Saying a trait has high heritability has never implied that the trait is fated to be. Height is both genetically determined and dependent on nutrition. (1) Common conditions, in which genetics plays a role, such as diabetes or heart disease can be corrected with insulin or cholesterol-lowering drugs and diet. (2) Common gene-influenced conditions such as myopia or allergic rhinitis can be corrected with eyeglasses or behavior modification (avoidance of allergens). The disabilities associated with rare single-gene conditions, such as phenylketonuria or Wilson disease, can also be prevented or significantly ameliorated by medical or nutritional therapy.

* Should both 1 & 2 be in Smt ?

Third, the more genome scientists learn about human genes, the more complexity is revealed. This complexity has become ~~even clearer~~ more apparent or more evident as more genes correlated with human genetic diseases are discovered. We are only beginning to explore the intricate relationship between genes and environment and between individual genes and the rest of the human genome. If anything, the lack of predictability from genetic information has become the rule rather than the exception. Simplistic claims about the inheritance and malleability of such a complex trait as cognitive ability are unjustifiable. Moreover, as the history of eugenics shows, it may be dangerous.

Genetic arguments cannot and should not be used to determine or inform social policy in the areas cited by Herrnstein and Murray. Since the lessons of genetics are not deterministic, they do not provide useful information on deciding whether or not to pursue various programs to enhance the capabilities of different members of society. Those decisions are moral, social, and political ones.

8/8/95

Cambridge Healthtech Institute's
UPCOMING BIOMEDICAL CONFERENCES – WINTER '96

Third Annual Conference on EXPLOITING MOLECULAR DIVERSITY: Small Molecule Libraries for Drug Discovery
anuary 29-31, 1996 • San Diego, CA
Cosponsoring Journal: Molecular Diversity
Corporate Support: Tripos Corp.

The use of combinatorial libraries has rapidly moved from curiousity to a fundamental technique that is revolutionizing high throughput screening for drug discovery. The technology addresses a prime bottleneck, which has been a limitation on the available diversity of compounds to be screened. Further progress is still needed to expand diversity and to optimize strategies for identifying new leads and for analoging of current leads. The progress of programs at many of the leading firms using combinatorial libraries, as well as innovations by various newer entrants into the field, will be presented. The third day of the meeting will feature targets and resulting compounds being developed by pharmaceutical and biotechnology endusers.

Advance Registration Deadline: 12/8/95 Poster Deadline: 1/5/96

SOLID PHASE SYNTHESIS
February 1-2, 1996
San Diego, CA

The demands of combinatorial libraries has focused attention on innovations in rapid, automated solid phase synthesis, particularly of small molecules. The effect of different options such as which kind of support, different types of linkers, choice of solvents and the chemistry being carried out will be examined. Issues related to management, automation and quality control of solid phase reactions, as well as identification of key challenges that need to be addessed will be discussed. The application of solid phase synthesis for carbohydrates, oligonucliotides and peptides will be touched on, but the empasis will be on synthesis of small molecules.

INTELLECTUAL PROPERTY ISSUES
February 5-6, 1996 • Santa Fe, NM

The protection of intellectual property, through the use of patents, technology transfer agreements, trade secrets or other means, is critical for the acheiving a reasonable return on investment in research-intensive fieds such as biomedicine. The exponential growth of sequence data, the unprecedented communication capabilities offered by the Internet, and unresolved questions of privacy, security and conflicts of interests means that the field of genomics is at the forefront of needing to face up to and grapple with these issues. Information on international differences of laws and interpretation, prospects for harmonization, ethical and public policy choices and implications, as well as business considerations, will be highlighted during this important conference.

Advance Registration Deadline: 12/8/95 Poster Deadline: 1/5/96

Third Annual HUMAN GENOME PROJECT: Commercial Implications
March • San Francisco, CA

Progress in map construction, sequencing of cDNA libraries and the demonstrated success of various intensive sequencing efforts has made the prospec of achieving the goals of the Human Genome Project appear realistic. Further progress will still be needed in such areas as gap-filling strategies, the use of bioinformatics to convert sequence data into useful structural and functional information, and even faster and less expensive sequencing processes. Incremental sequencing advances as well as breakthrough approaches to sequencing, including a session on miniaturization, will be featured. The third day of the meeting will again feature progress reports on efforts to translate data from sequencing into commercial products, with an emphasis on therapeutics.

Second Annual GENETIC SCREENING & DIAGNOSIS of Human Diseases
March • San Francisco, CA

The sequencing effort of the Human Genome Project is complementing and simplifying efforts of positional cloning, leading to a dramatic rise in the number of genes identified for inherited disorders, as well as genes and mutations that may predispose an individual to greater risk of other more common diseases. The technology for detection of such genes and mutations, as well as some of the very powerful implications of screening the genetic makeup of individuals, will be covered. Reports on efforts related to the identification and detection of genes and mutations for specific diseases, including cancers, Alzheimer's disease, and cardiovascular disorders, will be featured on the second day.

1037 Chestnut Street • Newton Upper Falls, MA 02164 • 617-630-1300 • fax 617-630-1325 World Wide Web: www.healthtech.com/conferences • E-mail: chi@world.std.com

FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH

National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: August 8, 1995

TO: ELSI Working Group Executive Committee
Lori Andrews
Troy Duster
Tony Holtzman
Nancy Wexler
Dan Drell
Elizabeth Thomson

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 2

Attached is a draft letter to journal editors, associations, etc. that will accompany The Bell Curve statement. If you have any revisions, please mark them directly on the document and FAX to me at [redacted]. I would appreciate receiving any revisions by Friday, August 11.

Thank you.

PLEASE RETAX TO DR. WEXLER.
DID NOT RECEIVE 2ND PAGE

The National Institutes of Health-Department of Energy Working Group on the Ethical, Legal, and Social Implications of Human Genome Research

August 7, 1995

DRAFT

Dear....

The enclosed statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group). Its purpose is to express ~~concern~~ about the claims for genetic determinism of behavioral traits that appeared in The Bell Curve ~~and subsequent books~~. We believe that ~~these~~ books are inappropriately drawing legitimacy from the success of the Human Genome Project, misrepresenting the state of genetic knowledge in this area and misusing genetics to inform social policy.

