FOIA Number: 2007-0143-F

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: Domestic Policy Council

Series/Staff Member: Diana Fortuna

Subseries:

OA/ID Number: 12024

FolderID:

Folder Title:
Children with Disabilities Conference Call

Stack:	Row:	Section:	Shelf:	Position:
S	97	2	10	3

Withdrawal/Redaction Sheet
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	Julie Becker to Debby; RE: Personal (2 pages)	10/19/1995	b(6)
002. letter	Janet Ketcham to Mrs. Gore; RE: Personal (1 page)	10/19/1995	b(6)
003. profile	RE: Personal (1 page)	10/19/1995	b(6)
004. profile	Background on Children and their families; RE: Personal [partial] (1 page)	10/23/1995	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12024

FOLDER TITLE:
Children with Disabilities Conference Call

2007-0143-F
db4493

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]

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

THE WHITE HOUSE

WASHINGTON

Add SSI

October 11, 1995

RURAL HOSPITAL CONFERENCE CALL

DATE:	**October 12, 1995**
TIME:	**11:45 a.m. to 12:30 p.m.**
LOCATION:	**Roosevelt Room**
FROM:	**Marilyn Yager/Jennifer Klein**

I. PURPOSE

To highlight the impact of the Republican Medicare and Medicaid cuts on rural hospitals and their communities through a discussion with six rural hospital administrators.

II. BACKGROUND

Both the House and Senate Reconciliation bills cut $270 billion from Medicare and at least $182 billion from Medicaid.

Our analysis of these cuts indicates that:

- Medicare spending in rural areas will be cut by $58 billion over seven years -- a 20% cut in 2002 alone. The Medicare cuts will force 9.6 million people on Medicare in rural America to pay higher premiums and deductibles.

- Medicaid spending in rural areas will be cut by $45 billion over seven years. As many as 2.2 million rural Americans will be denied Medicaid coverage, including over one million children.

According to the American Hospital Association, the typical rural hospital will lose $5 million in Medicare funding alone over seven years.

overall hospitals hard services @ home → nursing hard to compute

Imt SSI

40
-3
37
-5
32
6-7 mins
1-2 mins/ea

III. PARTICIPANTS

Secretary Donna Shalala

Rural hospital administrators (listed in speaking order)

1. Don Sipes, CEO, St. Lukes Northland Hospital, Smithville, MO
2. H.D. Cannington, Administrator, Jay Hospital, Jay, FL
3. John Kelly, Administrator, Soldiers and Sailors Memorial Hospital, Penn Yan, NY
4. Margo Arnold, CEO, West Side District Hospital, Taft, CA
5. Peter Hofstetter, CEO, Northwestern Medical Center, St. Albans, VT
6. Todd Linden, President/CEO, Grinnell Regional Medical Center, Grinnell, IA

Background information on each hospital administrator and the focus of their remarks is attached.

IV. SEQUENCE OF EVENTS

- You will open the conference call with a brief statement.
- You will ask Secretary Shalala to make brief statement.
- You will call on each of the Administrators to make brief comments. Each participants is prepared (in under 2 minutes) to highlight the particular impact of the proposed Republican Medicare and Medicaid cuts to their hospital and community.
- You will have the opportunity to ask follow-up questions and make additional comments.

V. MEDIA

Open press with regional satellites and audio to each locality. Each hospital has arranged for local media to join them for additional events and discussion following the conference call.

VI. REMARKS

Talking points are attached.

Background on Hospital Administrators
(Listed in Speaking Order Along with Topic)

1. **Don Sipes, CEO, St. Luke's Northland Hospital, Smithville, MO**

BACKGROUND: In addition to Don Sipe's position as CEO of Northland Hospital, he serves as rural advisor to the St. Luke's Health System in Missouri. St. Luke's Northland Hospital is a two-campus health care facility north of Kansas City, MO. In an effort to survive, these two hospitals integrated their services this past year, with one campus providing acute medical-surgical care and the comprehensive outpatient services and the other campus providing long term care, rehabilitation, mental health, and home health services.

Seventy percent of Northland Hospital's patients are Medicare and Medicaid beneficiaries. As the largest employer in Smithville, a community with a population of 2,500, the hospital's 125 employees provide a critical economic anchor.

FOCUS OF COMMENTS: **Overview of importance of Medicare and Medicaid to rural hospitals.** Don will highlight the fact that, since most rural hospitals in Missouri have approximately 60 to 80 percent Medicare patient mix, surviving in today's costly and aggressive health care marketplace is already difficult. Their Medicare admissions continue to rise every year. With several Missouri rural hospitals closing in the past several years, Northland Hospital is surviving only because they were able to integrate two facilities while they were still able to raise the capital to do so. He is also concerned about the effects of managed care on the elderly, most of whom do not yet have access to managed care in rural areas even if they wanted to choose managed care.

2. **H.D. ("HD") Cannington, Administrator, Jay Hospital, Jay, FL**

BACKGROUND: In 1979, Jay Hospital faced financial disaster and the inability to keep their physician staff. The community asked Baptist Health System to help them stay open and during the intervening years the hospital has taken many of the steps other rural hospitals have had to take to keep health services available to their small community: they added long term care services, home health, and provide a mobile clinic to deliver the essential primary and preventive care services needed by their community.

FOCUS OF COMMENTS: Impact on local community if hospital is forced to close. With a Medicare/Medicaid patient mix of 73 percent, "HD" Cannington believes his 55 bed hospital would close under the current Congressional proposals. "IID" believes the GOP cuts would be devastating for Jay Hospital (110 employees) and an economic disaster for the town of Jay (population 600). Losing the hospital, its physicians, and in turn the primary care and emergency services they provide would result in sicker people seeking care at greater distances. Ultimately, Medicare and Medicaid would pay more for the care the beneficiaries finally receive.

3. **John Kelly, Administrator, Soldiers and Sailors Memorial Hospital, Penn Yan, NY**

BACKGROUND: The Soldiers and Sailors Memorial Hospital is rural, non-profit hospital in the finger lakes region of New York. The Hospital has 217 beds, which include acute care, long-term care, and psychiatric care. They operate numerous rural health clinics throughout the county. Their Medicare/Medicaid patient mix is 75 percent.

FOCUS OF COMMENTS: Importance of Medicaid and the impact of these cuts -- especially Medicaid cuts -- on vulnerable rural populations. Jon Kelly's comments will site several specific ways the devastating Medicare and Medicaid cuts will hurt their rural community. Because Penn Yan is one of the poorest counties in the state, he will also comment on Medicaid and its critical role meeting the healthcare needs of rural Americans.

4. **Margo Arnold, CEO, West Side District Hospital, Taft, CA**

BACKGROUND: West Side District Hospital employs 160 people in a town of 5,900 people. As a high Medicare/Medicaid hospital (78 percent) they have struggled in recent years to make ends meet on providing acute care, and they have switched many beds into skilled nursing care to help cover their costs. The community is largely dependent on the oil industry and is long past the boom times of the 1970s.

FOCUS OF COMMENTS: Rural hospitals and long-term care for the elderly. Margo believes that the proposed Medicare and Medicaid cuts would close her facility, and with the next closest hospital an hour away, she believes lives would be lost. This 84 bed hospital recently converted 63 of their beds to long term care to help underwrite the acute care services of the facility. However, the Republican proposals would have a double effect on a their facility because the cuts are deep in both acute care and skilled nursing care.

5. **Peter Hofstetter, CEO, Northwestern Medical Center, St. Albans, VT**

BACKGROUND: Northwestern Medical Center is a 70 bed community hospital with a 58 percent Medicare/Medicaid patient mix. The hospital serves an immediate community of 7,300 people but, as the only hospital in Franklin and Grand Isle County, it serves a larger patient population of approximately 40,000 people. In the state of Vermont, they rank 14th highest out of 15 hospitals for bad debt write offs. Serving some of the lowest income areas of the state, Northwestern has sought innovative ways to expand access and primary care into every little hamlet up to the Canadian border. They have often benefited from the National Health Service Corps program, but these young physicians often leave after the term of their service.

FOCUS OF COMMENTS: Difficulties of attracting and retaining hospital personnel. Peter plans to focus his comments on how the Medicare/Medicaid GOP cuts will further exacerbate their struggle to attract and retain physicians. To expand primary care access in the Northern Vermont, Northwest Medical Center has been setting up clinics in five small towns to be staffed by nurse practitioners and physician assistants, with hospital staff physicians spending several days a week in these rural clinics. They believe that by improving people's access to primary care, lives as well as dollars are saved. However, they already cut corners to find the money to attract and pay physicians and nurse practitioners for their facility and further Medicare and Medicaid cuts are likely to close down their rural clinics altogether.

6. **Todd Linden, President/CEO, Grinnell Regional Medical Center, Grinnell, IA**

BACKGROUND: Grinnell Regional Medical Center is an 81 bed hospital in a town of 8,900 people. Todd Linden was recently sited by Modern Healthcare magazine as one of the nation's "Up and Comers" in the hospital industry and is widely known for his advocacy on behalf of rural hospitals. He currently serves as Chair of the Iowa Telemedicine Advisory Council and is actively seeking ways to help rural hospitals become more efficient with fewer resources.

FOCUS OF COMMENTS: Rural hospitals as "total community health provider." Grinnell Regional Medical Center is very dependent on Medicare (over 50 percent) as are many hospitals in Iowa. Todd will comment on their efforts over the past decade to become more efficient, eliminate waste, and develop better use of their space (very few hospitals fit the 1980s stereotype of hospitals with empty beds) by expanding into home health care, hospice, skilled nursing swing beds. Therefore, further cuts in Medicare leave them very few options other than eliminating services that are needed in their community. Because they are the "total health provider" in their community, they will be hit by large Medicare cuts in many different practice areas (home health, skilled nursing care, acute care, etc).

Tipper intro VP?

3

PRESIDENT WILLIAM J. CLINTON
TALKING POINTS FOR CONFERENCE CALL
WITH RURAL HOSPITAL ADMINISTRATORS

THE ROOSEVELT ROOM, THE WHITE HOUSE
OCTOBER 12, 1995

start w/ children what is

- I'm glad that you all are joining me today on this conference call to discuss the importance of continuing our investment in health care in rural America.

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

- I want to balance the budget, and I have a proposal to do it. I have said for a long time that we need to balance the budget to lift the burden of debt off of our children and to strengthen our economy.

