

Withdrawal/Redaction Sheet

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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001. memo	To Diana Fortuna from Curt Decker re: Mtg tomorrow (partial, DOB, SSN) (1 page)	02/07/1995	b(6)
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COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12025

FOLDER TITLE:

PAIMI [Protection and Advocacy for Persons with Mental Illness]

2018-0525-S

ry2255

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

PAIMI

EXECUTIVE OFFICE OF THE PRESIDENT

13-Feb-1995 04:06pm

TO: (See Below)

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: Resolution of PAIMI

Thanks to Richard Turman for his clarifying that Protection and Advocacy for Persons with Mental Illness (PAIMI) funds now go directly to P&As, rather than through the states. I had already learned this from Curt Decker, who is a well-informed advocate on this issue. Does this lend credibility to their argument that the block grant will slow down the disbursement of these funds to P&As, and give hostile Governors an opportunity to injure these programs?

I would ask that the DPC (Lynn Margherio or I) be involved in determining how to resolve this issue. We have gotten a lot of criticism, as you may know, that Carol and other high-level White House people with knowledge of disability programs were not involved in the original decision to block grant PAIMI. Without regard to whether that was the case, we should make sure that we are looking at this issue from a disability standpoint as well as NPR. Lisa Fairhall and Richard Green probably also want to be involved -- or perhaps they already are.

Also, Rego II will require decisions about all disability programs. As members of the HHS, SSA, and VA teams, Lynn and I will keep up on that. But if disability issues come up in the education, labor, or other teams, it would make sense that the staff to the National Disability Policy Review (Lynn, Lisa, Richard, and me) be informed in so we can coordinate. (Lynn and I will also check in with our colleagues on the DPC.)

Let me know if this presents any problems to anyone.

Distribution:

TO: Nancy-Ann E. Min
TO: Kenneth S. Apfel

CC: Richard J. Turman
CC: Lisa B. Fairhall
CC: Richard E. Green

CC: Lynn M. Margherio

FAX



Health Division



Office of Management and Budget
Executive Office of the President
Washington, DC 20503

TO: Diana Fortuna (cc)
Deborah Pearlstein

FROM: Lissa Tope

Fax Destination

Organization:

Phone Number:

Number of Attached Pages: 1

Notes:

Per my E-mail - Draft

PAIMI letter #3!

HD Fax Number: 202/395-3910

Voice Confirmation: 202/395-4922

202/395-4925

202/395-4926

202/395-4930

Health Division Front Office

Health & Human Services Unit

Health Programs & Services Branch

Health Financing Branch

DRAFT

Dear Representative Waters:

Thank you for your letter to the President regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. I have been asked to respond to your letter on his behalf.

As you know, the Administration is proposing to consolidate 107 Public Health Service activities into 16 Performance Partnerships or Clusters. These proposals will consolidate funding streams, create funding incentives to reward desirable results, and reduce micromanagement and wasteful paperwork. The Performance Partnership initiative is good for mental health programs and the mental health community because it will help to focus these programs on outcomes and outputs, as well empower communities to make their own decisions about how they can best address their mental health needs.

We share your concern for the protection of the rights of mentally ill Americans, and under our proposal, SAMHSA will continue to administer the PAIMI program as a separate grant, distributing funds directly to protection and advocacy agencies.

We look forward to working with you on these issues. Thank you again for your letter.

Sincerely,

DRAFT

Alice Rivlin

FAX



Health Division



Office of Management and Budget
Executive Office of the President
Washington, DC 20503

TO: Diana Fortuna

FROM: Lissa Tope

Fax Destination

Organization:

Phone Number: 456-7028

Number of Attached Pages: 1

Notes:

Per our conversation. -PAIANT Draft letter.

HD Fax Number: 202/395-3910

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DRAFT

Dear Representative Waters:

Thank you for your letter to the President regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. I have been asked to respond to your letter on his behalf.

We share your concern for the protection of the rights of mentally ill Americans. After initially proposing to consolidate the PAIMI program into the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Mental Health Performance Partnership in FY 1996, the Administration has decided that SAMHSA will continue to administer the PAIMI program as a separate grant, distributing funds directly to protection and advocacy agencies.

We look forward to working with you on these issues. Thank you again for your letter.

Sincerely,

Alice Rivlin

DRAFT

MEMORANDUM FOR THE PRESIDENT

FROM: Carol H. Rasco

SUBJECT: SSI Program for Disabled Children

DATE: March 7, 1995

You asked whether we could fix those features of the children's SSI program that supposedly allow parents to coach their children to misbehave and qualify for benefits. As you know, there has been considerable press coverage of children with mild behavioral problems qualifying for over \$400 a month in cash benefits (although anecdotes of coaching have not been substantiated by a search of case records). To address the problem and identify reforms, Congress last year created a Childhood Disability Commission, chaired by former Rep. Jim Slattery of Kansas. Our position has been that we should wait for the Commission's report before making wholesale changes to the program.

Three factors caused the number of children qualifying for SSI to triple since 1989: the addition of several behavioral disorders to the list of qualifying disabilities; a major outreach program; and a 1990 Supreme Court decision requiring a test of whether a child functions in an age-appropriate manner (the IFA test). Prior to the IFA test, children could qualify only if their condition was one of those enumerated in a set of "medical listings." Advocates argued that the medical listings exclude many rare conditions or combinations of conditions.

The difficulty is devising a change that targets the cases of abuse without throwing needy children off the rolls. The plan just passed by the House Ways and Means Committee eliminates the IFA test, which cuts off some children with fairly severe physical and mental disabilities. Today's story in the Washington Post on this subject presents a number of compelling cases of children who would lose benefits under the House plan.

The Ways and Means proposal would also eliminate cash benefits for all children except those in danger of institutionalization, and plow back 75 percent of these funds into a state block grant. States would then provide children with authorized services. Cash benefits have come under attack because families are not required to account for how they use them. On the other hand, cash allows families to decide how to spend the money and gives them the flexibility to meet their children's needs, such as allowing a parent to stay home to take care of a disabled child.

The Childhood Disability Commission just held its second meeting. Mindful of the time pressure, the Commission plans to complete its work by June or July, well ahead of its November deadline. However, this timing is problematic if the Senate goes along with the House's plan to alter the program dramatically now. We are preparing fallback options should that take place.

THE PRESIDENT HAS BEEN

2/21/95

FRIDAY, FEBRUARY 17, 1995

TO CLASS

CONFIRM

B

'Crazy check' guidelines invite parental flimflam, GAO says

BY TERRY LEMONS
Democrat-Gazette Washington Bureau

WASHINGTON — "Fundamental flaws" allow abuse of a federal aid program for mentally disabled children that has been dubbed "crazy checks" by critics, a General Accounting Office report reveals.

The GAO report criticizes the program's vague testing rules, which helped add 219,000 children to welfare rolls since 1991. Benefits for those children cost taxpayers \$1 billion a year.

The congressional group sent investigators to Arkansas and other states last year to look into allegations that many parents coached their children to misbehave in order to qualify for \$458 monthly checks.

It was "virtually impossible" to determine the frequency of parental coaching, GAO concludes. But the report notes the program's ambiguous testing procedures make it "susceptible to manipulation" by parents.

GAO officials also question whether government officials offer any "reasonable consistency" in administering the plan under the current guidelines. The Social Security Administration oversees the program.

Rep. Blanche Lincoln, D-Ark., said Thursday that the study underscores the need to fix the "crazy checks" program. Lincoln and several other House members requested the report, which was released in a draft form.

Lincoln said the GAO's findings will help her design legislation to tighten testing guidelines for the program.

House Republicans also are pushing a sweeping plan that would overhaul the program as part of the Contract With America.

The congressional attention follows reports of abuse and fraud for the part of the federal Supplemental Security Income program designed to help poor families care for their mentally disabled children.

Some parents in Arkansas and other states reportedly coached their children to misbehave in order to qualify for "crazy checks" payments. Critics also say some parents misuse the checks for expenses ranging from illegal drugs to gambling.

The program has nearly tripled in size since a 1990 U.S. Supreme Court decision eased eligibility requirements. Nearly 900,000 children qualified for the federal aid last year, up from about 300,000 prior to the court decision.

The program cost about \$4.5 billion last year.

The GAO report focused criticism on the program's individual functional assessment, or IFA, test. Use of the testing provision mushroomed after the Supreme Court decision.

"In our analysis, we found fundamental flaws in the IFA process," the GAO said.

The testing process allows officials to determine whether children behave in an "age appropriate" manner. The GAO suggested elimination of the IFA test because of its "highly subjective" nature, particularly for evaluating mental disabilities.

"The IFA process has been difficult to implement consistently and reliably, particularly for children with mental impairments, because the process requires ... a series of 'judgment calls,'" the report said.

Problems with the IFA also made the program vulnerable to parents coaching their children to misbehave, the GAO said.

But GAO officials were unable to determine how frequently coaching occurs.

"Unless parents admit to it, coaching is almost impossible to substantiate," the report said.

But the IFA helped fuel rapid growth in the "crazy checks" program at a cost to taxpayers of about \$1 billion annually, the GAO said. Out of more than 600,000 children joining the program between 1991 and 1994, the study showed 219,000 qualified under the IFA guidelines.

About 85 percent of those qualifying under the IFA test had mental disabilities, the GAO said. That included 39 percent with mental retardation, 22.2 percent with other mental illnesses, 14.7 percent with attention deficit disorder and 8.6 percent with conduct disorder.

The remaining 15 percent qualified because of physical disabilities.

GAO recommends abolishing the IFA guidelines and relying on more specific medical criteria to evaluate "crazy checks" applicants. Lincoln is preparing

legislation along similar lines.

"This change would reduce the growth in awards and at the same time target disability benefits toward children with more severe impairments," the report said.

Lincoln said "crazy checks" abuse needs to end.

"The federal government shouldn't be in the business of subsidizing children who misbehave," she said.

The IFA guidelines also would be eliminated under a plan approved Wednesday by Republicans on a subcommittee of the House Ways and Means Committee. The GOP plan calls for fundamentally altering the "crazy checks" program by giving states more authority over the program.

Republicans want to give federal block grants to the states, creating a potential savings of between \$5 billion and \$13.4 billion over five years. Democrats said the plan could strip benefits from 200,000 children.

The GOP measure faces more committee votes next month.

THE PRESIDENT HAS SEEN

2/21/95

Arkansas Democrat Gazette

FRIDAY, FEBRUARY 17, 1995

'Crazy check' guidelines invite parental flimflam, GAO says

BY TERRY LEMONS

Democrat-Gazette Washington Bureau

WASHINGTON — "Fundamental flaws" allow abuse of a federal aid program for mentally disabled children that has been dubbed "crazy checks" by critics, a General Accounting Office report reveals.

The GAO report criticizes the program's vague testing rules, which helped add 219,000 children to welfare rolls since 1991. Benefits for those children cost taxpayers \$1 billion a year.

The congressional group sent investigators to Arkansas and other states last year to look into allegations that many parents coached their children to misbehave in order to qualify for \$456 monthly checks.

It was "virtually impossible" to determine the frequency of parental coaching, GAO concludes. But the report notes the program's ambiguous testing procedures make it "susceptible to manipulation" by parents.

GAO officials also question whether government officials can offer any "reasonable consistency" in administering the plan under the current guidelines. The Social Security Administration oversees the program.

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House Republicans also are pushing a sweeping plan that would overhaul the program as part of the Contract With America.

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The GOP measure faces more committee votes next month.

Leon

we need to fix this.

CC: Q → C. Raso VP

B.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

27-Feb-1995 05:03pm

TO: Diana M. Fortuna

FROM: Carol H. Rasco
 Economic and Domestic Policy

CC: Jeremy D. Benami

CC: Jennifer N. Palmieri

SUBJECT: Children and SSI

When you are back from California we need to prepare an update memo to POTUS on this whole issue...I realize not much has happened since we sent last memo to him but with continuing press we need to update him.

Thanks.

