

# WITHDRAWAL SHEET

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| DOCUMENT NO. & TYPE | SUBJECT/TITLE                                   | DATE     | RESTRICTION |
|---------------------|---|----------|-------------|
| 1. Memo             | From Carol Rasco to POTUS re: Medicaid, 1p      | 12/19/95 | P6/B6       |
| 2. Letter           | From Dan Minish to Carol Rasco re: Medicaid, 2p | 12/13/95 | P6/B6       |

### RESTRICTIONS

**P1** National security classified information [(a)(1) of the PRA].  
**P2** Relating to 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].

**PRM** Personal records misfile defined in accordance with 44 USC 2201 (3).

**B1** National security classified information [(b) (1) of the FOIA].

**B2** Release could disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA].

**B3** Release would violate a Federal statute [(b)(3) of the FOIA].

**B4** Release would disclose trade secrets or confidential commercial financial information [(b)(4) of the FOIA].

**B6** Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA].

**B7** Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA].

**B8** Release would disclose information concerning the regulation of financial institutions [(b)(9) of the FOIA].

**B9** Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA].

**Information not found in this file can be found in Records Management. This especially includes information from 1993 and 1994.**

*file Medicaid*The Administrator  
Washington, D.C. 20201

JUN 27 1995

TO: Carol Rasco  
Assistant to the President for  
Domestic Policy

FROM: Bruce C. Vladeck *Bruce Vladeck*  
Through: Kevin Thurm *KT*

SUBJECT: Donations and Taxes Statute Enforcement

In the very near future, we intend to set up meetings with six states to discuss the exact amount of Federal money we believe was wrongly paid to them as Federal match to State funds raised through impermissible provider taxes. This will begin the disallowance process.

**Background: The Statute**

Public Law 102-234, the Donations and Taxes Statute, was enacted by Congress in 1991. It was designed to end financing schemes which improperly enhanced the Federal matching rate for State Medicaid programs. In the early days of the Clinton Administration, the Health Care Financing Administration (HCFA) worked very closely with the States to develop the regulations to implement the statute. The basic requirements of the statute are described in Attachment A.

If a tax does not meet the statutory/regulatory requirements, HCFA has the authority to recover related monies paid to the State. Specifically, the State's total amount of Medicaid expenditure shall be reduced by the sum of any revenues received by the State from impermissible provider taxes or donations, before any Federal matching funds are calculated.

**Background: Enforcement**

You may recall that last year, as part of our enforcement of the statute, HCFA identified States with health care-related taxes which we believed might be in violation of the law. These taxes fell into three categories: 1.) those which seemed clearly impermissible; 2.) those which might be permissible if the State received a waiver; and 3.) those about which we needed more information in order to determine their legality.

On December 19, 1994, HCFA sent letters to the nine States with taxes that seemed clearly impermissible, informing them that they maintained a health care-related tax program which appeared to violate the law. In these letters, we indicated the estimated tax revenue associated with each of the impermissible tax programs. In addition, we indicated the estimated Federal financial participation associated with the impermissible tax programs. We have now received responses from each of the nine States concerning the impermissible health care-related tax programs.

#### Progress in Three States

Two of the States have come into compliance with the law, and there is no need to take further action. The State of Alabama's impermissible tax program expired prior to the end of its transition period. Alabama did not collect any revenues associated with the impermissible tax program beyond its transition period, so the State owes the Federal government no money. The State of Nevada has already reduced its Medicaid expenditures for the impermissible tax revenues collected beyond its transition period (approximately \$500,000).

The State of Arkansas has been in consistent communication with HCFA's Dallas Regional Office (with whom they have a good relationship) on this issue. They have already been informed that we estimate that they owe us \$2 million in federal payments which matched impermissible taxes.

#### The Remaining Six States

The remaining six States were unable to provide additional information to change HCFA's opinion on the permissibility of their health care-related tax programs. Consequently, for these six states, we must now verify the actual tax revenues associated with the impermissible health care-related tax programs in order to begin the disallowance process.

We will send letters to these six States to notify them that HCFA continues to consider the health care-related tax programs impermissible and that a meeting will be scheduled with the State to determine the actual tax revenue associated with each impermissible tax program. We believe that when States receive these letters, they may contact the White House to complain (States already have a general idea of how much they owe the Federal government).

Once we hold this initial meeting, we will write to each State, explaining why their tax is impermissible and the amount of money we intend to disallow. The State then has the opportunity to counter our arguments. The entire disallowance process takes about six months or a little longer. We will ask for repayment of the disallowed money in a short but reasonable timeframe. After the process is completed, States can appeal HCFA's decision through the Departmental Appeals Board (DAB), and later through the court system. The Office of General Counsel has told us that States could petition to keep their money during the DAB process, as long as the State agreed to repay the money with interest if they lose the case. If the State lost the case and appealed to a district court, it could try to get an injunction to stop the collection of the disallowed sum during the court process.

Attachment B shows each State's tax program, the time period involved, the estimated tax revenue, and the amount of FFP. Although the attached chart reflects impermissible tax revenue collected as of June 30, 1994, we will verify and take action on actual impermissible tax revenue collected up to the date on which we take action.

It is worth noting that two of the States, Louisiana and Tennessee, are States to which we are currently providing technical assistance because these States are having trouble funding their Medicaid programs. However, these two States have been aware for a while that their taxes were likely to be found impermissible. In addition, we think it is important that Louisiana and Tennessee be fully alerted to impending fiscal problems which would result from our disallowance.

Attachments

## Attachment A

In general, there are four requirements that a health care related tax must meet in order to be permissible:

1. it must tax a class of items and services listed in the statute or designated by the Secretary in regulations;
2. the tax must be broad-based; i.e., it must tax all of the items or services or providers of those services, in a class;
3. the tax must be uniformly applied. The statute lists three specific kinds of taxes that are uniform, and permits the Secretary to determine that other kinds of taxes are also uniform; and
4. a tax may not hold taxpayers harmless for their tax payments.

According to the statute and regulations, States are not permitted to hold providers harmless directly through guarantees or other explicit repayment arrangements. In addition, States are not permitted to hold providers harmless indirectly through Medicaid payments. HCFA will consider a hold harmless provision to exist if the tax is applied at a rate in excess of 6 percent of provider revenue and more than 75 percent of providers receive more than 75 percent of their tax costs through Medicaid rate increases and other State payments (75/75 test). The regulations allow States until September 13, 1993 to revise a tax in excess of 6 percent that could not meet the 75/75 test. If the tax was not modified, funds received by the State on/or after September 13, 1993 will be disallowed.

ATTACHMENT B

|    | STATE  | TIME PERIOD       | ESTIMATED TAX REVENUE | ESTIMATED FFP |
|----|--|-------------------|-----------------------|---------------|
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|    | NF Gross Receipts Tax                                  |                   |                       |               |
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THE WHITE HOUSE  
OFFICE OF DOMESTIC POLICY

CAROL H. RASCO  
Assistant to the President for Domestic Policy

To: \_\_\_\_\_

Draft response for POTUS  
and forward to CHR by: \_\_\_\_\_

Draft response for CHR by: \_\_\_\_\_

Please reply directly to the writer  
(copy to CHR) by: \_\_\_\_\_

Please advise by: \_\_\_\_\_

Let's discuss: \_\_\_\_\_

For your information: \_\_\_\_\_

Reply using form code: \_\_\_\_\_

File: 3 → → Medicaid ✓

Send copy to: (original to CHR): \_\_\_\_\_

Schedule?  Accept  Pending  Regret

Designee to attend: \_\_\_\_\_

Remarks: Orig CHR

CC: FORTUNA ✓

KLEIN ✓



DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

The Administrator  
Washington, D.C. 20201

JUN 27 1995

TO: Carol Rasco  
Assistant to the President for  
Domestic Policy

FROM: Bruce C. Vladeck  
Through: Kevin Thurm

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Pat

2/2/10  
Pat  
Faxed ✓

Please fax this  
document to

R. Way very  
first thing on  
Thursday morning

Call & confirm  
receipt. I talked  
to her Wed night

via phone  
on this.

DR

THE WHITE HOUSE  
WASHINGTON

FAX COVER SHEET

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

TO: K. Way  
FAX #: 6-7023  
FROM: CAROL H. RANCO  
DATE: 9/15  
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DEPARTMENT OF HEALTH & HUMAN SERVICES

Chief of Staff

Washington D.C. 20201

**FACSIMILE**

DATE SEP 14 1994

*xc: KWay-  
Syr ✓  
Pr  
9/15*

TO: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Carol Rasco  
Assistant to the President  
for Domestic Policy

456-2216

FROM: (NAME, ORGANIZATION, CITY/STATE AND PHONE NUMBER):

Kevin Thurm  
Chief of Staff

690-6133

RECIPIENT'S FAX NUMBER: ( ) 456-2878

NUMBER OF PAGES TO SEND (INCLUDING COVER SHEET): 3

COMMENTS:



## DEPARTMENT OF HEALTH &amp; HUMAN SERVICES

Chief of Staff

Washington, D.C. 20201

SEP 14 1994

Note to Carol Rasco

RE: Decision on Arkansas Medicaid Waiver Request

As we previously discussed, I wanted you to be aware that the Health Care Financing Administration has reviewed a request for a freedom of choice Medicaid waiver from the State of Arkansas and is planning to deny the State's request.

The State proposes to implement a selective provider contracting program for inpatient obstetrical and newborn care services. In three counties, including Pulaski County, Medicaid beneficiaries in need of non-emergency labor and delivery services and routine newborn care services would be restricted to one contracting hospital in that county, or two hospitals in the case of Pulaski County. Medicaid law requires the State to document the impact of its waiver request on Medicaid beneficiary access to quality care and on cost effectiveness. Emergency services may not be restricted under these waivers.

On September 8, HCFA staff went to Little Rock to discuss the waiver with Arkansas officials. The director of HCFA's Office of Managed Care, Dr. Rodney Armstead, and staff from HCFA's regional office in Dallas met with State officials, including Tom Dalton, Director of the State's Department of Human Services, and administrators from three of the hospitals that won contracts. HCFA outlined its concerns with the State's request:

- o Selective contracting for labor and delivery services is problematic because it is difficult to distinguish which services are "emergency-related" and which are not, and to assure safe transfer of women in non-emergent labor to contracting hospitals. Contracting for these services with only a single facility in two of the three counties and two facilities in Pulaski County is troubling.
- o It is difficult to assure access to quality care when a substantial number of obstetricians/gynecologists and pediatricians would be required to change their practice patterns for Medicaid beneficiaries only.
- o Medicaid beneficiaries would have to change their patterns of care and may face new obstacles, such as travel time and transportation.
- o The State's initiative suffers from a lack of involvement and acceptance by the local medical society.

State officials responded that currently there is no shortage of primary care providers because the State's Medicaid payment rates approximate those of commercial (Blue Cross/Blue Shield) payers and because they make timely payments to providers. They also noted that additional providers have signed up for the program in recent weeks.

Page 2

However, although Medicaid primary care payment rates in Arkansas have risen substantially in recent years, thereby increasing the number of primary care providers, we have concluded that the State is unable to document sufficient access to care in Pulaski County. Only 77% of pediatricians there have accepted hospital privileges at the two contracting facilities, even though privileges are very easy to obtain. Further, the obstetricians/gynecologists and pediatricians in Pulaski County who have accepted these hospital privileges incurred only 56% of the hospital expenditures for those services in 1993, suggesting that many physicians are not prepared to participate in this program.

We have 90 days from the date of submission to approve or deny the State's request. The State has requested that HCFA make its decision shortly, before the 90th day, which is September 25, 1994.



Kevin Thurm



## DEPARTMENT OF HEALTH &amp; HUMAN SERVICES

Health Care Financing Administration

The Administrator  
Washington, D.C. 20201

## MEMORANDUM

TO: The First Lady

From: Bruce Vladeck, Administrator *B. Vladeck*

Subject: Medicaid issues in the State of Pennsylvania

Date: January 19, 1994

I understand that you are visiting the State of Pennsylvania tomorrow. You should be aware of two issues that you may be asked about during your visit.

First, as you know, some states have expressed their unhappiness with the Health Care Financing Administration's (HCFA's) implementation of changes to the Hyde Amendment. These changes have made it mandatory for states to pay for abortions resulting from incident of rape or incest. Governor Casey has recently written to the President on one aspect of our interpretation of the Hyde Amendment: the extent to which a state can impose reporting requirements.

Sally Richardson, Director of HCFA's Medicaid Bureau, in her December 28th letter to State Medicaid Directors, informed them that:

...States may impose reasonable reporting or documentation requirements on recipients or providers, as may be necessary to assure themselves that an abortion was for the purpose of terminating a pregnancy caused by an act of rape or incest.  
... To insure that reporting requirements do not prevent or impede coverage for covered abortions, any such reporting requirement must be waived and the procedure considered to be reimbursable if the treating physician certifies that in his or her professional opinion, the patient was unable, for physical or psychological reasons, to comply with the requirement.

Governor Casey has informed the President that he will not comply with the directive to waive state reporting requirements under these conditions. The Governor intends to uphold Pennsylvania's more strict reporting requirements, which do not allow for a physician-granted waiver.

01/19/94 20:09 8

JAN-19-1994 19:26 FROM

TO

94562878 P.03

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Attached are a set of talking points on reporting requirements and the Hyde Amendment (Tab A) and a more general set of talking points on implementation of the Hyde Amendment (Tab B).

A second issue which may arise during your visit concerns Pennsylvania's Disproportionate Share Hospital (DSH) payment. A brief update on this is also attached (Tab C).

JAN-19-1994 19:27 FROM

TO

94562878 P.04

TAB A

## TALKING POINTS RE: GOV. CASEY'S LETTER

Gov. Casey's January 14 letter to the President charges that the December 28 letter from HCFA to state Medicaid directors gave improper and unlawful instructions on how states must address the issue of reporting requirements in the case of abortions of pregnancies caused by rape or incest. Gov. Casey's letter is wrong on all counts.

\* Gov. Casey charges that the December 28 letter "purports to nullify state reporting requirements, such as Pennsylvania's. . ."

**That charge is simply not true. The HCFA letter specifically states that "States may impose reasonable reporting or documentation requirements on recipients or providers, as may be necessary to assure themselves that an abortion was for the purpose of terminating a pregnancy caused by an act of rape or incest."**

\* The only basis for the Governor's allegation is HCFA's requirement that any reporting requirement that a state already has or chooses now to impose must be waived if "the treating physician certifies that in his or her professional opinion, the patient was unable, for physical or psychological reasons, to comply with the requirement." Gov. Casey asserts that "[i]mplementing this directive would require me to disregard a validly enacted state statute."

No "disregard" of state statutes is necessary or required.

All that is required of state officials is that they permit a waiver in those individual cases, which are likely to be very few in number, where a physician certifies that a particular woman was unable to comply with the otherwise valid reporting requirement.

\* Gov. Casey asks that the December 28 directive be rescinded and asserts that it "places the Commonwealth and my Office in an unfair, untenable position" because of the conflict with state law.

In fact, however, the HCFA directive specifically permits a policy position that Pennsylvania once previously claimed as its own.

In litigation in 1984 in which a Pennsylvania court found a previous version of the state's reporting requirement to be unconstitutional, the state itself asserted as a defense the very kind of waiver provision included in HCFA's letter. The court in that case wrote, "Respondents [the state] in their brief point out that '[a]ny rape or incest victim who found it impossible, physically or psychologically, to comply with the 72-hour reporting requirement could not and would not be expected to comply.'" The court referred to that representation by the state as "a gratuitous statement of the obvious." Fischer v. Commonwealth Dept. of Public

**Welfare, 482 A.2d 1148, 1160 n.32 (Commonwealth Ct. 1984).**

**We do not know whether Pennsylvania's policy remains as it was in 1984. In any event, however, Pennsylvania argued for this position in the Fischer case, and at the time the state must have believed that this position was appropriate.**

**\* Gov. Casey also asserts that HCFA's December 28 letter is invalid under the Administrative Procedures Act because there was no formal notice-and-comment rulemaking process.**

**No formal notice and comment process is required where, as here, an agency issues an interpretive rule that merely implements the requirements enacted by Congress, as part of a statute. Such interpretive rules are a standard method used by federal agencies in communicating with persons and entities who participate in agency programs. If Pennsylvania wants to contest this interpretive ruling, there is an established process for doing so. [The process involves a formal finding that a state is in noncompliance, which has not yet occurred. That finding would be followed by a hearing before an appeals board.]**

**\* Lastly, Gov. Casey argues that there is no federal statutory authority for HCFA's December 28 letter, insofar as it addresses state reporting requirements.**

**There is ample statutory authority for the HCFA position. A reporting requirement cannot be used to bar coverage when insisting on compliance would be contrary to the principle in Medicaid law of covering medically necessary services. Although the states are free to impose reasonable reporting requirements, those requirements cannot have the effect of denying services that Congress has mandated must be covered. Federal law would be undermined if states were allowed to set conditions that effectively block the will of Congress.**

TAB B

**TALKING POINTS FOR MEMBERS OF CONGRESS  
ON MEDICAID AND THE 1993 HYDE AMENDMENT**

Hyde Amendment Changes Assist Rape and Incest Crime Victims

- Poor women who have been victims of rape and incest, who have suffered physical and mental abuse and who, beyond that, have been made pregnant by these acts, and who are eligible for Medicaid, will now be eligible for federal abortion funding.
- Further, the changes to the Hyde Amendment will have almost no impact on State budgets. HCFA estimates that coverage will be expanded to about 1,000 women, who have been victimized by the tragedy of rape or incest.

Implementation of the Law

- The decision to implement this policy nationwide was not discretionary. Under the Constitution, when state laws or constitutions conflict with federal law, the federal law takes precedence.
- Medicaid law mandates coverage of medically necessary physician services. When state laws have sought to restrict medically necessary physician services, those restrictions were allowed only if consistent with federal law.
- When Congress this year changed the Hyde Amendment to lift the ban on funding for abortions of pregnancies resulting from rape or incest, those abortions then became subject to the same standard for medically necessary physician services as any other medical procedure.
- Four U.S. Courts of Appeal have held that when a state funding law is more restrictive than the terms of the Hyde Amendment, the states have no choice but to fund abortions covered by the Hyde Amendment. This Administration merely followed that well-established point of law.
- During the early 1980's, Congress grafted onto the Hyde Amendment a provision that specifically relieved states of the Medicaid mandate to fund medically necessary abortions. That provision, the Bauman Amendment, made state funding of

medically necessary abortions for rape and incest optional. That language has been absent from the Hyde Amendment since 1984.

#### HHS's Implementation Process

- In December 1993 HHS issued a letter to advise states of the need to come into compliance with federal law.
- Because HHS notified states prior to the end of the first fiscal quarter (October through December 1993), states which have been paying for abortions resulting from rape or incest now have the opportunity to qualify for federal matching funds. Other States have until March 31, 1994 to amend their plans in order for those changes to be effective January 1, 1994.
- Some states have asserted that the implementation of the Hyde Amendment imposes an unfunded federal mandate on states and is therefore contrary to the President's Executive Order. The Clinton Administration understands the fiscal burdens experienced by states; indeed, that is the motivation underlying the Executive Order. The Executive Order, however, concerns areas of policy and regulation in which federal agencies have discretionary authority, which is not the case here.

#### HHS's Collaboration With States

- In the past year, HHS has followed the Presidential directive to consult with states on the implementation of federal health policies. HHS consultations have resulted in streamlined 1115 and managed care waiver processes, a common understanding of waiver policy principles, and enhanced flexibility in the Medicaid State Plan Amendment process. HHS has made considerable strides in working with states and has allowed state flexibility where the law has permitted.
- Over the Christmas week, the press learned of HHS's implementation plans on the Congressional Hyde Amendment changes. The premature publication of those plans precluded planned consultation with the NGA, APWA, NCSL and other state representatives on the implementation of this Congressional action.
- HHS will continue to work to assist states in complying with the Hyde Amendment.

TAB C

DSH DISPUTE WITH PENNSYLVANIA

- o The Medicaid Voluntary Contribution and Provider-Specific Tax Amendments of 1991 (Public Law 102-234) imposed limitations on disproportionate share hospital (DSH) payments for the entire nation and for individual States.
- o The Commonwealth of Pennsylvania has contested the Department of Health and Human Services and the Health Care Financing Administration's interpretation of the DSH limit for Pennsylvania under Public Law 102-234.
- o The issue in dispute is largely one of timing and accounting conventions. Pennsylvania believes that its DSH limit should be approximately \$1.5 billion; HCFA believes the Commonwealth's DSH limit is approximately \$967 million.
- o The Department of Justice has recently filed a motion for summary judgement in defense of the recently filed suit by the Commonwealth of Pennsylvania.
- o The Department of Justice has indicated that no discussion concerning this lawsuit should take place without the Department's approval.

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COMMONWEALTH OF PENNSYLVANIA  
OFFICE OF THE GOVERNOR  
HARRISBURG

THE GOVERNOR

January 14, 1994

The Honorable William Clinton  
President of the United States  
The White House  
Washington, D.C. 20500

Dear Mr. President:

I am in receipt of a December 28, 1993, letter, copy attached, that was sent to our state Medicaid director by Sally K. Richardson, Director, Medicaid Bureau, at the Health Care Finance Administration ("HCFA") outlining Ms. Richardson's interpretation of recent revisions to the Hyde Amendment and directing that certain steps be taken to comply with this interpretation of the new law.

Pennsylvania law limits public funding of abortions in the case of rape and incest only to instances which have been reported to the appropriate law enforcement agency. With a broad stroke, without a hearing or even notice to the state, Ms. Richardson's letter purports to nullify state reporting requirements, such as Pennsylvania's, in asserting that:

any such reporting requirement must be waived and the procedure considered to be reimbursable if the treating physician certifies that in his or her professional opinion, the patient was unable, for physical or psychological reasons, to comply with the requirement.

Implementing this directive would require me to disregard a validly enacted state statute, serving important public policy goals, based solely on the unfounded legal interpretation of a federal official. This I cannot and will not do, because such an interpretive ruling cannot legally preempt a state law and because HCFA's interpretation is not supported by the underlying federal law. I urge you to withdraw and rescind the directive contained in the letter of December 28.

Pennsylvania's reporting procedures serve the purpose of encouraging women to make known to law enforcement authorities incidents of rape and incest, thereby enhancing the ability of authorities to apprehend the perpetrators of these crimes and prevent the commission of further crimes. These procedures also insure that taxpayers' dollars are not spent to fund abortions in

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P.03

The Honorable William Clinton

January 14, 1994

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the case of fraudulent claims of rape and incest. As Governor, I cannot ignore these goals particularly where, as here, a federal agency has exceeded its authority in attempting to nullify our state law.

Pursuant to the Supremacy Clause of the United States Constitution, only properly promulgated federal rules and regulations with the force of law can preempt state law. If, indeed, the December 28 letter was intended to be a rule or regulation with the force of law, it would appear that the Administrative Procedures Act, 5 U.S.C. §500, et seq., would require that a notice and a comment period be available to allow states sufficient time to comply with the federal law and, if necessary, challenge HCFR's authority to promulgate these new rules. HCFR's letter met none of these requirements and thus, is at most an interpretive ruling or a statement of policy that does not have the force of law. Accordingly, this interpretive letter is a nullity and without any effect on the law of this Commonwealth as it applies to the rape and incest reporting requirements.

Moreover, even assuming the directive in HCFR's December 28 letter had been properly promulgated as a federal rule or regulation, in order to preempt state law it would need to be based upon statutory authority indicating that Congress intended to preempt state action in this area. Such authority is clearly lacking, however. The language of P.L. 103-112, as well as its legislative history, is completely devoid of any language pertaining to rape and incest reporting requirements, nor is there any indication of an intent to preempt state regulation as it applies to such reporting requirements. Indeed, HCFR's letter suggests otherwise, acknowledging the important state role of defining rape and incest, as well as the states' existing authority to impose reasonable reporting requirements. Because the waiver language appears to lack any statutory basis and seriously encroaches upon the states' traditional authority in this area, I have no intention of following it.

HCFR's conduct is in stark contrast to its past practice and position with respect to the "life of the mother" reporting requirements, where regulations were properly promulgated and states were permitted to implement their own requirements without federal interference. It also flies in the face of your recent Executive Order instituting measures to enhance federal/state relations and to, specifically, "establish regular and meaningful consultation and collaboration with state[s]."

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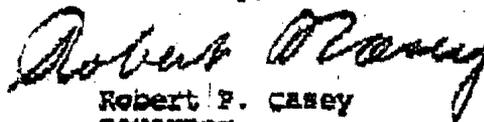
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The Honorable William Clinton  
January 14, 1994  
Page -3-

This directive places the Commonwealth and my Office in an unfair, untenable position. It directs me to ignore validly enacted state reporting requirements under circumstances in which HCFA has neglected to follow fundamental procedures necessary to preempt state law, and where in any event there is no federal statutory basis to preempt state law. A failure to follow this directive, however, could lead to the loss of all federal Medicaid funding -- funding that is critical to sustain necessary health care for the poor in Pennsylvania. Accordingly, I would request that HCFA change its interpretation relative to the waiver of state reporting requirements, and allow states to continue to regulate in this area.

This issue involves a serious question concerning the limits of federal power over the states and the process that is utilized to exercise such power. Given this broader issue, I believe it is essential that we take steps to resolve this conflict in a way that gives appropriate recognition to the proper role of the states in this important area of our law.

Sincerely,



Robert F. Casey  
Governor

THE WHITE HOUSE

WASHINGTON

TO: Mack McLarty  
Phil Lader  
Harold Ickes  
Mark Gearan

FROM: Carol H. Rasco

SUBJ: Pennsylvania's letter on medicaid abortion coverage

DATE: January 19, 1994

I did not want to start a full discussion on this matter this morning in the 8 a.m. meeting but want you to be aware of the following:

I have reminded HHS we do NOT need to escalate this matter in the coming week prior to the return of Congress. We all know that with the convening of Congress there is very likely to be an amendment filed immediately to anything available to change the Hyde wording as passed last year. Let that be the place the changes take effect, not here.

