FOIA Number: 2007-0143-F

FOIA MARKER

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Folder Title:
Mrs. Gore Medicaid Disability Conference Call 10/23

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Withdrawal/Redaction Sheet
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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. fax	Elaine Colbert to Deborah Fine; RE: Personal [partial] (14 pages)	10/27/1995	b(6)
002. fax	The University of New Mexico Health Sciences Center; RE: Personal Medical Information (1 page)	10/20/1995	b(6)
003. paper	RE: Personal Medical Information and Personally Identifiable Information (5 pages)	00/00/0000	b(6)

COLLECTION:
Clinton Presidential Records
Public Liaison
William White, Jr.
OA/Box Number: 14205

FOLDER TITLE:
Mrs. Gore Medicaid Disability Conference Call 10/23

2007-0143-F
db4563

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]

(1) Impact of cuts on children + families, esp. children w/ disabilities who often receive Medicaid services that enable them to stay w/ family, cmty, school
(2) w/out assistance, kids could → institution or family → broke
(3) Hard to put $/# on the impact - BUT Block granting w/ less $: Govs must choose who help
(4) ages 12-18
- income: lower + middle
- disability: CP, MR, accident
- work (full + part time)
(5) home + cmty based care critical to disab cmty BIG POINTS HERE

call

October 23, 1995

Copy

CHILDREN WITH DISABILITIES CONFERENCE CALL

DATE:	**October 24, 1995**
TIME:	**1:15PM**
LOCATION:	**The Radio Room** **Room 414, OEOB**
FROM:	**Debbie Fine, Domestic Policy Council** **Diana Fortuna, Domestic Policy Council**

I. PURPOSE

To highlight the impact of the Republican Medicaid cuts on children with disabilities, through a discussion with five children with disabilities on Medicaid and their parents or mentors. The discussion will focus especially on how Medicaid allows these children to get services at home.

II. BACKGROUND

Both the House and Senate Reconciliation bills cut at least $182 billion from Medicaid.

In addition to the services that Medicaid provides children with disabilities in hospitals and doctors' offices, Medicaid also pays for many services for these children at home. In-home Medicaid assistance pays for equipment like wheelchairs and communication devices; therapy, including teaching parents to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and home modifications needed to allow a child to live at home. These services are known as "model waivers," "home and community-based waivers," or "Katie Beckett waivers" for which states can apply.

Faced with the Republican budget cuts, these home and community-based programs will find it especially hard to compete with hospitals and nursing homes for scarce Medicaid dollars at the state level. **Without these services, some parents may have to give up their jobs or seek institutional placements for their children.**

Another program cut passed by the Republicans that these families may raise during the conference call is the Supplemental Security Income (SSI) program for children with disabilities. Last year, media reports charged that some parents encouraged their children to "act crazy" in order to qualify for these monthly cash benefits. Audits have not identified any widespread fraud, but Congress -- especially the House -- would cut the program significantly. Families with children with disabilities rely on SSI to meet a wide variety of needs, including replacing lost income for a parent who can't work full-time or at all because of his or her child's disability.

If you are asked about the SSI issue, you can state that the Administration strongly opposes the House plan to eliminate cash benefits for most of the children entering the program, and that we would like to see the Senate's cut in eligibility applied only prospectively, to new children joining the program, rather than retrospectively.

NOTE ON LANGUAGE: The most accepted term to use is "children with disabilities" rather than "children with special needs" or "handicapped children." Whenever possible, "children with disabilities" is preferable to "disabled children," and "individuals/people with mental retardation" is preferable to "the mentally retarded."

NOTE ON ATTACHED DATA: Please note that except where noted, the state-specific data included in the attached descriptions of each family are based on cuts made in the House Commerce Committee. Also, the date is for all children, not just children with disabilities.

III. PARTICIPANTS

Parents/mentors and children with disabilities (listed in speaking order):

1. Elaine and Alexandra (Alex) Colbert; Philadelphia, Pennsylvania
2. Penny and Joe Ford; Denver, Colorado
3. Trish Thomas and Travis Solomon; Laguna, New Mexico
4. Tom Zimmerman and Jason Sloan; Chicago, Illinois
5. Dan and Ryan Louney; Bedford, New Hampshire

The participants will be at a community, health center, or hospital where the child has received services. Some of the centers are planning their own press conferences following the call.

Background information on each parent and child and the expected focus of their remarks is attached.

IV. SEQUENCE OF EVENTS

- Mrs. Gore will open the conference call with a brief statement about the purpose of the call.

- The Vice-President will speak briefly about the Republican budget.

- Mrs. Gore will call on each of the parents to make brief comments. After each parent speaks, either the Vice President or Mrs. Gore will ask the child a question(s). Each parent is prepared (in under 2 minutes) to highlight how Medicaid has helped the family.

- You will each have the opportunity to ask follow-up questions and make additional comments.

V. MEDIA

Open to regional press. (There will be regional press at each location with the children and their parents.)

VI. REMARKS

Talking points are attached.

Vice-President Gore/Mrs. Gore
TALKING POINTS FOR CONFERENCE CALL
WITH CHILDREN WITH DISABILITIES AND THEIR PARENTS

Room 414, Old Executive Office Building
October 24, 1995

Mrs. Gore:

- Thank you all for taking the time to join the Vice-President and me today to discuss how Medicaid helps you, and families like yours who have children with disabilities, get the services you need at home so that your family can stay together.

- As you all know, many families, both lower-income and middle class, receive support from Medicaid to help care for their children with disabilities. Such programs were developed as an alternative to placing children in institutions so that families have more options.

- Medicaid pays for wheelchairs and communication devices; therapy, including teaching parents to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and minor home modifications needed to allow a child to live at home.

- We have a number of families on the line from around the country who know very well how Medicaid can help a child who has a disability. And we are looking forward to hearing from each of you a little about what these services have meant in your lives.

- Introduce Vice-President Gore.

Vice-President Gore:

- As you know, we are involved in a serious national debate about how to balance the Federal budget.

- We must balance the Federal budget, but we must do so in a way that reflects the values that we have always held dear in this country. Values like giving every American the opportunity to be responsible to make the most of his or her own life, and strengthening our families. This budget debate is not just about programs and dollars.

- The President's plan for a balanced budget reflects America's values. It calls for reasonable, moderate reforms in Medicaid, while keeping our guarantee to children and older Americans, including Americans with disabilities.

- In my judgement, the budget that the Republicans in Congress have offered violates those values. It will decimate Medicare and Medicaid -- by taking twice the level of Medicare cuts we have proposed, and more than three times the level of Medicaid cuts.

- The Republican budget would also severely cut back the Supplemental Security Income (SSI) program for children with disabilities, particularly the House approach. It would eventually prevent nearly one million children eligible under current rules from receiving cash assistance. It would also terminate benefits altogether for 170,000 children with disabilities. The loss of cash assistance would be devastating to many low-income families struggling to care for a child at home.

[Note: Many of the children on the conference call probably receive SSI cash benefits. The House SSI cuts are unlikely to affect the children on the call, because cutbacks for severely disabled children, as these children are, would only be made prospectively.]

- Cuts in Medicaid would be particularly devastating to children with disabilities because their families cannot access the private insurance market for all their child's needs, or often even at all.

    - Programs such as the Medicaid home and community-based waivers provide needed support for families and children with disabilities at home in most/all states.

    - In the past, before these programs were developed, many of these families would have had to seek institutional care for their children.

    - At the state level, home and community-based programs will find it difficult to compete with hospitals and nursing homes for scarce Medicaid dollars.

    - Without these services, some families would not be able to stay together.

- And now, I'd like to hear from each of you about what Medicaid services do for you, and to learn more about your families.

CONCLUDING REMARKS

- Thank you so much for taking the time to talk with us and share with us a little about your families.

- I think we have all heard first-hand from you about how important these services are for your families. And although we know you all know how to fight, because you are already fighting so hard to live together as a family and to pay for the services you need, we all have to get ready for the battle ahead to preserve fundamental supports for children.

- We want you to know that we are fighting with you and for you.

October 23, 1995

Background on Children and Their Families
(Listed in Speaking Order, Along With Potential Issues to Highlight)

1. **Elaine and Alexandra (Alex) Colbert; Philadelphia, Pennsylvania**
Location of call: Children's Seashore House; Philadelphia, Pennsylvania

The Republican budget cuts federal Medicaid funding to Pennsylvania by $3.1 million over seven years and by 22% in 2002 alone. These cuts would eliminate coverage for as many as 114,892 children in Pennsylvania in 2002.

BACKGROUND: Elaine is the single parent of Alex, her 14-year-old daughter. She works at the Parents' Union for Public Schools in the Parent Training Information Center, where she trains parents in the area of special education. She is able to work there part-time because of the flexible hours, which allow her to work while meeting the medical and educational needs of her daughter. Her dream would be to be able to work full-time. She currently has health insurance through her job, but she cannot afford the additional cost of the option to cover her daughter under this plan -- which has much more limited coverage than would meet Alex's medical needs anyway.

Alex has cerebral palsy and a learning disability. She is in 9th grade, and currently participates in a high school program that is a mix of regular and special education classes. Going to school and being with her friends are very important to her. She also volunteers at the hospital where she receives services. While her mom leads support group meetings for the parents of medically fragile children, Alex cares for the children. She now wants to become a pediatrician and open her own child care center. She recently received a reward from United Way for her volunteer work, which she has been doing for two years.

Medicaid pays for the following in-home services for her: braces for her legs; bi-monthly occupational therapy evaluation for gait regression; occupational and physical therapy assessments; aquatics; medical, dental and eye care; and psycho-educational testing. It has also paid for several surgical procedures on her legs.

FOCUS OF COMMENTS: Elaine will likely focus on the following:

- The importance of Alex receiving a good education.

- Doctors originally said Alex would not walk or talk. Without the Medicaid-funded services that Alex has been receiving since she was 8 months old, her condition would have regressed significantly and she would not be prepared to participate in school or in her community the way she can now.

Suggested Follow-Up Questions for Alex: Alex, I hear that you volunteer in child-care. What do you like most about that? Why do you do it? What do you want to be when you grow up?

2. **Penny and Joe Ford; Denver, Colorado**
Location of Call: Denver Center for Independent Living; Denver, Colorado

The Republican budget cuts federal Medicaid funding to Colorado by $2 billion over seven years and by 33% in 2002 alone. These cuts would eliminate coverage for as many as 50,921 children in Colorado in 2002.

BACKGROUND: Penny is the divorced, 47-year old parent of Joe Ford, one of 8 children. She works full-time as a consultant providing technical assistance to communities for building supports for infants and toddlers with disabilities. She has private insurance, in addition to receiving Medicaid assistance for Joe. The only other assistance her family receives is financial aid for her two daughters for college.

Joe is a quadriplegic and has cerebral palsy. He is 12 years old and is currently enrolled in a middle school program for highly gifted children -- children in the 99th percentile who have IQ's higher than 130 -- in the Denver public school system. Joe uses a computer to write, and will soon have a communications system to help him speak. Last year, he was elected President of the Student Council. He wants to be an attorney when he grows up. Medicaid pays for the following in-home assistance for Joe: co-payments for his durable medical equipment; a communications system; a bath chair; and personal attendant services twice daily to help with physical therapy, dressing, toileting, meal preparation, bathing, and teeth-brushing.

