# Withdrawal/Redaction Sheet
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| DOCUMENT NO. AND TYPE | SUBJECT/TITLE | DATE | RESTRICTION |
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| 001. email | Personal (Partial) (1 page) | 12/28/1995 | P6/b(6) |

**COLLECTION:**
Clinton Presidential Records
Domestic Policy Council
Jennifer Klein
OA/Box Number: 10855

**FOLDER TITLE:**
Disabled [2]

2014-0209-S
ms733

### RESTRICTION CODES

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

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
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P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
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**Freedom of Information Act - [5 U.S.C. 552(b)]**

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

29-Dec-1995 01:17pm

TO: Christopher C. Jennings
TO: Jennifer L. Klein
TO: Nancy-Ann E. Min
TO: BVladeck@hcfa.gov@INET@EOPMRX

FROM: Diana M. Fortuna
Domestic Policy Council

SUBJECT: Disability concerns in Medicaid

Attached is an effort by Bob Williams to address the concern of some in the disability community that our Medicaid proposal would discourage/not adequately encourage home and community-based services for people with disabilities. I thought you might find it useful in thinking about whether/how we might alter our position as the negotiations continue.

The first proposal is an 85% maintenance of effort for optional long-term care services, with exceptions possible. This gets at the heart of the concern, but not clear how do-able it would be with the Governors, or whether there is a better way to do it. Chris, I did get the sense that you felt some device to address this concern was worth pursuing.

The second and third are options for giving states more flexibility to redirect ICF/MR and nursing home funds to community services. I don't know whether states really want this. Bob says that states have pressed for greater freedom with ICF/MR dollars.

The fourth doesn't add flexibility for states, but adds a requirement that states consult with people with disabilities -- not sure that's too likely.

The fifth extends the CSLA demo to all states if they want; he says that Medigrant makes this possible, but we are silent on the future of CSLA.

The sixth defines a secretarial review process for the above; he admits this is unlikely.

increased percentage of its Medicaid long term services dollars for other purposes, so long as it could justify doing so to {THE SECRETARY AND/OR} the public, and most particularly those who rely on long term services, their family members and representatives.

RATIONALE: States will be under increased pressures to shift limited and optional service dollars to cover acute care and other mandated services. The above provisions attempt to strike a balance between the State's interest to manage Medicaid as it best sees fit and the shared Federal/State interest in sustaining the development and operation of quality long term services for persons with disabilities of all ages.

2. INCENTIVES TO DEVELOP HOME AND COMMUNITY BASED SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES:

PROPOSED PROVISION: A State may elect to spend Federal Medicaid funds it would otherwise use to provide ICF-MR services to develop quality home and community based services which increase the independence, integration, and productivity of persons with developmental disabilities of all ages, if it {DEMONSTRATES TO THE SECRETARY'S SATISFACTION AND} provides documentation to the public, and most particularly to those most affected by such a decision, that use of ICF-MR funds for this alternative purpose:

-- would be done in a budget neutral manner; and,
-- would not affect the quality of ICF-MR services still provided in the State

EXPLANATION: States have long held that they need the authority to spend ICF-MR money (over 2/3 of all Medicaid optional funds spent on people with developmental disabilities) in less restrictive ways. Specifically, they want to use ICF-MR funds to develop home and community based services which are both less costly and more likely to increase the independence, productivity and inclusion of such individuals.

States have similarly argued that block granting Medicaid would automatically achieve this purpose and give them the relief and authority to spend funds anyway they see fit. The proposed provision would permit States increased flexibility in this area, provided they could offer assurances to {THE SECRETARY AND/OR} the public, and most particularly those who rely on long term services, their family members and representatives.

RATIONALE: The proposed provision is once again meant to strike a delicate balance between a State's need to develop and expand home and community based services the best way it can with the limited resources at its disposal and the need to maintain quality ICF-MR services for as long as they continue to exist.

3. INCENTIVES TO DEVELOP HOME AND COMMUNITY BASED SERVICES FOR PEOPLE WITH SIGNIFICANT DISABILITIES:

PROPOSED PROVISION: A State may elect to spend Federal Medicaid funds it would otherwise spend on nursing home services to eligible individuals with disabilities under age sixty five to provide home and community based services to such persons if it {DEMONSTRATES TO THE SECRETARY'S SATISFACTION AND} provides

documentation to the public, and most particularly to those most affected by such a decision, that:

-- This would be done in a budget neutral manner; and,
-- This would not affect the quality of nursing home services to eligible individuals over age sixty five

EXPLANATION: As in the case with respect to the alternative use of ICF-MR funds, States need the capability to reinvest mandatory nursing home funds in the development of home and community based services for eligible individuals with disabilities below the age of sixty five. This particularly should be the case in regard to any such individual who is either in a nursing home or otherwise would be placed in one for lack of other available long term services. The proposed provision would enable a State to do this so long as it could justify its actions to {THE SECRETARY AND/OR} the public, and most particularly those who rely on nursing home services, their family members and representatives.

4. ELIGIBLE INDIVIDUALS WITH SIGNIFICANT DISABILITIES:

PROPOSED PROVISION: A State may define and extend eligibility to receive one or more home and community based services (e.g., personal assistance services) to a discrete group of individuals who have significant disabilities other than developmental disabilities. A State should define such a targeted eligibility group:

-- in consultation with and with the demonstrated support of a broad and representative cross section of eligible individuals and others who are likely to be most affected by it; and,
{-- IN A MANNER CONSISTENT WITH MODEL CRITERIA APPROVED BY THE SECRETARY AND DEVELOPED IN CONSULTATION WITH STATE POLICY MAKERS, PEOPLE WITH DISABILITIES, FAMILY MEMBERS AND OTHERS. }

EXPLANATION: The proposed provision is consistent with current law. However, it would also require States to consult with and gain the support of the disability community in defining who should be eligible to receive long term services. It likewise could promote a greater degree of uniformity in this area by having the Secretary issue model criteria, which States could choose to use in whole or in part to guide their decision making around eligibility for long term services.

RATIONALE: The proposed provision attempts to strike a balance between the States' need for flexibility and the Federal interest in promoting both the active involvement of people with disabilities in key policy decisions that affect them most and greater consistency among States in terms of what and who they cover in respect to home and community based services.

