

**Department of Developmental Services**  
**Correspondence to and from Dr. Strauss**  
**January 1997**



## DEPARTMENT OF DEVELOPMENTAL SERVICES

1800 9TH STREET  
SACRAMENTO, CA 95814  
TTY 654-2054  
(916) 654-3663



December 14, 1995

David Strauss, Ph.D.  
Department of Statistics, Room 2638  
University of California  
Riverside, California 92521-0138

Dear Dr. Strauss:

I am writing regarding your manuscript, "Comparative Mortality of People with Developmental Disabilities in Institutions and the Community," co-authored with Dr. Kastner, and submitted to the American Journal on Mental Retardation. As you and Dr. Kastner note, the results of your analysis raise potential policy implications for our system.

In order to develop a course of action for our system relative to your findings, and in keeping with your recommendation to perform additional research, I have asked that an independent consultant replicate your study, and perform additional analyses. To do so, I am requesting that your data be sent to this consultant as follows. Please provide the records for all 105,099 person-years, and for each record, please provide the following fields, with the CDER adaptive skill items represented in their original levels (i.e., prior to collapsing):

1. Mortality (0,1)
2. Age
3. Gender
4. Motor Skills
  - a. Ambulation
  - b. Rolling and sitting
  - c. Crawling and sitting
  - d. Arm use
  - e. Hand use
5. Self care
  - a. Eating
  - b. Toileting
  - c. Bladder control
  - d. Bowel control
  - e. Dressing
6. Mental Retardation level
7. Tube feeding
8. Placement

"Building Partnerships, Supporting Choices"

David Strauss, Ph.D.  
Page Two

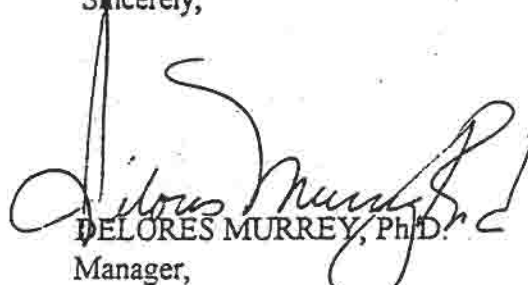
Please provide these data, preferably by December 26, 1995, via floppy disc in Lotus or Ascii, to:

Dr. Stan Taylor  
School of Business  
California State University, Sacramento  
6000 J Street  
Sacramento, California 95819-6088

(Or via electronic mail: SATAYLOR @ CSUS.EDU)

Thank you for your assistance in further analyzing these important data. Should you have specific questions regarding the data or format, feel free to call Dr. Taylor at (916) 278-5439.

Sincerely,



DELORES MURREY, Ph.D.  
Manager,  
Quality Assurance and Program  
Support Branch

cc: Stan Taylor, Ph.D.  
bcc: Greg Wagner, Ph.D.  
Doug Van Meter  
Jim White  
Harold Pitchford  
Eileen Cassidy  
Delores Murrey/files  
Bonnie Banks

## UNIVERSITY OF CALIFORNIA, RIVERSIDE

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SANTA BARBARA • SANTA CRUZ

DEPARTMENT OF STATISTICS  
FAX: (909) 787-3286

RIVERSIDE, CALIFORNIA 92521-0138

January 4 1996.

Dear Dr. Murrey,

Thank you for your letter. I have passed it on to Professor Richard Eyman, who is Director of the UC Riverside Life Expectancy Project and Principal Investigator on our current NIH grant.

Sincerely Yours,

A handwritten signature in cursive script that reads "D. Strauss".

David Strauss

Professor of Statistics  
Fellow of the American Statistical Association.

JAN 23 1996

## UNIVERSITY OF CALIFORNIA, RIVERSIDE

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SANTA BARBARA • SANTA CRUZ

School of Education  
Riverside, California 92521  
(909) 787-5228  
FAX: (909) 787-3942

January 12, 1996

Dr. Delores Murrey  
Department of Developmental Services  
1600 9th Street  
Sacramento, CA 95814

Dear Dr. Murrey:

I received your letter from Dr. David Strauss. The policy of the UC Riverside Life Expectancy Project is, and has always been, to provide copies of published articles when requested and to assist interested correspondents in obtaining any publically available data sources that our work may be based upon. In the present instance the CDER data is, of course, already available to you.