FOCUS OF COMMENTS: Penny will likely focus on the following:

- Because of the in-home Medicaid services available to Joe, Penny was able first to go back to school for a bachelor's degree in education, and eventually to take the full-time job she now has. Her daughter Jane, who often used to take care of Joe, was able to pursue acting in high school and is now starring in the school play this week.

- Although Penny has private insurance, that does not cover the personal assistance services that are essential for Joe. And though it does cover some of the costs of the equipment he needs, she cannot afford to pay for the remaining costs; for example, the wheelchair Joe is getting to replace his old chair costs $10,000 -- Blue Cross will pay $8,000 and Medicaid will pay $2,000.

- The assistance Joe gets under Medicaid allow him -- a highly gifted child -- to go to school, to write, to play with friends, and to pursue his dream of being an attorney. And it gives Penny the hope that if something happens and she's not around later on, he'll have a chance to succeed.

Suggested Follow-up Question for Joe: Joe, I read something you wrote about how you were playing on the gravel with your friends at school when your wheelchair broke. I know you are supposed to get a new wheelchair -- have you gotten that yet? What do you think the best thing will be about the new chair?

3. **Trish Thomas and Travis Solomon; Laguna, New Mexico**
Location of the Call: University of New Mexico Health Services Center; Albuquerque, New Mexico

The Republican budget cuts federal Medicaid funding to New Mexico by $902 million over seven years and by 24% in 2002 alone. These cuts would eliminate Medicaid coverage for as many as 20,467 children in Mexico in 2002.

BACKGROUND: Trish Thomas is a divorced, single parent of Travis Solomon, age 16, and his sister Kori, age 18. They are members of the Laguna Pueblo tribe and live on the reservation, west of Albuquerque. Trish works part-time at Family Voices, an advocacy coalition for children with special health needs. She, like so many other parents, is forced to work part-time because she needs the flexible hours to take care of her children -- and as a result cannot afford private insurance. Her family receives assistance through Medicaid, SSI, and the Indian Health Service; Medicaid pays for the bulk of Travis' assistance.

Travis has a serious visual impairment and bi-lateral hearing loss. Because of his hearing aids and years of speech and language therapy, he is able to speak and be understood by most people (he speaks similarly to Miss America 1995) and he is able filter out background noise well enough to hear. Travis lip reads, and can use the phone with his hearing aid. He attends the local Laguna schools, where math and science are his favorite subjects, and he hopes to continue his education and to eventually work in the electronics field. He would like to work on developing hearing aids so that they can be "fitted like eye-glass prescriptions." For Travis, Medicaid pays for the following in-home assistance: batteries, repairs and other equipment for his hearing aids; physical therapy; occupational therapy; speech and language services; and several surgical procedures to treat his visual impairment.

FOCUS OF COMMENTS: Trish will likely focus on the following:

- Families like Trish's depend on Medicaid to pay for in-home care to make sure that their children have the same chance as other children, particularly when private insurance or even public programs through the Indian Health Service do not provide what the children need.

- If it were not for the diagnosis of Travis at two-and-a-half, he would not have received such early therapy and treatment, including specialty services not available on the reservation and not affordable for Trish Thomas. In-home Medicaid assistance made this therapy possible. Without that assistance over the years, he would not be living at home with his mom and sister, participating in school, and contributing to the community.

Suggested Follow-Up Question for Travis: Travis, I understand that you're very good at math and science. What do you think you want to do when you grow up?

4. **Tom Zimmerman and Jason Sloan; Chicago, Illinois**
Location of Call: Access Living of Metropolitan Chicago; Chicago, Illinois

The Republican budget cuts federal Medicaid funding to Illinois by $6.1 billion over seven years and by 29% in 2002 alone. These cuts would eliminate coverage for as many as 128,969 children in Illinois in 2002.

BACKGROUND: Tom Zimmerman is a very close friend of the Sloan family, and a disability advocate who has testified on the Sloans' behalf several times. He is with Jason today because Jason's mother, Debby Sloan, has a very busy work schedule -- working full-time as a legal secretary during the days and at nights at a bowling alley. She is a divorced, single mother.

Jason is 18 years old and lives at home with his mother. He has mild to moderate mental retardation and has been technology dependent since birth -- he requires a mechanical ventilator attached by a tube to his throat to breathe. He participates in a special education program of the Chicago school system and works part-time in a sheltered workshop through the school to prepare him for a supported employment situation after school. No private insurance company would agree to cover Jason because of pre-existing conditions. Under the "Model Waiver Program," Medicaid pays for his ventilator and its supplies, and his in-home nurse and "job-coach". He requires 24-hour supervision.

FOCUS OF COMMENTS: Tom Zimmerman will likely make the following points:

- Jason's mom works full-time, days and nights, so that her son can live with her at home, so that they can play in the park, go to the zoo, and see each other on a regular basis as opposed to during visiting hours only in an institution.

- She could not get private insurance because of pre-existing condition clauses.

- Because of in-home Medicaid dollars, not only can Jason remain part of the community, where he makes an important contribution and brings a lot of joy to the people he comes into contact with, but he will be able to work. Working is very important to him.

- Without Federal guidelines or standards for these programs, parents like Debby Sloan may be forced to relocate to another state in search of adequate coverage.

Suggested Follow-Up Questions for Jason: Jason, do you like living at home with your mom? I hear you are in charge of the recycling program at your school? When you graduate from high school, do you want to work help your community recycle?

5. **Dan, Margaret (Margie), and Ryan Louney; Bedford, New Hampshire**
Location of the Call: The Moore Center; Manchester, New Hampshire

Please note that the current House bill does not cut New Hampshire Medicaid funding -- it actually increases the funding. The Senate Finance Committee bill, however, makes very serious cuts. Based on the Senate Finance Committee bill, New Hampshire will lose $1.2 billion in Medicaid funding over seven years and $249 million in 2002 alone.

BACKGROUND: Dan and Margie Louney are the parents of Ryan, who is one of five children (4 adopted). Dan, aged 62, lost his job a couple of years ago after working for General Electric for 22 years and for Balzers for 14 years. Margaret works part time as a teacher and special needs coordinator at the Moore Center, working with families who have children with disabilities. They now have private insurance that they purchase through Mutual of Omaha; however, their deductible is $7,000 and therefore the services that Ryan needs are either not covered or too expensive.

Ryan is 12 years old and is in the 6th grade. Although he was born with mild to moderate Down Syndrome, this is not why he is covered under the Medicaid model waiver. In March of 1994, Ryan had a serious skiing accident from which he broke an arm, a leg, and sustained multiple serious head injuries that put him in a coma for 5 and 1/2 weeks. Since then he has almost totally recovered, with the help of ongoing occupational and physical therapy. Now Medicaid pays for his ongoing therapy and for his regular medical services (annual check-ups, etc.). Ryan likes to read in school, go bowling, play on his basketball team, and recently he built and launched a model rocket ship with his friends at school. Won a medal in the Special Olympics — summer + winter. (skiing, running, baseball toss)

FOCUS OF COMMENTS: Dan Louney will likely focus on the following:

- Without Medicaid funding, the Louney family would not have been able to afford the treatments that Ryan requires.

- This can happen to any family. The experience was frightening enough without the additional stress and anxiety about the possibility of losing everything they had worked for in order to pay for the treatment Ryan needed.

Suggested Follow-Up Questions for Ryan: It sounds like you've made a great recovery after your skiing accident. What ~~do you enjoy most~~ about being back at school and back with your friends? 's your favorite thing

MEDICAID AND CHILDREN WITH DISABILITIES
FACT SHEET

Medicaid allows many children with disabilities to get services at home or in the community. These services have grown rapidly over the past 15 years. Prior to that time, an institution was too often the only option for a middle-class family with a child with a disability.

- In 1982, the case of Katie Beckett, a child with a disability, focused attention on this issue. Katie's middle-class parents learned that Katie would be eligible for Medicaid if she lived in an institution, but not if she got less expensive care at home.

- To remedy this situation, the Federal government authorized waivers for states to use to serve children (and adults) at home instead of in an institution. These waivers are commonly known as "model waivers" or "home and community-based waivers."

- Under these waivers, income standards for Medicaid eligibility are relaxed, and states can pay for services not normally covered by Medicaid -- assistive devices, respite care for parents, minor home modifications, supported employment services, transportation, and personal care. Such services often allow a parent to hold a job.

- All 50 states provide home and community-based services to children in some form, although the waivers may not serve all the families who want these services.

- There are probably over one million children with disabilities on Medicaid, although most of them do not require intensive services at home. There is no exact estimate because there is no single definition of disability, and because children with disabilities can qualify for Medicaid in a number of ways:

    - Their family's income may be low enough to meet a state's general eligibility guidelines.

    - They may be eligible for SSI benefits, which is automatically linked to Medicaid in most states. Children qualify for SSI if their families are low-income and they have a disability defined by the Social Security Administration.

    - They may qualify for a state waiver program, whether through the nature of the disability, family income, or their need for certain services. For example, a state may design a waiver program for up to 200 children who need respirators.

    - Many states run "medically needy" programs for families with large medical expenditures but incomes that are too high to qualify for Medicaid under normal circumstances. Medical costs for a child with a severe disability can easily impoverish a middle-class family.

Under the Republican budget, home and community–based services for children with disabilities will be especially vulnerable to state budget pressures. These optional programs do not have the lobbying power of nursing home, hospital, or physician groups.

IMPACT OF MEDICAID CUTS ON EDUCATION PROGRAMS FOR CHILDREN WITH DISABILITIES

Medicaid has important links to education programs for children with disabilities, both at home and in schools. These programs would come under particular pressure in states attempting to cope with a Medicaid block grant.

- **Infants and Toddlers with Disabilities:** The Department of Education provides funding to assist states in identifying infants and toddlers with disabilities and providing them early intervention and therapy services. Early intervention and therapies for these very young children is critical to maximize what they can later accomplish in school. This program (known as "Part H") also educates families about their infant's or toddler's disability and how best to support and care for their child. A total of 165,000 infants and toddlers now get help through the Part H program, and many of these children's services are paid for by Medicaid. For example, Medicaid funds 62% of the Part H program in Arkansas, 32% in South Carolina, 25% in Massachusetts, and 41% in New York State.

  Under a block grant, states would be under severe pressure to discontinue such services.

- **Special Education and Related Services:** In order to learn and benefit from school, children with disabilities sometimes need medically-related services in school. Services such as speech therapy and physical therapy, to which children are entitled as part of the special education program, are often paid for by Medicaid.

  If states elected to discontinue Medicaid for these services, these costs would be borne by local school districts.

SSI FOR CHILDREN WITH DISABILITIES
FACT SHEET

Families on the conference call may raise the fact that Congress is planning significant cuts in the Supplemental Security Income (SSI) program for low-income children with disabilities.

- Last year media reports charged that families abused this program by having their children fake mental disabilities in order to qualify for up to $450 a month in cash benefits.

- Audits have not identified widespread fraud, but Congress plans to cut the program significantly as part of welfare reform. The House cuts are particularly severe. Disability advocates know that eligibility will be sharply restricted, but hope to preserve cash benefits. The Administration reluctantly favors the Senate approach but believes that eligibility changes should be applied prospectively rather than penalizing children already on the rolls.

- Although fraud does not appear to be a problem, the children's SSI program has grown rapidly in the past decade. Much of the growth is due to a liberalized eligibility standard for mental disabilities, driven partly by a Supreme Court decision.