- But we need to do it in a way that reflects the values that we have always held dear in this country. Values like giving every American the opportunity to make the most of his or her own life, strengthening our families, and respecting the duty we all owe to each other. This budget debate is not just about programs and dollars; it's about providing for our children's futures and honoring our parents.

- My balanced budget plan reflects America's values. It secures the Medicare Trust Fund, while strengthening -- not gutting -- our Medicare program. It calls for reasonable, moderate reforms in Medicaid, while keeping our guarantee to children and older and disabled Americans. It addresses the budget deficit, while responding to the education deficit by continuing our national commitment to education and training. And it targets a tax cut to middle class, working families.

- In my judgment, the budget that the Republicans in Congress have offered violates those values. It will decimate the Medicare and Medicaid programs -- by taking twice the level of Medicare cuts I have proposed and more than three times the level of Medicaid cuts. It will force American families to choose between educating their children and making sure their parents have the health care they need.

- These cuts will be particularly devastating to rural communities and families because Medicare and Medicaid are the backbone of the health care system in rural areas.

  - As you well know, hospitals in rural areas struggle every day to make ends meet and are already closing at more rapid rates than hospitals in cities. And you depend more on Medicare and Medicaid payments than urban hospitals.

- When you look at the situation out there and the level of these cuts, it's easy to see what the Republican budget will mean for health care in rural America. Imagine what it will mean for your local hospital -- that is there not only for families in emergencies, but also for families with a child who needs to be immunized, or a mother or father who needs long-term care.

- I grew up in a community where we depended on the local community hospital for just about everything, and I can only imagine what drastic cuts like these would have meant for that hospital. And I can only imagine what it would have meant for my town if that hospital had been forced to close.

- I'd like to call on Secretary Shalala to say a few words.

- I would now like to hear from you about your hospitals and what the budget cuts will mean to your hospitals and communities.

1. Don Sipes, CEO, St. Luke's Northland Hospital, Smithville, MO
   Topic: Overview on importance of Medicare and Medicaid to rural hospitals

2. H.D. Cannington, Administrator, Jay Hospital, Jay, FL
   Topic: Impact on community if hospital closed

3. John Kelly, Administrator, Soldiers and Sailors Memorial Hospital, Penn Yan, NY
   Topic: Importance of Medicaid and impact of Medicaid cuts

4. Margo Arnold, CEO, West Side District Hospital, Taft, CA
   Topic: Rural hospitals and long-term care for the elderly

5. Peter Hofstetter, CEO, Northwestern Medical Center, St. Albans, VT
   Topic: How cuts will exacerbate struggle to attract and retain physicians

6. Todd Linden, President/CEO, Grinnell Regional Medical Center, Grinnell, IA
   Topic: Rural hospitals as "total providers" (i.e., providers of all types of health care)

GENERAL FACTS ABOUT RURAL HOSPITALS AND RURAL HEALTH CARE

RURAL HOSPITALS ARE ALREADY IN A PRECARIOUS FINANCIAL POSITION.

- **The number of rural hospitals in America dropped 17%** between 1983 and 1993, while the number of urban hospitals dropped 2%.
- **One in four rural hospitals operate at a loss:** *Twenty five percent* of rural hospitals had a negative total operating margin in 1992.
- **Rural hospitals already lose money on Medicare patients.** Rural hospitals lose roughly 2% on Medicare patients. Urban hospitals, in contrast, run a slight profit (.6% on Medicare patients).

RURAL HOSPITALS DEPEND ON MEDICARE AND MEDICAID

- **Medicare alone accounts for almost 40% of net patient revenue in the average rural hospital.** In some rural areas, Medicare represents as much as 80% of revenues.
- **The majority of rural patients are Medicare or Medicaid beneficiaries.** About 60% of the discharges in rural hospitals are Medicare or Medicaid beneficiaries -- 25% higher than the proportion in urban hospitals.
- **Rural Americans depend more on Medicaid and Medicare because they have lower incomes.** Rural residents had an average per capital income in 1993 of $16,028, compared to $23,843 for urban residents. The incidence of poverty among the non-metropolitan elderly is approximately 60% higher than among metropolitan elderly. Thus, an across the board increase in premiums will represent a far larger tax in percentage terms on the rural elderly than on the urban elderly.

REPUBLICAN BUDGET BUDGET TARGETS RURAL AMERICANS' HEALTH CARE AND RURAL HOSPITALS

- **Cuts Medicare for rural Americans by $58 billion -- a 20% cut** in 2002. This will mean higher out-of-pocket costs for the 9.6 million older and disabled Americans on Medicare in rural areas.
- **Budget cuts will cost the typical rural hospital $5 million over seven years**, according to the American Hospital Association. To put that figure in context, the typical rural community hospital has total expenses of less than $15 million every year.
- **Cuts Medicaid for rural Americans by $45 billion, denying coverage to as many as 2.2 million rural Americans, including over one million children.**
- **As many as 77,000 rural older and disabled Americans could be denied nursing home coverage.**
- **As many as 55,000 rural and disabled Americans could be denied home care benefits.**

1- Gen'l overview
2- Focus of ea person
3- Talking Pts
4- Fact sheet

U.S. Department of Health and Human Services

The Office of Disability, Aging and Long-Term Care Policy
Room 424-E, Humphrey Building
200 Independence Ave., SW
Washington, D.C. 20201

FAX (202)401-7733

TO: Diana Fortuna

FAX NUMBER: 456-7028

NUMBER OF PAGES: Cover + 18

DATE: 10/19/95

FROM:

Michele Adler	☐	Andreas Frank	☐	Maria Martino	☐
Kathleen Bond	☐	Mary Harahan	☐	Robyn Stone	☐
Floyd Brown	☐	Jennie Harvell	☐	Tammy Terrell	☐
Robert Clark	☐	Ruth Irwin	☐	Brenda Veazey	☐
Pamela Doty	☐	Ruth Katz	☑		
John Drabek	☐	Gavin Kennedy	☐		
Nancy Eustis	☐	Nadine Langon	☐		

I am in and out today & tomorrow. But phone mail is busy a lot. If you call and I don't answer in person, call 690-6172 or 6443 & leave a message with a person. Thx. Ruth

I tried but not get a busy signal. Sorry, I just got your message.

REMARKS/COMMENTS

Diana - This is from the Urban Inst. Report for ASPE. We may be able to update it - you'll note we do have an aggregate number for 94 (930,000) So maybe it can be broken out for us state x state

P.S. - For the 1st time today, I called my phone mail

expenditures in recent years, expenditures in constant dollars had almost doubled from 1980 to 1990, before eligibility changes were implemented.[44]

State supplementation payments have also increased over the past decade. Total state supplementation payments (in 1993 dollars) have increased from $116 million in 1980 to over $202 million in 1993.

Although the number of recipients was growing over this period, expenditures per child on SSI also grew over this time period. In 1993 dollars, total payments per child on SSI were $4,687 per year in 1980, $5,426 in 1990, and $5,587 in 1993.[45]

Medicaid

The Medicaid program is among the most important sources of funding for health services for children with disabilities. The complexity of the program, including the numerous criteria for becoming eligible and the variety of services provided, makes it difficult to consider as a single program. The 1993 Medicaid Source Book prepared by the Congressional Research Service reports that Medicaid is often thought of as three different programs:[46]

- a basic health insurance plan for most of its beneficiaries;
- a financing program for long-term medical and social services for the frail elderly and disabled;
- a funding stream for programs (largely state-operated) for the developmentally disabled and mentally ill, both institutional and community-based.

These three different "program" distinctions are not entirely separate. For example, a child receiving services through a Medicaid-funded, community-based, mental retardation

---

[44] If at 1993 caseload levels real per capita payments had remained at 1989 levels, total expenditures on blind and disabled children would have been $3.9 billion, $400 million less than actual expenditures.

[45] Because the caseload of children on SSI changes from month to month, total payments per child on SSI reported here are only estimates. They are calculated as the total annual real payments (from Table SSI.5) divided by total blind and disabled child caseload for December of the respective year.

[46] Information for the discussion in this section is drawn from Congressional Research Service, Medicaid Source Book: Background Data and Analysis, Washington, D.C., January 1993.

program may also receive acute care services, using Medicaid as a basic health insurance plan. Because of these overlaps, it is difficult to distinguish how many children with disabilities are receiving services under each program part, as well as to separate expenditures by program part.

Eligibility

There are at least five different ways children with disabilities can become eligible for Medicaid. These include: eligibility through SSI receipt, general eligibility provisions covering all children, medically needy programs, and special provisions for chronically ill or disabled children.

Eligibility through SSI

Most states are required to provide Medicaid eligibility to blind and disabled children receiving SSI. Thirty-one states and the District of Columbia provide Medicaid without separate application. Seven states opt to provide Medicaid to SSI recipients only if they make a separate application to the state agency that administers Medicaid. The states choosing this option are Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon, and Utah.

Some states do not provide Medicaid to SSI recipients automatically. States are allowed to use more restrictive eligibility standards for Medicaid than for SSI if they were using those standards before the implementation of the SSI program. About 18 percent of all SSI recipients live in these states.[47] The twelve states using more restrictive standards in 1994, known as "section 209(b)" states, were: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma, and Virginia. The more restrictive standards may include different definitions of disability or more restrictive income and asset eligibility criteria.

States using more restrictive eligibility requirements must allow applicants to deduct medical expenses from income before determining eligibility (called "spend down" provisions). In addition, states may optionally choose to provide Medicaid to persons not receiving federal SSI payments but who are receiving state supplemental SSI payments. As of January 1991, 34 states provided Medicaid automatically to persons receiving only supplemental state SSI payments.

---

[47] House Committee on Ways and Means, Overview of Entitlement Programs, Washington, D.C., July 1994.

States are required to continue Medicaid coverage for those who lose Medicaid under a variety of circumstances. The most important of these for children is the loss of SSI eligibility due to income increases, such as gaining social security benefits, when moving to adult status.

Because SSI eligibility insures Medicaid coverage for the majority of recipients, loss of eligibility for SSI, even because of a relatively small amount of additional earnings, can mean a major increase in costs for a family through medical expenditures. Although this is also a problem in other welfare programs, the SSI child with disabilities will more likely have higher cost and more persistent needs being met by Medicaid.