5. THE COMMUNITY SERVICES LIVING ARRANGEMENT DEMONSTRATION WAIVER

PROPOSED PROVISION: In respect to CSLA, the Administration's proposal could:
-- EITHER revive and extend the Community Services Living Arrangement Demonstration Waiver as something which all States could offer to eligible individuals (which is what

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

28-Dec-1995 12:46pm

TO: fortuna_d
TO: judy_heumann
TO: Ann Rosewater

FROM: Bob Williams

[001]

SUBJECT: Draft Medicaid provisions

Judy Heumann asked that I share this with you. It is only a draft and my attempt to balance the Administration's interest in preserving Medicaid as is and the disability community's interest in making what it views as necessary reforms. I do not know how much wiggle room we will have either now or as the debate proceeds to put such ideas forward but thought there was no harm in formulating them and having them in our in back pocket. (b)(6) look forward to your feedback. Thanks!

12/22/95 Draft -- Not for distribution. Text in {CAPS} likely to be seen as too burdensome by the States and could be dropped.

Revised: 12/27/95,

1. HOLD HARMLESS:

PROPOSED PROVISION: A State must spend at least eighty five percent of what it currently spends on optional long term services for eligible individuals with disabilities for such purposes, unless it can {DEMONSTRATE TO THE SECRETARY'S SATISFACTION AND} provide documentation to the public that spending such funds for other purposes is:

-- unlikely to have significant adverse effects on eligible individuals who are receiving long term services or have been identified to be in need of them;
-- necessary to meet the health care and long term services needs of all eligible individuals in the State, including those who rely on long term services to; and,
-- based on broad consultation with the public, including eligible individuals who rely on long term services, their family members and representatives.

EXPLANATION: Under the proposed provisions, each State would have the flexibility to spend up to fifteen percent of the Medicaid funds it currently uses to support long term services ON any other program purpose(s) it deems necessary and appropriate. This provides States with added discretion and flexibility to manage and administer the total overall Medicaid program the best way they know how. Moreover, a State could shift and spend an

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the Medigrant proposal does).
-- OR list the services provided under CSLA as examples of those community based services which any State can elect to provide eligible individuals so long as it is done in a budget neutral manner.

EXPLANATION: Eight States currently participate in the CSLA demonstration waiver program. The Medigrant proposal would extend CSLA as an option which any State could choose to offer. . The Administration's current proposal, on the other hand, is silent on the future of the CSLA waiver program. Its future would, therefore, be highly questionable. The proposed provision would attempt to address this in one of two ways as outlined above.

RATIONALE: CSLA importance is two fold: First, it allows States both the policy direction and the flexibility they require to develop highly cost effective and inclusive home and community based services for people with the most significant developmental disabilities. Second, it's the result of several hard years of work by the disability community and Senator Chaffee to pass comprehensive home and community based services legislation. CSLA represents a scale down version of this legislation and its loss would be viewed as harmful by the disability community.

{F. SECRETARIAL REVIEW PROCESS

1. THE SECRETARY SHALL DEVELOP A STREAMLINED EXPEDITIOUS PROCESS FOR REVIEWING ALL REQUESTS CONCERNING ALTERNATIVE USE OF MEDICAID LONG TERM SERVICES FUNDING. THE SECRETARY SHALL CONSIDER SUCH ANY SUCH REQUEST PRESUMPTIVELY VALID AND PROPER IF IT HAS THE DEMONSTRATED SUPPORT OF A BROAD AND REPRESENTATIVE CROSS SECTION OF ELIGIBLE INDIVIDUALS AND OTHERS WHO ARE LIKELY TO BE MOST AFFECTED BY IT.

RATIONALE: THIS PROVISION STRIKES A BALANCE BETWEEN THE STATE'S INTEREST TO MANAGE MEDICAID AS IT BEST SEES FIT AND THE INTERESTS AND NEEDS OF ELIGIBLE INDIVIDUALS. }

TO: Chris Jennings
Jennifer Klein
Nancy-Ann Min
Bruce Vladeck
Peter Edelman
Jack Ebeler
Robyn Stone

FROM: Diana Fortuna

DATE: December 15, 1995

As you know, the disability advocates have been remarkably supportive of our position on Medicaid to date. However, I understand that a few advocates are trying to persuade the full group that they should make an issue (quietly) of the per capita cap. They do know that our proposal is by far their best opportunity because of the magnitude of the numbers, but that may not stop them from raising the issue.

Alan Bergman of United Cerebral Palsy and others are saying that the per capita cap will put home and community-based services at a disadvantage compared to other services, particularly for the MR/DD population. His proposed solution is to require states to maintain "proportional effort" on long term services. (I pointed out to him the obvious defect of this idea.)

Attached is some material on this subject.

cc: Debbie Fine
Marilyn Yager

See especially pp 6-8

## The Clinton Medicaid Proposal

As part of his alternative plan to balance the federal budget within seven years, President Clinton has put on the table a proposal designed to reduce federal Medicaid spending by an estimated $54 billion while retaining most current federal statutory provisions, including requirements that states continue to guarantee eligibility under existing mandates. The Clinton proposal stands in sharp contrast to the Congressional Medigrant provisions contained in the 1996 budget reconciliation measure that the President vetoed last week.

### Overview

The chief features of the Clinton proposal are:

- Existing Title XIX law would remain on the books. However, various modifications would be made to restrain federal payments to the states while simultaneously giving the states additional program flexibility in selected areas. The Congressional Republican proposal would have repealed Title XIX and replaced it with a new Title XXI which would have established the Medigrant program. Under Medigrant, states would have been granted nearly unlimited flexibility in the administration of their programs.

- States would be subject to a ceiling on federal Medicaid payments. This ceiling would be calculated under a "per capita cap" methodology that would limit changes in federal payments to changes in a state's recipient population and indexing the per capita cap to a general economic measure.

- Federal payments to the states for disproportionate share hospital reimbursements would be cut by one-third.

- States would have the latitude of extending Medicaid eligibility to individuals who otherwise would not qualify for the program so long as such individuals have incomes of less than 150% of the federal poverty standard. States electing this option would still be subject to the ceiling on federal payments calculated under the per capita cap. In other words, eligibility expansions would have to be budget neutral.

- States would have the option of implementing "primary care case management" programs without seeking a federal waiver as is currently the case.

- States would have the option of implementing primary care managed health care plans without having to seek a federal waiver.

- The home and community-based waiver program would be converted to a Medicaid state plan option service.

- The so-called Boren Amendment which establishes a federal standard for payments to hospitals, nursing facilities, and ICFs/MR would be repealed and replaced with new statutory provisions concerning payments to certain types of providers. The new provision more or less parallels existing statutory provisions regarding payments to non-institutional providers.