HHS will continue to say that (a) there was no discretion in the way they gave the instruction given the amendment as it is worded and (b) when confronted now by questions regarding the fact states are issuing clear, firm statements HHS will state they will continue to work individually with states. No state is getting ready after the March 31 submission of the required state plan amendment to get cut off Medicaid totally. First of all there are about 14 appeals steps that HCFA within HHS can stretch out as long as needed, and I can assure you everyone knows how to play that game. Again, however, I will be stunned if Congress doesn't pass a remedy very quickly. Unfortunately for poor women, that remedy may set the issue of fairness back but that is another story.

Thank you.

File Calif XIX

3/6/95

To: Carol Rasco

Fr: Diana Fortuna

Here is some of  
the coverage from the  
Calif Medicaid rollout,  
FY1. Under the circumstances,  
it was pretty balanced.

## EDITORIALS

SF Chronicle 3/1/95 (5)

MAR - 6 1995

# Counties Unfairly Dealt Medi-Cal Cuts

**C**ALIFORNIA counties could suffer a staggering \$315 million drop in federal Medi-Cal funds this year — despite every indication that most of those counties would be penalized for the misdeeds of others.

Federal officials say their refusal to reimburse hundreds of millions of dollars in county Medi-Cal claims stems from county administrative costs that the federal government considers improper. But the Health Care Financing Administration, which oversees Medi-Cal expenditures, reportedly conducted a careful audit only in Los Angeles before it made its determination.

*It's only fair the federal government conduct an in-depth audit in counties that stand to lose*

"The potential disallowed practices . . . are not relevant to the majority of participating counties," Ted Lempert, president of the San Mateo County Board of Supervisors, wrote to the administrator of HCFA. "Our claims will withstand an audit, and we urge a more thorough and fair review by HCFA before disallowing the claim and damaging health care services in California."

San Mateo County stands to lose \$18.1 million, San Francisco County \$33 million, Santa Clara County \$48.7 million and Contra Costa County \$32 million under the federal

cutbacks.

Although the federal government's relationship is with the state, it seems only fair that the Medi-Cal oversight agency conduct an in-depth audit in those counties that stand to lose the money in order to ensure that agencies that have complied with federal rules are not wrongly penalized for the errors of others.

In this era of find-money-whenever-you-can, counties and other local governments are getting hit from all sides. The federal government wants to cut waste and save money, as does the state, which decided last year it was entitled to \$200 million in federal Medi-Cal money that the counties claim belongs to them.

San Francisco is not atypical in already receiving only 20 percent of the cost of treating a Medi-Cal patient in an outpatient setting. Additionally, the counties complain that payment rates (set by the state) are the lowest in the nation — \$35 per outpatient visit.

**T**here are going to be serious health care cuts throughout the state — including the closing of clinics and the elimination of public health nursing services — if the federal government goes through with its reported plan to disallow \$315 million in Medi-Cal reimbursements. Of course, the counties can legally challenge the cutbacks, but it would take years to resolve the issue in the courts.

The Medi-Cal system deserves scrutiny, but the least the federal government can do before imposing penalties is to make sure each of the targeted counties is at fault.

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# Medi-Cal Money Denied to Counties

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By Greg Lucas  
Chronicle Sacramento Bureau  
Sacramento

The federal government officially refused yesterday to pay \$315 million that California and its counties sought as reimbursement for providing health care services to the poor, driving the state budget \$200 million into the red.

Although Bruce Vladeck, chief of the federal Health Care Financing Administration, expressed sympathy for the fiscal problems

the move would cause cash-strapped counties and the state, he said that at least \$284 million of the \$315 million will never be paid.

The counties might be able to recoup the rest, he said.

"The folks most at risk in this process are the counties and the people they serve," Vladeck told reporters at a Capitol press conference. But, he said, "90 percent (of these claims) involve services we've already paid for."

At issue are funds distributed

by the federal government to pay counties for administration of the Medi-Cal health care system. Vladeck said the main objection to the counties' claims is that various services — such as nurses to explain a patient's prescription — are already reimbursed in another part of the Medi-Cal program.

Many counties had banked on the arrival of this money to help defray the costs of operating coun-

MEDI-CAL: Page A14 Col. 3

## MEDI-CAL

From Page A13

ty hospitals, clinics, public nursing programs and other treatment options related to Medi-Cal.

The state takes a hit because under the terms of last year's budget deal, the Wilson administration was supposed to keep \$200 million of an expected \$850 million in reimbursements under the program, which was created to pay half of the county administrative costs associated with operating Medi-Cal.

But with no money for the counties, there will be no money for the state.

Vladeck said 92 percent of the \$315 million is claims from Los Angeles County. The remaining 8 percent is split among another 33 counties.

The denied claims were the first filed under a new system created by the state and counties to increase federal reimbursements. The state argues that it created the system in consultation with the health care financing agency, but Vladeck said yesterday that the state's reimbursement criteria was never approved.

Denial of this batch of claims jeopardizes payment of future claims. The state legislative analyst estimates that California's 58 counties could lose \$2 billion in potential reimbursements through the fiscal year ending June 30, 1996.

Vladeck downplayed the impact of his agency's decision on future claims and said that claims by counties other than Los Angeles in the \$315 million might be honored.

"We believe that anywhere from a small to a very large fraction (of the counties' claims) ought to be allowable," said Vladeck, adding that the federal government would examine claims submitted by other counties. "But I can't guarantee that process will produce on a dollar-for-dollar basis everything the counties hoped for."

Although Los Angeles takes the biggest hit, the financial impact is significant for Bay Area counties.

Alameda County's budget for the current fiscal year, which ends June 30, counted on \$14 million in federal reimbursement, including unpaid claims from previous fiscal years.

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# County's condition critical after denial of Medi-Cal claims

By Sandy Harrison and David Bloom  
*Daily News Staff Writers*

The federal government on Wednesday rejected \$290 million in Medi-Cal claims made by Los Angeles County for the costs of health care to the poor, pushing the county into another round of tough choices to avoid economic disaster.

Since the current year's budget anticipated payment of the \$290 million in claims, their rejection creates an immediate shortfall in the county's budget.

And it could get worse if the federal government also rejects \$350 million in additional Medi-Cal claims for services county departments expect to provide this year, said Robert Plasky, a county management analyst.

County officials face two basic choices in dealing with the deficit — make deep cuts in services over the remaining four months in the current fiscal year, or tap reserves set aside to offset an expected deficit next year.

While tapping the reserves would solve the immediate problem, without some other revenue source it would only delay debate about potential budget cuts, since county financial officers have forecast a significant deficit for next year.

It means that we have to ad-

## Valley groups want rail line in 20-year plan

By David Bloom  
*Daily News Staff Writer*

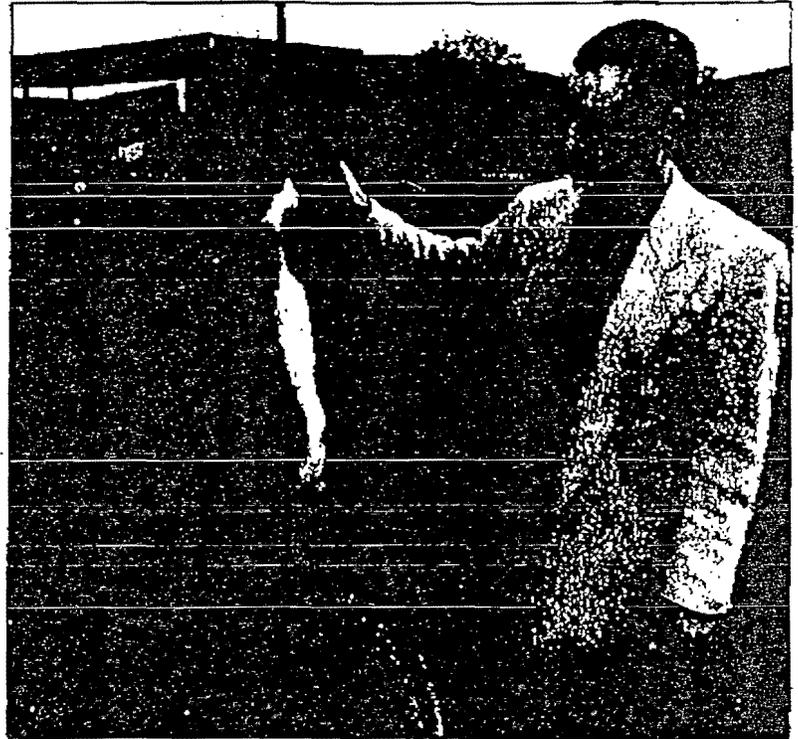
As transit officials near a decision on a new 20-year spending plan, San Fernando Valley groups are jockeying to get the second phase of the East-West Valley rail line back on the list of planned projects.

But with funding sharply restricted, they face tough competition from groups seeking a higher funding priority for rail lines along the Crenshaw Boulevard and Alameda Avenue corridors.

The Alameda corridor project — a high-speed rail and road link from the ports of Los Angeles and Long Beach to downtown highways and rail yards — is a particular threat to beat out the proposed East-West San Fernando Valley Rail Line.

The Alameda project is strongly backed by Los Angeles

See MTA / Page 11



Gus Ruehle/Daily News

Pierce College police Capt. Ken Renolds expects that the trained officers will split shifts in cars and on horseback.

## Pierce College police mounting horse patrol to rein in crime

By Howard Breuer  
*Daily News Staff Writer*

WOODLAND HILLS — Pierce College police say they are about to become the first in the state to patrol a community college by horseback — although they need to find horses large enough to carry some of the stouter members of the force.

College President Mary Lee believes the horses will give the

officers a more visible presence on campus and a better vantage point to spot car thieves.

She also thinks the mounts will make it easier for the officers to reach areas of the hilly, 420-acre campus that are inaccessible to patrol cars.

"People are more friendly to officers on horseback," she said. "In parking lot surveillance you

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1/2

# Government rejects county's Medi-Cal

COUNTY / Front Page 1

...a daunting shortfall as of July said Gary Wells, the Health Department's assistant finance director.

But Wells said it is possible that the federal government might still compromise and allow at least partial payment of the rejected Medi-Cal expenses.

The bright side is that (federal officials) have indicated that they'll work with us and seek alternate ways to make sure that the health safety net remains in force."

Anticipating that it would not receive that money, departments and Board of Supervisors have been scaling back operations significantly — including not filling vacancies and planning to close clinics.

More than \$104 million in pending reductions have been made throughout county operations, and a surplus that the county Health Services Department hoped to use for next fiscal year will be spent down this year.

Administrative appeals processes take as much as several years as there is a significant effort to speed up the review, Plasky said, and will further complicate the county's financial problems possibly

well into next fiscal year.

With the denial, the county now will appeal the matter and negotiate for some portion of the funds it is claiming under the program, county officials said.

"I don't think this is particularly disheartening," said Tom Silver, chief deputy to Supervisor Michael D. Antonovich. "The key here was to get a decision so we can get on with an appeal."

County officials said they hoped for a quick appeal and negotiations that would allow at least some portion of the money the county needs to come in.

Supervisors Gloria Molina and Yvonne Brathwaite Burke were part of a group of county officials meeting late in the day with Health Care Financing Administration officials in Los Angeles over the decision.

"The financial health of Los Angeles County, and our ability to deliver critical programs to residents, depends upon the federal government's willingness to reimburse past Medi-Cal costs," Molina said in a statement. "We must take a serious look at past monies and determine a process which will avoid future problems."

The decision adds new impetus to county budget-cutting efforts.

however, and will further cloud next year's already dark fiscal picture, county officials said.

State officials submit the requests for federal reimbursement on behalf of counties. In a letter to the state, the U.S. Health Care Financing Administration said the claims were denied because of flaws in the accounting system — resulting in double billing for services that already had been paid.

"The system lacks the capability to distinguish between allowable Medicaid administrative costs, and cost for services that have already been reimbursed by federal and other sources," the federal announcement said.

"It means we were asked to pay again for what we've already paid in full," said HCFA administrator Bruce Vladeck. "More than 90 percent of it involves administrative costs for clinic services we've already paid in full."

Specifically, the HCFA statement concluded that costs which were part of clinic services, for which reimbursement already has been made, were wrongly billed as administrative costs.

State Department of Health Services spokeswoman Lynda Frost said the federal denial of funding was a surprise because the state had

worked with federal officials in devising its new claim procedures.

"We're disappointed and we stand by the validity of the system," Frost said. "At this point we have to keep working with the federal government to identify what can be reimbursed. We are still going to try to get a lot of that."

The claims were first filed under a new system designed by the state and counties to increase federal reimbursements by qualifying more administrative costs for reimbursement. But federal officials say that what it actually did was result in multiple reimbursements for the same expense.

Plasky said the HCFA complaints were off base.

The county used definitions of claimable activities that had been approved by the state and the regional office of HCFA, he said, and any reimbursements the county received from non-Medi-Cal programs were subtracted from claims made under the Senate Bill 910 program.

"We're not double billing," Plasky said. "The rates that Medi-Cal pays for don't cover all the costs. They pulled out some elements that are good sound bits, but we still believe our claim was based

on legitimate codes that have been approved by the state and Region 9 of HCFA."

Specific items cited in the federal denial include:

- Programs in the Los Angeles County Alcohol and Drug Program Administration and Department of Mental Health receiving reimbursements from the state Department of Aging, the Social Security Administration, and other state and federal agencies that exceeded the total costs of the programs.

- Ineligible costs, such as housing referrals, child care referrals, energy assistance referrals, and legal service referrals, being billed as administrative costs.

- Services provided by nurses and pharmacists incorrectly billed as administration, even though they already were reimbursed as medical services by Medi-Cal.

- Medical services to prison inmates were improperly billed as administrative expenses.

- Public health campaigns involving alcohol, tobacco and drug abuse prevention were improperly billed as administrative costs.

*This story was reported by Sandy Harrison in Sacramento and David Bloom in Los Angeles.*

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Daily News 3/2/95

2/2

WASHINGTON

9

# U.S. denies \$315 million claim for Medi-Cal reimbursement

By Brad Hayward  
Los Capitol Bureau

In a blow to the state and its financially struggling counties, the federal government Wednesday denied a \$315 million reimbursement claim from California counties for the costs of running the Medi-Cal program.

Federal officials called the system used to calculate the reimbursement claims "seriously flawed." In many cases, they said, it generated requests for federal reimbursement for services the government already had funded.

The decision pokes holes in the current-year budgets of most counties, with the vast majority of the losses in Los Angeles County. The action also could tie up hundreds of millions of dollars in additional funds that counties were expecting through 1996, and it jeopardizes up to \$400 million in state revenues as well.

"We are very disappointed, especially considering how closely and cooperatively we worked with (federal officials) in developing the system they are now disowning," said Lynda Frost, spokeswoman for the state Department of Health Services, who said the state is appealing the decision.

The flap is over a new process the state recently created to allow counties to recoup their costs for administering Medi-Cal, a program that provides health services to the poor.

The state forwarded the counties' first reimbursement request under the new system to the federal government in September. But when federal officials reviewed the program, they found problems.

For example, officials said, when a clinic nurse would report medical test results or discuss prescription use with a Medi-Cal patient, the system would sometimes count the time spent as administrative, thus needing reimbursement when it was already

reimbursed under clinical services payments.

"We have been asked to pay more for something we've already paid in full," said Bruce Vladeck, chief of the U.S. Health Care Financing Administration.

In other cases, Vladeck said, the system produced reimbursement claims for programs ranging from housing to drug-abuse prevention that are not part of Medi-Cal at all.

Frost said the system had been set up to avoid such problems; she added that federal officials were familiar with the system as it was developed and did not complain about it until the state asked for the reimbursement. Vladeck said the final system wasn't what federal officials had expected to see.

Vladeck said some of the denied claims may eventually be reimbursed once county officials provide better information.

Of the \$315 million in denied claims, 92 percent would have gone to Los Angeles County.

But the losses to nearly all counties could increase because the decision imperils more claims that the federal government has not yet received. In the worst-case scenario, \$2 billion in county revenues could be jeopardized over a two-year period, according to the Legislative Analyst's Office.

And because the state planned to skim some money off the top of those reimbursements to counties, it could lose \$200 million in the current year and another \$200 million in the 1995-96 fiscal year.

"Statewide, the impact is going to be very significant," said Robert Caulk, director of Health and Human Services for Sacramento County. "Many counties were hoping that these funds would offset previous costs and allow counties to backfill for other losses in state and local revenues."

But Caulk said Sacramento County would be able to handle the blow even if it gets none of the \$4.3 million in reimbursements it

had budgeted for the 1994-95 year. "In the flow of things, this is not that large of an impact and is within a manageable range of things we run into over the year," he said.

Officials in Yolo County said the impact could be more serious there; the county expected \$482,000 in reimbursements this year. Placer County had assumed receipt of \$271,000, and El Dorado County, \$160,000, according to the California State Association of Counties.

*Sacramento  
Bee*

*3/2/95*

# Medi-Cal expected to refuse

By Rachele Kanigel  
STAFF WRITER

Health officials around the state are considering massive cutbacks — staff layoffs, clinic reductions and county hospital closures — in response to news they may lose millions of dollars in federal Medi-Cal funding.

The federal Health Care Financing Administration is expected to announce by Thursday that it will not pay \$315 million in Medi-Cal claims the government considers inappropriate.

Alameda County stands to lose \$10 million for the 1994-95 fiscal year and \$12 million for the 1995-96

anticipating a shortfall of \$2 million. The state of California expects to miss out on about \$200 million for each year.

Altogether, the state and counties could lose more than \$1.5 billion, said Bill Wehrle of the state legislative analyst's office.

"If we don't get this money it's going to be devastating to us," said Shahnaz Nikpay, director of finance for the Alameda County Health Care Services Agency. "It would mean less of everything — less staff, less hours, less responsive services. We may have to shut down some of our clinics."

In Contra Costa County, officials are considering lay-

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## \$315 million in claims

services, said Mark Finucane, health director for the county.

At issue is a dispute over how much the federal government should pay for the administrative costs of Medi-Cal, the government health program for the poor.

In 1992, the state Legislature passed a bill expanding the Medi-Cal administrative claims program. Since then the state and counties have begun to bill the federal government for a number of services they were already providing.

Wehrle concedes some of the counties got rather "creative" with their claims. Some billed the government for the cost of county sheriffs' departments providing drug and alcohol education program in public

schools — basing their claims on the number of Medi-Cal recipients living in those districts.

Other counties billed the government for the costs of outpatient clinic services not already part of the regular Medi-Cal reimbursement; pharmacists explaining the side effects of medications; public health nurses referring Medi-Cal patients to drug treatment services.

State and county representatives said federal officials in the regional office had said in numerous meetings that the counties could bill for such services.

But last year, federal officials in Washington began to question these claims after they soared from \$17 million in the 1992-93 fiscal year to \$315 million for a fraction of the 1993-94 fiscal year.

# U.S. officials warn counties about Medi-Cal claims

By Sam Detson  
SACRAMENTO BUREAU

SACRAMENTO — Federal officials warned Wednesday that more than \$1 billion in future Medi-Cal reimbursement claims by California counties could be in jeopardy.

The officials made the warning while confirming that they have disallowed \$315 million in Medi-Cal reimbursement claims by state counties.

Bruce Vladeck, chief of the U.S. Health Care Financing Administration, said the counties have been billing the state for administrative costs that had already been covered by other programs.

He stopped short of accusing the counties of deliberate wrongdoing but said California's new accounting system has multiplied the counties' demands for federal reimbursements without improving services to patients.

"We won't call it fraud or double-billing," Vladeck said. "We call it maximizing federal resources."

The \$315 million in denied claims included \$1,458,529 for Alameda County, \$539,926 for San Joaquin County, and \$67,862 for the City of Berkeley.

But the counties could eventually lose much greater amounts if they fail to reach agreement with federal officials on new standards for acceptable reimbursements.

Margaret Pena of the California State Association of Counties said counties' budgets are already counting on \$700 million in Medi-Cal reimbursements for the current fiscal year.

"We will see a tremendous and devastating impact on the counties as a result of the loss of these funds," Pena said.

Alameda County stands to lose \$10 million this fiscal year and \$12 million next year, while Contra Costa County could lose \$2 million.

Bill Wehrle of the state legislative analyst's office said California could lose more than \$1.5 billion from the federal decision.

U.S. Secretary of Health and Human Services Donna Shalala noted that other states' costs for administering Medicaid programs average 4.5 percent. But California's administrative costs were 6.3 per-

cent before the new system was adopted and have topped 14 percent since its introduction.

"We are required to disallow payment of the administrative claim because California's new Medi-Cal Administrative Claiming system (MAC), which was used to identify Medi-Cal administrative costs incurred by counties, is seriously flawed," Shalala wrote in a letter to Gov. Pete Wilson.

"The claim generated by the MAC system includes inaccuracies and in large measure appears to represent activities that were part of clinic services for which Medicaid payment has already been made."

Grantland Johnson, West Coast regional director of Shalala's department, said he will meet with representatives of the counties in San Francisco today to try to work out an agreement on standards for future reimbursements.

"We're here not just to deliver notice of disallowance but to hit the ground running and work with the state and counties like Alameda to expedite the process of settling the claims," Johnson said.

More than 90 percent of the denied claims were from Los Angeles County and involved a particular accounting practice that was not used by other counties. Johnson said Alameda and other counties have a chance of eventually recouping a significant portion of the claims that were rejected this week.

"Alameda feels strongly that, upon further review and after submitting additional documentation, the bulk of their pending retroactive claims will be determined to be eligible for reimbursement," he said.

But Vladeck said it could take a while to untangle the financial mess that federal regulators found when they audited the Medi-Cal program.

"We don't see any way to get most of it to the counties any time quickly," he said, and noted that the state won't be able to submit more claims until the dispute is settled.

Vladeck said the state's increased requests for reimbursement were "entirely an effort by the counties to get the federal government to pay a larger share of the costs for existing services."

Oakland Tribune

A-3

May 19 1995

12

# California News

Thursday, March 2, 1995

## Citing flaws, U.S. rejects

### Medi-Cal bills

#### Claims totaling \$315 million are denied

BY GARY WEBB

Mercury News Sacramento Bureau

SACRAMENTO — The federal government Wednesday formally refused to pay \$315 million worth of Medi-Cal claims from 34 California counties because the claims are allegedly improper.

In a letter to Gov. Pete Wilson, U.S. Health and Human Services Secretary Donna Shalala said the state's current system for billing the federal government for medical services given to the poor was "seriously flawed." Recent federal audits done in Northern and Southern California show the system resulted in some counties double-billing the Medi-Cal program for clinical visits and others charging for services unrelated to Medi-Cal.



Shalala

In Los Angeles County, which was the biggest offender, more than \$2.5 million worth of Medi-Cal claims were submitted for the time sheriff's deputies spent lecturing schoolchildren on drug abuse, on the theory that some of the kids probably were Medi-Cal recipients. Another \$60 million was claimed for the time probation agents spent counseling criminals.

The billing system originated in San Mateo County, which had hired a Maryland consulting firm to devise it. The system is known as "MAC," Medi-Cal Administrative Claiming. State and local officials said other counties, particularly in the Bay Area, were convinced the MAC system was so foolproof

that they built into their current budgets millions of additional Medi-Cal dollars.

And they weren't the only ones. In his 1995-'96 budget, Gov. Pete Wilson figured on getting \$200 million back from the counties' share of the MAC money as a fee for overseeing the program.

Hancine Fisher, a Los Angeles-based consultant with the Institute for Human Services Management of Rockville, Md., said in a brief phone interview that she did not "want to get caught up in this thing" and referred questions to San Mateo County officials.

"We had a fee-for-services contract with them," Fisher said. "The process originated there."

Mary Macmillan, legislative director for San Mateo County, said the consulting firm was hired on the recommendation of the state Medi-Cal department. Macmillan said county officials were assured by the consultants — who were paid roughly \$300,000 — that the billing process they were promoting was legal and had been used in other states.

Sources said the inspector general of the federal Health and Human Services Department has opened an investigation to see whether there was a conspiracy to defraud the federal government.

The impact of Wednesday's decision is considerably more far-reaching than the immediate loss of the \$315 million. Roughly \$1.5 billion worth of additional MAC claims are at various places in the

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CA News

3/2/95

pipeline between the counties and the federal government. Wednesday's announcement means it is likely many of those bills won't be paid, either.

Already, Santa Clara and Santa Cruz counties are losing \$1.3 million each. Alameda County loses \$1.4 million, and San Mateo County will lose \$257,000. It is not clear at this point how much overall the counties have billed.

The biggest losers will be counties that bet large parts of their public health budgets on getting MAC money this year and next. Los Angeles County, for instance, budgeted \$641 million, while Santa Clara County has nearly \$10 million in its budget. Alameda County was planning on receiving \$6.4 million this year.

In a letter Wednesday to Bruce Vladeck, head of the Health Care Financing Administration, Reps. Anna Eshoo, Norman Mineta, Tom Lantos, Pete Stark and Zoe Lofgren warned that loss of the federal funds "would be particularly devastating to San Mateo, Santa Clara and Santa Cruz counties" and said it was likely the counties would have to "make deep cuts into their mental health, public health, drug and alcohol services as well as to medical centers."

Vladeck, whose agency pays for the federal portion of Medi-Cal, agreed that "the folks most at risk in this process are the counties and the people they

serve." But he said federal law prevented him from paying the claims.

"We have been asked to pay more for something we've already paid in full," Vladeck said. "The state was clearly seeking to use administrative devices . . . to bring in more federal dollars without additional county or state dollars being put up at the same time."

