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Richard S. v. Dept. of Developmental Serv. of Cal.



MR-CA-004-011

Attorneys for: Richard S. et al.

UNITED STATES DISTRICT COURT
FOR THE CENTRAL DISTRICT OF CALIFORNIA

RICHARD S., CYNTHIA R., VALDINA)
R., and ROES 1 through 800,)
individually and on behalf of all)
those similarly situated by)
WILLIAM CABLE, M.D. as Guardian)
ad Litem)

Plaintiffs,

vs.

DEPARTMENT OF DEVELOPMENTAL)
SERVICES OF THE STATE OF)
CALIFORNIA, FAIRVIEW)
DEVELOPMENTAL CENTER, SOUTH)
COAST REGIONAL PROJECT, HARBOR)
REGIONAL CENTER, REGIONAL CENTER)
OF ORANGE COUNTY, SAN DIEGO)
REGIONAL CENTER, SOUTH CENTRAL)
LOS ANGELES REGIONAL CENTER,)
WESTSIDE REGIONAL CENTER, DENNIS)
G. AMUNDSON, as Director of the)
DEPARTMENT OF DEVELOPMENTAL)
SERVICES STATE OF CALIFORNIA,)
HUGH KOHLER, as Executive)
Director of FAIRVIEW)
DEVELOPMENTAL CENTER, LILIA TAN)
FIGUEROA, M.D., as Medical)
Director of FAIRVIEW)
DEVELOPMENTAL CENTER, DAWN)
LEMONDS as director of SOUTH)
COAST REGIONAL PROJECT, and Does)
1 through 500, inclusive,)

Defendants

CASE NO:

DECLARATION OF DAVID J.
STRAUSS, Ph.D., FASA, IN
SUPPORT OF PLAINTIFFS'
APPLICATION FOR TEMPORARY
RESTRAINING ORDER AND
PRELIMINARY INJUNCTION

Date: March 20, 1997
Time: 10:00 a.m.
Place: Federal District
Court, Santa Ana, California

1 I, DAVID J. STRAUSS, declare:

2 1. That I am a research statistician working in the area of
3 epidemiology and that I am professor of Statistics at the
4 University of California, Riverside, California. I am not a
5 physician and surgeon.

6 2. That If called as a witness in a Court of law I could and
7 would testify to the following facts which are of my own
8 personal knowledge:

9 3. That I obtained my bachelor's degree, with first class
10 honors, from Cambridge University. Thereafter, I obtained my
11 Masters and Ph.D. degrees in statistics from Sussex University
12 in the United Kingdom.

13 4. That attached hereto and incorporated herein as Exhibit #1
14 is a true and correct copy of my latest curriculum vitae.

15 5. That I have twenty five (25) years experience in research,
16 teaching, publishing and working in the fields of theoretical
17 and applied statistics. I am presently engaged in epidemiologic
18 research at the "Life expectancy Project", U.C., Riverside.

19 6. That for the past seventeen (17) years our research group
20 at the University of California, Riverside has received and
21 analyzed "client data" provided to us by the California
22 Department of Developmental Services ("DDS") regarding
23 Californians with developmental disabilities.

24 7. That for a number of years our research and analysis of the
25 California DDS client data at UCR has been supported by a
26 substantial grant from the National Institutes of Health in
27 Washington, D.C. ("NIH").

28

8. That the Department of Statistics and the "Life Expectancy

1 Project" at UCR is recognized as one of the leading research
2 centers, if not the leader, regarding the study of mortality and
3 morbidity of the mentally retarded and developmentally disabled
4 in the United States and Canada.

5 9. That some time shortly after its execution in February,
6 1994, I became aware of the class action settlement in the
7 "Coffelt Agreement" which called for expedited
8 deinstitutionalization of two thousand (2000) developmentally
9 disabled clients from California Developmental Centers.

10 10. That I was unaware in 1994 (^{DS}~~or since~~) of any study
11 published, commissioned or performed by the California DDS
12 concerning comparative mortality between the institutions and
13 clients discharged into community placement.

14 11. That shortly thereafter, on or about July, 1994, I provided
15 a senior DDS official with a copy of our groups manuscript
16 entitled "The Prediction of Mortality in Children with Severe
17 Mental Retardation The Effect of Placement" which was recently
18 published in slightly revised form in the peer reviewed October,
19 1996 edition of the American Journal of Public Health (attached
20 hereto and incorporated herein as Exhibit #2) is a true and
21 correct copy of said article).

22 12. That this study demonstrated "Own home residence and
23 community care facilities have an estimated 25% higher risk-
24 adjusted odds on mortality than institutions and health
25 facilities".

26 13. That on or about January, 1995, we permitted some copies of
27 our additional study; "Strauss, DJ and Kastner, TA (1996).
28 "Comparative mortality of people with mental retardation in

1 institutions and the community." American Journal on Mental
2 Retardation, 101" to be circulated (attached hereto and
3 incorporated herein as Exhibit #3 is a true and correct copy of
4 said article).

5 14. That in this study "Risk-adjusted mortality rates in
6 institutions and the community in California from 1980 through
7 1992 were compared with the aim of improving our understanding
8 of the capacity of the community health system to support
9 deinstitutionalization. Risk-adjusted odds on mortality were
10 estimated to be 72% higher in the community than in
11 institutions".

12 15. That I have been informed and believe that such article,
13 prior to its July 1996 publication date, was on or about
14 January/February 1995, widely circulated in the developmental
15 centers and its results known to the DDS, regional center and
16 developmental center personnel.

17 16. That in October, 1996, our department produced a follow-up
18 report (not published) "Strauss, DJ, Kastner, TA, Shavelle, R
19 "Comparative Mortality in institutions and in the community:
20 Additional findings" which we provided to the DDS. Such study
21 used a simpler method of calculation, did not use "statistical
22 modelling" as used in our earlier study and is widely used in
23 the epidemiologic community; "Using the different methodology,
24 we found that community care in 1985-92 was associated with a
25 74% increase in mortality -- a result strikingly close to the
26 earlier one. This is evidence that the previous result was not
27 an artifact of the statistical procedures. For 1993-94, there
28 was an 82% increase in mortality odds associated with the

1 community. This may be viewed as an independent confirmation of
2 our previous findings, since the 1993-94 data have no overlap
3 with the study period we used in Strauss and Kastner (1996).
4 Further, the 1993-94 experience is relatively recent and is much
5 more representative of the current situation" (attached hereto
6 and incorporated herein as Exhibit #4 is a true and correct copy
7 of the additional findings report).

8 17. That all raw data used in the above referenced studies and
9 in the follow up report were obtained from the DDS itself and
10 and from California public records containing vital statistics.

11 18. That I have personally spent hundreds of hours of hands on
12 work in collecting, organizing, analyzing, preparing and
13 drafting for publication the above referenced studies and
14 reports.

15 19. That the methodology used in the article entitled "Strauss,
16 DJ and Kastner, TA (1996). "Comparative mortality of people with
17 mental retardation in institutions and the community." American
18 Journal on Mental Retardation, 101" was peer reviewed by ten
19 (10) highly respected scientists in the field from three (3)
20 separate scientific journals prior to its publication in
21 October, 1996.

22 20. That the methodologies used in all our publications and the
23 follow up report are widely accepted throughout the statistical
24 and epidemiological communities.

25 21. That since the preparation of the above referenced articles
26 I have presented our data to several university departments and
27 at a meeting at the Centers for Disease Control ("CDC") in
28 Atlanta, Georgia.

1 22. That on or about February, 1997 I was provided with a copy
2 of a packet of purported letters (attached hereto and
3 incorporated herein as Exhibit #5 and entitled "Department of
4 Developmental Services Correspondence to and from Dr. Strauss
5 January 1997" is said packet) which I am informed and believe
6 was publically circulated as a "hand out" at a DDS meeting.

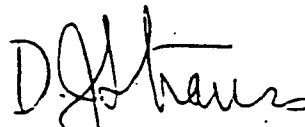
7 23. Following conversations with NIH, ^{was made} and a request ^{by the}
8 California Attorney General, on May 15, 1996, (Ex.#5) to NIH
9 under the Freedom of Information Act for documents relating to
10 UCRs NIH grant. . .

11 23. Since providing this grant information to the California
12 Attorney General (pursuant to the DDS request) the NIH has not
13 renewed grant funding.

14 I declare under penalty of perjury under the laws of the
15 State of California and of the United States that the foregoing
16 is true and correct.

17 Dated: 3/14/97

18 At: Riverside CA

19 

20 DAVID J. STRAUSS, Ph.D. - Declarant
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DEPARTMENT OF STATISTICS
FAX: (909) 787-3236

RIVERSIDE, CALIFORNIA 92521-0138

February 1997

Curriculum Vitae: David Strauss

Current Position: Professor, Department of Statistics, Univ. of California, Riverside, Riverside CA 92521. (909) 787-4631.

Director of the Statistical Consulting Center at UC Riverside.

Education: B.A., Mathematics (with First Class Honors), Cambridge University, England, 1968.

M.S., Statistics, Sussex University, England, 1969.

Ph.D., Statistics, Sussex Univ., England, 1971.

Employment: 1971-present: on faculty of Statistics Department, U. C. Riverside.

Honor: Elected Fellow of the American Statistical Association, 1992.

Publications: Some 70 articles, mostly peer-reviewed. See attached bibliography.

Primary research: Epidemiological studies in mental retardation/developmental disabilities.

Other research: Statistics theory (probability modelling; spatial statistics).

Statistical consulting and applications. Has published more than 25 papers on statistical applications in sociology, psychology, anthropology, geology and forestry.

Teaching:

Dr. Strauss has taught virtually all the courses offered by the statistics department. In recent years, he has specialized in large introductory undergraduate statistics, and in consulting and data analysis at the graduate level.

Was founder of the Statistical Consulting Center at UC Riverside in 1983.

Designed and implemented classes in consulting and analysis of data for statistics graduate students statistics at UCR.

Designed and implemented a graduate class in biostatistics/epidemiology for students statistics at UCR.

Editorial consultant for the following journals:

American Antiquity
American Journal on Mental Retardation
American Statistician
Annals of the Institute of Statistical Mathematics
Applied Statistics
Behavior Science Research
Biometrics
Biometrika
Communications in Statistics
International Journal of Wildland Fires
Journal of Applied Probability
Journal of Mathematical Psychology
Journal of the American Statistical Association
Journal of the Royal Statistical Society.
Mathematical Geology
Mathematical Sociology
Mathematical Reviews
Psychometrika
Social Networks

Invited presentations on mental retardation/ developmental disability.

- February 1997 Department of Pediatrics, University of British Columbia. "Prognosis for survival and improvement in function of children with severe developmental disability."
- February 1997 Department of Physiatry, University of British Columbia. "California research on persons with mental retardation: experiences with a large data base."
- February 1997 Department of Epidemiology and Public Health, University of British Columbia. "Patterns of mortality of persons with developmental disability: comparison of institutions and the community."
- February 1997 Department of Statistics, University of British Columbia. "Coping with confounding: lessons from the California mental retardation data base."
- January 1997 Langley-Porter Institute, UC San Francisco. "Patterns of mortality of persons with developmental disability."
- January 1997 Department of Statistics, UC Riverside. "Coping with confounding: lessons from the California mental retardation data base."
- September 1996 Ontario CA: "Tracking persons with developmental disability who left developmental centers, 1993-95." Presentation to joint meeting of CASHPCR, CAPT, and allied groups.
- September 1996 Minneapolis MN: Poster presentation ("Prognosis for survival and improvement of children with severe developmental disability"). Annual meeting of the Child Neurological Society; with Dr. Stephen Ashwal.
- April 1996 Sacramento CA: presentation at meeting of the California Association of Psychiatric Technicians, and allied groups. "Mortality studies at UC Riverside."
- March 1996 Centers for Disease Control, Atlanta Georgia: "Research at UC Riverside in developmental disability."

March 1996	Chaired session on "Adulthood and Aging", and gave presentation on recent mortality research, at the annual conference on theory and research in mental retardation, Gatlinburg TN.
March 1996	Plenary speaker at the annual meeting of the California Chapter of the Association for Retarded Citizens, San Francisco CA.
August 1995	Presentation at meeting of the Sonoma chapter of CASHPCR (parents' association at the developmental center), Sonoma CA.
June 1995	Chair of session and presenter of talk at the annual meeting of the American Association on Mental Retardation, San Francisco CA.
June 1995.	Poster presentation at the annual meeting of the American Association on Mental Retardation, San Francisco CA.
March 1995	Presentation at meeting of the Fairview chapter of CASHPCR (parents' association for children in Fairview developmental center), Costa Mesa CA.

Legal Experience

- 1991-1993: Statistical consultant and expert witness for Milberg Weiss et al., acting for plaintiffs in the Stringfellow acid pits litigation. The work included analysis of effect of Stringfellow on houses prices and analysis of medical effects on local residents.
- 1993: Consultant for McMenamin and Bennett, San Diego. The statistical issues concerned inferences about defective construction in a large housing complex, based on a small sample of observations.
- 1991-1992: Expert witness for defense (Morton Galane) in breach of contract suit against liquor suppliers in Las Vegas. Worked with statistical projections of lost profits.
- 1992: Consultant for Milberg, Weiss in a lawsuit concerning the San Onofre Nuclear Generating Station. The statistical issues concerned the analysis of data on the station's environmental impact.
- 1974: Expert witness in a Riverside CA murder trial, re. statistical issues of bias in racial composition of jury panels.

Recent statistical consulting experience.

Primary activity: Key Investigator on \$2,000,000 grant from the National Institute of Health (1/1992 to 1/1996, with small continuation funding through 1/1997) for epidemiological studies of issues related to developmental disability.

Other recent work

US Forest Service: Statistical consultant since 1974. Forest Service grant (\$39,000, during period 1988-89) for statistical analysis on effects of air pollution. Recent projects concern models for attack on forest fires, and a Bureau of Land Management grant (\$60,000 for 1992-93) to study the statistics of lightning strikes and their relations to fires. A similar continuation grant was awarded for 1993-94. Current work (1996-97): contract for statistical modelling/simulation of fire seasons.

1988-89: Recipient of a National Science Foundation grant for collaborative work on problems in geological statistics.

1990-1992: Statistical consultant for Hewlett-Packard (work on the analysis of customer satisfaction surveys).

1992-93: Received a grant from the US Department of Agriculture, for work on statistical problems in estimation of soil salinity.

1993-94: Awarded an additional National Science Foundation grant for related collaborative work in geological statistics.

BIBLIOGRAPHY - David Strauss

I. Published

1. Strauss, DJ. "Independence of Variables in Numerical Taxonomy." Systematic Zoology (1971), 12, 470-471.
2. Strauss, DJ. "Analysis of Drug Effects on Body Temperature." Biometrics (1971), 17, 721-724.
3. Strauss, DJ. "Classification Techniques." Collective Phenomena, (1973) 1, 119-126.
4. Strauss, DJ. "Analyzing binary lattice data with the nearestneighbor property." Journal of Applied Probability (1975), 12, 702-712.
5. Strauss, DJ. "A model for clustering." Biometrika (1975), 62, 467-475.
6. Strauss, DJ. and M. Orans. "Mighty Sifts: A critical appraisal of solutions to Galton's problems and a partial solution (with reply)." Current Anthropology (1975), 16, 573-594.
7. Strauss DJ. "Clustering on colored lattices." Journal of Applied Probability (1977), 14, 135-143.
8. Strauss DJ. "Runs of occupied cells." Biometrika (1977), 64, 170-171.
9. Strauss DJ. "Measuring endogamy." Social Science Research (1977), 6, 225-245.
10. Strauss DJ. "Evaluation of Classification Techniques." Trabajos de Estadistica (1977), 28, 167-182.
11. Ziemer RR and DJ Strauss. "A statistical approach to instrument calibration." U.S.D.A. Forestry Service Technical Report (1978).
12. Strauss DJ and M. Orans. "Residence and descent is hyper-diffusional?" Behavior Science Research (1978), 13, 1-24.
13. Strauss DJ and M. Orans. "Reply to Commentators" and "On the Cluster Reduction Method." Behavior Science Research (1978), 13, 51-63.
14. Strauss DJ "Some results on random utility models." Journal of Mathematical Psychology (1979), 20, 35-52.