- States would be given the option to cover "vocational training for individuals who are severely disabled".

- A variety of other changes also are included in the Clinton proposal.

These changes are discussed in greater detail below.

Before turning to the specifics of the Clinton proposal, it is worth pointing out that because Title XIX would be left on the books, certain existing statutory provisions that would have been affected by the Republican Medigrant (Title XXI) proposal would remain in force. In particular:

- Current Title XIX provisions regarding nursing facility standards would remain unchanged. Under the Medigrant proposal, most of these provisions were retained. However, there were some modifications. In particular, under Medigrant, federal PASARR requirements would have been relaxed. Under the Clinton proposal, current PASARR requirements would be retained.

- The Medigrant proposal would have resulted in the termination of the existing federal ICF/MR regulations in favor of states substituting their own standards. Under the Clinton proposal, the ICF/MR regulations would be unaffected.

- Generally, Medigrant was regarded as giving states broad flexibility in defining their coverages of various services, including "scope, duration and frequency". In addition, states would have been able to establish different packages of services for various eligibility groups. Under the Clinton proposal, existing federal requirements concerning the scope of covered services would be retained. In addition, the requirement that services offered in a state's program be available on a "comparable" basis to all recipients would be retained.

- Under Medigrant, statutory provisions regarding recipient "freedom of choice" would have been repealed, thereby permitting states to channel recipients to selected providers. Under the Clinton proposal, the fundamental freedom of choice provision is retained (modified only by the new options afforded states in implementing primary care case management and managed health care arrangements).

- Under Medigrant, CSLA services would be recognized as a service that all states could offer. The Clinton plan is silent as to CSLA and, consequently, the program would not be revived.

- Under Medigrant, the authority of the Secretary of HHS in reviewing and approving proposed state plan amendments would have been substantially circumscribed. Under the Clinton proposal, the Secretary's existing authority is largely retained.

Again, it is important to emphasize that the Clinton proposal modifies rather than repeals current law. Absent a specific provision to amend Title XIX under the Clinton proposal, Title XIX provisions remain in effect and would have to be followed by the states.

**Per Capita Caps**

The Congressional Republican Medigrant proposal would have established a cap over total federal payments for health care to the states and a state-by-state cap. Within this cap, states would have had wide-ranging flexibility in designing their Medigrant programs. In addition, under Medigrant, most states would have had the option of receiving their full Medigrant allotment at a reduced state matching rate.

The Clinton proposal would maintain the current formula for determining each state's federal medical assistance percentage rate. States would make claims for FFP as under current law. However, federal payments to a state would be subject to a ceiling based on what are termed "per capita caps". In particular:

- Four base period per capita spending rates would be established for each state. These rates would be determined for the following groups:

  - Non-disabled children;
  - Non-disabled, non-elderly adults
  - Elderly individuals
  - Children and adults with disabilities (defined as persons who are eligible for Medicaid solely based on "disability or blindness"

  Under the proposal, states which have implemented "health care reform waivers" (e.g., so-called superwaivers which extend Medicaid eligibility to individuals who would not otherwise be eligible) would be subject to special rules in determining the per capita cap. Essentially, these rules are aimed at putting these states on more or less equal footing with other states with regard to the base per capita spending rate calculation.

- The "base" per capita rate for each group would be determined by dividing FFY 1995 Medicaid spending for that group by the number of full-year equivalent recipients in the group during the same year. The amount of Medicaid spending upon which this calculation would be based would exclude: (a) disproportionate share hospital payments; (b) cost-sharing for Qualified Medicare Beneficiaries; (c) payments to Indian Health Services facilities; and, (d) state outlays for fraud and abuse activities. Future outlays in these areas would not be subject to the ceiling on federal payments derived from the per capita cap methodology.

- The "base" per capita rate for Medicaid program outlays would be supplemented by an additional allowance for state administrative expenses. Essentially, this allowance would be calculated by prorating administrative spending across the four groups by dividing total administrative outlays by total recipients and adding the per capita amount to the base rate described above. Consequently, the base rate for each of the four groups would include an allowance for administrative costs.

- This base per capita rate would be trended forward based on the average annual change in nominal gross domestic product for the previous five years. This "nominal" rate of change would reflect: (a) real economic growth; and, (b) inflation. In other words, the per capita rate would be indexed to overall nominal economic growth.

- Beginning in FFY 1997 (i.e., the year commencing October 1, 1996), federal payments to each state would be subject to a ceiling calculated by multiplying the number of recipients in each of the four groups by the indexed per capita cap for the group. The

total ceiling on federal payments a state would be under would be the sum of the ceilings for each of the groups. Again, the items that are excluded when the per capita cap is calculated (e.g., DSH payments) would not be subject to this ceiling.

- This scheme is structured so that: (a) a state's ceiling is directly tied to the number of recipients being served in each category; and, (b) a state is rewarded or penalized based on its efforts to contain Medicaid per capita costs. For example, if a state's actual per capita costs exceed the per capita cap, the associated FFP would be disallowed. If a state's per capita costs fall below the ceiling, then the state would be able to enrich its program (by adding services or expanding eligibility). Tying the ceiling to the number of recipients means that federal payments for Medicaid services would be elastic with the number of eligible individuals. A state that experienced an increase in recipients would see its ceiling increased. Since the per capita caps are tied to distinct groups, this also means that the ceiling calculation is sensitive to changes in the distribution or case mix of recipients by group.

- Even though ceilings are calculated for each group, it does not appear that the ceilings would be applied on a group-by-group basis. Instead, the controlling ceiling for a state would be the sum of the four group ceilings. This appears to mean that, if per capita spending for one group results in an overage vis-a-vis that group's ceiling, a state may "borrow" from the ceiling that applies to another group to make up the difference (provided that there is another group where per capita spending is below the per capita cap).

The per capita cap scheme is intended to: (a) enable existing federal mandates regarding Medicaid eligibility to be retained; and, (b) link federal payments to changes in the number of recipients. Over the next seven years, the number of Medicaid recipients is expected to increase by roughly 8-10 million individuals. One of the criticisms of the Medigrant proposal is that it largely decouples federal payments to the states from changes in the number of recipients and, hence, would have forced at least some states to narrow eligibility and/or eliminate service coverages in order to remain within the federal cap. The Clinton proposal is designed to require states to accommodate expected growth in the number of recipients. The cost containment device contained in the proposal is limiting the rate at which per capita spending can increase.