General Eligibility Provisions for Children

Low-income families receiving cash assistance from the Aid to Families with Dependent Children (AFDC) program are also automatically eligible for Medicaid. AFDC is a program of cash assistance for poor families. Given SSI is received by only a portion of all children with disabilities, it is likely that many poor children with some level of disability receive Medicaid through AFDC recipiency.

Over the last 10 years, eligibility for Medicaid for pregnant women and children (unrelated to participation in cash assistance programs) has been greatly expanded. There are a variety of both mandatory expansions as well as optional expansions of the population to whom states may provide Medicaid. These are not specifically related to children with disabilities (there are only age and income requirements) but they also may help children who are not eligible for Medicaid through SSI.

Some of the major expansions in coverage required include: (1) all pregnant women, infants, and children under age 6 in families with income under 133 percent of poverty; (2) all children between age 6 and 19 born after September 30, 1983 in families with income under 100 percent of poverty; and (3) an additional 12 months of coverage for families who lose AFDC benefits due to increased earnings. In addition, states have the option of covering non-AFDC women and infants under age one with family income between 133 and 185 percent of poverty. As of July 1993, 34 states are using this option.

Medically Needy

The medically needy program may benefit families with children who have large medical expenditures but income too high to qualify for Medicaid through SSI or AFDC.

Persons eligible for the medically needy program must meet the non-financial criteria for Medicaid, such as the disability criteria for SSI or family structure for AFDC. States may establish higher income or resource requirements for medically needy, up to 133 1/3 of the maximum payment under the state's AFDC program. They may also allow for "spend down": allowing deduction of medical expenses from income before assessing financial eligibility.

Medically needy programs are established at state option, although once established they must serve at least pregnant women and children. As of October 1993, 15 states did not have medically needy programs. State that do not have a medically needy program include: Alabama, Alaska, Arizona, Colorado, Delaware, Idaho, Indiana, Mississippi, Missouri, Nevada, New Mexico, Ohio, South Carolina, South Dakota, and Wyoming.[48]

Special provisions for chronically ill or disabled children: TEFRA and HCBS Waivers

Additional avenues of eligibility for children who are chronically ill or have a disability are available for children receiving care at home or in the community who would otherwise be in an institutional setting. Most children receiving care in an institutional setting are eligible for SSI (and therefore Medicaid) because, after 30 days, parental income is not considered in calculating eligibility; only the child's own financial resources are considered. When a child is living at home, however, parental income is considered available to that child when calculating eligibility. This can lead to a child being eligible for Medicaid if he or she is living in an institutional setting but not if he or she is living at home. The result is that some children may be in institutions in order to be eligible for Medicaid when they could receive care at home, care that could potentially be less costly.

There are two options available to states to allow children receiving care in the community or at home eligibility for Medicaid: the TEFRA option, and Home and Community-Based Services (HCBS) regular and model waivers.

[48] In addition to medically needy programs, states have the option of using the so-called 300-percent rule for eligibility for those requiring institutional care whose income is above the SSI eligibility level. This program allows eligibility for those who require institutional care, meet the state resource requirements, and whose income does not exceed three times the basic SSI payment level. Income applied to this standard must be gross income with no deductions allowed. States may use a lower level cut-off. In 1991, 35 states used the 300-percent rule option. Of these states, 17 did not have a medically needy program for those requiring institutional care. Two states, Missouri and Illinois, have neither a medically needy program nor do they use the 300-percent rule for those needing institutional care. In these states individuals may qualify for Medicaid under the spend down provisions required of states that do not automatically provide Medicaid to SSI recipients.

Changes in TEFRA (Tax Equity and Fiscal Responsibility Act of 1982) allowed states the option of extending Medicaid to certain disabled children under 18 who are living at home and would be eligible for SSI if they were living in a hospital, nursing facility, or intermediate care facility for the mentally retarded. This provision is sometimes called the Katie Beckett provision after the child whose case was used to publicize this need. The requirements for receiving Medicaid under this option include: (1) the child requires the level of care provided in an institution, (2) appropriate care can be provided to the child outside of an institution, and (3) the cost of care at home is no more than the cost in an institution. Children who have private insurance that covers the cost of institutional care are not eligible if their costs at home for Medicaid would be higher than in an institutional setting. States electing this option must cover all qualifying children. Currently, 18 states offer this provision.[49]

Medicaid also allows the states the option of applying for waivers to provide community-based services to individuals who would otherwise require (or be at risk of requiring) care in an institutional setting that could be covered by Medicaid. These waivers are called home and community-based services (HCBS) waivers or section 1915(c) waivers and can be used to provide services that would otherwise not be covered, although total Medicaid costs to individuals under a waiver cannot exceed the costs that Medicaid would pay for those individuals in institutional settings. Waivers can be used to target a subset of the state, such as certain geographic areas of a state or certain categories of beneficiaries. Eligibility depends on the specific waiver.

A variation of the 1915(c) waiver is called the "model" waiver. These waivers are used in the same way as the TEFRA option is used. For children who are receiving care at home but would be eligible for Medicaid if in an institutional setting, parental income is not considered in calculating Medicaid eligibility. The Health Care Financing Administration limits use of the model waiver to 200 individuals per waiver. Although the model waiver is similar to TEFRA, most states prefer the model waiver for two reasons. First, TEFRA requires provision of services to all who qualify, leading to uncertainty for a state in the total associated costs. Second, the model waiver allows flexibility in providing services usually not covered by Medicaid, while TEFRA limits services to those included in a state Medicaid program. Under a model waiver, states can provide optional potentially costly services to a limited set of individuals. Currently 14 states have model or regular HCBS waivers that

[49] Sally Bachman and Brian Burwell, "Medicaid Home and Community Based Services for Children with Disabilities," technical memorandum for the U.S. Department of Health and Human Services, October 1994.

serve children with special health care needs, including 2 waivers that serve only children with AIDS/ARC.

Administration

Each state operates its own Medicaid program through a state agency, usually the health department or welfare and social services department. The main functions of the state are to determine eligibility, process claims, certify providers, and assure the program is properly administered. States with automatic eligibility for Medicaid through SSI, have the option of having eligibility determination carried out by the Social Security Administration. Most Medicaid claims are issued by the state directly to providers, not to beneficiaries.

At the federal level, Medicaid is administered by the Health Care Financing Administration (HCFA). Because states must comply with federal mandates, the state plan for Medicaid must be approved by HCFA. If the state wants to waive certain federal requirements, the state must apply for a waiver and have it approved by HCFA. HCFA also oversees state Medicaid programs' compliance with federal regulations.

Medicaid services are financed jointly by states and the federal government. The federal share of a state's Medicaid payments is known as the Federal medical assistance percentage (FMAP). FMAPs are calculated annually based on a formula that gives higher federal matches to states with lower per capita incomes. The minimum FMAP was 50 percent and the maximum was 83 percent in 1992. On average, the FMAP was 58 percent in 1992.

Benefits / Services

Medicaid provides a broad variety of services to children with disabilities. By federal mandate, one set of services that must be offered by all state Medicaid programs. There is also an additional set of services that states can offer at their option.[50]

The following services are mandatory: inpatient hospital services, outpatient hospital services, rural health clinic services, federally qualified health center services, other laboratory and x-ray services, nursing facility (NF) services for individuals 21 or older, early and periodic screening, diagnostic and treatment (EPSDT) services for individuals under age

[50] States that have medically needy programs may offer a more restrictive set of services to this group.

21, family planning services, physicians' services, home health services for any individual entitled to NF care, nurse-midwife services, and services of certified nurse practitioners and certified family nurse practitioners.

There is also a set of services which state Medicaid programs may offer at their option. Optional serves are as follows: podiatrists' services, optometrists' services, chiropractors' services, other practitioners' services, private duty nursing, clinic services, dental services, physical therapy, occupational therapy, speech, hearing and language disorder, prescribed drugs, dentures, prosthetic devices, eyeglasses, diagnostic services, screening services, preventive services, rehabilitative services, intermediate care facilities (ICF) services for mentally retarded, inpatient psychiatric services for children under age 21, Christian Science nurses and sanatoria, nursing facilities (NF) for children under age 21, emergency hospital services, personal care services, transportation services, case management services, hospice services, respiratory care services. The number of states providing some specific optional services are listed in Table 11.

Medicaid provides some benefits that differ from those covered by traditional medical insurance. These include the EPSDT program and non-medical HCBS waiver services. Under the EPSDT benefit, states must periodically provide general health screening, vision, hearing, and dental services for Medicaid recipients under age 21. States are required to provide each service type at appropriate intervals. Any services necessary to treat illnesses or conditions identified by screening that are permitted under federal Medicaid regulations must be provided by a state even if the services are not normally covered by the state's Medicaid program. Essentially, EPSDT requires states to cover the full range of mandatory and optional services for eligible Medicaid children. In fiscal year (FY) 1991 federal and state payments for EPSDT services totaled $356 million. This figure does not reflect all examinations received by children enrolled in Medicaid as states may reimburse for some health supervision services that are not billed as EPSDT services.

Under the HCBS waiver program, additional services not regularly funded by Medicaid may be provided. The exact services depend on the specific state waiver. Some of the services available through waivers include case management, homemaker/home health aide services, personal care, adult day health services, habilitation services, respite care, supported employment services, minor home modifications, non-medical transportation, nutrition counseling, home-delivered meals, family therapy, psycho-social counseling, emergency response systems, medical supplies, and assistive devices. Some of these services are more commonly provided in waivers for the elderly than in waivers targeted at children with disabilities or persons with MR/DD.

Table 11
Number of States Providing Optional Medicaid Services, December 1993

Service	States Offering Services to Categorically Needy Only	States offering Services to Categorically Needy and Medically Needy	Total
Psychologists	7	20	27
Physical Therapy	13	28	41
Speech Pathology/Audiology	16	31	47
Private Duty Nursing	8	20	28
Maternal & Child Health Clinic	14	27	41
Mental Health Clinic	14	25	39
MR/Day Treatment	2	9	11
Physical Therapy	13	28	41
Speech Disorders	14	26	40
Hearing Disorders	15	26	41
Language Disorders	13	24	37
Prescribed Drugs	16	35	51
Prosthetic Devices	18	33	51
Rehabilitative Services	13	32	45
ICF/MR	22	29	51
Inpatient Psychiatric (under 21)	13	28	41
TCM (under 21)	5	12	17
Respiratory Care Services	5	12	17
Transportation Services	15	36	51
NF Services (under 21)	20	31	51
Personal Care Services	11	21	32

Source: U.S. Department of Health and Human Services, Health Care Financing Administration, "Medicaid spDATA System: Characteristics of Medicaid State Programs," part 1, December 1998, Table 3-1.1.