- Defining childhood disability is an inexact science. Professionals are not always in agreement about the distinctions that the Social Security Administration must make to determine whether a given disability is, for example, mild, moderate, or severe.

- There are now almost one million children with disabilities on SSI. Families receive up to $450 a month in cash benefits, along with automatic eligibility for Medicaid in most states. SSI eligibility begins at about 150% of the poverty level.

- SSI pays for a variety of costs for families with disabled children -- including lost income, diapers, home modification, respite care, equipment, special dietary items, etc.

- The House would cut 170,000 moderately disabled children from the program almost immediately. More worrisome, only children coming on the rolls who are at risk of institutionalization could get cash benefits. Other eligible children could apply for services from a new state block grant funded at only 75% of current spending.

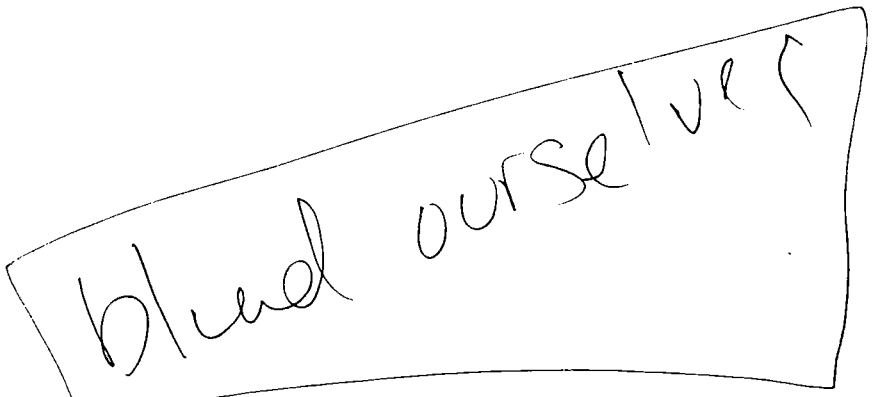
- The Senate would eliminate 170,000 children from the rolls over the next 18 months, but keep cash benefits for all eligible children.

- The Administration favors the Senate plan because it retains cash benefits, but believes even the Senate bill is too harsh because it applies the new eligibility rules retrospectively. The Administration believes the change should be prospective, except for children eligible as a result of "maladaptive behavior." We have just learned that some mental health advocates are upset about this last part of our position (even though overall our plan would cover more children than theirs) because they believe singling out children who exhibit maladaptive behavior is unfair.

Administration Talking Point on Children's SSI:

The Administration strongly opposes the House plan to eliminate cash benefits for most of the children entering the program. The loss of cash assistance would be devastating to low-income families struggling to care for a disabled child at home. Further, we would like to see the Senate's cut in eligibility applied only to new children joining the program, rather than retrospectively.

Are you all a



★ Betsy on OH accessibility

★ Kate Sellman ★
language interpreter

PARENTS UNION FOR PUBLIC SCHOOLS

IN PHILADELPHIA, INC.

311 S. Juniper Street, Room 602
Philadelphia, PA 19107
(215) 546-1166 (fax 215) 731-1668

-VP for Legislative Affairs

Date: 10/27/95

Sent To: Deborah Fine, Senior Policy Analyst
Fax No. 202 456-6218

Company: The White House

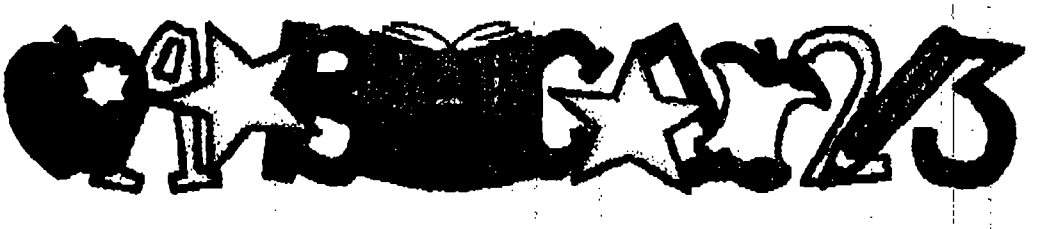
Sent From: Claire Calbert, Parent's Union for Public Schools

No. of Page: _____(including cover)

Comments:

Hi Debbie

Here are some letters from Philadelphia parents who received Medicaid like stated in a letter regarding Campaign due to the lack of interest from our City Mayor, Media, Newspapers, etc....



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b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

[001]

October 25, 1995

(b)(6)

Dear Vice-President and Mrs. Gore

Our son (b)(6) was born (b)(6) with a Cogenital heart defect. He has had 3 open heart surgeries and numerous medical and surgical procedures to sustain his short life. Though our family would be considered middle class, we would not have been able to afford (b)(6) hospitalizations and treatments with several therapist on our budget.

We need Medicade for our baby's care and to give him a chance to live a quality life. Without Medicade I would not be able to work, so we need these critical services that Medicade will provide for (b)(6) well being.

(b)(6) is presently in Jefferson Park Re-hab Hosp. for Children receiving much needed Speech therapy (for his feeding disorder) Physical and Occupational therapy. He is being evaluated for Child Link an Early intervention program for Children. These programs need federal government support and not state block grants which would leave very little money on services to the Child and their families.

Please support our efforts.

Sincerely,

(b)(6)

October 26, 1995

[redacted] (b)(6)

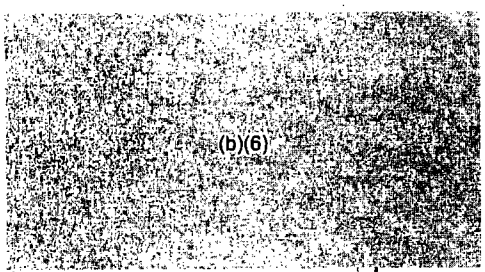
Dear Vice-President and Mrs. Gore:

My son [redacted] (b)(6) at the time is 3½ yrs. old. His diagnosis is Cerebral Palsy. I retired in 1993 before than he was on my insurance at work. But since I have retired he is completely on Medical Assistance. He needs a wheel chair, every two years he is very hard on chairs plus in between that time his chairs need repair work, new cushions. He also takes medication for high blood pressure.

I am also on Medicare now, if funding is cut in any way he would be denied a lot of services that are provided by Medical Assistance. He is also acquiring arthritis in his knees. Please support our efforts. We could not stand any cuts at this time.

Sincerely,

[redacted] (b)(6)



I am wating YOU Regardin
my son (b)(6) (b)(6) who
had been hospitalized for the
first 2 year of has lefe
I am so grateful for
all the medical technotgy
Caring Health professional
who Card for him when he
was Crit. Cally ill and.
helped me to learn
all of his care so I Could
Take him home.
without The assistace of
Medicaid (b)(6) would still
Be hospitielized or Institutinalize
Please dont BLOCK Grant this
To the states or deercase
Services to Children with
drsahility

(b)(6)

Dear, Vice President

Thank you for helping my daughter (b)(6). This was a big help for us, because we needed something like it. Thank you for giving the equipment to help us. This panel was very helpful, since she is getting better know, she off the "air", but she is still on the breathing, but that ok. Long as her heart is beating. I can't express how good it did for me.

Thank You

(b)(6)

October 25, 1995

Dear Vice President and Mrs. Gore:

I am a proud parent of a beautiful little girl, (b)(6). Only one day before delivery, my husband and I were told that our baby had a serious heart defect. To say the least, this put us in a state of shock.

Four months later after surgery and many uncertainties, our daughter will finally be coming home to her family. With the assistance that we'll receive from medicaid, (b)(6) will continue to get the medical attention in our home such as: home nursing, occupational therapy, speech therapy, home monitoring devices, medical equipment and early intervention.

The purpose of this letter is to express to you how grateful I am to know that we have these services available to us. Having these

Services offered through Medicaid allows me to keep my job in order that we can sustain our style of life, will allow all of us to be together as a family and finally will allow (b)(6) to progress because it has been proven that children with special needs thrive better once they have been in a family environment.

Without medicaid, I truly do not know how we could not have managed financially or mentally. It has been stressful for us, that medicaid will be there to help relieve some of the stress.

Please do not let families like ours down. Keep medicaid alive.

Sincerely,

(b)(6)

October 25, 1995

Dear Vice President & Mrs. Gore

My name is (b)(6) and I have a four month old daughter named (b)(6) who was born with a diaphramatic hernia.

I am writting this letter to express my dependence on medicaid. My wife and I have been career people all of our adult lives and have established a lifestyle that [redacted] now necessitates two incomes.

Our child (b)(6) needs in home nursing seven days a week and without medicaid providing the nursing services required to assist her our lifestyle would dwindle to the point where my my wife would have to quit her job and hence [redacted] subject us to giving up our quest for a house as well as [redacted] even maintaining our current credit obligations.

So please Sir & Madamon [redacted] use your influence to keep medicaid flourishing for us and all of the other dependent recipients across the country.

Sincerely

(b)(6)

[redacted] (b)(6)

October 25, 1995

Dear Vice President and Mrs. Gore:

I would like to take a few minutes to ask you a question. What will happen, to my dearest [redacted] (b)(6) if Medicaid is cut?? [redacted] (b)(6) is a 3 yrs and 3/4 (as she calls herself) ventilator dependent child. She had to have a spinal fusion @ the age of 9 months and must wear a chest brace jacket 24 hours a day. She does not walk and because of her medical needs she must use a power wheelchair to get around. If you are thinking about feeling sorry for her, please don't because she doesn't feel sorry for herself.

Anyone who has met her cannot believe that she has the medical limitations that she has. [redacted] (b)(6) has the spirit and temperament to light up a city. Her voice can be heard all over the house even though she has a tracheotomy. Because of Medicaid she attends early intervention 3 mornings a week. Because of Medicaid [redacted] (b)(6) can have a little bit of freedom

(9)

by getting around in her power chair. Because of Medicaid [redacted] (b)(6) is home with a loving family. I forgot to mention that [redacted] (b)(6) is my foster daughter.

I am a Respiratory therapist and I took care of [redacted] (b)(6) for 3 years in a Children's Rehabilitation Hospital and she could not find placement. My husband and I committed themselves to this child's care. We are a middle income family. We have love but we don't have much money. Please help us keep [redacted] (b)(6) in a loving home.

Sincerely,

[redacted] (b)(6)

(b)(6)

Oct 25, 1995

Vice President and Mrs Al Gore
White House

Dear Vice President and Mrs Gore

My name is (b)(6) and I have a son named (b)(6) has a neuromuscular disease called myotubular myopathy and he is ventilator dependent. He is such a (b)(6) is on medical assistance because of his condition but he is also on medical assistance because he had reached the limit ($1,000,000) on my private insurance (Blue Cross / Blue Shield). Medical assistance has enabled my son to remain at home because he receives sixteen hours of nursing care. It has also enabled him to attend public school (with his nurse) and have academically and physically.

Medical assistance has enabled me

to continue working and be a productive member of society. If medical assistance is block granted to the states the wonderful progress my son and other children with disabilities would surely disappear or regress. Also if MA is block granted the services (b)(6) receives would be curtailed or disappear - nursing, Physical therapy, speech, and occupational. Also if nursing is no longer available to my son I would not be able to continue work and would have to go on public assistance and become a nonproductive, non-taxpaying member of society.

I urge you not to let medical assistance be block granted or curtailed it would have a devastating effect on both the child and family.