Generally, the Clinton proposal provides for Medicaid spending increasing at a greater overall rate than the Republican Medigrant proposal. On a bottom-line basis (estimated spending versus estimated spending, not tied to current services projections), however, the two proposals are only roughly $50 billion apart due to differing baseline spending assumptions. The Republican Medigrant plan is more generous in its early years; the Clinton plan yields higher spending totals in the out years.

With regard to specialized Medicaid services for people with developmental disabilities, the per capita cap scheme has uncertain ramifications. In particular:

- The per capita cap that would apply to such services as ICF/MR and the HCB waiver program would be the cap associated with children and adults with disabilities. The spending base for calculating this cap would include: (a) all health care services for all disabled recipients (not just persons with developmental disabilities); and, (b) all long-term care spending for such individuals (including nursing facility services, personal care, and HCB waiver services). Nationwide, Medicaid spending for people

with disabilities is roughly $49 billion. Persons with disabilities make up about 16% of all Medicaid recipients (roughly totaling 6 million individuals). Medicaid spending for specialized developmental disabilities services in 1995 is estimated at roughly $14 billion. However, only about 5% of all Medicaid recipients with disabilities are served in specialized DD Medicaid programs. Thus while DD specialized services make up a substantial share of the base against which this per capita cap would be calculated, the cap will be based on total spending/total recipients for the group as whole.

- Under the per capita cap methodology, there are implied trade-offs between spending for specialized developmental disabilities services and spending for all other services utilized by recipients with disabilities (including health and other long-term care services utilized by individuals with developmental disabilities regardless of whether they are receiving specialized DD Medicaid services). For example, if a state proposes to substantially expand its HCB waiver program (or develop additional ICF/MR beds), then less money would be left to pay for all other services that fall under the disability group ceiling. Except in so far as the expansion results in a net increase in the number of recipients, the effect of expanding DD specialized services would be to enrich the services being furnished to existing recipients and, hence, boost a state's per capita spending. Since the large majority of individuals affected by an expansion of DD specialized services are likely to be individuals who already are Medicaid eligible, they already will have been factored into the calculation of the per capita cap. An expansion of DD specialized services generally could only be accommodated under the per capita cap scheme to the extent that per capita spending on other members of this population is increasing at a slower rate than the nominal GDP index.

- The foregoing means that DD authorities would unlikely to be able to independently expand specialized DD services, even if they have the necessary matching funds within their budgets. Under the per capita cap scheme, states are likely to attempt to control (as best they can) spending for each group with an eye toward how they stand with regard to the overall per capita cap. Absent any significant change in utilization and costs for other services, this means the spending for DD specialized services must be contained at no more than the proportion it represents of a state's overall disability cap. This would permit some very modest expansion, albeit well below the 9-10% annual rate of increase that states have sustained in DD specialized services over the past five years.

- Another implication of the per capita cap approach is that it essentially would freeze all states where they presently are in terms of spending for DD specialized services. The per capita caps are calculated on a state-by-state basis. States with low levels of DD specialized services utilization/spending would be trapped at that level (states with high utilization rates, however, could continue current levels of effort). Since the per capita cap is based on FFY 1995 outlays, all states would be required to revisit (and possibly retrench) planned expansions of specialized DD services. In particular, even though a state may have received HCFA's approval to substantially expand its HCB waiver program, the FFY 1997 ceiling may not accommodate that expansion.

- As with the Republican Medigrant proposal, the effect of the Clinton proposal is that the primary strategy states would have to pursue in order to expand the number of recipients of DD specialized Medicaid services is to reduce per capita outlays. In

many respects, the Clinton cap has much the same effect on DD services as the Medigrant proposal.

- Finally, state budgetary management of the ceilings under the Clinton ceiling would likely be very complex. Not only must a state keep an eye on spending for each group but also for all groups in combination. This would be a very difficult forecasting environment, particularly since all the groups share certain services. For example, a decision to increase physician reimbursement rates would ripple through each group but the exact impact would depend on physician services utilization rates within each group.

Given the budgetary complexities and the interactions both within and among groups, it would appear likely that states would adopt particularly conservative management strategies under the Clinton proposal. In turn, this would pose substantial problems for any proposal to expand Medicaid services/eligibility, including proposals affecting DD specialized services (again, regardless of whether the DD authority has the matching dollars needed to finance such an expansion or not).

**Other Provisions Affecting Federal Payments**

The Clinton proposal contains other provisions that would affect federal payments to the states. In particular:

- Under the proposal, all special administrative matching payment rates would be eliminated in favor of a uniform base nationwide rate of 50%. This would eliminate the special matching rates for MMIS development and operation, specialized medical personnel, and costs associated with meeting federal PASARR requirements.

- As noted earlier, federal disproportionate share hospital payments would be cut by one third. This change will have differential effects given the variability among the states in current payments.

**Eligibility-Related Provisions**

Also, as mentioned above, states would have the option to extend Medicaid eligibility to include individuals/households with incomes that fall below 150% of the federal poverty line. This provision has been included in order to relieve states from having to submit Section 1115 waiver requests in order to cover such individuals as part of a state's health care reform strategy. However, states expanding eligibility in this fashion must develop "budget neutral" strategies since such an eligibility expansion would have to be paid for under the ceiling calculated under the per capita cap scheme.

Since the legislation does not change underlying federal law, states would be free to extend coverage to groups that are recognized in law or terminate optional eligibility groups. To the extent that a state modified its eligibility criteria within the existing statutory framework, its federal ceiling would be increased or decreased in line with the change in the number of eligibles. This means, for example, that a state could adopt the TEFRA 134 option. To the extent that this increases the number of individuals with disabilities, a state's ceiling would rise. However, if the per capita costs of the individuals receiving this coverage were above

the per capita cap, the state theoretically would not receive FFP for the difference (all other things being equal).

**Managed Care Provisions**

Under present law, a state must obtain a special federal waiver (under Section 1915(b)(1) of the Social Security Act) in order to implement a primary care case management (PCCM) program. The Clinton proposal would eliminate the need for such waivers by inserting provisions concerning PCCM directly into statute. In other words, a state could elect to implement a PCCM program with a waiver so long as its program conformed to the provisions that would be incorporated into statute. The statutory requirements that would be imposed generally mirror current HCFA policies regarding PCCM services.