Jennifer: Because Leon and I have seen more clippings from POTUS on this I wanted you to see how we will proceed. Thanks.

Jeremy - Jyi

THE WHITE HOUSE
WASHINGTON

November 2, 1994

MEMORANDUM FOR THE PRESIDENT

FROM: Carol H. Rasco 
SUBJECT: Children's SSI Benefits

You noted on the weekly report that we need to stay on top of the issue of SSI payments to children with disabilities. I agree and wanted to take this opportunity to update you quickly on the issue.

The bill signed this August that made Social Security an independent agency also created a Childhood Disability Commission to look at issues surrounding the children's SSI program. The Commission will be named by the end of the year by Secretary Shalala and is to report by November 1995. The Commission will consist of experts such as doctors, psychologists, etc. who will look at eligibility criteria, the feasibility of providing benefits through noncash means, and the range of needs and available services to children with disabilities.

Over the past year, there have been numerous Congressional hearings and media stories highlighting possible abuse within the program. The Inspector General at SSA, the GAO and others have looked at the issue, however, and do not believe that the large increase in caseload over the past few years is due to fraud or abuse. The increase reflects the affect of both a Supreme Court decision and legislative and regulatory expansions of eligibility criteria.

We will also be looking at the issue as part of the National Disability Policy Review that Alice Rivlin and I are co-chairing to look at the entire range of federal disability policies.

The program is clearly a prime candidate for Congressional action, but we are hoping to delay any activity on the Hill until the Commission has reported. We will stay on top of the issue, and I will keep you posted on important developments.

Chen
Report to Congress on Child Support Enforcement. The report will show a 12 percent increase in child support collections from 1992 to 1993, to nearly \$9 billion, and the establishment of paternity for over a half million children. The report also shows, however, that nearly 3 million children do not receive the support that they should.

*What
they
are
up
to*
Upcoming SSI Press Story: John O'Donnell of The Baltimore Sun is preparing an extensive article on SSI disability payments to children. The story focuses specifically on payments -- negatively termed "crazy checks" by critics -- made to the emotionally disabled. This story has been covered widely, most recently last week on "Prime Time Live." SSA Commissioner Shirley Chater was interviewed for the Sun story. Newsweek has also interviewed Shirley Chater on this issue.

Upcoming Press Story on Gay Parenting: "NBC Today" is developing a segment on gay parenting. It plans to include an interview with NIH researcher, Dr. Michael Lamb, who reports that there is currently very little data on child development in gay households.

Housing and Urban Development

- **Political Travel:** Since Wednesday, Secretary Cisneros has been on a 12 day "Get Out The Vote" tour through Texas. On Saturday, he will participate in GOTV rallies with Senator Jeff Bingaman and Governor Bruce King in New Mexico. And on Wednesday he will announce with Governor Cuomo and Mayor Giuliani a partnership to improve the lives of homeless people who live in subway tunnels. Finally, between November 3-5, 1994, he will participate in a range of political events in California.
- **Official Travel:** On Tuesday, the Secretary will announce a \$613 million loan for improvements to the New York Hospital, with Governor Cuomo.

Veterans Affairs

- **Political Travel:** Today, Secretary Brown will be in Dublin, Georgia, with Democratic congressional candidate Craig Mathis for campaign-related events. On October 29, he will campaign in Tennessee with Senator Jim Sasser. On October 31, he will be in Palm Springs, California, with candidate Steve Clute. And, on November 1, he will participate in a campaign event in Long Beach, California, with candidate Peter Mathews.

Office of National Drug Control Policy

- Next week, on November 2, Director Brown will designate of a High Intensity Drug

House Panel Votes to Curtail Program for Disabled Children

By Spencer Rich
Washington Post Staff Writer

House Ways and Means Committee Republicans have approved a dramatic cut in the federal welfare program that supports severely disabled, low-income children.

Alarmed by a rapid increase in beneficiaries—which has pushed the caseload to 890,000—and convinced that a 1990 Supreme Court decision makes it too easy to qualify, committee Republicans led by Rep. Jim McCrery (La.) voted for major changes in the \$5 billion-a-year Supplemental Security Income (SSI) disabled children's program.

The changes would cut the program over the next five years by \$10.9 billion—reducing spending 33 percent below what would be spent under current law between 1996 and 2000. Proportionately that is far greater than the 11 percent being cut, for example, from food stamps. Under the proposal:

- Eligibility changes based on the 1990 court ruling would be nullified both retroactively and for future applicants. More than 225,000 children now receiving benefits as a result of the decision would be removed from the rolls.
- Only 30 percent of children who come onto the rolls in the future will receive cash benefits—those so disabled that they need "special personal assistance" much of the time to survive and avoid being institutionalized.
- The other 70 percent of those qualifying in the future would not receive cash benefits but instead could receive only Medicaid plus added state-administered services financed by block grants to the states. The grants would cost the government

Association for Elderly Attacks Proposed Medicare Cuts

By Spencer Rich
Washington Post Staff Writer

The nation's largest organization for the elderly yesterday attacked proposals to cut Medicare, saying the spending curbs could increase average out-of-pocket costs by \$575 and push them up as high as \$2,000 a year for some people by the end of the century.

"Older Americans believe they elected people in 1994 who would not cut Medicare, and they are shocked when they see these proposals," said Tricia Smith, senior legislative representative for the 33 million-member American Association of Retired Persons.

Meanwhile, a survey released yesterday by the nonprofit Employee Benefit Research Institute showed that 64 percent of Americans 18 or older favored tax increases to shore up the Social Security system. Twenty-eight percent of the respondents who were surveyed in January said no tax

increases should go into effect until after 2010, the year the baby boomers start retiring.

Concerned that Social Security might not be available when they retire, a third of respondents said the highest-income elderly should not receive benefits even though they had paid

"Older Americans ... are shocked."

— Tricia Smith, AARP

into the system. Only 9 percent believed Social Security benefits should be eliminated or reduced. Eighty-five percent of respondents said benefits should stay the same or be reduced for higher-income people.

In discussing Medicare, Smith told reporters that the AARP had conducted "numerous focus

groups across the country in the last few months" and found that the elderly had little idea that the new Republican-controlled Congress wants to cut projected Medicare spending over the next seven years by as much as \$300 billion.

Smith said the AARP assumed that about half the Medicare savings Congress would seek to help balance the budget by 2002 would come from higher costs to beneficiaries, the rest from cutting fees to service providers.

Under current law, the average elderly person would pay \$3,890 in premiums, copayments, deductibles and other out-of-pocket health outlays in 2000, not counting long-term care, AARP experts calculated. But the cost could go up by \$575 if the most commonly discussed changes are adopted: imposing new copayments for home health care, charging the well-to-do elderly more, increasing Medicare premiums by one-fifth, or increasing the amount patients pay before benefits kick in and then raising that amount annually.

less than if this group of children had continued to receive cash benefits, which go up to \$458 a month.

Groups representing the disabled are fighting the changes.

"It's an unprecedented assault on low-income families raising children with severe disabilities," said Rhoda Schulzinger of the Bazelon Center on Mental Health Law.

"Many hundreds of thousands of children who most people in this country would consider the most deserving of government support would be pushed off the rolls or rejected if applying for the first time," said Jonathan Stein of Community Legal Services of Philadelphia.

Stein cited examples of children who, he said, are severely disabled who would not qualify under the rules sought by McCrery:

- Six-year-old Jennifer Cox suffers from congenital bowel malformation requiring a colostomy. She also suffers from eye problems and lacks peripheral vision, causing her to run into walls. At 6, she was not yet toilet-trained.
- Kendra Whalon, 2, suffers from a rare growth condition in which one arm is twice as long as the other, causing loss of balance, motor impairment, spinal curvature and loss of lung volume.
- Monisha Smith, 10 months old, re-

quires a shunt to drain cerebrospinal fluid from her brain to her abdominal cavity. She suffers partial paralysis of the legs, bowel and bladder, a condition that requires frequent catheterization.

McCrery said the 1990 Supreme Court decision loosened eligibility, making it possible for children with relatively mild disabilities to get benefits.

He cited numerous reports of children whose parents instructed them to fake retardation or attention disorders to get the federal cash benefit.

"It is my intention that if any child

is severely disabled, he should be able to qualify," he said.

Until 1990, the program served children under 18 whose mental and physical disabilities were so severe that they met criteria spelled out by the Social Security Administration. However, in 1990, in a case brought by Stein, the Supreme Court ruled that if a child did not meet those criteria, he or she could still qualify if found unable to function at the appropriate age level. The program has grown from 290,000 recipients, costing \$1.3 billion in 1989, to 890,000 and \$5 billion today.

McCrery contends that the func-

tional capacity test is too subjective. He proposes to abolish it and to remove from the rolls all those who had qualified through it. Some children might well requalify because the program can grant benefits to children who, while not meeting a specific criterion, have disabilities equal in severity.

Stein said, "The functional test is essential. There are hundreds of rare diseases not listed in the specific medical criteria. Moreover, you can't test a 2-year-old for IQ."

McCrery also wants to make sure that the government's money goes to help the child and is not spent for other purposes by the family. That is why his proposal allows cash benefits for new applicants only if they need "special personal assistance" to live.

But Schulzinger argues, "Cash is by far the most flexible way to meet the day-to-day needs of your child—and particularly to allow a caretaker parent to stay at home to attend to the child—that's often what the child needs most."

Despite objections in committee from Reps. Sander M. Levin (D-Mich.) and Fortney "Pete" Stark (D-Calif.), McCrery's plan appears headed for the floor.

The Senate could be different.

"It's cruel," said Sen. Daniel Patrick Moynihan (D-N.Y.), ranking minority member on the Senate Finance Committee, which will handle the proposal in the Senate. Chairman Bob Packwood (R-Ore.) said last week that while he has "no philosophical objection" to a block grant, "it may be too much to digest this year."

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

22-Feb-1995 11:51am

TO: Diana M. Fortuna

FROM: Deborah N. Pearlstein
 Presidential Correspondence

SUBJECT: PAIMI etc.

Any news since last Friday's meeting? We're starting to get lots of mail on block grants for other disability programs as well, so deciding on language for PAIMI would be most helpful in generating form responses for the others.

Thanks!

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

15-Feb-1995 05:27pm

TO: Diana M. Fortuna

FROM: Deborah N. Pearlstein
 Presidential Correspondence

SUBJECT: RE: Form letter on PAIMI

Got your draft, thanks. Here's a crack at it -- feel free to hack it to pieces...

Thank you for writing to me about the Protection and Advocacy for Individuals with Disabilities program (PAIMI). I share your deep concern for the people this program serves, and I have forwarded your letter to my Domestic Policy staff for their consideration.

As my Administration works to promote the inclusion and independence of all of our citizens, I remain committed to safeguarding the rights of Americans with disabilities. That's why I am determined to ensure that our proposal to allow states greater flexibility in addressing the needs of their residents in no way compromises the integrity or efficiency of PAIMI.

I appreciate knowing your perspective on this important issue. As we move forward in our efforts to build a brighter future for all Americans, I welcome your continued involvement.

Bl Gt -

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E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

16-Feb-1995 11:19am

TO: Diana M. Fortuna

FROM: Deborah N. Pearlstein
 Presidential Correspondence

CC: Lynn M. Margherio

SUBJECT: RE: PAIMI draft

As I understand our current position on PAIMI, the sentence may be read to be factually correct in that the Admin. IS committed to state flexibility in general, and that our intention IS to maintain the integrity of the PAIMI program.

The concern, I think, is that "I am determined to ensure" might be a stronger statement than we are prepared to make right now, in which case we should hold off 'til after a firm decision gets made (on Friday?). I would caution against weakening the existing letter, as in, "I am working hard to ensure" or "I will seek to ensure..." A letter that's too carefully worded would be counterproductive.

From my non-policy perspective, I would recommend either leaving the letter as is (that is, not weakening it any further) or doing a Carol Rasco letter, (e.g. "On behalf of President Clinton, thank you for writing...") indicating that the President's proposal stands, but staff is working on various modifications to meet the goals of...