Sincerely,

(b)(6)

Extended Page

[redacted] (b)(6)

Dear Vice President,

On [redacted] (b)(6) my baby was delivered at Thomas Jeff Hosp at 28 weeks of age. [redacted] (b)(6) 's my daughters name. She weighed 1 lb 6 oz when she was born. My daughter remained at the hospital for seven months and during that time she needed intensive care. We could have never paid for her treatment. She needed respitory care such as ventilator oxygen tanks and expensive antibiotics. Medicaid paid for all my daughter's

treatment. (b)(6) was sent home on

oxygen and she needed home nursing care. Health Partners was very supportive with her needs. (b)(6) would have never survived without the help of Medicaid.

(b)(6) is doing well now she weighs 10 pounds and she no longer needs nursing care. We thank god for Medicaid every day.

Sincerely,

(b)(6)

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. fax	The University of New Mexico Health Sciences Center; RE: Personal Medical Information (1 page)	10/20/1995	b(6)

COLLECTION:
Clinton Presidential Records
Public Liaison
William White, Jr.
OA/Box Number: 14205

FOLDER TITLE:
Mrs. Gore Medicaid Disability Conference Call 10/23

2007-0143-F
db4563

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]
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THE CHILDREN'S DEVELOPMENTAL CENTER
1805 COLLEGE DRIVE
BATON ROUGE, LA 70808
(504) 923-3420 FAX #: (504) 922-9316

Number of Pages: _____ **Date:** 10/19/95 **Time:** _____

To: Debby

Company: White House - Office of Domestic Policy

Location: _____

Fax #: (202) 456-7028 **Phone #:** _____

From: Janet Ketchum

Comments: As per your conversation with Becky Ogle, I am sending you the name + phone # of a child with cerebral palsy for Mrs Gore to speak to.

Thank you.

THE CHILDREN'S DEVELOPMENTAL CENTER

call to thank

THE UNIVERSITY OF NEW MEXICO HEALTH SCIENCES CENTER
CARRIE TINGLEY HOSPITAL
1127 UNIVERSITY NE • ALBUQUERQUE NM 87102-1715 • (505) 272-5200

FAX TRANSMISSION

DATE: October 20, 1995

TO: Debbie Fine **COMPANY:** White House

CITY/STATE: Washington, D.C.

PHONE #:(202)_____ **FAX #:**(202) 456-7028

TOTAL NUMBER OF PAGES (INCL. COVER): 2

FROM: David D. Dryden **DEPARTMENT:** Carrie Tingley Hospital Administration

PHONE #: (505) 272-5201 **FAX #: (505)** 272-6500
Home Telephone(505) 298-1503

MESSAGE: Per our telecon this afternoon, attached is some brief biographical information on Veronica Guardian who we believe would do very well as a tele-conference participant on Tuesday, October 24, 1995. Please call me if you have questions.

Penny Ford

Debbie - Got this from Tom Hehir
Right city, good story. Judy Heumann
- Diana

The Medicaid Program Its Impact on our Daily Life

Penny Ford, Denver, Colorado (303) 691-3368

I have eight kids, and for each one, as time has gone on, I've had only two aspirations: A childhood focused on learning, and an adulthood of contribution. Many times during the early years of my son Joseph's life, I feared that our family's resources were too few to make learning, and learning to contribute, a reality for this youngest, as well as for my other, kids. It is a privilege to know and to care for Joseph, who recently turned 12; for every member of our family, having a person with a disability among us has been a joy. However, I believe that we, as a society, must recognize the need to uphold the gifts of persons with disabilities and their families through concrete assistance. Without that assistance, our contributions are lost. The Medicaid waiver program supporting children at risk for institutionalization, called the Katie Beckett waiver, is making our family's contributions possible through a variety of very real and very needed supports, services and equipment.

Although our family had never accessed government assistance for other purposes (other than financial aid for college for my four oldest children), I applied for the Katie Beckett waiver because we can only do so many things in a day; we can only lift so many pounds; we can only afford so many specialized but basic medical gadgets. This year, although we expect our private health insurance policy to pay more than twelve thousand dollars for wheelchair and other aids for Joe, our share of the equipment bill alone would run to many thousands of dollars. The personal care assistance Medicaid pays for is not even available through our private insurance policy.

In the past, this has meant that while other kids in the family were going to the library, Joe stayed home, because his old wheelchair is not sturdy or safe enough to make the eight block trip over the sometimes uneven sidewalks. While other kids were doing their homework, Joe was waiting for me to finish a business call in my kitchen so that he could get his jacket off and start the seemingly endless task of finishing up one day's work to get into bed and start another. And when his siblings wanted to participate in their own right, contributing to their own school and community, they frequently spent their time as the only back-up care available to Joseph.

Joseph himself has maintained a positive attitude through all of this. Interviewed last summer for a documentary featuring Stephen Hawking, Joe was asked how he manages to do what he does in his daily life. He answered, "I just do whatever I can, and I never give up." This amazing contributor wants to work as an attorney in his adult life. His current Medicaid services are making it possible for him to contribute, and to do so with dignity.

The assistance Joseph received has made an enormous difference in my life, as well. I am now 47 years old. When I learned that we would be getting this much-needed help, I enrolled in a college program to pursue a bachelor's degree in education. I have been able to take a job far from my home, knowing that at the end of my very long day, I would be able to be just a mom to my kids, and not a weight-lifter, a physical therapist, a speech therapist, or a nurse.

My daughter Jane, who used to act as my back-up in managing Joe's care and equipment, during the week of October 22 will star in her school play at Denver's West High School. She also has joined the speech club and recently spent an entire Saturday at a speech meet. These activities might have come to pass in any case, but all of us would have sacrificed precious energy and focus to make them possible.

Medicaid is making our contributions possible. It is paying a portion of the bills for an orthopedist who is making sure that Joe's back has every chance to stay straight; for a neurologist who will help us watch out for seizures which could seriously complicate Joe's condition; for a rehab physician who can assist Joe on the road to adult independence. Medicaid for kids like Joe is not a luxury, or a waste of anybody's money. It is about the value that we hold, as a nation, for the gifts of the individual, that none may be left behind.

quadriplegic cerebral palsy
walking - uses computer
can speak

private insurance + Medicaid
Medicaid
- co pays on durable medical equip
- bath chair
- communication system
- personal care attendant 2x day to follow upon PT to prevent secondary diseases i.e. muscle stretch, dresses him, sets up breakfast - he can eat, brushes teeth, bathes him.
- toileting

Denver Public School - highly gifted children
IQ's higher 130 - 99th %ile
in middle School

Mom - works in Early Intervention Full time

Single Parent
no income qualification in Denver program

→ 303/458-0852 'M

→ meet w/ Stephen Hawking

school?
Central Library?

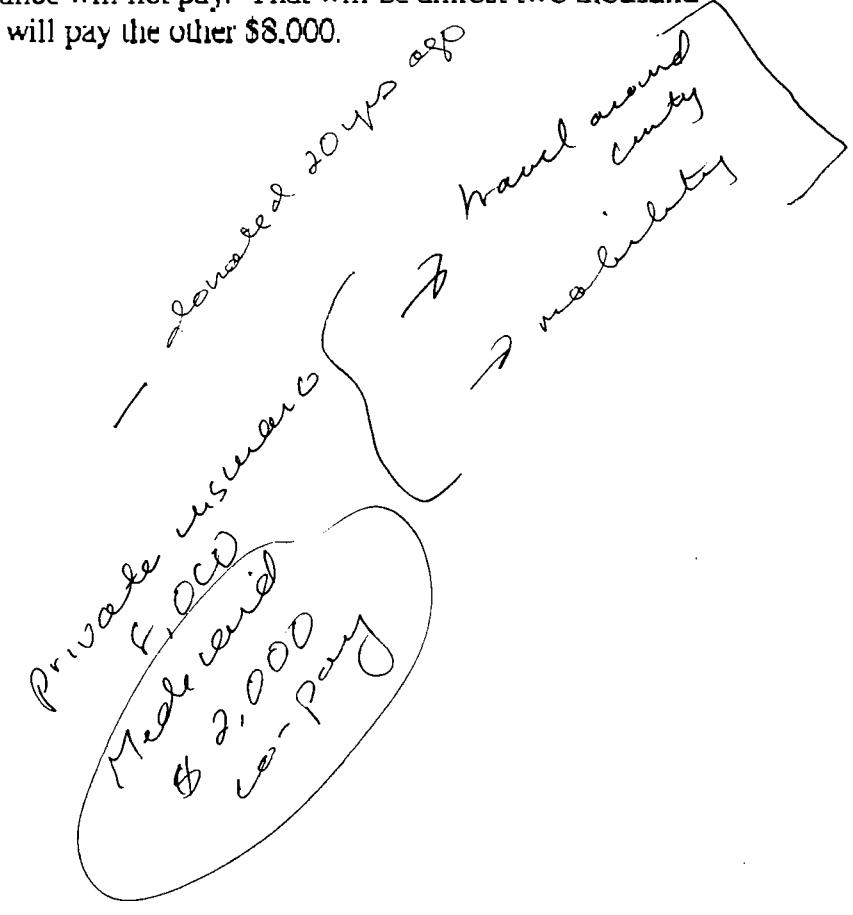
MY WHEELCHAIR

By Joe Ford

The first week of school this year, I went with two of my friends on the gravel at school. We were going around the whole field, and we got to a part with sand, we got stuck, and when we were trying to get out, the motor fell off. One of the teachers came and he had to push my old wheelchair out. When we got it back to the sidewalk, it leaked lubricating oil all over the sidewalk. Through a stroke of genius, the teacher figured out how to put the motor back on.

Just about every day, the footplate fell off my wheelchair. The chair is too big for me, and last week the back fell off of the chair when I got to school. The handle fell off because it was broken. The next morning before school started, the repair man came and made the temporary repairs. But he told us that the repairs will not last long.

A few weeks ago, I went to Children's Hospital to get fitted for a new chair. The new chair will have a seat that fits me, a motor and other parts that do not fall off, and will be able to go on the gravel at school. Medicaid paid for the repairs and will pay the amount for the new chair that my health insurance will not pay. That will be almost two thousand dollars. Blue Cross will pay the other $8,000.



→ U of NM Health Science Center

→ Access Living NM

→ Children's Sea Shore House

[PL] → Denver for Kids w/ CP

→ Moore Center Services

Debbie
2 - Open to regional press (there will be regional press at each location w/ children & their parents)

SCHNEIDER AND SCHNEIDER, P.C.
1633 N. North Park Avenue
Chicago, IL 60614
Fax No: 642-5810

Radio Studio, Rm 414

To: DEBORAH FINE

Fax: 202-456-7028 Date: 10-23-95

Re: MEDICAID CONF. CALL

From: TOM ZIMMERMAN

No. of Pages: 3 including the cover sheet

COMMENTS:

It is 2 min 45 secs .. what would you like to cut?

456-6766
6501

If you do not receive all of the pages, please contact Tom at tel. no. 642-2300.

VICE PRESIDENT & MRS. GORE -- 10/24/95

Thank you Mrs. Gore, Mr. Vice-President, and Mayor Daley for providing me with the opportunity to speak on behalf of my friend Jason Sloan. His mother Debra cannot be here today, she is at work.