15. Strauss DJ "Chance in Guttman Scaling." Social Science Research (1980) 9, 76-82.
16. Strauss DJ "Choice by Features." British Journal of Mathematical and Statistical Psychology (1981), 34, 50-61.
17. Strauss DJ "Testing Partial Correlations When the Third Variable is Measured in Error." Educational and Psychological Measurement (1981), 41, 349-358.
18. Robertson CA and DJ Strauss. "A Characterization Theorem for Random Utility Variables." Journal of Mathematical Psychology (1981), 23, 184-189.
19. Strauss, DJ and AK Romney. "Log-linear Multiplicative Models for the Analysis of Endogamy." Ethnology (1982), 21, 79-99.
20. Strauss, DJ and DN Neal. "Biases in the Step-point Method on Bunchgrass Ranges." Journal of Range Management (1983), 36, 623-626.
21. Strauss DJ "The Hammersley-Clifford Theorem." Invited contribution to the Encyclopedia of Statistical Sciences, NL Johnson and S Kotz, editors, (1983), 3, 570-572.
22. Strauss DJ "Luce's Choice Axiom and Generalizations." Invited contribution to Encyclopedia of Statistical Sciences, NL Johnson and S Kotz, editors, (1985), 5, 167-170.
23. Frank O. and DJ Strauss. "Markov Graphs." Journal of the American Statistical Association (1986), 81, 832-842.
24. Strauss DJ "A General Class of Models for Interaction." Society for Industrial and Applied Mathematics, Review (1986), 28, 513-527.
25. Strauss DJ "Random Utility Models." Invited contribution to Encyclopedia of Statistical Sciences, NL Johnson and S Kotz, editors, (1986), 7, 572-573.
26. Strauss, DJ and BC Arnold. "The Rating of Players in Racquetball Tournaments." Journal of the Royal Statistical Society, Series C, (Applied Statistics), 1987, 36, 163-73.
27. Arnold BC and DJ Strauss. "Bivariate distributions with Exponential Conditionals." Journal of the American Statistical Association (1988), 83, 522-527.
28. Strauss, DJ and PM Sadler. "Stochastic Models for the Completeness of Stratigraphic Sections." Mathematical Geology (1989), 21, 37-59.

29. Strauss DJ and LC Freeman (1989). "Stochastic Modeling and the Analysis of Structural Data." In Research Methods in Social Network Analysis, eds. LC Freeman, AK Romney, and D White, pp. 135-183. George Mason University Press.
30. Strauss DJ and PM Sadler. "Classical Confidence Intervals and Bayesian Probability Estimates for Ends of Local Taxon Ranges." Mathematical Geology (1989), 21, 411-427.
31. Strauss DJ, L Bednar, and R Mees. "Do 1% of Forest Fires Cause 99% of the Damage?" Forest Science, (1989), 35, 319-328.
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34. Strauss DJ and M Ikeda. "Pseudolikelihood Estimation for Social Networks." Journal of the American Statistical Association, (1990), 85, pp. 204-212.
35. Bednar L, R Mees and DJ Strauss. "Fire Suppression Effectiveness For Simultaneous Fires: An Examination of Fire Histories". Western Journal of Applied Forestry, (1990), 5, pp. 16-19.
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37. Clyde MC and DJ Strauss. "Logistic Regression for Spatial Pair-potential models." In Spatial Statistics and Imaging, ed. A. Possolo (1991), pp. 14-30, IMS Lecture Notes - Monograph Series. IMS: Hayward, Calif.
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50. Strauss, DJ, Eyman, RK and HJ Grossman (1996). "The prediction of mortality in children with severe mental retardation: The effect of residential placement." American Journal of Public Health, 86, 1422-29.

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54. Pary RJ, Strauss DJ, and White JF. A population survey of bipolar disorder in persons with and without Down Syndrome. Down Syndrome Quarterly, vol 1.
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2. Orans, M. and DJ Strauss. "On Z factors." Current Anthropology (1976) 17, 754-755.
3. Strauss, D. and M. Orans. "More on Solutions to Galton's Problem." Current Anthropology (1977), 18, 118-19.
4. Strauss, DJ and M. Orans. "On Wirsing's Method for Galton's Problem." Current Anthropology (1977), 18, 341.
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6. Strauss, DJ "Potential Models". Technical Report #111, Department of Statistics, University of California, Riverside, 1983.
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8. Strauss, DJ. "A Rating System for Racquetball." National Racquetball, April 1988, pp. 40-41.
9. Benoit J. and DJ Strauss. "Preliminary Development of a prediction model for Lightning-caused Forest Fires." Paper presented at the 12th Conference on Fire and Forest Meteorology, Jekyll Island, GA, October, 1993, 8 pages.
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13. Strauss DJ, Shavelle R and JF White. "Demographic and cost projections for persons with developmental disabilities." Technical Report # 231, Department of Statistics, UC Riverside, 1995.

II. In Press.

1. Strauss DJ, Kastner TA, Ashwal S, and White JF. "Tubefeeding and Mortality in Severely Disabled Children with Mental Retardation." To appear in Pediatrics, 1997.
2. Strauss DJ, Ashwal S, Shavelle R, Eyman, RK (1997). Prognosis for survival and improvement in children with severe developmental disabilities. To appear in Journal of Pediatrics, 1997.

III. Submitted.

1. Shavelle RM and Strauss DJ. "Improved sample survey using past values", 34 manuscript pages. Submitted February 1997.
2. Strauss DJ. "A note on Miettinen's multivariate confounder score." 16 ms pages. Submitted January 1997.
3. Mees RM and DJ Strauss. A model for costs of wildland fires. Submitted April 1996.
4. Strauss DJ, and Shavelle R. An extended Kaplan-Meier estimator and its applications. Submitted August 1996.
5. Strauss DJ, Kastner TA, and Shavelle RM. Mortality in groups of persons with developmental disabilities, 1985-94. Submitted December 1996.
6. Strauss DJ, Eyman RK, and Grossman HJ. Response to Durkin's American Journal of Public Health editorial.
8. Strauss DJ and Shavelle RM. A note on comparative mortality in institutions and the community. Submitted January 1997.
9. Strauss DJ, Shavelle RM, and Baumeister A. Mortality of persons with developmental disabilities released from California institutions. Submitted September 1996.
10. Strauss DJ, Shavelle RM, Anderson TW, & Baumeister A. Externally-caused deaths to persons with developmental disability. Submitted January 1997.

V. In progress.

1. Strauss DJ, Anderson T, Shavelle R, Sheridan F, and Trenkle S. Avoidable death in persons with developmental disability in institutions and community care: a comparative study.

V. Book Reviews.

1. Botvinnik, M. M. Computers, Chess and Long Range Planning, Nature, 1971.
2. Kirk, R. E. (Editor). Statistical Issues, Biometrics, 1972.
3. Wetherill G. Elementary Statistical Methods. Biometrics, 1973.
4. Seber G. G. The Estimation of Animal Abundance, Biometrics, 1974.
5. Hartigan, J. A. Clustering Algorithms, Biometrics, 1975.
6. Harris, R. J. A Primer of Multivariate Statistics, Biometrics, 1975.

Comparative Mortality of People With Mental Retardation in Institutions and the Community

David Strauss

University of California, Riverside

Theodore A. Kastner

Morristown Memorial Hospital (Morristown, NJ)

The role of institutions has come into question in recent decades, and the size of the institutionalized population has been drastically reduced. Risk-adjusted mortality rates in institutions and the community in California from 1980 through 1992 were compared, with the aim of improving our understanding of the capacity of the community health system to support deinstitutionalization. Risk-adjusted odds on mortality were estimated to be 72% higher in the community than in institutions. Some problems with health care delivery in the community were reviewed; these may help account for the difference. Consumers and guardians should weigh these considerations when making choices between institutional versus community-based care.

As recently as 40 years ago, professionals and consumers believed that the ideal location for services for people with mental retardation was the congregate care setting. Public concern over the quality of institutional care peaked with revelations in the 1970s of abuse and neglect in institutional settings, including the Willowbrook Center in New York City and the Pennhurst Center in Philadelphia. Congress passed certification procedures related to funding received by states through the Medicaid Program and gave civil rights protection to residents through

the Civil Rights of Institutionalized Persons Act of 1980.

These protections notwithstanding, the belief that institutional delivery systems were fundamentally flawed gained currency among social activists. This belief reflected a reformulation of principles for building social service systems. Chief among these was the concept of *normalization*, defined by Wolfensberger (1972) as the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (p. 28). This is closely allied to the concept of the least restrictive environment—that the places where people live and work should not restrict their participation in the mainstream of society. Almost all agree that normalization and provision of services in the least restrictive setting are important social goals. As means to achieving these

Editor's Note. This paper is on a very important but controversial topic. The results and the interpretation by the authors do not represent a position taken by *AJMR* or by the American Association on Mental Retardation. Rather, research and commentary on mortality rates in mental retardation are invited by *AJMR*. In all cases, papers submitted will be peer reviewed.—S.R.S.

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Method

Instrument

The source of the study data is the Client Development Evaluation Report (California Department of Developmental Services, 1978). The reliability of this instrument has been investigated elsewhere and considered to be satisfactory (Arias, Ito, & Takagi, 1983; Harris, Eyman, & Mayeda, 1982; Widaman, 1984; Widaman, Stacy, & Borthwick, 1985). A Client Development Evaluation Report is completed annually, and additionally when a client moves to a different placement, for any person receiving services from the California Department of Developmental Services. The report includes a 66-item Evaluation Element grouped into six domains of adaptive skills and behavior: motor and self-care skills together with social, emotional, cognitive, and communication domains.

Sample

The sample consisted of all adults with mental retardation, ages 40 or over, who had received services from the Department of Developmental Services between January 1980 and December 1992. The 40+ age group corresponds to one subgroup of interest, namely older adults; other subgroups, not considered here, include high-risk children (studied in Strauss, Eyman, and Grossman, in press) and younger adults. All persons in the study had been referred to one of the 21 regional centers that contract with the state to provide services to individuals in their area. Approximately 9% of this population, in accordance with the International Classification of Diseases etiology (U.S. Department of Health and Human Services, 1980), were categorized as having Down syndrome. These people were excluded from consideration, as older individuals with Down syndrome are known to have a very different aging pattern from other older persons with mental retardation (Eyman, Call, & White,

1991; Strauss & Eyman, in press; Zigman, Seltzer, & Silverman, 1994) and would require a separate study. Information on deaths was obtained from both Client Development Evaluation Report sources and the California Bureau of Vital Statistics.

In this study the unit of analysis was not an individual person, but rather a *person-year*. A person-year is taken to be the interval between two birthdays. Person-years are included only if there is evidence that the subject was in the Department of Developmental Services system at the beginning of the year and either died or was still in the system at the end. Further details and theoretical justification are provided in the Appendix. The procedure resulted in a set of 105,099 person-years, drawn from 18,362 subjects. The number of years contributed range from one to a maximum of 12, with an average of 5.73. For 92% of subjects, the person-years contributed were consecutive.

Variables

Our primary focus was on the relation of mortality and residence type. We controlled for variables such as age, gender, and levels of functioning as determined from the Client Development Evaluation Report. First, however, we present some descriptive statistics.

Table 1 shows the prevalence rates and mortality rates for selected variables. Each of the original Client Development Evaluation Report adaptive skill items has between four and nine levels, but all were collapsed here to a 3-point scale: the highest level item (score = 2), all intermediate levels (score = 1), and the lowest level (score = 0). This seemed appropriate because the mortality rates (computed as the ratio of number of deaths to number of person-years) proved to be generally rather similar among the intermediate levels, and the grouping substantially improved the discrimination when different variables from the same domain were additively combined. In addition, the

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Table 1
Proportions of Person-Years Classified as High, Intermediate, and Low by Skill Variables and
Corresponding Mortality Rates (in %)

Skill	Person- years	Mortality rates
Motor		
Amulation (3.35)*		
Low: does not walk	12.9	4.2
Intermediate: walks with support/walks steadily alone at least 3.05 m	13.7	2.9
High: walks well alone at least 5.2 m, balances well	73.4	1.3
Rolling and sitting (4.11)		
Low: does not lift head when lying on stomach	1.5	6.6
Intermediate: lifts head when lying on stomach/rolls from side to side or front to back/maintains sitting with minimal support for 2.5 minutes	8.5	4.00
High: assumes and maintains sitting position independently	90.1	1.6
Crawling and standing (3.70)		
Low: does not crawl, creep, or scoot	6.3	5.1
Intermediate: crawls, creeps, or scoots; pulls to standing/stands with support at least 1 minute/or unsteadily alone for 1 minute	16.0	3.1
High: stands well alone, balances well for at least 5 minutes	77.7	1.4
Arm use (4.09)		
Low: no functional use of arm	1.5	6.7
Intermediate: moves arm, but does not extend/or partially extends	10.7	3.1
High: fully extends arm	87.3	1.6
Hand use (4.03)		
Low: no functional use of hand	2.0	6.4
Intermediate: raking motion or grasps/uses thumb and fingers in opposition	16.1	2.7
High: uses fingers independently of each other	81.9	1.6
Self-care		
Eating (4.90)		
Low: does not feed self, must be fed completely	4.6	6.2
Intermediate: attempts to finger feed/finger feeds/feeds self with spoon and fork with spillage	39.6	2.2
High: uses eating utensils with no spillage	55.8	1.3
Toileting (3.81)		
Low: not toilet trained or habit trained	7.5	4.9
Intermediate: habit trained/indicates need/goes by self needs help	26.1	2.5
High: goes to toilet by self, completes by self	66.2	1.3
Bladder control (4.13)		
Low: no control	7.1	5.4
Intermediate: some control/control during day only	18.3	2.0
High: complete control	74.6	1.3
Bowel control (4.13)		
Low: no control	6.7	5.3
Intermediate: some control/control during day only	12.3	3.3
High: complete control	81.1	1.4
Dressing (4.73)		
Low: does not put on any clothes by self	6.6	5.4
Intermediate: cooperates in putting clothes on/puts some on self/puts on clothes but does not do details	42.1	2.2
High: dresses self completely including all fasteners and other details	51.4	1.1
Mental retardation level (1.51)		
Mild	33.1	1.5
Moderate	24.7	1.8
Severe	17.1	2.1
Profound	18.5	2.2
Suspected/other	6.5	2.3
Tube feeding (6.82)		
Has feeding tube	.54	12.4
Does not have feeding tube	99.5	1.8
Placement		
Own home	23.6	1.1
Community care	53.3	1.6
Health facilities	7.1	2.2
Institutions	16.1	1.8

Note. Data are based on the full set of 105,099 person-years. The overall mortality rate (number of deaths divided by number of person-years) was 1.88%. The crude relative risks are the ratios of mortality rates for the highest and lowest categories.

*Numbers in parentheses are crude relative risks.

simple high/intermediate/low scale may be more interpretable and usable by those working with other instruments.

The first variable, ambulation, shows a typical pattern. A substantial majority of individuals were at the highest level, and mortality rose sharply as the level of skill decreased. The relative risk for persons at the highest and lowest levels was 3.36 ($= 4.23/1.26$), suggesting that ambulatory skill is an important predictor. Note, however, that this is a "crude" relative risk, unadjusted for the effect of other variables. The next variable, rolling and sitting, refers to a lower level of skill. Very few of the cases were in the lowest category, and these had a high mortality rate. Again the relative risk is large. Also shown in Table 1 are three other motor skill variables used in subsequent analysis—crawling ability, arm use, and hand use—followed by the five predictors from the self-care domain. All show a similar pattern of association with mortality.