Cautious sounds reasonable about doing

In order to disseminate our statement as broadly as possible, we are submitting it to a variety of journals, newsletters, and other publications of professional and community organizations. Therefore, we would greatly appreciate your publishing the ELSI Working Group statement in [journal, newsletter, etc].

Please do not hesitate to contact me if you have any questions or need additional information. I can be reached at (312) 906-5359.

Thank you for your consideration.

Sincerely,

Lori B. Andrews, J.D.
Chair, ELSI Working Group

Enclosure

TD comments

8/7 Elke - I would appreciate your review one more time of this draft before it goes to WG Exec Comm - Thank you. Jean

The National Institutes of Health-Department of Energy Working Group on the Ethical, Legal, and Social Implications of Human Genome Research

August 7, 1995

Dear [editor]....

The enclosed statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group). Its purpose is to express concern about the claims for genetic determinism of behavioral traits that appeared in The Bell Curve and subsequent books. We believe that these books are inappropriately drawing legitimacy from the success of the Human Genome Project, misrepresenting the state of genetic knowledge in this area and misusing genetics to inform social policy.

In order to disseminate our statement as broadly as possible, we are submitting it to a variety of journals, newsletters, and other publications of professional and community organizations. Therefore, we would greatly appreciate your publishing the ELSI Working Group statement in [journal, newsletter, etc].

Please do not hesitate to contact me if you have any questions or need additional information. I can be reached at (312) 906-5359.

Thank you for your consideration.

Sincerely,

Lori B. Andrews, J.D.
Chair, ELSI Working Group

Enclosure

OK, I guess! Elke

8-03-1995 09:37 FROM NYU-SOCIOLOGY TO 913014020837309674З P.02

8/3 KH & EJ:
Could you please
review the ltr from
Dr Nelkin —
Thanks
Jean

New York University
Department of Sociology
269 Mercer Street
New York, N.Y. 10003
[redacted] FAX (212) 995-4140

August 2, 1995

Dear Jean,

The following letter should be retyped on ELSI letterhead and first circulated to the Executive Committee and then to appropriate journals, including the Human Genome Newsletter, AAAS, Nature, New Scientist, various genetics and psychology associations.

Sincerely,

Dorothy Nelkin

Dear----------,

The attached statement was developed by the NIH-DOE Joint Working group on the Ethical, Legal, and Social Implications of the Human Genome Project. Its purpose is to express concern about the claims for genetic determinism of behavioral traits that appeared in The Bell Curve and subsequent books. We believe that these books are inappropriately drawing legitimacy from the success of the Human Genome Project, misrepresenting the state of genetic knowledge in this area, and misusing genetics to inform social policy.

We would greatly appreciate if you would publish the statement in your newsletter or journal, and help us to disseminate it in whatever way you find appropriate.

Sincerely,

Jean —

Who should sign?

are these to be letters to the editor? I guess ELSI is entitled to write them and journals to decide whether to publish them. Human Genome News would be no problem

Elke

FROM: McKay, Jean

TO: ELSI-EC

DATE: 08-03-95
TIME: 16:05

CC: Hudson, Kathy
McKay, Jean
Thomson, Elizabeth <et22s>
drell, dan

SUBJECT: distribution of Bell Curve statement
PRIORITY:
ATTACHMENTS:

TO: Lori Andrews, Troy Duster, Tony Holtzman, Dorothy Nelkin, and Nancy Wexler, Dan Drell, Elizabeth Thomson, and Kathy Hudson

FROM: Jean McKay

This is my understanding of the next steps for "The Bell Curve" statement. Please let me know if this needs be changed:

Correct spelling, puncuation, etc. I will do this.

There was discussion about the myopia example, and the inclusion of diabetes as an example. If changes to the statement along these lines need to be made, please FAX to me the appropriate language. Lori--Dorothy suggested that you had such language.

Include statement:

"This statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research (ELSI Working Group), [date, names]. In addition, the following new members of the ELSI Working Group support the statement:..."

Organizations will be sent cover letter with statement. Dorothy has sent to me a draft letter that I will send to you for comment.

The statement will be sent to the following organizations: AAAS (Science), APA, Human Genome News, ASHG/ACMG, New Scientist, Nature (?), Nature Genetics, Journal of NIH Research. Please let me know of others that you wish to include.

Thanks.

Jean

FROM: McKay, Jean

TO: [redacted]

CC: McKay, Jean

SUBJECT: RE: distribution of Bell Curve statement
PRIORITY:
ATTACHMENTS:

Thank you.

REPLY FROM: McKay, Jean
Return-Path: <[redacted]
Date: Thu, 3 Aug 95 15:44:00 -0500
From: Lori Andrews [redacted]u>
Sender: Lori Andrews [redacted]
Organization: Chicago-Kent College of Law
To: [redacted]
Subject: RE: distribution of Bell Curve statement
MIME-Version: 1.0
Content-type: text/plain; charset="US-ASCII"
Content-transfer-encoding: 7BIT
X-mailer: Connect2-SMTP 4.00 MHS to SMTP Gateway

I will fax you Nancy's changes. Please ask Dot whether this is what she had in mind, since Nancy sent this after the conference call and thus the executive committee and the WG have not signed off on her suggested changes. Since Dot has been the primary author, I'd like to leave the issue up to her.