I was pleased to hear of your interest in extending the research results obtained by our group. Our group would happy to work with you directly on this. Please do not hesitate to contact us.

Yours Sincerely,

A handwritten signature in cursive script that reads "Richard K. Eyman".

Richard K. Eyman, Ph.D.  
Professor Emeritus  
Principal Investigator, UC Riverside Life Expectancy Project

cc: Dr. David Strauss

## DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET  
SACRAMENTO, CA 95814  
TTY 654-2054  
(916) 654-1963



January 29, 1996

David Strauss, Ph.D.  
Department of Statistics, Room 2638  
University of California  
Riverside, California 92521-0138

Dear Dr. Strauss:

Thank you for calling Greg Wagner, Ph.D., of my staff last Friday. He enjoyed the opportunity to talk with you regarding your study, "Comparative Mortality of People with Developmental Disabilities in Institutions and the Community." As I discussed in my letter to you of December 14, 1995, our department plans to develop an appropriate course of action for our system based upon your findings. To do so, we are requesting your original data, as specified in my December letter to you. After my discussion with Dr. Eyman, and his subsequent letter to me of January 12, 1996, and Dr. Wagner's recent discussion with you, I appreciate your willingness to work with us.

In his letter to me, Dr. Eyman stated that the policy of the Life Expectancy Project, "...is, and always has been, ... to assist interested correspondents in obtaining any publicly available data sources that our work may be based upon." Both you and Dr. Eyman have indicated that in the present case, those data (e.g., CDER) are available to us internally. Although that is true, we continue to request your original data. Otherwise, any potential "quirks" that may have effected the data in initial transmission from DDS to you would cause differences in the data set between your original data and those that we would access internally. Also, you have already done initial matching of UCI numbers, and acquired mortality data, which would otherwise present us with additional workload issues.

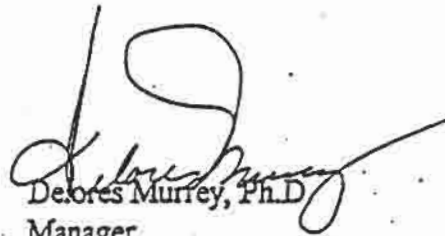
Because the availability of our consultants is very limited, I am requesting that these data be made available by February 9, 1996. Dr. Eyman informed me that competing demands and limited staff resources would impede the provision of the data until after March, so I would like to arrange for one of our staff to directly assist you. Please let me know which day(s), January 31 to February 9, 1996, would be best for you with regard to our sending a staff person to assist you.

"Building Partnerships, Supporting Choices"

David Strauss, Ph.D.  
Page Two

Again, thank you for your help. We respect your research, and appreciate the opportunity to conduct additional analyses of the data. Also, Dr. Wagner asked me to thank you for the additional studies on mortality in persons with developmental disabilities.

Sincerely,



Deores Murrey, Ph.D.  
Manager,  
Quality Assurance and Program  
Support Branch

cc: Dr. Richard Eyman

*ON FEBRUARY 2, 1996, IN A TELEPHONE CALL WITH STAFF, DR. STRAUSS STATED THAT UC RIVERSIDE WAS NOT GOING TO SEND THE DATA TO THE DEPARTMENT OF DEVELOPMENTAL SERVICES.*

4/8/96dm *DM*



## DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET  
SACRAMENTO, CA 95814  
TTY 654-2054  
(916) 654-1897



February 6, 1996

David Strauss, Ph.D.  
Department of Statistics, Room 2638  
University of California  
Riverside, CA 92521-0138

I am shocked and dismayed that you have refused to cooperate with my staff in providing data used in your manuscript, "Comparative Mortality of People with Developmental Disabilities in Institutions and the Community."

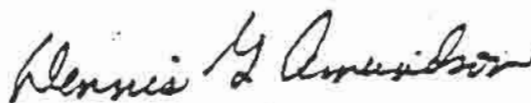
As you know, my Department has enjoyed a longstanding and productive relationship with you and the University, and we have routinely provided you with data for your research endeavors. With this in mind, I am very puzzled by your refusal to grant our request for copies of your original data. While it is true that some of the data in the study originated in our Department, it would be very time consuming and expensive to replicate the work you have already done.