States would also be granted the statutory option of implementing managed health care arrangements without having to request a Secretarial waiver. In particular, states would be permitted to limit recipient freedom of choice and mandate that individuals be served through a managed care arrangement so long as the recipient is given the choice between at least two such arrangements (e.g., two HMOs or an HMO/PCCM alternative). The construction of these provisions makes them applicable only to managed care arrangements that include primary health care services. Other arrangements (e.g., implementing a mental health managed care program) would still require a Secretarial waiver. The Clinton proposal also would modify certain other existing statutory requirements regarding managed care entities and build certain quality of care and other requirements into statute.

**HCB Waiver As a State Plan Service**

The Clinton proposal would eliminate the need for a state to obtain Secretarial approval to operate a home and community-based waiver program. This change would be accomplished by repealing Section 1915(c) of the Social Security Act (the current statutory authority for the HCB waiver program) and inserting some of the sections provisions into Section 1905(u) of the Act. The proposal would not affect the current requirement that persons served via the HCB waiver program must otherwise require institutional services (a requirement not included in the Medigrant proposal). The proposal explicitly states that HCB waiver services offered under a state plan are exempt from statutory requirements concerning statewideness and comparability and, further, permits a state to determine financial eligibility under special income rules. These are the provisions that today entail the granting of a Secretarial waiver. The proposal permits a state to cover any HCB waiver services of its own choosing. In other words, Secretarial approval would not be required for the coverage of services beyond those listed in Section 1915(c). However, the present restriction on the coverage of supported employment services would be retained.

As drafted, the proposal does not directly address the question of whether a state may limit the number of individuals participating in an HCB waiver program. The present authority to impose such limits is regulatory, although its basis lies in obtaining a waiver of comparability which would be inherent in the proposed state plan coverage. The proposal does not address such issues as recipient freedom of choice nor direct payment to providers; consequently, existing statutory requirements would continue to apply.

The effect of the proposal is merely to eliminate the requirement that a state submit a waiver request to the Secretary in order to launch an HCB waiver program. Changes to existing

programs would still need to be accomplished via amendment; the current HCB waiver amendment process more or less parallels that employed for state plan amendments. The change also would provide some measure of relief to states in performing HCB waiver calculations; however, a state will need to be able to continue to demonstrate that waiver services are cost-effective on an ex post basis. This likely would mean that the present HCFA 371 reporting requirements would be maintained.

**Other Changes in Coverage**

The proposal contains some additional changes in Medicaid coverages. These include:

- Allowing clinic services to be furnished under the direction of a nurse practitioner (present law requires physicians to direct such services);

- Permitting a state to cover IMD (Institutions for Mental Disease) for persons between the ages of 22 and 64 (presently such services are generally coverable only for individuals age 65 or over); and,

- Giving states the option of covering "vocational training for individuals who are severely disabled". Neither the term "vocational training" nor "severely disabled" are defined. It is important to emphasize that this coverage option is independent of the coverage of HCB services (the coverage would be added in a new section 1905(a)(26)). This option would be a regular state plan option and not conditioned by type of disability nor whether an individual had been previously institutionalized. At the same time, it is important to recognize that a state decision to cover these services would amount to an enrichment of its current program and, thereby, potentially trigger in an increase in spending that would result in a state exceeding its ceiling.

**Boren Amendment Provisions**

The Boren Amendment (Section 1902(a)(13) of the Social Security) establishes a federal payment standard for state payments to institutional providers (nursing facilities, ICFs/MR, hospitals). The Clinton proposal would modify Section 1902(a)(13) by requiring that states have a payment determination methodology (approved by the Secretary) that would yield rates that are "adequate to secure participation of sufficient numbers of qualified providers of such services to ensure that individuals eligible for medical assistance under the State plan have reasonable access to services meeting applicable quality and safety standards". This change more or less mimics existing Title XIX requirements concerning payments to non-institutional service providers.

However, the Clinton proposal would subject "home and community care services" to these provisions. The proposal still maintains the role of the Secretary in reviewing and approving the methodology employed by a state (for other state plan services, the Secretary does not exercise a similar role). By including "home and community care services" under these provisions, states would be required to obtain Secretarial approval for the methodology employed to establish rates for HCB services. Under present law and practice, states do not have to obtain this Secretarial approval for HCB services.

The proposal outlines certain circumstances under which rates determined by a state would be presumed to comply with the new statutory provisions. These circumstances include: (a)

a state pays the same rate as Medicare; (b) a state pays a facility's private pay rate; (c) a state pays a "prevailing local rate"; and, (d) rates are established through a competitive bidding process. Generally, current state payment methods do not generate rates that match these circumstances, particularly in nursing facility and ICF/MR reimbursement.

This change has been portrayed by Administration officials as a "repeal of the Boren Amendment". The Republican Medigrant proposal contains an explicit repeal of the Boren Amendment and does not substitute alternative provisions. In point of fact, the Clinton proposal may only amount to a rearrangement of the Boren Amendment and still leave states open to litigation challenging the basis of their rate determination methodologies.

**MMIS Requirements**

The proposal somewhat simplifies current federal requirements regarding the operation of a state's Medicaid Management Information System.

**Effective Date**

The Clinton proposal would be effective as of October 1, 1996 (FFY 1997). The Republican Medigrant proposal would have been effective October 1, 1995.

**Observations**

The Clinton proposal is aimed at preserving the current entitlement-based framework of the Medicaid program. The per capita cap features are designed to place some pressure on states to hold down service costs while accommodating expected growth in the number of Medicaid recipients. The proposal acknowledges some of the complaints that state policymakers have about current policy by eliminating the need for certain waivers and possibly addressing some of the issues that have arisen around the current Boren Amendment provisions. The proposal has been portrayed as giving states more flexibility in the administration of their Medicaid programs. However, the flexibility takes the form of simply giving the states more statutorily recognized options that carry with them new federal requirements.

With regard to specialized Medicaid services for people with developmental disabilities, the Clinton proposal probably would result in tying the hands of state MR/DD authorities in terms of future expansions in services offered or the number of individuals served. As with the Republican Medigrant proposal, expansions would need to be underwritten by reducing the costs of current services. The only new cost cutting option afforded states under the Clinton proposal lies in the changes in the Boren Amendment, which possibly might enable states to impose tighter controls on ICF/MR rates.