Not shown in Table 1 are the variables from the social, emotional, cognitive, and communication domains. Nearly all of these variables were associated with mortality, but more weakly so than the variables shown in Table 1. Preliminary multivariate modeling indicated that these domains provided little additional predictive information. Severity of mental retardation (Eyman et al., 1990; Eyman, Grossman et al., 1993; Eyman, Olmstead, Grossman, & Call, 1993) is included in Table 1, but it was not an important predictor in the presence of the other variables and, therefore, was not included in the subsequent analysis.

Tube feeding refers to use of either nasogastric or gastrostomy tube. Overall prevalence of tube feeding was 0.5% (Table 1), although the rate was much higher within the most debilitated subgroups. For example, it was 41% in the group of people who were age 70 or over and lacked all the motor skills. Although precise figures are unavailable, it is believed that the great majority (more than 90%) of tube-fed clients are fed by gastrostomy

tube. Such clients generally suffer from chronic difficulties with the swallowing reflex, often in combination with severe cerebral palsy or epilepsy. The crude relative risk associated with tube feeding (see Table 1) is strikingly large. A similar, though less dramatic, result had been noted in a group of children with severe disabilities (Eyman, Olmstead et al., 1993; Kastner et al., 1994). These findings do not demonstrate that tube feeding elevates mortality; to a large extent, the necessity for tube feeding serves as a marker for the presence of serious health problems.

Residential placements were grouped into four categories: own home, community care, health facilities, and institutions. Parent/relative homes were counted as own home. Community care included both small group homes and larger board-and-care facilities serving seven or more people. Health facilities provide intermediate health care. Institutions, now called Developmental Centers in California, are state operated. The most common placement was community care, and health facilities had the highest crude mortality rate (Table 1).

Table 2 stratifies the person-years into four age groups. For each age group, the table shows how the person-years break down according to selected variables. Also shown are the corresponding mortality rates. The first row shows the decline in the proportions by age and the increasing annual mortality rates, although these are difficult to interpret because of the confounding of age and cohort effects (Baltes, Cornelius, & Nesselroade, 1979).

Table 3 is stratified according to the four residence types instead of age groups. As expected, levels of skill are on average much lower in health facilities and institutions than in own home and small group homes. Table 3, interestingly, indicates that the lower mortality in community placement (see Table 1) largely disappeared when just one major factor, such as ambulation, was controlled.

The five motor-skill variables were of roughly comparable predictive value

Table 2
Person-Years

Characteristic
Gender
Male
Female
Ambulation
High: walk
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Table 3
Person-Years

Characteristic
Gender
Male
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Ambulation
High: walk:
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Intermediate
Low: does
Eating
High: uses
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Intermediate
Low: does
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Low: does
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High: goes
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Table 2
Person-Years (N = 105,099) by Age Group and Subject Characteristics

Characteristic	Age groups							
	40-49		50-59		60-69		70+	
	% ^a	Mortality ^a	%	Mortality	%	Mortality	%	Mortality
Gender								
Male	54.7	1.0	52.6	2.0	50.7	3.5	40.8	8.9
Female	45.3	1.0	47.4	1.7	49.4	3.0	59.2	6.4
Ambulation								
High: walks well alone at least 6.10 m, balances well	77.8	.7	74.9	1.4	69.7	3.5	54.2	5.2
Intermediate	12.5	1.5	14.3	2.5	20.1	4.5	30.3	9.2
Low: does not walk	9.7	2.9	10.2	3.9	10.3	6.7	15.5	12.0
Eating								
High: uses eating utensils with no spillage	53.7	.7	55.7	1.3	50.1	2.6	40.7	6.3
Intermediate	36.4	1.1	40.1	2.2	46.3	3.4	53.6	7.6
Low: does not feed self, must be fed completely	4.9	4.2	4.2	6.5	3.7	11.3	5.7	14.6
Rolling and sitting								
High: assumes and maintains sitting position independently	90.5	.8	90.1	1.6	90.4	2.3	63.5	6.8
Intermediate	7.9	2.3	8.5	3.7	8.5	6.6	15.1	10.4
Low: does not lift head when lying on stomach	1.6	5.6	1.4	5.8	1.2	9.9	1.4	15.5
Toileting								
High: goes to toilet by self, completes by self	68.0	.7	67.3	1.2	62.1	2.4	52.9	5.9
Intermediate	24.3	1.3	25.8	2.6	31.0	4.0	36.3	7.8
Low: not toilet trained or habit trained	7.7	2.9	6.8	5.2	6.9	7.9	10.1	13.9

^aBreakdown of person-years. ^bPercentage of annual mortality rate.

Table 3
Person-Years (N = 105,099) Classified by Residence Type and Subject Characteristics

Characteristic	Placement							
	Own home		Community care		Health facility		Institution	
	% ^a	Mortality ^a	%	Mortality	%	Mortality	%	Mortality
Gender								
Male	52.9	1.2	52.9	1.7	51.8	2.1	56.4	1.9
Female	47.2	1.1	47.0	1.5	48.2	2.3	43.6	1.7
Ambulation								
High: walks well alone at least 6.10 m, balances well	84.5	.8	84.2	1.3	43.9	1.8	58.3	1.1
Intermediate	10.7	2.1	13.0	2.9	27.4	2.2	17.3	1.7
Low: does not walk	4.8	4.3	2.3	2.5	28.7	2.8	24.4	3.5
Eating								
High: uses eating utensils with no spillage	80.2	.8	63.3	1.3	25.2	1.9	15.8	.8
Intermediate	17.7	1.9	35.4	2.0	65.3	2.1	69.5	1.5
Low: does not feed self, must be fed completely	2.1	8.1	.8	5.3	9.6	3.7	14.7	4.1
Rolling and sitting								
High: assumes and maintains sitting position independently	95.0	.9	96.9	1.5	73.9	2.1	75.5	1.2
Intermediate	4.3	3.7	3.1	2.4	23.8	2.1	18.5	3.1
Low: does not lift head when lying on stomach	.6	8.7	.2	2.5	2.3	7.1	5.9	5.0
Toileting								
High: goes to toilet by self, completes by self	86.7	.8	79.3	1.3	32.9	1.9	20.2	1.2
Intermediate	11.5	2.8	19.5	2.4	52.6	2.2	51.4	1.3
Low: not toilet trained or habit trained	1.9	7.1	1.2	5.1	14.5	2.8	28.3	3.0

^aBreakdown of person-years. ^bPercentage of annual mortality rate.

and showed substantial intercorrelation. Rather than make a somewhat artificial selection, we preferred to combine the items by summing the five values, resulting in a 10-point motor skills scale. The mortality rates suggested a grouping into four categories 0, 1 to 4, 5 to 9, and 10 rather than a linear scale, a pattern confirmed by subsequent multivariate modeling. The relative risk for the two extreme categories is 8.5. Similarly, the five main self-care variables (Table 1) were transformed to a 10-point scale, which also naturally grouped into the same four homogeneous categories. The five motor skills, not surprisingly, were all positively associated with the five self-care skills, correlations ranged from .37 to .62. The correlation between the summary motor and self-care 4-point scales was .59. This was not so large as to raise serious concerns over multicollinearity in the subsequent modeling.

Statistical Analysis

In this section we offer a relatively non-technical outline of the statistical methods. Further details, together with issues of statistical theory, are provided in the Appendix. As explained there, the modeling procedure, based on person-years data derived from longitudinal repeated observations, is not new. For example, it has been routinely used in the Framingham Heart Study (Cupples, D'Agostino, Anderson, & Kannel, 1988).

Our focus in the present study was on the relation of the outcome variable, survival, to the predictor variables. The latter included residential placement—the variable of main interest—and the covariates, or potential confounding variables: for example, age, gender, motor skills, self-care skills, and tube feeding. It was convenient to treat the data as cross-sectional rather than longitudinal, with the chance of surviving in a given person-year being modeled in terms of residence type and the covariates. Logistic regression (Hosmer & Lemeshow, 1989) was used.

According to this, the logarithm of the odds on survival in a person-year are expressed as a linear function of the various predictor variables. In symbols,

$$\ln(\text{Prob}(\text{Survive})/\text{Prob}(\text{Die}))$$

$$= \beta_0 + \beta_1 \text{Age} + \beta_2 \text{Mobility score} + \dots$$

For binary predictors, such as presence or absence of tube feeding, the logistic regression coefficients give the *odds ratio* for mortality when other variables are controlled (Hosmer & Lemeshow, 1989). Except for age, all predictor variables in the analysis were binary. For the four-category motor-skills variable, three binary variables MOTOR1, MOTOR2, MOTOR3 were constructed, each representing a contrast of one of the three lower levels of motor skill (i.e., 0, 1 to 5, and 6 to 9) against the highest level (10). This fourth level thus serves as referent group.

The residence types were modeled with a binary variable for each of the following: own home, health facilities, and institutions. Each variable represents a contrast with community care, used as referent group here because it was by far the largest (Table 1). The logistic model was developed using standard variable selection techniques (Hosmer & Lemeshow, 1989). The fit of the final model appeared to be satisfactory, according to the Hosmer-Lemeshow test (Lemeshow & Hosmer, 1982).

To provide a graphical comparison of community care and institutional mortality rates at different levels of risk, we partitioned the person-years into eight groups (risk octiles) that were homogeneous with respect to risk. Thus, for example, the first group (lowest risk) consisted largely of person-years where the subject was in his or her early 40s and had optimal mobility and self-care skills. By contrast, a person-year in which the subject was tube fed, immobile, and was 90 years old would fall into the eighth group. This procedure allowed us to graph two quantities across the risk octiles—(a) the fraction of the person-years that were

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Variable
Intercept
Age
Males
Females
Gender
Self1*
Self2*
Self3*
Age*Self1*
Age*Self2
Age*Self3
Feed tube
Motor1*
Motor2
Motor3

Own home*
Health facilities
Institutions*

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lived in each residence type and (b) the mortality rates (number of death divided by number of person years)—separately for each residence type. Details on the construction and statistical theory of the risk octiles is provided in the Appendix.

Results

The main findings of the study are condensed into the logistic regression model of Table 4. This shows only those variables making a substantial contribution. Unlike the relative risks in Table 1, the odds ratios here were corrected for effects of the other risk factors.

Table 4
Logistic Regression Model Predicting Annual Mortality Probability

Variable	Odds ratio*	95% confidence interval for odds ratio* (lower, upper)
Intercept	—	—
Age		
Males	1.070*	(1.06, 1.08)
Females	1.087*	(1.07, 1.10)
Gender	.53	(.33, .84)
Self1*	30.25	(11.96, 75.51)
Self2*	13.04	(6.52, 26.10)
Self3*	3.74	(1.99, 6.99)
Age*Self1*	.96	(.94, .97)
Age*Self2	.97	(.96, .98)
Age*Self3	.98	(.97, .99)
Feed tube	3.12	(2.30, 4.24)
Motor1†	3.25	(2.36, 4.75)
Motor2	1.61	(1.33, 1.95)
Motor3	1.40	(1.25, 1.57)
Own home*	1.00	(.87, 1.16)
Health facilities*	1.04	(.87, 1.25)
Institutions*	.58	(.49, .68)

Note: Based on 105,099 person-years.

* Some odds ratios and confidence intervals are in plain text, rather than bold text, to acknowledge the fact that they lack a natural intuitive interpretation. * Because age interacts with self-care, these figures hold only for the referent self-care group. * Contrast of lowest self-care (lowest level on all 5 scales) with referent group (highest level on all 5 scales). * Contrast of intermediate self-care and referent group. * Interaction term, product of Age and SELF1 indicator variable. † Contrast of lowest motor skill level with referent (highest) level. * Contrast of placement with community care as referent.

The age and gender rows of the table indicate that, other variables held constant, mortality rates increased at 7.0% per year for females and 8.7% per year for

males. Male mortality rates were about equal to female rates at age 40, but were nearly 50% higher by age 65. (It is not surprising that a simple linear age term proved adequate; a mortality rate whose logarithm increases linearly with age corresponds to the classical Gompertz model [Cox & Oakes, 1984], known to fit the age range of roughly 35 to 75 years in many demographic applications [Keyfitz, 1985].)

Tube feeding use was a strong predictor even when other risk factors in the table were taken into account, increasing mortality odds by 3.1. The first motor skill entry in Table 4, MOTOR1, compares the mortality odds for those scoring zero on the motor variable (i.e., lowest level on all five motor items) with the odds for the referent group (full motor skills). The odds ratio, 3.3, indicates a strong predictive effect. The intermediate levels correspond to smaller, but still substantial, odds ratios. The self-care variables show a similar pattern, though an interaction with age was present. (The interaction took the form of a tendency for the differences between the risks associated with the four self-care variables to diminish with increasing age. Note that the odds ratios for the age and self-care interaction terms lack a simple intuitive interpretation; in recognition of this, these quantities are not boldface in Table 4.)

As stated previously, we were primarily interested in the residence variables. Community care (small group homes) was taken as referent group. Odds ratios for both own home and health facilities were estimated at 1.0. As can be seen from Table 4, the 95% confidence intervals indicated no significant mortality differences between these placements and community care. The institution term, however, was highly significant, with the odds ratio of .58 corresponding to a 42% reduction in mortality odds compared to community care. Equivalently, the risk-adjusted odds on dying in a given year were estimated to be 72% higher in the community than in institutions.

Figure 1 shows how the person-

years were distributed among the four residence types, within each of eight homogeneous risk groups. As explained in the Appendix, these risk octiles were derived from the logistic model of Table 3. Institutions had disproportionately many higher risk subjects, which explains their elevated crude mortality rate (Table 1). Figure 2 offers a graphical comparison of

mortality rates in institutions and community care within the risk octiles. As explained in the Appendix, it would not be appropriate to carry out formal statistical tests etc. on the results of Figure 2. Nevertheless the lower mortality in institutions, which was expected from Table 3, seems consistent across the risk spectrum.

Discussion

Our major finding was that the risk-adjusted mortality rates of people with mental retardation were higher in the community than in institutions, regardless of the level of risk. Because the study was observational rather than experimental, this result should be viewed tentatively. It is conceivable that the difference was due to the confounding effect of unobserved variables. This, however, may appear somewhat less likely in view of our finding (not detailed here) that the addition of each mortality predictor to the model tilted the comparison in favor of institutions. For example, the crude mortality rates strongly favored the community (Table 1), but control for a single major risk variable largely canceled this out (Table 3). The findings, moreover, are consistent with those of a corresponding study of children with severe disabilities (Strauss et al., in press).

In this study we do not offer an explanation for the findings. Possible causes of increased mortality in community settings can only be inferred from other sources in the field. However, a significant body of literature exists. Health care in the community is generally considered to be a problem for persons with mental retardation. Shortcomings have been noted regarding Medicaid reimbursement, the lack of trained practitioners, and coordination of care (Crocker & Yankauer, 1987; Garrard, 1982; Kastner & Luckhardt, 1990; Minihan, 1986; Minihan, Dean, & Lyons, 1993; Ziring et al., 1988). Problems noted in a survey of physicians in Maine included poor quality of medical records

and information of diagnosis of physical multiple care patients issues (Ages of pre-residing agnosed heart disease & Kasner & O'Brien Knobbe, found an client in Nathans in ed care, near prevents retardation coordinating more frequent comparison care (Crocker & Yankauer, 1993). E alone or to the fi
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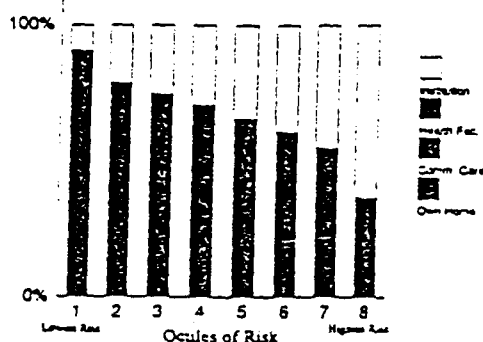


Figure 1. Breakdown of person-years by placement within eight homogeneous risk octiles.