Return-Path: [redacted]
[redacted]>
Date: Thu, 3 Aug 95 15:14:00 -0500
From: Lori Andrews [redacted]u>
Sender: Lori Andrews [redacted]u>
Organization: Chicago-Kent College of Law
To: [redacted]
Subject: RE: distribution of Bell Curve statement
MIME-Version: 1.0
Content-type: text/plain; charset="US-ASCII"
Content-transfer-encoding: 7BIT
X-mailer: Connect2-SMTP 4.00 MHS to SMTP Gateway

FORWARDED MESSAGE from McKay, Jean (JEANM @ SMTP [redacted])
at 8/3/95 3:03p

>TO: Lori Andrews, Troy Duster, Tony Holtzman, Dorothy Nelkin, and Nancy
>Wexler, Dan Drell, Elizabeth Thomson, and Kathy Hudson
>
>FROM: Jean McKay
>
>This is my understanding of the next steps for "The Bell Curve" statement.
>Please let me know if this needs be changed:
>
>Correct spelling, puncuation, etc. I will do this.
>
>There was discussion about the myopia example, and the inclusion of
>diabetes
>as an example. If changes to the statement along these lines need to be
>made, please FAX to me the appropriate language. Lori--Dorothy suggested
>that you had such language.
>
>Include statement:
>
>"This statement was developed by the NIH-DOE Joint Working Group on the
>Ethical, Legal, and Social Implications of Human Genome Research (ELSI
>Working Group), [date, names]. In addition, the following new members of
>the ELSI Working Group support the statement:..."
>
>Organizations will be sent cover letter with statement. Dorothy has sent
>to
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>
>The statement will be sent to the following organizations: AAAS (Science),
>APA, Human Genome News, ASHG/ACMG, New Scientist, Nature (?), Nature
>Genetics, Journal of NIH Research. Please let me know of others that you

>wish to include.
>
>Thanks.
>
>Jean
>
>
***** NOTES from Lori Andrews (LANDREWS @ KENTNET) at 8/3/95 3:05p
There were many other organizations discussed on the conference call as potential recipients. I recall the mention of fellowship programs and the neurology and psychiatry organizations (and other groups that are likely to have an interest in behavioral research); genetic counseling programs might be appropriate as well. We might also try to obtain a listing of the Science and Ethics and Science and Policy Centers at various universities for this and future mailings. Science journalists are also an appropriate target. I'm not sure what Dot had in mind in terms of revisions to the myopia sentence. Did she mean the revision that Nancy sent yesterday afternoon? If so, let me know if you did not get it, in which case I will fax it to you immediately. I myself have not written new language for that sentence.
The language you have drafted for attribution seems right on target.
Thanks! Lori

Return-Path: [redacted]
Subject: Re: Statement on The Bell Curve
To: [redacted] (McKay, Jean)
Date: Wed, 26 Jul 1995 16:11:57 -0500 (CDT)
In-Reply-To: [redacted] from "McKay, Jean" at Jul 14, 95
    10:41:00 am
X-Mailer: ELM [version 2.4 PL24alpha3]
Content-Type: text
Content-Length: 1242

Hi Jean- Thanks for calling today--sorry I seemed out of sorts-I'm a bit overwhelmed at the moment and thinking about more meetings makes me even more overwhelmed--it will all settle down soon.

I did read the Bell Curve statement and certainly agree with the points. However, since I did not read the book, I cannot comment on the references to the book's thesis. The entire premise sounds dangerous and unfounded, so I guess you can count me in as a "semi-educated" yes. !! Thanks for your hard work. Beth Fine>

> TO: Ms, Anderson, Dr. Bowman, Ms. Eisenberg, Ms. Fine, Dr. Kitcher,
> Dr. Murray, Dr. Rapp, and Dr. Mulvihill
>
> FROM: Jean McKay
>
> In follow-up to the discussion of the ELSI Working Group statement on "The
> Bell Curve," please let me know if you agree with the statement and wish
> to be included as a signatory on this document. The statement was in the
> purple folder that was distributed at the meeting. Please let me know if
you
> need a copy of the statement. I can be reached via e-mail at
> jeanm@od.nchgr.nih.gov, by telephone at [redacted] and by FAX at ([redacted].
>
> If possible, I would appreciate your response by Wednesday, July 19.
>
> Thank you.
>
> Jean
>
>
>
>

On Bell Curve Shit

FROM: McKay, Jean

TO: andrews, lori
duster, troy
nelkin, dorothy

DATE: 07-24-95
TIME: 09:00

CC: McKay, Jean
kitcher, phil

SUBJECT: Re: October Working Group meeting
PRIORITY:
ATTACHMENTS:

From Philip Kitcher...

FORWARDED FROM: McKay, Jean
Return-Path: [redacted]
X-Sender: [redacted] (Unverified)
Mime-Version: 1.0
Content-Type: text/plain; charset="us-ascii"
To: "McKay, Jean" [redacted]
From: [redacted] (philip kitcher)
Subject: Re: October Working Group meeting
X-Mailer: <Windows Eudora Version 2.0.2>
Dear Jean:

I do understand Dorothy's frustration, and think we should sign on to the original unless Troy and Lori feel that my amendments would be fairly uncontroversial. I don't want to cause trouble, but simply to help produce the best statement we can. Hope that's understood.

Philip

P.S. Please forward this to Troy, Dot, and Lori. Thanks.

FROM: McKay, Jean

TO: [redacted]

DATE: 07-24-95
TIME: 08:59

CC: McKay, Jean

SUBJECT: Re: October Working Group meeting
PRIORITY:
ATTACHMENTS:

I know that your comments were taken in the spirit in which they were given. I will forward your e-mail to Lori, Troy, and Dot.

Thank you.

Jean

REPLY FROM: McKay, Jean
Return-Path: [redacted]
X-Sender: [redacted] (Unverified)
Mime-Version: 1.0
Content-Type: text/plain; charset="us-ascii"
To: "McKay, Jean" [redacted]
From: [redacted]
Re: October Working Group meeting
X-Mailer: <Windows Eudora Version 2.0.2>
Dear Jean:

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Philip

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Return-Path: [redacted]
X-Sender: [redacted]
1.0
Content-Type: text/plain; charset="us-ascii"
To: [redacted]
From: [redacted]
bell statement
Cc: [redacted]
<Windows Eudora Version 2.0.2>

Dear Jean:

I'm happy to sign on to the "Bell Curve" statement. But I'd be even happier if it were made a bit sharper and more precise. Here are my suggestions for improvement.