In previous conversations with my staff, you suggested that competing demands on your time and limited staff resources limited your ability to assist us. When we offered to send our own staff to assist with data retrieval, you still refused to provide the data requested.

Without question, your findings could have profound implications for the people served by our Department. You are no doubt aware that the Coffelt lawsuit settlement agreement requires us to continue downsizing our State institutions through accelerated community placements. We need your original data so that we can verify your findings and develop an appropriate course of action.

Because of your steadfast refusals to cooperate, I am asking University officials to intervene on our behalf. By virtue of this letter, I am also formally requesting this data from you under the provisions of the Public Records Act (see Government Code Sections 6252, 6253, 6256 and 6257). This requires you to respond within 10 days. Attached please find a copy of our letter to you dated December 14, 1995, which describes the specific data requested.

Sincerely,



DENNIS G. AMUNDSON  
Director

cc: Dr. Richard Eyman  
Raymond L. Orbach, Chancellor

## DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET  
SACRAMENTO, CA 95814  
TTY 654-2054  
(916) 654-1897



February 6, 1996

Raymond L. Orbach, Chancellor  
University of California  
4148 Hinderaker Hall  
Riverside, CA 92521

Dear Chancellor Orbach:

I am appealing to you to intercede on our behalf in obtaining data used in a research study by Dr. David Strauss, a Professor in the Department of Statistics at University of California, Riverside.

Enclosed are copies of recent correspondence between my Department and Dr. Strauss relative to his manuscript, "Comparative Mortality of People with Developmental Disabilities in Institutions and the Community."

The Department of Developmental Services directly operates six State institutions serving 5,000 people with developmental disabilities and contracts with 21 nonprofit Regional Centers to provide community-based care for approximately 130,000 individuals with developmental disabilities.

In his study, Dr. Strauss concludes that individuals with developmental disabilities living in community residential programs have a greater rate of mortality than those being cared for in State institutions. Since we are continuing to downsize our State institutions by accelerating community placements, Dr. Strauss' findings obviously have profound policy implications for us to consider.

Since our Department has consistently assisted Dr. Strauss' research efforts, we are dumbfounded by his refusal to supply us with core data to verify and analyze his findings.

I would appreciate your prompt response to this appeal. Our request is clearly warranted from a policy standpoint, and is legally enforceable under the Public Records Act.

Thank you for your assistance.

Cordially,

*Dennis G. Amundson*

DENNIS G. AMUNDSON  
Director

CC: E. Wilson



OFFICE OF THE EXECUTIVE VICE CHANCELLOR  
RIVERSIDE, CALIFORNIA 92521

February 16, 1996

Dennis G. Amundson  
Director, Department of Developmental Services  
1600 9th Street  
Sacramento, CA 95814

Dear Mr. Amundson:

I write to acknowledge receipt of your February 6, 1996 letter to Chancellor Orbach, requesting his assistance in obtaining a data set that you have requested from Professor David Strauss of the UCR Department of Statistics:

This is to advise you that I have referred this matter to the office of the University of California General Counsel.

Sincerely,

A handwritten signature in cursive script, appearing to read "D. Warren".

David H. Warren  
Executive Vice Chancellor

cc: Chancellor Orbach  
Professor Strauss  
Counsel Takemiya

## THE REGENTS OF THE UNIVERSITY OF CALIFORNIA

OFFICE OF THE GENERAL COUNSEL

*Aug 20/96  
Delors-4*James E. Hoist  
GENERAL COUNSEL

March 20, 1996

Michael Mount, Chief Counsel  
Department of Developmental Services  
1600 Ninth Street  
Sacramento, CA 95814Re: Department of Developmental Services California Public  
Records Act Request to Professor David Strauss,  
University of California, Riverside

Dear Mr. Mount:

I have met with Professor David Strauss of the Department of Statistics at the University of California, Riverside, to discuss the request by the Department of Developmental Services for the Professor's data underlying his manuscript, "Comparative Mortality of People With Developmental Disabilities in Institutions and the Community."<sup>1</sup>

So that we are clear, let me state my understanding of your Department's request. As stated in the February 6, 1996 letter to Chancellor Orbach from Director Amundson, I understand that you seek "core data" underlying Professor Strauss' manuscript, "to verify and analyze his findings." It is clearly data upon which his research, culminating in the manuscript, was based.<sup>2</sup>

<sup>1</sup>Although the correspondence between the Department and Professor Strauss dates back, as far as I know, to mid-December 1995, the Department's request was first put in the form of a request under the California Public Records Act on February 6, 1996, in two letters from the Director, one to Chancellor Raymond L. Orbach, and the other to Professor Strauss, responded to by Executive Vice Chancellor David H. Warren on February 16, 1996, indicating that the matter had been referred to my office.

