

Department of Developmental Services
Other Correspondence and Articles
January 1997





CASH / PCR

California Association of State Hospital Parent Councils for the Retarded

November 13, 1996

Dennis Amundson
Director
Department of Developmental Services
1600 Ninth Street
Sacramento, California 95814

Dear Mr. Amundson:

Thank you for speaking at the Advisory Council meeting Tuesday, November 5, at Agnews Developmental Center. I am deeply concerned about what you said regarding the recently published Strauss/Kastner study, "Comparative Mortality."

As you will recall, I asked if your office had taken advantage of Dr. Strauss' offer to visit and review the original data drawn from DDS records. (The letter offering these services is attached.)

In response to my question, you said your office had just the previous day gone to Dr. Strauss' office and had been completely rebuffed. In follow-up, I am now shocked to learn from Dr. Strauss and his staff that this is simply not true. Your representatives have yet to take advantage of his offer. ✓

We certainly can make room for understanding your attack on Dr. Strauss' study. It is genuinely upsetting to us all. However, your personal attack on his credentials is irrelevant to the fundamental issue regarding comparative mortality rates. Falsely representing to the assembled parents and staff at Agnews that you confronted Dr. Strauss and were rebuffed is unconscionable.

You must know that Dr. Strauss is highly regarded by his peers. He is a Fellow of the American Statistical Association, and has published numerous articles over his illustrious career. The article you find so distressing underwent a scrupulous peer review by the *American Journal on Mental Retardation* prior to its publication in July. He and Dr. Kastner have no motive to distort the facts.

We, the parents of retarded children, are perplexed by your fervent denunciation of Drs. Strauss and Kastner's research. The primary data for this research was, may I remind you, obtained from DDS records. That this study casts the Centers, for which you are responsible, in a light more favorable than community care facilities, may be different from what you had hoped. But, it is not a legitimate reason for attempting to discredit Dr. Strauss personally.

Amundson
Page 2

Furthermore, we are amazed that following your unrelenting attempts to access the report's data while under peer review, you have yet to act on Strauss' September 5 offer. We trust that you will do so without delay. Your delay is even more baffling in light of your efforts through the Attorney General to extract the data. Honest and careful evaluation of the report on its merits could help restore the Department's credibility with parents.

Regarding your apparent misstatement to us on November 5, we await your explanation. We must be able to rely on the credibility of State officials – *where else can we turn?* Should you require confirmation of your remarks, KNTV San Jose should be able to assist.

Sincerely,



Robert Cross
Vice President
CASH/PCR

cc: Governor Pete Wilson
Lieutenant Governor Gray Davis
Sandra R. Smoley, Secretary, Health and Welfare Agency
Robert Schladale, Asst. Sec., Health and Welfare Agency
Senator Mike Thompson
Assemblyman Gary Miller
Dr. David Strauss
Dr. Theodore Kastner
Outreach, CAPT
Roz Plater, KNTV
Doug Beeman, *Press Enterprise, Riverside*

Enclosure .

DEPARTMENT OF DEVELOPMENTAL SERVICES

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654-1897



November 22, 1996

Robert Cross, Vice President
CASH/PCR
2000 "O" Street, Suite 250
Sacramento, CA 95814-5224

Dear Mr. Cross:

Thank you for your letter of November 13, 1996. I'm sorry that you were perplexed by some of my responses to questions concerning Dr. Strauss at the November 5 advisory board meeting at Agnews Developmental Center.

Contrary to your statement, I did not take issue with Dr. Strauss' credentials. He has an excellent reputation as a researcher, and Dr. Strauss has enjoyed the support and cooperation of the Department of Developmental Services (Department) for many years.

I did, however, take issue with Dr. Strauss' stonewalling tactics with regard to his article Comparative Mortality of People with Developmental Disabilities in institutions and the Community. For nearly a year the Department has been trying to obtain the raw data and detailed methodology used in his research study. We have been continuously frustrated in our efforts to work collaboratively with him in securing this information. His rationalizations for non-cooperation changed many times along the way. First, he cited cost factors and lack of time. Next it was a need to secure approval from his colleague, Dr. Eyman. Then the university cited his "academic freedom" that would be violated. And then, finally, there were promises to cooperate with us after his study was published.