John Rodriguez, director of the state's Medi-Cal program, said he believed the MAC system had the blessing of Vladeck's agency, since HCFA officials from the regional office in San Francisco actively participated in planning the new billing process.

"There is no way they can say they weren't heavily involved in this process," Rodriguez said. "This whole system evolved with their help."

But Vladeck said that while it was "very clear there have been extensive conversations between the representatives of the state and HCFA" regarding the billing system, "it is also absolutely clear to us that there was never an approval granted or implied. In fact, we did not see the new system and all of its details until after the time the (\$315 million) claim was submitted."

When the details finally were produced, Vladeck said, "it differed in important respects from what we thought we had been talking to the state about during the previous two years."

Vladeck said his agency will work with the counties to salvage what claims could be legally paid but that it was likely the bulk of them would be refused. He said a court challenge by the state and counties was likely.

**and time around**

Marines are part of a 100-strong force sent to Somalia to form a protective cordon around 2,400 U.N. troops as they withdraw from Somalia.

**Looters at the ready**

■ Somali looters may interfere with the military operation and the loading of ships.

See story, Page 8A

chief operating officer. "This is a company that traditionally has managed its headcount very carefully," said Harvey Frank, who as staffing manager is faced with the task of finding qualified applicants. "This is a landmark in our history in that we are for the first time saying we have the ability to go out and find the best talent out there and invest in our future." Most companies don't formally announce their job-creation targets, but Silicon Graphics' growth plans are thought to be among the best. See JOBS, Back Page

*San Jose Mercury News*

2/28/95

# Santa Clara, San Mateo counties face costly Medi-Cal bill dispute

BY GARY WEBB AND HOLLY A. HEYSER  
Mercury News Staff Writers

SACRAMENTO — A high-level dispute between state Medi-Cal officials and a federal health agency is expected to cost California counties nearly \$2 billion in the next two years and plunge the state's debt-ridden budget an additional \$400 million into the red.

Any day now, state officials are expecting to receive a letter from Washington formally refusing to pay for three years' worth of Medi-Cal bills from county public health programs. For many counties in the Bay Area — which already have spent a fortune providing services on the assumption the money eventually would be repaid by the federal government — that decision will leave gigantic holes in their budgets this year and next, possibly forcing layoffs or severe curtailment of health care

programs for the poor.

In San Mateo County, health services Director Margaret Taylor said she is bracing for up to \$10 million in cuts starting June 1 if federal money owed for the past three years doesn't materialize. The county could cut one-fourth of clinic services used by 24,000 people a year and eliminate half of the beds for seriously mentally ill people at the county's lock-in facility.

It could lose more than 20 public health nurses who make house calls for people with AIDS, disabled people and battered women. It could cut basic non-emergency services for abused elderly people and people with Alzheimer's disease. And the county hospital could start diverting emergency room patients to other hospitals in the area.

All told, the cuts could lead to 100 layoffs and

See **MEDI-CAL**, Page 11A

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**How one young trader rocked financial world**

■ The audacious strategy of Nicholas Leeson, a 28-year-old Briton, came crashing down Sunday night and caused the collapse of his employer, the investment bank Barings PLC. Regulators on Monday were trying to find Leeson, who disappeared last week, though as of that time he faced no criminal charges for his ill-fated gamble on Japanese stock prices. BUSINESS, PAGE 1E

**Woody-Mia miniseries unexpectedly first rate**

■ He never thought he'd be doing it, but television critic Ron Miller gives a rave review to "The Mia Farrow Story." The Fox two-parter — unauthorized by the story's principals — starts tonight and concludes Thursday. LIVING, PAGE 1D



Nicholas Leeson put \$29 billion of his bank's money on the line — and lost a billion.

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| Horoscope       | 6D | Television    | 8D  |

**WEATHER**

■ Partly cloudy, highs 60-65. PAGE 8B

**NEWS SUMMARY**

■ Complete summary of today's news. PAGE 2A  
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# Government disputes m

## ■ MEDI-CAL

from Page 1A

drastic service reductions. "It would be the worst cuts we've ever faced," Taylor said. "I know they didn't cut this much after Proposition 13."

Although Medi-Cal recipients still would be able to receive services and medication from private doctors who agreed to serve them, they would have a much harder time getting appointments at clinics or the county hospital, Taylor said.

"The private (health) community's going to end up seeing more Medi-Cal patients," she said. "This is really a problem for all of us in health care."

Santa Clara County faces a potential loss of \$16 million for its three years of unpaid expenses, on top of an expected \$30 million to \$40 million shortfall in the county's \$1.2 billion budget for the fiscal year that begins in July.

But officials there were more conservative about where the cuts might fall, noting that the \$16 million makes up less than 1 percent of the annual budget. "We're not going to react by shutting anything down at this point," said Gary Graves, the county budget director. "For now, we're going to push it into next year and take a good look at services and develop a plan that makes sense."

In both counties, the Medi-Cal administrative

funds have been used to pay for a wide variety of services for the needy, such as alcohol and drug prevention programs, mental health workers, and services for people in homeless and battered women's shelters.

Only five counties — Alpine, Mariposa, Modoc, Mono and Sierra — did not participate in the program. All other counties are likely to wind up holding the bag.

### State budget sleight of hand

The costly debacle is yet another example of what happens when state lawmakers — instead of raising taxes or cutting services — try accounting tricks to balance severely strained budgets.

In this case, a bill that was passed unanimously by the California Legislature and signed by Gov. Pete Wilson in October 1991 shifted a slew of expenses that were being paid by the counties onto the shoulders of the federal government.

"When budgets get tight, it's sort of a cottage industry to find ways to get the Medi-Cal program to pay for things," said Bill Wehrle, a Medi-Cal expert for the Legislative Analyst's Office. "This particular innovation turned out to be a little more creative than the feds cared for, at least so far."

The bill bluntly said its purpose was to restructure Medi-Cal's billing processes to achieve "maximum possible federal financial participation." Sponsored by former state Sen. Dan McCorquodale, D-Modesto, the measure reclassified a lot of the work already being done by public health nurses and social workers to make it appear they were doing work the federal government would pay for.

Officials familiar with the bill said the idea originated in San Mateo and Los Angeles counties and was eagerly seized upon by state health officials and the Wilson administration as a way of saving dwindling state resources.

There was only one problem: The federal Health Care Financing Administration, the agency that pays for Medi-Cal, never agreed to go along with it.

### Assumed federal approval

Margaret Pena, a lobbyist with the California State Association of Counties, said state and county officials apparently were under the impression that HCFA had approved the scheme, since officials with HCFA's regional office in San Francisco had an active role in helping the state formulate the plan.

But at a high-level meeting in Washington in January, Pena said, top HCFA officials made it clear the idea had never been sent up the line for approval in Washington.

"We were told that it was one thing to provide input and advice but that it was something else to approve it," Pena related. She said HCFA brass told state and county officials there was no way the federal government was going to pay California's bills because that would open the floodgates to the other 49 states.

"They said they were looking at an exposure of \$10 billion," Pena said.

HCFA paid the first bill the state sent it, for \$17 million, but when it got a second bill for \$315 million, red flags went up all over the agency, according to an HCFA official who asked not to be named.

## EXPECTED IMPACT

The federal Health Care Financing Administration is expected this week to deny up to \$2 billion worth of Medi-Cal reimbursement claims from most of California's 58 counties. Here are brief summaries of the impact on counties:

### Alameda County

- The county faces a potential loss of \$10 million this year and \$12 million next year. While the loss could force the county to lay off employees and cut programs, it is too early to discuss specific cuts. The administrative funds have been used for:
- Public health nurses, mental health workers, social workers, and dental prevention programs in local schools.
- About 25 percent of the money pays for programs at county hospitals, including translation services and helping determine whether people are eligible for Medi-Cal.

### San Mateo County

- The county faces \$10 million in cuts starting June 1, which would precipitate about 100 layoffs. Cuts could include:
- Cutting by 25 percent outpatient clinic services for health care, mental health services and public health. Some clinics could be closed or their hours severely limited.
- Cutting in half the number of available spaces for lock-in mental health patients, from 100 beds to 50.
- Eliminating all public health nursing services, such as home visits for people with AIDS, not covered by grant funds.
- Diverting emergency patients from the county hospital to private hospitals.
- Eliminating adult and senior protective services such as care for abused elderly people or people



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San Jose (17)  
Mercury News  
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# medical bills

## ADMINISTRATIVE COSTS

These figures represent the maximum reimbursements counties could seek in Medi-Cal administrative costs for this fiscal year and the total amount for four fiscal years. The amounts listed here do not represent the counties' actual budgeted expenditures.

| County        | 1995-'96      | Total        |
|---------------|---------------|--------------|
| Alameda       | 17.0 million  | 49.6 million |
| Contra Costa  | 8.0 million   | 32.0 million |
| Monterey      | 3.2 million   | 10.3 million |
| San Benito    | 300,000       | 600,000      |
| San Francisco | 0             | 27.4 million |
| San Mateo     | 5.9 million   | 18.1 million |
| Santa Clara   | 13.2 million  | 48.7 million |
| Santa Cruz    | 4.2 million   | 14.7 million |
| Statewide     | 829.6 million | 2.7 billion  |

Source: Legislative Analyst's Office

MERCURY NEWS

The agency dispatched a team of auditors to Los Angeles County — which turned in the biggest portion of the bill by far — and afterward announced it was withholding payment on the state's entire bill because the charges appeared improper.

The auditors found Los Angeles was charging Medi-Cal for such things as the time probation workers spent with prison inmates, the lectures deputy sheriffs gave schoolchildren on the evils of drugs, and arranging for baby sitting for indigent patients.

In response to the extensive audit findings, state Health and Welfare Director S. Kimberly Belshe said HCFA had no right to tell the state how to run its program and that the San Francisco office had given "implicit approval" to the idea.

If the money is not paid, Belshe warned, it "puts county health programs at risk of closure."

It also throws an already unbalanced state budget even further out of whack. Despite HCFA's apparent rejection of the state's claims last year, Wilson's budget writers went ahead and included in the 1995-'96 budget released in January a figure of \$200 million a year they expected to receive from the counties as part of the federal Medi-Cal payments.

Pena said the counties believe they do not have to pay this money to the state unless they get the money from HCFA first, "and so far, no one from the state has disagreed with that interpretation."

That means state budget writers will have to trim the money from the budget or find another source to tap for the revenue.

Pena said the state and counties intend to appeal HCFA's decision to the courts and estimated it will be two or three years before the case is decided.

"However, they won't be paying us the money in the meantime," she said.

Mercury News Staff Writer Elizabeth Wasserman and Thomas Farragher of the Mercury News Washington Bu



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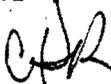
THE WHITE HOUSE

WASHINGTON

April 4, 1995

MEMORANDUM FOR THE PRESIDENT

FROM:

Carol Rasco 

RE:

GAO Report on Medicaid Waivers

At a hearing today before Rep. Kasich and the House Budget Committee, GAO released a report on the effect of cost pressures on state Medicaid programs. The report's major finding is that some of the Medicaid waivers we have granted are not budget neutral. The report examines waivers granted to four states (Hawaii, Oregon, Florida, and Tennessee) and concludes that federal spending has the potential to be higher in each of them -- except for Tennessee -- than it would have been without the waivers. (We have granted Medicaid waivers to a total of seven states.)

GAO's other findings are that (1) it "appears inappropriate" to bypass Congress on the coverage expansions in the waivers; and (2) the Administration has chosen to apply the savings from managed care in these states to coverage expansions rather than to deficit reduction. This last point is true -- each of these four states requested that we allow them to enroll Medicaid beneficiaries in managed care and use the savings to extend coverage to others.

HHS and OMB have responded to GAO by noting:

- o GAO's methodology is flawed, and the waivers HHS has granted are in fact budget neutral. Although GAO acknowledges that projecting Medicaid costs on a state-by-state basis is very difficult, it proceeds to apply a uniform and rigid methodology in each state.
- o We do acknowledge that other accounting approaches might come to a different conclusion. However, even if one accepts the GAO accounting methodology -- which we do not -- the federal government actually realizes a small savings for the four states examined, because of the magnitude of the savings in Tennessee.

- o We also acknowledge, with no apologies, that we have been more active on waivers than previous administrations, and have provided more flexibility to states in a number of areas, including how to calculate budget neutrality.

The Wall St. Journal spoke to Rep. Kasich and to HCFA Administrator Bruce Vladeck last night about this issue. I understand that Kasich made the point that we chose to use managed care savings in these states to expand coverage rather than reduce the deficit. Robert Pear of the New York Times attended the hearing.

OMB has prepared talking points for the press office on this issue, and HHS prepared background information for the Democrats. We have also contacted the National Governors' Association to encourage them to support our waiver policies.

We have a strong defense here that we have approved waivers that deliver care more efficiently, cover more people, and don't increase the deficit, and that in each case we have done so in response to a request from a Governor. Nevertheless, the report will play into the hands of those who want to block grant Medicaid and will provide ammunition to Kasich on the deficit. In fact, at the hearing it was used for that purpose: Republicans pushed Comptroller General Bowsler to comment on the block grant approach. In response, he stated that they are probably the best way to contain Federal Medicaid expenditures.

cc: Laura Tyson

THE WHITE HOUSE

WASHINGTON

April 5, 1995

MEMORANDUM FOR LEON PANETTA

FROM: CAROL RASCO *CR*

SUBJECT: Background Medicaid Information for Democratic Governors Meeting *file*

Attached for your use, you will find three background documents that we have prepared for your meeting with the Democratic Governors. They are:

- 1) a 1-page summary of the dollar impact a Medicaid block grant capped at 5% would have on the four Democratic Governors' states;
- 2) a 2-page analysis of how the states would have to respond to \$190 billion reduction in federal funding to the Medicaid program; and
- 3) a brief summary of the waiver status of these states as well as any other notable Medicaid issues that could come up from the four Governors.

I hope you find this information to be helpful. If you have any questions about the enclosed, please do not hesitate to contact me.

cc: Susan Brophy  
Marcia Hale  
John Emerson

# DRAFT

## Medicaid Block Grant

A Medicaid block grant that has a fixed growth rate of 5% would reduce federal expenditures under the CBO baseline by \$192 billion between 1996 and 2002. By the year 2002, federal spending on Medicaid would be reduced by over 30%.

The Kaiser Commission on the Future of Medicaid recently examined the state-by-state impact of a 5% block grant. They found:

- Effects vary greatly, with the largest impact in the south and in mountain states;
- Lower income states would be more adversely affected since a greater portion of their Medicaid expenditures are paid for by the federal government under FMAP.

### Colorado

Colorado predicts that its Medicaid expenditures will grow at approximately 11% annually between 1994 and 1996. It is a high DSH state.

Colorado would lose \$1.6 billion in federal Medicaid expenditures under a block grant, according to the Kaiser report. This is a 20% reduction over the period.

### Delaware

Delaware has applied for an 1115 waiver to enroll non-elderly recipients in managed care and expand coverage to 100% of poverty. It predicts that its expenditure growth rate without the waiver will be about 10.5%, and with the waiver will be about 9.5% (M-CPI plus 4%). Both these rates are significantly higher than 5%.

Delaware would lose \$327 million in federal Medicaid expenditures under a block grant, according to the Kaiser report. This is a 19% reduction over the period.

### Missouri

Missouri has applied for an 1115 waiver to enroll its non-elderly recipients in managed care and expand coverage to uninsured children up to 200% of poverty. It predicts that its expenditure growth rate without the waiver will be about 9.5%, and with the waiver will be about 9%. Both these rates are significantly higher than 5%.

Missouri would lose \$1.3 billion in federal Medicaid expenditures under a block grant, according to the Kaiser report. This is a 9% reduction over the period.

### Vermont

Vermont has applied for an 1115 waiver to enroll its AFDC recipients in managed care, extend a pharmacy benefit to low-income elderly, and expand coverage to 150% of poverty. It predicts that its expenditure growth rate without the waiver will be over 9%, and with the waiver will be over 7.5%. Both these rates are significantly higher than 5%.

Vermont would lose \$328 million in federal Medicaid expenditures under a block grant, according to the Kaiser report. This is a 16% reduction over the period.

# DRAFT

## EFFECTS OF CAPPING MEDICAID

### SUMMARY

- Medicaid is a safety net for over 35 million mothers and children, the elderly, and people with disabilities.
- Republicans have proposed (through the use of a block grant with a 5% cap on growth) to cut federal Medicaid funding by more than \$190 billion between now and 2002 -- a 30% cut in 2002 alone.
- Though the Republicans claim that all they are doing is providing added flexibility to states, what they are really doing is cutting \$190 billion in critical health care services.
- Even under optimistic assumptions, managed care could produce only about \$10 billion in savings between now and 2002. The remaining \$180 billion in cuts proposed by the Republicans would have to come from deep cuts in coverage, services, and payments to health care providers.

If the \$180 billion in cuts were divided equally among these categories:

- ▶ Total payments to hospitals, physicians and other providers would be cut by \$60 billion between now and 2002. The cut in 2002 alone would be about \$17 billion.
- ▶ Eliminating outpatient prescription drugs would roughly offset one-third of the cuts in 2002. And, in 2002, eliminating coverage for roughly 2.5 million mothers and children and over three-quarters of a million elderly and disabled together would offset the remainder of the cuts.
- Even these dramatic figures probably understate the true level of cuts under the Republican proposals, since states, like the federal government, are looking to spend less on Medicaid, not more. Under Republican block grant proposals, states could save money only if they cut more than \$190 billion out of Medicaid.

### VARIATION ACROSS STATES

- An across the board 5% cap on Medicaid spending does not recognize significant differences across states, leaving some states even harder hit than these numbers suggest.
  - ▶ Growth rates can vary significantly across states (e.g., for differences in population, regional medical costs, enrollment patterns, or service mix) and over time in a given state. For example, states such as Florida with large numbers of elderly residents would bear a disproportionate burden as the population ages.
  - ▶ When a recession occurs in a state, the number of people without work that qualify for Medicaid can rise dramatically, increasing program costs. With a cap on Medicaid, states would bear this burden.
- A new analysis of Medicaid block grants conducted by the Urban Institute for the Kaiser Commission of the Future of Medicaid finds that a 5% cap on the growth of federal Medicaid payments would cost states over \$167 billion between 1996 and 2002. [Note: This estimate is less than the CBO baseline estimate].
  - ▶ New York, California, Texas, Florida and Ohio would lose the largest amounts.

New York would lose \$18.5 billion, California over \$14 billion, Texas almost \$11 billion, Florida \$9.5 billion, and Ohio over \$7 billion.

- ▶ States in the South and Mountain regions would have the biggest percentage reductions in federal payments. Reductions during the period would average over 21% in states such as Florida, Georgia, Arkansas, Montana, West Virginia and North Carolina.

## NO EVIDENCE THAT THIS LEVEL OF GROWTH IS ACHIEVABLE WITHOUT SEVERE CUTS

- Republicans claim that managed care can generate enormous savings. But, there is no evidence that managed care alone can achieve the level of cuts they are proposing.
  - ▶ States already are aggressively pursuing managed care, but the populations for whom care can readily be managed -- children and AFDC adults -- account for less than one-third of total Medicaid spending. And, over one-third of these recipients already are in managed care.
  - ▶ Applying managed care techniques to the services typically used by the elderly and disabled (such as long-term care) is largely untried, making the potential for savings hard to predict.
  - ▶ The potential for managed care savings also varies tremendously across states. States that have already applied managed care broadly will be less able to achieve additional savings. In rural states, where HMO coverage is not readily available even in the private sector, efficient managed care also is not a real option.
- Some may point to low Medicaid growth rates in certain states as evidence that a 5% cap on growth is achievable.
  - ▶ While a few states may be able to hold growth down to 5% for a few years, no state has demonstrated the ability to sustain such a low growth rate for any significant period of time.
  - ▶ Since 1992, 19 states have applied for state-wide health reform demonstration waivers from the Department of Health and Human Services. Under these waivers, states are able to change their Medicaid programs to increase efficiency and expand coverage. No state has projected a annual growth rate over the period at or below 5%.
- Republicans justify these cuts by claiming that Medicaid spending is out of control, but the facts show otherwise. The truth is that both the Congressional Budget Office and the Administration project that Medicaid spending per person will grow no faster than health insurance spending in the private sector.

April 5, 1995

Delaware Medicaid Waiver

It is possible that Gov. Carper of Delaware will raise the issue of his pending Medicaid waiver. The Governor is frustrated that this waiver has not yet been approved. He called Secretary Shalala to complain last Friday, and she attempted to reassure him about the Administration's commitment to work with him.

The waiver is now stuck on the issue of budget neutrality. HHS and OMB initially expected that this issue would not be a problem, because all sides agreed to use the Administration's national Medicaid growth projections to construct baseline costs for the waiver. However, the national projections have come down significantly since the waiver was submitted eight months ago. In March OMB proposed using the latest figures, and Delaware balked -- not surprising given how long the waiver has been pending. On the other hand, budget neutrality calculations are under extra scrutiny at this point, given the recent GAO report and yesterday's House Budget Committee hearing.

We can tell the Governor at this point that we are committed to working with him to resolve this expeditiously.



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

## MEMORANDUM

TO : Judith Heumann  
Assistant Secretary, OSERS

FROM : Thomas Hehir *TH*  
Director, OSEP

SUBJECT: Medicaid *file*

DATE: OCT 5 1995

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

Page 2 - Judith Heumann

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

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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.

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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 Holleran, 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 Holleran



*Vicare Tortosa*      *COB*      *HH5*      *Wed*  
 UNITED STATES DEPARTMENT OF EDUCATION  
 OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

APRIL 11, 1994

**TO:**

*Richard W. Riley*  
Secretary

*Janice S. Jackson*  
Acting Assistant Secretary, OESE

*Marshall E. Smith*  
Undersecretary

*Kay L. Casstevens*  
Assistant Secretary, OLCA

*Frank S. Holleman*  
Chief of Staff

*Howard Moses*  
Deputy Assistant Secretary, OSERS

*Terry Peterson*  
Counselor to the Secretary

*Thomas F. Hehir*  
Director, OSEP

*Judith Heumann*  
Assistant Secretary, OSERS

**FROM:**

*Connie Garner* *CG*  
ED Health Policy Liaison  
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 I 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.

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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.

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**COSTS TO THE EDUCATION COMMUNITY**

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**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).

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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 stated categories representing the majority of children (1.3 million), receiving related services:

**Aged 6-21:**

|                          |         |                              |
|--------------------------|---------|------------------------------|
| <input type="checkbox"/> | 2.4 M   | Learning Disabled            |
| <input type="checkbox"/> | 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            |
| ★                        | 1,372   | 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 I 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 I of the IASA.

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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 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;

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

# Veterans, AIDS Patients May Lose Benefits

*Shalala, Brown Say Hill Changes in Medicaid Could Be Devastating*

By Spencer Rich  
Washington Post Staff Writer

Hundreds of thousands of veterans and people with AIDS could lose existing health benefits as a result of Medicaid changes approved by congressional Republicans, two cabinet members and the AIDS Action Council said yesterday.

Department of Veterans Affairs Secretary Jesse Brown and Health and Human Services Secretary Donna E. Shalala said an analysis by the two departments found that "more than 600,000 veterans are enrolled in Medicaid," the federal-state health program for the poor, but only 100,000 receive any care from the VA.

"Under the House proposal to block-grant the Medicaid program and reduce projected spending by \$182 billion over the next seven years, Brown and Shalala said, "as many as 172,000 veterans could lose their Medicaid coverage by 2002," many of them severely disabled and ineligible for Medicare.

The reason is that not only does the House reconciliation bill allow less money for benefits than under existing law, but it also would repeal any individual guarantees to Medicaid and allow state governments wide discretion to determine eligibility, administration officials said.

The problems of these veterans are "some of the most costly, including AIDS and psychiatric care," Brown and Shalala said. Brown said the VA is threatened already with "devastating congressional budget cuts" and "will not be able to care for veterans pushed out of other health care programs." They added that because of proposed changes in Medicare, it is possible that 400,000 veterans on Medicare "may find it financially necessary to try to use VA health care."

Richard Fuller, an official of Paralyzed Veterans of America, said the scenario raised by the two secretaries is "serious."

Meanwhile, Mark Barnes, AIDS Action Council executive director, said House Medicaid changes could "devastate health care for the AIDS community" by reducing funds and allowing states to decide who will be covered. He said a large proportion of people with AIDS have no other health care or if they do, it is does not cover some of their most vital needs, such as anti-AIDS drugs. An

California, Florida, New York and Washington. Moreover, the spokesman said, the House bill requires each state to set aside a fixed portion of its total Medicaid spending for the disabled.

Barnes said that with proper medication, a person with AIDS can live as long as five to 10 years in reasonable health, but without Medicaid, many can't afford the drugs they need.

## THE BUDGET BATTLE WINNERS AND LOSERS

HHS official said yesterday that of nearly 200,000 people known to have AIDS, almost half are on Medicaid, including 90 percent of the child patients. Barnes said he believes these figures understate the number of AIDS patients on Medicaid.

Rep. Tim Hutchinson (R-Ark.), chairman of the health and hospitals subcommittee of the House Veterans Affairs Committee, disputed the Brown-Shalala charges.

"They're crying wolf one day after the other," he said. "They're assuming Medicaid and Medicare are somehow not going to handle veterans, but we are providing more money for Medicare, Medicaid and veterans' benefits than we are now spending. . . . I don't think there's going to be any forcing of veterans onto the VA for health care, but if there were they'll be able to handle it because there's going to be a 25 percent reduction in the number of veterans in the next seven years."

A spokesman for the House Commerce Committee, which wrote the Medicaid provisions, said the potential difficulties facing veterans and AIDS patients are based on Medicaid grants to the states in the committee bill, but that ignores the addition of \$12 billion nationwide for the program by the House. He said half of that would go to states identified by Brown as having the most veterans:

David Tuzo, a 33-year-old New York transportation worker said in an interview that after he contracted AIDS, "I became ill and weak" and had to stop work. He qualified for Social Security disability benefits and Medicare although he had not reached retirement age.