Hope this helps. Talk to you soon.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

24-Feb-1995 05:17pm

TO: Diana M. Fortuna

FROM: Elisabeth S. Topel
 Office of Mgmt and Budget, HD

CC: Nancy-Ann E. Min
CC: Barry T. Clendenin
CC: Richard J. Turman

SUBJECT: RE: PAIMI program

The Secretary will be transmitting the specs to the hill toward
the end of next week. Once the specs have gone to the Hill, the
~~policy will be official.~~

DRAFT

Dear Representative Waters:

Thank you for your letter to the President regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. I have been asked to respond to your letter on his behalf.

We share your concern for the protection of the rights of mentally ill Americans. The Administration has decided that SAMHSA will continue to administer the PAIMI program as a separate grant, distributing funds directly to protection and advocacy agencies.

We look forward to working with you on these issues. Thank you again for your letter.

Sincerely,

DRAFT

Alice Rivlin

Fax # 6-7028

FAX**Health Division**

Office of Management and Budget
Executive Office of the President
Washington, DC 20503

TO: Diana Fortuna**FROM:** Lissa Tope**Fax Destination****Organization:****Phone Number:** 395-4929**Number of Attached Pages:** 1**Notes:**

New PAIMI draft letter incorporating Deborah Pearlstein's comments. Please let me know if this is acceptable, so I can pass it on to Nancy-Ann. ☺

HD Fax Number: 202/395-3910**Voice Confirmation:** 202/395-4922

202/395-4925

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202/395-4930

Health Division Front Office**Health & Human Services Unit****Health Programs & Services Branch****Health Financing Branch**

CAR to states

PAR

PA Assine

↘ got asid
gate area

Curt Becker - 2/8/95
Wall of - 7/2/95

15 states - Govs out together
Gov must submit plan - Sec app
Assertion to P&A
Some states must be approved
Keg 3 app of process

ADD/P&A
CMAA

Program Admin Review (P&A)
SAMHSA - that's what they want to be
KAPS - 3 P&A's
P&A - 6013

Only take most extreme cases

P&A's also get state grants, private grants, other grants
at first some D. Gallman

III. COMPLIANCE ISSUES

1. P&A Independence - Section 142(a)(2)(G)

The P&A System must be independent of any agency which provides treatment, services, or habilitation to individuals with developmental disabilities.

RE: Guardianship Program - 45 CFR Section 1386.20(b)

An agency of the State or private agency providing direct services, including guardianship services may not be designated as a P&A agency.

In March of 1984 the Department of Health and Human Services issued above regulation, 45 CFR Section 1386.20(b), to further clarify the statutory language in Section 142(a)(2)(G). This regulation is in full force and effect today. In that regulatory document, published March 27, 1984, there appeared the following discussion of non-designation of guardianship agencies as P&As:

"This paragraph of the NPRM proposed to preclude an agency of the State which provides guardianship services from being designated as the Protection and Advocacy Agency. . .

...The Department wishes to make clear the intent of this section. It prohibits designation as the P&A agency of any agency which provides direct services, including those which provide guardianship services, in order to avoid conflicts of interest. This section is not intended to dictate the kinds of cases which P&A agencies can handle. We have clarified Section 1386.20(b) by inserting the following phrase after the word State: " or private agency providing direct services, including." States affected by this section will be given one year from the date of issuance of this regulation to redesignate their P&A agencies in the event that redesignation is necessary to comply with 1386.20(b)." (emphasis added)

Even though Federal officials have reviewed KAPS since the issuance of the regulation, and have even complimented the agency on its guardianship program none of the prior Federal reviews have included a legal review of KGP in relation to this particular requirement.

Findings

- o KAPS is under contract with the Kansas Department of Social and Rehabilitation Services for receipt of its Federal funds under Protection and Advocacy programs, even though the Federal statutes require direct funding of private non-profit protection and advocacy systems. KAPS staff report

With performance expectations 5
in SD's - would more - begged
CMAA now has reg on street - 1st since '86

prob w/ our appr.
SAMHSA Gov in consolidation the 4/3?
P&A's w/ state been
w/med & for target
Activity - NRPAS today get
w/consen
a problem

Nat'l Assoc. SAMH Prog Drs. Clark Ross

NRA - don't want to work together
7/7

Legis -

Widgans in a consultation

Fed oversight of P&A
80's - some inefficacy
No conflict of int
Protect from Gov/State

Gov can yank w/ a reason w/ protection

Kassebaum

*Call Com re financing (penalty for loss)

no problems with this arrangement, however this contractual arrangement is in direct violation of the independence requirement in the statutory and regulatory provisions cited above. According to the contract the Federal grantee is the Kansas Department of Social and Rehabilitation Service, a service providing agency. The contract states:

" . . .Whereas, MH/RS has been designated to receive and administer, on behalf of the State of Kansas, federal funds appropriated and designated for the support of protection and advocacy services; . . .

There are two problems here. This contract may be invalid because the Governor's assurances indicate that the KAPS agency is the designated agency. At the same time if SRS is, in fact, the designated agency, then State's P&A System is not operating in compliance with Federal law.

Either way, the Governor and KAPS must resolve this contractual situation immediately.

- o KAPS operates the State funded Kansas Guardianship Program (KGP), a statewide guardianship service program for people with disabilities. Federal officials have examined the KGP program guidelines and policies and have concluded that KGP is a guardianship services program and cannot be characterized as a "legal or lay advocacy" program in the context of services authorized by Federally funded State protection and advocacy systems. (emphasis added)
- o The KGP is viewed by private attorneys, legal services attorneys, other advocacy and disability groups, consumers, and the judiciary as a guardianship services program.
- o Consumers and other advocacy groups reported that Kansans with disabilities who may not want to continue a guardianship relationship would not typically approach KAPS for legal representation to terminate guardianship because they see KAPS as the agency who arranged for them to be appointed a guardian in the first place.
- o The operation of KGP by KAPS is in direct violation of the above cited statute and regulation and presents a major conflict of interest in providing legal and lay advocacy services and appropriate remedies to Kansans with disabilities.
- o All referrals for the KGP program come from the primary service provider agency for people with disabilities in the State, Kansas Social and Rehabilitative Services (SRS). This creates a conflict of interest situation where KAPS is financially dependant on a service provider that could be

the subject of a legal complaint filed by KAPS on behalf of a client served by the provider.

- o Public commentaries repeatedly stated that the disability community identifies KAPS as the guardianship service program and NOT as the P&A System for Kansans with disabilities.
- o Consumers/parents/other advocacy groups report confusion when it comes to whether the P&A would represent people with severe disabilities who wished to challenge guardianship or modify an original guardianship order that included a KGP guardian.
- o The agency board minutes and the focus of the agency's energy and outreach indicate that KAPS is recognized and promoted as the Kansas Guardianship program and not as the P&A Systems for Kansans with disabilities.

Recommendations/TA Resources

- o KAPS must immediately sever their contractual relationship with SRS and notify the Grants Office at the Administration for Children and Families that they are the official grantee and that funds should be granted directly to them.
- o The State and KAPS must take immediate action to legally separate the operation and the administration of the P&A System from the KGP. Either KGP should be spun off as a totally separate entity with its own staff and board or the P&A System should be redesignated. Legal separation should occur as soon as is practicable to prevent continuing conflicts in client casework.
- o KAPS and the State should consult with legal counsel to assist with corporations and contract work related to the separation of the programs and the contractual arrangement with SRS.
- o ADD Regional and CO offices will be available to KAPS to offer technical assistance on program and fiscal compliance issues on request.
- o KAPS should contact the Federally sponsored Advocacy Training and Technical Assistance Center (ATTAC) to obtain information on how other States operate and to request targeted TA and, if need be, on-site consultants. TA, materials and training should be requested in the following areas: establishing a private non-profit, conflict of interest policies for the agency and the governing board, governance of a private non-profit, and roles and

Post-it Fax Note 7671		Date 1-27-95	# of pages 8
To Diane Fortune	From Stan Herr		
On/Dept. DPC	Co. MyPlan		
Phone # (202) 456-5570	Phone # (410) 706-3191		
Fax # 202-456-7024	Fax # 706-3856		

Jan. 27, 1995

Dear Diane:

Here's some background on the P&A issue we discussed.

As I mentioned, I think the position of NAPAS is very well-taken and someone in SAMHSA or OMB is making a colossal mistake.

The legislative history behind the various P & A acts was that the states in places like Willowbrook and other state mental institutions were grossly abusing the legal and human rights of persons with mental disabilities. Hence Congress specified that P&As should be independent of state government and the providers of mental health and related services.

This block grant proposal would make the PAIMI program extremely dependent on state governments, and would have a dramatically chilling effect on the pursuit of the legal and other remedies that Congress has expressly mandated for them. It would also suggest to the States that this is just one of the menu of service options that a state could fund or not, whereas Congress devised the P&As as a civil rights program that had to be created as a condition for other forms of federal assistance to flow.

I hope this information is helpful. This is the type of issue that I would have raised to Carol's attention and sought to reverse if I were still with the DPC. Curt Decker, Executive Director, is a very credible advocate and is capable of pushing lots of buttons in DC and around the country that could hurt administration credibility across a wide front of disability matters. It's a real red flag that could deprive mental patients of the advocacy help they need.

Hope this information is helpful. Please feel free to call if I can be of further help.

Best wishes to Carol and the DPC gang!

Stan Herr



Attachment previously faxed (7 pages)

JAN-26-95 THU 16:03

N A P A S

NAPAS

National Association

Post-it Fax Note 7671		Date 1-27-95	# of pages 8
To Diane Fortune	From Stan Kern		
Co./Dept. DPC	Co. Md Lane		
Phone # (202) 456-5570	Phone # (410) 766-3191		
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Zena Naiditch (IL)

At-Large

Stoney Polman (MI)
Hikmah Cardiner (PA)
Harry Sarkisian (AZ)

Executive Director

Curtis L. Decker, J.D.

ACTION ALERT

January 25, 1994

**PRESIDENT RECOMMENDS BLOCK GRANTS FOR
PAIMI,
MENTAL HEALTH SERVICE PROGRAMS
other Disability Programs Likely to Follow**

As part of an overall effort to reduce the number of individual program lines in the FY96 budget, the Clinton Administration intends to roll the Protection and Advocacy for Individuals with Mental Illness (PAIMI) into the Mental Health Block Grant administered by the Substance Abuse and Mental Health Services Administration (SAMHSA). This would, most likely, result in the elimination of this critical program.

PAIMI is a \$22 million program that provides grants to politically independent agencies in each state to protect the rights of individuals with mental illness under federal and state law and to investigate allegations of abuse and neglect of individuals in state hospitals and other residential and care and treatment facilities.

PAIMI should not be block granted:

* The role of the PAIMI program -- to protect and advocate for individual rights -- often puts the Protection and Advocacy (P&A) program in an adversarial posture with state service systems. Block granting P&A programs would make them particularly susceptible to political interference, a fact that would lead to the elimination of the system in many states.

* Protection and Advocacy programs are not service programs in the ordinary sense, they are civil rights programs that monitor abuse, neglect and service delivery. To be effective, they must remain independent of the service delivery system.

* The ability to monitor service programs at the state and local level will be crucial as the federal government shifts more and more service delivery responsibility to the states. P&As are a cost effective way to monitor state compliance with federal laws and regulations.

FAX: (202) 408-9520 TDD: (202) 408-9521
Electronic Mail: HN4537@handsnet.org

JAN-26-95 THU 16:04

N A P A S

FAX NO. 2024089520

P. 03

Refused

Post-it Fax Note 7671		Date 1-27-95	# of pages 8
To Diane Fortune		From Sk. Hen	
Co./Dept. DPC		Co. McLean	
Phone # (703) 456-5570		Phone # (410) 706-3191	
Fax # 202-456-7028		Fax # 706-5856	

CC: Lynn M. Ashford

PRESIDENT RECOMMENDS BLOCK GRANT, cont.

