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Folder Title:
Children with Disability

Stack:	Row:	Section:	Shelf:	Position:
S	31	2	9	3

Budget

File under
Children w/ Disab.
Conf. Call

(1) Impact of cuts on children + families, esp. children w/disabilities who often receive Medicaid services that enable them to stay w/ family, cmty, school
(2) w/out assistance, kids could → institution or family → broke
(3) Hard to put $# on the impact - BUT Block Granting w/ less $: Govs must choose who help

all (4). ages 12-18
- income: lower + middle
- disability: CP, MR, accident
- work (full + part time)

(5) home + cmty based care critical to disab cmty BIG POINTS HERE

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?

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

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

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

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

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

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

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

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

MEDICAID AND CHILDREN WITH DISABILITIES
FACT SHEET

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

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

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

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

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

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

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

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

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

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

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

IMPACT OF MEDICAID CUTS ON EDUCATION PROGRAMS FOR CHILDREN WITH DISABILITIES

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

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

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

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

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

SSI FOR CHILDREN WITH DISABILITIES
FACT SHEET

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

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

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

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

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

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

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

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

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

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

Administration Talking Point on Children's SSI:

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

December 1, 1995

MEMORANDUM FOR DISTRIBUTION

FROM: Debbie Fine

SUBJECT: Meeting with Disability Groups on the Budget

Date: Friday, December 1, 1995
Time: 2:30 PM
Location: Room 180, OEOB

AGENDA:

- I will welcome participants, open the meeting, and turn it over to Marilyn Yager to moderate.
- Marilyn will make brief remarks.
- Chris will give an overview of the Congressional process and our strategy.
- Nancy Ann will give an overview of where we are substantively with Medicare and Medicaid.
- Marilyn will open for questions on the above until Chris and Nancy Ann need to leave.
- Diana will give an overview on SSI.
- Marilyn will open it up for more questions.

(Please note that Chris and/or Nancy Ann may need to leave this meeting at 3pm. Jennifer, Marilyn and Diana will stay for the whole meeting to answer questions.)

BACKGROUND:

Generally, the disability groups have been very supportive of the President and the leadership he has shown in the past couple of months. They have been active both in Washington and in the states -- I am told by organizers here that the grassroots seem to be more energized now than they have been in some time. One activity to note is a national Save The Health Care Safety Net Day (December 7th) that several constituencies are organizing.

In spite of their support, the current negotiations process makes the groups across constituency very nervous. This is a good opportunity for us to bring in the disability groups to give them an overview of the Congressional process, our strategy, and to brief them on where things are substantively -- particularly with Medicare, Medicaid and SSI. It will also give us an opportunity to hear from them what they are most concerned about, what kinds of activities they are organizing around the country and on the Hill, and with what message.

Attached are the following: a position paper on the Republican Medicare and Medicaid proposals from Consortium of Citizens with Disabilities, and a couple of examples of alerts

going out from Justice For All, a disability grassroots network.

Thanks so much for your help.

PARTICIPANTS:
From the White House:
Diana Fortuna
Skila Harris
Chris Jennings
Bob Jones
Jennifer Klein
Nancy-Ann Min
Marilyn Yager

Please note that also sitting in from Department of Education will be Howard Moses and Constance Garner from Judy Heumann's office.

From the Groups:
AIDS Action Council
American Association of Occupational Therapists, Christina Metzler
American Association of University Affiliated Programs, Donna Meltzer
American Council of the Blind, Julie Carol
American Foundation for the Blind, Alan Dinsmore
American Rehabilitation Association, George Krumbhaar
American Speech-Language-Hearing Association, Roger Kingsley
The Arc, Martha Ford
Bazelon Center for Mental Health, Chris Koyanagi
Blinded Veterans of America
Center on Disability and Health, Bob Griss
Consortium of Citizens with Disabilities, Kathy McGinley
Disabled American Veterans, Rick Schultz
Democratic National Committee, Bob Sevigny
Epilepsy Foundation, Julie Ward
Gallaudet University, Andrew Firth
Justice For All, Justin Dart (and Becky Ogle)
National Association of Medical Equipment Suppliers, Becky Ogle
National Assocation of People with AIDS, Amy Slemmer
National Council on Independent Living, Ann Marie Hughey
National Easter Seal Society, Katy Beh Neas
National Mental Health Association, Al Guida
National Parent Network on Disability, Patty Smith
Paralyzed Veterans of America, Robert Eastman
Powers, Pyles, Sutter, & Verville, Peter Thomas
Self Help for the Hard of Hearing, Brenda Battat
United Cerebral Palsey Association, Alan Bergman and Celane McWhorter
World Institute on Disability, Simi Litvak (San Francisco, California)