"But," he said, "I needed drugs which were not covered by Medicare," which offers no outpatient prescription drug benefit. And "with Social Security income of \$704 a month, I couldn't afford \$400 a month for the drugs" and sought help from Medicaid.

Under the Medicaid "block grant" provisions passed by the House, no individual would be guaranteed Medicaid benefits, and each state would make its own rules on eligibility.

The Senate reconciliation bill also offers no guarantees of coverage, with the exception of an amendment by Sen. John H. Chafee (R-R.I.) that would require states to cover all low-income pregnant women and children under 13 and people qualifying for welfare under the federal supplemental security income program for the aged, blind and disabled.

But as Chafee stated on the Senate floor, the states would decide what the benefits would be for each category. "The states could say, 'for this group there will be one aspirin a year' . . . but at least you have to cover everybody in the group."

**TALKING POINTS FOR CAROL RASCO**  
**KAISER COMMISSION ON THE FUTURE OF MEDICAID**  
**NOVEMBER 13, 1995**

- I'm glad to be here tonight to talk with you about the Republican Medicaid proposals and the Administration's views on these proposals.
- I can't think of a time when the *name* of your Commission was more appropriate; at no time has the future of Medicaid been more uncertain. And, more importantly, at no time has the *work* of this Commission been more important. Your commitment to these issues is unsurpassed, and your expertise and advice are crucial in this debate.
- The President has made it clear that he will veto the Republican budget reconciliation bill if it is sent to him (as it certainly will be) in its current form. He thinks that their budget will have terrible effects on Medicare and Medicaid and, more generally, on the health care system in this country. You simply can't take \$440 billion out of these programs without affecting the entire system. You simply can't end Medicaid and turn it over to the states without changing the way health care is delivered in this country -- not only for the 36 million Americans on Medicaid, but also for everyone.
- The President also thinks that this debate goes far beyond dollars and programs. It is really a discussion about the values we have shared in this country. Values like honoring our parents and providing for our children. Values like giving every American the opportunity to make the most of his or her own life. We believe that the Republican budget does not match up to those values.
- The hard work will begin after a veto. We will hold firm to our principles and our priorities. We will insist that Medicaid coverage be preserved. And we will insist that this coverage not be only an empty promise.
- But as the saying goes, the devil is in the details. At each turn, there are difficult policy choices that have real impact on states, doctors and other health care providers, and most importantly on the people who need Medicaid. Bruce and a great team at the Department of Health and Human Services are ready. But we also hope we can look to you for analysis and expertise about policy options and their implications.

THE WHITE HOUSE

WASHINGTON

December 8, 1995

Randall L. Rutta  
Vice President, Government Relations  
National Easter Seals Society  
Office of Public Affairs  
1350 New York Avenue, N.W., Suite 915  
Washington, D.C. 20005

Dear Mr. Rutta:

Thank you for your recent letter concerning the Medicaid program, as well as *The Columbus Dispatch* articles. I found them both informative and very interesting, and I appreciate your bringing them to my attention.

I have enclosed copies of the President's remarks on vetoing the Republican budget, and I hope that they will answer some of the questions you may have concerning the President's stance on this issue.

If I can be of any further assistance, please do not hesitate to contact my office at (202) 456-2216. Once again, thank you for your input on this critical program.

Sincerely,



Carol H. Rasco  
Assistant to the President  
for Domestic Policy

Give Ability A Chance

**National Easter Seal Society**  
Office of Public Affairs

1350 New York Avenue N.W., Suite 915  
Washington, D.C. 20005  
202 347.3066  
202 347.7385 (TDD)  
202 737.7914 (fax)

NOV 16 1995

November 15, 1995



Carol H. Rasco  
Assistant to the President for Domestic Policy  
The White House  
1600 Pennsylvania Avenue, Northwest  
Washington, DC 20500

Dear Ms. Rasco:

The National Easter Seal Society recognizes that the budget reconciliation legislation currently under consideration in Congress would dramatically affect Medicaid, Medicare and other essential programs serving people with disabilities and their families. The national society believes that any changes to these core programs be carefully considered and that no reforms be adopted that diminish access to needed services and service providers for people with disabilities.

To support your understanding of the important role of Medicaid in the lives of children with disabilities and their families, I am attaching a series of articles published recently by *The Columbus Dispatch* (Columbus, Ohio) that describe the challenges and joys of raising a disabled child at home and among family. Two of the three families featured in these stories have received Easter Seal services, including home health and personal care, physical therapy, and speech services.

The national society finds that the *Columbus Dispatch* series accurately highlights the experiences of families with children with significant disabilities who have received support from the current Medicaid program:

The Carter Family includes parents Greg and Meri-Ellyn, two sons, and Lauren, age 7 who has cerebral palsy, mental retardation, and blindness. Greg has a full-time job and Meri-Ellyn stays home with the children. Until recently, the family received \$45,000 from Medicaid in the form of home nursing care and physical therapies, which allowed Lauren to live at home. Despite the fact that Lauren cannot be left alone, her needs were determined to be non-emergency in nature and her Medicaid benefits were terminated. Lauren now lives apart from her family in an institution that costs \$55,000 annually.

The Sapp Family includes parents Dale and Martha Rose, two daughters and Dale Jr. Dale Sr. has a full time job and Martha Rose takes care of the children. Dale Jr. is seven years old and has multiple disabilities,

including mental retardation, and uses a wheelchair. To keep Dale Jr. at home, Medicaid provides the Sapp's services worth \$105,000, including speech and physical therapy, prescription drugs, hospital services and other needed medical care. Without this support, the Sapp's would be forced to place Dale in an institution, with an annual cost of \$240,000.

The Biel Family includes parents Louis and Mary and two children. Both parents have full time jobs and private health insurance. Daughter Kathleen is ten years old, has cerebral palsy, mental retardation and uses a wheelchair. Medicaid provides the Biel's with \$87,000 worth of physical and occupational therapies, hospital and other medical care. Without this support, the Biel's would be forced to place Kathleen in an institution, which would cost \$240,000 annually.

The Carters, Sapps, and Beils are among the millions of families across America that rely on Medicaid support to meet the extraordinary health and developmental needs of their children with significant disabilities. Thanks to Medicaid, these children lead more independent and successful lives at home, with family. Most often, assistance at an early age enhances the ability of these children to develop physical, emotional, and social skills, advances their capacity to learn, and enables them to participate more fully in family and community life. Similarly, adults with disabilities rely on Medicaid to achieve health, employment, and personal goals that directly relate to their ability to lead independent and productive lives.

For the 4.9 million children and adults with disabilities who depend on Medicaid and associated programs, such as early intervention and assistive technology, there are few, if any, alternative sources of support. Medicaid is the linchpin that fosters individual development, learning and independence, and enables families to stay together, most often as primary caregivers for persons with disabilities.

To date, Medicaid has operated as federal-state partnership. Some of the country's most innovative, cost-efficient approaches to home and community-based service delivery and EPSDT early detection and intervention have originated under Medicaid. Although many legitimate needs have not been met by Medicaid and related programs, the current array of services and supports are crucial to the health and quality of life for millions individuals and families, and represent a wise, cost-effective commitment of public funds.

The *Columbus Dispatch* stories clearly show the direct relationship between investing in services to support families and the alternative, which is most often higher-cost institutional care. According to the newspaper, many of these families have full time jobs. Most choose to keep their children at home, despite the fact that their lives would be less stressful if their child was placed outside of the home. Nevertheless, these families believe that children belong at home with their families. They also know that their family status is dictated by whether or not they continue to receive Medicaid support.

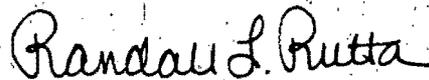
The National Easter Seal Society is pleased to share the *Columbus Dispatch* series with you. Please read these articles. Please consider the fundamental role of Medicaid in the lives of these families and millions of families like them as you vote to reform this vital program.

Easter Seals strongly believes that people with disabilities must be assured full access to the wide range of Medicaid services and providers currently available as mandated and optional services, under EPSDT and waiver programs. Please ensure that any legislation enacted includes: federal guarantees and protections for people with disabilities under state-directed Medicaid programs; recognizes the need to continue Medicaid participation in related areas of programming, such as early intervention; and provides for the allocation of adequate resources to appropriately service persons with disabilities and their families.

Easter Seals is dedicated to helping people with disabilities live with equality, dignity and independence. Each year, Easter Seal societies nationwide serve more than one million people. As a national nonprofit service agency, Easter Seals annually commits millions of dollars that are contributed by private citizens and companies to improving the lives of children and adults with disabilities. Contributed funds fill-in service gaps and extend necessary care that Medicaid, Medicare and other public programs fail to cover and that families cannot afford. Contributed funds are stretched frighteningly thin in the attempt to meet the urgent needs of people with disabilities who seek Easter Seal assistance. In fact, many Easter Seal societies report that they are reluctantly placing growing numbers of individuals on waiting lists. Despite Easter Seals' best efforts, any sizeable reduction of public financial support for or dramatic down-sizing of federal participation in Medicaid, Medicare and related programs will mean that many essential service needs of children and adults with disabilities will go unmet.

On behalf of the National Easter Seal Society, thank you for your consideration of our views on the importance of a strong, federally-supervised Medicaid and Medicare program and the attached *Columbus Dispatch* articles. Please do not hesitate to contact me with questions or comments concerning these issues.

Sincerely,



Randall L. Rutta  
Vice President,  
Government Relations

Enclosure

# The Columbus Dispatch

SEPTEMBER 17, 1995

## A father's vow

### THE CARTER FAMILY

Home: West Chester, Ohio

Father: Greg, 34, department manager for Best Buy in Dayton

Mother: Meri-Elyn, 27, homemaker

Children: Lauren, 7 (Greg's child from a previous marriage); Dustin, 7 (Meri-Elyn's child from a previous marriage); Christopher, 1 (Greg and Meri-Elyn's child)

Annual income: \$32,000

Lauren's primary diagnosis: Cerebral palsy and severe mental retardation

Difficulties: She is blind, partially paralyzed on her right side from a stroke and eats through a tube inserted in her stomach. She cannot talk or use sign language.

Annual cost of waiver: \$45,000 for the Individual Options Waiver

Annual cost of care if not at home: \$55,000 in a facility that treats children who are medically stable



Chris Russell / Dispatch

With support from her father, 7-year-old Lauren Carter bonds with her half brother, Christopher, 1. Greg Carter and his fiancée, Meri-Elyn Eubank, enjoy the children's connection.

*For eight months, The Dispatch followed the extraordinary lives of Lauren, Dale Jr. and Kathleen, three severely disabled children whose parents care for them at home.*

*Home health care carries a steep price — both financial and emotional — but these families believe it outweighs all other options. Their commitment forces them to negotiate — and battle — a Medicaid system that controls their ability to provide that care.*

*In a four-day series beginning today, three reporters and three photographers chronicle the fragile lives of these families — the turbulence, the joy, the successes and the failures.*

# Threat of losing disabled daughter has dad fighting for her home care

By Michael J. Berens  
Dispatch Staff Reporter

**W**ITH NIGHT CAME the promise. Exhausted and home late from work, as usual, Greg Carter nudged open his daughter's bedroom door to watch her sleep. She was curled tightly on a mattress encircled by padded, wooden walls — more box than bed.

Carter had spent hours with hammer and pine crafting the only safe world he could for Lauren, whose 7-year-old body moves strangely and independently of a younger mind.

He watched her now, ignoring the walls, imagining her as a tiny Sleeping Beauty.

*I will never leave you.*

Though Lauren could not understand the words, surely she could feel his thoughts. He prayed that she would never see his fear.

The threat of losing Lauren had arrived like a bombshell with the morning mail that November day.

A letter from the Ohio Department of Human Services informed Carter that the family's Medicaid benefits were being canceled. The money to pay nurses to watch Lauren while he works would no longer be supplied, nor would money for Lauren's special education and therapy.

The state's reason: Lauren is not sick enough.

Lauren has the type of cerebral palsy that contorts muscles and causes mental retardation. She is blind, partially paralyzed from a stroke, unable to speak except for birdlike screeches and fed through a tube in her stomach.

Lauren is a danger to herself and cannot be left alone, but she does not require emergency care daily. Because of this, the letter stated, she no longer qualifies for help.

Carter went to bed that night certain that Ohio was trying to destroy his family with a perverse Medicaid lottery in which parents pray that their children remain critically ill — or risk losing benefits.

The loss of benefits extends beyond dollars, though. If Carter could no longer afford to care for Lauren at home in West Chester, Ohio, the only alternatives seemed to be foster care or institutionalization.

Carter wanted the state to help him care for Lauren in his home. There should be no other alternative, he felt.

By morning, Carter's shaky hands were pounding a typewriter. Though he did not understand the Medicaid system — or who ran it — he fingered the date, "Nov. 7, 1994," and began, "To whom it may concern."

As a 34-year-old single father and businessman, Carter knows the wisdom of attacking a problem quickly and succinctly. His written request for an appeal hearing consisted of four paragraphs of his best vocabulary.

Medicaid benefits are "vital" to allowing Lauren to live at home, he wrote. "I do not understand the assessment that Lauren is not disabled. Despite the fact that she is cute and vivacious, she is completely and totally disabled — by any

As Carter signed the letter, his pulse was pounding like drums in his head.

The battle had begun.

## A MATTER OF WAIVERS

To the parents of dying children, Sandy Sterrett is both sainted and hated.

A self-described bureaucrat for the Department of Human Services, Sterrett — along with other department officials — decides which sick kids get special Medicaid benefits and which do not.

She is the "whom it may concern" Carter was seeking.

Agreeing with staff reports that Lauren is not sick enough, Sterrett approved the decision to take away the benefits.

Traditionally, Medicaid is reserved for the poor on welfare. Under federal guidelines, a family of four cannot earn more than \$15,150 annually. Even a \$5 birthday gift leads to a maze of paperwork.

Such requirements, though, were prompting parents of sick children to quit their jobs to go on welfare. Poverty with a Medicaid card was better than losing a child to foster care or an institution.

A solution was offered in 1981 when the federal government created Medicaid waivers. The net result: Income caps were waived, and parents could remain working taxpayers while their children received Medicaid. A key benefit enables nurses to care for sick children in their homes while parents work.

Waivers have been wildly embraced. Parents overwhelm the state with applications.

Waivers do, however, come with federal strings attached: States are given a limited number, and they must pay 40 percent of the costs.

Two types of waivers are provided through Human Services. A third, the Individual Options Waiver, is overseen by the Ohio Department of Mental Retardation and Developmental Disabilities.

Carter's daughter was placed on a Human Services waiver in 1993, but department officials a year later decided that Lauren's stable medical condition meant she should be placed on the options waiver, state records show.

The options waiver is the most popular, with a waiting list of 7,828 people. Lauren might wait 10 years for benefits.

Sterrett is never happy about removing a family from a waiver, she said, but — as she explains to many overwrought parents — waivers are not a right.

Ohio does not have a duty or a moral obligation to provide home medical care for all children who qualify for waivers, Sterrett said. The goal is to provide cost-effective care, wherever that may be.

Decisions admittedly are subjective. Many parents still feel as if the state uses a mixture of voodoo and other primitive practices to interpret complex but vague federal guidelines.

Sterrett knows that many parents see her as coldhearted, ruthless and more interested in the bottom line than lives.

Secure within her spacious, corner office on the 32nd floor of the Rhodes Tower on W. Broad Street, she is removed from her staff, which works in a cramped labyrinth of state-issued cubicles.

On days when pressures cannot be capped, Sterrett thinks of her three children — normal, thank God — and feels a rip in her heart for the thousands of parents begging for help.

"Sometimes, I close the door to my office, and I cry," she said.

stark dards!

## A QUEST FOR ANSWERS

### *Inhuman Services.*

That's the label Greg Carter deemed appropriate for the state agency that left him numb in the days after he sent his letter.

During a half-dozen phone calls, he had asked: Why did Lauren qualify for a Medicaid waiver a year ago but not now? Why was Ohio cutting all financial help to his home yet was willing to spend more money for foster care or institutional care?

The questions went unanswered.

His calls to Human Services were daily, sometimes hourly, as the secretaries — long familiar with Carter's firm voice — adopted their own defense: "I'm sorry, nobody is available right now."

"I made it my life's work to become their personal nightmare," Carter recalled. "Somebody was going to listen to me."

His request for an appeal hearing with Human Services was granted for Dec. 15, but he said condescending remarks from department

underlings suggested that he was doomed to fail in seeking to have the waiver reinstated.

Carter was sure the state's decision was personal. The bureaucrats did not like him, his family or his lifestyle, he reasoned.

He is a divorced father with an impaired child living with a divorcee, Meri-Ellyn Eubank. He had seen the brows wrinkle on the nurses who had visited his home during the past year.

Eubank, 27, has a son from a previous marriage — Dustin, 7. Dustin is a ringer for *Home Alone* actor Macaulay Culkin and just as mischievous. Together, Carter and Eubank also have a son — Christopher, 1.

Carter plans to marry Eubank. She has become Lauren's mother in all ways except name.

Maybe he would marry her after beating this waiver problem. They had agreed to keep Lauren forever, but failure haunted him. He had lost his daughter before.

## TRUBLE SIGNS

Lauren seemed normal when she was born Sept. 12, 1987, in Louisville, Ky. The seizures started three weeks later. As brain damage became apparent, the cerebral palsy was diagnosed.

With normal children, parents follow a well-traveled biological route from toddler to teen-ager to adult. Lauren would forever be a child. Her every breath, measured in dollars, is as uncertain as the meaning of life.

In less than a year, Carter's marriage deteriorated. He fought for custody of Lauren, but she remained with her mother, Cindi Carter, in Louisville. Carter eventually moved to Cincinnati — close enough for weekend visits but out of reach of his ex-wife.

Five years later, a telephone call brought Lauren back to her father.

The midday frenzy had peaked in the electronics department of Circuit City, a national retail chain fighting for a toehold in the Cincinnati area. Carter, the department manager, answered the call on line No. 1.

"Would you be interested in custody of your daughter?" asked a worker from a Kentucky children services agency.

Lauren had become an emotional and financial burden for his ex-wife, the worker explained.

Carter, who can count on both hands the number of times he has cried, wept like a baby that day, shaking uncontrollably as customers and employees watched.

Lauren was coming home.

For many nights after, Carter would stand in Lauren's bedroom late at night and admire her shiny, black hair and china-doll face. She could look so normal.

"As a father, you come home after the kids are asleep and you go in and look at them. You can say, 'There's my kids. They're sleeping. They're protected. They're in my house. And life is good, and you go to bed.'"

But life wasn't so good anymore.

# Ailing and waiting

## State can't meet demand for help with home care

By Michael J. Berens and Nancy J. Smeltzer  
Dispatch Staff Reporters

**A**MOTHER'S INSTINCT delivered the diagnosis long before any doctors or machines.

As she held her newborn daughter seven years ago, Cindy Carpenter had a sense that their lives would never be normal.

Weeks later, Carpenter learned that Megan had a rare brain disease. Her medical bills have reached six figures.

Within three years, annual premiums from private insurance — obtained through her husband, who was self-employed — rose from \$11,000 to \$140,000.

Then Carpenter's marriage deteriorated, leaving the mother from Fairfield, Ohio, alone to raise Megan and two other children.

Like thousands of other Ohioans, she found herself financially drained — but resisting welfare — while desperately trying to care for Megan at home.

In 1991, Carpenter learned about Medicaid waivers — a magic pill, of sorts, for those who get one.

### A much-needed lift

Originally, Medicaid was designed to help the poor on welfare. Waivers, approved by the federal government in 1981, amended the design to give medical benefits based on need, not income.

The waivers were introduced as a solution to a growing problem: Parents of disabled children were quitting jobs to go on welfare so they could qualify for Medicaid.

Under the system, income caps traditionally imposed on Medicaid recipients are waived. With a waiver, parents of a disabled child can work while the child receives nursing or attendant care at home.

Likewise, waivers allow disabled adults to leave nursing or group homes — or any type of institutional care — to achieve a level of independent living.

The system has catches: Waivers are limited in number, and states must pay 40 percent of the costs to qualify for the federal share of 60 percent.

### What's available

In Ohio, waiver programs were not introduced until the late 1980s. Today, the state offers five programs.

One caters to senior citizens, and another is for patients with AIDS. The remaining three are available to people with mental or physical disabilities, or both. Generally, applicants must require daily medical care.

Two of these three waivers — the Medically Fragile and Disability waivers — are offered through the state Department of Human Services. Strict federal guidelines determine qualification.

The state's most popular program, the Individual Options Waiver, is overseen by the Department of Mental Retardation and Developmental Disabilities. Guidelines for this waiver, created in 1991, are more

general and cover a wider spectrum of disabilities.

As more and more people learned about the program, demand for the options waiver began to outstrip state funding and, by 1992, a waiting list was created.

As of June, the list contains 7,828 names and grows steadily. Many children and adults suffering life-threatening diseases will wait more than a decade before their application for benefits is considered.

The options waiver is the only Ohio waiver with a waiting list.

Nationwide, 200 waiver programs serve more than 250,000 people, according to a study in the *Journal of the American Medical Association*.

For Cindy Carpenter, the timing was good. She qualified for the waiver in 1992, before the waiting list had grown too large.

Without the help, Carpenter, 37, said her only alternatives are a life on welfare or foster or institutional care for Megan.

### A system revamp

Shortcomings abound in the waiver system.

*The Dispatch* has found:

- The mental retardation department has not studied its waiting list and does not know how many critically ill people have applied for benefits. Nor does it know how many on the list are children.

- Neither the department nor any other state agency knows how many "medically fragile children" live in the state, despite being charged with administering programs for the disabled. Such children, by state definition, are considered to have life-threatening disabilities.

- No state agency serves as a clearinghouse for waiver information. Services are carved among the state departments of Mental Retardation, Human Services, Aging and Health.

Some of these problems are being tackled, said John Pekar, deputy director of residential services for the mental retardation department.

Pressed by the burgeoning waiting list and public complaints, Pekar said, the department has launched an overhaul of the Individual Options Waiver.

Until recently, the Individual Options Waiver was managed by the state. Under changes implemented in June, Ohio's 88 counties now oversee the waiver's day-to-day administration.

The state's maximum of 2,512 options waivers is being divided among counties based on population, Pekar said, and each county is maintaining a waiting list.

Families with disabled children told *The Dispatch* that they believe the state is trying to disperse a political problem, but Pekar said county control

will allow people to be served more efficiently.

*The Dispatch* polled a dozen mental retardation department administrators from the state's largest counties and found support for the state's move, and that most are "cautiously optimistic" about success.

To help curb costs, the counties are renegotiating hourly rates for "homemakers" — people who help the disabled with daily chores. Homemakers earn an average of \$14 an hour.

Homemakers typically assist with meals and bathing, or serve as nighttime guardians while the disabled person is asleep.

Hourly rates will be adjusted in a case-by-case review, Pekar said, noting that watching a sleeping person might not qualify for the maximum hourly rate.

Even with such savings, though, the number of people served by the waiver will not increase. To obtain more waivers, the state must petition the

federal government, then pay 40 percent of the costs.

Pekar said the state is reluctant to commit more money to waivers for fear that the federal government will withdraw financial support — a possibility that has been foreshadowed in recent legislative hearings.

The state must weigh the current financial burden of waivers against a future ability to pay, Pekar said, especially if the federal government reduces Medicaid funding.

"At least we are serving a segment of the population now," he said.

## The numbers

Under federal guidelines, the average per-person cost of a waiver may not exceed the average cost of institutional care.

The restriction has not been a problem for Ohio.

The Individual Options Waiver costs \$80 million a year in state and federal money combined. Put another way, the 2,512 recipients receive an average of \$31,847 annually.

By comparison, per-patient institutional care in Ohio costs about \$55,000.

Despite the disparity in numbers, the state doesn't give a waiver to every person who qualifies because it fears that doing so would force the average waiver cost to skyrocket.

About a dozen waiver holders receive \$105,000 in benefits a year, the maximum allowed.

To offset such high-cost waivers, officials say, the program must be balanced with low-cost waivers, allowing the state to remain eligible for the waivers and federal matching money.

Jeff Davis, deputy director of legislation and public information for the mental retardation department, said the state will continue to seek more waivers but not immediately.

State officials are well-aware that such news is little comfort to those who continue to fight — and wait — for their dream of home health care.

## Medicaid, other options

*The working parents of a disabled child have three basic alternatives in seeking financial help from the government to cover the costs of the child's medical care:*

### ■ Foster care or institutional care

A child can be placed in foster care, but parents often lose legal custody of their children. Or, a disabled child can be placed in a care facility, and the parents keep legal custody of their children.

### ■ Welfare

Parents can quit their jobs and go on welfare, automatically qualifying for a Medicaid card.

### ■ Medicaid waiver

A waiver, which removes income caps imposed on Medicaid recipients, enables parents to obtain home nursing care for their disabled child. Three of Ohio's five waiver programs are available to children, each with a limited number of openings. The programs that are open to children, funded by a 60-40 match of federal and state money, are split between the Ohio Department of Human Services and the Ohio Department of Mental Retardation and Developmental Disabilities.

*No state agency serves as a clearinghouse for waiver information. Parents should decide which waiver best characterizes their child's disabilities, then apply at the appropriate county agency.*

### County Department of Human Services

#### ■ Medically Fragile Waiver

For people who need daily nursing care because of a chronic and unstable medical condition, such as cerebral palsy, muscular dystrophy or spinal cord injury.

Serves: 346  
Number of children: 271  
Annual cost: \$9.8 million

#### ■ Disability Waiver

For people who require nursing-home services because of disability or disease. Patients must need nursing care to qualify, but they are not considered medically unstable.