- * PAIMI and P&As are a consumer driven. Each program is required to establish priorities based on local need. The priority setting process is governed by a locally based board comprised of consumers and family members.
- * The cost effectiveness of the P&A system has consistently been demonstrated through the large number of individuals served or who have benefited from systems change activities despite the small funding levels.
- * Historically, the federal government has advanced civil rights, not the states. Since this P&A system is mandated to advocate and protect one's civil rights, this system should remain a federal responsibility.
- * With passage of the Americans with Disabilities Act, citizens with disabilities have just recently begun to realize the fulfillment of our nation's promise to guarantee the human and civil rights of all Americans. Destruction of the federal system designed to enforce these rights would make passage of the ADA a hollow promise.

ACTION NEEDED:

The Clinton Administration must be told that individuals with disabilities will not allow their rights to take a back seat to ill conceived attempts to reduce the size of the Clinton budget. Fax, write or e.mail the White House and share your support for PAIMI and the rights of individuals with disabilities.

Fax: 202- 456 - 2883.

Write: The Honorable William J. Clinton
The White House
Washington, DC 20500

e.mail: President@whitehouse.gov

For Additional Information Contact Matthew Summy at 202-408-9514.

JAN-26-95 THU 16:05

N A P A S

FAX NO. 2024089570

P. 04

DATE

Alice Rivlin, Director
Office of Management and Budget
Old Executive Office Building
17th and Pennsylvania Avenue, NW
Room 252
Washington, DC 20503

Dear Director Rivlin,

In the effort to streamline the Public Health Service budget, you are about to do serious damage to a small but critical program, Protection and Advocacy for Individuals with Mental Illness. PAIMI is a \$22 million program that provides grants to independent agencies in each state to protect the rights of individuals with mental illness under federal and state law and to investigate allegations of abuse and neglect of individuals in state hospitals and other residential care and treatment facilities.

Currently, this program is authorized through free standing legislation. Under the law, the Secretary of Health and Human Services makes grants directly to "eligible systems" to carry out the provisions of the law. The ability of the Secretary to make these grants directly -- without governor interference -- is crucial. PAIMI's charge is to protect and advocate for the rights of our society's most vulnerable individuals, those in institutions. This charge, often places the Protection and Advocacy (P&A) system in an adversarial posture with state service systems. Block granting P&A programs would make them particularly susceptible to political interference, this would lead to the elimination of the only rights protection system for individuals with disabilities in many states.

PAIMI is not a mental health service program in the ordinary sense. It is a program that provides crucial monitoring of abuse and neglect in state residential care facilities and state service programs. To be effective, PAIMI must be kept independent of the service delivery system and must be protected from any potential political interference.

I urge you to keep the PAIMI program as a separate line in the President's budget. In its nine years of existence, PAIMI has served hundreds of thousands of Americans and benefited untold thousands more through systems change activities. Now, more than ever, as program responsibility is shifted from the federal government to the states, it is of the utmost importance to have a proven, cost effective monitoring program in place at the federal level. Do not put the rights of the most vulnerable individuals with disabilities in jeopardy by block granting this vital program.

Sincerely,

YOUR NAME

JAN 26-95 THU 16:05

N A P A S

FAX NO. 2024089520

P. 05

FEDERALLY-DIRECTED PROTECTION AND ADVOCACY FOR PERSONS WITH DISABILITIES

"By giving millions of retarded Americans ready access to the legal system, we guarantee their inalienable rights as citizens and strengthen the fabric of our society."

*Richard Nixon, 1973
on passage of the Developmental Disabilities Act*

I. INTRODUCTION

Congress is now debating the proper role of the federal government in providing services to citizens, including people with disabilities. There is strong support for placing more responsibility for service delivery with the states, while retaining the federal government's role in coordinating demonstration and research projects. As responsibility for service delivery devolves to the states, another appropriate role for the federal government is oversight and monitoring. Indeed, these functions must be implemented at the federal level to ensure conflict-free service delivery. As described below, the federally-directed but locally administered protection and advocacy system as now structured provides an appropriate level of state control and effective monitoring and oversight of services delivered to persons with disabilities.

II. ADVOCACY IS AN APPROPRIATE FEDERAL ROLE

A. Realizing Constitutional and Statutory Protections

A federally directed advocacy system is necessary to ensure that fundamental rights guaranteed by the Constitution are a reality in the daily lives of people with disabilities. Inherent in the concept of due process - the basic operating principle of our judicial system - is that advice, counseling and representation are available to those who believe their rights have been impaired.

Similarly, a federally directed system enables people with disabilities to effectively use the myriad but essential statutory protections available to them. Many Federal services programs, including Social Security, Medicare, Medicaid, SSI, vocational rehabilitation and special education, to name only a few, contain administrative and judicial procedures to address grievances. Federally-directed advocacy programs offer professional assistance to people with disabilities who are unable to speak for themselves in navigating through the requirements of statutory due process.

B. Monitoring of State Action

States are now the largest provider of services for people with disabilities, and their role will increase as more authority, flexibility and resources are transferred to them. In order to ensure that services are provided to eligible individuals who are most in need in the manner the law intends, the Federal government must monitor state activities through variety of cost effective mechanisms. The protection and advocacy systems is one such mechanism. Its role should be expanded as the state role expands.

C. Funding Equity

The formula for state grants in the protection and advocacy system assures equitable funding. For instance, minimum allotment requirements guarantee that all states, regardless of size, are able to conduct a viable program, while giving larger states allotments which address the needs of their populations. This national approach also allows for targeting special populations that would otherwise be overlooked.

D. Comprehensiveness and Consistency

A federally-directed system ensures comprehensive and consistent delivery of advocacy services in each state. This is especially important as major advocacy programs traditionally have been federal in scope and mandate. Moreover, such a system allows for efficient federal provision of training and technical assistance.

E. Political Neutrality

Federal direction is necessary to minimize political interference at the state level. Such federal control is necessary to ensure the preservation of advocacy programs -- in every state -- in the face of potential political opposition by individual states.

JAN-26-95 THU 16:07

N A P A S

FAX NO. 2024089520

P.07

III. ***A FEDERALLY-DIRECTED PROTECTION AND ADVOCACY SYSTEM IS VITAL TO ENSURING EFFECTIVE DISABILITY RIGHTS PROTECTIONS NATIONWIDE***

A. **Background -- the Origins of the P & A System**

After becoming aware of the inhumane and despicable conditions at Willowbrook, a New York State institution for persons with developmental disabilities, Congress enacted the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (the DD Act) -- to protect the human and civil rights of this vulnerable population. Protection and Advocacy systems (P & As) were established, as a central component of the DD Act, to ensure that these protections became a reality. Congress recognized that such a federally directed system of legal advocacy is necessary "to ensure the humane care, treatment, habilitation and protection of mentally retarded and other persons with developmental disabilities. The Federal Government has the responsibility to provide equal protection under the law to all citizens."

Similarly, following congressional hearings and investigations which substantiated numerous reports of abuse and neglect in state psychiatric hospitals, former Senator Weicker introduced the bill which eventually became the Protection and Advocacy for Individuals with Mental Illness Act of 1986 (the PAIMI Act). The PAIMI Act, modeled after the DD Act, extends similar protections to persons with mental illness. The Act was precipitated by, among other things, the finding that persons with mental illness have been subjected to abuse and neglect, including lack of treatment, adequate nutrition, clothing, health care and adequate discharge planning; and that existing state systems for monitoring the protection of the rights of this population "vary widely and are frequently inadequate."

Under the Protection and Advocacy for Individual Rights (PAIR) program, established by the Rehabilitation Act, as amended, P & As also have the authority to serve persons with disabilities who are not eligible under the DD and PAIMI Acts. PAIR represents a vitally important component of a comprehensive effort to advocate for the rights of all persons with disabilities.

JAN 26, 95 THU 16:07

N A P A S

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P. 08

The current federally-directed P & A system structure has a number of features which are especially important in guaranteeing effective protections for the human and civil rights of persons with disabilities.

B. Elements of State Control

1. Governor's Designation

Under the existing P & A system, each state's chief executive determines which entity serves as the P & A within the state. However, once designated, the P&A is protected against decertification. This system feature, in existence for nearly twenty years, has proven to be a workable approach for ensuring an appropriate level of state control. The Governor's responsibility is to ensure some state oversight of the P & A, without programmatic interference.

2. Consumer Control of Governance

The P & A statutes require significant consumer involvement in governing the system. This again ensures local control by those persons most affected. Governing boards must be comprised of persons who broadly represent and are knowledgeable about the needs of the P & A's clients. For instance, the PAIMI Act requires that at least 60% of the P & A's advisory board members be individuals who have received or are receiving mental health services, or family members of such individuals.

3. Priority Setting with Community Input

All the programs in the P & A system must have an open and statewide priority setting process to identify issues for case selection and systemic advocacy. This process must promote full participation by the disability community. This allows each state to develop a work plan for its agency which highlights the most pressing issues in that locality and takes into account the organization of the service system in that state.

4. Grievance Procedure

Each program must have an internal grievance procedure for clients and prospective clients to assure that such persons have full access to the services of the system. This provides credibility for a system which is demanding the same accountability of the larger service delivery system. It also provides a meaningful way for clients to impact the operation of the P & A system.

CC Lynn M
Return to Diane

statutory history

Protection and Advocacy Systems were initially developed to address public outcry in response to the abuse, neglect and lack of programming in state institutions for persons with disabilities. Congress created distinct statutory programs to address the needs of different populations of persons with disabilities.

The Protection and Advocacy for Persons with Developmental Disabilities (PADD) Program was created by the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (Public Law 94-103). This Act mandated that each state and territory establish a protection and advocacy system no later than October 1, 1977 as a condition for receiving its minimum state grant allotment under the Act for the provision of services to persons with developmental disabilities. P&As are required by the Act to pursue legal, administrative and other appropriate remedies to protect and advocate for the rights of individuals with developmental disabilities under all applicable federal and state laws. The governor in each state and territory designated a program as the P&A system, and has provided assurances that the system is independent of any service provider. Amendments added during the 1994 Congressional reauthorization of the Act expanded the system to include the establishment of a Native Americans Consortium P&A program.

The U.S. Department of Health and Human Services, Administration for Children, Youth and Families, Administration on Developmental Disabilities (ADD) administers the PADD program.

The Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program was established in 1986 by Public Law 99-319. This program is modeled after PADD. The PAIMI program was created to protect the rights of persons with mental illness under federal and state law and to investigate allegations of abuse and neglect of persons residing in residential care and treatment facilities. PAIMI, which faces reauthorization in 1995, has since been expanded to provide advocacy services for persons in homeless shelters, jails and detention centers, as well as cases of abuse and neglect while being transferred to such a facility. PAIMI programs may also provide services to individuals who may have been subjected to abuse and neglect in facilities operated by the Department of Veterans Affairs. The system designated to serve as the PADD program in each state and territory is also responsible for administering the PAIMI program.

The U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (CMHS) administers the PAIMI program.

The Protection and Advocacy for Individual Rights (PAIR) Program was established by Congress under the 1978 Amendments to the Rehabilitation Act, but no funds were appropriated for the program until FY 1991 and it did not reach its formula grant trigger until 1993. (Thus, for the first time, it became a nationwide program; previously, only 12 states were funded under PAIR, as a demonstration project.) PAIR grants, to P&A system nation-

wide, the authority to protect and advocate for services to persons with disabilities who are not eligible for the PADD and PAIMI programs, or whose issues do not fall within the jurisdiction of CAP. PAIR is similar to other P&A programs in that it grants authority to pursue legal, administrative and other appropriate remedies. However, PAIR is funded at a considerably lower level than PADD and PAIMI; consequently, available services under the program are quite limited in comparison to the others. Nevertheless, the PAIR program represents a vitally important component of a comprehensive effort to advocate for the rights of all persons with disabilities. The system designated to serve as the PADD program in each state and territory is also responsible for administering the PAIR program.