Instead of the paragraphs beginning at the second line of p.2 ("First, Herrnstein and Murray invoke ...") I'd prefer:

First, Herrnstein and Murray claim that "it is beyond significant technical dispute that cognitive ability is substantially heritable". They are able to defend this statement only by employing a technical notion of heritability that does not carry the everyday implications of genetic determination. As a number of authors have pointed out, saying that a trait has high heritability in the technical sense has never implied that the trait is fated to be. Heritability estimates are relevant only to the specific environment in which they are measured: change the environment and the heritability of a trait can change remarkably. In many populations, height is highly heritable, but, as is well known, height is influenced both by the genes a person carries and by diet. Furthermore, Herrnstein and Murray are quite wrong to suppose that their alleged high heritability for intelligence shows that it is impossible to alter differential cognitive ability, so that remedial education is not worth the effort or cost. Common conditions that are highly heritable (in the technical sense), such as myopia and allergic rhinits, can be corrected with eyeglasses and behavioral modifications respectively. Thus, even if Herrnstein and Murray were right about the high heritability of intelligence, their controversial conclusions about genetic determination would not follow.

However, a second flaw in their argument affects the assertion that intelligence is highly heritable. Herrnstein and Murray base this claim on studies that purport to show that individuals with the same genotypes (monozygotic twins) perform in similar ways on intelligence tests, even when reared in different environments. These studies face significant methodological difficulties, most notably in ensuring that the allegedly different environments really vary along the dimensions that are relevant. Until we are better able to separate genetic and environmental contributions

to performance on intelligence tests (and to understand the relation between such performance and the trait, intelligence, that we are trying to assess), the kinds of studies cited by Herrnstein and Murray will be inconclusive.

Third, recent research on the human genome is making it ever clearer that the relationships among genotypes, environments and phenotypes are extremely complex. Contemporary work in molecular human genetics shows that the ability to predict phenotypes from genetic information is exceptional, rather than the rule. The intricacy of the development of traits that we think of as relatively "simple" is becoming ever more apparent. Under these circumstances, to make simplistic claims about the inheritance of such a complex trait as cognitive ability is unjustifiable. Moreover, as the history of eugenics shows, it may be dangerous.

COMMENTARY: I've changed the order of points 1 and 2, because it seems to me that point 1 is fundamental, and, in the existing version, there's an uncomfortable mixing of the two kinds of considerations in the first paragraph. I've tried to say more exactly what the technical notion of heritability doesn't imply. With the point about heritability estimates, I've tried to be a bit more explicit -- that point is muffled in the final sentences of what is now the paragraph stating the first point. In the third paragraph, it's important, I think, to make the argument in such a way that shows it isn't just a recapitulation of the idea that heritability doesn't imply genetic determination.

I hope that these changes are acceptable. If not, as I said, I'll go with the original version. Its heart is clearly in the right place, and my concern is only to make it as effective as possible.

Please could you transmit this message to Dot Nelkin. I don't have her e-mail address, and she should *definitely* have a copy, since she put so much work into the original.

Best wishes,

Philip

FROM: McKay, Jean

TO: [redacted]u [redacted]

CC: Hudson, Kathy
McKay, Jean
Thomson, Elizabeth <et22s>
andrews, lori

SUBJECT: Re: Statement on The Bell Curve
PRIORITY:
ATTACHMENTS:

Thank you for your response.

Jean

REPLY FROM: McKay, Jean
Return-Path: [redacted]
Organization: U of Pittsburgh, Human Genetics
To: "McKay, Jean" [redacted]>
Date: Tue, 18 Jul 1995 15:58:03 EST5EDT
Subject: Re: Statement on The Bell Curve
CC: "McKay, Jean" [redacted]>
X-pmrqc: 1
Priority: normal
X-mailer: Pegasus Mail v3.1 (R1a)
Message-ID: [redacted]>

> In follow-up to the discussion of the ELSI Working Group statement on "The
> Bell Curve," please let me know if you agree with the statement and wish
> to be included as a signatory on this document. The statement was in the
> purple folder that was distributed at the meeting. Please let me know if
you

Jean,

I accept signatory role on this document. The third line is not a sentence as is; did a word get deleted? "We are especially concerned about the impact [?of] The Bell Curve...."

John Mulvihill

FROM: McKay, Jean

TO: [redacted]

DATE: 07-18-95
TIME: 08:31

CC: McKay, Jean
Seawright, Wanda
drell, dan

SUBJECT: Re: Statement on The Bell Curve
PRIORITY:
ATTACHMENTS:

Please send your expenses to DOE; however, I am not sure to whom. I think that Dan Drell is at a meeting this week, but he may be reading his e-mail, so I will forwarded your e-mail and this response to him.

Thanks.

Jean

REPLY FROM: McKay, Jean
Return-Path: <[redacted]
Organization: U of Pittsburgh, Human Genetics
To: "McKay, Jean" [redacted]ov>
Date: Mon, 17 Jul 1995 22:27:10 EST5EDT
Subject: Re: Statement on The Bell Curve
CC: "McKay, Jean" [redacted]ov>
Priority: normal
X-mailer: Pegasus Mail v3.1 (R1a)
Message-ID: [redacted]u>
Jean,

Answer tomorrow on Bell Curve.

Question tonight is, Do I send expenses to you or anyone in NCHGR or to someone (who?) in DOE, since I am their representative? No answer from Drell yet, but maybe he's on vacation (or at another meeting).

John Mulvihill

FROM: McKay, Jean

TO: Hudson, Kathy
Thomson, Elizabeth <et22s>
andrews, lori

CC: McKay, Jean

SUBJECT: Re: Statement on The Bell Curve
PRIORITY:
ATTACHMENTS:

Jeff Murray's response to The Bell Curve statement.