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF THE UNDER SECRETARY

To: Ken Apfel
Nancy Ann Min
Jennifer Klien
Diana Fortuna
Chris Jennings

From: Marshall Smith
Undersecretary

Judith Heumann
Assistant Secretary for Special Education and Rehabilitative Services

Re: Medicaid

Date: December 7, 1995

We are pleased that the President's new Medicaid proposal retains the basic framework of Title XIX, particularly in the areas of eligibility and benefits, including EPSDT. As you know, Medicaid plays a key role in ensuring that we meet the nation's first education goal: all children be ready to learn. Moveover, schools have undertaken an increasing role in providing access to health services -- much of which are reimbursable through Medicaid -- particularly for low-income and disabled students. In the case of students with disabilities, schools are required by law to provide health services that are necessary for the child to benefit from their education. This requirement under the Individuals with Disabilities Education Act (IDEA) has been critical in ensuring both the health and education of children with disabilities.

We hope that regardless of any changes within Medicaid, children will receive health services within an coherent, accountable system that continues to ensure that appropriate services are available in home- and community-based settings, including schools. For children with special needs, providing services in appropriate settings can prevent more costly hospital or institutional care, and eliminate or reduce later primary or secondary illness or disability that are likely to result in conditions more costly to treat in the future.

However, as we move to a new Medicaid framework, we have several fears. First, if it becomes impossible to maintain the current EPSDT entitlement, services to the most vulnerable populations may be threatened. Second, access to care may be compromised because managed care providers will have insufficient incentives to work with existing home- and community-based providers -- including schools -- that are currently effective in ensuring

access for children. Third, schools which have come to rely on Medicaid as an important source of financing for health services may be less able to access Medicaid to support the provision of health services that students need and that schools are required to provide under the IDEA.[1] Finally, as states have more flexibility in designing home- and community-based options, there may be insufficient incentives to provide services in noninstitutional settings.

For these reasons, we have particular concerns about the outcome of forthcoming negotiations on the ultimate Medicaid legislation. This memorandum lays forth some preliminary ideas about how to address these concerns in the context of continuing negotiations with Congress.

## I. LEVELS OF COVERAGE AND SERVICES FOR CHILDREN

In the event that it becomes necessary to consider alternatives to the current EPSDT entitlements, we have several thoughts that we would like to discuss further.

Issue #1: Consider keeping EPSDT available to all eligible children but restrict the mandatory treatment services to children and youth who are:

--- below a certain age or,

--- are disabled or,

--- need services to prevent or ameliorate a primary or secondary illness or disability likely to result in an exacerbation of the condition in the future.

Since entitlement to treatment services is a major issue of contention, it would be worth pursuing how to protect the availability of these services for those populations that need it the most. That cut could be by age, disability status or effect of failure to receive services.

Issue #2: Maintain a guaranteed basic health benefit that meets the needs of all eligible children aged 21 and under. This benefit should include preventive services; primary care services; and other health services needed to maintain or stabilize health outcomes, or to prevent or mitigate an adverse change in health outcome.

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[1] For example, last year the school districts in New York City, Chicago and Houston billed Medicaid $85 million, $40 million and $14.9 million, respectively.

This definition could be implemented in conjunction with EPSDT or some modified "menu" of required services and would act as a limitation on the services that must be provided. Alternatively, the definition could be used in lieu of a "menu" approach to defining the benefits package.

## II. STRENGTHENING HEALTH OUTCOMES

If the entitlement to EPSDT is significantly reduced or eliminated, strengthening health outcomes will be critical to ensuring adequate services for children. Quality assurance parameters will help guide: (1) the provision of care and services, and (2) access to care in the most appropriate setting. Moveover, even if EPSDT remains in its present form, it may be worth considering pressing for child-specific health outcomes (which could be identified by states in their plans) in the negotiation process because they could improve the effectiveness of the EPSDT program in the managed care environment.

Issue #1: Require that state plans include child health outcome performance standards that ensure appropriate services. Examples of outcomes might be:

- o children receive the complete immunization series recommended by the American Academy of Pediatrics;
- o uncorrected vision, hearing or other preventable health problems are treated;
- o lower rates of adolescent substance abuse, school-age parenting, and mental health problems.

Issue #2: Require that state plans include minimum standards of access that help to ensure that services are reasonably accessible to recipients. Such a requirement would provide incentives for managed care providers to work with existing community-based providers, including schools and early intervention programs, because those providers are more often located in the child's community.

This requirement would also benefit disabled adults by encouraging that services be delivered in a manner that allows them to remain at home and in their communities and maintain gainful employment.

Issue #3: Require that state plans include performance standards to ensure that disabled

children receive necessary services in appropriate settings. Such a requirement would help children get the services they need to avoid institutionalization and would encourage managed care providers to work with existing community-based providers. An example of such a requirement might be:

- o disabled children receive health services necessary to maintain functional capability in school, at home, and in their community rather than being hospitalized or institutionalized.

## III. MAINTAINING CURRENT LAW ON RELATION OF MEDICAID AND IDEA: PAYOR OF FIRST RESORT

Issue: Retain provision in Title XIX, that makes Medicaid the payor of first resort for those services deemed medically necessary, even though they are an entitlement to the child under IDEA.

Currently, Medicaid is prohibited from refusing to pay for medically-necessary health services solely because they are entitled under IDEA. Thus, current law ensures that Medicaid is the "payor of first resort" with regard to the medically-necessary health-related services provided under IDEA.

If at any time Title XIX ceases to be the negotiating document, we want to highlight the importance of maintaining this provision. The effect of eliminating it would be that schools and other entities would lose medicaid reimbursement for health services provided under IDEA to medicaid-eligible disabled children. Since schools are legally required to provide health related services to children with disabilities, local education budgets would have to assume full financial responsibility for the costs and delivery of medically-necessary health services to medicaid-eligible children receiving services under the IDEA.

## IV. ADDITIONAL MECHANISMS FOR STRENGTHENING THE RELATION OF MEDICAID AND SCHOOLS

Because of the important role schools play in providing access to services for children, and because of the importance Medicaid has assumed in financing some of those services, we also put forward some specific ideas about how to improve the position of schools as providers which might be pursued if it becomes appropriate in the negotiations.

Issue #1: Require states to define their relationship with schools and other community-based providers in the provision of health services to medicaid-eligible children

This would require the state medicaid agency to consider the role of schools without mandating any particular relationship with them. We believe that this would encourage states and managed care providers to consider the benefits of providing services in a cost-effective and accessible manner through schools and other community based providers.

Issue #2: Encourage States to make available a "supplemental insurance package" to schools 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 Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP) and the evaluations related to those services. Additional options could include the remaining benefits under the State's Medicaid program 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); or, (2) purchased from managed care organizations or provider groups through partial or 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 insurance package.