<sup>2</sup>In Director Amundson's letter of February 6, 1996 to Professor Strauss, he characterizes it as "data for your research endeavors," and as "your original data." See also letter of

Michael Mount, Chief Counsel  
March 20, 1996  
Page 2

I recognize that some of the data upon which the "Comparative Mortality" manuscript is based was provided by the Department to Professor Strauss, and is otherwise publicly available from the Department. In addition, Professor Strauss obtained additional statistical information from other public resources (e.g., Vital Statistics records). However, it is clear to me that Professor Strauss has, by the application of his expertise and scholarship, and in fulfilling his responsibilities to the University to perform academic research, combined and analyzed the data pursuant to specific algorithms he created for purposes of this study. His results, methodology and analysis are contained in the paper that will be published, in July 1996, in the American Journal on Mental Retardation.<sup>3</sup> As you are aware, acceptance of a manuscript for publication in a peer-reviewed scholarly journal represents a determination by the reviewers that the explication of the methodology, analysis and results is sufficiently thorough and accurate as to permit replication by others in the field.

Based on the foregoing, on behalf of Professor Strauss and the University of California, I must respectfully deny Director Amundson's request. The California Public Records Act exempts from disclosure, among other things, "records the disclosure of which is exempted or prohibited pursuant to provisions of federal or state law, including, but not limited to, provisions of the Evidence Code relating to privilege" (Gov. Code, § 6254(k)), as well as records as to which "the public interest served by not making the record public clearly outweighs the public interest served by disclosure of the record." (Gov. Code, § 6255.) Not only are these records protected by judicially recognized privileges, it is also my opinion that a request such as by Director Amundson's must yield to the compelling nature of Professor Strauss' and the University's legitimate interests in maintaining the integrity of academicians' research and preserving academic freedom from unwarranted encroachment.

Of course, immediately upon publication of the manuscript, we will be pleased to make it available to you. As indicated above,

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January 29, 1996, from Delores Murrey, Manager, Quality Assurance and Program Support Branch, to Professor Strauss, in which she uses the term "your original data" repeatedly.

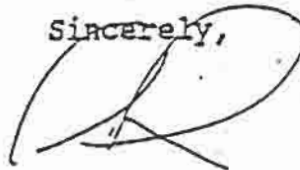
<sup>3</sup>As I believe you are aware, Professor Strauss has a collaborator and co-author of the manuscript, Dr. Ted Kastner, Medical Director, Morristown Memorial Hospital, New Jersey.

Michael Mount, Chief Counsel  
March 20, 1996  
Page 3

the manuscript should be sufficient to enable your department to replicate Professor Strauss' work.<sup>4</sup>

Please feel free to call me if you have any questions.

Sincerely,



Fred Takemiya  
University Counsel

bb

cc: R. L. Orbach  
D. J. Strauss  
D. H. Warren

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<sup>4</sup>I am not persuaded that the fact that it might be "very time consuming and expensive to replicate the work [Professor Strauss has] already done" (letter of Feb. 6, 1996, from Director Amundson to Professor Strauss) constitutes sufficient justification to disclose his original data.



## DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET  
SACRAMENTO, CA 95814  
TTY 654-2054  
(916) 654-1897



April 9, 1996

The Honorable Mike Thompson  
California State Senate  
State Capitol Room 3056  
Sacramento, CA 95814

Dear Senator Thompson:

Thank you for offering to intervene with University of California officials to require disclosure of vital data used in a mortality study conducted by Professor David Strauss, an employee of U.C. Riverside.

As you requested, I am enclosing copies of correspondence on this issue dating back to December of 1995. For reasons only known to Dr. Strauss, he has continuously stonewalled all efforts by my Department to obtain his core data and study methodology. Finally, in frustration, I officially requested the information under the California Public Records Act.