Participation

The Health Care Financing Administration tracks state-level enrollee and expenditure information for the Medicaid program. In this administrative data, enrollees are usually categorized into four groups: aged, adults, blind/disabled, and children. Children categorized as blind and disabled are usually those receiving Medicaid through SSI eligibility or SSI-related eligibility and children in long-term care paid for by Medicaid. However, some children with disabilities (depending on the definition used) are eligible for Medicaid by other routes, such as through the AFDC program or due to recent expansions in Medicaid eligibility for children. These children are probably not counted in the "blind and disabled" category. Therefore, the information reported here underestimates participation and expenditures for children under 21 in the blind and disabled category.[51]

Table 12 reports the number of blind and disabled child (under age 21) Medicaid enrollees by state in 1993.[52] Altogether, over 796 thousand blind and disabled children in the United States were enrolled in Medicaid in 1993. This is compared to almost 31 million Medicaid recipients in total and over 4.4 million blind and disabled recipients in 1992.

The vast majority of these children qualified for Medicaid through SSI, since at the end of 1993 over 766 thousand children were receiving SSI payments. While not all SSI recipients are automatically eligible for Medicaid, the majority are. Information reported to HCFA by states shows that 89 percent of children categorized as blind and disabled enrollees are also receiving cash assistance, for the most part through the SSI program. The majority of the remaining 11 percent are in residential care paid for by Medicaid (such as inpatient psychiatric care or intermediate care facilities) or eligible through state medically needy programs.

---

[51] Data on individual Medicaid payments can be used to examine participation and expenditures for all children with disabilities defined by service use, expenditure level, or diagnostic group. One study by Marilyn Ellwood and Elicia Herz, "Longitudinal Analysis of High Cost Medicaid Children in California", Systemetrics, October 1990, finds for California that of all children on Medicaid with expenditures of $25,000 or more in 1983, more than 25 percent were eligible through some criterion other than SSI or institutionalization. These results are not nationally representative, but suggest that the numbers reported in this background report may indeed underestimate participation and expenditures. On-going studies are attempting to examine expenditures for children eligible through SSI versus expenditures for all children with high costs.

[52] Data for Arizona and Rhode Island are not included. Arizona's program is run under a waiver and Rhode Island did not report the information used.

Table 12
Blind and Disabled Medicaid Enrollees Under Age 21, by State for 1993

State	Blind and Disabled Child Enrollees	Enrollees Per Thousand Residents Under 18	State Has Medically Needy Program	Waiver Exp. As % of Total Medicaid Payments
United States	**796,279**	**11.9**		**1.9**
Alabama	28,349	26.3	No	3.5
Alaska	661	3.5	No	0
Arkansas	20,571	32.4	Yes	0.3
California	70,748	8.2	Yes	1.1
Colorado	8,249	8.8	No	6.7
Connecticut	1,105	1.4	Yes	5.8
Delaware	2,633	15.0	No	4.2
District of Columbia	2,266	19.7	Yes	0
Florida	46,491	14.7	No	0.9
Georgia	27,051	14.7	Yes	1.7
Hawaii	662	2.2	Yes	3.0
Idaho	3,926	11.8	No	2.7
Illinois	33,791	11.0	Yes	2.6
Indiana	5,085	3.4	No	0
Iowa	7,586	10.3	Yes	0.2
Kansas	6,056	8.9	Yes	2.4
Kentucky	20,314	20.9	Yes	1.8
Louisiana	35,982	28.9	Yes	0.1
Maine	3,197	10.4	Yes	3.3
Maryland	10,809	8.7	Yes	2.7
Massachusetts	14,931	10.7	Yes	2.3
Michigan	32,068	12.8	Yes	1.8
Minnesota	7,022	5.7	Yes	4.9
Mississippi	27,000	35.6	No	0.2
Missouri	6,764	5.0	No	2.4
Montana	2,480	10.7	Yes	5.6

Continued next page

State	Blind and Disabled Child Enrollees	Enrollees Per Thousand Residents Under 18	State Has Medically Needy Program	Waiver Exp. As % of Total Medicaid Payments
Nebraska	3,464	7.9	Yes	5.9
Nevada	2,071	5.9	No	2.0
New Hampshire	2,661	9.4	Yes	11.3
New Jersey	21,561	11.4	Yes	5.1
New Mexico	6,180	12.8	No	4.1
New York	74,140	16.6	Yes	0.1
North Carolina	4,781	2.8	Yes	1.7
North Dakota	954	5.5	Yes	8.0
Ohio	34,086	11.9	No	0.5
Oklahoma	8,859	10.2	Yes	1.4
Oregon	4,817	6.2	Yes	13.4
Pennsylvania	42,138	14.7	Yes	2.9
Rhode Island	NA	NA	Yes	3.4
South Carolina	14,050	14.8	No	2.4
South Dakota	2,763	13.3	No	7.1
Tennessee	30,064	23.7	Yes	0.5
Texas	54,711	10.6	Yes	0.3
Utah	2,732	4.1	Yes	6.1
Vermont	1,595	11.1	Yes	7.6
Virginia	14,870	9.4	Yes	2.6
Washington	10,331	7.4	Yes	5.8
West Virginia	11,310	26.1	Yes	3.2
Wisconsin	21,205	15.8	Yes	3.4
Wyoming	1,188	8.6	No	1.6

Note: Arizona and U.S. Territories not included. Data for Rhode Island are not available.

Source: Urban Institute calculations using HCFA forms 2064 and 2082. Enrollees include state reports of blind and disabled children under age 21.

Like SSI, Medicaid enrollment for children with disabilities varies across states, as shown in Table 12. Variation in enrollment per capita across states reflects differences in state incomes as well as individual state Medicaid program's eligibility. For example, some states do not have a medically needy program. Also, states vary in their use of Home and Community-Based Waiver services.

Expenditures

As with participation, Medicaid expenditure data are collected from states by HCFA by categories of enrollee. Table 13 reports expenditures for all children under age 21 categorized as blind and disabled enrollees by state.[53] In the United States, total state and federal expenditures by Medicaid in 1993 for blind and disabled children was almost $6 billion. This compares to total Medicaid spending in 1992 of $119 billion. On average across states, federal spending was 58 percent of total Medicaid spending in 1992.

Medicaid spending on blind and disabled children varies across states. For most states, spending ranged from $5,000 to $10,000 per enrollee. Spending variations across states are due to a number of factors including differences in state Medicaid program eligibility and optional Medicaid services provided.

The average Medicaid spending for blind and disabled children shown in Table 13 masks large variations in Medicaid spending across children with different needs. For example, children in residential settings where Medicaid is paying all expenses, including room and board, have high annual expenditures compared to children who qualify for Medicaid but have little additional medical costs. Expenditures for children under age 21 receiving services in inpatient psychiatric facilities, intermediate care facilities for mental retardation (ICF/MR), or nursing and other facilities in 1993 are shown in Table 14. Many more children are served in inpatient psychiatric facilities (51,000) than in the other two categories combined (18,000). However, per recipient, inpatient psychiatric services are less expensive ($20,000) than nursing facilities ($39,000) or ICF/MR services ($54,000). Differences in annual expenditures reflect length of stay as well as cost per year. Annual expenditures for these services far outweigh the average per child Medicaid spending for all blind and disabled children in the United States of $7,350.

[53] These expenditures may understate total Medicaid expenditures on children with disabilities for the same reasons reported participation numbers may be understated.

Table 13
Medicaid Expenditures for Blind and Disabled Children Under 21, 1993

State	Expenditures on Blind and Disabled Child Enrollees (in thousand $)	Expenditures per Blind and Disabled Child Enrollee	Expenditures per Resident Under Age 18
United States	**$ 5,853,963**	**$ 7,352**	**$ 87.2**
Alabama	112,307	3,962	104.3
Alaska	12,173	18,416	64.4
Arkansas	117,882	5,730	185.6
California	593,333	8,387	69.0
Colorado	71,370	8,652	76.1
Connecticut	80,652	27,740	39.6
Delaware	26,299	9,988	150.3
District of Columbia	21,827	9,633	189.8
Florida	230,693	4,962	72.8
Georgia	144,831	5,354	78.7
Hawaii	5,603	8,464	18.7
Idaho	25,954	6,611	77.9
Illinois	235,832	6,979	76.9
Indiana	93,053	18,481	63.3
Iowa	63,302	8,345	86.2
Kansas	63,548	10,493	92.9
Kentucky	105,757	5,206	108.9
Louisiana	289,084	8,034	232.6
Maine	39,472	12,346	128.6
Maryland	85,495	7,910	68.9
Massachusetts	188,874	12,650	135.6
Michigan	198,538	6,191	79.2
Minnesota	63,232	9,005	51.5
Mississippi	90,787	3,362	119.8
Missouri	58,958	8,716	43.3
Montana	27,580	11,121	118.9

State	Expenditures on Blind and Disabled Child Enrollees (in thousand $)	Expenditures per Blind and Disabled Child Enrollee	Expenditures per Resident Under Age 18
Nebraska	21,623	6,242	49.3
Nevada	30,883	14,912	87.7
New Hampshire	7,518	2,825	26.6
New Jersey	214,672	9,956	113.2
New Mexico	47,319	7,657	98.4
New York	764,843	10,316	171.2
North Carolina	58,252	12,184	34.2
North Dakota	10,238	10,732	59.5
Ohio	208,821	6,126	78.0
Oklahoma	61,704	6,965	71.0
Oregon	26,922	5,589	34.4
Pennsylvania	344,046	8,165	119.8
South Carolina	84,755	6,032	89.0
South Dakota	23,724	8,586	114.1
Tennessee	110,574	3,678	87.1
Texas	429,739	7,855	82.9
Utah	27,048	9,901	40.7
Vermont	11,987	7,515	83.2
Virginia	76,354	5,135	48.1
Washington	79,015	7,648	56.7
West Virginia	52,172	4,613	120.2
Wisconsin	117,582	5,545	87.6
Wyoming	6,495	5,467	47.1

Note: Arizona, Rhode Island, and U.S. Territories not included.