This approach would also address the concerns of the individual school districts about:(1) the burden of children's health expenditures when the costs are not evenly distributed; (2) coordinating any continued State's children mandates. The ability to group or pool risk across when purchasing this plan would decrease overall costs to the school districts.

Issue #3: Prohibit states from excluding payments to schools or other qualified entities that provide health services to medicaid-eligible children under other Federal laws.

Schools are eligible for reimbursement, under both current Title XIX and under the Republican proposal. However, for the reasons discussed above, schools may well have difficultly obtaining reimbursement -- even though they are required to provide related services to students with disabilities under IDEA.

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

December 1, 1995

**THE ATTACHED IS A BACKGROUND DOCUMENT ON ISSUES OF MEDICAID FUNDING FOR HEALTH CARE SERVICES TO CHILDREN AND CHILDREN WITH DISABILITIES.**

cc Chris Jennings
Jennifer Klein
Nancy-Ann Min

(from Judy Heumann)

400 MARYLAND AVE., S.W. WASHINGTON, D.C. 20202-2500

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

November 28, 1995

TO : Marshall E. Smith
Undersecretary

THROUGH : Judith E. Heumann
Assistant Secretary, OSERS

FROM : Connie Garner
ED Health Policy Liaison
Policy Analyst, OSERS

SUBJECT : THE MEDICAID TRANSFORMATION ACT OF 1995: AN UPDATE

## INTRODUCTION

The Republican Budget Reconciliation Bill is scheduled to be sent to the President for signature. If enacted into law, the MediGrant Program contained in the bill would replace the current Medicaid program with block grants to states, with the intent of cutting federal Medicaid spending by $163 billion over the next seven years.

The Transformation of the Medicaid Program Act maintains mandatory coverage for pregnant women and children under the age of 13, who meet the state income eligibility, and any disabled individual, as defined by the State. The program eliminates all mandated services except immunizations and pre-pregnancy family planning services.

The purpose of this memo is to offer policy options, recognizing the Administration's goals of controlling medicaid growth and increasing state flexibility, related to the issues of:

(1) strengthening child health outcomes as a performance goal;

(2) guaranteed health services for children;

(3) protection to agencies, e.g., schools and early intervention programs responsible for interfacing medicaid with other public programs.

## ISSUE

Currently, more than 18 million children under the age of 21 are enrolled in Medicaid -- more than half of these children are from working families. Approximately 20% are expected to have a physical, mental, or developmental diagnosis requiring treatment at some point during their childhood. About 5% are disabled enough to be limited in their activities of daily living.

The elimination of the mandated children's benefit, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) will be a significant loss of benefits to children currently covered under Medicaid, as the bill:

(1) eliminates guaranteed health coverage for low income adolescents;

(2) eliminates guaranteed preventive, diagnostic, and treatment services for low-income and disabled children, and

(3) eliminates guaranteed Medicaid reimbursement to school districts that provide medically-necessary services to children with disabilities.

Although States are required to provide services to children under the age of 13 and disabled individuals, as defined by the State, the following concerns remain:

(1) guaranteed health coverage for non-disabled children 13-21 is eliminated;

(2) the definition of disabled children 13-21 will vary from state to state, thus some children with special needs may not qualify for services;

(3) there is no minimum level of health services guaranteed to those children covered under the mandate;

(4) the size of the proposed cuts and the funding formula, coupled with the elimination of guaranteed services will pit children against adults, and disabled children against non-disabled children for available services.

President Clinton and Secretary Riley have always been viewed as instrumental in ensuring that childrens' issues remain 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 to protect and secure health coverage for children currently eligible under Medicaid.

## POLICY OPTIONS

To assist the Administration in the continued refinement of the President's proposal to balance the budget, the Department of Education has developed several proposals based on the following key principles:

- ❑ Investing in the health and well-being of our children is a national priority;
- ❑ Children receiving timely health services are better prepared to succeed in school, and in life;
- ❑ No child should lose basic health care coverage as a result of medicaid reform;
- ❑ The health needs of children should be covered within a coherent, accountable system guaranteed to meet their basic needs;

- The distribution of cuts and constraints necessary to control Medicaid costs should be shared in an equitable manner across constituencies;
- Cost savings should be realized as a result of Medicaid reform.
- Measurable increases in child health outcomes can and should be achieved within a cost efficient health care delivery system.

## GUARANTEED CHILDREN'S HEALTH BENEFITS

### OPTION #1:

***Maintain a guaranteed basic health benefit that meets the needs of all eligible children aged 21 and under. This benefit should include preventive services; primary care services; and other health services needed to maintain or stabilize health outcomes, or to prevent or mitigate an adverse change in health outcomes.***

**PRO:**

Handing a large public debt to the next generation is unquestionably anti-child. However, due to the relatively low cost of their care, millions of children stand to lose guaranteed services in order to make modest gains in reducing the federal budget, leaving all children in this country without a safety net.

Children under the age of 21 comprise 57% of the medicaid population, but account for only 23% of the expenditures. Based on a four-state study of children's Medicaid conducted by HHS, the average cost per child for Medicaid services was $1,006. This figure accounts for all services to children received under Medicaid including services provided through EPSDT and home and community-based waivers.

More than 18 million children, including more than 1 million children with disabilities and special health care needs, received comprehensive health benefits based on pediatric standards of care developed by the American Academy of Pediatrics.

For children with special needs, Medicaid provided community-based health services that prevented more costly hospital or institutional care. Providing special therapies, family training and support, and assistive devices both at home and in school allow families to stay together; parents to work; and children to live and grow up with the health supports necessary to transition to gainful employment.

Continuing to provide a basic health benefit package to eligible children and youth will ensure a solid foundation for the long term health and well-being of our youngest citizens. By affording eligible children early periodic, screening, diagnosis, and appropriate health interventions in home and community-based settings, including schools, we can prevent, eliminate or reduce later primary or secondary illness or disability that are likely to result in conditions more costly to treat in the future.

**CON:**

The continuation of a guaranteed childrens' benefit can be viewed as a growing unfunded Federal mandate (the child medicaid rolls grew by one third during the first 4 years of the decade), during a

time of increased budgetary constraints. In addition, any Federal mandate will be considered an infringement on state flexibility.

However, avenues aimed at reducing the overall need for Medicaid, such as state insurance reform, rather than eliminating necessary basic services might prove more effective in long term cost containment. For example, from 1992 to 1993, an estimated 3 million children lost private health insurance and became medicaid eligible as parents lost jobs or employers stopped providing health insurance.