Serves: 2,098  
Number of children: 180  
Annual cost: \$11.8 million

### County Department of Mental Retardation and Developmental Disabilities

#### ■ Individual Options Waiver

For people with mental retardation or developmental disabilities. Without home care, these patients would be in a facility for the mentally retarded.

Serves: 2,512  
Number of children: 593  
Annual cost: \$84 million

#### *The waiting list:*

The Individual Options Waiver is limited to 2,512 people. As of June, the waiting list for the waiver had 7,828 names. Officials estimate at least a 10-year wait for those at the bottom of the list.

Also in June, the state relinquished supervision of the list to county mental retardation agencies in an effort to reduce the waiting period and overhaul the system.

#### Waiver approved

A family qualifies for Medicaid benefits for one year. Approval is required annually.

#### Waiver denied

Applicants may appeal. If the appeal is denied, the basic alternatives of welfare, foster care or institutional care remain.

Sources: Ohio Department of Human Services, Ohio Department of Mental Retardation and Developmental Disabilities

*Dispatch graphic*

# One-on-one with bureaucracy

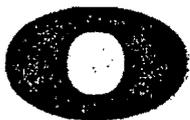
## Caring for ill son is her destiny, mother says

Story by Laurie Loscocco

Dispatch Staff Reporter

Photos by Lynn Ischay

Dispatch Staff Photographer



**O**N THANKSGIVING NIGHT 1988, Martha Rose Sapp walked out of her home into the back yard and stared at the sky. Tears streamed down her face.

For most of the holiday, she had been asking God why.

Why did her first-born child, a boy, appear destined for a life of illness? His brain, she knew, had not formed properly. He suffered seizures. His life would never be normal.

She asked herself what she did wrong for her baby to suffer such a fate. She asked herself why this had happened to her.

That night, Martha Rose shook herself out of the place she'd dwelt all day.

"What's wrong with you?" she thought. "You should be thankful. You should feel privileged. You were chosen to be this baby's mother. God must have thought you were pretty special."

Dale Sapp Jr. is now 7, and many of his mother's worst fears have been realized.

He cannot walk or talk or go to the bathroom by himself. He "eats" through a tube inserted into his stomach.

He has had more surgeries than birthdays. His torso is battle-scarred, with a diagonal slash intersecting a vertical one. Skin from his thigh now resides on his shoulder, from which a large growth was removed in November.

In the spring of 1994, he almost died when infection stampeded through his brain, spinal column, pancreas and appendix.

"There was bile coming out of his G-tube (the tube that carries liquid nourishment into Dale's stomach), his belly was swollen, and his Foley (catheter) bag was filled with fluid," Martha Rose remembered. "My head was just spinning, and this poor kid is screaming."

### First major surgery

Martha Rose and Dale Sapp Sr. moved from Cleveland to Columbus in 1987, when Dale took a job as an executive chef with Stouffer's Dublin Hotel.

The couple had lived on the Northwest Side about a year when Dale Jr. was born on June 16, 1988.

In December, Dale had the first major operation of his life. A shunt was placed in his brain to drain fluid that accumulates there as a result of a malformation of his brain and spinal cord.

At 10 months, he required additional surgery.

"All of these doctors started coming out of the woodwork," Martha Rose recalled of the hospital stay.

At the time, the Sapps knew little about the medical and social-services systems in the community. They know too much now.

Until 1987, Martha Rose worked as a nurse, caring for hospital patients with head injuries, seizures and respiratory problems.

"It was somebody's way of getting me ready to deal with Dale," she says.

## Concerns about care

About a dozen specialists are involved in the care of Dale Jr.

"That's where the system fails these kids," Martha Rose said. "They treat them specialty by specialty instead of seeing the whole child."

Repeated encounters with the medical system have given both parents the opportunity to form judgments. They are most bothered by the health-care workers who pretend to know their child better than they do.

Because of her nursing background, Martha Rose knows what medicine can do for her son and what it cannot. When she feels that the professionals involved are not giving her child 100 percent, she said, "I become the mother from hell."

While Dale Jr. was hospitalized for four months last year, a resident urged Martha Rose to leave the room before he performed an unpleasant procedure on the child.

"I ripped the curtain off the track, went into a little room and cried my eyes out," she recalled. "All I wanted was a little respect. Nobody knows Dale as well as I do. I've watched them shove needles in his head. I've seen procedures. How bad can it be? If I can't take it, I'll leave."

Both parents think Dale is more aware of his world than others do. His eyes flutter rapidly back and forth, and he cannot look directly at people for long. But, his mother said, "if somebody does something funny, he laughs."

"He's been on phenobarb all his life," she said, referring to phenobarbital, a drug that suppresses seizures. "He's a drug addict. Maybe if he were off all these drugs, he could talk."

"We have to keep in mind that this is a child with rights, too. If you or I are thirsty, we help ourselves to a drink of water. What about when he's thirsty? We delegate what this kid does."

To make sure her son doesn't suffer unnecessarily, Martha Rose has asked that doctors leave standing orders for pain medicine each time he is hospitalized. She also encourages everyone from specialists to aides to include Dale in conversations — to speak to him, not just about him.

The many hospital visits and trips to doctors' offices leave Martha Rose, if not entirely at ease, at least familiar with the system.

## An intimidating procedure

Valentine's Day wasn't so sweet for Dale Jr.

In the North Side office of Dr. Edward Kosnik, the boy was undergoing his eighth electroencephalogram. A horribly raw, relentless screaming attested to that.

The test, which would determine whether Dale's medications needed to be changed, doesn't really hurt. But to a child who can't understand what's happening, the experience is overwhelming.

Dale's mother held him down on an examination table as technician Connie Ford placed dozens of brightly colored wires onto the boy's scalp. If not for the shrieking, the sight of Dale's head might have seemed comical.

In sympathy with her son, Martha Rose screamed back.

"I love my child. I really do," she said, laughing.

Finally, preparations were complete, but Dale had to relax before the test could begin.

His mother slipped a tape of lullabies into a cassette player she had brought. Careful not to disrupt the wiring, she took Dale gently from the exam table and rocked him, stroking his cheek and talking to him the way she would an infant.

He gazed into her eyes, blinking. After 40 minutes of struggling and screaming, Dale began to fall asleep.

## Financial help

To parents of children with multiple handicaps, the medical maze is mind-boggling, but the social-services gamut is even more so.

When it became clear that Dale's life would require assistance on many levels, the Sapps entered

the world of government waivers, which pay for services such as speech therapy and home schooling.

Essentially, the waivers set aside certain Medicaid requirements so that patients can be cared for at home instead of in an institution.

Since 1992, the Sapps have received the Individual Options Waiver, overseen by the Ohio Department of Mental Retardation and Developmental Disabilities. They got into the program just in time: The options waiver, for which families must reapply annually, has a waiting list today of more than 7,800 Ohioans.

Generally, "once you get into the system, it's cool," Martha Rose said. "Getting into the system is a hassle."

## Uncertain future

The past few times her big brother was hospitalized, Amanda Sapp needed to know: "Is it time for him to die now?"

The question is understandable from a 5-year-old who has spent her life watching Dale move from one crisis to the next. Amanda's parents don't know how to answer it.

"I've seen parents nurse their kids for 30 years," Martha Rose said. "I pray that Dale goes before me, so I wouldn't have to worry about him."

In all likelihood, the Sapps will outlive their son. He's been dodging bullets since birth, and, because he has so many problems, he probably cannot continue to do so.

The Sapps haven't asked for a specific prognosis. At one point, Martha Rose thought, "Should I be contacting the Special Wish people for a trip?" On the other hand, she noted: "There were doctors years ago who said he'd never move."

Dr. Joseph Banks is the pediatrician for Dale Jr., Amanda and their 3-year-old sister, Ashley. He has a pretty clear idea of how Dale will die — a seizure or an infection — but he can't predict when.

Nobody who has cared for the brown-haired, green-eyed child is willing to write him off. He has defied incredible odds.

For now, Dale's complicated, ever-changing medical life continues. The Sapps recently learned that he probably does have a genetic disorder.

"One day at a time," his mother says simply. Sometimes, life's too exhausting to ask for more.

# Daughter's well-being depends on parents' mastery of the system

Story by Nancy J. Smetzer

Dispatch Staff Reporter

Photos by Eric Albrecht

Dispatch Staff Photographer

**A**MID THE SEA of beach towels, lawn chairs and wet footprints on the poolside deck, the empty wheelchair called attention to itself.

A pony tailed swimmer who looked to be about 6 wandered past, staring at the clunky apparatus. Her eyes couldn't help asking: Who belongs to this beast?

Squinting, she scanned the bobbing bodies in the pool at the Gahanna Swim and Tennis Club. At that moment, a smiling Kathleen Biel, nestled in the arms of her father, blended with the crowd.

Had fate not determined otherwise, 10-year-old Kathleen would have been swimming on her own — and leaving footprints, instead of tire tracks, on the deck.

Kathleen's life is measured in minuscule marks of success: a smile, a nod, a grasp.

She cannot tell her parents — or her 2-year-old brother, Eric — that she loves them, nor can she tell them when she is hungry or hurts. She cannot sit up, brush her hair or feed herself.

Kathleen has cerebral palsy and is mentally retarded.

If only she could speak — in words, phrases and sentences — or if others could interpret the language of her eyes, soft sighs and soulful moans.

Her parents, Gahanna residents Mary and Louis Biel, can read Kathleen's body movements, but much goes unsaid and unheard.

The Biels constantly strive to find a connection that will allow them to communicate with their daughter, to reach inside the faulty shell of a body and find the person within.

Caring for Kathleen at home is a 24-hour commitment that can be draining, financially and emotionally. The Biels choose to bear the price, fighting for every dime, running on three or four hours of sleep a night and often putting their marriage in a precarious position.

## THE BIEL FAMILY

**Home:** Gahanna

**Father:** Louis, 46, respiratory therapist at Ohio State University Medical Center

**Mother:** Mary K., 42, operations director, Easter Seal Rehabilitation Center

**Children:** Kathleen, 10, and Eric, 2

**Annual income:** \$60,000

**Kathleen's primary diagnosis:** Cerebral palsy and mental retardation.

**Difficulties:** She cannot walk, talk or use sign language, and is fed through a tube inserted in her stomach.

**Annual waiver cost:** \$87,000 for the Individual Options Waiver

**Annual cost of care if not at home:** \$240,000 in facility that treats children who are medically unstable



Mary Biel joins Kathleen at the girl's first Brownie meeting.

Among parents of chronically ill children, the Biels are in an enviable position: They work full time; they have health insurance that helps pay for medications and doctor and hospital visits; and they receive help from the federal and state governments.

Louis, 46, is a respiratory therapist at Ohio State University Medical Center, and Mary, 42, is operations director for Easter Seals.

The system that allows the Biels to care for Kathleen at home is working in their favor. For how long, though, they don't know.

## Good news, bad news

The state program that allows the Biels to continue working while Kathleen receives medical care at home — the Individual Options Waiver — is equal parts blessing and curse.

"Frankly, waiver dependency scares us to death," Mary told the caseworker assigned to Kathleen's case. "It's scary to be dependent on these programs."

Just as frightening, though, is contemplating life without the waiver.

For the first three years of Kathleen's life, the Biels shouldered all of their daughter's medical costs.

In 1987, they were accepted into the waiver program that was the precursor to the options waiver, overseen by the Ohio Department of Mental Retardation and Developmental Disabilities. The Biels were among the first 100 people in Ohio to get the waiver.

Now they struggle to stay.

As part of the fight, the Biels — like the 2,500 other Ohioans who today receive the options waiver — must reapply for the benefits each year.

Ever-present threats are potential reforms in federal health-care regulations, cuts in Medicaid and significant revisions in the way the waiver is awarded.

The Biels' review this year took place in February. Five months later, Mary sat down with caseworker Nancy West to rework the plan because it exceeded the \$105,000 ceiling on the waiver by \$40,000.

Mary quickly found the problem — a typographical error — then proceeded to trim \$15,000 more from the plan.

By the end of the hourlong meeting, Kathleen's home care was secure for the remainder of the year, and Mary and Louis were guaranteed temporary peace of mind.

## Learning, developing

Special education.

For children such as Kathleen, the concept is an understatement.

Kathleen may never read a book, sing a song or add a column of numbers. Simply communicating — via a special switch on her home computer — would be a giant step forward.

When Kathleen attends school — which isn't often because of frequent illnesses — the process fills a social need.

Her lesson plan is more basic than reading, writing and arithmetic. She focuses on learning how to behave — when to smile, how to wait her turn, when to be quiet, how to interact with children.

The Biels want Kathleen to be around more "normal" children, in an environment where she is exposed to a mix of people and experiences, to help her social development.

Most of Kathleen's education, though, takes place at home — as part of a deal the Biels have with Gahanna-Jefferson Public Schools.

Federal law requires school districts to provide free and appropriate education for all children.

Working with a special-education team from the district, Mary in June negotiated the specifics of Kathleen's education for the upcoming academic year.

The routine was one mirrored by the parents of 850 other special-needs children who attend school in the district.

The process is not unlike negotiating the contract on a house, with give-and-take on both sides. After 90 minutes of discussion, Mary left with a written agreement. The goals for Kathleen include:

- 60 minutes of physical therapy weekly.
- 60 minutes of occupational therapy weekly.
- 36 hours of activities monthly at High Point Elementary School.

## A small victory

Life for the Biels, in Louis' words, revolves around the "push, haul, shove and carry factor."

Even a simple endeavor, like the pool outing in June, can be a struggle.

After gathering the usual towels and sunscreen plus extra T-shirts, medications and emergency supplies, Louis, Kathleen, Eric and caretaker Patty Bennett were out the door.

Kathleen smiled as her arms jerked skyward in uncontrolled spasms of delight. She approved of the trip.

At the pool, Kathleen quickly attracted attention.

"Like most people, they're scared," Louis said. "They'll ignore her or stare."

On the playground, some children showed a curiosity about Kathleen and her chair.

"What does she have?" a boy standing off to the side asked, his eyes skipping between Kathleen and Patty.

After Patty explained, he wondered: "Can you catch it?"

"No," Patty replied. "She's had it from birth."

Patty, who has answered such queries countless times, used the moment to try to educate others about Kathleen — and make

her seem less intimidating.

When he has his daughter with him, Louis dreads crowds. He fears that Kathleen will get hurt, and he hates the stares.

The exchange this day, though, buoyed Louis' spirits.

"This is wonderful for her," he said. "We were thinking about it the other night — how sad it is that she doesn't have friends."

The children provided a little sunshine.

"We come to the pool to have normal times, to do normal things," Louis said.

This afternoon, they succeeded.

# The Columbus Dispatch

SEPTEMBER 18, 1995

## A revealing report

By Michael J. Borens  
Dispatch Staff Reporter

In mid-December and quite by accident, Greg Carter learned horrible secrets about himself.

He spotted the manila folder while visually prowling the conference table at a hearing in which he was appealing the state's decision to cancel his daughter's Medicaid benefits.

"May I see that?" Carter asked during a recess, pointing to the bulging file marked with his name.

To his surprise, a hearing official nodded approval and also agreed — after Carter had braved good fortune with a second request — to copy dozens of pages from it.

After the hearing, Carter went to his apartment in the Cincinnati suburb of West Chester, Ohio, and tossed the copies on a table near his father, who was in town from Kentucky to baby-sit.

When Carter returned the next day, his father was waiting in the living room, the copies in hand.

"Have you read these?" Bob Carter asked, his voice betraying urgency. "I think you better take a look."

His son began to scan the pages, confident that they contained little more than medical updates about his young daughter, Lauren, who has cerebral palsy and many other ailments, including blindness and mental retardation.

"Oh, my God," he cried as his eyes met the words.

"Lauren is frequently found with stool from head to toe (and) in her mouth."

"Parents refuse to allow her access to the house, and she remains in bed with a barrier to prevent her escape."

The 18-page report, among other pages, had been prepared by private nursing supervisor Linda Elliott-Amann, whose agency

### Father discovers inflammatory file during hearing

contracted with the Ohio Department of Human Services to oversee Lauren's home nursing care.

"Lies! Lies! Lies!" Greg Carter shouted.

The report also leveled subtle criticisms at Carter and his fiancée, Meri-Ellyn Eubank:

"Dad states he has been unable to schedule any appointments or become involved as he would like since he works 60-70 hours per week. He states that he and his common-law wife do not have a life."

The report noted that Eubank was "overwhelmed" when caring for Lauren and her two sons — Dustin, then 6, and Christopher, 5 months.

Weaved among medication notes, Elliott-Amann's observations seemed almost spylike.

"Dad asking for increased (nursing) hours to allow family time to be out together. (Nurse told me privately, after the meeting, that they are never home.)"

The bottom of each page carried either Carter's or Eubank's signature. Anyone reading the report would believe that one of them had read the accusations and signed in agreement.

Elliott-Amann, Carter deduced, must have returned to her office after visiting Carter's home and added the comments on the pages.

The appeal hearing days before suddenly entered Carter's mind. He replayed the details from memory, finding new meaning in the awkward glances and critical comments he had confronted.

## A LONG-DISTANCE HEARING

Click-click.

A tabletop speaker telephone came to life with the voice of Ceil Zurick, an administrator for the state Department of Human Services, who was 100 miles to the north in her Columbus office.

Carter closed his eyes in disbelief. He was with two officials at the department's Butler County office near his home on Dec. 12. Zurick — both judge and jury of the appeal — was half a state away.

There is nothing human about this hearing, he thought.

Carter spoke to the machine.

Lauren is a fragile but active 7-year-old whose cerebral palsy has left her with the physical and mental power of a 2-year-old at best, he explained. She requires home nursing care, which enables him to work and support Lauren, Eubank and their two other children.

Zurick acknowledged that Lauren is severely disabled but said she is not sick enough to qualify for Human Services' Medically Fragile Waiver, which provides money for home nursing through Medicaid for children needing daily medical care.

Lauren, who is medically stable, instead qualifies for the Individual Options Waiver, offered through the

Ohio Department of Mental Retardation and Developmental Disabilities, she said.

Zurick acknowledged that the options waiver has a waiting list of 7,828 people and that Lauren might be 10 years from benefits.

Pending a decision within a few months, Lauren would continue to receive home nursing and benefits.

"Thank you," Zurick's voice concluded.

Click-click.

## A CURIOUS VISIT

With Christmas just days away, Carter had temporarily freed himself of his depression about the appeal and shock over the report when a knock at his front door shattered the protective holiday spirit.

"Hello, I'm with Butler County Child Protective Services," the woman said.

Carter paled as she explained

that the agency had received an anonymous telephone complaint that Lauren was being neglected. Specifically, the social worker said, the caller claimed that Lauren was barricaded in her bed most of the day.

Carter suspected that the complaint was lodged by a nurse he and Eubank had fired because she wouldn't stop smoking around the children.

The social worker stayed less than an hour, examining Lauren and complimenting Carter on Lauren's bed, which he had handcrafted years ago with high safety rails made of wood.

"Consider this complaint closed," she said before leaving.

Protective Services later confirmed that the allegation of neglect was unfounded.

Months later, Carter would discover that Human Services had investigated the allegations in the nurse's report and concluded that they were without merit. Human Services officials say they are compelled by law to report evidence of abuse to a child protective agency. The state filed no such report in the Carter case, state records obtained by *The Dispatch* show.

Still, Carter remained uneasy about the allegations — fearful that, though baseless, they might be used against him.

His concern would prove well-founded.

## How many sick kids?

Though the state is charged with administering dozens of programs for medically fragile children, it has never conducted a study to determine how many sick children live in Ohio.

The state defines "medically fragile children" as those under 18 who require nursing care and ongoing therapy or routine use of a life-sustaining medical device, or both.

Neither the Department of Human Services nor the Department of Mental Retardation and Developmental Disabilities knows how many Ohio children fit this definition.

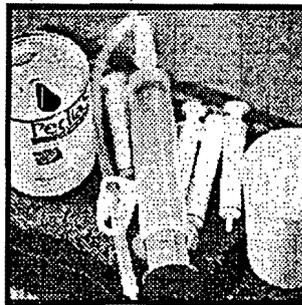
The state estimates the number of medically fragile children by using a formula developed in 1987 in Massachusetts that multiplies the population of all children in Ohio by .08 percent:

|   |   |              |
|---|---|--------------|
| Total Ohio children under age 18        | = | 2,799,744    |
| Formula percentage                      | x | .0008        |
| <b>Total medically fragile children</b> |   | <b>2,239</b> |

Ohio has about 1,050 children on Medicaid waivers — less than half the number of children who would be eligible based on the state estimate.

Source: Ohio Department of Health

Chris Russell/Dispatch



Dispatch graphic

## THE STATE'S FAX

Since his appeal hearing, Carter had been calling the governor's office seeking intervention.

The Department of Human Services became aware of the calls soon after the holidays. In February, a two-page fax was sent from the department with a caution in bold type: "HEADS UP ON LAUREN CARTER."

Department officials say they aren't sure who received the fax, although a handwritten note on one page shows that it was sent Feb. 23 to the offices of Gov. George V. Voinovich and William T. Ryan, deputy director of Medicaid for Human Services.

The note bears the signature of Ceil Zurick, the department administrator who had presided over Carter's appeal hearing.

After receiving a tip from a

friend who is employed by a Butler County agency that works with children, Carter discovered that the fax also had been sent to that agency and a similar one in the county.

He obtained copies of the fax through a public-records request for his file at the Butler County Board of Mental Retardation and Developmental Disabilities.

Though Human Services already had discounted the private-duty nurse's report, the department fax quoted the

allegations. The fax also defended the cancellation of Lauren's Medicaid benefits and, in the last paragraph, noted that foster-care options were being explored.

Human Services officials said the fax does not appear in state files on Lauren: Carter and does not represent an official department action.

Ryan does not recall receiving the fax, he said, nor does anyone at the governor's office.

Zurick was unavailable for comment.

Joseph Silver, senior staff attorney for the department, said federal privacy laws prohibit the state from commenting on the Carter case.

At *The Dispatch's* request, Carter and Eubank signed a letter authorizing Human Services to release files or comment on any aspect of the case.

Even with the family's permission, Silver said, the department cannot comment.

### THE HARSH REALITIES

Eubank and Carter hesitate to discuss the nursing report for fear that the lies will shadow their lives.

Elliott-Amann is traveling out of state and unavailable for comment, said Susun Sharp, administrator of Primary Care Professional Management Services of Cincinnati, the nursing agency for which Elliott-Amann works.

In a written statement to *The Dispatch*, Sharp said Elliott-Amann's monthly case-management report was "based on the reported observations of nursing professionals" and on the "personal observation" of Elliott-Amann in Carter's home.

The parents' signature on the reports is required by Human Services to verify the monthly visits, Sharp said. Some statements written or typed in the report were added after Carter or Eubank signed the pages, she said.

Carter's or Eubank's signature does not indicate that the parents agreed with the report or that they had seen everything written in it, Sharp said.

Though references to "stool" and "barriers" might be interpreted by Carter as accusations, she said, the comments were intended as neutral nursing notes.

The report, Carter and Eubank believe, clearly implies that the family neglected Lauren. "I had no idea that everything I said was secretly written down," Eubank said.

The report does not mention that Eubank, 27, plans to marry Carter, 34, within a few months. They have been waiting for an ebb in the tide that seems to only rise.

"It's really hard," Eubank said. "I'm not Lauren's mother, but I'm treating her like she is mine. I have two sons in addition to Lauren — and Lauren is a one-person show."

Yes, life is overwhelming, Eubank acknowledged. She told Elliott-Amann as much, but the remark was one any mother might make on any day. Now the admission was being used as evidence against the family.

Lauren sometimes reaches down into a dirty diaper like a gun-fighter on the draw, then smears herself, Eubank said.

"How can you stop this? You can't. It's part of the challenge of having a child like this."

Lauren's bed, indeed, is unusual: Her mattress, placed on the floor, is surrounded by padded, 4-foot walls made of wood. But Carter designed the bed with heart — as a way to protect Lauren.

Shorter walls would enable Lauren to hoist herself to freedom in the middle of the night and possibly stumble down the stairs.

### A SIMPLE QUESTION

Since leaving a job at Circuit City to become a manager for Best

Buy near Dayton, Carter has been working 50-plus hours a week. Lauren's needs quickly consume his \$32,000 annual salary.

Carter's desire to be with Lauren has cost him promotion opportunities in a retail career in which the customer is always first.

Though the sacrifice was voluntary, Carter and Eubank dream of a normal life. They wish for a morning of careless slumber the way other families covet a Hawaiian vacation.

The couple's apartment, sparsely furnished and neat, is dominated by Carter's homemade desk — a sheet of wood atop two file cabinets — that supports his papers, books and computer in a corner of the

living room.

Two couches, a television and a videocassette recorder, a playpen and a basic dinette set fill the smallish rooms.

A home is not what's inside it, Eubank said, but what's inside the people who live there.

"The state is making it very difficult for us to keep our child in our home," she said. "The state suggested foster care. Well, we have a family; we have a nice place to live; we have everything we need right here.

"Why can't we keep Lauren here?"

# Family adapts so 7-year-old can fit in

Story by Laurie Loscocco

Dispatch Staff Reporter

Photos by Lynn Ischay

Dispatch Staff Photographer

**S**OMETIMES WHEN THEY SEE boys riding bikes or playing catch, Martha Rose and Dale Sapp Sr. ache. Their 7-year-old should be out playing, skinning his knees and throwing sticks.

Yet Dale Sapp Jr. cannot walk. He cannot get himself a snack from the refrigerator or leave muddy footprints in the hallway. He cannot tease his sisters, then get in trouble for it. His parents cannot scold him for breaking a window or nag him to pick up his messy room.

When Dale Jr. was about 5 months old, his mother — then his doctors — discovered that he had a seizure disorder.