FORWARDED FROM: McKay, Jean
Return-Path: [redacted]
To: "McKay, Jean" [redacted]>
Subject: Re: Statement on The Bell Curve
In-Reply-To: [redacted]>
Message-Id: [redacted]
Mime-Version: 1.0
Content-Type: TEXT/PLAIN; charset=US-ASCII

jean
in the spirit of getting out a statement on this which is important please do so if the others are happy with it but i have a couple of concerns about it so please leave my name off

if there is thought to still change things then a couple of minor points are that in second papra pg2 at end myopia is not yet defined as being any more "genetic" than cognitive ability is and is equally controversial in the field so it is a bad example that wil be used against this statement and this sent could be left out or changed
next i dont think the next papra really helps suppoert the argument all that well

finally from a global perspective i think the point should be that genetics should not drive social ppolicy this is the error they make, the argument about the genetic comp to cognitive ability is not relevant and indeed and group of 50 very respected behavioral geneti have signed a letter in the wall street journal agreeing with herr and murray that there is a genetic component to cog ability and since this could be shown

someday if we argue this is wrong if it turns out to be correct we lose the force of the argument which again is that it is not the way to make policy

thanx for listening
and if you are half as good as everyone says you are you should get paid twice as much!!
be cool
jeff

FROM: McKay, Jean

TO: andrews, lori
duster, troy
kitcher, phil

CC: Hudson, Kathy
McKay, Jean
Thomson, Elizabeth <et22s>

SUBJECT: Re: October Working Group meeting
PRIORITY:
ATTACHMENTS:

Forwarded e-mail from Dorothy Nelkin.

FORWARDED FROM: McKay, Jean
Return-Path: [redacted]
X-VMS-To: IN%'[redacted]
MIME-version: 1.0
Content-type: TEXT/PLAIN; CHARSET=US-ASCII
Content-transfer-encoding: 7BIT

Department of Sociology
269 Mercer Street
New York University
New York, NY 10003
Tel (212) 998-8347 FAX (212) 674-4050

July 18, 1995

Dear Jean McKay, Phil Kitcher, Lori Andrews, Troy Duster,

Thanks for sending Phil Kitcher's statement. As I mentioned at the meeting, the previous version, approved by the Working Group, had been revised and re-organized many times in order to gain a consensus among the working group members. I understand Phil's reasoning, but he must understand that this is a statement made by a committee, not an individual. Thus, if we were to make the considerable changes in order and wording that he requested, we would be obliged to recirculate it once again to those who approved it, including Jon who did the final draft and is as fed up as I am with the obstacles to releasing this rather straight

forward statement. Given summer schedules, recirculating it would delay it still another few months. I believe we should either release the approved version soon or drop the whole thing. I am unable to take the time to once again scrutinze a new version and simply cannot deal with any more minute negotiations on a document that has already been revised beyond belief and delayed beyond its useful impact.

Please send this on to Phil, Lori, and Troy, and ask Lori to make a final decision. Sorry to be so grumpy but really!!

I do not at this point believe that I can get to Stanford for the meeting on October 9. Will let you know later if my schedule clears, but am loaded with long trips in October which are beginning to interfere with my teaching schedule.

Sincerely,

Dorothy Nelkin

FROM: McKay, Jean

TO: nelkin, dorothy

DATE: 07-17-95
TIME: 10:27

CC: McKay, Jean
andrews, lori

SUBJECT: bell statement
PRIORITY:
ATTACHMENTS:

Dot,

Attached are Philip Kitcher's comments on The Bell Curve statement. He requested that I forward them to you. I'd be happy to revise the statement based on these, or any other comments, if you would like me to.

Jean

FORWARDED FROM: McKay, Jean
Return-Path: [redacted]
Subject: bell statement
Cc: [redacted]
X-Mailer: <Windows Eudora Version 2.0.2>
Dear Jean:

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Please could you transmit this message to Dot Nelkin. I don't have her e-mail address, and she should *definitely* have a copy, since she put so much work into the original.

Best wishes,

Philip

FAX TRANSMISSION SHEET

West Regional Center
Washington PAVE
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741
FAX (206) 984-7520

Midwest Regional Center
PACER Center
4826 Chicago Avenue South
Minneapolis, MN 55417
(612) 827-2966
FAX (612) 827-3065

CAPP/NPRC

Collaboration Among Parents And Health Professionals
National Parent Resource Center
95 Berkeley Street, Suite 104 • Boston, MA 02116
(617) 482-2915 • FAX (617) 695-2939

Northeast Regional Center
Parent Information Center
P.O. Box 1422
Concord, NH 03302
(603) 228-0402
FAX (603) 228-4365

Health Care Financing
Julie Beckett
CAPP/NPRC
239 University Hospital School
Iowa City, IA 52242-1011
(319) 335-4291

DATE: 7/14/95

National Resource Parents

- ☐ Polly Arango FAX # (305) 887-6817
- ☐ Nancy DiVenere Parent to Parent of Vermont FAX # (802) 655-7817 put PPV on all faxes
- ☐ Carla Lennon Iowa Pilot Parents, Inc. FAX # (515) 576-6299
- ☐ Bev McConnell DRO DSCC/CSHCS FAX # (313) 256-1844
- ☐ Donna Gore Olson Indiana Parent Education Project FAX # (317) 251-7488
- ☐ Kathy Peeples Mississippi Interagency Coordinating Council FAX # (601) 981-1616
- ☐ Florene Stewart Poyadue Parents Helping Parents Special Children's Family Resource Ctr. FAX # (408) 288-7945 put PHP on all faxes

CONSULTANTS:

- ☐ Cindy Arceneaux Department of Health FAX # (404) 679-0537
- ☐ Kathleen Kirk Bishop School of Social Work FAX # (802) 656-8565

FROM:

CAPP / NPRC CENTRAL OFFICE STAFF

- ☑ Betsy Anderson
- ☐ Lennine Perkins
- ☐ Barbara Popper
- ☐ Janet Vohs
- ☐ Nora Wells

FAX #
(617) 695-2939

[redacted]

MEMO:

NUMBER OF PAGES BEING SENT (INCLUDING THIS PAGE) 2

- ☐ *FOR YOUR INFORMATION*
- ☑ *PER YOUR REQUEST*
- ☐ *PLEASE COMPLETE AND RETURN*

FROM: McKay, Jean

DATE: 07-14-95
TIME: 10:43

TO: bowman james
eisenberg, rebecca
fine, beth
kitcher, phil
mulvihill, john
murray, jeff
rapp, rayna

CC: andrews, lori
duster, troy
McKay, Jean

SUBJECT: Statement on The Bell Curve
PRIORITY:
ATTACHMENTS:

TO: Ms, Anderson, Dr. Bowman, Ms. Eisenberg, Ms. Fine, Dr. Kitcher, Dr. Murray, Dr. Rapp, and Dr. Mulvihill

FROM: Jean McKay

In follow-up to the discussion of the ELSI Working Group statement on "The Bell Curve," please let me know if you agree with the statement and wish to be included as a signatory on this document. The statement was in the purple folder that was distributed at the meeting. Please let me know if you need a copy of the statement. I can be reached via e-mail at jeanm@od.nchgr.nih.gov, by telephone at (301) 594-2740, and by FAX at (301) 402-0837.