Your letter correctly references Dr. Strauss' September 5, 1996, letter to me offering to share his calculations with qualified experts with the Department as observers. I accepted Dr. Strauss's invitation to visit the University of California, Riverside computer center. In consultation with Dr. Strauss, staff members were finalizing preparations for the visit. Unfortunately, in follow-up phone conversations with my staff, Dr. Strauss imposed additional and unconventional requisites on his offer, including a requirement that any experts hired by the Department must be sanctioned by Dr. Strauss and work without compensation. Frankly, we interpreted these new demands as further excuses to frustrate our efforts.

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In any event, I stand corrected if I indicated that my staff was turned away at Dr. Strauss' doorstep. I'm informed that his latest rebuffs were actually made in telephone conversations with my staff--not in person.

Having been put in a position that we were unable to meet Dr. Strauss' demands, we sought his cooperation in identifying the names or UCI numbers of the persons who died in the period covered by his study. Dr. Strauss declined to provide the Department with this information. The Department is now in a position to dig out this information on our own as a result of some computer tapes recently supplied by Dr. Strauss. We thank him for that.

From my standpoint, it serves no purpose to have an adversarial relationship with Dr. Strauss. Over the past year I have attempted on several occasions to establish a collegial relationship with Dr. Strauss along our common interests in understanding the contributing factors in mortality.

I would like to set the record straight with regard to your assertion that the Department has attacked Dr. Strauss' study. This is simply not true. We have never had access to vital information that is needed to either verify or discredit his research. We were, however, shocked by his findings since it seems to contradict most of the literature and previous research in this area, including Dr. Strauss' co-author, Theodore A. Kastner. In an article entitled Mortality in Persons With Mental Retardation Living In The Community, Dr. Kastner stated "...mortality rates reflect the condition of the individual with mental retardation rather than other factors." Prior to the Strauss article, research has indicated that institutional mortality rates are higher than community mortality rates.

It should also be noted that other researchers have raised questions about the methodology used by Dr. Strauss, including professors from the California State University, Sacramento and Columbus Medical Services. And then most recently, researcher Maureen S. Durkin of Columbia University in an article published in the October, 1996, American Journal of Public Health, suggests that Dr. Strauss in adjusting his analysis failed to distinguish between "impairment and disability" and that "this omission may have resulted in over control for level of impairment, thus producing a mortality disadvantage for children in community settings that is apparent but not real."

From the Department's standpoint, the biggest disappointment in Dr. Strauss' study was that it failed to answer the question of why people died at an apparently higher rate. Obviously, if Dr. Strauss' assertions are true, we need to get to the reasons for this disparity in death rates and take any remedial actions that may be indicated.

As a part of its continuing interest in the health and well being of individuals with developmental disabilities, the Department is undertaking a review of factors associated with mortality. Specifically, we are going to immediately undertake two focused mortality reviews briefly summarized below:

I. RETROSPECTIVE MORTALITY REVIEW

The purpose of this review is to determine why people are dying and if there is a relationship between survival rates, individual consumer characteristics and residential setting. The data will be analyzed for each consecutive year over a five-year period beginning January 1, 1991, and ending December 31, 1995. Separate analysis will be conducted in two phases to determine: (1) if different rates of mortality are correlated with type of residential setting for the five-year period;

(2) for the years 1994-95, the underlying cause of death as it relates to consumer characteristics, e.g. level of self-care, motor ability, disability, etc. This two-year study will examine the underlying causes of death and determine the relationship of these deaths to known risks. Specifically, it will look at the number of deaths that occurred during this time frame, the cause of death and if the death was avoidable in accordance with standard epidemiological criteria. A team of nurses and professionals will be used to collect the data and a panel of physician experts will complete the analysis of the data.

II. PROXIMATE MORTALITY REVIEW - 1997

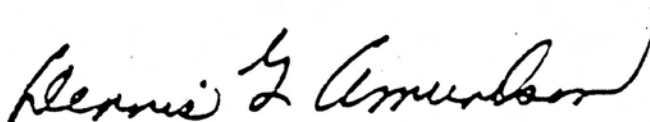
The purpose of this review will be to identify the potential causes and contributing factors in consumer deaths. The department will contract with an independent research entity to conduct a comprehensive case-by-case qualitative review of all consumer deaths that occur during a one year period. The review will examine the causes of death, health care coordination, access to health care services and opportunities for preventive health care. Information will be obtained by review of medical records, death certificates, coroner reports and interviews with health providers and families. A multidisciplinary team will determine the causes of death and whether such deaths were avoidable.