Astonishingly, Fred Takemiya, Legal Counsel to U.C., denied my request with the following admonishment:

**"Not only are these records protected by judicially recognized privileges, it is my opinion that a request such as by Director Amundson's must yield to the compelling nature of Professor Strauss' and the University's legitimate interests in maintaining the integrity of academicians' research and preserving academic freedom from unwarranted encroachment."**

Obviously, we are very troubled by this response, particularly since it comes from another agency of State Government. How can academic freedom be more important than the public's right to know about mortality rates of persons with developmental disabilities?



For your information, I am also enclosing correspondence from other scientists questioning Dr. Strauss' research methodology. Perhaps he's concerned that his findings won't stand up to acceptable scientific standards.

Thank you again for your offer to help. Please let me know if you need additional information.

Cordially,

~~DENNIS G. AMUNDSON~~

DENNIS G. AMUNDSON  
Director

Enclosures

Same Letter Sent to:

The Honorable Kenneth Maddy  
The Honorable Diane Watson  
The Honorable Ross Johnson

bc: Douglas Arnold  
Paul Carleton  
Doug Van Meter  
Eileen Cassidy  
Mike Mount  
Harold Pitchford  
Delores Murrey  
Ken Buono

either required or advisable. As the United States Supreme Court remarked in its only case on point:

In our view, petitioner's reliance on the so-called academic freedom cases is somewhat misplaced. In those cases government was attempting to control or direct the content of the speech engaged in by the university or those affiliated with it. (*University of Pa. v. EEOC*, 493 U.S. 182, 197, 107 L.Ed.2d 571, 110 S.Ct. 577 (1990)). The Public Records Act does not impose any content-based restrictions on speech. We cannot but agree with the Supreme Court when it stated:

In essence, petitioner asks us to recognize an expanded right of academic freedom to protect confidential peer review materials from disclosure. Although we are sensitive to the effects that content-neutral government action may have on speech, and believe that burden that are less than direct may sometimes pose First Amendment concerns, we think the First Amendment cannot be extended to embrace petitioner's claim. (Citations omitted.) 493 U.S. at 199.

Moreover, from the point of view of the First Amendment, the speech of employees of the University is not somehow superior to the speech of other agency employees. Even assuming there were plausible grounds for doing so, it would be difficult to grant special First Amendment protection to public university employees while denying it to other state employees. It is true that courts traditionally have been reluctant to interfere unnecessarily in the internal functioning of universities. *University of Pa.*, at 199. However, the present situation is different. The Public Records Act was enacted by popular initiative and has been amended numerous times by the Legislature. Neither the people nor the Legislature created a general exemption from the Act for public universities or for academics.<sup>4</sup> We see

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4. For a discussion of the pre-1990 *University of Pennsylvania*, supra, cases, see the following: (But see, contra, *Dow Chemical Co. v. Allen & Miller* (7th Cir. 1982) 672 F.2d 1262, 1274 - 1277 (Academic freedom upheld as a basis for affirming order not to disclose documents underlying study by university regarding ongoing, incomplete toxicity studies pertaining to possible cancellation of a herbicide.)) (See *Mount*

Michael Mount  
May 15, 1996  
Page 10

*Huffines* (1991) 101 N.C.App. 292, 399 S.E.2d 340, 341.) The Court concluded that since the information in the applications pertaining to the particular type of research project, whether surgery would be performed, pre and post operative procedures, whether the animals would experience pain or to be euthanised did not contain trade secrets. Since the information did not constitute trade secrets under the North Carolina statute, the information should be disclosed.

The North Carolina Court also disposed of the academic freedom claim as did the Washington court: the Court found that it was bound by the *University of Pennsylvania* decision, *supra*, and therefore, there was no academic privilege. (Id. at p.343-344.)

We could conceivably use this case as authority to argue that protocols are discoverable. (See also, *SETA UNC-CH, Inc. v. Huffines* (1992) 107 N.C.App. 440, 420 S.E.2d 674.) However, since the decision appears to require disclosure of information that is in the form of raw data versus manipulation of that data, the opinion does not address the deliberative process exemption to our disclosure act. Therefore, the University could distinguish this case on that basis.