If possible, I would appreciate your response by Wednesday, July 19.

Thank you.

Jean

Yes, I would like to sign on to this statement.

Betsy Anderson
Federation for
Children w/ Special
Needs

FROM: McKay, Jean

TO: mulvihill, john

DATE: 07-14-95
TIME: 11:20

CC: McKay, Jean

SUBJECT: Statement on The Bell Curve
PRIORITY:
ATTACHMENTS:

Dr. Mulvihill,

I had initially entered the wrong e-mail address for you. Hopefully, the attached e-mail will now reach you.

Jean McKay

FORWARDED FROM: McKay, Jean
FROM: McKay, Jean

TO: bowman james
eisenberg, rebecca
fine, beth
kitcher, phil
mulvihill, john
murray, jeff
rapp, rayna

DATE: 07-14-95
TIME: 10:43

CC: andrews, lori
duster, troy
McKay, Jean

SUBJECT: Statement on The Bell Curve
PRIORITY:
ATTACHMENTS:

TO: Ms, Anderson, Dr. Bowman, Ms. Eisenberg, Ms. Fine, Dr. Kitcher, Dr. Murray, Dr. Rapp, and Dr. Mulvihill

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Thank you.

Jean

Return-Path: [redacted]

[redacted] Jul 95 11:01:08 EST5EDT
From: Mail Delivery System [redacted]u>
To: [redacted]
Date: Fri, 14 Jul 95 11:01:04 EST5EDT
Subject: Delivery failure notification
Message-ID: [redacted]

With reference to your message with the subject:
"Statement on The Bell Curve"

One or more addresses in your message have failed with the following responses from the mail transport system:

User [redacted]> not known at this site.

Should you need assistance, please mail [redacted]u.

---------- Returned message follows ----------

Return-path: [redacted]

Subject: Statement on The Bell Curve
Date: Fri, 14 Jul 95 10:41:00 edt
Message-ID: [redacted]v>
Encoding: 21 TEXT
X-Mailer: Microsoft Mail V3.0

TO: Ms, Anderson, Dr. Bowman, Ms. Eisenberg, Ms. Fine, Dr. Kitcher, Dr. Murray, Dr. Rapp, and Dr. Mulvihill

FROM: Jean McKay

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Thank you.

Jean

American Bar Foundation

750 North Lake Shore Drive
Chicago, Illinois 60611
(312) 988-6500

Fax/Telecopy Transmittal Cover Sheet

Fax Telephone Number: (312)988-6579 Date: 7/13/95

Fax Contact Number: (312)988-6500 Time: 11:35 AM

[redacted] Name: Jean McKay

Fax Number: [redacted]

[redacted] Name: [redacted]

Telephone Number: [redacted]

Comments: Could you please E-mail the new members & ask if they are willing to join the rest of the ~~[illegible]~~ unanimous UR's in signing on to the Bell Curve Statement?

Also please revise roster as shown, plus add E-mail addresses. [illegible]

to Orlando 7/13

Confirmation? Yes( ) No( ) If Yes, Please Contact Sende[r]

Total Number of Pages Transmitted Including Cover Sheet: 4

Please move up Troy's name. We only had a Chair + no vice chair with Nancy so there wasn't a previous term with a name on top. Lori

NIH-DOE ELSI WORKING GROUP **July 6, 1995**

ROSTER

Vice-chair

Chairman: Lori Andrews, JD
Chicago-Kent College of Law
Illinois Instit. of Technology
565 West Adams Street
Chicago, IL 60661
[redacted]

Betsy Anderson, Director
CAPP National Parent Resource Center
Federation for Children with Special Needs
95 Berkely Street
Suite 104
Boston, MA 02116
[redacted]

James Bowman, MD
Professor Emeritus,
Depts. of Pathology, Medicine, Committee on Genetics
University of Chicago
5841 South Maryland Avenue
Chicago, IL 60637
[redacted]

David Cox, MD, PhD
Dept. of Genetics M-322
School of Medicine
Stanford University
Stanford, CA 94305
[redacted]

Troy Duster, PhD, Director
Institute for the Study of Social Change
2420 Bowditch Avenue
University of California
Berkeley, CA 94720
[redacted]
FAX: [redacted]

Rebecca Eisenberg, JD
University of Michigan Law School
439 Hutchins Hall
625 South State Street
Ann Arbor, MI 48109
[redacted]

Beth Fine, MS, CGC
Asst. Prof. of Obstetrics & Gynecology
Graduate Program Genetic Counselor
Northwestern Univeristy Medical School
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Chicago, IL 60611
[redacted]

Neil Holtzman, MD, MPH
Genetics & Public Policy Studies
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[redacted]

Philip Kitcher, PhD
Department of Philosophy
Univ of California-San Diego
MSC 0302
[redacted]

Joseph McInerney
Biological Sciences Curriculum Studies
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Colorado Springs, CO 80918-3842
[redacted]

Jeffrey Murray, MD
Department of Pediatrics
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University of Iowa
Iowa City, IA 52242
[redacted]

Dorothy Nelkin
Department of Sociology
New York University
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New York, NY 10003
[redacted]

Rayna Rapp, PhD
Department of Anthropology
New School for Social Research
65 Fifth Avenue
New York, NY 10003
[redacted]

Marsha Saxton, MS
The Project on Women and Disability
One Ashburton Place
Room 1305
Boston, MA 02108
[redacted]

Nancy Wexler, PhD
Hereditary Disease Foundation
1427 7th Street, Suite #2
Santa Monica, CA 90401
Tel: [redacted]