The U.S. Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration (RSA) administers PAIR.

The Client Assistance Program (CAP) was established as a mandatory formula grant program by the 1984 amendments to the Rehabilitation Act to assist persons with disabilities in securing vocational rehabilitation services mandated under the Act. Every state and territory, as a condition for receiving allotments under the Rehabilitation Act, must have a Client Assistance Program. The creation of CAP reflected Congressional belief that persons with disabilities may require assistance in obtaining information and access to the services available through the programs, projects and facilities funded under the Rehabilitation Act. CAP provides information and assistance to individuals seeking or receiving services under the Rehabilitation Act, including assistance in pursuing administrative, legal and other appropriate remedies to ensure the protection of their rights. >

The U.S. Department of Education, Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration administers CAP.

Assistive Technology. Originally passed by Congress in 1988, the Technology-Related Assistance for Individuals with Disabilities Act (the Tech Act), set up a lead agency in each state to coordinate activities to facilitate access to, provision of and funding for assistive technology devices and services for individuals with disabilities. In 1994, the Tech Act was expanded to include funding for P&As "to assist individuals with disabilities and their family members, guardians, advocates and authorized representatives in accessing assistive technology devices and assistive technology services" through case management, legal representation and self-advocacy training. Existing P&As are to receive between \$40,000 and \$100,000 in FY 1994 to conduct these activities.

The U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR) administers the Assistive Technology program.

pda and cap activities

P&A and CAP activities may include:

- (1) investigating, negotiating or mediating solutions to problems expressed by persons eligible for P&A and CAP services;
- (2) providing information and technical assistance to individuals, attorneys, governmental agencies, service providers and other advocacy organizations;
- (3) providing legal counsel and litigation services to eligible persons and groups who satisfy the established priorities of P&As and CAPs for the provision of services; and
- (4) providing education and training for their staff, governing boards, advisory councils, volunteers, service delivery professionals, constituency groups, and the community.

In addition, P&As and CAPs interact with elected and appointed officials to share information which will assist policy makers in making legislative and administrative changes which benefit persons with disabilities.

appropriations

Congressional Appropriations

The following chart demonstrates the history of congressional support for P&A and CAP programs:

U.S. Congressional Appropriations Fiscal Years 1976-94 (in \$ millions)

	PADD	CAP	PAIMI	PAIR
1976	1.5			
1977	3.0			
1978	3.0			
1979	3.8			
1980	7.5			
1981	7.5			
1982	7.68			
1983	7.32			
1984	8.4	6.0		
1985	13.75	6.3		
1986	14.6	6.412	9.5	
1987	15.0	7.5	10.5	
1988	19.148	7.1	10.555	
1989	19.76	7.682	12.4	
1990	20.48	7.901	14.001	
1991	20.98	8.313	15.614	.976
1992	22.500	9.140	19.5	1.074
1993	22.506	9.296	20.8	2.480
1994	23.753	9.547	21.957	5.5

Formula Grants

Each designated system receives funding to implement the PADD, PAIMI, PAIR and CAP programs through a formula grant. The formula, while slightly different for each of the four programs, is essentially based on the population and per capita income in the state.

Each state is given a minimum allotment which is incrementally increased as the population of the state increases. Approximately 20 states receive a minimum allotment for each program.

In FY 1994, the minimum allotment for PADD, PAIMI and CAP was \$226,266, \$259,782 and \$100,000, respectively. The minimum allotment for territories is \$121,052, \$139,242, and \$45,000, respectively. In contrast, the largest state received \$1,957,574 for PADD, \$1,911,186 for PAIMI, and \$956,935 for CAP.

PAIR allotments include \$100,000 for each state and \$50,000 for each eligible territory.

summary & analysis

P&As (with exception of PAIR) and CAPs are required to submit annual Program Performance Reports (PPRs) to the federal administering agencies: Administration on Developmental Disabilities (ADD), Center for Mental Health Services (CMHS) and Rehabilitation Services Administration (RSA). These reports require programs to compile data on the number and demographic composition of individuals served.

Currently, the administering agencies utilize different definitions to determine client eligibility. Eligibility for the four programs are defined by their respective statutes.

ADD and CMHS agree on the definition of what constitutes a client in terms of the level of services provided by the PADD and PAIMI programs. A client is defined as an individual for whom the P&A system provides a direct service or intervention. Each individual client is counted only once during a fiscal reporting period, regardless of the number of times he/she returns for assistance or the number of services provided. Individuals carried over as clients from the previous year are included in this count.

Eligibility for PADD advocacy services, require that one meet the definition of developmental disabilities as defined in the DD Act. Developmental disabilities are chronic and attributable to mental and/or physical impairments which are evident prior to age twenty-two. Such disabilities tend to be life-long and result in substantial limitations in three or more of the following major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living, and/or economic self-sufficiency. In addition, each program establishes priorities for case selection. The priorities vary from State to State and are based on consumer input and review.

Individuals eligible for services under the PAIMI Act must reside in residential facilities which provide care and treatment, or have been discharged from such a facility within the past 90 days. Under the 1988 amendments, PAIMI programs were given the authority to represent clients in certain situations involving prisons and jails, and transportation to and from such facilities. In 1991, the jurisdiction was expanded again to include facilities assisting persons who are homeless, as well as federal facilities. PAIMI programs also establish priorities for case selection and vary from State to State.

RSA defines a client of CAP as one who has a record of confidential information maintained on file, and one who has requested assistance in a situation requiring some type of intervention with a Rehabilitation Act project, program or facility. Under this definition, a new client is counted each time a case is opened without regard to the number of times a case may have been opened and closed for a particular individual during the reporting year.

The data collected on the number of clients served by all three programs should reflect only

those individuals for whom a "significant service" was rendered. "Significant service" has not been clearly defined by the administering agencies but generally is more than information and/or referral and includes such criteria as at least one hour of devoted staff time, some type of follow-up by staff to the client and/or the collection and review of information.

Client data should not reflect individuals who benefited from the resolution of class actions or other problems involving groups or individuals who only receive information or referral. Individuals who receive only educational services from the program are not counted as clients of the program. The number of information/referral contacts and persons benefiting from educational activities are collected separately within the PPR.

Total Clients Served

The P&As and CAPs served approximately 66,538 individuals¹ from October 1, 1992 to September 30, 1993. This number represents a decrease from FY 1992, when the three federally mandated programs represented over 71,082² clients.

50 CAP handled more cases in FY 1993, representing 11,246 clients, an increase of 443 cases from the 10,803⁰ reported in FY 1992.

PAIMI and PADD both demonstrated decreases in the number of clients represented. Under PAIMI, 18,394 clients were served in FY 1993, 1,985 fewer than in FY 1992. PADD served a total of 36,898 clients in 1993 while representing 39,900 the prior year. States which demonstrated decreases of 100 or more clients were largely medium to large states, several of whom experienced a significant loss in supplemental state funding which had previously increased their ability to serve greater numbers of clients. Programs also indicated that the eligibility guidelines were more strictly enforced as reporting requirements have tightened.

In FY 1992, state PADD programs were required by the Administration on Developmental Disabilities to develop a Statement of Objectives and Priorities, in order to insure that these programs were serving unserved or under-served persons with developmental disabilities as a

¹ Fiscal Year 1993 figures do not include Guam CAP or DD data and are unofficial and therefore subject to change upon federal review.

² This figure is official and amends the reported clients served in the 1992 NAPAS Annual Report which reported a total of 70,303 clients served in FY 1992.

high priority. In response, the programs developed priorities, after receiving public comment, which insured that the most vulnerable populations or those with complex advocacy needs were served before less vulnerable populations. The need to prioritize was necessary as the demand for representation exceeded the ability of the P&A to provide quality services. A noticeable shift occurred as state PADD programs developed more sophisticated skills in addressing the complex issues facing clients as those individuals move from institutional settings to community based environments. These clients' need for appropriate services is more complex, and involve not only habilitation but also access to financial entitlement programs, housing and employment.

Advocacy and Outreach For Eligible Clients Who Are Racial/Ethnic Minorities

P&As and CAPs continue to improve their representation of racial and ethnic minorities. Nationally, the racial demographic for all three programs is statistically consistent with the national average, with the exception of individuals who identify themselves as Asian Americans or Pacific Islanders. These groups continue to be underserved by all three programs.

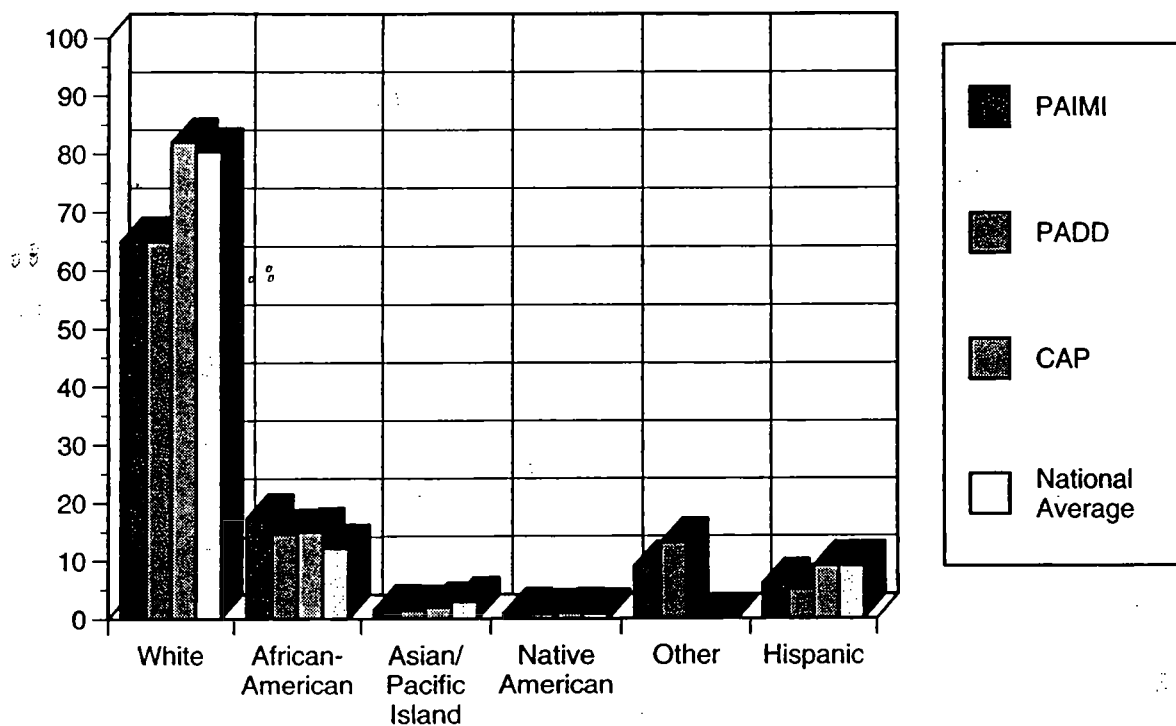
PAIMI and CAP programs have improved their data collection related to racial and/or ethnic groups during FY 93. PAIMI reported only 9% of their clients as unknown or other, an improvement from FY 92 when 18% of their clients were not identified according to racial or ethnic group. CAPs collected racial or ethnic information on all but 612 clients. PADD programs failed to report information on over 13% of their clients.

PADD and PAIMI numbers fall slightly behind the national demographic data in the representation of individuals who identify themselves as Hispanic. This may be due to how the information is collected on the PPRs which require individuals to be identified first as white, African-American, Asian-American, Pacific Islander or Native American and only then allows identification as Hispanic.

The Board of Directors of NAPAS has a standing Multi-Cultural Committee which provides advice and support on a variety of multi-cultural issues including data collection. The NAPAS Multi-Cultural Committee is reviewing how persons are asked to identify for the purpose of data collection and will be making recommendations to the administering agencies in the future. The Multi-Cultural Committee also provides advice and support for all NAPAS training activities related to cultural content. Multi-Cultural training will continue to be a NAPAS priority.