Source: Data from Urban Institute calculations using HCFA forms 2064 and 2082. Enrollees include state reports of blind and disabled children under age 21.

Table 14
Number of and Expenditures on Medicaid Recipients under Age 21, by Selected Service Category, 1993

Service Category	Recipients under Age 21	Expenditures (in thousands)	Expenditures per Recipient
Inpatient Psychiatric Services	51,470	1,045,800	20,319
Intermediate Care Facilities for Mental Retardation	12,526	681,210	54,384
Nursing Facilities	5,506	214,509	38,959
Total	**796,279**	**5,853,963**	**7,352**

Note: Data from Arizona, Rhode Island, and U.S. Territories not included. Data from Urban Institute calculations using HCFA forms 2064 and 2082. Recipients are all individuals under 21 actually receiving services. Total is for all blind and disabled child enrollees eligible for Medicaid services.

Table 15
Distribution of Annual Medicaid Expenditures per Noninstitutionalized Child Eligible through SSI in California, Georgia, and Michigan, 1984

	Expenditures per Noninstitutionalized Child Recipient Eligible through SSI		
	California	Georgia	Michigan
Average Annual Expenditure per Recipient	$2,104	$2,016	$1,255
Median Annual Expenditure per Recipient	396	411	239
Annual Expenditure per Recipient at			
25th Percentile	132	133	80
75th Percentile	1,347	1,697	788
90th Percentile	3,943	5,137	2,566
95th Percentile	7,678	9,374	4,754
Highest Annual Expenditure per Enrollee	536,085	83,595	216,128

Source: Marilyn Rymer Ellwood, "SSI-Related Disabled Children and Medicaid," June 1990, Table 10, p.17. Data are for recipients only.

There is also significant variation in Medicaid expenditures among noninstitutionalized children. Table 15 shows the distribution of annual Medicaid expenditures per noninstitutionalized child on SSI in 1984 for three states, California, Georgia, and Michigan.[54] While average annual expenditures ranged from $1,000 to $2,000, median expenditures ranged from $200 to $400. The calculations are affected by a small percentage of Medicaid recipients who have very high annual expenditures. Recipients in the 95th percentile had expenditures more than 20 times higher than the median expense. Similar variation exists for noninstitutionalized Medicaid eligible blind and disabled children who are not receiving SSI.

Other sources of Medicaid spending for children with disabilities include the TEFRA option and the HCBS waiver program. Table 16 shows the states that currently use the TEFRA option, the number of children covered and expenditures, where available. Overall 8,481 children were identified as receiving services through TEFRA. More than half of these identified children live in Wisconsin or Minnesota. Cost per recipient varied from $5,140 in Wisconsin to $19,911 in Massachusetts.

HCBS regular and model waiver programs served over 185,000 individuals in 1991 and spent $1.7 billion. HCBS spending in general has been growing rapidly over time. Figure 3 shows the growth in total HCBS waiver program expenditures from 1982 to 1991, for persons of all ages. Table 17 lists the states that have HCBS model or regular waiver programs targeted at children with special health care needs. These numbers do not include children served by waivers that are not limited to children, for example, data on the many waivers serving developmentally disabled recipients are not reported by age. The HCBS waivers listed served 1299 children, a small percentage of all persons served under this program. The total expenditure for children was over $13 million. Because each waiver provides different services and targets different populations, the cost per recipient varies widely from $1,106 to $116,266. An additional 1782 children were served under 2 waivers specific to children with AIDS/ARC at a cost of over $2.5 million.[55]

---

[54] Marilyn Ellwood, "SSI-Related Disabled Children and Medicaid," prepared for the U.S. Department of Health and Human Services, Office of Family, Community and Long-term Care Policy, June 1990.

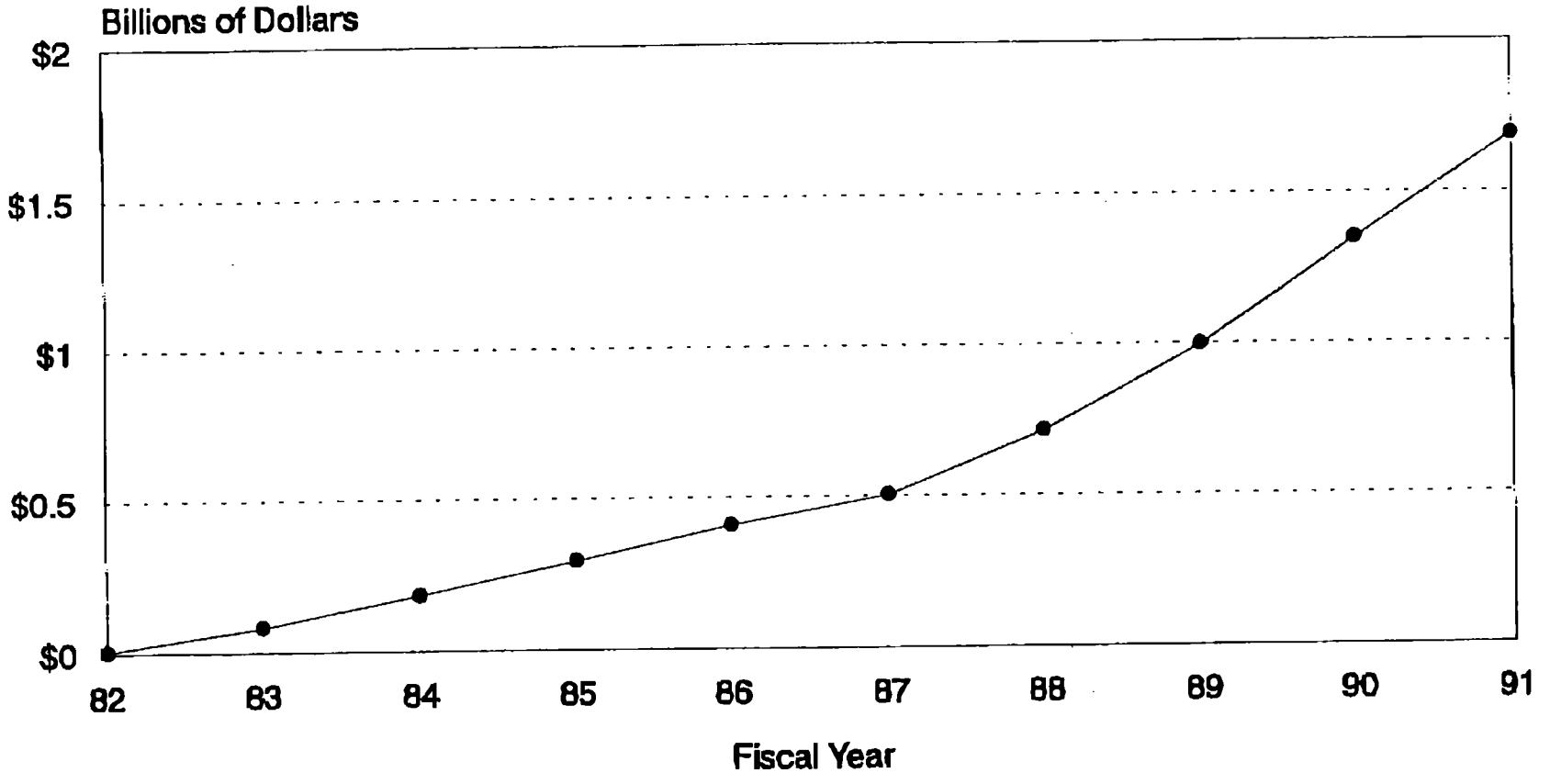
[55] Information for TEFRA and HCBS waivers from Sally Bachman and Brian Burwell, "Medicaid Home and Community Based Services for Children with Disabilities," technical memorandum for the Department of Health and Human Services, October 1994.

Table 16
States Using Medicaid TEFRA Option

State	Number of Recipients	Total Medicaid Expenditures for TEFRA Eligibles	Expenditures/ Recipient	Year of Data
Arkansas	227	N/A	N/A	1990
Delaware	620	$ 4,539,411	7,322	1993
Georgia	84	N/A	N/A	1990
Idaho	483	3,404,891	7,049	1993
Massachusetts	210	4,181,372	19,911	1993
Maine	160	N/A	N/A	1990
Michigan	92	N/A	N/A	1990
Minnesota	3226	25,796,988	6,510	1993
Mississippi	576	2,417,013	4,196	1993
Nebraska	9	N/A	N/A	1990
Nevada	141	2,759,950	19,574	1993
New Hampshire	16	N/A	N/A	1990
Pennsylvania	N/A	N/A	N/A	
Rhode Island	84	N/A	N/A	1990
South Dakota	2	N/A	N/A	1990
Vermont	28	N/A	N/A	1990
West Virginia	2	N/A	N/A	1990
Wisconsin	2531	13,011,137	5,140	1991

Source: Sally Bachman and Brian Burwell, "Medicaid Home and Community Based Services for Children with Disabilities," technical memo to Department of Health and Human Services, October 1994. Data gathered by authors from personal contact with State Medicaid personnel.

Figure 3
Federal and State Medicaid Home and Community-Based Waiver Program Expenditures, FY 1982-1991



Source: Congressional Research analysis of HCFA Form 64 for fiscal years 1990-1991; and Nancy Miller, Medicaid 2176 Home and Community Based Care Waivers: 1982-89, paper presented at the 1990 American Public Health Association annual meeting.

Table 17
Medicaid Home and Community Based Services Model and Regular Waivers for Children with Special Health Care Needs, 1990-1991

State	Waiver Type	Waiver Recipients	Waiver Expenditures	Cost per Recipient
Total		1299	$13,204,809	$12,331
Georgia	Model	24	739,918	30,830
Illinois	Model	185	343,725	1,858
Kentucky	Model	1	116,266	116,266
	Model	7	245,575	35,082
Maryland	Regular	173	4,028,648	23,287
	Model	9	977,6625	108,625
New Mexico	Regular	79	1,207,719	15,288
New York	Model	180	199,126	1,106
	Model	181	261,625	1,445
Ohio	Regular	200	1,124,993	5,625
Pennsylvania	Model	17	1,426,787	83,929
Rhode Island	Model	27	102,912	3,812
	Model	35	993,008	28,372
South Carolina	Model	1	15,001	15,001
Texas	Regular	160	675,757	4,223
Virginia	Model	20	493,666	24,683

Note: Table does not include children who receive services through state HCBS waivers that are not targeted to children. It also does not include two state waivers in California and New Jersey that provide services to 1,782 children with AIDS/ARC at a total expenditure of $2,501,964.