More bad news followed: Dale is hydrocephalic, meaning he has an abnormal amount of fluid in the brain. Chronologically, he is 7; developmentally, he's about 1.

Dale has had a host of other health problems. He is fed through a tube into his stomach. When he isn't in his wheelchair, he gets around by scooting along the floor, like an infant learning to crawl.

His life does not fit most people's definition of a "normal" childhood. But what his parents — and others like them — have found is that they must redefine their definition of *normal* every day, then hope that other people understand.

## Bomb's away

Dale's way of having fun is throwing things.

He throws blankets off his hospital bed, then laughs as Mom picks them up — over and over again.

He throws a bag filled with toys at his caregiver.

He throws a long link of plastic chain at a reporter who's joined him for a doctor's visit.

It's his form of mischief, of being an impish, melt-the-heart little boy.

His parents, and those who care for him and about him, constantly strive to make him happy.

His dad built him an adapted go-cart that goes round in circles.

His mom takes him horseback riding at a farm that specializes in riding lessons for people with physical and mental impairments.

"We try to fit him into our world as much as possible," said Martha Rose, 32.

Sometimes, the challenge is tremendous.

A vacation, for example, requires much more than the usual effort.

"You have to take the whole damn house with you," Martha Rose said.

Dale's medical supplies, equipment, monitors and food all must be packed. In addition, special considerations — Where's the nearest hospital? Is ambulance service available? — must be addressed ahead of time.

From day to day, little things are important.

When the weather turned warmer in the spring, for example, Martha Rose talked about buying her son boxer shorts and T-shirts — in the colors of the rainbow.

"I want to give him some dignity," she said. "He's a 7-year-old boy. How do I know that he doesn't care if people see him in diapers? I think he's aware of his world."

The family has found, more often than they would like, that their concept of normal doesn't always coincide with others'. They've learned to expect the stares — as difficult as they are to take.

Before he had surgery in 1994, Dale had a hemangioma, a benign tumor made up of dilated blood vessels, on his left shoulder. It was about the size of a small grapefruit.

"People would stare at him at the pool," said Dale Sr., 34. "A lot of times, you want to cover him up. He's just a normal little child."

At a restaurant, a diner asked Martha Rose why she would take a child such as Dale there.

Martha Rose gave her an earful: "Dale has every right to be a part of this world, like you and I do," she told the diner.

## A special first

The farm is about an hour from the Sapps' home on the Northwest Side. By the time Martha Rose, Dale Jr. and his two sisters arrived, the April sky threatened rain.

Dale, about to experience his first ride on a horse, initially resisted the glasses and helmet riders must wear, but he was quickly distracted by a gentle, 22-year-old crossbred horse named Shane.

The animal's presence relaxed Dale — a common reaction among disabled riders, said Karen Sanchez, who runs Equine Assisted Therapy in Centerburg, Ohio.

When Martha Rose decided that her son might like horses, she sought out the farm, which specializes in therapeutic riding.

In working with riders, Sanchez said, "we try to get them to use what they can."

Two volunteers helped hold Dale up on Shane. Because Dale can't talk, Sanchez and the volunteers taught him to rock from side to side to tell the horse to walk on. They taught him another command for "whoa."

As the rain began, the wind swirled around the farm, but Dale and his mother seemed oblivious to the elements.

"So, am I nuts or what?" Martha Rose said, clearly

delighted that her son was having a normal childhood experience. "Do you hear him? He's laughing! He's having a riot!"

Her son was grinning from ear to ear.

Kids and horses. What could be more normal?

## Subtle reminders

Reminders that Dale is different come in many forms:

■ In June, Martha Rose bought birthday presents for her son — toys parents might buy for a toddler, such as a Fisher Price school bus and puzzle book.

The checkout clerk noted the number of toys and guessed that somebody was having a birthday. She asked how old the child would be.

"Seven," Martha Rose answered.

Another awkward moment.

■ When she first started going to friends' houses, Dale's little sister Amanda noticed something missing.

"Where do you keep your wheelchair?" she'd ask.

■ Amanda, 5, and her 3-year-old sister, Ashley, play a game: They take their stuffed dog, Max, to surgery to try to stop his seizures. They wheel him in on a toy tea cart. Max has a shunt, a few intravenous lines and a broviac, a catheter leading to his aorta. It's kind of like the one their brother had when he was really sick.

## A lonely feeling

Martha Rose talks tough. She doesn't hesitate to tell people exactly what she's thinking because she has little time for BS.

Under the sometimes-bristly exterior, though, she hurts. Her husband hurts, too.

They feel isolated — sometimes from the rest of

the world, sometimes from each other.

At a picnic for Amanda's preschool class, Martha Rose found it difficult to strike up meaningful conversations with parents of "normal" children.

"They were making small talk with me. ... I heard these people planning vacations, and I heard a woman talk about how she couldn't find a bathing suit. I'm thinking, big ——— deal. A bathing suit's

a bathing suit. If I ever go on vacation, I have to worry about how many cans of Peptamen I need."

Peptamen is the liquid food that sustains Dale.

"If I didn't have the kids with me that day, I would have felt so alone," she said. "I have no 'normal' friends. All the friends we have are through Dale — they're parents of other medically fragile kids."

With them, she finds it far easier to relate, to find a safe place. But finding the time is a problem.

"None of them have lives, either," Martha Rose said, half-smiling.

She imagines a day without medicines, feeding machines or worries about sudden fevers.

"I don't know if I resent it," she said. "There's a little bit of envy there."

The bottom line, she said, is that "you deal with it."

"Life with these kids is like a roller coaster," Martha Rose said. "If your day's crummy, you deal with it. And if you have a good day, then that's cool."

Cool is watching her son instruct a horse to walk on, laughing and letting raindrops fall where they may.

# When child is healthy, life is good

Story by Nancy J. Smeltzer

Dispatch Staff Reporter

Photos by Eric Albrecht

Dispatch Staff Photographer

**A** GREETING PARTY OF NINE waited and watched as Mary Biel parked her maroon-and-pink van at the back door of Jefferson Elementary School in Gahanna.

The young girls showed patience as Mary climbed over the back seat to loosen the straps that keep her daughter's wheelchair in place. She opened the van's double doors and rolled 10-year-old Kathleen onto the lift.

"Is that the new person who's going to be in our Brownie troop?" one of the group asked.

"Cool," said another, before heading into the school. "You guys," she hollered to anyone within range, "Katie's here."

Kathleen heard the voices and smiled, her blue eyes glistening and her arms jerking upward. She was ecstatic.

Inside the school, the Brownies introduced themselves to Kathleen, who looked from girl to girl and grinned as if acknowledging their presence.

Mary explained to Kathleen's new friends that her

daughter has cerebral palsy and is mentally retarded. Then she fielded a few questions: Will she ever walk? Does she choose her own clothes? Where does she sleep?

Seeing in the girls a shyness that comes from fear of the unknown, Mary tried to reassure them: "You can touch Kathleen. She has a 2-year-old brother who jumps up and down on her. You don't have to be afraid of hurting her."

The girls moved in closer.

## A friend indeed

Such moments of normalcy are rare for Mary and Louis Biel.

The Gahanna residents — whose lives center on a

child who cannot walk or talk — crave them. They want Kathleen to be around other children as much as possible, for the social interaction.

Mostly, Mary, 42, and Louis, 46, want people to see their daughter for the person she is, not the person she might have been.

Young Kristy Frazier was perhaps best at that.

In Kris, Kathleen had a special friend. Three summers ago, the 7-year-old neighbor visited regularly, ringing the Biels' doorbell to inquire: "Can Kathleen come out and play?"

Kris and her two younger sisters were Kathleen's guides to child's play: Kathleen was their audience when the girls were puppeteers, their customer when they were waitresses and their competitor when they played games.

"Katie thought this was the greatest thing in the world because someone was attempting to play with her," said Patty Bennett, who cares for Kathleen five days a week at the Biels' home.

The day Kris and her family moved from the neighborhood — in 1993 — was a sad one for the Biels.

On her last visit, Kris brought a gift that now hangs in Kathleen's bedroom.

The sign, clearly the work of a child, declares: "Katy Love Kris."

## A special day

Kathleen's health dictates the family's social calendar. She is easily felled by infections and colds, which can quickly deteriorate into bigger problems.

The Biels prefer when Kathleen can be the center of attention for reasons other than her disabilities. Her 10th birthday provided such an occasion.

On Feb. 25, Kathleen had her first party at home in three years.

The house had a festive air, with crepe-paper streamers looped around the kitchen chandelier and helium-filled balloons hugging the ceiling.

Kathleen's grandparents had driven in from West Virginia. Next-door neighbors Sally and Don Wire stopped by, and friends Fran Keelen and her 26-year-old son, Shane McCoy, who also has cerebral palsy, came from across town.

A mountain of presents in the living room reached the top of Kathleen's wheelchair. Louis guided a colorfully wrapped box toward his daughter's hands. Kathleen's arms and fingers, tense with excitement, caught the edge of the paper.

*Rip.*

She threw her head back at the accomplishment, her eyes sparkling and her mouth forming a smile. Under the paper was a Birthday Barbie.

Kathleen opened a few more gifts — another Barbie, a poster, a piece of jewelry — before the effort had sapped her strength. She was content to watch her dad open the remaining presents and to bask in the "oohs" and "ahs" of her guests.

The party later adjourned to the kitchen, where Louis, Mary and Patty blew out the candles on Kathleen's cake. Kathleen — who eats liquid through a tube in her stomach — watched as the group enjoyed cake and ice cream.

Seeing the irony in the situation, Mary slipped her daughter a tiny bite of ice cream. When Kathleen coughed, Mary could only apologize: "I'm sorry, baby."

## A decorating decision

Only the seashells would do.

While shopping for wallpaper for her daughter's bedroom, Mary flipped through sample books page by page, holding them up for Kathleen to review.

When Kathleen saw the border of shells, she perked up.

Mary tried the same routine at a second store, but Kathleen seemed uninterested in any of the patterns.

"You like the seashells at the first store, don't you?" Mary asked.

The decision was made.

The shopping trip underscores the pains Mary took in decorating Kathleen's bedroom. Like the rooms of other 10-year-old girls, Kathleen's has a collection of dolls and a jewelry box filled with necklaces and bracelets.

She hasn't slept in the room for more than a year now, though — not since she has had attendants

caring for her overnight. Instead, she sleeps in the family room — at the other end of the house — where the attendants can care for her without disturbing her parents or her brother, Eric.

## Doing her part

A bright spot in Kathleen's day is helping with the laundry.

Patty folds the clothes and places them in a basket, then puts the basket on Kathleen's lap and wheels her around the house. Together, the two unload the goods.

Such exercises are part of an effort by Mary and Patty to include Kathleen in daily activities.

When Mary cooks — maybe four times a month — Kathleen holds the bowl while her mom stirs. When Patty cleans, Kathleen carts the cleaning supplies on her chair. When she changes the bedding, Kathleen carries the sheets to the laundry chute.

Yet with a chronically ill child, life can get only so normal.

Underscoring that reality are Kathleen's medications, which occupy an entire cabinet in the kitchen along with the handwritten book Patty calls "Katie's training manual."

The book contains Kathleen's seizure log for the past 2½ months and a host of vital information: when to call the emergency squad because of a seizure; what to do when a fever rises rapidly; where to find her medications and when to administer them; and how to reach the poison control center, doctors and hospitals.

"We have so many bases to cover, and we cover them all," Patty said.

In case of an emergency, Louis and Mary carry a cellular phone on every outing with Kathleen.

Standing in line waiting for a pay phone isn't an option.

## A warm welcome

That first day of Brownies was better than Mary had hoped for.

She had wanted to get her daughter into a Girl Scout troop so Kathleen could build relationships.

After all, Mary had grown up in Girl Scouts. Her mother was a troop leader.

Mary's enthusiasm waned, however, when she called the Girl Scout Council in early March to inquire about a neighborhood troop and was told that a leader "willing" to accept Kathleen had to be found.

"I thought they would be a little bit better," she said.

Mary, expecting a battle, was surprised when the call from Troop 1148 came a few weeks later.

Troop leaders Jerri Heine and Bev Nelson said the 8-, 9- and 10-year-old girls never hesitated to welcome Kathleen when told that she wanted to join their troop. That Kathleen cannot speak wasn't a problem.

"We'll learn sign language," they offered. Or whatever language Kathleen speaks.

At Kathleen's first meeting, 8-year-old Susan Golowin rushed to be at her side during the closing ceremony. Susan worried, though, when she learned that Kathleen couldn't pass the handshake that is a key part of the troop's "friendship circle."

Susan quickly improvised: Instead of a handshake, she gave Kathleen a wink.

And the troop sang: "Make new friends, but keep the old. One is silver, and the other is gold."

Mary returned home with Kathleen that evening on a high.

"You wouldn't believe it," she told Louis of the girls' warmth.

Kathleen's father later would attend a meeting and find out for himself.

#### THE SAPP FAMILY

**Home:** Northwest Columbus

**Father:** Dale, 34, executive chef at Stouffer's Dublin Hotel

**Mother:** Martha Rose, 32, homemaker

**Children:** Dale Jr., 7; Amanda, 5; Ashley, 3

**Annual income:** \$50,000

**Dale Jr.'s primary diagnoses:** Hydrocephalus, a condition characterized by an abnormal increase in fluid in the brain.

**Difficulties:** Among other brain-related disorders, the boy is mentally retarded and cannot walk, talk or use sign language. He eats through a tube inserted in his stomach

**Annual cost of waiver:** \$105,000

**Annual cost of care if not at home:** \$240,000 in facility that treats children who are medically unstable



Dale Jr. shares a hug and a nose rub with his mother, Martha Rose Sapp, after he reached out for her.

# The Columbus Dispatch

SEPTEMBER 19, 1995

With appeal denied,  
father scrambles  
to find last-minute help.

## Hope running out

By Michael J. Berens  
Dispatch Staff Reporter

Lauren Carter fumbled through her blindness before nestling into the perfect cuddling spot on her father's chest and shrieking, "Ca-caaa!"

"I think she knows that I'm her father," Greg Carter said softly, gently rocking his upper body. "I'll never know for sure, though."

There are times — such as this day in March — when he is grateful that his 7-year-old daughter's cerebral palsy and mental retardation make her oblivious to the world.

"Ca-caaa!" Lauren yelled again, wrapping her arms and legs tightly around her dad while struggling for control against spastic muscles.

"Damn, all I want to do is keep her at home," insisted Carter, sitting on the floor of his Cincinnati-area apartment with his fiancée, Meri-Ellyn Eubank, and their two boys, Dustin, 7, and Christopher, 1.

Smiling broadly and still being held by her father, Lauren leaned forward as she and Christopher's foreheads came together. The two seemed to share a moment of silent communication.

Carter had no way of telling Lauren about the guilt he was feeling.

Three weeks earlier, in mid-February, he learned that the Ohio Department of Human Services had denied his appeal to

Please see **HOPE** Page 2A

have Lauren reinstated to its Medicaid waiver program.

Department officials had re-evaluated Lauren's enrollment in the program late last year and determined that, based on the rules, she wasn't sick enough to qualify.

The appeal represented one last hope for Carter, but its rejection meant that he would no longer receive money for his daughter's home nursing care — and, in effect, could no longer afford to care for Lauren.

Like many other parents of sick children, Carter believes that the state has enough money, if properly managed, to provide home medical care for every disabled child in Ohio.

But William T. Ryan, deputy director of Medicaid for Human Services, says the state cannot afford to help every disabled child, forcing the department to help the sickest based on federal guidelines.

Lauren is trapped between the opposing viewpoints — severely disabled by public standards but not sick enough by state standards.

The way Carter sees it, the system defies logic.

During the previous year, the waiver program — a combination of federal and state money — paid about \$45,000 for Lauren's nursing care. For 39 hours a week, a nurse watched Lauren while Carter worked and Eubank cared for the boys.

According to state estimates, institutional care for Lauren would cost Medicaid at least \$55,000 annually.

"It's almost like the state is doing everything they can to get her out of the house," Carter said. "Why can't they just give me the money they plan on spending anyway?"

Carter was beyond desperate as he called dozens of state officials in search of a last-minute reprieve.

When his efforts failed, he turned to the woman who had helped him before — Cindy Carpenter, the mother of a disabled daughter who lives 15 miles away in the neighboring suburb of Fairfield, Ohio.

Carter, acknowledging a sense of overwhelming guilt, told Carpenter that he was contemplating what once was unthinkable: placing Lauren in an institution.

## A HELPING HAND

Carpenter is a rapid-fire talker whose wit and barbs find targets with equal precision.

Her political adeptness has earned her respect — and sometimes fear — among state officials, who quickly discovered that she is no ordinary woman.

Carpenter is the skeptic who demanded that a mild-shock skin test be conducted on her before allowing it to be performed on her 7-year-old daughter, Megan.

Though doctors swore the test wouldn't hurt, Carpenter nearly passed out from the pain. She refused to let doctors touch Megan, who is deaf and has a rare brain disorder that resembles autism.

Carpenter also is an activist who in 1991 staged a sit-in with Megan outside the Statehouse office of Gov. George V. Voinovich to protest a lack of funding for disabled children.

She won the heart of Voinovich, who later supported an increase in the number of Medicaid waivers for disabled children.

"I should have been born a man," joked Carpenter, who stands 5 feet 4.

The 37-year-old single mother balances the needs of Megan with her son, Kenny, 13, and older daughter, Shannon, 17.

"I just have a different perspective than most people. I don't even feel normal when I'm with other moms. I look at life differently than they do. I don't get all tense about expectations for my kids.

"I say, 'Hey, the kids are alive today.'"

After the sit-in, state Rep. Michael A. Fox, impressed with Carpenter's command of people and politics, hired the spunky constituent from his southern Ohio district.

Between campaign filings and fund-raisers, Carpenter has turned the Hamilton Republican's office into a clearinghouse for families with disabled children.

Calls for help arrive daily, she said.

## A REVERSAL OF FORTUNE

Carter first called in September 1993. He had recently won custody of Lauren from his ex-wife in Kentucky and needed help from Medicaid to pay for nursing care.

The Department of Human Ser-

vices had turned down Carter's request, explaining that Lauren didn't qualify for its Medically Fragile Waiver. Other waiver programs were full, officials said.

On Sept. 21, 1993, Carpenter drafted a two-page fax — her chief weapon against the government she serves — to Jacqui Sensky, the governor's executive assistant of human services.

Carpenter noted that Lauren's cerebral palsy places her on the borderline of qualifying for the Medically Fragile Waiver, which provides nursing care at home for children who need daily medical care.

Pleading Carter's case, she pointed out that she was working with two Butler County families who had given up fighting the state and were placing their children in institutions.

"I am really tired of it," Carpenter concluded. "I hope you can help with Lauren. Her father will do a great job raising her if we can only help him a little."

Human Services reversed its decision, giving Carter the waiver in November 1993. Carter believes the only reason Lauren received the benefits is Carpenter's expertise.

A year later, though, the waiver was being canceled.

Human Services officials urged Carter to apply for the Individual Options Waiver through the Ohio

Department of Mental Retardation and Developmental Disabilities. The options waiver program, however, has a 10-year waiting list.

By the time Carter called Carpenter the second time, his appeal was exhausted and the state's decision was made.

Carpenter told him that she could do nothing to help.

## RESTRICTED BY RULES

Calling it a gesture of good will, Human Services did not immediately cancel Lauren's Medicaid benefits to give Carter more time to choose: foster care or institutionalization?

Sandy Sterrett, a Human Services administrator, said the agency tries to avoid sudden cancellations of benefits to give families time to make such decisions.

Each year, she said, some children who probably aren't qualified for a waiver receive benefits until the state has overwhelming evidence that these children do not meet federal guidelines for the programs.

Lauren was one of those children.

Federal guidelines are stretched for "borderline" children, Sterrett said, because the state wants to provide benefits to the

families for at least one year.

Parents are warned that benefits could end a year later, she said.

Sterrett does not dispute that political influence has helped some parents get waivers. In the past, "the squeaky wheel got the waiver," she said, adding that cases are now handled neutrally.

Carpenter's influence was not a factor in Lauren's case, Sterrett said. The department is not happy when a child who is removed from the waiver ends up in foster care or an institution, she said.

Human Services cares about these children and works hard to find alternative funding or placement, Sterrett said, but federal rules restrict money that the heart says to give.

## A NO-WIN DECISION

By early May, Carter was a broken man.

Hoping for a miracle, he resisted the idea of institutionalizing Lauren, but he consented to letting state officials look for a facility.

"I went to one of the institutions and looked around," Carter recalled. "I see these kids who are bedridden, wheelchair-bound, really pretty bad off, and I look and say that my

daughter does not really belong here."

He asked himself over and over: Do I keep Lauren or give her up?

His two boys, he knew, deserve a normal childhood filled with activities such as Little League, an afternoon at the movie theater or a day at the pool — all impossible now.

His fiancée already had given two years of her life to Lauren, who would demand every minute of every day until death. His relationship with Eubank was about to crack under the stress.

To care for Lauren at home, Carter would have to quit his job, give up the modest apartment for something even smaller and go on welfare to get a Medicaid card.

Could he sacrifice his life with Eubank and the boys?

The state was offering a magic pill of sorts — one that would eliminate his family's financial troubles. All he had to do was give up Lauren.

But what about his promise to his daughter?

*I will never leave you.*

He had made the vow on the November night he learned that she was losing Medicaid benefits.

By May 17, he had made up his mind.

# Family's strength tested daily

Story by Laurie Loscocco

Dispatch Staff Reporter

Photos by Lynn Ischay

Dispatch Staff Photographer

**S**HARE DAY HAD ARRIVED for the class of 5-year-olds at St. John's Preschool in Worthington.

Some of the children brought fresh-picked flowers or favorite stuffed animals to show their classmates.

Amanda Sapp brought her brother.

Early that May morning, she had carefully picked out what Dale would wear: an Ernie T-shirt and a pair of shorts. She had been to his school lots of times; this would be his first trip to hers.

When Amanda's turn to share came, she and her classmates formed a line and walked down the stairs and outside, where Dale was waiting.

Amanda and her mother, Martha Rose, explained a few important things about the boy in the wheelchair.

His favorite color is red. His favorite food is pizza, though he can eat only crumbs at a time. And when he has a seizure, Amanda advised, "call 911 and be brave."

When the time came for the children to return to the classroom, they waved to Dale and sang out a chorus of "byes."

Asked later why she chose to share her brother, Amanda said, "Because he's special, and he's my brother, and I love him."

Martha Rose knows well that her older daughter's feelings toward Dale aren't always so loving. More than once, Amanda has felt anger toward her brother.

"I've heard her say she hates Dale, and that she wishes he'd go back where he came from," Martha Rose said.

The words sting but are understandable.

"These kids get dragged to all the doctor's appointments," she said. "They should be home playing. I feel like I need to spend more time with them, but when?"

Dale, who turned 7 in June, was born with hydrocephaly, a condition in which fluid accumulates in the brain. He cannot walk or talk and has had many complications. Sometimes, he has seizures and stops breathing.

Dale lives on a cul-de-sac on the Northwest Side with his mother, father, Dale Sr., and two sisters, Amanda and Ashley, 3.

When the realities of Dale's many needs clash with the normal needs of other family members, life can get rough.

## A clash of opinions

Caring for a chronically ill child at home can test the toughest of families.

"We're a high-risk group," said Martha Rose, 32. "I don't know too many people with medically fragile children who have perfect lives."

Sapp, who once worked as a nurse, now stays at home with the children. Dale Sr. is an executive chef at Stouffer's Dublin Hotel.

The Sapps agree that Martha Rose is the glue that holds the complex household together. They disagree, though, on the toll it has taken.

Martha Rose says she is fed up with running the show single-handedly. Dale says she won't let anyone else contribute.

One day in the spring when Martha Rose's grandmother asked, "What happened to you?" Martha Rose knew what she meant.

"I've become ugly and bitter," she said. "I'm sick of being the calendar person, the scheduler. ... I'd like to be weak every now and then and say screw it, but I can't. Somewhere in this whole process, I've lost me."

Increasingly, she said, she feels that a major change is in store.

"I'm going back to work. I don't know how and I don't know when, but I am. And I think that two years from now, it will be just my kids and me."

She acknowledges that she has cried wolf before about ending her marriage. This time, she says, she is serious.

One problem is that her husband "has to share me with three people," she said. "What he doesn't understand is that I have to spread myself so thin."

She also wishes that he'd be more involved in his son's life.

Dale Sr., 34, agrees that his wife takes care of their

son "100 percent plus. That's her profession. ... Martha Rose likes to be in charge, and I think she gets tired of explaining everything to me."

He feels left out, he says.

He knows the stress Martha Rose suffers, he says, but he thinks she must understand that he is burdened, too. He works long hours and avoids bringing work-related problems home because there is no room for them.

Dale Sr. finds relief by building play equipment for Dale Jr. and other special-needs children and by volunteering.

He would rather not discuss his marital problems — a notion that irritates Martha Rose.

Again, she feels, she must carry a burden alone.

## A different person

Martha Rose knows she has changed dramatically.

"I used to let people walk all over me," she said. "Dale taught me not to do that. He needs me to advocate for him."

It is hard to imagine anyone walking over Martha Rose. She does not hesitate to praise or scorn, and, when it comes to her son, she puts up with little.

She speaks for Dale Jr. because he cannot speak for himself. In so doing, she pits herself against anyone who would slight him or do him the smallest injustice.

"You do not say 'no' to Martha Rose," said Dr.

Joseph Banks, the Sapp children's pediatrician. Banks, a tall man with a collection of lab coats bearing the likenesses of cartoon characters (the Looney Tune ones courtesy of Martha Rose), worries as much about the family as a whole as he does about Dale Jr.

Unlike Dale Jr., the rest of the Sapps can feel emotional pain ever so acutely. When Banks talks about Dale's eventual death, he does so with mixed emotions.