I am a longstanding advocate for people with disabilities. Currently, I hold a volunteer position on the Illinois Planning Council on Developmental Disabilities Speaker's Bureau, centering on mainstream employment for the disabled, and I hold a volunteer position as an Illinois State Board of Education Surrogate Parent, concentrating on the educational needs of disabled children. I enjoy working with policymakers, and I welcome this opportunity to talk about Medicaid's positive impact on Jason Sloan.

Jason is an 18-year-old young man who has been mentally delayed and technology dependent since birth. Jason has moderate mental retardation, with an IQ of 40. And Jason has a brain stem dysfunction, whereby he is not able to breathe on his own. He has a long plastic tube connecting his throat to a portable ventilator, which pumps air into his lungs and forces him to breathe.

Like many 18-year-olds, Jason lives at home with his mother and two dogs. Debby works full-time during the day, and part-time at night, to keep the family together. However, Debby was denied private health insurance, because of Jason's pre-existing condition. Ordinarily, Jason would have been sent to live in an institution, and Debby would only be able to see him during visiting hours. But because of Medicaid's home services programs, Jason can live at home with his mother.

At home, Jason and Debby can play in the park, go to the zoo, or sporting events. They can go out to eat. Medicaid pays for Jason's ventilator and medical supplies, and Medicaid pays for 16 hrs/day of skilled nursing care in the home.

At home, Jason goes to the school of his choice with his friends. The Chicago school system has a state-of-the-art model special education system for disabled children and young adults.

At his special school, Jason enjoys working in the school's workshop, making products that are actually packaged and sold in stores. The school's workshop prepares him to eventually work in supported employment positions at companies, side-by-side with co-workers and interacting with customers. And Medicaid pays the nurses to act as Jason's job coach, to help Jason integrate into corporate America.

You see...the Medicaid dollars for in-home services allow Jason to remain part of his community, and I think Jason brings a lot of joy to the people he comes in contact with.

Debbie's Med. HC

If Medicaid is block granted:

(a) There must be Federal controls to keep some services mandatory... controls on how states have to distribute the money, and to whom... and the states must be required to contribute at least as much money as they did before.

(b) These must be national requirements, so Debby will be able to move to a different state, perhaps in pursuit of a better job for herself, without fear of losing her son.

In conclusion, we've seen Illinois tighten its belt in the Budget Implementation Act of 1996, wherein Illinois has chosen to cut $91 million of Medicaid Optional Services, including cuts in Dental, Vision and Prescription Drugs. If Medicaid funding is cut $182 billion at the Federal level, Illinois may have to further tighten by limiting eligilibility to **both** in-home **and** institutional services...leaving people like Jason out on the street with **no** future whatsoever.

I thank you very kindly.

Questions

1. Do you like living at home with your mother?
2. I understand you are in charge of the recycling project at school?
3. Would you like to get a job at a recycling company after you graduate from high school?

fear of Medicaid
--- ↑ cost
— ↓ standard of living
— pol pressure of institutions
vs pvd

TESTIMONY -- 8/24/95

— Speaks + understands

where? School or Access Living

Thank you Dr. Flemming, Senator Moseley-Braun, Representative Durbin, Mr. Bloncado for providing me with the opportunity to testify on behalf of my friend Jason Sloan, the young man seated here to my right/left. His mother Debra cannot be here today, she is at work. Jason has been ~~mentally delayed~~ and technology dependent since birth, and he is a Medicaid recipient under the DSCC Model Waiver. Jason is 18-years-old, and like many 18-year-olds, he lives at home with his mother.

mild to moderate mental retardation — IQ in 40s

— requires mechanical ventilation to breath attached by tube to nose

— divorced

— legal secretary — full time night — bowling alley

How are you doing today, Jason? (fine)

The gentleman seated behind Jason is his favorite nurse, Monroe.

— no private insurance b/c no one would accept b/c pre-existing condn

talking points

The current Federal Medicaid programs offer many benefits to people with disabilities, like Jason. Most of the benefits of the current programs flow from the fact that Jason lives at home with his mother. The DSCC and DORS home services Medicaid Waivers keep the family together.

(a) Debby struggles to earn a living, so she can be with her son every day. If Jason were forced to live in an institution, she could only see him during visiting hours.

Jason, would you like to leave your mother and go live in an institution? (No)

(b) At home, Jason and Debby can:

- play in the park
- go to the zoo, or sporting events
- They can go out to eat

Many of **these** things you or I may take for granted, but they are simply not available in institutional living.

(c) At home, he can go to the school of his choice with his friends, whereas they bring tutors into institutions.

(d) At home, he can work in supported employment positions at companies, side-by-side with co-workers and interacting with customers. And Medicaid pays Monroe to act as Jason's job coach, to help Jason integrate into corporate America. That's not available in an institution.

Many Debby's school system

needs watch 24 hrs day

Medicaid services' - $ for in-home nursing by choice 16 hrs/day (trained nurse) = pollsen wagon

- 2 vents + supplies (tubing)

- School (Chicago school system for disabled) special ed's, nurse goes w/→ school

gym class

home ec — washing dishes, vacuuming

Sheltered workshop — companies → product

1

Tim work w/ Mc Donald's

→ supported employment (req. job coach)

loves people

really unpolished to work

(e) You see...the Medicaid dollars for in-home services allow Jason to remain part of his community, and I think Jason brings a lot of joy to the people he comes in contact with.

Am I right, Jason? (it's hard to be humble)

(f) There's also DSCC & DORS case management to ensure Jason is receiving the proper services from qualified health care providers, **Ilke Monroe,** who has been with Jason for the past 6 years. That continuity of care ensures stability in Jason's life. Institutions do not provide residents with hiring & firing decisions, and there is no 1-to-1 ratio either...there may be 1 Monroe to care for 5 or 10 Jason's in the institution.

(g) The fiscal beauty is that the cost of providing in-home services to Jason is approx. $15,000/month -v- $55,000/month in an institution. So we're saving just under half-million dollars per year **and** giving Jason a higher quality of life.

Notwithstanding all of these benefits, there are some necessary changes to the current programs that will actually cut costs while improving services:

(a) First, let the families **purchase** the medical supplies, instead of requiring them to rent. It costs $1,000/month to rent 2 ventilators for Jason, whereas it costs $7,000 to **purchase** them. With approx. 50 people on vents in Illinois, that's a cost savings of $600,000/year, **and** the families will own the vents.

(b) Second, eliminate the nursing agency **requirement** under DSCC. Jason's nursing agency **receives** $30/hour, but it only **pays the nurses** $15/hour...the other $15 goes to administrative overhead. If we paid $15/hour directly to the nurses, with approx. 25 people on vents under DSCC, that's a cost savings of $2.25 million/year, **and** the families can hire & fire health care providers, as is done under DORS.

(c) Finally, move as many people as possible out of institutions, and back into their homes and communities. If we moved just 100 people back into their communities in Illinois, that's a cost savings of $48 million/year **and** we're giving them a higher quality of life.

If Medicaid is block granted:

(a) There must be Federal controls to keep some services mandatory... controls on how states have to distribute the money, and to whom... and the states must be required to contribute at least as much money as they did before.

(b) These must be national requirements, so Debby will be able to move to a different state, perhaps in pursuit of a better job for herself, without fear of losing her son.

In conclusion, we've seen Illinois tighten its belt in the Budget Implementation Act of 1996, wherein Illinois has chosen to cut $91 million of Medicaid Optional Services, including cuts in Dental, Vision and Prescription Drugs. If Medicaid funding is cut $182 billion at the Federal level, Illinois may have to further tighten by limiting eligibility to **both** in-home **and** institutional services...leaving people like Jason with **no** future whatsoever.

SCHNEIDER AND SCHNEIDER, P.C.

1633 N. North Park Avenue
Chicago, IL 60614
Fax No: 642-5810

To: Debbie

Fax: 202-456-7028 Date: 10/19/95

Re: MEDICAID BILL

From: Debby Sloan

No. of Pages: 5 pages including the cover sheet

COMMENTS:

Dear Debbie --

I just received a telephone call from Tom Wilson at Access Living. He said that you were looking for a parent with a child on Medicaid. Jason is currently receiving his services under the "Model Waiver Program". Please call me and I will be happy to explain in detail. A very close family friend, Tom Zimmerman, has been working very closely with me and attending the presentations, due to my work schedule, which is sometimes very difficult for me. Thank you.

If you do not receive all of the pages, please contact _____ at tel. no. (312) 642-2300.

Debby

called principal at school

Parents Union

Patty

$ was only able to work part time before - now where she works flexible → couldn't take other jobs + meet ed + med needs

TO: Debbie Fine

FROM: Janet Lonsdale of Parents Union for Public Schools in Phila.

RE: Parent and child with a disability getting services through Medicaid.

DATE: October 19, 1995

Alex - loves school, has friends

Debbie,

The parent who we identified is Elaine Colbert. Elaine is a single parent of a 14 year old daughter with Cerebral Palsy and ~~a Specific~~ Learning Disability. Elaine works as a special education advocate. Her daughter's name is Alexandria (Alex) and she currently attends a high school program taking a mix of regular education and Special Education classes. Alex receives the following services through Medicaid: braces, bi-monthly occupational therapy evaluation for gait regression, aquatics program, medical, dental and eye care, psycho educational testing and occupational and physical therapy assessments.

9th grade

Elaine and Alex live at:

1737 W. Bristol Street
Philadelphia, PA 19140
(215) 324-8846 - Home
(215) 546-1166 - wk phone

Parents' Union for Public Schools (Parent Training Center) (information under IDEA)

Elaine and Alex can be reached on Monday either at home or at Elaine's workplace. It would be helpful to them to have advance notification to enable Elaine to have Alex home from school.

Thank you so much for your interest.

work at parents' union - just got health insurance in March, covers employees only - doesn't make enough $ to add kid on + wouldn't cover much of the therapy, only a little for braces.

→ ~~could~~ would regress go to school but wouldn't have app materials academically or to function on a daily basis - or to walk

PARENTS UNION FOR PUBLIC SCHOOLS IN PHILADELPHIA, INC.

311 S. Juniper Street, Room 602
Philadelphia, PA 19107
(215) 546-1166 (fax 215) 731-1688

Date: 10.19.95

Sent To: Debbie Fine

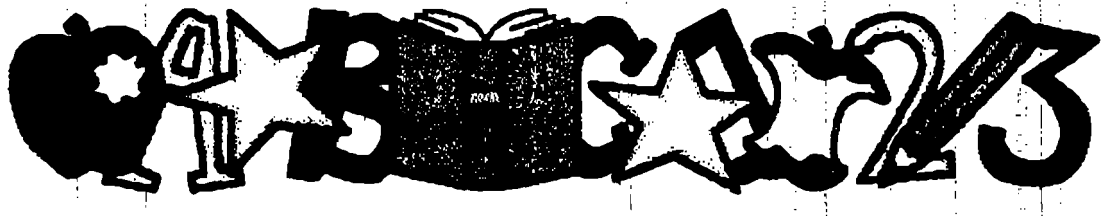
Fax No. 202.456.7028

Company: 1

Sent From: Janet Lonsdale

No. of Page: 2. (including cover)

Comments:



home 603 472 5879

Somewhat garbled speech

Ryan
- basketball team once every other week + play w/out
- on tball team alternate weeks - good at
- bowling

Profile of Family Medical History

Family involved: Mr. and Mrs. Daniel J. Louney

Dan Louney speak

18 Windsong Circle
Bedford, NH 03110

Family Members: father; Dan Louney, age 62, retired/part-time teacher/student at UNH-M → part-time
mother; Margaret "Margie" Louney, Coordinator Parent-to-parent Network
children; Margaret "Meg", age 29, teacher/special needs coordinator
Mary Kate, age 27, teacher/autistic children
Maureen (Louney) Heffernan, age 26, housewife
Daniel Anthony, age 23, student (SUNY, Albany) — w/an aid
Ryan Patrick, age 12, student (full inclusion), 6th grade
Ryan has Down syndrome — moderate IQ for Down Syndrome
(four children adopted)

- a waiter at a Mexican restaurant
- loves his dog
- reads on 2nd grade level
- work group to rocket ship models

Medical Insurance: Covered by employer (General Electric 22 yrs; Balzers 14 yrs)
Covered by COBRA for 18 mos. until 1/31/95
~~Ryan covered by Medicaid since April 1994~~ — prior to covered
Coverage for Dan and Margie, Mutual of Omaha since 2/1/95
family deductible, $7000 → on this plan services were not covered as too expensive for rehabilitation

Medical History: No major family problems with one exception, Ryan's skiing accident on 3/2/94.
Hospitalization covered by HMO (COBRA), Medicaid applied for as backup.
Accident included a broken arm, broken leg, and 51/2 weeks in a coma.
Three months in two hospitals; total cost $155,000 + all covered by HMO
Ryan dependent on Medicaid since termination of COBRA coverage.