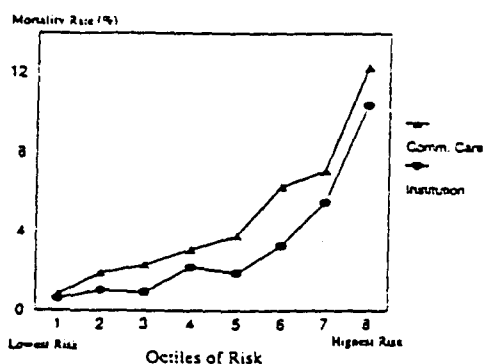


Figure 2. Mortality rates for community care and for institutions within risk octiles. (Using community care as referent population, we directly standardized institution rates). Note that the finding of a 72% increase in mortality in the community refers to the ratio of the odds of dying in a given year. Although the ratios of community to institutional rates appear to vary across the eight groups in the figure, there is no suggestion of any systematic trends in these ratios. As explained in the Appendix, it is not appropriate to base statistical tests or confidence intervals on the results of Figure 2; such procedures are more properly applied to the logistic model itself (Table 4).

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and information; cognitive/verbal limita-
tions of these patients, which hinder di-
agnosis and treatment; difficulty for
physicians in communicating with mul-
tiple caregivers; maladaptive behavior of
patients in office; and potential liability
issues (Minihan et al., 1993). In two stud-
ies of previously institutionalized persons
residing in the community, rates of undi-
agnosed thyroid disease and undiagnosed
heart disease in persons with Down syn-
drome were elevated (Barnett, Friedman,
& Kastner, 1988; Friedman, Kastner, Pond,
& O'Brien, 1989). In another such study
Knobbe, Carey, Rhodes, and Horner (1995)
found an 80% reduction in annual per-
client medical expenditure. Kastner,
Nathanson, and Friedman (1993) exam-
ined causes of 14 deaths in the commu-
nity; nearly half of the deaths were judged
preventable. Finally, persons with mental
retardation lacking access to health care
coordination services required longer and
more frequent hospitalizations than did a
comparable group receiving coordinated
care (Criscione, Walsh, & Kastner, 1995;
Criscione, Kastner, Walsh, & Nathanson,
1993). Each of these weaknesses, either
alone or in combination, could contribute
to the findings of the present study.

Institutions overcome many of these
barriers because they offer a centralized
setting in which provider training, reim-
bursement, record-keeping, and quality
assurance functions are in place. How-
ever, many institutions suffer from profes-
sional isolation, poor morale, and
administrative and financial neglect on the
part of policy makers and advocates. To
an extent, the lack of support for institu-
tions has led to an erosion in their ability
to provide high quality care.

What does this mean for persons
with mental retardation who currently
reside in institutions? There is no certain
answer. Results of the present study do
not allow us to conclude that either insti-
tutional care or community-based care is
superior. Each service system offers
strengths and weaknesses with potential
risks and benefits. The individual needs of

persons with mental retardation vary
greatly, and for some individuals care in
one setting may be more desirable than in
the other. These risks and benefits can
only be understood in the context of an
individual person's needs and their sub-
jective experience of the care received.
The inability to fully quantify these risks
and benefits in an objective fashion has
led to a high level of confusion and
anxiety among consumers, guardians, and
families, which, in turn, has fueled the
vocal public debate over the future of
institutional care.

On the basis of our findings, we
have several recommendations. First, we
recommend a policy of selective deinsti-
tutionalization, as originally proposed in
1974 by the National Association of Super-
intendents of Public Residential Facilities
for the Mentally Retarded and later adopted
in the 1975 Developmentally Disabled
Assistance and Bill of Rights Act (P.L. 94-
103) (Landesman & Butterfield, 1987).
These policies will likely support a con-
tinuing role for institutions in the treat-
ment of some people with mental
retardation. Second, we recommend that
consumers who consider relocation from
institutional settings to the community be
fully informed of the potential risks and
benefits of this choice. Given the limited
knowledge about the likelihood of spe-
cific outcomes in either setting, we believe
that policy makers and advocates should
defer choices of residential care to con-
sumers and professionals. Third, the health
and other service needs of institutional
residents could be evaluated and alterna-
tive placement decisions made dependent
on the availability of adequate access
within the community.

Finally, and most important, we en-
courage additional research to determine
whether the findings of this study are
consistent with experiences in states other
than California. If so, it will be important
to learn the causes of elevated mortality
rates in community settings in order to
improve outcomes. In the meantime, con-

sumers should be allowed to weigh the available evidence against their personal needs, desires, and aspirations.

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APPENDIX

Statistical Issues and Procedural Protocol Related to the Person-Years Analysis

Statistical Modeling

At first sight it may appear attractive to treat the individuals in the study as a cohort and model the survival time in terms of residence type and the covariates, perhaps with a Cox regression (Collett, 1994). There were reasons not to adopt a cohort perspective, however. One issue is that the Client Development Evaluation Reports did not contain precise information on when the client was at risk. One should not "credit" a client for surviving time periods during which he or she may have been out of the service system, so that if death had occurred it would not have been recorded. Second, many clients entered the system after the beginning of the study period or were older than 40 in 1980. In either case there are issues of left censoring, in addition to the more customary right censoring. There were even cases of clients who left the system for several years and then returned. Finally, the focus in this study was entirely on prediction of risk rather

Note. Some of the discussion in this Appendix concerns advanced topics in biostatistics.

than of survival times, so that it was not essential to work with a cohort.

The approach taken here was the standard epidemiological one of analyzing mortality rates in terms of risk factors (Breslow & Day, 1987). Mortality rates were, as is customary, taken to be the number of deaths divided by the number of person-years at risk. One convenient approach to the analysis is through logistic regression on the person-years. If the data had actually been derived from a cohort, this approach would be a version of discrete survival analysis (Cox, 1972; Efron, 1988; Singer & Willett, 1991).

As noted in the *Method*, this procedure is not new (Cupples et al., 1988; Prentice & Gloeckler, 1978). Although we were not working with a cohort, the analysis could alternatively have been carried out with a Cox regression; the results are generally very similar (Prentice & Gloeckler, 1978). As noted by Cupples et al. (1988), the model is based on three assumptions that are important to check, as additional terms would be needed in the model if they were violated. In the context of this study the assumptions are:

1. The "baseline" hazard function does not depend on calendar year.
2. The relation of the risk factors to the mortality does not depend on calendar year.
3. A Markov assumption: only the current risk profile is needed to predict the outcome.

Using additional variables that allow for departures from these assumptions (Cupples et al., 1988; Kahn & Dawber, 1966), we found no suggestion of any such model violations.

Details of Construction of the Person-Years Data

The *i*th person-year means the period between *i*th and (*i*+1)th birthday. The *i*th person-year is included only if a number of conditions are met, such as that the year does not begin in 1992 (reason: incomplete year, because the study period ended on 12/31/92).

The following are rules for deciding which Client Development Evaluation Report should be chosen to represent the *i*th year:

1. If the person has exactly one Client Development Evaluation Report in *i*th year, this report is used.
2. If none, the most recent previous Client Development Evaluation Report or the earliest subsequent one is used—whichever is closest in days to the *i*th year.
3. If more than one, let their times be ordered as
 i th birthday = $t_0 < t_1 < \dots < t_k < t_{k+1}$ = (*i*+1)th birthday or death date.

For $j = 1, \dots, k$, let the *j*th SPAN $s_j = t_{j+1} - t_j$. Rule: pick the *j* with the biggest span. (Reason: it is the most representative)

The Theory and Construction of the Risk-Octiles

We were interested in comparing mortality rates for the various types of residence within groups at different risk levels. It may be, for instance, that relative risks of living in an institution compared to the community are different among individuals who are old and infirm than among those who are young and healthy. For this purpose it was necessary to stratify the person-years into groups that were homogeneous with respect to risk. A familiar strategy for this is simply to stratify (cross-classify) the person-years according to the risk factors, such as age-group, mobility score, presence/absence of tube feeding, etc. As is common in models with many predictors, however, the difficulty here is that

the result will be too many strata containing too few data (Kleinbaum, Kupper, & Morgenstern, 1982).

The procedure followed here was based on that of Miettinen (1976). (a) We computed a logistic regression function that included all the variables, including those for placement (see Table 4). (b) For each person-year, we calculated a predicted mortality probability by substitution into the logistic function, but with all placement variables set to zero. This rank-ordered the person-years according to predicted mortality risk, after adjustment for placement effects. (c) We then partitioned the person-years into eight homogeneous risk octiles. Cut-points were selected so that the expected number of deaths in institutions, computed on the basis of the community care mortality rates, were equal. (Miettinen often preferred five risk groups in his applications. The large data set in the present study was sufficient to support a substantially larger number of strata, however. We judged that in this case it would not be helpful to work with more than eight strata in our application. Also, by using groups with equal numbers of deaths, we ensured that the stratum-specific standard errors were approximately equal.) (d) Finally, we plotted mortality rates for community care and institutions for each risk octile. The rate for institutions was first directly standardized (Fleiss, 1981) with respect to risk, using community care as standard population. (This corrects for bias arising from the fact that even within an octile, the institution person-years tend to be associated with slightly higher risk covariate patterns than do the community person-years.)

It would be tempting to take advantage of the stratification to test for mortality differences between the placements, perhaps using the Mantel-Haenszel procedure (Kleinbaum et al., 1982). It is known, however, that in the present context this is not valid (Pike, Anderson, & Day, 1979). Even less appropriate would be to test the differences separately for each risk group, as this would in addition result in great loss of power. For this reason we followed accepted practice by confining our testing and computation of confidence intervals to the logistic regression modeling (Table 4). See also Breslow and Day (1980) on this point.

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COMPARATIVE MORTALITY IN INSTITUTIONS AND IN THE COMMUNITY:
ADDITIONAL FINDINGS.

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SUMMARY

In previously published research we compared mortality rates of persons with developmental disabilities living in state institutions and in community settings.¹ The population was persons aged 40 or over who received services in California between 1980 and 1992. After adjusting for differences in age, mobility, and other risk factors, we found that mortality was 72% higher in the community than in the institutions. It was noted that the difference may be in the quality of community medical services.

The present report is a brief account of more recent work on the topic. The primary differences are (a) data are reported for the 10-year period 1985-1994, which is substantially more recent than the study period used in Strauss and Kastner (1996); (b) we use much simpler analytic methods that do not rely on statistical modelling; and (c) in the new work we stratify the data into clinically meaningful subgroups, based on the individuals' level of skill.

Using the different methodology, we found that community care in 1985-92 was associated with a 74% increase in mortality--a result strikingly close to the earlier one. This is evidence that the previous result was not an artifact of the statistical procedures. For 1993-94, there was an 82% increase in mortality odds associated with the community. This may be viewed as an independent confirmation of our previous findings, since the 1993-94 data have no overlap with the study period we used in Strauss and Kastner (1996). Further, the 1993-94 experience is relatively recent and is much more representative of the current situation.

¹Strauss, DJ and Kastner, TA (1996). "Comparative mortality of people with mental retardation in institutions and the community." American Journal on Mental Retardation, 101, pp. 26-40.

Introduction

This report is intended as a brief and non-technical summary of our recent extensions to the work of Strauss and Kastner (1996)--hereafter, SK. The reader is referred to SK for full details on the subjects, variables, etc., together with the statistical theory used there. A full account of the present work will be shortly submitted for peer review.

As in SK, the unit of analysis is the person-year. Here we used a simpler definition of person-year, one that yielded about 20% more person-years. Again, person-years lived in the state institutions were compared with those lived in small group homes and other community settings. As in SK, variables taken into account were age, gender, self-care skills, and motor skills. Each of the two skills were coded on a four-point scale: None, Poor, Fair, and Good. See SK for details. The study period was taken to be the 10-year period January 1985 to December 1994, which is substantially more recent than the 1980-92 period considered by SK.²

The report focusses on relative risk, as measured by the odds ratio.³ We are concerned here with the relative risks of dying in a given year in two groups. For example, an odds ratio of 1.0

²It should be noted, however, that our results for the later period are very similar to those derived from the 1980-84 period.

³The odds ratio is the standard epidemiological measure of comparative risk. See, for example, Kleinbaum, Kupper, and Morgenstern (1982). Epidemiological Research. Belmont, CA: Wadsworth.

indicates that the risks in two groups are equal; an odds ratio of 2.5 for group A relative to group B would indicate a 150% higher risk in A than in B.

Results

Since SK had considered data only up to 1992, we stratified the data into two time periods as follows.

Period	Number of Person-years	Odds Ratio ^a (community to institutions)	95% confidence interval
1985-92	97,387	1.74	(1.49, 2.05)
1993-94	31,133	1.82	(1.34, 2.46)
1985-94	128,520	1.75	(1.52, 2.02)

The odds ratio for 1985-92, 1.74, represents a 74% increase in mortality in the community, as compared to the institutions. This is very close to the 72% increase obtained by SK. We emphasize that the present result was based on a simple odds-ratio procedure which involved no statistical modelling. SK, by contrast, employed a more complex logistic regression model. Having carried out literally dozens of analyses on this data, we have in fact found that different models and procedures give virtually identical results.

^aTechnical note. It was necessary to stratify by age, gender, motor skills and self-care skills in these calculations. This was effected with the use of the Mantel-Haenszel estimator (Kleinbaum et al., p. 343). The related statistical tests and procedures that were needed in this connection will not be discussed here.

The odds ratio for the two years 1993-94, 1.82, represents an 82% increase in mortality odds in the community.⁵ This comparison of mortality in institutions and the community is based on data with no overlap at all to that of SK. As such, it represents independent verification of their finding. Further, the time period 1993-94 is closer to the present day than SK's and thus better reflects current conditions.

Finally, we stratified the data into groups according to the subject's score on the most important mortality predictors--the motor-skills and the self-care skills variables. Since each scale has four levels, there are 16 possible categories. Table 1 shows the odds ratios computed separately within each group.

Consider, for example, the upper left cell, which corresponds to subjects with no motor or self-care skills at all. Most of these individuals have profound mental retardation, and some are in a persistent vegetative state. The table shows an odds ratio of 2.46. This means that the persons with no motor or self-care skills and living in the community were about 2.5 times more likely to die in a given year than similar people living in institutions. This is a 146% increase in odds on mortality.⁶ The range given in the table,

⁵This is statistically significant at the 1% level.

⁶It is statistically significant at the 5% level, so that just considering the data on persons with no motor and self-care skills we could conclude that the observed difference was unlikely to be an artifact of chance.

1.05 to 5.76, is a 95% confidence interval. The blanks in the table indicate uncommon combinations where there was insufficient data to warrant the computation of an odds ratio.⁷ For example, there were of course no individuals at all with good self-care skills but lacking all motor skills. In all 10 cases where an odds ratio could reasonably be computed the community death rate was higher, sometimes by a factor of 2.

Conclusion

Using a very different methodology from that of SK and working with a more recent time period, we obtained strikingly similar results to those of the previous study.

⁷ Specifically, we only worked with cells where there were at least three deaths in each residential setting.

Table 1. Odds ratios for the community care relative to institutions, controlling for motor and self-care skills; n=128,520 person-years.

Motor	Self-Care skill level			
	none	poor	fair	good
none	2.46 ^{a,*} (1.05, 5.76) ^b	---- ^c	----	----
poor	1.43 (0.88, 2.32)	2.24 ^{a**} (1.56, 3.22)	1.06 (0.42, 2.64)	----
fair	1.64 (0.42, 6.36)	2.04 ^{a**} (1.50, 2.77)	1.59 ^{a**} (1.13, 2.23)	----
good	----	1.77 ^a (1.06, 2.94)	1.71 ^{a**} (1.25, 2.35)	1.24 (0.64, 2.41)

^aOdds ratio, community relative to institutions, computed with stratification by age and gender groups. Note: * --significantly different from 1.0 at $P < 0.05$; ** -- $P < 0.01$.