For the reasons mentioned above, I do not recommend pursuing litigation at this juncture. Instead, I recommend pursuing a FOIA request, and post-publication requests to the Journal and to the author(s). I make this recommendation particularly since Dr. Strauss' article is scheduled for publication in less than 1 1/2 months, July 1996, and because the courts seem to uphold the deliberative process privilege until after publication. And, if we have any difficulty obtaining the protocols, progress and final reports, etc., after publication, we can sue the FOIA and/or author at that time. Should you have any questions or wish to discuss this memo, please feel free to call me.

BRM  
Encl.

cc: Charlton G. Holland, Sr.AAG  
Stephanie Wald, Supv. DAG

UCRIVCLI.MEM

CONFIDENTIAL  
ATTORNEY-CLIENT PRIVILEGE

DANIEL E. LUNGREN  
Attorney General

State of California  
DEPARTMENT OF JUSTICE



50 FREMONT STREET, SUITE 300  
SAN FRANCISCO, CA 94105  
(415) 356-6000

FACSIMILE: (415) 356-6257  
(415) 356-6344

May 15, 1996

Carol Florence  
National Institute of Health  
Building 31, Room 2A32  
Bethesda, Maryland 20892

RE: Professor David Strauss' article, "Comparative Mortality of People with Developmental Disabilities in Institutions and Community"

Dear Ms. Florence:

This letter serves to confirm our telephone conversation of April 23, 1996, and as a formal request for documents under the Freedom of Information Act (FOIA). My understanding is that University of California, Riverside, Professor David Strauss served as the lead author of an article entitled "Comparative Mortality of People with Developmental Disabilities in Institutions and Community" which is scheduled for publication in the July 1996 American Journal on Mental Retardation. Dr. Strauss' co-author is Dr. Ted Kastner, Medical Director, Morristown Memorial Hospital, New Jersey. From our correspondence, it would appear that the principal investigator on the current NIH grant is Professor Richard Eyman, Director of the University of California, Riverside, Life Expectancy Project.

On behalf of my client, Dennis G. Amundson, Director of the California Department of Developmental Services (Department), I request copies of any and all information in the possession of the NIH pertaining to this funded grant that resulted in the above-referenced article, including but not limited to the following: the grant application, the grant's derivative funded noncompeting supplemental grant applications, protocols, progress reports, and final reports of any review or evaluation of grantee performance conducted or caused to be conducted by the Department of Health & Human Services, competing grant applications (initial, competing continuation, and supplemental) for which awards have not been made, evaluative portions of site visit reports, and summary statements of findings and recommendations



DEPARTMENT OF STATISTICS  
FAX: (909) 787-3236

RIVERSIDE, CALIFORNIA 92521-0138

Mr. Dennis Amundson  
Department of Developmental Services  
1600 9th Street  
Sacramento CA 95814

September 5, 1996

Dear Mr. Amundson,

I refer to your letter of February 6, requesting copies of the original data used in the article by Dr. Kastner and myself. The article was recently published in the American Journal on Mental Retardation.

As you know, the original data on which our calculations were based are public information from your own department. I enclose a copy of this on a magnetic tape. It is in the form of a SAS data file.

We regard the derived calculations as work product and hence not in the public domain. Nevertheless, now that the article has been published we are willing, in the interests of open discussion, to make this work product available to qualified persons. Specifically, if an impartial statistician or biostatistician with solid credentials wished to visit our computer center, we would be willing to conduct and display any analyses that interested the visitor. Any senior faculty member of UC Berkeley or UCLA would be a suitably qualified expert. A member of your staff would be welcome at the meeting.

We trust that this process will allay any concerns you may have regarding our research.

Yours Sincerely,

David Strauss, Ph.D., F.A.S.A.  
Professor.

/cont.







DEPARTMENT OF STATISTICS  
 FAX: (909) 787-3286

RIVERSIDE, CALIFORNIA 92521-0138

December 10, 1996

Dear Dr. Murrey,

Thank you for your call today regarding our request for CDER data. To avoid misunderstandings, perhaps you'd be kind enough to FAX me your reply. The number is 909-787-3286.