Representative from the National Advisory Council for Human Genome Research:

Anita L. Allen, JD, PhD
Professor of Law
Georgetown University
Law Center
600 New Jersey Avenue, N.W.
Washington, D.C. 20001
[redacted]

Liaison from the American Society of Human Genetics:

Maimon Cohen, PhD
President, ASHG
Division of Human Genetics
Dept. of Obstetrics/Gynecology
University of Maryland
655 W. Baltimore Street
Room 11-037
Baltimore, MD 21201-1509
[redacted]

Liaison from the American College of Medical Genetics:

Michael Kaback, MD
Children's Hospital-San Diego
Genetics Laboratory
8110 Birmingham Way
San Diego, CA 92123
[redacted]

NIH-DOE STAFF

Kathy Hudson, PhD
Assistant Director for Office of Policy Coordination
National Center for Human Genome Research
National Institutes of Health
31 Center Dr., MSC2152
Building 31, Room 4B09
[redacted]

Dan Drell, PhD
Office of Health and Environmental Research
ER-72/GTN
Department of Energy
19901 Germantown Road
Germantown, MD 20874
[redacted]

Jean McKay
Program Policy Analyst
ELSI Working Group
Office of Policy Coordination
National Center for Human Genome Research
National Institutes of Health
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Building 31, Room 4B09
Bethesda, MD 20892-2152
[redacted]

Elizabeth Thomson, RN, MS
Coordinator, Genetic Services Research
Ethical, Legal and Social Implications Branch
National Center for Human Genome Research
National Institutes of Health
Building 38A, Room 617
[redacted]

Anne Rufo, MA
Legislative Analyst
Office of Policy Coordination
National Center for Human Genome Research
National Institutes of Health
31 Center Dr., MSC2152
Building 31, Room 4B09
Bethesda, MD 20892-2152
[redacted]

Wanda Seawright
Staff Assistant
Office of Policy Coordination
National Center for Human Genome Research
National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892-2152
[redacted]

Put your phone # for

Put their direct line in since we use the WG's direct #s.

Distributed
to WG
9/10

ELSI Working Group Statement on The Bell Curve

In 1994, a highly publicized book, Richard Hernnstein and Charles Murray's The Bell Curve, claimed that IQ is largely genetically determined and that the differences in IQ between ethnic groups are substantially explained by genetic factors. We are especially concerned about the impact The Bell Curve, and a series of subsequent "bell curve" clones developing similar themes, because we believe that the legitimate successes of the Human Genome Project in identifying genes associated with various human diseases should not be used to foster an environment in which mistaken claims for genetic determination of other human traits gain undeserved credibility.

Hernnstein and Murray suggest that fundamental IQ differences between people explain social problems such as crime, welfare dependence, and single parenting. Now that socio-cultural barriers to personal advancement have largely been removed, they say, social success and high IQ are highly correlated. Programs to eliminate inequalities are thus doomed to failure. Hernnstein and Murray are especially concerned that high birth rates among the poor and the "dysgenic" behavior of women with high IQs, who are not bearing enough children, are threatening the population with genetic decline. According to them, these trends are "exerting downward pressure on the distribution of cognitive ability in the United States."

The authors follow this analysis with policy recommendations. They propose eliminating welfare, which they feel subsidizes birth among poor women, thus lowering the average intelligence of the population. They suggest ending remedial education programs because the results are not worth the cost, given the claimed significant genetic determination of IQ differences. They urge the development of programs of social support that would encourage women from the higher socio-economic classes to have more children.

Neither Hernnstein nor Murray are geneticists, nor have they carried out studies themselves on the genetic basis of behavior. Their lack of training and experience in genetics does not disqualify them from evaluating genetic research nor from drawing their own conclusion. However, as geneticists and ethicists associated with the Human Genome Project, we deplore The Bell Curve's misrepresentation of the state of genetic knowledge in this area and the misuse of genetics to inform social policy.

We urge consideration of the following three points:

First, Hernnstein and Murray invoke the authority of genetics to argue that "it is beyond significant technical dispute that cognitive ability is substantially heritable." But, the research in this field is still evolving, the studies they cite face significant methodological difficulties, and the validity of their results is disputed. Some geneticists have pointed out the enormous problems in attempting to separate genetic components from environmental contributors, particularly given the intricate interplay between genes and the environment for such a complex human trait as IQ.

Second, even if there were a consensus on the heritability of cognitive ability, the lessons from genetics are misrepresented. The authors argue that it is not possible to alter differential cognitive ability so that remedial education is not worth the effort or cost. But, this is neither an accurate message from genetics nor a necessary lesson from efforts at remedial education. Heritability estimates are relevant only for the specific environment in which they are measured. Change the environment and heritable traits can change remarkably. Saying a trait has high heritability has never implied that the trait is fated to be. Height is both genetically determined and dependent on nutrition. Common genetic conditions such as myopia or allergic rhinitis can be corrected with eyeglasses or behavioral modification (avoidance of allergens).

Third, the more genome scientists learn about human genes, the more complexity is revealed. This complexity has become even clearer as more genes correlated with human genetic diseases are discovered. We are only beginning to explore the intricate relationship between genes and environment and between individual genes and the rest of the human genome. If anything, the lack of predictability from genetic information has become the rule rather than the exception. To make simplistic claims about the inheritance and malleability of such a complex trait as cognitive ability at this stage of genetic research is unjustifiable. Moreover, as the history of eugenics shows, it may be dangerous.

It follows that the arguments from genetics cannot be used to determine nor inform social policy in the areas cited by Hernnstein and Murray. Since the lessons of genetics are not deterministic, they do not provide useful information on deciding whether or not to pursue various programs to enhance the capabilities of different members of the society. Those decisions are moral, social, and political ones.

July 5, 1995

NOTE TO KATHY HUDSON

RE: ELSI WG statement on The Bell Curve

I have reviewed the statement prepared by the WG on The Bell Curve, and offer the following comments:

- The document needs to be "signed" by the WG and dated.
- The arguments set forth in the statement are not adequately supported by citations from the literature.
- Reorganization/editing of the document may be helpful.
- It is not clear to whom this statement is directed.
- Would it be possible to present the WG position on The Bell Curve in a broader context?