→ frightening

husband lost position of 14 years -
Ryan covered under Balzers

prior to skiing - minimal services required.

reason for services used as back up at 1st - but now full b/c can't afford full family coverage

$7000 deductible

skiing accident -
hit 2 trees
broke limbs, sustained ~~a s~~ multiple serious head injuries →
coma for 5 1/2 weeks
Recovered and ~~was~~ has been rehabilitating + still ; PT and OT therapies

Soup kitchen at Manchester productive + responsible

FAMILY VOICES FAX

Phone 505/867-2368 FAX 505/867-6517

To Ms. Debbie Fine FAX # 202/456-7028

From Polly Arango & Julie Beckett Date 10/20/95

Page 1 of 2

Remarks:

As requested by Julie Beckett, attached is a bio for a young Native American teenager whose chronic condition requires Medicaid. His reservation is just west of Albuquerque. He gets many medical services in Albuquerque. Please

Family Voices
A National Coalition of Families and Friends Speaking On Behalf of Children with Special Health Needs
Box 769
Algodones, New Mexico 87001

call me or Julie w/ questions. I have also asked the CEO of our Children's hospital to find a Medicaid Child + family; CEO's name is Dave Dryden.

Carrie Tingley

To: Ms. Debbie Fine
From: Trish Thomas
505/867-2368
About: My son Travis Solomon
Date: 10/20/95

Julie Beckett of Family Voices asked that this be submitted. My son and I would be happy to help you in your efforts to save Medicaid on behalf of vulnerable people like my son and the millions of other children who also depend on Medicaid as a safety net. When private insurance or even public programs like Indian Health Service do not provide what our children need, we depend on Medicaid to make sure that our children have the same chance as other children.

Travis Solomon is 16 years old and is a member of Laguna Pueblo in western New Mexico. He has a serious visual impairment that has led to 11 surgeries, including a recent corneal transplant in one eye. Travis also has a bi-lateral hearing loss, which means he is deaf. He wears hearing-aids and because of years of speech therapy, is able to speak and be understood by those who listen carefully (similar to the former Miss America). Travis has been a recipient of Medicaid off and on ever since his first diagnosis. Medicaid has paid for the care related to his vision and hearing impairments, and all the therapies that have enabled him to remain a member of his community, living at home with his mother and older sister, and attending the local Laguna schools. Because of his health status and his family's income, Travis receives SSI benefits, including Medicaid. Without his Medicaid card, Travis would not have been able to have his most recent eye surgery, with the many pre- and post-operative clinical visits and ongoing expensive medicines. Because we are American Indians, we are also eligible to receive their health care from Indian Health Services (IHS). However, over the last few years, IHS in New Mexico has suffered numerous cut backs, with the greatest impact to clinics and contracts with health providers, so IHS cannot be depended upon for services children with chronic conditions. Travis can speak on his own behalf and tell his story. His sister Kori, who is 18 and who has attended his therapies and participated in his special care for many years, and who now takes him to his many weekly ear and eye appointments (so that I can work), can also speak on his behalf.

Thank you for your consideration . And thank you for working on behalf of children like Travis.

VPOTUS/MRS. GORE CONFERENCE CALL WITH CHILDREN WITH DISABILITIES:

Joe Ford (12 years old) and Penny (mother) Ford
Denver Center for Independent Living
Contact: Dan Lopp, 303/837-1020
777 Grant St.. Suite 100
Denver, CO

Jason Sloan (18 years old) and Tom Zimmerman (family friend)
Access Living of Metropolitan Chicago
Contact: Rene David Luna, 312/226-5900
310 S. Peoria St.
Suite 201 (2nd floor conference room)
Chicago, Ill.

Ryan Louney (12 years old) and Margaret Louney (mother)
Moore Center Services
132 Titus Avenue
Manchester, NH 03103
Contact: jan Larsen 603/6666501

Travis Solomon (16 years old) and Trish Thomas (mother)
University of New Mexico Health Sciences Center
2211 Lomas Blvd., NE
Albuquerque, NM
Contact: Gail Sutton 505/277-3679 or 3322

Alexandra Colbert (14 years old) and Elain Colbert (mother)
Children's Seashore House
3405 Civic Center Blvd.
Philadelphia, PA
Contact; Terry Burns 215/895-3613

THOMAS A. ZIMMERMAN, JR.

Mr. Zimmerman is a longstanding advocate for people with disabilities.

Currently... He holds a position on the Illinois Planning Council on Developmental Disabilities Speaker's Bureau, centering on mainstream employment for the disabled;

He holds a position as an Illinois State Board of Education Surrogate Parent, concentrating on the educational needs of disabled children; and

He is in the process of forming the Disabled Children's Charities, a non-profit organization focused on the disabled community's integration into independent residential living.

Mr. Zimmerman will be testifying on behalf of Mr. Jason Sloan, an 18-year-old young man who has been mentally delayed and technology dependent since birth, and who is a Medicaid recipient under the Model Waiver.

Jason Sloan
Chicago, IL
- mentally delay
- technology dependent
- Medicaid Recip
under model
waiver

FAX

U.S. DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

OFFICE OF SPECIAL EDUCATION PROGRAMS

OFFICE OF THE DIRECTOR

FAX No: (202) 260-0416
Phone: (202) 205-5507

Switzer Building - Room 3090
Switzer Building - Room 3086

DATE: 10/18/95

TO
Dena Fabricant

FROM
Thomas Hehir

Number of Pages (NOT including this cover page): 10

UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

October 18, 1995

NOTE TO DIANA FORTUNA

Attached please find the following documents:

(1) A set of talking points on the Impact of Medicaid changes for children and schools.

(2) A one page Impact Statement on Part B.

(3) A one page Impact Statement on Part H.

(4) A State-by-State breakout of kids severed by Part H

(5) A one page anecdote by a parent about the positive impact of Medicaid on her son and her family.

Thomas Hehir
Director, OSEP

TALKING POINTS

IMPACT OF MEDICAID CUTS ON SCHOOLS

The current medicaid entitlement for basic preventative and acute medical services protects some of the most vulnerable populations from arbitrary decisions of Government. Poor children, disabled children and their families are currently entitled to services that allow them to live healthy, independent lives as part of our community. The proposed elimination of this entitlement put them and the agencies that serve them such as schools and community-based organizations in serious risk. The proposed cuts in Medicaid coupled with the elimination of the entitlement for specific services would likely have the following effect on schools and the children they serve:

(1) SCHOOL HEALTH PROGRAMS:

Many schools utilize the Children's Benefit program under Medicaid to support their school health initiatives. The entitlement that poor children have under EPSDT to basic preventative and acute care services is utilized to develop comprehensive programs. Under a block grant states may choose to discontinue these programs. If they do, the health of poor children could deteriorate and these children will not be in an optimal condition to learn.

(2) CONTRIBUTED SERVICES FROM COMMUNITY-BASED ORGANIZATIONS:

Many school districts receive services from community-based organizations such as mental health centers or social service agencies. These agencies in tern bill Medicaid for the services. These "wrap-around" services are often essential to keep kids in school and maximize their learning. These type of agencies will have difficulty competing at the state level for a piece of the block and again kids and schools could lose.

(3) SUPPORT FOR FAMILIES AND THEIR CHILDREN WITH DISABILITIES:

Many families, both poor and middle class, receive support from Medicaid for their disabled children. This includes in-home support, assistance in purchasing equipment like wheel chairs or communication devices as well as various therapies. This enables families to keep their disabled children at home. Without these services some parents may have to give up their jobs or seek institutional placement for their children. We risk returning to the days when these children were warehoused in institutions. Further, there may be pressure on school districts to fund services currently paid for under Medicaid or the residential placements parents may seek if these lose in-home support.

(4) BILLING FOR REIMBURSEMENT FOR RELATED SERVICES:

Many school districts bill Medicaid for related medically-services (occupational therapy, speech therapy, physical therapy, and counseling) provided under the IDEA. These services are mandated by both EPSDT and IDEA. Given the proposed elimination of the entitlement under Medicaid for these services, States are unlikely to continue to support payment for these services and would shift the total burden to local schools. Last year Chicago received 28 million in direct medicaid support for these services.

(5) THE IDEA EARLY INTERVENTION PROGRAM FOR INFANTS AND TODDLERS WITH DISABILITIES:

The Early Intervention program provides important services to infants and toddlers and their families which serve to maximize development during the critical early years. This program is heavily funded by Medicaid in many states with some states funding over 50% of the program under this entitlement. This program could be seriously jeopardized if the entitlement for these services are eliminated and it becomes one of many competing programs for a block.

The Role of Medicaid Funding in the IDEA Part H Program

Since 1986, when Public Law 99-457 was enacted, States have been working intensely to put into the place the early childhood provisions of that legislation. Among other provisions, this law demonstrated the federal government's commitment to assist States in providing early intervention and preschool services to all young children with disabilities. What the lawmakers envisioned was a service system in every State that could respond to a broad range of children and families and offer whatever early intervention, special education, and related services were needed to meet the special needs of eligible children and their families. Importantly, they also envisioned a service system that would be largely created by coordinating already existing services and funding sources, and then expanding the system where necessary by accessing funds available from a variety of government and private sources.

Funds provided through the Part H Program for Infants and Toddlers with Disabilities were intended to be "glue money" (to coordinate and leverage funds and other resources from other sources within a State) and to serve a payor-of-last-resort purpose. Actual payment for most services was to be made from a variety of federal, state, local, and private sources (including Medicaid, federal and state health funds, State education funds, private insurance, parent fees, and local funds).

As States have fully implemented their service systems, the role of Medicaid funds in paying for services has been crucial. In the great majority of States, Medicaid reimbursement for services represents a substantial portion of the total State budget for the Part H program. Indeed, in some States, Medicaid represents over half of the total early intervention budget.

In Arkansas, for example, the total early intervention budget is $11,930,561, of which $7,465,390 (or 62%) is paid for through Medicaid. In South Carolina, Medicaid expenditures for early intervention services was $4,165,204 in FY 1995, which represented about 32% of the total State budget for Part H (approximately $13 million). In Massachusetts, a relatively wealthy State, the total early intervention budget is $44 million, 25% of which ($11 million) is funded through Medicaid reimbursements. New York received $35 Million in Medicaid reimbursement, which constituted 41% of their Part H budget.