In closing, please be assured that the Department is extremely concerned about mortality issues raised by Dr. Strauss' studies, and we will vigorously attempt to verify his findings and take any remedial measures that are indicated.

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If you would like further details about the status of our mortality review projects, please feel free to contact Delores Murrey, Ph.D. of my Quality Assurance staff. They can be reached at 916-654-3663.

Cordially,



DENNIS G. AMUNDSON
Director

c: Governor Pete Wilson; Lieutenant Governor Gray Davis
Sandra R. Smoley, Secretary, Health and Welfare Agency
Robert Schladale, Assistant Secretary, Health and Welfare Agency
Senator Mike Thompson, Dr. David Strauss, Dr. Theodore Kastner
Outreach, CAPT; Roz Plater, KNTV; Doug Beeman, Press Enterprise, Riverside

State condemns UCR study

► A Riverside professor is reeling from the bureaucratic attack. After all, his survey found state care of the developmentally disabled saves lives.

By Douglas E. Beeman
The Press-Enterprise

RIVERSIDE

UCR professor David Strauss combed through 12 years of state records on mentally retarded patients and reached a surprising conclusion: Patients who live in community homes are at 72 percent greater risk of dying prematurely than those in state institutions.

His finding contradicted the prevailing assumption in the field that patients in

group homes and other less restrictive settings are better off than those in institutions.

No one was more startled than the state agency that runs the institutions. But rather than treat the study as an endorsement of the institutions, Dennis Amundson, director of state Department of Developmental Services, reacted by attacking Strauss and trying to discredit his research.

Strauss, a soft-spoken professor of statistics at the University of California, Riverside, said he was taken aback. In 25 years of statistical research, Strauss said, "I've never had anything remotely like this occur."

The study by Strauss and his co-author, New Jersey researcher Dr. Theodore Kastner, comes as the state is closing institutions and sending more patients

Please see **STUDY, A-9**



Jay Racz / The Press-Enterprise

UCR Professor David Strauss

STUDY: War rages over retarded placement

Continued from A-1
into small group homes. Many of these patients are severely retarded or have severe behavioral problems. Parent groups opposed to such closures have embraced the study's conclusions.

So when state officials caught wind of Strauss' findings, the state Department of Developmental Services went on the offensive.

Amundson asked to see Strauss' data, which was drawn from the agency's own records. Strauss and the university said no, for legal reasons and to ensure the work isn't scooped by another researcher.

Amundson then turned elsewhere. Because a National Institutes of Health grant paid for Strauss' work, Amundson sought any documents the federal agency might have. He got some documents, but not everything he had sought.

He suggested to the American Journal on Mental Retardation that Strauss' methodology might be flawed.

Amundson said the state agency simply wanted to verify the findings and, if true, figure out why.

In an August letter to Robert Gettings, executive director of the National Association of State Directors of Developmental Disabilities, Amundson encouraged other states to conduct their own studies to challenge Strauss' conclusions

In that letter, Amundson indicated he feared the study might be used in a court challenge of the department's efforts.

In an interview, Amundson complained that Strauss' unwillingness to hand over his data "prevented us from analyzing a very alarming study," Amundson said. He added: "Who the hell does he think he is?"

Amundson concedes Strauss' findings could have significant implications for the state. As part of a court settlement, the state agreed over five years to reduce the number of institutionalized patients by 2,000. It achieved that in less than four years. There are now about 4,400 developmentally disabled patients in state institutions, Amundson said.

If Strauss is correct, then "obviously we've got some huge problems and we're going to have to do something about them," Amundson said.

But Amundson believes Strauss' findings are skewed by a bias in favor of institutionalized care.

He accused Strauss of aligning himself with parents opposed to the state's downsizing efforts, and soliciting money from parents for his research.

"He's certainly raising my neck hairs about his objectivity," Amundson said.

Strauss said that when he began his research, he never contacted parent groups — they contacted him. And although parent groups and others have promised \$20,000 to complete some related work, that money will go to the university to pay a researcher. Apart from his university salary, "I have not received any financial compensation at all from this study," he said.

Strauss denied any bias in favor of state institutions.

"Most people with mental retardation under good conditions do belong in community care," Strauss said. At the same time, he believes there are shortcomings with the supervision and care — especially health care — of people who live in community homes.