If the message is that there is not enough evidence to support the conclusions of The Bell Curve, then the statement needs to show this. (Saying it isn't so isn't enough.)

Per Lori's request, I have sent a copy of this statement to Drs. Duster and Wexler, and Ms. Nelkin for their review and comment. It is my understanding that this document will be kept "on file," in case someone is interested in the position of the WG on this book.

Please advise.

Thanks.

Jean

ELSI Working Group Statement on The Bell Curve

A recent, highly publicized book, Richard Hernnstein and Charles Murray's The Bell Curve, claims that IQ is largely genetically determined and that the differences in IQ between ethnic groups are substantially explained by genetic factors. We are especially concerned about the impact of The Bell Curve, because we believe that the legitimate successes of the Human Genome Project in identifying genes associated with various human diseases should not be used to foster an environment in which mistaken claims for genetic determination of other human traits gain undeserved credibility.

Hernnstein and Murray suggest that IQ differences between people explain social problems such as crime, welfare dependence, and single parenting. Now that socio-cultural barriers to personal advancement have largely been removed, they say, social success and high IQ are highly correlated. Programs to eliminate inequalities are thus doomed to failure. Hernnstein and Murray are especially concerned that high birth rates among the poor and the "dysgenic" behavior of women and high IQs, who are not bearing enough children, are threatening the population with genetic decline. According to them, these trends are "exerting downward pressure on the distribution of cognitive ability in the United States."

The authors follow this analysis with policy recommendations. They propose eliminating welfare which they feel subsidizes birth among poor women, thus lowering the average intelligence in the population. They suggest ending remedial education programs because the results are not worth the cost, given the claimed significant genetic determination of IQ differences. They urge the development of programs of social support that would encourage women from the higher socio-economic classes to have more children.

Neither Hernnstein nor Murray are geneticists, nor have they carried out studies themselves on the genetic basis of behavior. Their lack of training and experience in genetics does not disqualify

them from evaluating genetic research nor from drawing their own conclusion. However, as geneticists and ethicists associated with the Human Genome Project, we deplore The Bell Curve's misrepresentation of the state of genetic knowledge in this area and the misuse of genetics to inform social policy.

We urge consideration of the following three points:

First, Hernnstein and Murray invoke the authority of genetics to argue that "it is beyond significant technical dispute that cognitive ability is substantially heritable." But, the research in this field is still evolving, the studies they cite face significant methodological difficulties, and the validity of their results is disputed. Some geneticists have pointed out the enormous problems in attempting to separate genetic components from environmental contributors, particularly given the intricate interplay between genes and the environment for such a complex human trait as IQ.

Second, even if there were a consensus on the heritability of cognitive ability, the lessons from genetics are misrepresented. The authors argue that it is not possible to alter differential cognitive ability so that remedial education is not worth the effort or cost. But, this is neither an accurate message from genetics nor a necessary lesson from efforts at remedial education. Heritability estimates are relevant only for the specific environment in which they are measured. Change the environment and heritable traits can change remarkably. Saying a trait has high heritability has never implied that the trait is fated to be. Height is both genetically determined and dependent on nutrition. Common genetic conditions such as myopia or allergic rhinitus can be corrected with eyeglasses or behavioral modification (avoidance of allergens).

Third, the more genome scientists learn about human genes, the more complexity is revealed. This complexity has become even clearer as more genes correlated with human genetic diseases are discovered. We are only beginning to explore the intricate relationship between genes and environment and between individual genes and the rest of the human genome. If anything, the lack of

predictability from genetic information has become the rule rather than the exception. To make simplistic claims about the inheritance and malleability of such a complex trait as cognitive ability at this stage of genetic research is unjustifiable. Moreover, as the history of eugenics shows, it may be dangerous.

It follows then that arguments from genetics cannot be used to determine nor inform social policy in the areas cited by Hernnstein and Murray. Since the lessons of genetics are not deterministic, they do not provide useful information for deciding whether or not to pursue various programs to enhance the capabilities of different members of the society. Those decisions are moral, social and political ones.

July 5, 1995

NOTE TO KATHY HUDSON

RE: ELSI WG statement on The Bell Curve

I have reviewed the statement prepared by the WG on The Bell Curve, and offer the following comments:

- The document needs to be "signed" by the WG and dated.
- The arguments set forth in the statement are not adequately supported by citations from the literature.
- Reorganization/editing of the document may be helpful.
- It is not clear to whom this statement is directed.
- Would it be possible to present the WG position on The Bell Curve in a broader context?

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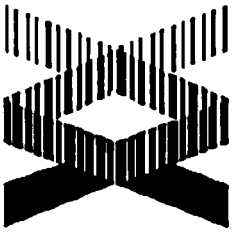
FAX TRANSMITTAL SHEET

NATIONAL CENTER FOR HUMAN GENOME RESEARCH



National Institutes of Health
Building 31, Room 4B09
Bethesda, MD 20892

TEL: (301) 402-0955
FAX: (301) 402-0837

DATE: July 5, 1995

TO: Troy Duster
Dot Nelkin
Nancy Wexler

FROM: Jean McKay

NUMBER OF PAGES INCLUDING COVER: 4

Attached is the ELSI Working Group statement on The Bell Curve, revised by Lori Andrews. Your review and comments would be appreciated. You may mark your comments directly on the document and FAX to me.

Thank you.

Orig
PLA
Wbg/95

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June 29, 1995

NOTE TO KATHY, ELIZABETH, AND ANNE

RE: ELSI WG statement on <u>The Bell Curve</u>

Attached is the latest version of the WG statement on <u>The Bell Curve</u>. Lori provided this document to me during our June 28 meeting. The plan is to send to Dot Nelkin, Troy Duster, and Nancy Wexler for a final review, and then keep it on file as the WG statement on this book.

I would appreciate your review and comments on this document.

Thanks much.

Jean

Incorp. Dot Nelkin comments

I = Dot Nelkin Comments (4)

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