Source: Sally Bachman and Brian Burwell, "Medicaid Home and Community Based Services for Children with Disabilities", technical memo to U.S. Department of Health and Human Services, October 1994. Data abstracted from 1991 HCFA Form 372 from each state.

NH 2 parents, 8 Downs, brain trauma Katie Beckett waiver Hehir

Wardwell?/Clarkson - waivers

EXECUTIVE OFFICE OF THE PRESIDENT

19-Oct-1995 08:19pm

DF to add: * MA filled gap of priv ins

Transition to Adulthood
Tried to get priv ins.
Education/hopes for future
~~AIDS~~
Family
Financial devastation

TO: (See Below)

FROM: Marilyn Yager
Office of Public Liaison

SUBJECT: VPOTUS children's conference call

The Vice President will be doing a disabled children's conference call on Tuesday at 1:15 pm eastern time to kids in the following media markets:

Parent vs child
Opposite shifts

Sioux City, Iowa
Albuquerque, New Mexico
Seattle, WA
Manchester, NH

As you all know, Mrs. Gore's conference call on Monday will be in the following markets:

Denver, CO — Penny/Joe Ford
Portland, OR
Philly, PA
Baton Rouge, LA
Detroit, MI
Chicago, ILl

Distribution:

TO: Jennifer L. Klein
TO: Jason S. Goldberg
TO: Gene B. Sperling
TO: Lorraine McHugh
TO: Emily Bromberg
TO: Deborah L. Fine
TO: Diana M. Fortuna
TO: Lisa A. Berg
TO: Julia R. Green
TO: Andre Oliver

Chicago
Jason Sloan - 18
- works, transition
- 2 parents, Jobs mom
- Job coach
- turned down ins.
- mech vent?, w/d/RR
- Sheltered employment
- Clarify Zima rel?
- Can't talk?
- Q: How are you enjoying working?

Phila — Elaine/Alex - 14, CP, LD
Q: How are you enjoying school?
Favorite class
Parent training
Able to go to school

New Mexico
non-segue
1. Indian; early MA enabled s/h
Travis Solomon, 16
Reg classes?
Electronics - high aid/p - Q
Speech an issue? Miss America
Det to Albuquerque
2. Veronica Guardian
2 parents - father on SSI
Nurse

Denver — 12, single parent
1 - Penny/Joe Ford
- Family theme - PAS
- Gifted/attorney - high IQ
No other fam assistance
Private ins.
Q: wheelchair (attorney)
I read what you wrote

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.

TESTIMONY -- 8/24/95

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.

How are you doing today, Jason? (fine)

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

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.

(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, **like 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 eligilibility 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.

Debby

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

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. memo	Julie Becker to Debby; RE: Personal (2 pages)	10/19/1995	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12024

FOLDER TITLE:
Children with Disabilities Conference Call

2007-0143-F
db4493

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]

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. letter	Janet Ketcham to Mrs. Gore; RE: Personal (1 page)	10/19/1995	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12024

FOLDER TITLE:
Children with Disabilities Conference Call

2007-0143-F
db4493

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]

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 Ketcham

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.

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

19-Oct-1995 08:23pm

TO: Diana M. Fortuna

FROM: Carol H. Rasco
Domestic Policy Council

SUBJECT: RE: FYI for Monday's children and the budget rollout

s
Make sure Molly gets a final version of whatever you get sign off on as she is working on an event I will do in Ark. on Monday.

Thanks.

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
003. profile	RE: Personal (1 page)	10/19/1995	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12024

FOLDER TITLE:
Children with Disabilities Conference Call

2007-0143-F
db4493

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]

The Arc of Multnomah County

Advocating for Inclusion of Individuals with developmental disabilities

19 SW 11th Avenue, Suite 234 • Portland OR 97205-2692
hone 503-223-7279 FAX 503-223-1488

FAX

COVER SHEET

O: Debbie Fine Page 1 of 2

ompany The White House

ax No. 202-456-7028 Phone No. _____

rom: Vicki Smead, Manager Child & Family Services

lessage: I apologize for the lateness of this document. We only received the request around 12:00pm Pacific time.

Please let me know if you would like to use this family for the teleconference.

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.

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.

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

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.

Elaine and Alex live at:

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

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.

getting ahead

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

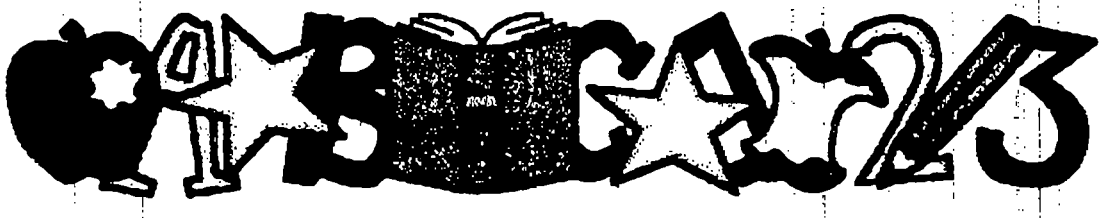
Fax No. 202.456.7028

Company: 1

Sent From: Janet Lonsdale

No. of Page: 2. (including cover)

Comments:



Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

SSI

LIFELINE FOR CHILDREN WITH DISABILITIES

PRODUCED BY THE JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW IN COLLABORATION WITH FAMILIES AND CHILDREN THROUGHOUT THE UNITED STATES
SPRING 1995

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

17-Oct-1995 12:58pm

TO: Diana M. Fortuna

FROM: Carol H. Rasco
Domestic Policy Council

CC: Deborah L. Fine
CC: Jeremy D. Benami

SUBJECT: RE: Impact of Medicaid cuts on special ed related services

Yes I am aware of the impact as to early childhood but will gladly receive the memo.... as I told some parents yesterday as well as when I said what I did in the meeting with Apfel, people without special needs children will feel the effects of this if their chidlren go to public schools as the children who are "normal" will be penalized due to disabled children who do NOT get early childhood services and will then be more time consuming in schools, require more specialized services AND there won't be enough dollars by a longshot to cover those services. I too am quite hopeful this info can be ready for the Gene Sperling book on kids for Monday.

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

MEMORANDUM

TO : Judith Heumann
Assistant Secretary, OSERS

DATE: OCT 5 1995

FROM : Thomas Hehir
Director, OSEP

SUBJECT: Medicaid

The purpose of this memorandum is to delineate my concerns with the proposed changes Congress is considering concerning the medicaid program. My concerns are informed by my experience prior to my coming to the Department as Associate Superintendent of the Chicago Public Schools where I was responsible for both special education and school health services and by my current role as Director of the Office of Special Education Programs. I believe that plans to eliminate the entitlement for medicaid services for poor and disabled students will have a very negative impact on the health status of poor children, in general, and could be potentially devastating for disabled children and their families both poor and middle class.

I believe the President and the Administration should take strong vigorous action to oppose the gutting of the medicaid program. The following is a summary of my analysis of the impact.

(1) Early Intervention Program for Infants and Toddlers

This program (Part H) of IDEA is a voluntary program with the States which provides early intervention services for children who have disabilities or are at risk of disability and their families. Though the program is voluntary, all the States participate. Part H of IDEA pays a small percentage of the cost of the program with services being provided from a variety of sources. One of the main funding sources for the program is Medicaid, particularly in poorer States. For instance, Arkansas funds 62 percent of its early intervention program from Medicaid. Even more affluent States like Massachusetts rely heavily on Medicaid with 25 percent of the cost of the program being borne by this funding source. Staff within OSEP believe that without the Medicaid entitlement, some States may not choose to fund this program. The result would be that deaf infants would not get a head start on language development, physically

disabled infants would not receive therapies which might enable them to walk, and parents would not receive assistance in understanding how to maximize the development of their children with mental retardation. These children will start school without being ready to learn and they will have missed critical developmental opportunities. Though, some States may indeed opt to fund this program out of the block, others may not. Will we go back to the days when parents of children with significant disabilities or who have chronic medical problems be forced to change residence to receive programs for their children?

(2) Ongoing Support for Families Who Have Children With Significant Disabilities or Serious Medical Conditions.

Many children with disabilities, children with chronic health impairments, and children with serious acute illness and their families need in-home services in order to prevent hospital, residential, or institutional care. Poor families, as well as many working and middle class families, are entitled to these services under Medicaid (States can waive income requirements to provide Medicaid services for families with very sick or significantly disabled children under what is referred to as Katie Becket waivers, instituted by former President Reagan in response to a plea by a parent of a child with significant health support needs.) The support provided to these children allows families to stay together, parents to work, and children to live in their communities. Absent the entitlement, will some States opt for institutional care over in-home care? Would managed care-driven plans seek to have school districts pay for expensive residential care options under the IDEA? Will we resurrect the institutions of the past where large numbers of disabled children were kept in deplorable conditions in the name of efficiency? The entitlement to education under IDEA coupled with the entitlement for health services under Medicaid has enabled hundreds of thousands of children to live a life of dignity with the hope of a real future. America can be proud of the fact that we have gone from over 100,000 children with mental retardation in State institutions in the late sixties to under 6,000 today. Federal entitlements created this change.

(3) Providing Funding to Schools to Provide Special Education Related Services

Many school districts bill Medicaid for special education related services, which are also entitlements under EPSDT, (Occupational therapy, speech therapy, physical therapy etc.). These funds help defray the costs of special education. This practice is becoming increasingly

widespread, particularly in urban and poor districts. Last year Chicago netted $28 million in reimbursement for these services. Without the entitlement for Medicaid, there will be little incentive to continue to fund these services because they are largely habilitative not preventive in nature. Further, school districts will continue to be required to fund these services under IDEA so there will be pressure on school districts to pick up this cost again. I am concerned that resentment over the cost of special education fueled by the low level of federal support (approximately 7 percent of cost) will become even greater if this happens. Further, the Republican Congress has already denied the President's request for a 3 percent increase in special education funding and is projecting level funding for the program. The actions of the Republican Congress are making a bad situation for disabled children much worse. As you know, I have recommended that in the FY 97 budget request that we seek to double the Federal contribution to special education over four years. We should take the lead in improving this situation by fighting the Medicaid cuts and seeking to increase IDEA funding. If we do not reverse these actions, I believe that the IDEA entitlement might be the next entitlement to go, particularly, given the likely political pressure caused by the decreased funding support from the Federal Government.