Strauss' study, published this summer in the American Journal on Mental Retardation, found a 72 percent higher death rate among people living in community group homes compared with people living in state institutions in California.

Strauss said he has now completed several other statistical studies comparing mortality risks of state institutions against the risks in community facilities in California.

All point to the same conclusion: The mentally retarded are at greater risk of dying prematurely in the community than in state institutions.

Just why this is the case is not clear, Strauss said.

State institutions employ doctors, dentists and others who are skilled in dealing with mentally retarded clients, and can respond quickly. In the community, physicians and dentists may be less experienced with mentally retarded patients and more reluctant to take them on, he said.

Deaths may occur due to choking on food and overdoses of medication — in some cases at rates four times higher than the rate for developmentally disabled

people living in their parents' homes, Strauss said. And the difference between community facilities and state institutions is even greater, Strauss said.

Robert Cross of Los Gatos, vice president of a Northern California parents group, expressed dismay at Amundson's "fervent denunciation of Drs. Strauss and Kastner's research."

In a Nov. 13 letter to Amundson, Cross added:

"That this study casts the (state developmental) centers, for which you are responsible, in a light more favorable than community care facilities may be different from what you had hoped. But, it is not a legitimate reason for attempting to discredit Dr. Strauss personally."

(Reprinted in Contra Costa, Vacaville, Marysville,
San Mateo, Sacramento, San Bernardino,
Ventura (Camarillo), & San Francisco news papers).

THE PRESS-ENTERPRISE

HOWARD H. HAYS JR.
Chairman

MARCIA MCQUEEN
Editor and Publisher

JOEL BLAIN
Editorial Page Editor

Protesting too much

Pardon UCR statistician David Strauss if he thinks someone is doing a number on his research, but it does seem that way.

He and fellow researcher Theodore Kastner found that mentally retarded patients in state institutions are a lot better off than in community homes. They analyzed 12 years of state records and concluded that patients in community homes are a 72 percent greater risk of suffering premature death than those in institutions.

The study, one would think, would be good news to the Department of Developmental Services, which runs the institutions, the kind that would enliven its public relations department. Instead, department Director Dennis Amundson is doing everything — in fact, way too much, it seems — to discredit the conclusions.

He has sought out others to challenge the Strauss-Kastner conclusions and has gone so far as to question David Strauss' objectivity, claiming the UC Riverside professor of statistics is taking the cause of patient families that generally favor institutionalized care. If there are ques-

tions about objectivity here, it is Director Amundson's that should be under scrutiny.

The researchers' study was written up and subjected to peer review. Their methodology and conclusions should continue to be questioned, even challenged. That's part of the process. They may turn out to be wrong.

But Mr. Amundson seems too anxious to reach that conclusion. There are obvious reasons why that may be the case. Government wants to save money by placing more and more of these patients in community homes than in more costly institutions. Any information that suggests this might not be the best policy threatens continued savings from reducing the number of institutionalized patients.

Mr. Amundson should show interest in the Strauss-Kastner study. But his interest should be in finding out whether the mentally retarded are receiving the best care they should, and not in finding someone to contradict the conclusions.

By all means, the research should be replicated, but while it is being tested, Mr. Amundson might try sitting back and enjoying the praise.

What wasn't mentioned

■ Your article on the study of death rates among the disabled and retarded by Dr. David Strauss left something out. The story didn't explain why anyone was surprised that people who live in a cage under a doctor's supervision would have a lower death rate than people who take their chances in the world. Also, who is "better off," the long-lived guy in the cage or the guy with the life?

ED WILSON
Riverside

Stonewalling tactics

■ ... It is the Department of Developmental Service's mission to provide the best possible care to persons with developmental disabilities, regardless of where they live...

Contrary to the statement in your November 24 editorial, I have not, nor do I intend to "discredit the conclusions" of Dr. Strauss' study. Furthermore, I do not take issue with Strauss' credibility. Dr. Strauss has an excellent reputation as a researcher...

What I have taken issue with is Strauss' consistent stonewalling tactics regarding his study. For nearly a year, we have tried to obtain his methodology and raw

data to verify his findings and determine why there is an apparently higher death rate.