As exemplified above, the Medicaid program is a significant source of funds for early intervention services. It is also clear that the use of Medicaid funds for early intervention services varies substantially across States. The reasons for

this variability include (1) the number of children and families in poverty within the State, (2) the number of children and families enrolled in the Medicaid program within the State, and (3) the number and nature of the services that are billable to Medicaid as defined in the State's Medicaid plan.

Given the significance of Medicaid funds in supporting States' early intervention programs, any diminution of these funds or their entitlement provisions would seriously jeopardize the Part H program. In some States, the very existence of the Part H program would be threatened.

Table AH1

Number of Infants and Toddlers Receiving Early Intervention Services
December 1, 1994

STATE	0-1	1-2	2-3	BIRTH THROUGH 2 TOTAL	POPULATION	PERCENTAGE OF POPULATION
ALABAMA	147	435	720	1,302	180,511	0.72
ALASKA	87	121	202	390	32,368	1.20
ARIZONA	226	557	699	1,471	205,039	0.72
ARKANSAS	355	595	692	1,642	101,298	1.62
CALIFORNIA	4,122	6,834	8,515	19,471	1,695,405	1.15
COLORADO	780	1,056	1,623	3,459	159,325	2.17
CONNECTICUT	237	606	1,060	1,903	135,500	1.40
DELAWARE	316	448	514	1,277	29,742	4.29
DISTRICT OF COLUMBIA	35	67	102	204	25,821	0.79
FLORIDA	1,424	2,592	3,099	7,115	567,377	1.25
GEORGIA	598	1,122	1,519	3,239	325,946	0.99
HAWAII	1,407	1,258	1,217	3,883	57,239	6.78
IDAHO	157	302	410	869	51,843	1.68
ILLINOIS	985	2,952	4,000	7,937	549,180	1.45
INDIANA	1,004	1,469	1,665	4,138	242,796	1.70
IOWA	92	345	569	1,006	110,452	0.91
KANSAS	171	375	654	1,200	108,749	1.10
KENTUCKY	206	487	641	1,334	155,144	0.86
LOUISIANA	368	901	1,364	2,633	202,451	1.30
MAINE	39	147	289	475	44,403	1.07
MARYLAND	538	1,151	2,104	3,794	223,953	1.69
MASSACHUSETTS	1,653	2,569	3,892	8,114	247,643	3.28
MICHIGAN	599	1,208	1,791	3,598	407,712	0.88
MINNESOTA	392	732	1,443	2,567	190,119	1.35
MISSISSIPPI	47	142	232	422	124,276	0.34
MISSOURI	516	874	932	2,322	221,299	1.05
MONTANA	91	150	241	482	34,218	1.41
NEBRASKA	70	239	427	736	67,659	1.09
NEVADA	134	268	326	728	67,808	1.07
NEW HAMPSHIRE	118	263	411	792	46,419	1.71
NEW JERSEY	332	1,095	1,583	3,010	341,223	0.88
NEW MEXICO	227	500	753	1,480	82,824	1.78
NEW YORK	824	2,583	6,054	9,461	826,290	1.14
NORTH CAROLINA	474	1,316	4,207	5,997	301,038	1.99
NORTH DAKOTA	35	86	89	210	25,071	0.84
OHIO	3,245	5,024	7,777	16,056	462,468	3.47
OKLAHOMA	309	613	765	1,687	141,495	1.19
OREGON	167	411	678	1,256	121,760	1.03
PENNSYLVANIA	984	2,274	3,091	6,349	467,630	1.36
PUERTO RICO	718	1,481	2,067	4,183	.	.
RHODE ISLAND	124	252	426	802	41,973	1.91
SOUTH CAROLINA	233	585	773	1,591	162,938	0.98
SOUTH DAKOTA	46	98	215	359	31,879	1.13
TENNESSEE	1,527	1,001	628	3,156	217,040	1.45
TEXAS	1,515	3,353	4,602	9,470	939,926	1.01
UTAH	383	585	592	1,560	108,425	1.44
VERMONT	33	102	179	314	21,732	1.44
VIRGINIA	480	1,185	421	2,086	279,008	0.75
WASHINGTON	227	693	1,322	2,242	232,222	0.97
WEST VIRGINIA	337	562	639	1,538	64,196	2.40
WISCONSIN	367	1,069	1,885	3,321	204,350	1.63
WYOMING	57	140	226	423	19,230	2.20
AMERICAN SAMOA	9	16	10	35	.	.
GUAM	12	29	86	134	.	.
NORTHERN MARIANAS	2	9	20	31	.	.
BUR. OF INDIAN AFFAIRS	.	.	.	.	.	.
U.S. AND OUTLYING AREAS	29,568	55,258	80,435	165,253	11,704,510	1.41
50 STATES, D.C. & P.R.	29,530	55,204	80,319	165,053	11,704,510	1.41

POPULATION FIGURES ARE JULY ESTIMATES FROM THE BUREAU OF THE CENSUS.

NO CENSUS DATA ARE AVAILABLE FOR OUTLYING AREAS.

PLEASE SEE DATA NOTES FOR AN EXPLANATION OF INDIVIDUAL STATE DIFFERENCES.

DATA AS OF OCTOBER 1, 1995.

SOURCE: AR_AH1.SFW

TALKING POINTS FOR THE FIRST LADY REGARDING MEDICAID CUTS AND CHILDREN WITH DISABILITIES

The most vulnerable children and families effected by cuts in Medicaid are children with disabilities. Currently, over 18 million children under age 21 are enrolled in Medicaid. Approximately 20 percent can be expected to have a physical, mental or developmental problem requiring treatment at some point. About 5 percent are disabled enough to be limited in their normal daily activities.

The children's benefit (EPSDT) within the Medicaid program has given children with disabilities the opportunity to stay at home with their families; to go to school in their neighborhood communities; to avoid further complications related to their disabilities; and to have the supports they need to participate as productive and integral members of society.

Severe cuts to Medicaid have implications for these children and the systems that support them that extends far beyond traditional medical care. For the past 20 years, this country has recognized the importance and benefit of providing a meaningful education to disabled children. This education includes the supports necessary for the child to be able to learn. These supports include (1) therapies, such as physical, occupational, and speech therapies; (2) assistive devices, such as communication devices; and, nursing assistance--- all necessary for the disabled child to be able to stay in school, learn, become employed and participate as active, productive adult citizens.

State education agencies and school districts across the country are benefitting from the financial support that Medicaid provides in meeting the needs of disabled children. Without this continued support, the cost of and responsibility for providing these medical services will become the sole responsibility of state and local school districts.

There are approximately 4.7 million children aged 6-21 receiving special education and related services under the Individuals with Disabilities Education Act. An estimated 1.3 million of these children are receiving health-related services. The current cost to state and local education agencies is approximately $2.2 billion. Because 40 - 60 % of these children have health coverage through Medicaid, state and local educational agencies receive reimbursement from Medicaid for these services.

The following represents data from states on their use of Medicaid to support disabled children in schools:

Louisiana in 1992 received $4.8 M for services provided to disabled children;

Arkansas in 1992 received $1.2 M for services provided to disabled children;

Page 2 - Points

California in 1994, based on a three year research study, projected $300. M in 1st year's billings/payments.

Baltimore County, MD in 1993 received $1.2 M for services provided to disabled children.

Chicago City Schools in 1994 received $28 M in reimbursement for health-related special education expenditures.

Parent from Julie B.
— Margaret Mikol
212 421 9160
son adopted
learning disabilities

→ Dr Irving Caminsky
VP of Assn for Retarded Citizens

— Lou Cooper, MD - Dir
212 523 3365 fax 523 8055

EXECUTIVE OFFICE OF THE PRESIDENT

— Sarah Fliegel

Sandra

20-Oct-1995 08:22am

— ~~Diana Aitken~~
908 654 7726

Natl Parent Network Bd
State-wide parent network in NJ
Native Am

TO: (See Below)

FROM: Marilyn Yager
Office of Public Liaison

SUBJECT: invites for the children's hopsital event

I have confirmed the number of seats we have for the First Lady's children's hospital event in new York on Monday:

8

Intergovernmental - 12 seats
Political/Congressional - 12 seats
Women' Office - 12 seats
Disability Groups - 12 seats
Health/Children - 12 seats

You must invite your own guests. They should be at the hospital by 10:00am on Monday, October 23. They should use the 167th Street and Broadway entrance to the Hospital

Provide all your confirmed names to Lisa Villareal or myself by Saturday 2:00pm.

As you know this is for the First Lady's remarks on Children and the Budget at the Babies and Children's Hospital of New York (at Columbia-Presbyterian.

→ ~~Natl Multiple Sclerosis Society~~ Natural

8 — Samosa

1 — Joan Kruzer

~~4~~ ✓ — Patty Smith

~~4~~ ✓ — The Arc

UCP

Easter Seals

March of Dimes

— Michael Losco

2 — ~~Julie~~

Joan 12 ~~212 667 0702~~

Distribution:

TO: Emily Bromberg
TO: William R. Daley
TO: Betsy Myers
TO: Barbara D. Woolley
TO: Deborah L. Fine

CC: Lisa S. Villareal

Patty Smith
h 703/359 9484

Mary
Alba
Anastasia

Some 2a ~~3a~~ 2 wcs

Tim Westmore
(w) 662 9595
(h) 544 1035

UPORUS

1:15 – 1:45 Tues

~~HA — Sioux Falls~~

WA, Seattle

NM, ~~Albuquerque~~

NH, Manchester no AIDS

↓ Larry Robinson

Julie Beckett

Louisiana

1 2pm Friday

Chicago probably spoke

Jason — work priv. uns.

call 4:15 Baton Rouge no AIDS

Philly probably (Parents center)

← Portland

Denver probably spoke Ford or Hazy

(JFK center)

need to call

[illegible] 7pm ☆ Parents

— Becky —

Easter Seals
Chicago

→ call back

— ~~Amy Slemmer~~
Jeff Levi
checking Julie Beckett
319 395 7349

Cedar Rapids

checking Patty Smith — people in

—

Maternal + Child Health
Pediatric

Dr. McPherson

day or night
~~PHOTOS~~ 212 307 9010 →

452 W. 57th St
Apt 2E
NY, NY 10019
☆ fax: 212 262 5517

→ Mary Somosa — teens w/ cerebral palsey
NY City Task Force on Medicaid
recipients
☆ media coverage

11 years old

— Joan Keizer

— Kathy McGinley — Virginia
703 820 1797

979 75 31

Parent Call

VP + ~~STORYS~~ Iowa

Julie Beckett - Family Voices
Patty Smith } parent people
Diane Lipton
Jennifer Simpson
Judy Herman
Carol

- ~~targeted States~~
- ~~how many~~

Becky Ogle

(6 states) ★

parents vs kids

- open remarks
- queries
- respond
- close

descriptions of people + concerns

- tps - (w/ queue)
- background info

local pressroom → ages of kids

→ kid on phone (2 phones)

[10-14] ?
can speak

Striving for Kids

Mrs Gore

Mayor's w/ kid - PC

Michigan - Detroit / Flint
Colorado - Denver
PA - Philly
IL - Chicago
Louisiana - Baton Rouge
Oregon - Portland

45 minute

- kid w/ AIDS
-

1 or 2 parents

~~Children~~'s Hospital

[disability groups in audience
rpt

↑ concerns eligibility
waivers] severe disab
mental
? ARC?

group home
(9)] 18 ideal

~~★~~ press home #15
[cob]

(5-10)

---

groups →
★ Children / Medicaid

OCTOBER 18, 1995

MEMORANDUM TO OPL STAFF

FROM: MARILYN YAGER

*****ALERT ****ALERT*****ALERT****

Per my e-mail yesterday and the opl staff meeting this morning, you are all aware that the White House will be focusing on children and the budget on Monday October 23. We are in the process of producing what is likley to be the best budget document ever -- a State by State Children's Budget Document.