(4) School Health Services

When I was Associate Superintendent for the Chicago Public School, I was responsible for school health services in addition to special education. In that role, I joined with the Commissioner of Health in implementing an EPSDT program in our schools. The program, which started as a pilot, has been expanding since I left Chicago. The program has demonstrated that: (1) the health status of poor children in the city is very poor, (2) many of the conditions identified in the children had direct impact on their ability to perform in school (untreated ear conditions, untreated asthma, etc.), and (3) a school-based health program can effectively and efficiently address these needs. As you know, the Department has been supporting school-linked services through our ESEA, GOAL 2000, and IDEA legislative proposals. Medicaid is envisioned as a major source of support for these programs. I am concerned that, absent the entitlement, many of these efforts will lack the support they need. Given the politics at the State level surrounding the allocation of a block, some inner-city school districts, that lack sufficient political clout at the State level, will not have funds to continue these initiatives.

I believe that the Department should inform the White House of the implications that the Medicaid loss of the entitlement will have for disabled children, poor children, and the school districts that serve them. Personally, I have seen nothing coming out of the 104th Congress which compares to this action in its potential negative impact on children. I believe we, as Democrats, should aggressively oppose this action. We have made great progress in this country in serving disabled students, particularly, through the use of strong Federal entitlements. I believe the President, and Secretaries Shalala and Riley should be speaking out loudly against these actions. By taking such a stand, we will be providing a strong contrast between our values and those of our opponents. I sincerely believe most Americans do not support withdrawing support for disabled children and their families. I also believe that, though we failed in our health reform legislation, that Americans do not want any children to go without necessary health services and would oppose actions that have the potential to do just that.

I will be glad to assist in any way you deem necessary.

UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES
THE ASSISTANT SECRETARY

October 8, 1995

Note to Tom Hehir, Fred Schroeder, Theda Zawaiza and Connie Garner:

Subject: Appropriate Department of Education Response to Pending Congressional Action on Medicaid

I believe Tom's October 5 memorandum provides a good, broad outline of the arguments from Education's perspective as to why the pending Congressional action on Medicaid is detrimental to the best interests of children, and disabled children in particular. I have only one question regarding the specifics of the memorandum, that being the reference to the "Katie Becket" provisions. It is my understanding that this has always been a State option, and that many States have already opted out on these services. We probably need to keep straight what is mandatory and what is optional for purposes of what is likely our next efforts in briefing the Secretary and the Undersecretary.

I also want to bring to your attention the attached briefing materials that were developed by the White House for its meeting with senior citizens and disability activists regarding the negative impact of the proposed changes in Medicare-Medicaid. The impact of the block-grant proposal of the Republican Congress included data and analysis on what it meant in diminished services to children and disabled individuals. The state-by-state impact statements also address children. A review of the press coverage on the briefing indicates that the coverage has not been devoid of concern for children. Statements by the First Lady in this area have also gained coverage.

But it can always be better. In response to Tom's concerns – and the concerns of all of us -- I will immediately request a meeting with Frank Holleman, Mike Smith and Kay Casstevens to best discuss how we can supplement the White House's efforts in this area, in a manner that supports the overall policy goals of protecting the quality of services available to at-risk children without jeopardizing essential features of IDEA during its reauthorization. We can also discuss what statements or actions the Department may be able to make in coordination with the White House.

Connie's analysis of the Medicaid changes on IDEA Part B and H and other education programs will be critical to providing the White House solid information. In addition, Theda and Connie are following up with HCFA to identify specific levels of reimbursements for related services under Medicaid. This is in response to an inquiry made by Paul Marchand during last Thursday's weekly briefing with the Undersecretary. The impact of the changes on rehabilitation and independent living programs must also be a part of our concern. We need to re-double our efforts in completing these tasks.

We must move quickly, and we will.

Howard Moses

cc: Judith E. Heumann
Kate Seelman
Frank Holleman

Viera Fontera

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

APRIL 11, 1994

TO:

Richard W. Riley
Secretary

Marshall E. Smith
Undersecretary

Frank S. Holleman
Chief of Staff

Terry Peterson
Counselor to the Secretary

Judith Heumann
Assistant Secretary, OSERS

Janice S. Jackson
Acting Assistant Secretary, OESE

Kay L. Casstevens
Assistant Secretary, OLCA

Howard Moses
Deputy Assistant Secretary, OSERS

Thomas F. Hehir
Director, OSEP

FROM: *Connie Garner*
ED Health Policy Liasion
Policy Analyst, OSERS

SUBJECT: Medicaid Transformation Act of 1995: Impact of the MediGrant Program on Education Programs for Children

ISSUE

On September 19, 1995 the full House Commerce Committee acted to pass a proposal which will replace the current Medicaid program with grants to states, with the intent of cutting federal Medicaid spending by $182 billion over the next seven years. The MediGrant Bill eliminates the individual entitlement to medical assistance for all populations, including the entitlement to Early Periodic Screening, Diagnosis and Treatment (EPSDT). This will be a significant loss of benefits to all disadvantaged children, but particularly to: (1) Medicaid eligible children with disabilities receiving services under the Individuals with Disabilities Education Act (IDEA); and, (2) children enrolled in targeted assistance schools under Title 1 of the Improving America's Schools Act (IASA).

Currently, over 18 million children under age 21 are enrolled in Medicaid. This includes approximately 11 million children receiving either AFDC or SSI and 7 million children not receiving cash assistance. 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.

During the national health care reform debate, Secretary Riley was viewed as instrumental in ensuring that children's health issues remained a priority on the policy agenda. As the President continues to work with the Congress to reach a balanced budget, there remains the opportunity for the Secretary to work with the White House in an effort to protect and secure health coverage for children currently eligible under Medicaid.

The purpose of this memo is to: (1) analyze the impact of the proposed elimination of mandated services under EPSDT within the MediGrant proposal; and, (2) suggest strategies to strengthen children's coverage within a capped block grant or per capita cap model. How this issue is addressed is of significant importance to the education community because of its relationship to: (1) the national goal of having all children start school healthy and ready to learn; (2) the Administration's philosophy that investing in children is the best and most effective national investment; and, (3) the existing special education and early intervention mandates under IDEA, which include health related services.

BACKGROUND

Historical Perspective on Medicaid/EDSDT

Medicaid is a federal/state means-tested entitlement program designed to provide national health care for persons of low income.

States enter into a contract with the federal government through the creation of a state plan. Current law mandates states to: (1) provide services to **certain groups of eligible persons** and, (2) provide all Medicaid recipients with a **core group of mandated services**. States have an option to include **additional classes** of individuals to the program as well as add **optional services** to the State plan, such as the TEFRA (Katie Beckett waiver). Although the Early Periodic Screening, Diagnosis, and Treatment(EPSDT) component of Medicaid was enacted in 1967, Congress federalized the program in OBRA'89, expanding screening and treatments for physical and/or mental conditions as long as they are reimbursable at the Federal level, regardless of their inclusion in the State plan. Thus, all "medically necessary" services including screening, vision, hearing, dental, and other necessary diagnostics and/or health care treatments are now mandated as an entitlement to all children birth to age 21 under Medicaid.

Proposed Changes to Medicaid

If enacted into law, the new MediGrant Program would replace the individual and state entitlement with a block grant to each of the states with few federal mandates or oversight responsibility. The impact on children would be the elimination of EPSDT as an entitlement, except for immunizations. ***Although the bill does require a state to devote a percentage of funds towards maintaining their efforts for currently mandated services, there is no guarantee children will receive necessary health coverage*** (particularly if co-payments are instituted and the maintenance of effort provision addresses all previously mandated services of which EPSDT is only one part).

In order to reduce the rate of growth of Medicaid spending, Federal payments to states would be capped with an annual percent increase averaging 4% from FY 1997 to 2002 which would not keep up with current program growth rates (10%). In order to curb the growth rate, states would essentially have four choices: raise taxes; decrease services; decrease the number of individuals covered; manage resources better (restrictive managed care contracts). Because of this financial disincentive and the elimination of any Federal entitlement, it is projected by HHS/Urban Institute data that 4.4 million children could lose health coverage by the year 2002.

COSTS TO THE EDUCATION COMMUNITY

Mandate of the Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act is the primary federal legislation that mandates early intervention, and special education and related services for children with disabilities. Many of the health services that children with disabilities need are provided through the education system under the mandate of IDEA.

The centerpiece of the Act is a formula grant program, authorized under Part B which requires States to make available to all children with disabilities, aged 3-21, a free appropriate, public education. To ensure that a child benefits from this education experience, Part B requires school districts to determine whether an individual child requires health-related services such as physical, occupational, or speech-related therapies, diagnostics and evaluation, and psychological counseling, and, if so, to provide the services at no cost to the family. The determination of necessary medically-related services is made by a team composed of the child's parents and school personnel and are reflected on the student's Individualized Education Plan (IEP).

Part H of the IDEA provides for an early intervention program, which assists states in the implementation of a comprehensive, interagency, statewide system of services for infants and toddlers with disabilities. Many of the primary interventions under Part H of IDEA are medically-related and are reflected on the child's Individualized Family Service Plan (IFSP)

Financing of Medically-Related Services Under IDEA

The medically-related services component of IDEA is critical to the health and educational achievement of children with disabilities.

State education agencies and early intervention programs bear the costs of medically-related services on IEP's and IFSP's, however, when a child is Medicaid-eligible, the costs of those related services are reimbursable under EPSDT. This is a significant financial contribution to school districts in meeting the needs of children with disabilities as we estimate that approximately 40-50% of children with disabilities are Medicaid eligible (according to the National Longitudinal Transition Study of Special Education Students, children with disabilities are twice as likely than the general population to: (a) come from families whose household income is less than $12,000 or less; and, (2) be receiving Medicaid and/or other public assistance. While approximately 23% of all children are medicaid-eligible, extrapolations from the longitudinal study and current reports from states support that approximately 40% of children served under IDEA are eligible for benefits under Medicaid).