^b95% confidence interval for the odds ratio.

^cOdds ratios and confidence intervals are not computed unless there are at least three deaths in both groups, as otherwise the results are highly unstable.

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The Prediction of Mortality in Children with Severe Mental Retardation:
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The Prediction of Mortality in Children with Severe
Mental Retardation: The Effect of Residential Placement

ABSTRACT

Objectives.

To assess the predictors of mortality in severely disabled children with mental retardation, and to compare risk adjusted mortality rates for those living in institutions and in the community.

Methods.

Statistical analysis of a set of 24,469 person-years, derived from a population of all children with severe mental retardation and fragile medical condition who are registered with the California Department of Developmental Services. Variables considered included age, several measures of mobility, presence or absence of tube-feeding, level of retardation, and certain adaptive skills.

Results.

Reduced mobility and the use of tube-feeding were associated with a large increase in mortality risk. Own home residence and community care facilities have an estimated 25% higher risk-adjusted odds on mortality than institutions and health facilities.

Conclusions.

The differential mortality in the placements points to a possible effect of quality of care. One consequence of the current trend towards deinstitutionalization may be an increased mortality rate in children with severe developmental disability.

INTRODUCTION

Numerous studies of people with mental retardation have shown that immobility, in combination with either feeding and toileting difficulties or severe cerebral palsy, is associated with higher mortality.¹⁹ Those in a persistent vegetative state, which includes immobility, are subject to an especially high mortality rate.¹⁰ Although all of these studies have identified mobility and other risk factors as important in predicting survival, no study to date has attempted to compare mortality rates in different residential placements while controlling for such factors simultaneously. In a previous study that controlled for ambulation alone, similar mortality rates in institutions versus the community had been reported.¹¹

Our interest in comparative mortality among different placements derives from studies that report problems with the delivery of medical care to people with developmental disabilities in community settings (primary own home and small group homes).¹²⁻²³ For example, difficulties noted in a survey of physicians in Maine included poor quality of medical records, problems with communicating with multiple caregivers, maladaptive behavior of patients in the office, and potential liability issues.¹⁷ A New Jersey study of the causes of 14 deaths in the community judged that nearly half the deaths were preventable.²¹ Such studies raise the question of whether mortality rates in the community are greater than in facilities such as state institutions, which have the

resources to provide a higher level of medical care. This would have implications for the current trends towards deinstitutionalization, which have resulted in a 60% reduction in the number of clients residing in large institutions in the United States since 1967.²⁴

This paper addresses three questions: 1) What are the most sensitive predictors of mortality, from a large number of potential candidates based on previous research? 2) Does residential placement make a difference in mortality after these risk factors are controlled? 3) If there is such a difference, is it the same for the most medically disabled individuals (at highest risk) compared to those with fewer disabilities?

METHODS AND MATERIALS

Data source.— The subjects were children with severe developmental disabilities who have received services from the California Department of Developmental Services (DDS) between January 1, 1980 and December 31, 1992. All were referred to one of the 21 regional centers contracted by the state to provide services to clients in their geographic area. The regional centers, which are privately owned corporations, coordinate all services including the choice of residential placement.

The data source was the Client Development Evaluation Report (CDER).²⁵ A CDER is completed once per year, and additionally on moving to a new placement, for anyone

receiving services from DDS. The CDER consists of a 100-item Diagnostic Element and a 66-item adaptive behavior Evaluation Element, providing demographic, health, and behavioral data. Information is collected by case workers or psychiatric technicians who have been trained in the use of the instrument. Evaluations are based on personal observations, supplemented where appropriate with interviews with parents. Mortality information was obtained from DDS sources, supplemented by annual computer tapes issued by the California Bureau of Vital Statistics.

The inter-rater reliability of the CDER items employed has been investigated elsewhere,²⁵⁻²⁷ and in recent unpublished work. Reliability, as assessed by Cohen's kappa, exceeded .8 for the motor skills variables and .7 for all the variables used in the analysis here, with the exception of interaction with peers ($\kappa = .60$). The concurrent validity of the CDER adaptive skills items, relative to a shortened version of the American Association on Mental Retardation's Adaptive Behavior Scale, has been judged satisfactory, correlations between the factor scores ranging from .50 to .88.²⁸⁻²⁹ In addition DDS periodically evaluates the CDER information, since it is used to reimburse service providers.

Sample.— As in Eyman et al.,¹² we focused on the severely disabled, medically fragile younger clients. Mortality for this group is much higher than for the more ambulatory robust children, and the patterns of causes of death are very different. In

addition, this target group included virtually all children with profound and severe mental retardation known to regional centers throughout the state. Hence there is no issue of selection bias.

An operational definition of severely disabled and fragile for this study was based on four variables reported in the CDER:

- (1) Crawling or Standing: Cannot pull to a standing position.
- (2) Ambulation: Does not walk.
- (3) Eating: Does not feed self, must be fed completely.
- (4) Toileting: Not toilet trained or habit trained.

We shall refer to these collectively as Condition A. Of the more than 150,000 clients known to DDS and represented by at least one CDER, some 11,000 were children with one or more CDERs meeting Condition A.

A distinctive feature of the study was that the unit of analysis was not an individual person, but instead a person-year. A year was taken to be the interval between two birthdays. To avoid bias, a given person-year was included in the sample only if it was complete: roughly speaking, the conditions are that (1) it meets Condition A, (2) the age is between 2 and 14 inclusive, and (3) there was evidence that the child was in the system from the beginning of the year, and either died or was still in the system at the end. More complete details are available from the first author. Such a procedure was

necessary to exclude time intervals for which the individual was not known to be in the system throughout. An example may clarify the procedure: suppose a child enters the system at age 4 years 6 months and stays in Condition A throughout until death at age 7 years 4 months. Three person-years would be contributed: the complete year between fifth and sixth birthdays, the complete year between sixth and seventh birthdays, and the year beginning at the seventh birthday. The incomplete year preceding the fifth birthday would not be included.

The procedure yielded a set of 24,469 person-years, arising from 7,241 children; not all of the 11,000 children who had one or more CDER's meeting Condition A contributed a complete person-year. Table 1 classifies the subjects by age at first contributed person-year, and by the number of years he or she contributed. The first contributed person-year was at age 2 for about half the children. The majority of the children contributed three or fewer person-years, though a maximum number of 12 is possible. There were in all 1,330 deaths in the 24,469 person-years, for an overall annual mortality rate of 5.44%.

Description of Variables.—Table 2 gives percentage composition and mortality rates for a number of variables reported in the CDER's. The first eight of these were ultimately selected for use in our modeling.

1. Rolling and Sitting. This is a nine-point scale, ranging from "Does not lift head when lying on stomach" to "Assumes and maintains sitting position independently." Coders report the highest level of skill attained. As the table shows, the group at highest risk has a relative risk of about six (10.19/1.73), compared to the group at lowest risk. The importance of mobility as a predictor of mortality has been documented.^{1,3,10}

On the basis of the mortality rates shown in Table 2 for the rolling-and-sitting variable, we chose to collapse it to a new variable MOBIL with four levels as follows:

MOBIL1 = first level of rolling-and-sitting (Cannot lift head)

MOBIL2 = second level (Lifts head when lying on stomach)

MOBIL3 = levels 3-5 (Lifts head and chest when lying on stomach, rolls from side to side, or rolls from front to back)

MOBIL4 = levels 6-9 (Rolls both back to front and front to back, or sits with at most minimal support for at least 5 minutes).

2. Hand Use. We used a simple dichotomy of "No functional use of hand" versus "Uses fingers independently."
3. Crawling and Standing. According to Condition A, only two groups were included in this study. These are "Does not creep, crawl, or scoot" and "Creeps, crawls or scoots without the ability to stand." The crawling variable is thus dichotomous.

4. Tubefeeding. This is an indicator of whether the subject was tubefed; the CDER currently does not distinguish between nasogastric or gastrostomy tubefeeding, but gastrostomy feeding is known to account for the great majority of the instances in this population. Tubefeeding is associated with a markedly higher mortality risk (9.48 to 4.21), with a crude relative risk of 2.25; it was thus an important mortality predictor, as previously noted by Eyman et al.¹³
5. Placement. Placements were grouped into four categories: Own Home, Community Care, Health Facilities, and Institutions. Parent/relative homes were counted as Own Home. Community Care included small homes such as foster care as well as larger board-and-care facilities which serve seven or more people. Health facilities provide intermediate health care. Institutions, now called Developmental Centers in California, are operated by the state. Table 2 shows that the crude mortality rate for institutions (8.74%) was almost double that of the other placements. Skilled nursing facilities were excluded from this study because of complexities involved with time spent in the facility: children are referred to this placement during a serious illness but return to their former placement when improvement is noted. Nearly all the those who remain are chronically ill, with medical conditions that preclude other placement.

In addition, we screened all the remaining variables from the 66-item Evaluative Element of the CDER for mortality prediction. The following three variables emerged as

having some predictive value; all showed the expected rise in mortality rates with increasing disability.

6. Interaction with Peers. This four-point scale was dichotomized according to whether or not the child enters into social interactions. Once again the main contrast in mortality rates was between the lowest level of the scale and the other three. The rate for the former (6.66%) was more than double the rate for the latter.
7. Auditory Perception. This is a seven-point scale that we ultimately dichotomized according to whether the child appeared to distinguish voices from other sounds. Again the relative mortality at the lower level was more than double that at the higher level.
8. Expressive Language. This is a seven-point scale, dichotomized according to whether the child expresses words. The relative risk for this variable also exceeded 2.

-Two other variables that were eventually excluded from the multivariate modelling nevertheless deserve comment:

- (a) Mental Retardation Level.³⁷ Categories are mild (IQ between 50-55 to 70-75), moderate (35-40 to 50-55), severe (20-25 to 35-40) and profound (less than 20-25). California uses an additional category, suspected MR, for those whose level of disability has not been established. It might be expected that the level of

retardation would be an important mortality predictor; as Table 2 suggests and some preliminary modeling confirmed, however, the variable contributed rather little when the others were taken into account.

- (b) Table 2 shows the decline in frequencies (proportion of person-years) with Age. This is partly due to mortality, but mostly to the children whose condition improved enough for them to graduate out of Condition A. As Table 2 shows, the age-specific mortality rate is fairly constant: there was no hint here of the usual decline with age. This suggests that for those who remain in a fragile condition, survival prospects do not improve over time.

Statistical Analysis. It may seem at first sight that a cohort survival analysis, such as a Cox regression,³¹ should be employed here. In fact, however, a cohort perspective would be somewhat inappropriate for a number of reasons: (1) Our observations do not yield survival times in any natural way: subjects are observed only during a 1980-92 window (giving rise to left censoring as well as the usual right censoring), and may move in and out of the "severely disabled" state (Condition A); (2) Special rules were required to determine when the subject is actually in the system, and thus at risk; (3) because the study focussed on the effect of the predictor variables (mobility etc., plus residence) on the hazard rate³² rather than on the duration of survival times, an analysis of hazards was sufficient.

Instead, it was convenient to model the hazards directly in terms of the predictor variables, using logistic regression.³³ Note that if we actually were working with a cohort study, the logistic regression approach here would be a version of discrete survival analysis.³⁴⁻³⁶ The units of the analysis were the 24,469 person-years (reduced to 24,465 because four contained missing values on one or more variables). This logistic modelling of person-year data is closely related to Poisson regression.³⁷ Note that, just as in Poisson regression, no assumption is made regarding independence of the several person-years contributed by a single individual; technically, the individual's contribution to the likelihood function is the product over the person-years of the conditional survival probabilities, the conditioning events being that he is alive at the start of the year.

In general the baseline hazard function (i.e., the mortality probability corresponding to a reference covariate pattern as a function of age, or other "time" variable) depends on both the subject's age and the calendar year. In this instance, however, the hazard analysis showed that:

- (a) There were no discernable trends in the age-specific baseline hazard rates.
- (b) When the age range (2-14) was partitioned into age-groups there were no significant differences between the age group-specific baseline hazard rates.
- (c) There was no evidence of interactions (effect modification) between age-groups and other major predictors.
- (d) No substantial temporal dependencies (i.e., effects associated with the calendar

year) were observed.

In view of this, age and calendar were excluded from the analysis; this implies a constant baseline hazard function.

All covariates used in the models considered were binary. The rolling-and-sitting variable, which had been reduced to four categories as described above, was coded with three binary variables MOBIL1, MOBIL2, and MOBIL3; these are contrasts of the first three categories against the fourth. In this way odds ratios and related quantities are easily obtained (Hosmer DW, Lemeshow S. 1989;38-81). For residence, binary contrasts for each of Community Care, health facilities, and institutions were defined. Own home was taken as the reference group because it was the largest.

Model building and diagnostic analyses were carried out using standard procedures (Hosmer, DW, Lemeshow S. 1989;82-175), including stepwise logistic regression and likelihood ratio testing for groups of two-way and higher interactions. An overall test of the model presented in Table 3 showed no evidence of lack of fit (Hosmer and Lemeshow test,³⁸ $\chi^2 = 3.5$, 8 df; $P = .9$).

In order to compare mortality rates for the different placements within strata that are homogeneous with respect to risk, we adapted the "multivariate confounder score" procedure of Miettinen.³⁹ The logistic regression equation defined by Table 3, but with all

placement variables set to zero, was used to generate a predicted probability of death for each person-year. These probabilities were estimates of risk, adjusted for placement effects. They were then used to rank order all the 24,465 person-years from highest to lowest risk. Next, the person-years were partitioned into eight homogeneous "risk octiles", the boundaries chosen in order to give equal expected numbers of deaths in each. This choice results in approximately equal variances for the octile-specific mortality rates. Finally, we computed and plotted mortality rates for (a) own home and community care, and (b) health facilities and institutions. The latter rate was directly standardized⁴⁰ to adjust for the tendency within each octile for institutions and health facilities to have relatively more person-years with higher risk. (The own home and community group was selected as the standard population because it was the larger of the two.)

RESULTS

The main results are condensed into Table 3, which summarizes a series of logistic regression analyses. Thirteen binary variables were ultimately retained. These fall into three groups: five binary variables for the main effects and interactions of rolling-and-sitting and use of tube-feeding, five for other predictors, and the last three for contrasts between the residence types.

The joint relationship of tube-feeding and rolling-and-sitting to mortality is expressed

in Table 3 by five contrasts against a reference group. The reference group consists of person-years for subjects at lowest risk, i.e., those not tubefed and with the highest level of mobility (MOBIL4, indicating at least full rolling ability and including those with ability to sit). The first variable (TF & MOBIL1) contrasts those who are tubefed and unable to lift their head when lying on their stomach with the reference group. The odds ratio of 4.02 indicates the former group to have about four times higher odds of dying in a given year than the reference group, other variables held constant. This odds ratios may be interpreted as being roughly equal to the relative risk for the two groups.⁴⁰ Those who are tubefed but possess more mobility (TF & MOBIL2,3,4) had 2.64 times the mortality odds of the reference group; this ratio was substantially the same for subjects at all three of the higher levels of the rolling-and-sitting scale.

For those not tubefed, the odds ratio was 2.76 for those who could not lift head (Not TF & MOBIL1); this declined to 1.80 for those who could lift their heads but no more (Not TF & MOBIL2), and to 1.4 for those at the next level (Not TF & MOBIL3). This last group still had significantly higher risk than the reference group. The Hand Use variable was significant; those with no functional use of their hands had an estimated odds ratio of 1.19 compared to those with some hand use. Table 3 shows that those who could not creep, crawl, or scoot had about 40% higher mortality odds than those who could, again underscoring the importance of mobility to survival. The three "adaptive" variables, Interaction with Peers, Auditory Perception, and Expressive Language, also contributed

appreciably to the prediction; absence of any of these skills is accompanied by an increase in odds on mortality of some 20-30%.