November 9, 1995

MEMORANDUM FOR NANCY-ANN MIN

FROM: Debbie Fine

SUBJECT: Questions and Answers for National Multiple Sclerosis Society

Date: November 9, 1995
Time: 3:15 to 3:30PM
Location: They will call into your office.

BACKGROUND:

You are participating in the National Multiple Sclerosis Society's (NMSS) National Leadership Conference, held in Orlando, Florida. You will be a guest 'public policy decision maker' in one of the workshops, entitled The Washington Scoop. This a radio show format, and is called Disability and Health. It will focus on the key federal issues in the 104th Congress as they pertain to people living with MS and other chronic illnesses and disabilities. You will focus on the impact of the proposed Republican budget on Medicare, Medicaid and long-term care.

The radio show host, Dr. Robert Enteen, will be situated with Martha Keyes, VP for Public Affairs for NMSS (and former U.S. Representative.) He will ask you 3 or 4 questions, listed below along with suggested answers.

Other guests include: Representative Clay Shaw (R-FL); Marty Ford, The Arc; and a representative from the Social Security Administration.

Please note that suggested answers in the form of bullets may be longer than you need, but it seemed that more information was better. On the last question, you may have some talking points that are more up to date -- I have basically attached the veto talking points from last week with some changes.

NOTE ON LONG TERM CARE: This community strongly prefers home and community based services to nursing homes. They notice that we tend to talk about nursing homes much more often than home care options, so whenever possible when talking about long term care please refer to home and community-based care or services as an important choice.

NOTE ON LANGUAGE: The most accepted term to use is "people with disabilities" rather than "people with special needs" or "handicapped people." Whenever possible, "people with disabilities" is preferable to "disabled people or the disabled."

Thanks so much for doing this on such short notice.

1. Can you tell us a little about how the current Republican budget proposal will impact people with disabilities, specifically focusing on cuts to Medicare and Medicaid?

- Let me start by giving a little background on the role that Medicare and Medicaid plays in the lives of people with disabilities.

- Medicare and Medicaid provide health care services and long-term supports to people with disabilities of all ages. In 1995, more than 6 million people with some form of disability will be served by Medicaid, and 4.1 million people with disabilities under age 65 will be served by Medicare.

- In fiscal year 1995, Medicaid payments for people with disabilities totaled $52.8 billion. For the same period, Medicare payments for people eligible for Medicare because of a disability were $18.5 billion.

- As you all know, people with disabilities on Medicare qualify for the same services as other Medicare beneficiaries. Medicare covers hospital services, physician services, laboratory services, skilled nursing facilities, home health care, and durable medical equipment.

- Under Medicaid, all states cover a minimum set of services, including hospital, physician and nursing home services. States have the option of covering an additional 31 services. Many of the services that people with disabilities need are optional services. These include: prescription drugs; physical, occupational and speech therapy and other types of rehabilitation services; assistive devices and equipment, like wheelchairs and communication devices; and long-term care, including home and community based services.

- I would like to say specifically about Medicaid -- that people with disabilities will be among those hit hardest by the Republican Medicaid proposals. As you know, Medicaid provides a safety net for people with disabilities of all ages and across disabilities -- children, the frail elderly and their families, people with MS, people with mental retardation, and people with AIDS, just to mention a few. Many families, both lower-income and middle class, receive support from Medicaid.

  Medicaid has been critical to efforts to move people from institutions into communities to live with their families. Although these services are considered "optional" under Medicaid, in reality they are critical where people with disabilities are concerned.

- Under the Republican proposal to block grant Medicaid and cut it by about $170 billion:

  Up to about 1 million individuals with disabilities could lose Medicaid coverage.