Several programs across the country now have full time outreach staff positions to coordinate the provision of advocacy and training services to staff regarding the needs of minority populations within their state. NAPAS, through its Training and Technical Assistance activities, has provided a significant amount of training to P&As to develop strategies for outreach and promotion of cultural competency. In addition, two half day seminars on cultural diversity were conducted for CAPs.

Compared by Race to National Average

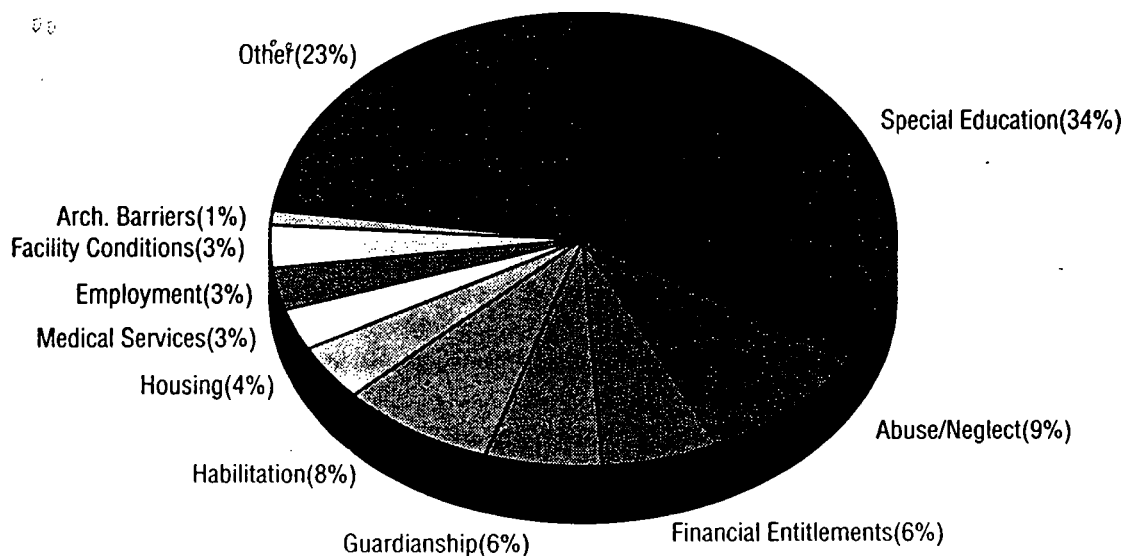


case studies

In addition to the many significant cases and initiatives that P&A and CAP agencies have pursued individually, a number of P&As were (and continue to be) involved in a multi-state cooperative legal initiative designed to restrict the improper use of painful aversive "treatment" at a facility for persons with disabilities. This initiative is being coordinated by the NAPAS Advocacy Training and Technical Assistance Center (ATTAC) and one of its legal back up centers, the Center for Public Representation. The initiative has had some early success - which reinforces NAPAS' view that such collective legal strategies enhance the effectiveness and visibility of P&As.

NAPAS has determined to go forward with additional multi-state legal initiatives in the coming months. The initiatives that are under review and development would focus on using Americans with Disabilities Act (ADA) enforcement to improve access to governmental processes (e.g., the electoral process) for persons with disabilities, and would address the excessive institutionalization and maltreatment of children with mental illness and serious emotional disturbance.

Case Problems PADD



	Special Education		Guardianship		Medical Services		Arch. Barriers
	Abuse/Neglect		Habilitation		Employment		Other
	Financial Entitlements		Housing		Facility Conditions		

Lynn - Avoid 10-11-30

Turman

2/6

PAIMI - W/in MH perf partnership
Self-aside

ease process of applic + admin
(Now: states get)

13 restrictions now

275 existing
P+H + P+A

#21

326 in total

SAMHSA - MH grant
3

CDC, HRSA, SAMHSA

Other P+A3 → Educ.

* Is it temporary? (MOE)

GC?

Maybe change

Call ~~Reid~~ / Nelba

Arns

- Gov may not apply timely

- Gov designates P+A PD
- same agency PAIMI

- Apply directly

- States aware on experiment
in their interest

- No legislation: letter to HHS

* Can we tell world re APICS

Budget 43 - set fds
aside
for continuation
(same level)

2% tech assistance

not endangered?

No 4-19 mechanism remains

* MH \$ wasn't cut

- Turnover to F-
if not legally det'd

Not all concerned
Ward Allen... on PAI - P... W... L... or L... L...

Not so much cuts
than thru negot.
M - a state agency
most are not
concerned

Substance Abuse and Mental
Health Services Administration
Rockville MD 20857

JAN 30 1995

~~CONFIDENTIAL~~

DETERMINED TO BE AN
ADMINISTRATIVE MARKING

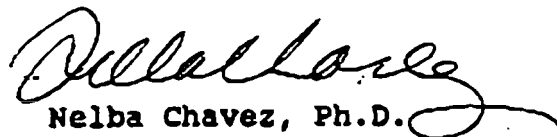
MEMORANDUM TO: Center Directors INITIALS: DJ DATE: 5/14/2018
FROM: Administrator 2018-0525-5
SUBJECT: Communications About the FY 1996 Budget

I wanted to let you know that I have completed my calls to the major constituency groups concerning the broad outlines of the budget. Attached is a copy of the talking points that we used in making these calls and a list of the organizations contacted. I also would like to share this information with the members of each Council, and have therefore, requested that a conference call be set up for me and you and your Council members for next week.

I believe it would be appropriate at this time for you to convey the same message (orally) to your division directors and other key staff, if you have not already done so. However, please ask them to share information on a need to know basis, and not to discuss the budget with outside individuals or groups until after the President's budget is released.

Also, consistent with discussion at the Management Team Meeting on January 24, we are making plans to ensure that staff and other interested individuals are notified about key aspects of the budget proposals after February 6. These plans include the development of a fact sheet and a Qs and As document. We plan to send this out to all SAMHSA employees on the LAN, and also do a mailing of this material to all of the constituency groups that are part of the Strategic Planning process. A draft of this material will be circulated for your review the end of next week.

With regard to press inquiries, I am requesting that all inquiries be referred to the SAMHSA Office of Communications to help ensure that a consistent message is conveyed to the press.


Nelba Chavez, Ph.D.

Attachments

cc: Management Team

TALKING POINTS
1996 PRESIDENT'S BUDGET

JAN 25 1995

- o Calling to alert you to some major changes which will be proposed when the President announces his budget on February 6.
- o As you know, details of budget proposal must remain confidential, and cannot be disclosed to you until the first week in February.
- o However, sure you have been hearing rumors regarding SAMHSA and its programs, so would like to provide you a broad outline of how the budget will affect the Agency.

GENERAL

- o Perhaps most importantly, the Administration continues to believe in SAMHSA programs, and is not proposing to abolish or merge SAMHSA with other agencies.
- o Overall, the SAMHSA budget will not be cut in 1996.
- o However, some changes will occur in the context of an overall shift in federal programs and relationships. SAMHSA will need to:
 - Consolidate the large number of discrete programs we now have,
 - Continue and strengthen partnerships with States, community groups, and other concerned organizations such as yours,
 - Focus on performance and outcome measures in conjunction with accountability for changes in State health status, and
 - Streamline our internal operations.

CONSOLIDATIONS

- o Beginning in 1996, SAMHSA will administer four programs, separate mental health and substance demonstration programs and two "Partnership" Block Grants.
- o The most significant change will be the consolidation of most of our categorical demonstration, service and training programs into two larger, more flexible demonstration programs.
- o The demonstrations will focus on knowledge development rather than service delivery. We fought hard to maintain this key federal responsibility.

-2-

- o We intend to set the demonstration agenda through a process involving States and other interested parties.
- o All continuation commitments for currently-funded demonstration projects will be honored.
- o The State Partnership Block grants will be similar to the current Block Grants, but without most of the earmarks and requirements. Instead, SAMHSA will work together with States to monitor progress against broad program goals addressing the State's health status.
- o In both the demonstration and the Block Grant areas, we will continue to emphasize primary prevention as a key component of our mental health and substance abuse programs.

Streamlining

- o Downsizing the demonstration effort and reinvention initiatives will require us to further downsize the SAMHSA staff complement beginning in 1996.
- o While this will be difficult, it will be do-able. We have already begun working internally to restructure the Agency to adapt to the new budget and program realities.

SUMMARY

- o While we cannot tell you much more at this point, we believe you can see the overall picture for SAMHSA.
- o We are optimistic about SAMHSA's future. We will be a leaner operation, but continue to focus on our national leadership and knowledge development objectives.
- o Of course, this means we are going to rely even more heavily on your future assistance and advice. We appreciate the support you have given us, and our frequent communication is going to be essential for this new program arrangement to work in everyone's best interest.

PAD

Persons With
Developmental
Disabilities

Protection &
Advocacy For
Individuals
With

January 27, 1995

SAMHSA CONSTITUENTS – LIST I

Those Nelba has spoken with as of January 27, 1995.

Substance Abuse Groups

Community Anti-Drug Coalitions of America (CADCA)

Legal Action Center (LAC)

**National Association of State
Alcohol and Drug Abuse Directors, Inc. (NASADAD)**

- **National Association of Alcohol
and Drug Abuse Counselors (NAADAC)**

Prevention, Intervention, Treatment Coalition for Health (PITCH)

- **The Society of Americans for Recovery (SOAR)**
- **Therapeutic Communities of American (TCA)**

American Psychological Association (APA)

**Judge David L. Bazelon Center
for Mental Health Law**

Federation of Families for Children's Mental Health

National Mental Health Association (NMHA)

National Association of State Mental Health Program Directors (NASMHPD)

National Alliance for the Mentally Ill (NAMI)

National Community Mental Healthcare Council (NCMHC)

National Coalition for the Homeless (NCH)

National Alliance to End Homelessness (NAEH)

National Families in Action

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

02-Feb-1995 04:55pm

TO: Diana M. Fortuna

FROM: Carol H. Rasco
 Economic and Domestic Policy

CC: Jeremy D. Benami
CC: Lynn M. Margherio

SUBJECT: RE: Protection & Advocacy proposal

I think there should be a thorough discussion of this issue with
our General Counsel's office. We sure don't want this White House
to get blindsided by groups that we haven't thought about yet on
this issue and I sure think Mrs. Gore's office needs to be briefed
/ consulted before any decisions made. Why don't you all do those
two things and let's re-evaluate at that point?

Thanks.