What the department is interested in — why people died at an apparently higher rate — was not covered in Strauss' study. If his assertions are true, we need to find the reasons why. The department is extremely concerned about mortality issues raised by Dr. Strauss' studies. Based upon computer tapes he recently provided, the department is now in a position to conduct reviews to verify his findings, determine causes of death, and to initiate remedial actions if indicated.

By the early part of next year, the department will have data to determine what the specific risks are for community living in California. This will enable us to better inform persons with developmental disabilities and their families about potential risks connected to community living options.

DENNIS G. AMUNDSON
Dept. of Developmental Services
Sacramento

DEPARTMENT OF DEVELOPMENTAL SERVICES

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November 27, 1996

Editor
Riverside Press-Enterprise
PO Box 792
Riverside, CA 92502-0792

Dear Editor:

Regarding the editorial "Protesting too much," (Riverside Press-Enterprise, November 24, 1996), the Department of Developmental Services provides support to more than 135,000 children and adults with developmental disabilities living in the community, and nearly 4,500 residing in developmental centers.

It is the Department's mission to provide the best possible care to persons with developmental disabilities, regardless of where they live, as is provided for by California Law--a mission that we live by each day.

Contrary to the statement in your 11/24/96 editorial, I have not, nor do I intend to "discredit the conclusions" of Dr. Strauss' study. Furthermore, I do not take issue with Strauss' credibility. Dr. Strauss has an excellent reputation as a researcher and he has enjoyed the support and cooperation of the Department for many years.

What I have taken issue with is Strauss' consistent stonewalling tactics regarding his study. For nearly a year, we have tried to obtain his methodology and raw data to verify his findings and determine why there is an apparently higher death rate.

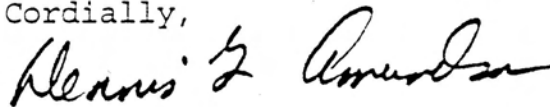
What the Department is interested in--why people died at an apparently higher rate--was not covered in Strauss' study. If his assertions are true, we need to find the reasons why. The Department is extremely concerned about mortality issues raised by Dr. Strauss' studies. Based upon computer tapes he recently provided, the Department is now in a position to conduct reviews to verify his

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findings, determine causes of death, and to initiate remedial actions if indicated.

By the early part of next year, the Department will have data to determine what the specific risks are for community living in California. This will enable us to better inform persons with developmental disabilities and their families about potential risks connected to community living options.

Cordially,

A handwritten signature in cursive script, appearing to read "Dennis G. Amundson".

DENNIS G. AMUNDSON
Director



supported living
and employment for
people with mental
retardation & challenging
behaviors • non-profit
corporation

November 27, 1996

Dear Editor:

I am deeply concerned about Douglas Beeman's misleading article quoting a UC researcher's findings that persons with developmental disabilities live longer in state institutions than in community homes.

Apparently Professor David Strauss analyzed 12 years of records of mentally retarded individuals, and concluded that 72% of those living in the community risk dying prematurely than those in institutions.

While institutions have medical services readily available, findings suggest that people with disabilities are better off in institutions than community homes. This isn't so! The trend is to close institutions!

Quality of life is equally important as health. Expert James Conroy conducted a study which followed 246 persons discharged to group homes from developmental centers.

His study found persons in community homes were more satisfied with living arrangements (settings and supports) and participated more in the community. Contrary to Strauss, there was "no evidence...of any increase in the mortality associated with movement from developmental centers to the community." One problem with community living, according to the study, was with access to health care and medication monitoring.

The solution isn't moving people back to institutions. We must urge the Legislature to provide adequate funding for people to live in community homes.

Sincerely,

Stephanie Chapralis, M.A.
Executive Director, Las Trampas, Inc.
P.O. Box 515, Lafayette, CA 94549

sent to Contra Costa Times
200 word limit

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Assembly California Legislature



SHEILA JAMES KUEHL
ASSEMBLYMEMBER, FORTY-FIRST DISTRICT

Speaker pro Tempore

December 18, 1996

Dennis G. Amundson, Director
Department Of Developmental Services
1600 9th Street
Sacramento, California
95814

Dear Mr. Amundson,

I am writing to express my concern about the continuing downsizing activities of the Department of Developmental Services. I have grave misgivings, not only about the purpose, but also about the repercussions of these actions, particularly in light of the recent study by David Strauss and Theodore Castner, with which I know you are familiar. Throughout this year, I have received increasingly alarming correspondence from many constituents as well as other concerned family members of persons with developmental disabilities. They vigorously oppose deinstitutionalization because they feel such actions place clients in potentially inappropriate and acutely dangerous situations, and I agree with their concerns.