Cuts in Medicaid would be particularly devastating to people with disabilities because they would lose their guarantee of coverage under Medicaid, and they are often shut out of the private health insurance market.

Even if people with disabilities were covered, states would no longer be required to provide the minimum set of services covered today (known as "mandatory services"). There is no guarantee that people would get even the most basic services, including doctor and hospital services, that are provided by every state Medicaid program today.

The deep funding cuts under the block grant proposals might force states to eliminate coverage for other services that are critical to adults with disabilities: personal care, therapies, assistive devices and equipment, home and community-based supports, prescription drugs, and home modifications, for example.

States often use Medicaid funding to provide early intervention services for infants and toddlers with disabilities. Early intervention and therapies for these very young children is critical to maximize what they can later accomplish in school. Under a block grant, states would be under severe pressure to discontinue such services.

Block grants would force states to put people with disabilities in managed care, although neither the public nor private sector knows how to set adequate payment rates, ensure referrals to specialists, or assure quality for people with disabilities under managed care.

Families of children with severe disabilities might be forced to impoverish themselves paying for medical care for their children. Parents might have to give up jobs to stay home to care for their children.

While the elderly may receive acute care under Medicare, additional services such as prescription drugs and long-term care - which are not covered under Medicare - would be eliminated.

2. With the kind of cuts and changes that the Republicans have proposed, what are the prospects for people with disabilities who require long term care services?

- The prospects for long-term care are seriously set back both for those who choose home and community-based services and for those who choose nursing homes.

- As I mentioned earlier, in addition to many other services, Medicaid pays for home and community-based services that allow people with disabilities to live in their communities, hold jobs, or go to school. Such programs have developed over the past 15 years as an alternative to institutions. Prior to that time, an institution was too often the only option for middle-class and low-income people with disabilities.

- These home and community-based programs would come under particular pressure in states attempting to cope with a Medicaid block grant. They will find it especially hard to compete with hospitals and nursing homes for scarce Medicaid dollars at the state level.

- Without these services, people with disabilities and parents of children with disabilities may have to give up their jobs or seek institutional placements. Medicaid helps families get services at home so that families can stay together.

- Furthermore, Medicaid is the largest payor for nursing home care. Approximately 68.5% of nursing home residents rely on Medicaid to pay for their nursing home care. The average annual cost of nursing home care is $38,000 per year.

- And as a condition of Medicaid financing, nursing homes and institutions for individuals with mental retardation must comply with strict federal quality standards. They require facilities to provide all needed services, limit the use of physical and chemical restraints, and ensure that all nurse aides are trained and qualified.

- The House Republican budget throws away decades of progress by repealing federal quality standards for nursing homes. Senate Republicans allow states with "equivalent or stricter" standards and enforcement to receive waivers from the federal requirements. However, the federal government would have no way to ensure that states enforce these standards.

- Both the House and the Senate repeal federal standards for institutions caring for people with mental retardation and developmental disabilities and do not require states to assure even the most basic rights, such as protection from abuse and neglect. States do not have quality standards for these institutions in place today.

- Not that long ago, most people with mental retardation were relegated to large institutions with substandard conditions. Federal standards have greatly improved conditions in institutions and have created a wider range of choices for families, including services at home and in the community. A recent Senate amendment purports to restore quality standards in nursing homes, but without Federal enforcement authority. In addition, this change does not restore quality standards in ICF/MRs.

- Furthermore, Medicaid protects spouses of nursing home residents from exhausting their assets and income to pay for nursing home care. Since this law went into effect in 1989, it has protected about 450,000 spouses of nursing home residents. Most of these spouses are women. Republicans claim to have fixed this, but in reality their bills will not protect against spousal impoverishment. Both bills repeal current requirements for beneficiary rights to notification, hearings and appeal. Both bills make it more difficult for the federal government to ensure that states comply with spousal protections. And under the House bill, people can no longer sue the state to enforce these protections.

- But I want to return to the impact on home and community based services that people with disabilities of all ages, and their family members, often prefer to receive and have fought so hard for. The progress you have made is seriously threatened by the proposed cuts to Medicaid.