Sincerely Yours

David Strauss  
 Professor

Post-it™ Fax Note	7671	Date	12-10-96	# of pages	1
To	Dr. Murrey	From	DAVID STRAUSS		
Co./Dept.		Co.			
Phone #	916-654-2186	Phone #	(909) 787-4631		
Fax #	916-654-3666	Fax #	(909) 787-3286		

## DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET  
SACRAMENTO, CA 95814  
TY 654-2054  
(16) 654-3663



December 13, 1996

David Strauss, Ph.D, Professor  
Department of Statistics  
University of California, Riverside  
Riverside, CA 92521-0138

Dear Dr. Strauss:

Thank you for your recent letter dated December 10, 1996. As you requested I am providing you with a written response to your request for the December 1995 and June 1996 updates of the CDER data.

In our seventeen year tradition of collaboration with the University of California, Riverside and our continued effort to provide the data necessary for your continued research in the area of mortality, the Department of Developmental Services would be pleased to comply with your request for the above updates to the CDER. However, to continue this tradition of collaboration we will also need your help. Please give me a call to discuss the details of this data transfer.

In the spirit of cooperation, we would again like to request the UCI numbers of all the deceased persons by year of death referred to in your study, "Comparative Mortality of People With Developmental Disabilities in Institutions and the Community," published in the American Journal of Mental Retardation, 1996. We continue to be interested in reviewing your calculations, without additional prerequisites, for this study.

This data is extremely important to our efforts to review the actual cause and contributing factors surrounding the deaths of those individuals included in your mortality study. While your findings are very interesting, we must be able to identify the cause of death for each of the individuals represented in your study. As you are aware, we need to know "why" people died to formulate any public policy response to a potential increase in community mortality. Your study does not provide us with this information. It is important that we receive this data from you since individuals and families are continuing to choose the community as their residence of choice. Without such data we will be unable, in a timely and accurate manner to determine what policy changes concerning the placement of persons in the community from our developmental centers are necessary to ensure their continued safety and well-being.

In addition, to the above request, we would like to receive the same information from other studies you have conducted:



Strauss, D., Eyman, R. K., & Grossman, H. J. (1996) The prediction of mortality in children with severe mental retardation The effects of placement. American Journal of Public Health.

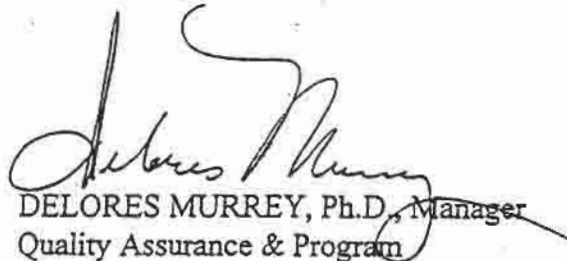
Strauss, D., & Eyman, R. K. (1996). Mortality of people with mental retardation in California, with and without Down syndrome, 1986-1991. American Journal on Mental-Retardation, 100, 643-653.

Strauss, D. & Kastner, T. A. & Shevelle, R.S. (1996). Comparative mortality in institutions and in the community: additional findings, Technical report No. 242.

Your cooperation in this matter will be greatly appreciated and will assist us in our efforts to move forward in this area. It is critical to the lives of those we all care for and want to be safe and succeed in whichever living arrangement they may choose.

I look forward to talking with you personally in the near future. Season's Greetings.

Cordially,

  
DELORES MURREY, Ph.D., Manager  
Quality Assurance & Program  
Support Branch  
Developmental Centers Division

UNIVERSITY OF CALIFORNIA, RIVERSIDE

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DEPARTMENT OF STATISTICS  
FAX: (909) 787-3286

RIVERSIDE, CALIFORNIA 92521-0138

Dr. Delores Murrey  
Department of Developmental Services  
1600 9th Street  
Sacramento CA 95814

December 22, 1996

Dear Dr. Murrey,

Thank you for your letter of December 13, responding to my December 10 request for December 1995 and June 1996 updates of the CDER data. I note your request for mortality data related to various studies that our group has carried out. However, let us not confuse separate issues. As you know, the CDER data is public information. I repeat my request that you send it to us, as you have in previous years.

Yours Sincerely

A handwritten signature in cursive script, appearing to read "D. Strauss".

David Strauss  
Professor