This document will provide state impact numbers on how children will be affected by cuts in Medicaid, SSI (disability), education, EITC, housing, nutrition, and so on.

The White House will be releasing this document early Monday morning with Children's events all day Monday by the First Lady, Cabinet secretaries, and other senior officials. **It is critical that the groups help encourage this focus on children by holding state and local press events.** Even though we are prepared to release the document early Monday morning, we will provide the embargoed document on Friday after 4:30 pm to those groups that are definitely doing events on Monday morning, so that they may get the information to state people in time for a Monday event.

I have typed a memo that I plan to send to the Medicaid groups urging them to put together state press conferences on Monday. I have put this memo on the I-drive should you wish to use it, however, if you use it, you must change the contact name at the bottom to your own staff name.

It is on i:drive under i:\data\child.10.

PLEASE WORK THIS CHILDREN'S DAY WITH YOUR GROUPS.

October 19, 1995

MEMORANDUM TO ORGANIZATIONS CONCERNED ABOUT CHILDREN

FROM: MARILYN YAGER
DEPUTY ASSISTANT TO THE PRESIDENT AND
DEPUTY DIRECTOR OF THE OFFICE OF PUBLIC LIAISON
THE WHITE HOUSE

RE: CHILDREN'S DAY

As you may know, the Administration will be releasing a detailed State by State Children's Budget Document on Monday, October 23 outlining the impact of the Republican Congressional budget proposals on children. To coincide with the release of this document, Mrs. Clinton, the Cabinet, and other senior Administration officials will be speaking around the country about the devastating impact the House and Senate Budgets would have on children.

The Children's Budget Dcument will specifically address **Medicaid, SSI, education, housing, nutrition, earned income tax credit**, and other programs critical to children. Each state will have several pages that outline the estimated impact to children of significant cuts in these programs.

The Children's Budget Document will be available for pickup on Monday morning from 8:00 am to 10:30 am at the Pennsylvania Avenue Entrance to the Old Executive Office Building (corner of Pennsylvania Avenue and 17th Street).

PLEASE NOTE: We would urge you and your nationwide members to use this document as a resource for state and local press events on Monday, October 23 to help educate local communities about the impact on children in their communities. Please let us know if your state and local members are planning to hold press events on Monday and we will provide you with an embargoed copy of the Children's Budget Document on Friday afternoon after 4:30pm. Contact: Andre Oliver at 456-7032 or Ann Eder at 456-5161.

THE WHITE HOUSE

WASHINGTON

October 23, 1995

Trish Thomas
P.O. Box 1387
Laguna, New Mexico 87026

Transmitted by facsimile: 505/867-6517

Dear Ms. Thomas:

This is to confirm the invitation and participation of you and your son Travis Solomon in a conference call with the Vice President and Mrs. Gore tomorrow, October 24, 1995.

We are looking forward to having you on the call. Thank you for help and for your cooperation.

Sincerely,

Deborah Fine
Senior Policy Analyst
Domestic Policy Council Office of Policy Development

THE WHITE HOUSE

WASHINGTON

October 23, 1995

Elaine Colbert
c/o The Parents Union for Public Schools
311 South Juniper Street, Room 602
Philadelphia, Pennsylvania 19107

Transmitted by facsimile: 215/731-1688

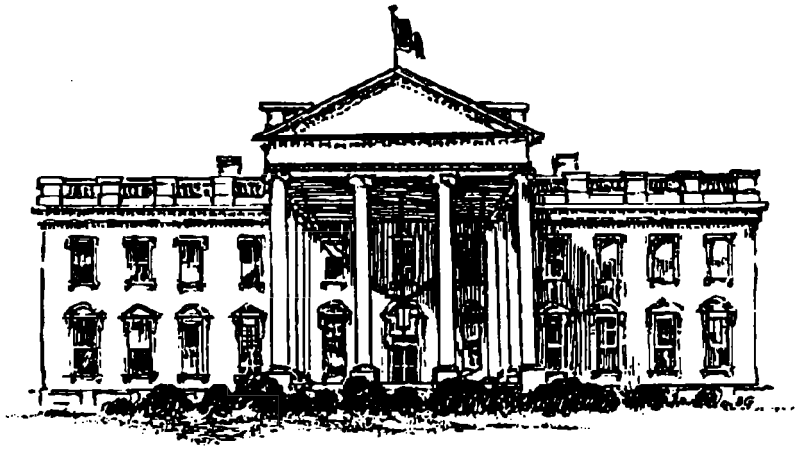
Dear Ms. Colbert:

This letter is to confirm the invitation and participation of you and your daughter Alexandra in a conference call with the Vice President and Mrs. Gore tomorrow, October 24, 1995.

We are looking forward to having you on the call. Thank you for help and for your cooperation.

Sincerely,

Deborah Fine
Senior Policy Analyst
Domestic Policy Council Office of Policy Development



THE WHITE HOUSE

To: Fine, Debbie Date: 10-25-95

From: FINE_D Page 1 of 5

THE WHITE HOUSE

VICE PRESIDENT AND MRS. GORE TO DISCUSS IMPACT OF REPUBLICAN BUDGET CUTS ON CHILDREN

Washington, D.C. -- Vice President Al Gore and Mrs. Gore will participate in a telephone conference call with five children with disabilities at 1:15 p.m. EDT on Tuesday, October 24. The Vice President and Mrs. Gore will discuss their concerns about the impact of Republican budget cuts on children with disabilities. Each child and his/her parent or friend will talk to Vice President and Mrs. Gore about their situations and health care needs. The conference call will be made available live via a listen-only audio dial-in line.

PARTICIPANTS:

Denver, CO
* Joe and Penny Ford
Denver Center for Independent Living, 777 Grant Street, Suite 777, Denver, CO

Joe, 12 years old, is a quadriplegic and has cerebral palsy. A very gifted student, he aspires to be an attorney. His mother Penny is a divorced, 47-year old single parent of eight. Penny has private insurance and receives in-home Medicaid assistance for Joe. Joe's in-home Medicaid services has enabled Penny to complete her bachelor's degree and take the full time job she now holds.

The Republican budget cuts federal Medicaid funding to Colorado by $2 billion over seven years and by 33% in 2002 alone. These cuts would eliminate coverage for as many as 50,921 children in Colorado in 2002.

Chicago, IL
* Jason Sloan and Tom Zimmerman
Access Living of Metropolitan Chicago, 310 S. Peoria St., Suite 201, Chicago, IL

The Republican budget cuts federal Medicaid funding to Illinois by $6.1 billion over seven years and by 29% in 2002 alone. These cuts would eliminate coverage for as many as 128,969 children in Illinois in 2002.

Jason, 18 years old, lives at home with his mother and works part-time in a supported employment situation. He has mild to moderate mental retardation and has been technology dependent since birth. Medicaid funded attendant services enable Jason to work and remain part of the community. No private insurance company would cover Jason due to pre-existing conditions. Jason's mother works two jobs so her son can live with her at home. Zimmerman is a disability advocate and close family friend.

Laguna, NM
* Travis Solomon and Trish Thomas
University of New Mexico Health Sciences Center, 2211 Lomas Blvd. NE, Albuquerque

The Republican budget cuts federal Medicaid funding to New Mexico by $902 million over seven years and by 24% in 2002 alone. These cuts would eliminate Medicaid coverage for as many as 20,467 children in Mexico in 2002.

Trish Thomas is a single parent of Travis Solomon, 16 years old, and his older sister, Kori. Members of the Laguna Pueblo tribe, they live on a reservation west of Albuquerque. Trish works part-time at an advocacy coalition for children with special health needs. Travis has a serious visual impairment and bi-lateral hearing loss. In-home Medicaid assistance made early therapy and special services, which Trish could otherwise not afford, available to Travis. He now is able to speak and be understood by most people.

Manchester, NH
* Ryan and Daniel Looney
Moore Center Services, 132 Titus Avenue, Manchester, NH

Based on the Senate Finance Committee bill, New Hampshire will lose $1.2 billion in Medicaid funding over seven years and $249 million in 2002 alone.

Twelve year old Ryan has Downs Syndrome. Medicaid is covering rehabilitative services he needs after being injured in a serious skiing accident. His father, Daniel, will be on the call with him.

Philadelphia, PA
* Alexandria and Elaine Colbert
Children's Seashore House, Philadelphia, PA

Fourteen year old Alex attends 9th grade at a high school program that mixes regular and special education classes. She has cerebral palsy and a learning disability, requiring several in-home services. Her mother, Elaine, has health insurance through her job at the Parents' Union for Public Schools, but is unable to afford the additional cost of the option to cover her daughter.

The Republican budget cuts federal Medicaid funding to Pennsylvania by $3.1 million over seven years and by 22% in 2002 alone. These cuts would eliminate coverage for as many as 114,892 children in Pennsylvania in 2002.

Please note that the Vice President and Mrs. Gore emphasized the following points in their remarks: (This is not a transcript; if we can get one I will fax it out.)

- As you all know, many families, both lower-income and middle class, receive support from Medicaid to help care for their children with disabilities. Such programs were developed as an alternative to placing children in institutions so that families have more options.

- Medicaid pays for wheelchairs and communication devices; therapy, including teaching parents to perform needed therapies at home; respite care for parents who need an occasional break in caring for a disabled child; and minor home modifications needed to allow a child to live at home.

- We must balance the Federal budget, but we must do so in a way that reflects the values that we have always held dear in this country. Values like giving every American the opportunity to be responsible to make the most of his or her own life, and strengthening our families. This budget debate is not just about programs and dollars.

- The President's plan for a balanced budget reflects America's values. It calls for reasonable, moderate reforms in Medicaid, while keeping our guarantee to children and older Americans, including Americans with disabilities.

- The budget that the Republicans in Congress have offered violates those values. It will destroy Medicare and Medicaid -- by taking twice the level of Medicare cuts we have proposed, and more than three times the level of Medicaid cuts.

- The Republican budget would also severely cut back the Supplemental Security Income (SSI) program for children with disabilities, particularly the House approach. It would eventually prevent nearly one million children eligible under current rules from receiving cash assistance. It would also terminate benefits altogether for 170,000 children with disabilities. The loss of cash assistance would be devastating to many low-income families struggling to care for a child at home.

- Cuts in Medicaid would be particularly devastating to children with disabilities because their families cannot access the private insurance market for all their child's needs, or often even at all.

- Programs such as the Medicaid home and community-based waivers provide needed support for families and children with disabilities at home in most states.

- In the past, before these programs were developed, many of these families would have had to seek institutional care for their children.

- At the state level, home and community-based programs will find it difficult to compete with hospitals and nursing homes for scarce Medicaid dollars.

- Without these services, some families would not be able to stay together.

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