Skila Harris

Michelle Hiroto

Withdrawal/Redaction Marker

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	To Diana Fortuna from Curt Decker re: Mtg tomorrow (partial, DOB, SSN) (1 page)	02/07/1995	b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12025

FOLDER TITLE:

PAIMI [Protection and Advocacy for Persons with Mental Illness]

2018-0525-S

ry2255

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

FEB-07-95 TUE 15:32

N A P A S

FAX NO. 2024089520

P. 01

*Forwarded:
received,
lis.*

To: Diana fortuna

From: Curt Decker

Date: February 7, 1995

Re: Mtg Tomorrow

Names	Date of Birth	Soc. Security
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Paul Marchand		
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Joe Manes		
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Matthew Summy		
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Curt Decker		
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Al Guida		
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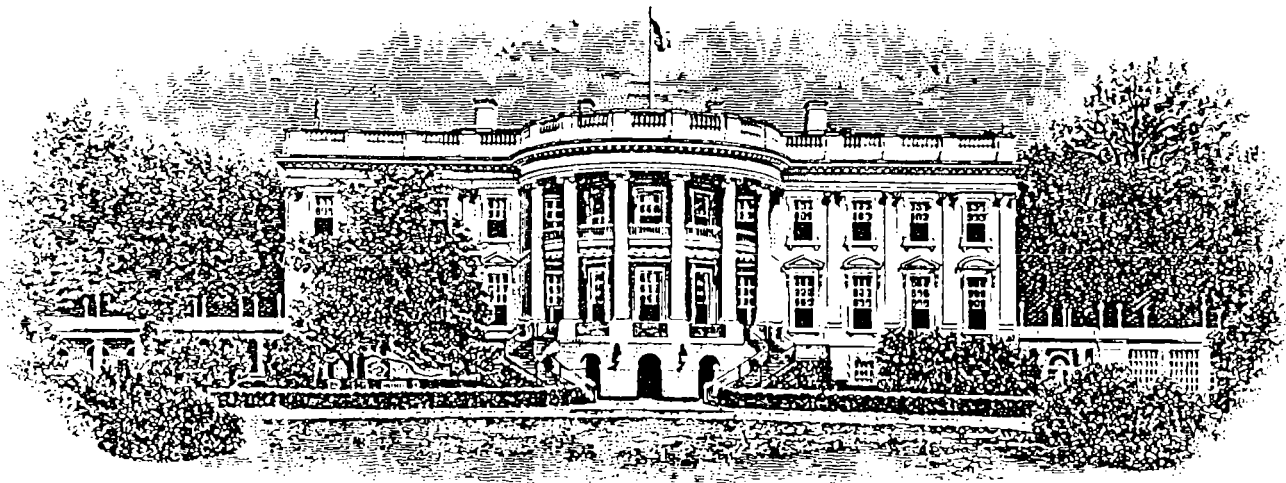
(b)(6)

(b)(6)

[001]

9am Wed 2/8 } 211 - OE OB

The White House



DOMESTIC POLICY

FACSIMILE TRANSMISSION COVER SHEET

TO: WAVES

FAX NUMBER: 395 - 5349

TELEPHONE NUMBER: _____

FROM: Lynn Margherio

TELEPHONE NUMBER: x65561

PAGES (INCLUDING COVER): 2

COMMENTS: _____

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

30-Jan-1995 01:41pm

TO: Lynn M. Margherio
FROM: Lisa B. Fairhall
 Office of Mgmt and Budget, LVE

CC: Richard E. Green

SUBJECT: RE: data reports

Responses have been trickling in over the fax, with promises of hard copies to follow. Some agencies (HHS and ED) have not yet respond

ed.

Others (Commerce, DOJ) are expected this week. Many of the individuals coordinating the exercise in the agencies have claimed that they did not receive the instructions until the middle of last week. The responses to date have varied in terms of depth and completeness -- Richard and I will be reviewing them over the next few days, to see whether the agency efforts have been credible.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

07-Feb-1995 07:18pm

TO: diana M. Fortuna

FROM: Richard J. Turman
 Office of Mgmt and Budget, HD

CC: Nancy-Ann E. Min
CC: Barry T. Clendenin
CC: Elisabeth S. Topel

SUBJECT: Protection and Advocacy

In response to your question about how specific to be with constituency groups about the current plans to 'wall off' protection and advocacy within the new Mental Health Performance Partnership, we checked with Nancy-Ann, and it is ok to indicate that this is planned.

As a practical matter, it may be best to leave it at that, since all the details haven't been worked out and the Administration hasn't actually sent any legislation to the Hill.

Give a call with any further questions.



National Association of Protection & Advocacy Systems

FACSIMILE TRANSMISSION SHEETDate: 1-31-95

Time: _____

To: Lynn Margerio

Firm: _____

Fax Number: 456-7028From: Curtis Decker

Number of Pages to Follow: _____

Please call 202-408-9514 if you did not receive
the complete number of pages.

Notes: _____

January 25, 1995

**PROTECTION AND ADVOCACY (P & A) SYSTEMS
FOR PERSONS WITH DISABILITIES**

"By giving millions of retarded Americans ready access to the legal system, we guarantee their inalienable rights as citizens and strengthen the fabric of our society."

*Richard Nixon 1973
on passage of the DD Act*

I. INTRODUCTION

Congress is now debating the proper role of the federal government in providing services to citizens, including people with disabilities. There is strong support for placing more responsibility for service delivery with the states, while retaining the federal government's role in coordinating demonstration and research projects. As responsibility for service delivery devolves to the states, another appropriate role for the federal government is oversight and monitoring. Indeed, these functions must be implemented at the state level to ensure conflict-free service delivery. As described below, the federally-directed but locally administered protection and advocacy system as now structured, provides an appropriate level of state control and effective monitoring and oversight of services delivered to persons with disabilities.

II. ADVOCACY IS AN APPROPRIATE FEDERAL ROLE

A. Realizing Constitutional and Statutory Protections

A federally directed advocacy system is necessary to ensure that fundamental rights guaranteed by the Constitution are a reality in the daily lives of people with disabilities. Inherent in the concept of due process - the basic operating principle of our judicial system - is that advice, counseling and representation are available to those who believe their rights have been impaired.

Similarly, a federally directed system enables people with disabilities to effectively use the statutory protections available to them. Many federal service programs, including Social Security, Medicare, Medicaid, SSI, vocational rehabilitation and special education, to name only a few, contain administrative and judicial procedures to address grievances. P & A advocacy programs offer professional assistance to people with disabilities who are unable to speak for themselves in navigating through the requirements of statutory due process.

B. Monitoring of State Action

States are now the largest provider of services for people with disabilities, and their role will increase as more authority, flexibility and resources are transferred to them. In order to ensure that services are provided to eligible individuals who are most in need in the manner the law intends, the federal government must monitor state activities through a variety of cost effective mechanisms. The protection and advocacy system is one such mechanism. Its role should be expanded as the state role expands.

C. Funding Equity

The formula for state grants in the protection and advocacy system assures equitable funding. For instance, minimum allotment requirements guarantee that all states, regardless of size, are able to conduct a viable program, while giving larger states allotments which address the needs of their populations. This national approach also allows for targeting special populations that would otherwise be overlooked.

D. Political Neutrality

It is necessary to minimize political interference at the state level. And, it is necessary to ensure the preservation of advocacy programs -- in every state -- in the face of potential political opposition by individual states when the programs are protecting against abuse and neglect within state operated or licensed programs.

III. A PROTECTION AND ADVOCACY SYSTEM IS IMPORTANT TO ENSURING EFFECTIVE PROTECTION AGAINST ABUSE AND NEGLECT NATIONWIDE**A. Background -- the Origins of the P & A System**

After becoming aware of the inhumane and despicable conditions at Willowbrook, a New York State institution for persons with developmental disabilities, Congress enacted the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (the DD Act) -- to protect the human and civil rights of this vulnerable population. Protection and Advocacy systems (P & As) were established, as a central component of the DD Act, to ensure that these protections became a reality. Congress recognized that such a system of legal advocacy is necessary "to ensure the humane care, treatment, habilitation and protection of mentally retarded and other persons with development disabilities. The Federal Government has the responsibility to provide equal protection under the law to all citizens."

Similarly, following congressional hearings and investigations which substantiated numerous reports of abuse and neglect in state psychiatric hospitals, former Senator Weicker introduced the bill which eventually became the Protection and Advocacy for Individuals with Mental Illness Act of 1986 (the PAIMI Act). The PAIMI Act, modeled after the DD Act, extends similar protections to persons with mental illness. The Act was precipitated by, among other things, the finding that persons with mental illness have been subjected to abuse and neglect, including lack of treatment, adequate nutrition, clothing, health care and adequate discharge planning; and that existing state systems for monitoring the protection of the rights of this population "vary widely and are frequently inadequate."

Under the Protection and Advocacy for Individual Rights (PAIR) program, established by the Rehabilitation Act, as amended, P & As also have the authority to serve persons with disabilities, often physical, who are not eligible under the DD and PAIMI Acts. PAIR represents a vitally important component of a comprehensive effort to advocate for the rights of all persons with disabilities.

The P & A system has a number of features which are especially important in guaranteeing effective protections for the human and civil rights of persons with disabilities.

B. Elements of State Control.

1. Governor's Designation

Under the existing P & A system, each state's chief executive determines which entity serves as the P & A within the state. However, once designated, the P & A is protected against decertification. This system feature, in existence for nearly twenty years, has proven to be a workable approach for ensuring an appropriate level of state control. The Governor's responsibility is to ensure some state oversight of the P & A, without programmatic interference.

2. Consumer Control of Governance

The P & A statutes require significant consumer involvement in governing the system. This again ensures local control by those persons most affected. Governing boards must be comprised of persons who broadly represent and are knowledgeable about the needs of the P & A's clients. For instance the PAIMI Act requires that at least 60% of the P & A's advisory board members be

individuals who have received or are receiving mental health services, or family members of such individuals.

3. Priority Setting with Community Input

All the programs in the P & A system must have an open and statewide priority setting process to identify issues for case selection and systemic advocacy. This process must promote full participation by the disability community. This allows each state to develop a work plan for its agency which highlights the most pressing issues in that locality and takes into account the organization of the service system in that state.

4. Grievance Procedure

Each program must have an internal grievance procedure for clients and prospective clients to assure that such persons have full access to the services of the system. This provides credibility for a system which is demanding the same accountability of the larger service delivery system. It also provides a meaningful way for clients to impact the operation of the P & A system.

February 7, 1995

Ms. Claudia A. Campbell
IPACHI
Suite B100
4455 Connecticut Avenue, N.W.
Washington, D.C. 20008

Dear Claudia:

Thank you for writing to me about the protection and advocacy system for Americans with disabilities. I appreciate knowing your perspective on this important issue, and I have forwarded your letter to my Domestic Policy staff for consideration.

As my Administration works to promote inclusion and independence for all of our people, I'm glad to know I can count on your involvement.

Sincerely,

BC/DNP/MM/bws (Corres. #2043290)
(2.campbell.ca)

cc: w/inc Diana Fortuna, OPD 224



THE PROTECTION AND ADVOCACY SYSTEM
FOR PEOPLE WITH DISABILITIES IN
THE DISTRICT OF COLUMBIA

SAMPLE

January 25, 1995

William J. Clinton
President of the United States
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

BY FACSIMILE

Dear Mr. President:

I write an impassioned plea regarding the grand scheme announced last night in your State of the Union Address. During your Address, you mentioned the New Covenant. You said it was grounded in an old idea -- that **ALL** Americans have a right and a responsibility to rise as far as their talents and determination will take them. The Protection and Advocacy System of the United States abides by that same mission statement -- to help **ALL** people with disabilities rise as far as their talents and determination will allow them to soar.

In your address you said that it is time for Congress to stop passing on to the states the cost of decisions that Washington made -- that is, unfunded mandates. In almost the same breath you also spoke of deregulation. By issuing block grants (the deregulation scheme) to the States, you undermine the Americans With Disabilities Act of 1990 and other federal mandates designed to protect persons with disabilities. In the past funds for the Protection and Advocacy of Individuals with Mental Illness (PAIMI) was a formula grant, with each state receiving funds based on the population to be served. The same thing was done for the Protection and Advocacy of Individual Rights (PAIR), and the Protection and Advocacy for Developmental Disabilities (PADD). The Protection and Advocacy System in America administers all of these programs to America's unique population. By doing away with formula fundings in favor of block grants, you do away with hope and opportunity for people with disabilities. When you block grant instead of earmark funds, **THE FUNDS WILL NOT GO WHERE THEY BELONG**. The Governors of the States will decide that those previously earmarked funds should go for other areas they feel are more pressing thus leaving the people with disabilities where they were before the passage of the Rehabilitation Act of 1973 -- in the dark ages and rendered powerless. In effect PAIMI, PAIR, PADD and the Client Assistance Program (CAP) will become unfunded mandates. I am sure, Mr. President, that this is not part of your game plan.

The Americans With Disabilities Act of 1990 is our civil rights act. It offers people with disabilities an opportunity to integrate into the society that has not allowed us entree in the past. The Protection and Advocacy System enables our unique population to exercise their rights to the fullest. I am sure you

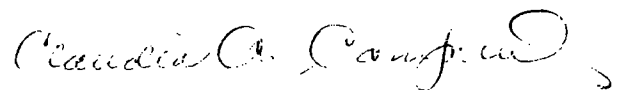
William J. Clinton
The President of the United States
January 25, 1995
Page Two

understand that when people are in a cost-cutting frame of mind, the nature of it is to look at where and what can be eliminated or cut back with the least disruption to the whole, that is, trimming off the edges. I plead that before you sign off on any block granting legislation that you understand that the edges you are trimming are the disenfranchised -- people with disabilities. We have not been fully integrated into society and it is the Protection and Advocacy System that advocates for our legal rights and paves the way in helping the non-disabled community to understand our rights.