There are approximately 4.7 million children aged 6-21 receiving special education and related services under Part B of IDEA. An estimated 1.3 million of these children are receiving health-related services. The current statistics are as follows with the starred categories representing the majority of children (1.3 million), receiving related services:

Aged 6-21:

❑	2.4 M	Learning Disabled
❑	1.0 M	Speech/Language Impaired
★	553,992	Mentally Retarded
★	414,279	Severe Emotional Disturbance
★	66,249	Hearing Impaired
★	109,746	Multiply Disabled
★	56,616	Orthopedically Impaired
★	83,279	Other Health Impaired
★	24,935	Visually Impaired
★	1372	Deaf/Blind
★	18,903	Autism
★	5,295	Traumatic Brain Injury

The excess per child cost for special education and related services in 1994 was $6,133. The Federal government paid $429, and the state and local communities provide the remaining $5,704 from general education funds. It is estimated that 30% of the $5,704 or $1,711 per child was spent on health-related services for children with moderate to severe disabilities. ***The cost to the education community is approximately $2.2 billion. Assuming that 50% of that amount could be potentially reimbursed from Medicaid, the elimination of the Medicaid entitlement would cost the education community minimally $1.1 billion if states elect not to include these services in their state system.***

Approximately 154,000 children ages 0-2 receive early intervention services through Part H of IDEA and 493,000 children ages 3-5 receive preschool services through Part B of IDEA and Chapter 1. Estimates on costs attributable to health related services are not available for these children, but the total Federal contribution to providing these 647,490 children the services mandated under IDEA was $804 million in 1994.

Implications for the Improving America's Schools Act (IASA)

Under Title 1 Section 1115 of the IASA, there is a provision that if health, nutrition and other social services are not otherwise available to eligible children in a targeted assistance school, and funds are not reasonably available from other public and private sources to provide services, then a portion of the IASA funds may be used as a last resort to provide services such as basic medical equipment, eyeglasses,and hearing aids. Many of these services in addition to screening, hearing, and vision services, are currently provided through medicaid-funded school based clinics deemed federally-qualified health centers. With the elimination of all Federal provider payment requirements under Medicaid, payments to federally qualified health centers will no longer be required unless a state elected to use this mechanism for service delivery.

It is estimated that 90% of the school districts (14,000) in the Country, serving 6,403,064 children, receive funding through Title 1 of the IASA.

Schools will still be confronted with the multiple health-related needs of children in targeted assistance schools. If Medicaid funds are not available to support the health needs of these children, schools will be under increased pressure to use IASA funds to provide services. Schools will be faced with the choice of: (1) using these funds for academic instruction, knowing that some students will not benefit from the instruction because of their health needs; or (2) providing for health needs of children, resulting in a diminution of funding for academic instruction.

Under Title XI of IASA, the term "coordinated services project" means a comprehensive approach to meeting educational, health, social service, and other needs of children and their families. This is accomplished through community-wide partnerships that link public and private agencies through a coordination site at or near a school. Funds for this program, however, cannot be used for direct health services. Even though schools and other community agencies work collaboratively to meet the educational, health and social service needs of children and families, they may not be able to meet the major health needs without EPSDT services or established relationships with managed care organizations if the state elects to provide benefits to this population.

DISCUSSION/RECOMMENDATIONS

As the House Bill moved to the Senate, Sen. Chafee was successful in adding an amendment that would continue mandated basic coverage of services to the following groups: children 12 and under <100% of the poverty level; pregnant women <100% of the poverty level; families with disabled children. What is undefined is the definition of basic coverage. In addition, the Senate passed an amendment that requires a state to spend 1% of its funding on federally qualified health centers. HHS estimates that this amount will essentially maintain funding levels for FQHC's but there will be state by state variability as to the impact depending on how much a state relies on these centers for service delivery.

The Administration proposal is built on the principles of reducing growth in spending; expanding state flexibility; and assuring coverage to vulnerable populations. The per person cap would be determined through 4 bands which are population-based: children, adults, disabled (which would include children with disabilities), and the elderly. Through a process of risk adjustment, capitation rates would be assigned to each of these populations.

In determining what would be considered mandated services, four categories are being analyzed: hospital benefits; inpatient and outpatient benefits; lab and x-ray services; and possibly EPSDT. The question remains as to whether EPSDT will still contain the service array that it currently provides as a mandated package (see attached list of EPSDT services). In offering flexibility, the Administration would propose eliminating the need for applying for waivers e.g., 1915 A (managed care) and 1915 B (home and community-based). Thus, most states will be have more flexibility in moving their Medicaid populations into managed care arrangements.

There are several areas where the Secretary can be instrumental in supporting the White House proposal for reforming Medicaid:

- Supporting the inclusion of EPSDT as a service package for children under the defined basic benefit and being a participant in the design of a scaled down version of EPSDT, should that be an Administration fall back position;

- Assure that the Department of Education is involved as the definition of basic benefit is defined for any continued mandated services for children;

- Under **Provider Payments** support the maintenance of a floor for FQHC's as they are: (1) instrumental in assuring children are healthy and ready to learn, particularly in targeted assistance schools; and, (2) are the only source of health care in some rural areas;

- Under **Objectives Goals and Performance Under State Plans** support the inclusion of additional child health outcomes exemplifying prevention beyond immunizations and infant mortality, such as demonstrating developmental achievement.

- Strengthen the ability of schools to coordinate with managed care organizations (MCO's), on behalf of students receiving medically necessary services in schools under IDEA and Section 504 of the Rehabilitation Act.

CONSIDERATIONS:

Given the political and financial impact to the IDEA mandate if the EPSDT entitlement under Medicaid is eliminated, the final option of strengthening the coordination of schools with MCO's is further discussed.

This last option could be accomplished by offering a "supplemental insurance package" to school districts and other agencies to pay for health related services under IDEA. This package, at a minimum, would cover the medically-necessary related services in a child's IEP or IFSP and the evaluations related to those services. Additional options could include the remaining benefits under the "State's children package" for children with disabilities. This package could be purchased from: (1) the State Medicaid Agency (as a discounted fee-for-service option if the State carves out school services e.g., Virginia); or, (2) purchased from managed care organizations or provider groups through full risk contracts.

This would allow state educational and early intervention agencies to be part of the managed care system by using their existing IDEA dollars (aggregate Federal, state,and local), along with a share of the child's per capita amount under Medicaid to pay for the supplemental plan. This would also address the concerns of the individual school districts about the burden of children's health expenditures when the costs are not evenly distributed. The ability to group or pool risk across districts when purchasing this plan would decrease overall costs to the school districts.

This approach would also: (1) ease the school districts of some of the administrative burden of providing health-services to medicaid eligible students under IDEA; (2) coordinate better any continued State children's mandates with other Federal programs; and, (3) assure that services to disabled children are available, while providing flexibility to schools in how those services are acquired.

MEDICAID ELIGIBILITY:

Mandated eligibility groups are as follows:

- AFDC recipients;
- SSI recipients except in what are referred to as section 209(b) states which have a different financial means test from the federal government and which include Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma, and Virginia;
- pregnant women and children up to age 6 at 133% of the federal poverty level;
- children born after September 30, 1983, with family income up to 100% of the federal poverty level;
- children in foster care and adoption assistance under Title IV-E of the Social Security Act;
- continuation coverage for adults with disabilities under sections 1619(a) and (b) of the Social Security Act - the work incentive provisions for individuals with disabilities enrolled in the SSI program; and qualified Medicare beneficiaries.

States have the option to add the following classes of people in their Medicaid State plan:

- pregnant women and infants up to age 1 year up to 185 % of the federal poverty level; children under state adoption agreements;
- individuals in institutions (hospitals, skilled nursing facilities, intermediate care facilities for persons with mental retardation or related conditions) who would otherwise be eligible for AFDC or SSI, including up to 300 % of SSI payments and children under eighteen years of age after 30 days of continuous institutionalization regardless of parental assets and income;
- children under the age of 18 with severe disabilities who are eligible for the level of care in a Medicaid certified institutional "bed", or whom home and community-based services are available and estimated to cost no more than institutional care and for whom the State may waive the parental deeming of income and assets, known as the Katie Beckett waiver through TEFRA 134;
- incomes up to 300% of SSI for individuals enrolled in Medicaid home and community-based waivers;

- a medically needy program for persons who meet the categorical eligibility for AFDC but where the State can set the income level up to 133% of the state AFDC payment level.

MEDICAID SERVICES:

States are mandated to provide the following services to Medicaid recipients:

- inpatient hospital services;
- outpatient hospital services;
- rural health clinic (including federally qualified health center) services; other laboratory and x-ray services;
- nurse practitioners' services;
- nursing facility services and home health services for individuals age 21 and older;
- early and periodic screening, diagnosis, and treatment (EPSDT) for individuals under age 21;
- family planning services and supplies;
- physicians' services;
- nurse-midwife services.

States have the option to include any of the following services to their State Medicaid plan:

- podiatrists services;
- optometrists services;
- chiropractors services;
- psychological services;
- other licensed practitioners services recognized by state law (such as nutritionists, dieticians, health counselors, etc.);
- private duty nursing;
- clinic services;
- dental services;
- emergency hospital services;
- personal care services;
- transportation;
- case management;
- hospice services;
- diagnostic services;
- preventive services;
- rehabilitative services;
- ICF/MR/RC;
- inpatient psychiatric services;
- Christian Science nurses/sanatoria;
- physical therapy;

E.P.S.D.T.

A child now is **entitled** to all health services reimbursable under section 1905(a) of Title XIX

- Podiatrists services
- Optometrists services
- Chiropractors services
- Psychologists services
- Other Liscensed Practioners services recognized by state law (such as nutrionists, dieticians, health counselors, etc.)
- Private duty nursing
- Clinic services
- Dental services
- Emergency hospital services
- Personal care services
- Transportation
- Case management
- Hospice services
- Diagnostic services
- Preventive services
- Rehabilitative services
- ICF for persons with mental retardation and related conditions
- Inpatient psychiatric services
- Christian Science nurses/sanatoria
- Physical therapy
- Occupational therapy
- Speech-language-hearing disorders
- Prescribed drugs
- Dentures
- Prosthetic devices
- Eyeglasses
- Respiratory care services for children who are ventilator dependent

October 23, 1995

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?

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
004. profile	Background on Children and their families; RE: Personal [partial] (1 page)	10/23/1995	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12024

FOLDER TITLE:
Children with Disabilities Conference Call

2007-0143-F
db4493

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]

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, (b)(6) (b)(6) 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. [004]

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.

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?

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.

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.