The final three rows of the table refer to the placement variables, a major focus of the study. The own home group was used as the reference. The Community Care variable contrasts the mortality of community care with that of own home. Although the odds ratio (1.09) is in the direction of a higher mortality rate than Own Home, it is not significantly different from 1. Both of the other two contrasts, those of health facilities and institutions with own home, are in the direction of a reduced mortality risk. The odds ratios for both of these placements compared to own home, .81, correspond to a 19% reduction in mortality odds. Equivalently, own home is associated with a 23% increase in mortality odds, relative to either health facilities or institutions. Thus the apparently superior mortality rate of own home over institutions observed in Table 2 is actually reversed when the confounding variables are controlled. It may be noted that when own home and community care are combined and the logistic analysis re-computed, the odds on mortality for the combined group exceed those for institutions and health facilities by 25%.

Table 3 shows that the health facilities-own home comparison is on the borderline of statistical significance (odds ratio = .81; $P = 5.6\%$), while the institution-own home comparison results in the same odds ratio, with a P-value of 2.4%. For some purposes we have combined institutions and health facilities since they both represent the higher

levels of medical care, have very similar mortality patterns, and are represented by relatively small sample sizes (see Table 2). The contrast of own home and the combined group is significant at the 1% level (all p-values quoted are two-tailed). This result goes beyond earlier studies which have shown that the lower mortality in own home can be accounted for by controlling for certain predictor variables.^{4,11} In the present study we also compared mortality in the lower level of care placements (own home and community care) with the higher level of care placements (health facilities and institutions), controlling just for the two variables rolling-and-sitting and tube-feeding. This resulted in a set of eight 2x2 placement-mortality tables, not shown here. Even when only these two variables were controlled, health facilities and institutions showed slightly lower mortality ($P = 4.5\%$, Cochran-Mantel-Haenszel test).

It was of interest to compare mortality rates by placement at different levels of risk. As described above, we partitioned the person-years into eight risk-homogeneous groups or "risk octiles." Figure 1 shows the breakdown of the person-years by residential type within the octiles. For clarity, and for reasons discussed earlier, own home and community care have been grouped. In this group the proportions in the octiles decline steadily as the risk increases. As may have been expected, health facilities tend to cater to the higher risk groups, though not the very highest ones. These highest-risk person-years are concentrated in the institutions, which explains the high (unadjusted) mortality rate for institutions noted previously.

Mortality rates are plotted against octiles of risk in Figure 2. For reasons noted above, health facilities and institutions have been combined. Figure 2 shows, for each octile, the mortality rates for the own home and community group, and the health facility and institution group. The pattern of a lower mortality rate for institutions and health facilities appears to be rather consistent across the risk octiles, with no suggestion of a trend.

DISCUSSION

We have identified the functional disabilities that are most predictive of an unfavorable prognosis in a large population of severely disabled and nonambulatory children with mental retardation. All the disabilities are a consequence of devastating neurological deficits. The most important predictors are mobility and the use of a feeding tube. The importance of tube-feeding and mobility had been recognized previously,¹³ but the multivariate analysis resulted in greater refinement of the mobility variables, together with a quantitative assessment of predictive power. For example, Table 3 shows that subjects unable to lift their heads are subject to markedly greater risk than those with this ability. The predictive value of the can/cannot lift head distinction is a new finding that results in substantially improved discrimination.

We have seen that four distinct levels of rolling-and-sitting are associated with

importantly different mortality rates. Other predictors making a contribution are hand use and the abilities to creep, crawl, or scoot, speak intelligible words, recognize voices, and interact with peers. The predictive utility of these variables had also not previously been assessed.

The results of the study can be used in a number of ways. For a given individual with a specific profile of mobility, hand use, tube-feeding, and so on, the logistic regression model presented in Table 3 provides an immediate estimate of the annual mortality rate. Table 3 also identifies some major variables that should be considered for stratification (subdivision) of the population of younger persons with mental retardation before one undertakes life-table or survival analyses. A further use of the model is to identify combinations of covariate values that are similar with respect to their associated hazard levels; in this way one can identify a group of subjects who are at similar risk to a target individual and then, for example, construct a life table for him or her. Finally, the variables identified, together with their odds-ratios, provide an informal guide to the survival prospects of a given individual.

The differential mortality rates among the various placements is noteworthy. The odds on dying for those in their own home or in small group homes are estimated to be 25% higher than the odds for institutions and health facilities, other factors held constant. We have seen that consideration of the crude mortality rates (Table 2), without controlling

for any predictors, would incorrectly point to the opposite conclusion. The issue appears to be a case of spurious association resulting from the excess of higher-risk patients in institutions and health facilities.

The analysis here is based on an observational study not a controlled experiment, and as such yields results that must be judged as tentative. A definitive judgment on whether institutions are "safer" than own homes would require a properly randomized experiment, and this would be ethically infeasible. In the absence of such an experiment it is conceivable that there are confounding factors, not measured here, that somehow favor institutions and health facilities; controlling for these might then change the result. As pointed out by a referee, one way this could happen is through "overcontrolling": if community care resulted in better outcomes for mobility or other functioning than institutional care, then controlling for such factors would introduce a bias against the community placements. We are not aware of any evidence of such placement differences, however. Further, it seems likely that own home placements, for example, vary substantially in quality and quantity of care. To identify the causes of the differences, and to measure their relationship to mortality, are important issues for future work.

On the other hand we have seen that as more variables in the study are statistically controlled, the more the comparison favors the placements with higher level of care. Thus Table 2 showed institutions and health facilities to have the highest mortality rate when

no variables were controlled; when the two major predictors (tube feeding and mobility) were controlled, the comparison slightly favored the institutions and health facilities, being in fact marginally significant; and these placements appeared substantially better in the fully controlled model of Table 3. We have also seen that the institutions were disproportionately represented in the highest risk groups. Variables such as mobility and tube feeding serve as markers for health risk, and if one could control for health risk precisely by including all relevant variables the comparison might be expected to tilt still further towards the higher-care placements.

One explanation for the difference is that the greater access to medical care, and especially emergency care, in these placements is being expressed in a reduced mortality rate. Further study on the causes of deaths, based on examination of medical records, would be helpful here. It would also be of interest to carry out similar studies in states other than California.

Mortality is, of course, only one of a number of outcome measures relevant to the current debate over deinstitutionalization. Other criteria include cost,⁴¹ issues of family cohesion, and the desirability of the least restrictive environment.⁴² Nevertheless, the results here raise the possibility that the trend towards deinstitutionalization is accompanied by increased mortality in children with severe developmental disabilities, as in recent years even highly debilitated children have been moved out into the community.

Parents, guardians, and others concerned with placement decisions may wish to take this into account.

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Table 1- 7,241 Children, classified by age at first contributed person-year and by number of person-years contributed.	
Age at first person-year	Percent
2 yrs	51.1
3 yrs	10.9
4 yrs	7.2
5 yrs	5.0
6 yrs	4.0
7 yrs	3.7
8 yrs	2.8
9 yrs	2.8
10 yrs	2.6
11 yrs	2.6
12 yrs	2.5
13 yrs	2.5
14 yrs	2.4
Number of person-years Contributed	Percent of children contributing that number of person-years
1 yr	30.1
2 yrs	20.4
3 yrs	13.5
4 yrs	9.1
5 yrs	7.2
6 yrs	5.5
7 yrs	4.5
8 yrs	3.5
9 yrs	2.7
10 yrs	2.1
11 yrs	1.2
12 yrs	0.3

Table 2-Percentages of client-years and mortality rates for some CDER variables (n=24,465)		
	<u>Client Years</u> %	<u>Mortality</u> %
ROLLING AND SITTING		
Does not lift head when lying on stomach	25.1	10.19
Lifts head when lying on stomach	22.2	5.37
Lifts head and chest using arm support when lying on stomach	7.1	3.80
Rolls from side to side	9.0	4.25
Rolls from front to back only	6.5	3.42
Rolls from front to back and back to front	14.3	2.40
Maintains sitting position with minimal support for at least five minutes	8.4	2.62
Sits without support for at least five minutes	3.1	2.89
Assumes and maintains sitting position independently	3.3	1.73
HAND USE		
No functional use of hands	45.0	7.85
Has use of hands	55.0	3.46
CRAWLING		
Does not Creep, Crawl or Scoot	83.3	6.87
Creep, Crawls, or Scoots	16.7	2.28
TUBE FED		
No Feeding Tube	23.2	9.48
Has Feeding Tube	76.8	4.21
RESIDENCE TYPE		
Own Home	56.5	4.78
Community Care	14.2	5.35
Health Facility	8.7	4.67
Institution	10.9	8.74

Table 2: Continued

	<u>Client-Years</u> %	<u>Mortality</u> %
INTERACTION WITH PEERS		
Does not have interaction with peers	65.2	6.66
Has interaction with peers	34.8	3.15
AUDITORY PERCEPTION		
Does not react, demonstrates startle, or turns head or eyes to sound source.	48.9	7.30
Responds differently to voices	51.2	3.66
EXPRESSIVE LANGUAGE		
Does not have expressive language	36.8	8.12
Has expressive language	63.2	3.98
MENTAL RETARDATION		
Mild	2.4	4.10
Moderate	5.2	3.63
Severe	21.3	4.00
Profound	48.7	6.31
Not/Suspected	22.1	5.77
AGE		
2 yrs.	15.1	4.68
3 yrs.	12.7	5.85
4 yrs.	10.8	5.94
5 yrs.	9.1	5.85
6 yrs.	8.0	5.08
7 yrs.	7.3	4.62
8 yrs.	6.6	5.78
9 yrs.	6.1	4.57
10 yrs.	5.5	5.47
11 yrs.	5.1	5.51
12 yrs.	4.8	6.34
13 yrs.	4.4	6.28
14 yrs.	4.1	5.46

TABLE 3-Logistic Regression Model for Mortality Probability,
Based on 24,465 Client-Years.

Variable	DF	Odds Ratio ^a	95% Confidence Interval
Intercept	1	0.01**	
TF & MOBIL1 ^b	1	4.02**	(3.12,5.19)
TF & MOBIL2,3,4 ^c	1	2.64**	(2.08,3.35)
NotTF & MOBIL1 ^d	1	2.76**	(2.17,3.51)
NotTF & MOBIL2 ^e	1	1.80**	(1.42,2.28)
NotTF & MOBIL3 ^f	1	1.40**	(1.11,1.78)
Hand Use	1	1.19*	(1.03,1.38)
Crawling	1	1.36*	(1.07,1.71)
Interaction w/Peers	1	1.29**	(1.10,1.50)
Auditory	1	1.21**	(1.06,1.39)
Language	1	1.23**	(1.08,1.40)
Community Care ^g	1	1.09 ^{ns}	(0.92,1.29)
Health Facility ^g	1	0.81 ^{ns}	(0.65,1.01)
Institution ^g	1	0.81*	(0.70,0.94)

* p < .05; ** p < .01.
ns = not significant.

^a Odds Ratios refer to odds on dying in a given year for each designated variable relative to those children in the reference category.

^b Binary variable contrasting those tubefed and unable to lift head when lying on stomach (i.e. MOBIL1) with the reference group. The reference group consists of those not tubefed and at the highest of the four mobility levels, MOBIL4 (i.e., with full rolling ability; see text for complete definition).

^c Contrasts those tubefed but with the ability to lift head when lying on stomach (i.e. MOBIL2, MOBIL3, or MOBIL4) with the reference group.

^d Contrasts those not tubefed and MOBIL1 with the reference group.

^e Contrasts those not tubefed and MOBIL2 with the reference group.

^f Contrasts those not tubefed and MOBIL3 with the reference group.

^g Contrasts with Own Home as reference group.

Figure Captions

Figure 1: Composition by residence type of eight ordered risk groups.

Figure 2: Mortality Rates by Placement.