"It sounds terrible to say, but those of us who care about this family would like to see it come earlier, so they can have a life," he said. "Look at the toll it's taking on this family."

Caring for Dale Jr. "has really taxed" Martha Rose and Dale's relationship, he said. Banks is concerned that Martha Rose is stretched to the breaking point. In June, he urged her to fill a prescription for Valium.

"Whenever I see her, I try to give her a hug," he said. "She's always thinking of other people, and she's usually smiling. But I worry about her."

Dale Sr., a soft-spoken man who admits to having a temper, doesn't wear his emotions on his sleeve.

"He's suffering so much inside," Banks said. "This is his son, after all."

And Dale Sr. worries about the girls, who must vie with the most special of brothers for their mother's attention. Ashley, the youngest, has a speech problem, making Amanda the sole "normal" child.

"She's got middle-child syndrome, times two," Martha Rose said.

Like other children, Amanda uses negative behavior to win her mother's notice when she feels she's not getting the attention she needs.

During a visit to Dale Jr.'s gastroenterologist at Children's Hospital in May, Martha Rose tried to ask questions while her daughters clamored, "Mommy, Mommy, Mommmmmmy!"

Somehow, their mother managed to keep talking.

With Martha Rose deep in conversation with the doctor, the job of disciplining the children was left to Dale's caregiver. He clamped Amanda's hands together while she repeatedly screamed "I hate you."

A complicated thing, this family's relationship. Sometimes it seems held together by a high-tension wire that's been rubbed too often.

At the center, still, is an innocent boy in a wheelchair — the firstborn child of a young couple who, like all young couples, dreamed of happily ever after.

Thankfully, he'll never feel guilt for any of it.

# Relationships require extra commitment

Story by Nancy J. Smeltzer  
Dispatch Staff Reporter

Photos by Eric Albrecht  
Dispatch Staff Photographer

**T**WO-YEAR-OLD ERIC BIEL chose the indirect route to his big sister's side. He climbed over the bed railing and across the outstretched legs of both caretaker Jo Ann Mueller and 10-year-old Kathleen, then settled in.

As the trio watched a video from the bed, Eric gripped a bottle of juice with his left hand and caressed Kathleen's gnarled hand with his right. When Kathleen laughed at the funny parts of the show, Eric smiled as he drank.

By 9 that January night, the Gahanna home of Mary and Louis Biel had grown quiet for the first time. Such times, Mary said, make the sacrifices involved in working and caring for a disabled child and a 2-year-old worthwhile.

Their home is a revolving door of attendants, nurses and technicians — "invited intruders," Mary calls them — who tend to Kathleen. They are as much a part of the family as Eric, who the Biels adopted 18 months ago to fill a void for themselves and for Kathleen.

Mary and Louis wanted a child who could interact in a way Kathleen cannot. Their daughter, who has cerebral palsy and is mentally retarded, requires round-the-clock attention. She cannot walk, talk or feed herself.

The Biels were willing to adopt a disabled child. With the home set up for Kathleen, they could easily accommodate another with special needs.

"We thought we had a lot to offer a child," Louis said. "And at the same time, we thought Kathleen needed a sibling."

Still, the Biels had reservations about adoption. They were unsure how Kathleen would react to sharing their time and attention or whether a new child would be comfortable with Kathleen.

The adoption agency suggested Eric, who at the time was 6 months old and struggling in foster care.

Eric's health problems seem to center on developmental delays, Mary said. He doesn't talk yet, has poor muscle development and some hearing loss. The full extent of his problems won't be known for a few years.

To the Biels' delight, Kathleen and Eric have become fast friends. Eric clings to his sister, often climbing in bed with her or hitching a ride on the footrest of her wheelchair.

Having a little brother around has helped Kathleen become more social, said Patty Bennett, who cares for Kathleen five days a week.

"When Eric came," Patty said, "it was the first time she ever played with toys."

## A test of vows

The Biels have been married about 12 years — long enough that Louis can't remember not being married.

"So much has happened, it's like Mary and I have been together forever," he said.

Since Kathleen's birth in 1985, Mary and Louis have faced their share of rocky roads.

"The reality of the situation is that her care is very stressful," Mary said.

Louis thinks their marriage works because they love each other. They have made an effort to stay together by taking advantage of counseling.

"I find nothing wrong with it," he said. "It's the natural thing to do even if you don't have these stresses."

Louis works on many issues — anger and patience chief among them.

In the Biel household, Mary, 42, is the diplomat; Louis, 46, the defender.

He worries about Kathleen — but not now, not while he can protect her. The future is what frightens him.

"What's going to happen to her when I'm gone?" he wondered aloud. "Will she be treated with respect and kindness, or will she be treated as another glob that has to be dealt with?"

Just as his feelings for Kathleen are fierce, so, too, are his feelings for his wife.

"I love Mary very much," he said.

The personal sacrifices are ongoing, but Louis has never questioned his obligation.

"What else would you do?" he asked. "What else would you expect to do?"

## Open to counseling

Many marriages crumble under the demands of caring for a chronically ill child.

The responsibility requires so much time and attention that couples have little left for anything else — even each other.

Parents of disabled children face tough odds in trying to hold onto their marriages, according to a 1992 study of statistics from the National Health Interview Survey's Child Health Supplement.

Having a child with a single disability increases the risk of divorce 25 percent, the study shows; having a child with multiple disabilities pushes it to 50 percent.

For the Biels, the most difficult periods have followed Kathleen's major surgeries. Since her birth, they have gone for counseling twice.

"Both times we felt like we we're not going to be able to live together," Mary said. "From my way of thinking, it was a crisis."

They initially sought help about five years ago after Kathleen's first major surgery — to rebuild her stomach around the bottom of the esophagus.

In anger, Louis said he wanted a divorce, but

Mary wasn't about to let him leave: "Just shut up, and do your child care," she told him.

To some extent, she could understand his frustration.

"Why would you want to be married to someone who is always so miserable?" she said.

Mary watched their relationship deteriorate.

"You must become adversarial in the hospital setting, and it carries over," she said.

When Kathleen underwent hip surgery last summer, the Biels returned to counseling. They continue to see a counselor today.

Lack of sleep often plays a role in arguments.

Recently, the Biels spent the first few minutes of

a lunch bickering until Mary stopped, looked at Louis and asked: "Isn't sleep deprivation a real personality enhancer?"

Adding fuel to the fire are the grief they feel in watching their daughter suffer and the anger they harbor toward a medical system that, in their opinion, works poorly.

Tension escalates over who is in control or whose turn it is to change diapers, spend the night at the hospital or talk to the doctor.

"The bottom line is that there is no energy left to be tolerant of each other's differences or each other's problems," Mary said. "All the energy that could go into making this better is expended."

## Airing it out

Life's stresses inevitably become the topic du jour at monthly meetings of the advocacy group Families for Acceptable Care and Treatment of Medically Fragile Children.

That's why the meetings — held at the Easter Seal Rehabilitation Center on the South Side — inevitably become a place for parents of chronically ill children to vent.

In February, John Hollis of the Epilepsy Association of Central Ohio was invited to speak about seizures, but his words held the attention of few of the 20 or so people in attendance. Most whispered among themselves.

Seizures are a topic the parents are well-versed in. They wanted to know what to do about sour relationships, potential federal cuts in Medicaid or pending changes in the state's Individual Options Waiver, which helps pay for home care for chronically ill children.

Hollis relinquished the floor, knowing that the whispering would only intensify with the group's frustration.

Mary spoke about how much time the families spend keeping their children alive and fighting the system to keep their children at home.

Hollis asked what he could do.

"Help," Mary said. "You wish other people would help us keep the pieces together."

Mary acknowledged that she is tired of fighting the system. Waging such battles requires constant vigilance, and she doesn't always have the strength.

Others in the group agreed: They are tired and angry.

The discussion then turned to marriage.

One woman spoke volumes when she proclaimed: "My marriage is fine. My sex life sucks."

### A change in perspective

Not long after Kathleen was born, Louis grieved for the person she might have been.

In time, though, he has learned to be happy for the person his daughter is.

"I don't see what she doesn't have," he said. "I see what she has."

Kathleen and other children like her "are special people we're allowed to have to let us know what life is all about," Louis said. "If you don't get involved or understand what they represent, you're missing out on a lot."

The way Louis sees it, he's a lucky man.

"Everyone wants some meaning to life. ... I have one. It's a privilege to have it. It's a privilege to be Kathleen's father."

## Where to get help

Parents of disabled children face a maze of bureaucracy in seeking help. Here are some starting points for deciphering the Medicaid waiver system and finding services:

### SUPPORT GROUPS

#### ■ The ARC of Ohio

1335 Dublin Rd., Suite 205-C  
Columbus, Ohio 43215  
487-4720 or 800-875-2723

The 44-year-old parent-based advocacy group is linked to a statewide and national network of offices.

#### ■ Families for Acceptable Care and Treatment, or FACT

1335 Dublin Rd., Suite 126-D  
Columbus, Ohio 43215  
228-5523

The family support and advocacy group meets monthly and seeks public and legislative attention for disabled children.

### AGENCIES

#### ■ Easter Seals

565 Children's Dr. W.  
P.O. Box 7166  
Columbus, Ohio 43205  
228-5523

The nonprofit organization offers programs and information to parents of disabled children.

#### ■ Ohio Department of Health's Bureau for Children With Medical Handicaps

P.O. Box 1603  
Columbus, Ohio 43266  
466-1700

The state agency offers a variety of diagnostic and home-based services for disabled children.

#### ■ March of Dimes Birth Defects Foundation

500 W. 3rd Ave.  
Columbus, Ohio 43212  
486-5243

The nonprofit organization offers help to parents of children with birth defects.

### AGENCIES THAT PROVIDE MEDICAID WAIVERS

Parents who wish to apply for a Medicaid waiver should call county or state offices of Mental Retardation and Developmental Disabilities or Human Services. Here are Columbus-area contacts:

■ Franklin County Human Services, 462-4000

■ Franklin County Board of Mental Retardation and Developmental Disabilities, 475-6440

■ Ohio Department of Human Services, 466-6742

■ Ohio Department of Mental Retardation and Developmental Disabilities, 466-3814

Dispatch graphic

# The Columbus Dispatch

SEPTEMBER 20, 1995

By Michael J. Berens  
Dispatch Staff Reporter

**W**ITH A RESOLVED mind but uncertain heart, Greg Carter pushed his daughter's wheelchair into the Heinzerling Developmental Center of Columbus, entering a fragile world where children seldom grow old.

Numb with resignation, he found himself in the lobby surrounded by the experienced smiles of nurses and administrators who were aware that he, too, had just crossed a personal threshold.

*Lauren does not belong here.*

Carter believes that his 7-year-old daughter fell victim to a tug of war between his desire to care for her at home and a mighty Medicaid system that pulled them to this place.

He wheeled Lauren into the conference room for a check-in meeting. His fiancée, Meri-Ellyn Eubank, carried a small, vinyl suitcase filled with Lauren's clothes and possessions.

Strapped in her wheelchair for safety, Lauren fidgeted at the table's edge — occasionally yelling incoherently — as the adults discussed her future, sealing their agreement with the signing of legal and medical papers.

Carter knew that his daughter, who is mentally retarded and has cerebral palsy, probably would never understand that Heinzerling is now her home.

## A facility tour

A brisk breeze tempered a muggy 78 degrees — above average for May 17 — as a storm slipped across the city, leaving behind a half-inch of rain.

Inside, Carter and Eubank found themselves in an equally unpredictable environment.

As they made their way to Lauren's room, they passed four disabled children lying prone on floor mats in one room, an alert boy incapable of movement who rested on

a floor mat in the hallway and a black-haired girl struggling to hold herself up in a wheelchair in the cafeteria.

The images are depressing, Carter thought, yet Heinzerling also seems remarkably cheery.

The children's rooms exude personality — from the Elvis and Bart Simpson posters on walls to Minnie Mouse stickers on bed frames.

The hallways are lined with orange carpet and large murals of zoo animals.

Nearly every child has a portable cassette player. Melodies of Raffi, Barney and Sesame Street waft to the children, who are unable to speak but share a communication with the music.

"The music works a magic on the children," a nurse said.

Outside Room 211, Carter paused.

"This is really hard for me," he said softly.

Nurses stood nearby with sympathetic faces, the anguish of check-in day never lost on them.

Carter lifted Lauren into her new bed, suspiciously comparing its construction with the bed he had made for his daughter at home in West Chester, Ohio.

He used pine. Heinzerling installed Plexiglas walls to box in the mattress, which was set low to the floor on a steel frame.

"Oh, no," Carter told a nurse. "This bed is not going to work."

Carter's concern was safety.

"Lauren can put her arms over the side and pull herself up and over," he explained.

When he told the nurses that the bed's walls needed to be a few inches higher, a supervisor explained that Medicaid rules prohibit walls above 3 feet.

# A new life for Lauren

"What does Medicaid say when my daughter climbs out and cracks her head open?" Carter snapped.

A compromise was reached: Instead of raising the walls, the staff would lower the mattress.

Two maintenance workers — handyman surgeons of sorts — wheeled in large, blue carts full of tools and other instruments as they began a two-hour operation.

Carter stood in the hallway as the men circled the bed with tape measures and drills.

The irony of the situation didn't escape him: Except for the materials, the bed is identical to Lauren's bed in their apartment.

Last year, in a nursing report prepared for the state, Carter's handiwork was criticized as an unsafe attempt to barricade Lauren.

"Look, this is the same bed," Carter said bitterly to his fiancée. "I'm accused of bad things. When the state does it, then it's OK."

## NOT THE PERFECT FIT

As Carter and Eubank learned more about Heinzerling, the center's employees got to know Lauren.

Her mobility and strength, they discovered, easily surpass the most active of the young patients. Despite having little coordination, Lauren is a constant whirl of motion. She jumps, bends, twists and pinches. Her legs can support weight, but, for safety's sake, she must be held.

"This facility was not designed for an active child like Lauren," social worker Linda McGuire said.

Founded in 1959 by Otto and Mildred Heinzerling, the original 34-bed children's facility — called Peck O'Wee Ones — was built on the city's East Side.

Today, Heinzerling — nestled among a quiet oasis of trees and grassy fields on the city's South Side — has facilities for adults and children.

The \$4.5 million Heinzerling Developmental Center, built in 1982, houses 104 adults with severe mental retardation. Across the street, an equal number of similarly ill children live in the \$2.9 million Memorial Foundation, built in 1979.

Heinzerling has no playgrounds, despite the open areas on the grounds. The small courtyard

wasn't designed for play because few children can leave their wheelchairs.

*My daughter does not belong here.*

Carter could not rid himself of the thought, despite the friendly staff members who enthusiastically promised to change their routines so Lauren would get plenty of exercise.

The state had ruled that Lauren isn't sick enough to continue qualifying for Medicaid benefits under the Department of Human Services' Medically Fragile Waiver, which pays for home nursing care.

Now Lauren isn't sick enough to fit properly into Heinzerling.

Carter had crunched the numbers: Home care would cost the state about \$45,000 annually; institutional care would cost at least \$55,000 a year, according to conservative state estimates.

"It makes no sense," Carter said. "This is a system that destroys families."

### THE UNAVOIDABLE FAREWELL

With Lauren, words were never necessary.

Carter squeezed his daughter in a giant hug, holding her at eye level while gently rubbing his forehead against hers.

*I love you.*

His eyes spoke silently. He slowly twirled and nuzzled Lauren's body, hoping that she might know he is her father — and always will be.

Nurses quietly walked away, recognizing that the inevitable moment had arrived, just as it does for every parent on the first day.

Eubank stayed in the background, too, her eyes moistening as Carter and Lauren remained locked together.

"I feel so sorry for him right now," she said.

Carter carried Lauren to a recreation room, his eyes never leaving hers.

*Goodbye.*

His grip lingered as heart and mind clashed again, climaxing in a burst of pent-up tears as he handed Lauren to a waiting nurse. He dashed from the room back to where his fiancée was waiting. With his head locked forward, Carter strode

out the doors of Heinzerling.

"If I look back," he said, "I'll never be able to leave."

### A DIFFERENT LIFE

Carter and Eubank married June 24. The small ceremony, held in a park gazebo near their home, was followed by a Florida honeymoon.

Because their daughter was at Heinzerling, the Carters brought a teddy bear to the wedding with a picture of Lauren taped to its furry, white belly.

Their dreams of marriage and quiet time together have become a bittersweet reality. They visit Lauren most weekends, making the 240-mile round-trip from West Chester in a day.

"This year has been a hell for me and Meri-Ellyn," Carter said. "I hope someone sees our lives and realizes this system must change."

The system, Carter said, forced a choice between the welfare of his daughter and that of his wife and their two boys, Dustin, 7, and Christopher, 1.

"You know, I wonder if anyone really cares," he said. "Parents like

us are really in the minority. It's easy just to ignore us."

Lauren is doing well at Heinzerling, where she celebrated her 8th birthday Sept. 12. She has been weaned off some medications and is working toward eating solid foods.

With major improvement, Lauren could be transferred to a residential facility, where patients require less medical supervision. A Medicaid waiver remains a distant option for the family because of the waiting list.

"I miss Lauren every day," Carter said. "I know she is fine, but not having her with me is very, very hard."

Lauren's absence doesn't go unnoticed by her stepbrother, either.

She and Dustin had spent many hours gently wrestling, forming a bond based on touch and movement.

The first night Lauren spent at Heinzerling, Dustin went into her old bedroom and climbed the walls of her special bed.

"I feel closer to her in the bed," he told his mother.

He plans to sleep there until Lauren comes home again.

## Places for children

*Institutional care is an alternative to home care, although most facilities have waiting lists. Many nursing homes offer some beds to children. Here are some of the largest facilities in Ohio that treat disabled children:*

### FRANKLIN COUNTY

■ **Heinzerling Foundation Developmental Center**  
Capacity: 104  
Columbus

■ **Northland Terrace Medical Center for Subacute Care and Rehabilitation**  
Capacity: 260  
Columbus

### OHIO

■ **Brookside**  
Capacity: 104  
Warren County  
Mason

■ **St. Joseph's Children's Home**  
Capacity: 47  
Hamilton County  
Cincinnati

■ **Camelot Lake**  
Capacity: 36  
Butler County  
Fairfield

■ **Stillwater Center**  
Capacity: 92  
Montgomery County  
Dayton

■ **Hattie Larlham Foundation**  
Capacity: 130  
Portage County  
Mantua

■ **Sunshine Children's Home**  
Capacity: 84  
Lucas County  
Maumee

Sources: Ohio Department of Health, Ohio Department of Mental Retardation and Developmental Disabilities

Dispatch graphic

# Despite significant toll, parents wouldn't have it any other way

Story by Nancy J. Smeltzer

Dispatch Staff Reporter

Photos by Eric Albrecht

Dispatch Staff Photographer

**M**ARY AND LOUIS BIEL had a memorable New Year's Eve — but for the wrong reasons. A family celebration went awry when their daughter's leg caught on a bedspread and got pulled behind her while she was in her wheelchair.

The accident landed the Gahanna couple in an all-too-familiar place: Exam Room 16 of Children's Hospital.

"Oh, darling, I love you. I love you," Mary consoled a tearful Kathleen, caressing her head, holding her hand and looking in her eyes.

The words soothed her daughter momentarily — until the steady beep of a monitor down the hall startled Kathleen, prompting more tears.

A parade of hospital workers had passed through but none with any news.

"I hate this," Louis said.

The wait might be three hours; it might be eight. The Biels never know.

This time, the diagnosis came fairly quickly: The leg was broken, the resident doctor said, but no surgery would be required.

The Biels spent the next several hours making sure that Kathleen's broken leg didn't turn into a life-threatening experience.

Since birth, the 10-year-old has spent a lot of time inside the sterile walls of Children's. She was born with cerebral palsy, which has left her mentally retarded and unable to walk or talk.

Because she cannot communicate, her parents can only guess how she feels.

The Biels pay a hefty price — emotionally and financially — to care for Kathleen at home. Yet they do so willingly. They believe the loving, caring atmosphere they provide for Kathleen cannot be found in an institution.

## A big change

People with disabilities never frightened Mary. She always worried about their families.

"I felt so heartsick for them because their job is so difficult, and it changes their lives so much to live with that person forever and then to lose the responsibility after they are too old to take care of them," Mary said.

She was introduced to the world of the disabled in her first job as an aide at a sheltered workshop. In such an environment, people with disabilities are taught work skills and behaviors to help them get jobs.

"I loved it," she said. "I thought it was my calling."

Mary got to know the families and watched as they struggled to keep their jobs, pay their bills and care for a child whose needs taxed them physically.

She couldn't help thinking of those families when she learned Feb. 24, 1985, that her daughter had been born with birth defects.

That life was now hers.

"When I had Kathleen — when I started to realize how severe her disability was — it wasn't a process of accepting it. It was: 'Holy crap, my life is going to be like those people's are. Why don't I shoot myself and get it over with?'"

The extent of Kathleen's health problems wouldn't be known for at least five years.

"I love Kathleen so much, I don't like to say this, but it's like a cloud that hangs over you for the rest of your whole life," she said. "You try to not let it be a cloud."

Every six months for the first five years of her life, Kathleen faced a medical disaster. Each time, the Biels learned more about the severity of their daughter's illnesses.

As they moved from doctor to doctor and specialist to specialist, the couple paid the bills on a combined income of about \$24,000. A third of their income, Mary estimates, went to out-of-pocket medical expenses.

To help shoulder some of the cost, the Biels applied for and received a Medicaid waiver, which allows them to care for Kathleen at home. They don't consider institutionalization an option.

"Louis and I did it for three years before we had the waiver," Mary said. "The only reason we survived was because my parents gave us money."

## Different lives

Ten years ago, Mary and Louis were working for Mary's father in Columbus selling auto-repair equipment.

Mary also was commuting to Charleston, W.Va., to complete her master's degree in counseling. Her graduation that spring coincided with Kathleen's birth, which occurred seven weeks earlier than expected.

The week his daughter was born, Louis started a new job as an insurance salesman. By the time he left six years later, he was making \$40,000 a year.

The job didn't have the financial stability that was necessary with a daughter as needy as Kathleen.

He opted to pursue a new career path. His childhood dream of becoming a doctor led him to the field of medicine. He chose respiratory therapy.

Louis just finished his first year as a therapist at Ohio State University Medical Center.

"I am no longer only the parent of a handicapped child," he said. "I'm inside the medical system."

The work has provided him with stability and knowledge of the system and has allowed him to better care for his daughter. No longer is he fearful when Kathleen struggles to breathe.

Mary, too, has a job she enjoys and one that allows her to help Kathleen.

She is the operations officer for Easter Seals, work that puts her in touch with the services and facilities for people with disabilities like her daughter's.

Mary keeps a close eye on services, such as the waiver system, that frequently become potential targets of state and federal budget axes.

"I'm obsessed with this waiver," she said. "I'm obsessed with it being funded and people getting some family support. And nobody else would be if their child didn't have a disability, I don't believe. ... I was very good when I worked in the field before I had Kathleen. I was very compassionate, but you can't totally walk in somebody else's shoes."

Though the Biels now earn a combined \$60,000 a year, they fear a future without the waiver.

"Our life is comfortable because we have help," Mary said.

The Biels' waiver — which pays for \$87,000 in attendant care annually — allows both to work full time while attendants care for Kathleen five days and three nights a week.

The Biels are hoping a third income soon will help lessen their dependency on the waiver: They are selling an alternative brand of products — soaps, lotions, vitamins — made from the oil of the leaves off a melaleuca tree found in New South Wales, Australia.

The Biels take other steps, too, to ease their waiver dependency.

They both carry private insurance through their

employers, paying about \$250 a month in premiums. Mary's insurance carrier paid about \$46,000 in costs for Kathleen last year — money she saved the state, she notes.

## Running on empty

Exhaustion is a constant for the Biels.

In March, the whole family — including 2-year-old Eric — was felled by pneumonia.

"We're getting too old, too tired for this," Mary said.

Kathleen's care through the night is a formidable job. The first nine years of their daughter's life, the Biels provided all overnight care. That ended with Kathleen's hip surgery last summer, when the family was forced to get round-the-clock help.

Now the Biels use part of their attendant-care hours to cover three night shifts a week. Mary and Louis share the duty the remaining four nights, trying to squeeze sleep into a night of repositioning Kathleen, who sleeps in a sitting position and cannot right herself if she tips over; changing diapers; and giving medications.

The Biels trade nights, hoping one can catch enough sleep to function the next day.

If Kathleen could talk, she could tell her parents about her pain — where she hurts, when she is hungry, when she is tired.

Instead, it's a guessing game — the way it was on New Year's Eve at Children's Hospital.

If only Kathleen could have told someone how badly her leg hurt — or didn't hurt.

Maybe then, three weeks later, Mary would not have been told that Kathleen's leg was not broken after all. What looked like a break was a shadow from a vein.

Mary's only response: "I don't want to pay for this."

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# Sacrifices

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## a daily part

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## of son's care

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Story by Laurie Loscocco

Dispatch Staff Reporter

Photos by Lynn Ischay

Dispatch Staff Photographer

**N**OT LONG AGO, children like Dale Sapp Jr. were the kids nobody knew. Born with numerous and severe abnormalities, they lived in institutions, which were equipped technically — if not always sensitively — to deal with their many needs.

The realities of such kids' lives — the catheters, the convulsions, the occasional screams — were removed from the lives of "normal" people in "normal" neighborhoods.

Today, though, many parents choose to care for their chronically ill children at home. Wheelchairs rest alongside bicycles; intravenous medicines share space in the refrigerator with milk; and recitals and baseball games vie for slots on the calendar with doctor's appointments and physical therapy.

Through the seven years of Dale Sapp Jr.'s life, his parents, Dale and Martha Rose of the Northwest Side, occasionally have been asked whether they'd consider placing their son in an institution.