3. We have all heard that the President will veto this budget. What happens next?

- As you know, for months President Clinton has called on the Republican leadership to change their budget to reflect America's values -- family, community, opportunity, and responsibility.

- Now, he will veto their budget and send it back to them to fix.

- After the President rejects the Republican misguided budget, it is up to the Republicans to take action and change their plan to reflect America's values.

- Before -- or after -- a veto, there will be nothing to talk about until the Republicans turn away from their misguided budget plan that disregards America's values and mortgages our future.

- President Clinton has made clear that a real balanced budget based on American values:

  Invests in education and training, so America's families can thrive in the new economy.

  Honors our commitment to people with disabilities and America's elderly, helping them live with the health and economic security they deserve.

  Protects the environment and public health, so our children grow up in a clean and safe world.

  Rewards work over welfare and provides tax relief for middle class families.

  Balances the budget to lift the burden of debt off our children.

- The Republican budget decimates Medicare and Medicaid; slashes education, the environment, and technology; levies $148 billion in new taxes and fees on working families, people with disabilities and older Americans; and gives huge tax cuts for the wealthiest Americans.

- The Republicans are trying to blackmail the nation into defaulting on its loans for the first time in history, and the President will not allow that.

- The onus will be on Congress to change their plan to reflect America's values.

August 15, 1995

MEMORANDUM FOR MARILYN YAGER AND DIANA FORTUNA

SUBJECT: DISABILITY CONFERENCE CALLS

FROM: Debbie Fine

DATE: Tuesday, August 15, 1995
TIME: 3:00PM
PHONE: x66755 CODE: 4424

PURPOSE:

The purposes of this call are to:

- educate participants about where we are in the budget process in terms of a timeframe;
- underscore the critical impact on this community and on all Americans;
- mobilize for activity throughout the next few months; and
- get feedback from participants on activities in their communities.

BACKGROUND:

These are all generally supportive disability rights activists in the states. Their level of activity and focus of activity will vary -- both in terms of issue, partisanship and sophistication. I have found these calls to be very helpful and productive in the past with this community, despite the complaints that go along with them.

Every participant received the 4-pager prepared by Diana on the impact of cuts on the disability community, the state data on Medicare and Medicaid, the county data on Medicare and Medicaid and the the one-pager on older and disabled Americans, students and working families, etc.

FORMAT: (Please note that my goal is to keep these calls to half hour if possible.)

OPEN Debbie Fine

BUDGET OVERVIEW Marilyn Yager
(Brief description of process, timeframe, and message.)

DISABILITY SPECIFIC IMPACT DIANA FORTUNA
(Brief walk-through, with a note that we are still preparing HUD and DOT impact.)

DISCUSSION

Attached is a list of participants. Thanks for your help.

Conference Call

Disabilities and the Budget
Tuesday August 15th
3:00-4:00pm
202-456-

-6755
Edward Smith
Director, Civil Rights Division
N. Carolina Office of Administrative Hearings
Raleigh, North Carolina

Robert Kilbury
Executive Director
Coalition of Citizens with Disabilities in Illinois
Sherman, Illinois

Joan Kinzer
President
Democrats with Disabilities
New York, New York

Becky Ogle
Co-Chair
Justice for All
Alexandria, Virginia

Paul Schroeder
National Program Associate in Telecommunications
Technology American Foundation for the Blind
Chicago, Illinois

-66766
Bobby Simpson
Commissioner
Arkansas Rehabilitation Services
Little Rock, Arkansas

Curtis Richards
Education Finance Consultant
Sacramento, California

Max Starkloff
Founder and President
Paraquad, Inc
St Louis, Missouri

Nancy Ward - we call
Chairperson
Self Advocates Becoming Empowered
Lincoln, Nebraska

Jim Parrish
Chairman
Florida Democratic Caucus on Disability Issues
Miami, Florida

-66777
Mary McKnew
Special Assistant to the Governor of Washington
Olympia, Washington

Hugh Hallenberg - we call
Chairman
California Democratic Party
Disability Caucus
Los Angeles, California