Figure 1

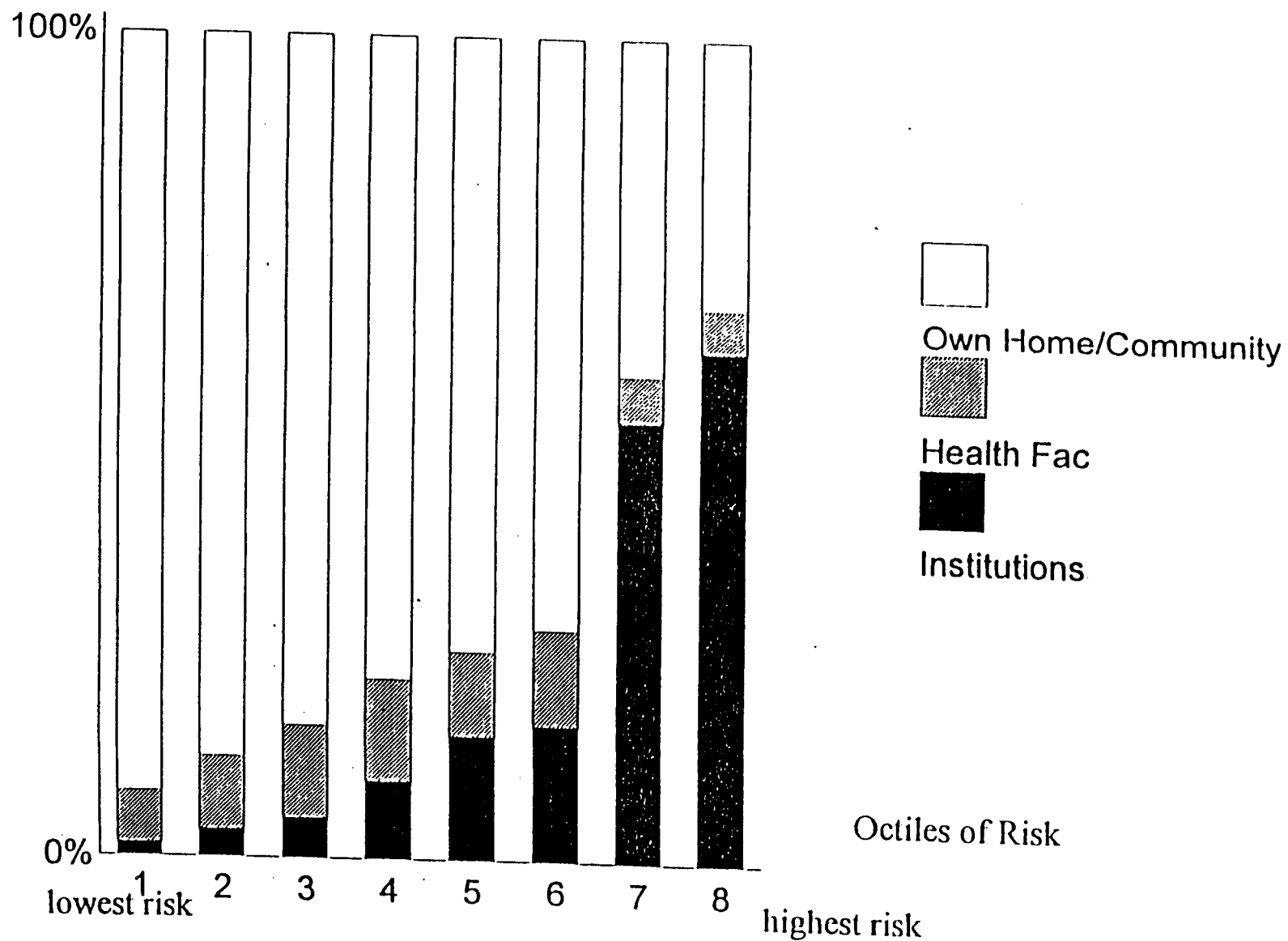
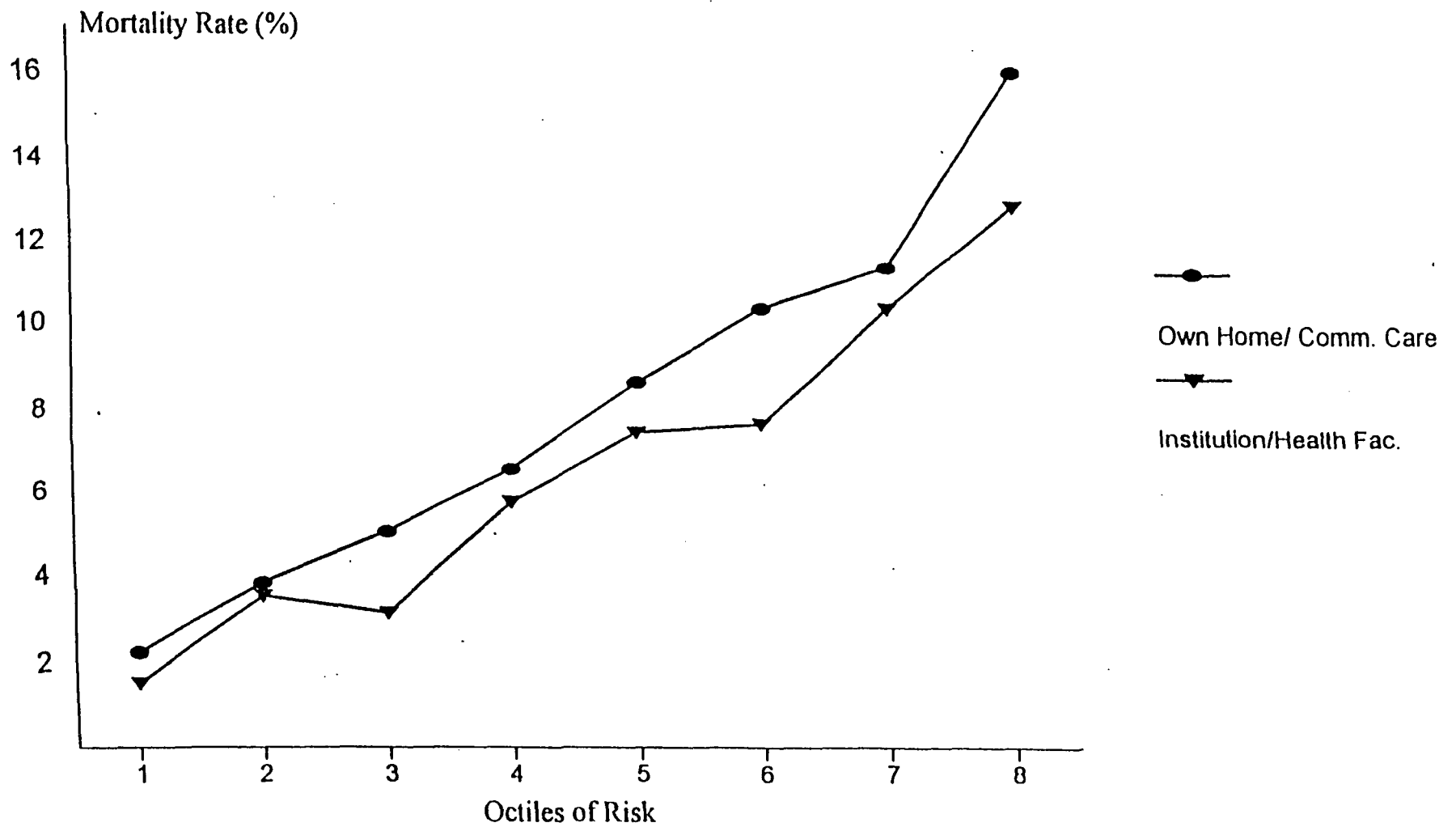
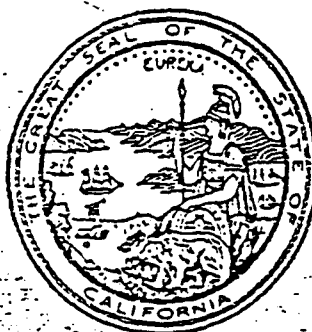


Figure 2



Department of Developmental Services
Correspondence to and from Dr. Strauss

January 1997



DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET
SACRAMENTO, CA 95814
TTY 654-2054
(916) 554-3663



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.

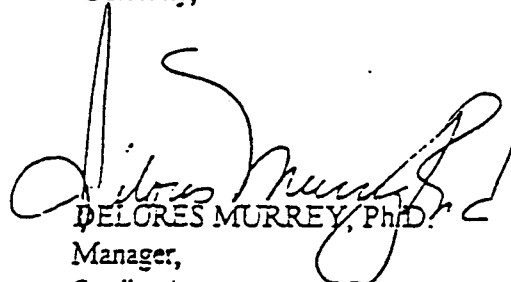
Please provide these data, preferably by December 26, 1995, via floppy disc in Lotus or Ascii, to:

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,



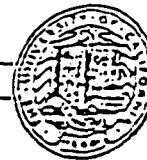
DELORES MURREY, Ph.D.
Manager,
Quality Assurance and Program
Support Branch

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

"Building Partnerships, Supporting Choices"

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SANTA BARBARA • SANTA CRUZ

DEPARTMENT OF STATISTICS
FAX: (909) 737-3226

RIVERSIDE CALIFORNIA 92521-0125

January 4 1996.

Dear Dr. Murray,

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

Sincerely Yours,

A handwritten signature in dark ink, appearing to read "D. Strauss", written over a horizontal line.

David Strauss

Professor of Statistics
Fellow of the American Statistical Association.

JAN 23 1996

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SANTA BARBARA • SANTA CRUZ

School of Education
Riverside, California 92521
(909) 787-5223
FAX: (909) 787-5942

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 dark ink, appearing to read "Richard K. Eymann".

Richard K. Eymann, 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) 554-1953



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.

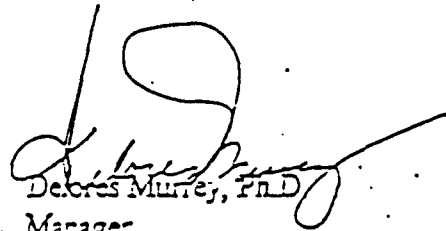
Because the availability of our consultants is very limited, I am requesting that these data be made available by February 9, 1996. Dr. Eyman informed me that competing demands and limited staff resources would impede the provision of the data until after March, so I would like to arrange for one of 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,



Debra 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) 654-1397

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."

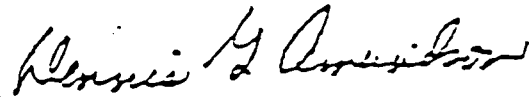
As you know, my Department has enjoyed a longstanding and productive relationship with you and the University, and we have routinely provided you with data for your research endeavors. With this in mind, I am very puzzled by your refusal to grant our request for copies of your original data. While it 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 Eymann
Raymond L. Orbach, Chancellor

DEPARTMENT OF DEVELOPMENTAL SERVICES

1500 9TH STREET
SACRAMENTO, CA 95814
TTY 654-2054
(916) 554-1397



February 6, 1996

Raymond L. Orbach, Chancellor
University of California
4148 Hindenaker 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,

Handwritten signature of Dennis G. Amundson in dark ink.
DENNIS G. AMUNDSON
Director

CC: F. Wilson

UNIVERSITY OF CALIFORNIA, RIVERSIDE

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SANTA BARBARA • SANTA CRUZ

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 dark ink, appearing to read "D. H. Warren", is written over a horizontal line.

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



James E. Hout
GENERAL COUNSEL

March 20, 1996

Michael Mount, Chief Counsel
Department of Developmental Services
1600 Ninth Street
Sacramento, CA 95814

Re: 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."¹

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.²

¹Although 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.

²In 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.³ 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(X)), 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,

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.

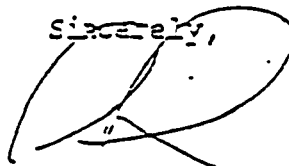
³As I believe you are aware, Professor Strauss has a collaborator and co-author of the manuscript, Dr. Ted Kastner, Medical Director, Morristown Memorial Hospital, New Jersey.

Michael Mount, Chief Counsel
March 20, 1996
Page 3

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

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

Sincerely,

A handwritten signature in dark ink, appearing to be 'Fred Takaniya', written over a large, loopy 'Q' or 'D' shape.

Fred Takaniya
University Counsel

bb

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

⁴I 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

DEPARTMENT OF DEVELOPMENTAL SERVICES

1600 9TH STREET
SACRAMENTO, CA 95814
TTY 554-2054
(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,

~~AMUNDSON, DENNIS G.~~
~~DENNIS G. AMUNDSON~~
DENNIS G. AMUNDSON
Director

Enclosures

Same Letter Sent to:

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

cc: Douglas Arnold
Paul Carleton
Doug Van Meter
Eileen Cassidy
Mike Mount
Harold Pitchford
Deiores Murtey
Ken Buono

Memorandum

TO : Michael Mount, Chief Counsel
Department of Developmental Services
1600 P Street
Sacramento, CA 95814

Date : May 15, 1996

Telephone: CALNET (31) 531-6344
(415) 356-6344
FACSIMILE: (415) 356-6257

FROM : BEVERLEY R. MEYERS 
Deputy Attorney General
Health, Education & Welfare
Office of the Attorney General - San Francisco

SUBJECT: University of California -- Records request from Professor David Strauss

QUESTION PRESENTED AND BRIEF ANSWER

I am writing in response to Director of the Department of Developmental Services (Department) Dennis G. Amundson's request to obtain the core data and study methodology underlying Professor David Strauss' manuscript/article "Comparative Mortality of People with Developmental Disabilities in Institutions and the Community". My understanding is that if the Department wished to file a lawsuit to obtain this information, we would have to receive the approval of the Governor's Office as well as the Attorney General's Office. At this time, based upon the research that I have conducted so far, I do not recommend filing a lawsuit, but instead pursuing a Freedom of Information Act (FOIA) request, and post-publication requests from the American Journal on Mental Retardation, and author directly. According to the March 20, 1996 letter from University of California counsel representing Professor Strauss, the American Journal on Mental Retardation will publish the article in its July 1996 edition.

THE DEPARTMENT CAN OBTAIN MUCH IF NOT ALL OF THE INFORMATION SOUGHT BY MEANS OTHER THAN A LAWSUIT.

I spoke with Dr. John Krueger ((301) 443-5330) at the National Institute of Health (NIH), Division of Research Investigations, Office of Research Integrity, who informed me that it was advisable to contact the journal that would be

1.

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publishing Dr. Strauss' article, and seek Dr. Strauss' underlying data and methodology that way because many journals require that certain information be available for disclosure as part of their pre-publication criteria. I was informed by both Dr. Krueger and attorney, Barbara Bowman, NIH, Division of Policy and Education, that the general rule is that if a grant is funded, then such items as the grant application, the grant itself, protocols, and progress reports would be available pursuant to the FOIA.¹ (See *SEITA UNC-CH, Inc., v. Haffines* (1991) 101 N.C.App. 292, 399 S.E.2d 340, 341, citing 5 USC § 552, et seq.) I spoke directly with Carol Florence at the NIH who actually handles the FOIA requests, and confirmed that we should ask for these items and direct the request to her. (Her phone number is (301) 496-5133, and fax number is (301) 496-7101.) With the Department's permission, I would like to send the enclosed letter, making the FOIA request on behalf of the Department. Please advise whether the Department wishes that I send the letter.

Concerning publication in the July 1996 American Journal on Mental Retardation, I contacted the editor, Professor Steve Schroeder, University of Kansas ((913) 864-4295). He indicated that the Journal has no pre-publication disclosure requirements as a condition of publication. He did read me his April 4, 1996 letter to Director Amundson, in which he stated that he would publish Dr. Strauss' article on schedule, but with a footnote disclaimer inviting research and alternative views on this topic. He indicated also that he read the Department's reviewers' comments with interest, and would encourage them to submit either a regular research article on an updated data set from the CDER database or to recast their remarks into a reader's reaction format. Dr. Schroeder mentioned that he spoke to both Dr. Strauss and his collaborator, Dr. Kastner regarding the Director's March 26, 1996 letter, and that Dr. Kastner indicated he would disclose the raw data and protocol, but Dr. Strauss would not agree to do so. Dr. Schroeder said that it is customary in the psychology field to disclose the complete data

1. (See also, *Forsham v. Califano* (D.C. 1978) 587 F.2d 1128, 1137 ("Scientists engaged in research on federal grants must accept the fact that any documents filed with the federal government, whether on the scientists' own initiative or an audit or other lawful demand, are subject to the FOIA.")

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set, i.e., raw data and protocol after publication, but that the Journal did not have this requirement.

THE LAW DOES NOT SUPPORT AN ABSOLUTE RIGHT TO THE INFORMATION SOUGHT.

A. Should We Pursue a Lawsuit? We Would Do So Under the California Public Records Act.

The first question is which vehicle would we use to seek the raw data, methodology, analysis, and results of Dr. Strauss' study. The choices appear to be the federal FOIA or California Public Records Act. We must initially rule out the FOIA because we are not seeking information from a federal agency, but instead from a state agency, UC Riverside. Pursuant to the FOIA, 5 USC § 552, requests are directed to an "agency" of the Federal Government. Specifically, agency is defined in 5 USC § 552(1) as "any executive department, military department, Government corporation, Government controlled corporation, or other establishment in the executive branch of the Government (including the Executive Office of the President), or any independent regulatory agency". Since our current request is to the University of California, which is not a Federal agency, then it is not subject to the FOIA. (See *Progressive Animal Welfare Society v. University of Washington* (1994) 125 Wash.2d 243, 884 P.2d 592, 605.) On the other hand, if the NIH did not honor our request, the NIH, a Federal agency, would be subject to suit under the FOIA. (See *Forshan v. Califano* (D.C. 1978) 587 F.2d 1126, 1131, 1135.)

Our ability to sue then is governed by the California Public Records Act. I would agree with the University's counsel that the inquiry is based upon Government Code section 6254, et seq., the Public Records Act. Section 6254(k) exempts from disclosure "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". Section 6255 exempts from disclosure records to which "the public interest served by not making the record public clearly outweighs the public interest served by disclosure of the record." I have been unable to find any California case law specifically interpreting these code sections in the context of academic integrity, the principal reason raised by the University for non-disclosure.

3. It is Unclear Whether We Could Ultimately Prevail in a Lawsuit.

In construing the "memorandum" exemption which protects deliberative materials produced in the process of making agency decisions, but not factual materials pursuant to Government Code § 6254(a), an exemption not at issue here, a California Court of Appeal construed the California Public Records Act here as having essentially the same purpose of the FOIA regarding deliberative memoranda. (*California for a Better Environment v. Department of Food & Agriculture* (1985) 171 Cal.App.3d 704, 711.) The Court said a reviewing court may look to the reasoning of the analogous federal case law in construing this particular subsection. (*Id.* at pp. 712-13.) Since there is no California case law directly on point, it would appear that a California court would look to federal law to construe the claim of academic integrity as a bar to disclosure. I note also that using *California for a Better Environment*, we could certainly argue that the University should be required to disclose the raw data it used underlying the article. The problem in citing this case is that the University could argue, by analogy, that any documentation reflecting Dr. Strauss' "deliberative process" should not be disclosed."