Each time, they've refused.

Caring for 7-year-old Dale — who cannot walk, talk, bathe or feed himself — is not without steep costs.

The Sapps have given up their privacy: Their home is a carousel of nurses, therapists, teachers and caregivers.

They have given up a career: Martha Rose stays home to care for Dale and his two sisters, Amanda, 5, and Ashley, 3.

They have given up the ability to go someplace — anyplace — on a moment's notice: Provisions must be made for medicines, feedings and emergencies.

To some extent, they have sacrificed each other: Their marriage is in jeopardy.

In return for the sacrifices, their boy gets to wake up every morning in his own house. He gets to play in his own back yard, with a large wooden swing set his daddy made.

Instead of the clang of institutional metal, he gets to hear the giggles of his sisters.

He gets a hug from his mom, just because she's there.

The Sapps will care for Dale at home as long as possible.

"A lot of times, when I think about Dale's future, I get very depressed," Dale Sr. said.

"I really don't want him to go into a (nursing) home. Here, he has love, and sisters who crawl all over him and make him laugh. He'd probably die in a home."

"He belongs here," his mother said. "This is his home."

Martha Rose hesitates to find fault with parents who opt to place their children in institutions. Though the choice is a cop-out for some, she believes, others are unable to handle the burden.

## Both mom and nurse

That Martha Rose is a nurse — who at one point in her career cared for people not unlike her oldest child — is both a blessing and a curse.

She has the technical skills to perform some of the duties, but she sometimes feels as if she must do it all.

Last year, before Dale Jr. was released from a four-month hospital stay — during which he came within a whisper of death — hospital staff members tried to talk to the Sapps about placing Dale in an extended-care facility. Martha Rose wouldn't hear of it.

"She said, 'I will *not* let anyone else take care of my child,'" said Dr. Joseph Banks, Dale's primary doctor.

So she took her critically ill son home to a house that had been all but emptied of its regular furniture and rearranged to resemble an intensive-care unit.

An abscess on the appendix was the likely source of an infection Dale had contracted. Because of the problems, a shunt that runs from a ventricle in his brain to an abdominal cavity — used to drain fluid from Dale's brain — had to be moved outside the body.

Before Dale was discharged from the hospital, one end of the shunt had been moved outside the skull. Each day,

Martha Rose drew fluid out of the shunt so it could be sent to a lab and tested for infectious organisms. A wrong move during the procedure could have caused serious complications.

Despite her nursing background, Martha Rose was frightened.

"It's different when it's your own child," she said. "You're a mother first, a nurse second."

As recently as seven to 10 years ago, a child as sick as Dale was not sent home, said Joann Hilt, a nurse who worked at the Sapp home until this spring.

"In this home, there was an advantage because Mom's a nurse," Hilt said. "But I've seen other parents who've had to learn everything. It's remarkable to me what these mothers do."

As a home-care nurse, Hilt sees the tightrope some families must walk every day.

"Everything in these homes revolves around these kids. ... They have to be put in front of everyone else. It can be really hard on the siblings."

For nurses, the experience of home care is both rewarding and challenging.

"You're on your own," Hilt said. "There's no supervisor to turn around to and ask a question. A lot of times, you have to act before you can get ahold of somebody."

The Sapps say their experience with home nursing has been varied. Some nurses have been warm and caring —

like extensions of the family. Others have been pushy.

"I've moved furniture around and changed rooms around several times because a nurse wanted it that way," Dale Sr. said. "I feel like, hey, this is *our* home. I feel bad because Dale's room isn't a little boy's room anymore. Dale sleeps downstairs, and his room has been taken over by the girls."

## Lost privacy

The responsibilities are many.

Caring for Dale at home means being in charge of ordering and receiving supplies — from diapers to the liquid concoction that runs through a tube into Dale's stomach, his only means of nourishment.

It means coordinating the schedules of a dozen professionals.

It means being "on" every day.

Air-clearing fights with the spouse are out because the aide is in the next room.

"It's a total invasion of privacy," Martha Rose said. "I can't walk around in just a long T-shirt if I want to. I have to be *modest*," she said, laughing.

"That's what happens once you let the system in. But you have to let the system in if you want to have anything for your child."

When Martha Rose isn't shuttling children to doctor's appointments, dance classes and preschool, she is usually on the phone. She may be trying, for the umpteenth time, to get approval for a lift for the family van so she doesn't have to rely on another person to help hoist her 55-pound son in and out each trip.

She may be trying to reach the special-education teacher or schedule a nurse. Or she may be struggling again to understand what her insurance plan does and doesn't cover.

"I hate who I've become," Martha Rose said. "You have to fight for everything. You're on the phone all day; you argue with people every day. There's not a week that goes by when there's not some crisis."

Banks, who also is Ashley's and Amanda's pediatrician, worries that the family — Martha Rose in particular — may not be able to hold up under the stress.

"They're paying a heavy price, financially and emotionally," he said.

Banks did some of his training at the former Columbus State School, where children like Dale once lived. The memories make him shake his head.

Such "institutions" generally are a thing of the past. Some children with multiple disabilities now reside in settings called long-term-care facilities, and others live in group homes.

Then there are families such as the Sapps, who struggle from day to day to fit their complicated child into the routine of suburbia.

More than once, Martha Rose has asked herself: "Why me? Why Dale?"

She is not inclined to believe that she'd be better off without her son.

"If someone came to my door tomorrow and said I could be the richest woman in the world and that my life would be easy — but only if I'd give Dale up — I'd say no. What would my life be like without Dale?"

## Pressures catch up with Dale Jr.'s mom

By Michael J. Berens

Dispatch Staff Reporter

**M**artha Rose Sapp's world crumbled on Aug. 5.

Overcome by stress and depression, she admitted herself into Harding Hospital, a North Side psychiatric facility, where she spent a week battling her ailments.

Heightening her decline was a medical report she and her husband, Dale Sr., had received from an Indiana clinic where Dale Jr. had undergone tests.

The report showed not only that their son is deteriorating faster than expected but also that their daughters — Amanda, 5, and Ashley, 3 — may be carriers of a genetic flaw that could cause disabilities in their own children.

"I stood over the kitchen sink and broke down in tears," Martha Rose said. "I think the news from the clinic was the final straw."

That Saturday, Martha Rose said, she gripped a bottle of Excedrin in her right hand and a bottle of Tylenol in her left as she contemplated taking her life.

"It got to the point to where I was thinking suicide," she said. "As a nurse, I knew how much it would take to kill me."

After calling friends for help, she sought emergency treatment at Harding. She continues with outpatient counseling.

Assuming that the Indiana diagnosis is confirmed, Martha Rose expects to tell her daughters that they are carriers of a gene that causes one in four infants to be born severely disabled.

"The doctors in Indiana told me that I had beaten the odds twice because I have two healthy little girls," Martha Rose said. "But my daughters will need to be told that they could someday have children like Dale."

While the family awaits final word from the doctors, Dale Jr. continues a slow decline as his brain tissue calcifies.

"I don't want to hide anything," Martha Rose said. "I want people to know what my life is like and what is happening to my family."

"Only tomorrow will bring the answers."

THE WHITE HOUSE  
WASHINGTON

*file*

December 11, 1995

MEMORANDUM FOR PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

FROM: Carol H. Rasco  
Assistant to the President for Domestic Policy

SUBJECT: President's Radio Address on Medicaid

It was good to meet with you all on Friday. I know you had a very productive meeting.

I wanted to make sure each of you had a transcript of the President's weekly radio message in case you did not hear it on Saturday. Please note that the President mentions persons with AIDS as among those who would be adversely affected by the Republican budget proposal on Medicaid. He added that on his own during the preparation session.

As I shared with you at the meeting on Friday, I deeply appreciate all that you are doing to help this Administration do the work at hand on HIV/AIDS issues.

I wish you and all those you hold dear a happy holiday season and the promise of hope in the new year!

THE WHITE HOUSE

Office of the Press Secretary

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Embargoed for Release  
Until Saturday, December 9, 1995  
at 10:06 A.M. EST

RADIO ADDRESS BY THE PRESIDENT TO THE NATION

The Oval Office

THE PRESIDENT: Good morning. As you all know, we're engaged in a great debate over how best to balance the budget. We must balance the budget. Since I became President, we have cut the terrible deficit we inherited nearly in half. Now, we must finish the job.

But let's remember why we want a balanced budget: To strengthen our economy and lift the burden of debt from future generations. To do that, we have to balance the budget in the way that reflects our most fundamental values -- increasing opportunity; asking all to assume responsibility; strengthening our families and the economy; recognizing the duty we owe to each other, to our parents, our children and those who need and deserve our help.

This past week, I took two steps to advance these values. First, I vetoed the Republican budget plan that was sent to me by Congress. I did it because that budget violates our values and would have hurt our economy. I did it because in so doing I vetoed the most massive cuts in Medicare and Medicaid in history, a tax increase on working people, and deep, deep cuts in education and the environment.

This effort to balance the budget through wrongheaded cuts and misplaced priorities is now over. Then, I sent to the Congress a plan to balance the budget in seven years without devastating cuts in these areas. My seven-year balanced budget plan reflects our values and protects our investments in the future. It reflects a good-faith effort to find common ground on the budget. At stake is far more than just numbers and abstract programs and proposals, and far more than the normal political debates in Washington. This debate is about people, the lives they lead, the hopes they have, the desires they have for a better life.

Nowhere is this choice clearer than in our different approaches to Medicaid. For three decades, the Medicaid program has meant that if your child was disabled in an accident, or your husband got Alzheimer's, or your parent needed nursing home care, you would get the help you need.

The Republican budget would cut Medicaid by \$163 billion. It would repeal the guarantee of health care for poor children, people with disabilities, pregnant women and older Americans. Now, this repeal was not an afterthought or an unintended consequence. The congressional Republican majority is actually insisting on it. What would this mean?

Well, in 2002 alone, the year the budget is supposed to be balanced, the Republican budget could deny quality health coverage to nearly 8 million people; deny meaningful health care to over a million people with disabilities, even to 150,000 veterans, and to tens of thousands of people with AIDS, many of whom are able to keep working, or who can get the help they need without their families being forced into poverty because of the assistance they get from Medicaid.

Today, a poor child who gets sick has access to a family doctor. Under this bill, nearly 4 million poor children could be denied quality medical care. If they got sick, they'd have to pray for charity care at a crowded hospital emergency room. Today, pregnant women know they can get prenatal care for their sake and the sake of their unborn children. But under the Republican plan, hundreds of thousands of pregnant women could be denied regular check-ups and other basic services that could lead to an increase in infant mortality or children born with irreversible problems.

Today, elderly women who have devoted themselves to their families know they can count on medical care, even if they don't have much money. But under the Republican plan, as many as 330,000 older Americans could be denied nursing home care.

Today, middle class parents know that in the awful event their child is disabled in an accident and their savings are gone, they'll get help to keep the child at home. Under the Republican plan, hundreds of thousands of disabled children could lose help for home care.

Earlier this week, I had the pleasure of meeting the Striggles family from Forestville, Maryland.

Franklin Striggles works hard as a security guard. He and his wife, Denise, have health insurance from his job. But it doesn't begin to pay the cost of caring for their son, Angelo, an energetic seven year old who has spinabifida, and who's now confined to a wheelchair. That's where Medicaid comes in.

With Medicaid, this working family can keep a job, raise and educate their other children, and give little Angelo good care. To see Angelo and his family, it's clear how much love and learning he gets from living at home with his brother and sister. It pains me to think that if the Striggles family lost Medicaid coverage, Angelo could be torn from his family, even forced to be placed in a state institution.

If the Republican cuts in Medicaid take effect, the blunt reality is that as many as 4 million children will simply be denied needed medical care. They'll either be turned away from medical facilities, denied preventive care, or be turned out too soon. That is unacceptable in a country that cares about its children. And I will not permit it to happen.

Yes, the deficit is a burden on future generations, but so is the neglect of our children. And we do not have to sacrifice our children to balance the budget. That's why I vetoed these cuts last week. Now, some Republicans continue to insist on unconscionable cuts in health care for our children as part of a balanced budget.

So I'll say once more: If necessary, I'll veto these deep cuts in health care for children again and again and again. I'll do it because they are not necessary to balance the budget. And they, too, will place an awful burden on future generations.

My seven-year balanced budget plan trims Medicaid and keeps costs down. It cuts federal spending, lets states be more efficient, targets the money more wisely. But it doesn't end the guarantee of health care for millions of Americans who depend upon it now.

We expect every family to pay its bills and to care for its children. Well, our country can do the same. We don't have to hurt our children to balance the budget.

It's time for men and women of both parties to put aside their narrow interests and extreme ideology and together pursue the national interest. I have reached out to bridge the differences between us so that our country can move forward. If we'll all just work together and keep our eye on the future, we can get this job done.

Thank you for listening.

END

2/7/96

FEB 8 1996

Claro  
 Pat Miller's  
 note on ~~the~~ NSA  
 American Man  
 in New Tex  
 News

By

#3 Some states may require special provisions. Also perhaps let states choose base year.

#4 Formula vs. Factor

#5 Includes vs. Sum

#6 Medicare hospital wage index (applied to previous year) vs. medical inflation

#7 Full federal funding

#8

95\$ Formula  
People  
Case Mix  
Medical Inflation

#9 Needs to be specified

---

Aug.

#10 Same as #6

#11 Special grants not matched

#12 All rural health centers & EPSDT's

#13 Condition of participation (not state mandate)

#14 Trade off only at present - not agreed to

---

(+) (people) not (\$) Umbrella calculated on federal share not federal & state share

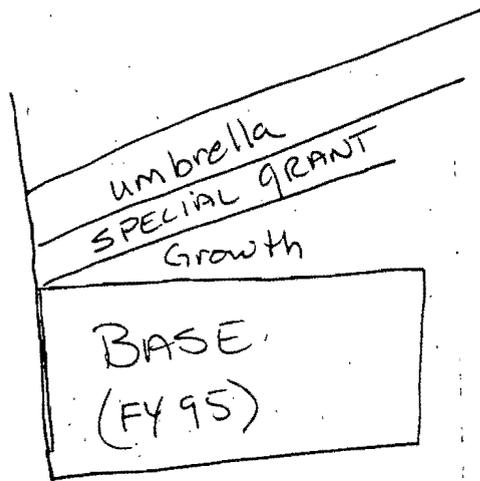
(++) Surplus needs to be used to offset in category before surplus

(+++). Need >1% to penetrate umbrella

THE PRESIDENT HAS SEEN

217196

Claro  
Port Moresby  
Museum ~~on~~ NGA  
Museum Man  
Museum  
By



**UMBRELLA**

#1 All Mandatory Eligible  
Mandatory & Optional Benefits  
Optionals

Under 6 - 133%  
Under 12 - 100%  
Pregnant - 133%  
Disabilities - yes to 80% & yes to 240% if states define  
Elderly - yes SSI to 80% & Optional

Pregnant 133%-185% - no  
Infants above 133% - no  
1902-R2 up to 300% - no

New Groups - "off welfare or illegals - no

**MANDATORY**

*Mandatory & Optional*

|     |     |
|-----|-----|
| yes | yes |
| <6  | 1   |

**OPTIONAL**

<6 - 133%  
<12 - 100%  
Pregnant to 133%  
Disabilities to 80%  
Disabilities to 240% State definition

possible inclusion for  
calculation errors only



Pregnant 133% - 185% no  
Infants > 133% no  
1902-R2 to 300% no

#2 No match - fully federally funded

THIS FORM MARKS THE FILE LOCATION OF ITEM NUMBER \_\_\_\_\_  
LISTED IN THE WITHDRAWAL SHEET AT THE FRONT OF THIS FOLDER.

EXECUTIVE OFFICE OF THE PRESIDENT

19-Dec-1995 08:51am

TO: FAX [REDACTED] Minish, Dan)

FROM: Carol H. Rasco  
Domestic Policy Council

CC: Jeremy D. Benami FYI  
CC: Patsy Fleming FYI  
CC: Jeffrey Levi FYI  
CC: Julie E. Demeo : for files

SUBJECT: Greetings!

Dan:

Thank you for your letter of December 13. Seldom does a letter touch me as yours did...and even more seldom do I use a fax to answer a letter but I wanted you to have a response immediately.

As you spoke of the Republican efforts on Medicaid I felt a real kinship with you....I have a developmentally disabled 22 year old son, Hamp, and he is on Medicaid...it is the only insurance available to him as no company will sell us a policy of any type for him now that he is over 18. He lives in a group home in Arkansas and works part time at the state health department. I daily tremble in fear of having to tell him the group home might close. Many people do not see your son or mine as Medicaid patients, and yet there are many families in American like yours and mine who experience daily the very positive benefits of this program. I hope you will continue to share your feelings far and wide...the Jays and Hamps throughout the country need our voices and as many others as possible.

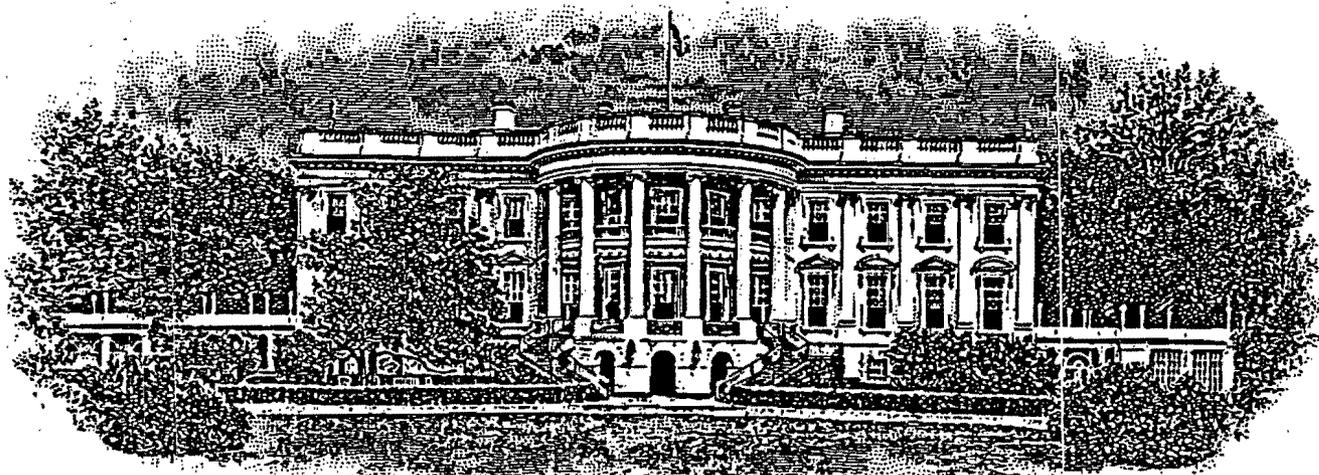
The President's strong voice is one that is working hard daily for our children. I will make certain he sees your letter today.

I wish for you, Jay and all your family a joyous holiday season and a very Happy New Year! I will continue to look forward to hearing from you.

FEB 7 1996

FEB 6 1996

# The White House



DOMESTIC POLICY

## FACSIMILE TRANSMISSION COVER SHEET

TO: Carol Rocco

FAX NUMBER: 62878

TELEPHONE NUMBER: 62216

FROM: Chris Jennings

TELEPHONE NUMBER: 65560

PAGES (INCLUDING COVER): 4

COMMENTS: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Handwritten initials/signature*

February 6, 1996

**TO:** Distribution

**FROM:** Chris Jennings  
Jennifer Klein

**SUBJECT:** Medicaid Talking Points and Background Information

Attached are our "cleared" talking points that we are using for questions about the National Governors Association's Resolution. Also attached is a one-pager that outlines our preliminary concerns about some of the specifics in the NGA resolution.

We hope you will find this information useful. Please call us with any questions.

Thanks

## TALKING POINTS ON GOVERNORS' MEDICAID POLICY RESOLUTION

- We are pleased that the Governors' have passed a policy resolution that affirms our national commitment to the guarantee under Medicaid. We are also pleased that they have continued the financial partnership between the federal government and the states that allows Medicaid funding to follow increases in enrollment.
- As Congress considers this resolution, we need to make sure that that guarantee is real.
  - There must be a national guarantee to meaningful benefits.
  - There must be national guidelines for eligibility that protect those who are eligible under current law. For example, under current law, coverage for three million children between 13 and 17 is being phased in. That commitment should continue.
  - And we must preserve adequate enforcement to assure this guarantee.

**CONCERNS/OUTSTANDING QUESTIONS**  
**ABOUT THE NGA MEDICAID RESOLUTION**

- **Eligibility concerns include:** *The repeal of the current law's phase-in for coverage of about 3 million children age 13-17; the devolution of the "disability" definition to the states; the limitation to "frail" elderly population seems to not include all elderly who are currently eligible; and the elimination of the required coverage of premiums for low-income Medicare beneficiaries between 100-120 percent of poverty is repealed.*
  
- **Benefit concerns include:** *The total discretion given to states to alter the amount/duration/scope of services; the repeal of the current law's comparability and statewideness requirement that ensure that recipients in particular groups or locations are not discriminated against; the apparent elimination of any defined benefit package for currently optional populations; and the vague redefinition of the "T" in the EPSDT children's health benefit.*
  
- **Enforcement concerns include:** *The state-based right of action process advocated by the Governors (and whether it will work to effectively ensure the guarantee).*
  
- **Financing concerns include:** *The exclusion of pregnant women and children, as well as the medically needy, from the Federally-financed "umbrella" pool payments; the inclusion in the base formula of the allowance that states can reduce their matching Medicaid rate -- the result producing an additional \$200 billion reduction in state Medicaid spending over seven years, bringing the total Federal/State cut to \$290 billion; the allowance for states to, once again, tax health care providers to help finance their state match; allowing for provider taxes will likely push up the cost of the program that CBO scores.*
  
- **Quality concerns include:** *The adequacy of the quality protections for plans under Medicaid, such as HMOs and other managed care plan; the apparent repeal of the state-based enforcement of Ronald Reagan's Federal nursing home standards. (The difference between them and us has always come down to definition and enforcement.)*

Plein to CLR

The President's plan achieves \$59 billion (vs. \$85 billion for the Republicans) in Federal Medicaid savings from a per capita cap mechanism, combined with savings from Disproportionate Share payments. He retains the individual guarantee, enforced through the Federal courts, to a set of meaningful (and nationally defined) benefits, and he provides for unprecedented flexibility for Governors in administering/delivering these health care services.

**"Bottom-Line" Essentials for Any Deal on Medicaid**

- (1) Dollars need to follow people. As we are committed to reduce Medicaid per person costs and constrain the overall growth of the program, the Federal Government must maintain its shared financing partnership with the states. When a state faces an economic downturn, it must have an immediate and reliable Federal financing partner to help pay for unanticipated enrollment increases. Such an approach will assure that Federal dollars follow the increasing number of covered people.
- (2) There must be a workable enforcement mechanism that guarantees eligibility to Medicaid coverage. We believe that preservation of the Federal court right of action for recipients (not providers, since the President is repealing all vestiges of the Boren amendment) assures this guarantee. Any alternative to this approach must satisfy the President that the enforcement of the Federal guarantee is not undermined.
- (3) There must be a meaningful and Federally-defined benefits package for all eligible populations -- regardless of what state they live in. This means that states must still ensure that their mandatory benefit packages must not only be consistent with a meaningful and nationally-defined mandatory benefit, but that they also meet current comparability (non-discriminatory protections across populations) and statewide requirements.
- (4) There must be real, workable and significant flexibility for states to administer their programs. Our repeal of Boren, elimination of waiver requirements for managed care, and elimination of the cost-based reimbursement requirement for health clinics are just a few of the many new and unprecedented flexibility provisions that we are committed to enacting.

## MAJOR CONCERNS OF YESTERDAY'S NGA DOCUMENT

- **Package of flexibility provisions went well beyond discussion with the President.** (Items not mentioned in yesterday's POTUS meeting with the Governors are *italicized*). The summary of flexibility provisions mirrors the many provisions of the Republican Medigrant II bill that our base Democrats and groups would find totally unacceptable. Taken together with the write-up of the financing provisions, the new proposal might well be labeled by the outside world as a block grant with a contingency fund.
- **Eligibility concerns include:** The repeal of the current law's phase-in for coverage of about 3 million children age 13-17; the devolution of the "disability" definition to the states; and *the elimination of the required coverage of premiums for low-income Medicare beneficiaries between 100-120 percent of poverty is repealed.*
- **Benefit concerns include:** *The total discretion given to states to alter the amount/duration/scope of services; the repeal of the current law's comparability and statewideness requirement that ensure that recipients in particular groups or locations are not discriminated against; the apparent elimination of any defined benefit package for currently optional populations; and the vague redefinition of the "T" in the EPSDT children's health benefit.*
- **Enforcement concerns include:** The state-based right of action process advocated by the Governors (and whether it will work to effectively ensure the guarantee) and the cynical sense that the elites and our base groups may not "validate" that this will work to protect the guarantee.
- **Quality concerns include:** *The adequacy of the quality protections for plans under Medicaid, such as HMOs and other managed care plan; the state-based enforcement of Ronald Reagan's Federal nursing home standards. (The difference between them and us has always come down to definition and enforcement.)*
- **Financing concerns include:** The exclusion of pregnant women and children, *as well as the medically needy*, from the Federally-financed "umbrella" pool payments; *the inclusion in the base formula of the allowance that states can reduce their matching Medicaid rate -- the result producing an additional \$200 billion reduction in state Medicaid spending over seven years, bringing the total Federal/State cut to \$290 billion; the allowance for states to, once again, tax health care providers to help finance their state match; allowing for provider taxes will likely push up the cost of the program that CBO scores, since CBO remembers what happened in the late 80's and early 90's when states used this creative financing scheme to access more Federal dollars and to reduce their state burden.*