Monies needed to carry out the Protection and Advocacy System in the individual states will simply not reach us. Please understand that what I write is not a snowballing job or is meant to be a scare tactic. It is fact. These funds would come to the states in a discretionary mode. The individual states could then do anything with it, including withholding it altogether from the state Protection and Advocacy office. As an example, earmarked money meant for the Protection and Advocacy system in Maryland was withheld last year by its governor. There, then Governor Donald S. Schaefer became angered because the Maryland Protection and Advocacy System sued the state to implement services to persons with disabilities. Governor Schaefer took it personally and punished the Maryland P&A by withholding its funds for almost a year. Who suffered? The people who needed it most -- the disabled population.

People with disabilities are now some 49 million strong in the United States and implementing block grants to the states to assist this population is simply not the appropriate step to ensure justice for all of us.

Respectfully submitted,



Claudia A. Campbell
Disability Law Advocate
and Consumer

February 1, 1995

The Honorable Justin Dart
907 Sixth Street, S.W.
Washington, D.C. 20024

Dear Justin:

Thanks for your letter of December 16. As always, I appreciate knowing your perspective.

This Administration remains committed to ensuring the full implementation and aggressive enforcement of the Americans with Disabilities Act and related laws, and I look forward to supporting reauthorization of the IDEA in the coming weeks.

As we continue working to promote inclusion and independence for all of our citizens, I'm glad to know I can count on your involvement. I wish you and Yoshiko all the best in the coming year.

Sincerely,

BILL CLINTON

BC/DNP/MM/lynn (Corres. #2034566)
(2.dart.j)

cc: Diana Fortuna, OPD ^{winc}
cc: Monica Mullens, 93 OEOB

907 6TH STREET, S.W., APT. 516C
WASHINGTON, D.C. 20024
202-488-7684

December 16, 1994

President Bill Clinton
The White House
Washington, D.C. 20500

Dear President Clinton:

Congratulations on your address to the nation yesterday!

We, the 49 million Americans with disabilities face grave challenges to our right to participate in society. Powerful members and backers of the new majority in Congress are calling for legislation that will eliminate our basic rights of citizenship under the ADA and the IDEA and will devastate virtually all the programs designed to empower us as productive participants in the mainstream.

This would condemn us to generations of sub-human status, and cost the nation hundreds of billions in welfare and lost productivity. It would dash the hopes and dreams of more than 500 million people with disabilities in other lands - "America tried equality for people with disabilities, it didn't work. Why try it here?"

We are going to fight for our rights, and we are going to win! But when are we going to win, and at what cost?

Mr. President, we need your help. We deeply appreciate your courageous leadership for our rights in the past, and the behind-the-scenes support you are giving us now. We trust that, if necessary, you will publicly fight and veto any attempt to amend the ADA or to effect any significant limitation of our educational or other rights as Americans.

We are with you now, next year, in the election of '96 and beyond – however long it takes to accomplish the historic tasks you have set before us. God bless you and Mrs. Clinton!

Justin and Yoshiko Dart

THE WHITE HOUSE

WASHINGTON

FAX COVER SHEET

OFFICE OF THE ASSISTANT TO THE PRESIDENT FOR DOMESTIC POLICY
SECOND FLOOR, WEST WING
THE WHITE HOUSE
WASHINGTON, DC 20500
(202)456-2216 PHONE
(202)456-2878 FAX

TO: Dina Fortuna
FAX #: 267028
FROM: CAROL H. PASCO
DATE: 2/15/95
NUMBER OF PAGES (including cover sheet): 7
COMMENTS: Per our conversation

If you have any problems with the fax transmission, please call
Katherine at (202)456-2216.

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Merry Nielsen
2703 Hopeton Drive
San Antonio, Texas 78230

January 26, 1995

President Bill Clinton
The White House
Washington, D.C.

Dear President Clinton,

As a past member of the PAIMI Advisory Council of Advocacy, Inc. of Texas, I am writing to urge you not to block grant the PAIMI program.

I know the importance of funding for mental health programs. Also I know how difficult it has been to get it included in the overall health concerns. Please don't take away what we have struggled so hard to obtain.

As a past board member of the Mental Health Association of Texas, I chaired FAIR(Family and Individual Reliance) support groups for family members and individuals who are mentally ill. Those of us who have personally experienced mental illness in our families, know first-hand the necessity of advocacy.

Thank you for your support.

Sincerely,

Merry Nielsen

Merry Nielsen

P.S. I am a longtime Democrat and greatly support and appreciate you and your presidency.

FAX COVER LETTER

TO: President Bill Clinton
Washington DC
ATTN: The White House

DATE: 1-27-95
TIME: 11:00

FAX# 202-456-1414

TOTAL NUMBER OF PAGES, INCLUDING COVER LETTER 2

FROM: Ida Angie Vilela
San Antonio TX 78210

210-534-3236

FAX#: _____

REFERENCE: Mental Health Block Grant Proposal

If you do not receive all the pages of this fax please call (210)222-0341. Thank you.

SPEEDY
PRINT SERVICE

January 27, 1995

The President of the United States
The White House
1600 Pennsylvania, NW
Washington, DC 20500

Dear Mr. President,

I write to you on behalf of many families who have children with disabilities. I am the president of Parents Empowering Parents, a not for profit organization whose members advocate for Special Education services from schools and for related services from state and community service providers. Thousands of children receiving Special Education services are diagnosed as having mental illnesses.

Advocacy, Incorporated is the Protection and Advocacy (P & A) system in the state of Texas. Advocacy, Incorporated is the recognized non-profit entity which protects and advocates for the rights of all persons with disabilities. Because of the nature of its role Advocacy, Incorporated is often placed in an adversarial posture with state service systems.

Historically, the federal government has advanced civil rights rather than the states.

THEREFORE, WE PARENTS AND ADVOCATES OF CHILDREN WITH DISABILITIES URGE YOU NOT TO INCLUDE PROTECTION AND ADVOCACY SERVICES IN THE MENTAL HEALTH BLOCK GRANT.

We feel that if it is left up to the states, they will choose not to fund P & A programs at all.

Thank you for your consideration on this very important issue.

Yours truly,

For Angie - E. C. 2.1

Ida Angie Villala
La Mision Child Care Center
2512 South Hackberry
San Antonio, TX 78210
210-534-3836

BCID

Brooklyn Center for
Independence of the Disabled, Inc.
3044 Ocean Avenue, Suite 1-3
Brooklyn, NY 11230-7302
718-998-3000 VOICE
718-998-7206 TTY
718-998-2743 FAX

DATE: January, 27, 1995

TO: PRESIDENT BILL CLINTON
WHITE HOUSE

FAX: 1-202-456-2878

FROM: GULSEREN YILDIZ

No. of Pages (including the cover) 2

Please call if there is any problem with the transmission.

Sent by PRINCESS DAVIS

Time: 2:15 pm



2044 Ocean Avenue, Suite B-3
Brooklyn, New York 11230-7302
718-798-3000 VOICE
718-798-7406 TTY
718-798-3743 FAX

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The White House
1600 Pennsylvania Avenue
Washington, DC

Dear President Clinton:

Please do not block grant the Protection and Advocacy for Individuals with Mental Illness program. It serves people who are in or have recently been in mental health institutions. It investigates complaints of abuse and neglect and provides legal and other advocacy. It is a civil rights program for very vulnerable people. It needs to be politically independent.

Many of the people it serves are harmed by state agencies. If PAIMI money is put into a block grant, it is very unlikely state officials will continue a viable program which advocates for people who have problems with state agencies.

The PAIMI program has been very useful to the people our group represents.

Brooklyn Center for the Independence of the Disabled (B.C.I.D.) is a consumer controlled cross-disability organization which provides services and advocacy for people with disabilities here in Brooklyn.

Sincerely,

Gulseren Yildiz
Gulseren Yildiz
Executive Director/BCID

JUDITH B. LAVINE

9 Newman Avenue - P.O. Box 16311
Rumford, RI 02916
(401) 434-2120 phone 431-0043 fax

February 14, 1995

Honorable William J. Clinton
President of the United States
The White House
Washington, DC 20006

FEB 14 1995

Dear President Clinton,

I am very upset to learn about the possible blocking of the Protection and Advocacy (PAIMI) grant for people with mental illness. In trying to save monies by cutting the Public Health Service budget, you are, in fact, endangering the lives of Americans with mental illness - seriously and fatally. Protection and Advocacy for Individuals with Mental Illness (PAIMI) needs to be a separate line item in your budget because this is the only hope people with mental illness have in saving themselves from abuse and neglect in state psychiatric hospitals. If this item is cut from your budget, all people with mental illness will lose what little rights they have. If you have not seen for yourself, you have no idea how much abuse and neglect takes place! PAIMI is the last resort for these people in overcoming abuse, neglect, discrimination, and barriers to life's essentials.

Enough people with mental illness die as it is even with these Protection agencies in place. Do you want the responsibility of this number increasing tenfold? Realistically, where else can these people turn? It is our duty as Americans to protect the rights of those less fortunate than ourselves! Even more so, if PAIMI is a last resort.

Do you realize that the lawyers and paralegals in the Protection and Advocacy agencies are paid one-half to one-third less than any STATE employee in a comparable position AND that there are no costly pension plans? PAIMI employees are conscientious, caring (certainly not in it for the money) individuals who make a big difference in the quality of lives of people with mental illness. It is up to the federal government to continue to advance civil rights because that is what America is all about - not about deterioration and elimination of disability rights. What injustice that would be! What a waste the Americans with Disabilities Act would be!

I look forward to a favorable response to this plea so that those with mental illness can have a chance for a normalized, dignified, and productive life.

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Recover from Disease

Eliminate Allergies

Overcome Problems and
Enhance Strengths

Aromatherapy with
Essential Oils

Crystal Healings • Vogel

Classes:

Talk to your angels
Learn your psychic senses
Use your healing energy
Your soul's purpose
Utilizing dowsing
Crystals & its uses

Licenses:

Mental Health #3387
Rehabilitation #943

Certifications:

Nat'l CRC #20059
Clinical Hypnosis #C027

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San Antonio TX 78210

210-534-3836

FAX#: _____

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Ida Angie Villlela
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2044 Ocean Avenue, Suite 1-3
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718-998-3088 VOICE
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718-998-3743 FAX

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WHITE HOUSE

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Executive Director/BCID

JUDITH B. LAVINE

9 Newman Avenue - P.O. Box 16311
Rumford, RI 02916
(401) 434-2120 phone 431-0043 fax

February 14, 1995

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The White House
Washington, DC 20006

FEB. 14 1995

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Time-Line Therapy

Sports Psychology

Past Life and Future Life
Healing Therapy

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Recover from Disease

Eliminate Allergies

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Enhance Strengths

Aromatherapy with
Essential Oils

Crystal Healings - Vogel

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Talk to your angels
Learn your psychic senses
Use your healing energy
Your soul's purpose
Utilizing dowsing
Crystals & its uses

Licenses:

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Rehabilitation #943

Certifications:

Nat'l CRC #20059
Clinical Hypnosis #C027

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

27-Jan-1995 01:30pm

TO: Diana M. Fortuna

FROM: Carol H. Rasco
 Economic and Domestic Policy

CC: Jeremy D. Benami

CC: Lynn M. Margherio

SUBJECT: RE: Block granting protection & advocacy grant

It is my understanding that the budget is locked in, even narrative has gone to print. I would suggest that we look with HHS at the criticisms we are hearing to start preparing talking points and letter responses.

Thanks.