In *Forsham v. Califano*, *supra* at p.1181, plaintiffs, specialists in the treatment of diabetes sought to obtain the raw data of the University Group Diabetes Program, because the plaintiffs, questioned the validity of the study. The findings had been published in the Journal of the American Diabetes Association. Plaintiffs made a series of FOIA requests for the raw data through the federal agencies sponsoring the grants. The Court held that "the public at large does not have a right under the Freedom of Information Act to the underlying raw data in the hands of the investigators and university groups who

2. (Cf. *Times Mirror Co. v. Superior Court* (1991) 53 Cal.3d 1325, 1339-42 (Under the "deliberative process" exemption to disclosure of public records (Gov. Code § 6254(a)), the key question is whether the disclosure of materials would expose an agency's decisionmaking process in such a way as to discourage candid discussion within the agency. Even if a document's content is purely factual, it is exempt from disclosure if it is related to the process by which policies are formulated or inextricably intertwined with the policy making process.)

conducted the UGDP study program on diabetes under grants from the federal government." (Id. at p.1133.) Since the federal agencies did not have the raw data, they were not required to acquire it from the investigators. One helpful point made by the Court was "the Freedom of Information Act does not depend on a showing of need or interest by the particular applicant for the records. Any showing of need is irrelevant." (Id. at p.1134.)

In *Progressive Animal Welfare Society v. University of Washington* (1995 Wash.Sup.Ct.) 884 P.2d 592, the Washington Supreme Court construed Washington's Public Disclosure Act. Unlike California's Act, Washington had a provision exempting raw data, and similar to California, had a subsection exempting information that fell within the "deliberative process" of an agency. (RCW § 42.17.310(1)(h) & (1)(i).) An issue was whether information in a university's researcher's unfunded grant proposal involving use of animals in scientific research must be disclosed. (Id. at p.595.) The trial court did not order disclosed material which might reveal valuable formulae, designs, drawings and research data, trade secrets, or other confidential information. The apparent basis of the court's decision was the provision exempting raw data from disclosure.³ (Id. at p.596.) As to the deliberative process exemption, the court concluded that:

"unless disclosure would reveal and expose the deliberative process, as distinct from the facts upon which a decision is based, the exemption does not apply. [Citations.] In order to rely on this exemption, an agency must show that the records contain predecisional opinions or recommendations of subordinates expressed as part of the deliberative process, that disclosure would inhibit the flow of recommendations, observations, and opinions; and finally, that the materials covered by the exemption reflect policy recommendations and opinions and not the raw factual data on which a decision is based. [Citation.] Subjective evaluations are not exempt under this provision if they are treated as raw factual data and are not subject to further deliberation and

3. The court said the purpose of this provision was to prevent private persons from using the Act to appropriate potentially valuable intellectual property for private gain. (Id. at p.599.)

consideration. [Citation.] Once the policies or recommendations are implemented, the records cease to be protected under this exemption." (Id. at p.600.)

Although the University in our case has not articulated the deliberative process privilege so far, I would expect them to do so in any future litigation. And, it would appear that should a California court look to the analysis of this Washington case, it could be inclined to find the deliberative process exemption in California Government Code § 6254(a) applicable. Therefore, the court could rule that prior to publication, the protocols or extrapolation of the raw data would not be discoverable.

As to raw data, it would appear that we would be entitled to that pre-publication. (Cf. *University of Washington*, supra, p.600, n.5 (merely raw data contained in NIH peer review written evaluations ("pink sheets"), not covered by any other exemption, are discoverable even where the grant proposal remains unfunded).) My understanding is that this information, e.g., the raw data, has already been available to us, since in large part, we generated it. It appears that what is critical to us is obtaining Drs. Strauss' and Kastner's protocols. This case, *University of Washington*, does not provide authority to advocate disclosure of this information.

C. Academic Freedom is a Questionable Basis for Withholding Documents. Nevertheless, a Lack of a Qualified Privilege Does Not Require Disclosure.

The various courts seem reluctant to acknowledge an actual privilege for academic freedom or a "researcher's privilege". Nonetheless, even if a privilege is acknowledged, it is a qualified one that is used in balancing whether to provide the information. Although there does not seem to be the acceptance of such a privilege, per se, in California (or elsewhere), courts may still deny disclosure. And, it seems, in our case, the deliberative privilege would still deny disclosure of protocols, etc. pre-publication of Dr. Strauss' article.

Concerning the University of Washington's claim of academic freedom, in *University of Washington*, supra, the Washington Supreme Court found none in this context. The Court said:

"[e]ven if it did apply, we are not convinced the extension of freedom of speech doctrine advocated by the University is

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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 371, 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.⁴ We see

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

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no constitutionally compelling reason to do so." (Id. at p.603.)

Accordingly, this logic, although not binding, could be persuasive in our case. I would not expect a court to find an actual academic freedom privilege in our case. However, a court could still limit disclosure until after publication using the deliberative privilege.

In the only California case remotely on point, *Scharf v. Regents of the University of California* (1991) 234 Cal.App.3d 1393, petitioners challenged the process of academic peer review for tenure employed by the University of California, which in pertinent part, included consideration of confidential information that was not made available to the professor applicant. The court upheld the statutes at issue based upon this facial challenge. The court noted that California cases describe the university's need for confidentiality in the tenure

Sinai School of Medicine v. American Tobacco Co. (2nd Cir. 1989) 880 F.2d 1520, 1528 - 1530 which relied upon *Dow Chemical*, supra, (The Second Circuit Court of Appeals affirmed the District Court's order requiring disclosure of redacted information in studies determining that cigarette smoking may cause cancer and smoking in conjunction with exposure to asbestos increase the risk of causing cancer geometrically rather than arithmetically. The Seventh Circuit has recognized a qualified privilege to protect scholars from the premature disclosure of their research, or prior to publication. (Id. at p.1528.) (But see, *Wilkinson v. FBI* (C.D.Cal. 1986) 111 F.R.D. 432, 440 - 443 (This Central California District Court discussed the "researcher's privilege", concluding that based upon the facts before the court, it was unnecessary to determine whether the researcher's privilege or academic freedom privilege should be recognized in this case. Plaintiffs were seeking to assert an "archival privilege", i.e., whether placing records in an archive can exempt them from disclosure. The court concluded that it did not.)

Indeed, in *S.E.T.A. INC.-CH., INC. v. Huffines* (1992) 420 S.E.2d 674, 445-446, the court concluded that it was not clear in 1989, when respondent asserted "academic freedom" as a justification for nondisclosure that this was unreasonable. Huffines then cites *University of Pennsylvania*, supra, for the proposition that no such privilege exists now.

process to prevail over the interest in disclosure of information pertaining to a single individual. (Id. at p.1409.) Reaching this conclusion, the court cited *Kahn v. Superior Court* (1987) 188 Cal.App.3d 752, 769 - 770 in which that court stated:

"Even though 'academic freedom' may be used to shield nonacademic and insidious motives for denying tenure [,] ... in California the fostering of academic excellence finds support in the constitutional right of privacy." (Id.)

It does not appear that these cases are on point or helpful in terms of arguing that California case law compels pre-publication disclosure of such deliberative processes as protocols. If anything, they compel the opposite conclusion.

The court did quote the U.S. Supreme Court case of *University of Pennsylvania v. EEOC*, supra, stating:

"Finding that there is neither a qualified common law privilege against disclosure of confidential peer review materials nor a First Amendment right of 'academic freedom' against disclosure of such documents, the Supreme Court held that a university does not enjoy a special privilege requiring a judicial finding of particularized necessity of access beyond a showing of mere relevance, before peer review materials pertinent to charges of discrimination in tenure decisions are disclosed to the government agency charged with enforcing title VII. In the course of reaching this result the court expressed doubt about the validity of the claim that confidentiality is essential to the achievement of academic excellence....The foregoing language simply expressed the view of the court that the disclosure of materials relevant to charges of racial or sexual discrimination will not likely be as harmful to academic interests as had been claimed." (Id. at pp.1410-1411.)

It thus appears that a California court has recognized the absence of an academic privilege in the tenure review context. We could argue, by analogy, that no such privilege should exist in the research context.

In a 1991 North Carolina Court of Appeals case, plaintiffs sought applications for approval for four experiments submitted for review to the Institutional Animal Care and Use Committee from the University of North Carolina. (*SEER UNC-CH, Inc., v.*

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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 euthanized 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, *SEHA 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.

EFM:
Encl.

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

UCRVCCLMEX

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DANIEL E. LUNGREN
Attorney General

State of California
DEPARTMENT OF JUSTICE



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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 Eymann, 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

Carol Florence
May 15, 1996
Page 2

of peer review groups. Apparently, funding for the article, was at least in part, granted by the National Institute of Child Health and Human Development.

You had indicated that from the date of the request, your Office ordinarily takes about 6 to 10 weeks to provide the information requested.

I thank-you for your time and attention. Should you have any questions or require additional information, please feel free to call me.

Sincerely,

DANIEL E. LUNGREN
Attorney General

BEVERLEY R. MEYERS
Deputy Attorney General

BRM

UCRVPOLR2



National Institutes of Health
Bethesda, Maryland 20892

July 19, 1996

Ms. Beverley R. Meyers
Deputy Attorney General
State of California
Department of Justice
50 Fremont Street, Suite 300
San Francisco, California 94105-2239

Dear Ms. Meyers:

Please excuse my tardy response to your Freedom of Information request.

I have enclosed the most current (years 07 and 08) funded grant years: awards summary statements, progress reviews/reports) for Dr. Richard K. Eyman's grant entitled, "Life Expectancy of Mentally Retarded People." If you would like earlier years, please let me know.

Dr. David Strauss has been named the new P.I. for this grant. This is reflected on the current year, 09, which has not been funded at the present time. I will know more about whether the 09 year will be funded after our October Council meets. You may wish to make inquiry at that time.

If I can be of further assistance to you, please contact me at your convenience.

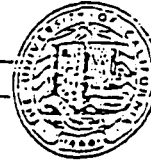
Sincerely yours,

Carol M. Fiorance
Freedom of Information Coordinator
National Institute of Child Health
and Human Development

Enclosure

UNIVERSITY OF CALIFORNIA, RIVERSIDE

BERKELEY • DAVIS • IRVINE • LOS ANGELES • RIVERSIDE • SAN DIEGO • SAN FRANCISCO



SANTA BARBARA • SANTA CRUZ

DEPARTMENT OF STATISTICS
FAX: (909) 757-3236

RIVERSIDE, CALIFORNIA 92521-3123

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,

A handwritten signature in dark ink, appearing to read "D. Strauss", is written over a horizontal line.

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

/cont.

(letter to Mr. Dennis Amundson, page 2)

c. Dr. F. De La Cruz, NICHHD
Dr. Richard Eymann, UCR
Dr. Ted Kastner
Joseph Preston, CASEPCR
Dr. Steven Schroeder, AJMR
Ronald Smith, ARC
Polly Spare, VOR
Fred Takeniya, UC Counsel's Office
Dr. David Warren, UCR
Dan Western, CAPT

Notes from Voice Mail from Dr. Strauss:

David Strauss called Saturday, October 13, 1996 to relay his terms for the proposed statistics lab site visit. Before the visits takes place, Dr. Strauss asked that:

1. Since the visit is a "public interest service," neither he nor the visiting expert be paid.
2. Dept must agree that the report by the visiting expert be "immediately available" to UCR.
3. For the sake of "closure" Dr. Strauss is requesting "written assurance" that the Dept will "stand by" the findings of the expert visitor.
4. Lastly, Dr. Strauss, reflecting the thinking of his "group", suggested that because the Strauss and Kastner article was reviewed by 10 unpaid, independent, and neutral peer reviewers, representing three separate journals, who all agreed on the methodological soundness of the study, there really is no "reasonable issue" to debate. Can't we go forward?

DEPARTMENT OF DEVELOPMENTAL SERVICES

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

October 16, 1996

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

Dear Dr. Strauss:

Thank you for your letter of September 5, 1996, responding to our request for your original data files and calculations used in the article "Comparative Mortality of People with Mental Retardation in Institutions and the Community." We are in receipt of the magnetic tape in the form of a SAS data file. As you are aware, we cannot read, use, or verify the contents of the tape because an eight-millimeter tape is incompatible with our equipment. I have been unable to access the contents of the tape, therefore, the information contained on the tape has not been useful to us in reviewing the findings in your article. We are processing the necessary paper work to reimburse you for reformatting the eight-millimeter tape into a compatible program that we can access with our equipment.

After we have received a usable form of the data, Department staff and a qualified statistician of the Department's choice will be in touch with you to decide a convenient time to visit the University of California, Riverside (UCR) computer center. The purpose of that visit is to understand the statistical procedures used in your study so that an independent review can be completed. Thank you for agreeing to share the calculations used in the above article. A staff member will be in contact with you to arrange for the transfer of the data and establishment of a visit to UCR to review your procedures.

If you have any questions, please contact Delores Murrey, Ph.D. at (916) 654-3663.

Cordially,



DENNIS G. AMUNDSON
Director

DEPARTMENT OF DEVELOPMENTAL SERVICES

1500 9TH STREET
SACRAMENTO, CA 95814
(916) 225-2054
31. 21897



November 22, 1996

David Strauss, Ph.D.
Department of Statistics, Room 2638
University of California
Riverside, CA 92521-0158

Dear Dr. Strauss:

The Department of Developmental Services (Department) received the computer tapes which, according to your assistant, Robert Shavelle, Ph.D., contain CDER data used in the analysis for your article "Comparative Mortality of People with Mental Retardation in Institutions and the Community." The invoice for \$975 was received on October 23, 1996, and payment was mailed on November 18, 1996.

It is nearly a year since we began our attempt to collaborate with you to understand the specific details of deaths reported in your article. I would like to set the record straight regarding the Department's view of your research. Although we are frustrated by your resistance to share information with us regarding the deaths reported in your article, we in no way question the integrity of your research or credentials. Specifically, we are perplexed by your assertions, both publicly, and privately to our staff, that you are willing to cooperate while at the same time the Department's efforts to initiate collaboration are continually thwarted.

In your letter of September 5, 1996, regarding the Department's request for assistance in understanding the calculations reported in the above article, you indicated a willingness "to conduct and display any analysis" that interested the Department. In a letter dated October 16, 1996, the Department accepted your invitation and agreed to visit your statistics laboratory. Preparations included finding a suitable consultant, establishing a funding mechanism, and preparing questions for discussion.

When I learned that you amended your invitation to include several prerequisite conditions, I and my staff, were baffled. As I understand those conditions, you insist that neither you nor the Department's epidemiological consultant be paid, that you have "immediate access" to the consultant's findings and that you be given, in advance, a "written assurance" that the Department "standby" the consultant's findings regarding the calculations used in your study. These prerequisites are not congruous with the Department's purpose and interest in visiting the University of California, Riverside statistics laboratory. For one thing, it is unrealistic to expect that an expert epidemiologist would work for the Department for free. Demanding "written assurance" from the Department regarding its actions in this matter fosters an atmosphere of distrust and is a highly unusual demand in the context of professional collaboration. I repeat that

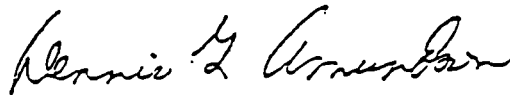
"Building Partnerships. Supporting Choices"

the sole purpose of our visit is to understand the real implications of your study and to discover the tangible steps the Department could take, if indicated, to reduce consumer risk.

The Department is committed to finding ways to improve the quality of life for its consumers. In that regard, we are interested in examining the specific circumstances of the consumers' deaths reported in your article. After you retracted your invitation for a visit to UCR, Department staff, on October 30, 1996, asked you if you would share the UCI numbers for each deceased consumer in your study. They have subsequently informed me that you declined to supply the Department with a list of the UCI numbers. Your refusal to supply the UCI numbers is paradoxical because of your recent comment to one of our staff that you wanted to work cooperatively with the Department. Your willingness to share the UCI numbers, which are crucial to the Department's effort to identify the specific cause(s) and circumstances of consumer deaths, would signal a genuine willingness to work cooperatively with the Department on this problem. The Department is eager to move forward in determining where and how suspected risk factors operate. Are you interested in collaborating with the Department? If so, I would appreciate a timely response to our request for information.

If you have any questions, please contact Delores Murry, Ph.D., at (916) 654-3663.

Sincerely,



DENNIS G. AMUNDSON
Director