The Strauss study concludes that clients placed in state institutions have a mortality rate 42% lower than clients placed in community care homes. Strauss further found that, regardless of risk factors like motor skills, tube feeding, and self-care ability, Development Centers in California still observed greater client survival with a 72% mortality rate differential. This phenomenon requires me to inquire about the wisdom of the Department's actions. In addition, your public attempts to discredit the study have surprised me since its comments reflect so well on the abilities of the Development Center staff, training programs, and procedures.

Parents and advocates of developmentally disabled persons have voiced a clear opinion in this matter. Downsizing has frightened parents and stirred them to extraordinary action in fundraising and lobbying to keep the choices guaranteed to them in the Lanterman Act of 1993. Parents contend that some regional centers may have inappropriately steered clients toward community placements and discharged some individuals prematurely from state facilities in order to create the bed vacancies that are now being used to justify closing centers. Parents also

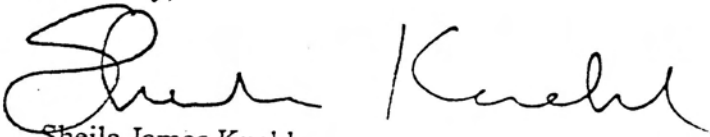
maintain they have been deceived about the specialized care and supervision capabilities of some community placements or have experienced instances where facilities have failed to inform parents of treatment plans.

As you know, the Lanterman Act states that "agencies serving persons with developmental disabilities shall produce evidence that their services have resulted in consumer or family empowerment, and more independent, productive, and normal lives for the persons served." I believe this provision places a responsibility on the Department to show that the private sector placements are meeting this burden and to respond to the questions raised by the Strauss study's statistics. It is also important to justify any further actions to downsize and shift client placements away from state Development Centers. The Strauss study and ongoing public protest certainly calls into question the viability of community care for all clients and the ability of community care to meet the requirements of the law.

I am concerned about the ability of the Department to exercise proper oversight of these community facilities, particularly as clients with more specialized and multiple needs flow rapidly into this population. Coordination of medical, educational, psychiatric, and therapeutic services on a 24-hour basis has already proved problematic in the eyes of parents. In some cases, negligence has already led to fatality or to more hospitalization for severe behavioral regression or injuries. Current oversight procedures have not prevented under-staffing or the employment of ill-trained staff in many community placements. We cannot justify this greater risk of long-term or permanent regression for clients in community placements.

Please respond to these issues at your earliest convenience as they hold great importance to me as well as to the population your department serves. I know that we share common goals in acting to protect the welfare of developmentally disabled persons. Thank you for your attention to this matter.

Sincerely,

A handwritten signature in black ink, appearing to read "Sheila Kuehl". The signature is written in a cursive, flowing style.

Sheila James Kuehl
Speaker pro Tempore

NCK

ARC**California**

120 T Street, 2nd Floor
 Sacramento, CA. 95814-2213
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Christopher A. Poulos, President
 Gary A. Tonks, Executive Director

A RESOLUTION FOR ACTION BY THE ARC-CA EXECUTIVE COMMITTEE:

WHEREAS, over 2,000 persons, including many who are medically fragile, have been moved from Developmental Centers in three years, and;

WHEREAS, many individuals have been moved without proper preparation and planning and/or against expressed parental wishes and are at risk, and;

WHEREAS, the Department of Developmental Services deflection policy has deprived individuals who need and want the Centers from access, even when there is no appropriate alternative, and;

WHEREAS, there is substantial evidence based on research and empirical data from parents and professionals that these policies and practices result in injury and death;

NOW THEREFORE BE IT RESOLVED:

1. That the state impose a **TWO YEAR MORATORIUM** on the continued movement of individuals from the Developmental Centers;
2. That the State discontinue the deflection policy, and;
3. That the Legislature initiate an investigation to include:
 - a. An Auditor-General report on the use of Regional Center funds.
 - b. Quality of care in residential settings including regularity of monitoring and effectiveness of regulations.
 - c. A review of the effects of deinstitutionalization by nationally recognized epidemiologists.

DECEMBER 14, 1996

Adopted unanimously, Arc-California Executive Committee