Bob Kafka
Co-Director
ADAPT
Austin, Texas

Ron Grooms
Campaign Specialist
Aimes, Iowa

Bob Sevigny
Director
Disability Outreach, DNC
Washington, DC

-66799
Anne Thomas
Assistant to the President and
Director of Equal Opportunity Programs
Albuquerque, New Mexico

Celane McWhorter / Jennifer Simpson
Washington, DC

Mike Auberger
Director
ADAPT
Denver, Colorado

Susan Rogers
National Mental Health
Consumer Self Help Clearing House
Philadelphia, Pennsylvania

Fred Fay - we call
Chair
DNC Disability Advisory Council
Concord, Massachusetts

Tari Susan Hartman
EIN SOF Communications
Los Angeles, California

Clinton Presidential Records
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WASHINGTON WATCH

DEPENDABLE, TIMELY INFORMATION FOR AMERICA'S DISABILITY COMMUNITY

Volume 1, Issue 32 December 5, 1995

Clinton Responds to Disability Community on Medicaid

In response to the thousands of calls to the White House on the potentially devastating impacts of the Congressionally proposed Medicaid block grants, President Clinton has taken a very strong stand regarding the need to continue Medicaid as a national entitlement for people with disabilities. Congratulations to the "grass roots". You are making a difference and need to keep up the pressure.

On November 24th, President Clinton's chief of staff, Leon E. Panetta, sent a letter to Senate Majority Leader Robert Dole, Speaker of the House Newt Gingrich, Senate Budget Committee Chairman Pete Domenici and House Budget Committee Chairman John Kasich listing nine principles *that will have to be addressed to the President's satisfaction before he can sign a balanced budget plan*. This letter was in response to the agreement made by the President in the new Continuing Resolution (CR) that reopened government until December 15th in which the President agreed to a "good faith" effort to balance the federal budget in seven years if *it protects our commitment to health care, education, the environment and tax fairness.*

The letter went on to state:

Ensure adequate funding for Medicaid by:

- *Maintaining Medicaid as a national guarantee of specified and adequate benefits for low income families with children, Americans with disabilities and elderly Americans.*
- *Maintaining the quality of health care received by nursing home residents.*

The President also addressed the needs of people with disabilities who receive Medicare.

Continue Medicare's guarantee of high quality medical care for senior citizens and people with disabilities by ensuring trust fund solvency and protecting beneficiaries.

- *Ensure the viability of the Medicare Trust Fund for at least 10 years.*
- *Protect Medicare beneficiaries from premium increases beyond current law and from programmatic changes that would drive up their overall health costs.*
- *Keep Medicare first-class medical care by ensuring that resources available for each Medicare beneficiary keep pace with growth in private health care costs.*
- *Ensure the viability of hospitals and other critical health care providers in underserved rural and urban areas.*

The President also insisted on maintaining tax fairness with no tax increases on families or individuals with incomes less than $30,000 a year and to concentrate tax relief on the middle class.

Clinton's strong commitment to people with disabilities is very welcome and must be supported in the coming weeks of negotiations since the few gains which we had achieved in the Senate version of the Medicaid block grant (see *WW* No. 27) were lost in the Senate-House Conference Committee Reconciliation Bill. These losses included the Chafee/Conrad amendment for a national disability definition based on SSI and the Wellstone/Chafee amendment to allow states to provide Medicaid to children with severe disabilities above 250% of the federal poverty level (Katie Beckett). The Medicaid block grant is totally unacceptable to the disability community.

The President, Senate Democrats, and a coalition (Blue Dog) of conservative and moderate House Democrats have been discussing a "per-capita cap" as an alternative to the block grant to reduce Medicaid spending in the future. The per-capita cap is not proposed as a limit on the dollars to be spent on each person but is proposed as a formula by which states will draw down federal funds. *Washington Watch* will keep you appraised as this alternative concept develops.

In the meantime we urge you to use our 800 number to call the White House and thank President Clinton for supporting Americans with disabilities and urge him to hold the line on his demand for a national guarantee of Medicaid benefits to children and adults with disabilities.

UCPA's *toll free action line* to White House: 800-284-7324
(action line is open from 9:00 am to 5:00 pm Eastern Standard Time)
White House phone number: 202-456-1111
White House fax number: 202-456-2461
Email: president@whitehouse.gov