## OPTION #2:

- ***Maintain a guaranteed basic health benefit that meets the needs of all eligible children aged 13 and under. This benefit should include should include preventive services; primary care services; and other health services needed maintain or stabilize health outcomes, or to prevent or mitigate an adverse change in health outcomes.***

- ***Maintain guaranteed periodic screening and assessment for children aged 13 to 21.***

### PRO:

The MediGrant proposal recognizes the need to provide eligible children under the age of 13 with mandatory health coverage. The proposal falls short of meeting its intent, however, by not providing a guarantee of the basic services necessary to ensure healthy outcomes for the eligible infants, toddlers, preschoolers, and school-age children. Research supports the importance of having young children receive primary and preventive health care services to ensure appropriate growth, development and the ability to learn.

Continuing a guaranteed children's benefit program for young children will support state medicaid programs and other public and private entities, such as schools, to develop and maintain coordinated efforts for young children which: (1) improve access to health services, particularly in high-poverty schools; and, (2) provide medicaid-eligible children with disabilities the health services needed to ensure access to and benefit from their early intervention and educational programs.

As states' negotiate with managed care organizations to deliver medical services to the medicaid population, there is no guarantee that periodic screening and assessments will be included in a basic benefit package for children. At a minimum, periodic screening and assessment services should be guaranteed to the medicaid-eligible adolescent population.

Because of the physical and emotional changes associated with the teenage years, adolescents are especially susceptible to engaging in risk-taking behaviors, which can lead to primary or secondary illness.

Consider the following statistics from a national survey of adolescents in grades 9-12 in public and private high schools:

- 32% had smoked cigarettes during the last 30 days;

- 31% reported episodic heavy drinking;

- 27% had thought seriously thought about suicide;

- 72% reported not using seat belts while driving in a car.

Through guaranteed screening and assessment, adolescents in need of intervention can be identified and referred to available resources, particularly in the area of mental health. In a recent national study of more than 17,000 children, 20% under age 18 reported having experienced an emotional or behavioral problem that lasted for at least three months or required psychological help. This percentage rose to 25% among adolescents, ages 12 to 18.

**CON:**

Although this alternative provides a guaranteed health benefit for children aged 13 and under, it leaves out the treatment needs of the adolescent population. Providing effective prevention and primary care interventions to poor and/or disabled adolescents at risk for serious health, developmental, and emotional problems is important.

The linear model of prevention works well for vaccines, but not for the complicated at-risk adolescent -- occasional encounter visits for acute care needs with minimal attention to health supervision is ineffective.

**OPTION #3:**

***Maintain a guaranteed basic health benefit package that meets the needs of all eligible children under the age of 6. This benefit should include preventive services; primary care services; and the health services or interventions needed to maintain or stabilize health outcomes, or prevent or mitigate an adverse change in health outcomes.***

**PRO:**

Growth and development are most rapid in the early years of life, and the most preventable and treatable health events occur during this time. The earlier in a child's life that problems or potential health risks are identified, the greater the chance of preventing, eliminating, or minimizing their impact and cost over time.

At a very minimum, medicaid-eligible infants, toddlers and preschoolers should be guaranteed a health benefit package that meets their needs. For young children with developmental delay, early treatment and supports can make the difference to a child going to school ready to learn, or missing a critical developmental opportunity resulting in secondary disability and the increased need for later special education.

Consider the following examples:

- A young child with untreated ear infections occurring in the early years can lead to chronic mastoiditis, functional hearing loss and delay in the acquisition of language skills.

- A young child with cerebral palsy receiving ongoing physical therapy is more likely to: (a) maintain functional capability; and (b) avoid flexion contractures and joint subluxation resulting in expensive surgery and hospital inpatient days.

All States have developed early intervention programs for infants and toddlers with disabilities that provide developmental and health services to vulnerable young children. Forty to sixty percent of the children enrolled are currently medicaid eligible, thus medicaid reimbursement for services represents a substantial portion of a total States' budget for this program. Given the significance of Medicaid funds in supporting these programs, any diminution of these funds or their guaranteed services would place the existence of early intervention programs in serious jeopardy.

CON:

This option may still be viewed as an unfunded Federal mandate that impinges on state flexibility. In addition, this option does not guarantee basic health services to the school-aged population of young children.

## FURTHER RECOMMENDATIONS

### OTHER RELATED PROGRAMS

RECOMMENDATION:

***Add a non-discriminatory provision to the bill that prohibits a state from excluding payments to schools or other entities that provide health services to medicaid eligible children under other Federal laws.***

At present, there is an interdependent relationship between the nation's educational programs and Medicaid programs. School districts and early intervention programs may seek Federal Medicaid reimbursement for the costs of early intervention and related services provided to medicaid-eligible children with disabilities. Second, Medicaid is prohibited from refusing to pay for medically-necessary health services just because they are entitled under the Individuals with Disabilities Education Act 1(IDEA). Finally, current law ensures that Medicaid is the "payor of first resort" regarding the medically-necessary health-related services provided under the IDEA.

In the Reconciliation Bill these federal law provisions will cease to have effect. Concerns about eliminating this provision of payment by Medicaid for medically-necessary health services on an IEP or IFSP are as follows:

1. It would create an uncoordinated system of health care for disabled students needing health services while in school.

2. Schools and other entities could lose reimbursement for health services provided under IDEA to medicaid-eligible disabled children.

3. Since schools are legally required to provide health related services to children with disabilities, local education budgets will in some states, have to assume full financial responsibility for the costs and delivery of medically-necessary health services to medicaid-eligible children receiving services under the IDEA.

RECOMMENDATION:

***Add a provision that makes available a "supplemental insurance package" to schools districts and other agencies to pay for health-related services under the Individuals with Disabilities Education Act (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 Medicaid program 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); or, (2) purchased from managed care organizations or provider groups through partial or 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 insurance package.

This approach would also address the concerns of the individual school districts about: (1) the burden of children's health expenditures when the costs are not evenly distributed; (2) coordinating any continued State's children mandates. The ability to group or pool risk across when purchasing this plan would decrease overall costs to the school districts.

## STRENGTHEN HEALTH OUTCOME PERFORMANCE STANDARDS

RECOMMENDATION:

***Add child health outcome performance standards (beyond immunization rates) that ensure:***

- ***children receive the complete immunization series recommended by the American Academy of Pediatrics;***
- ***uncorrected vision, hearing or other preventable health problems are treated;***
- ***disabled children receive health services necessary to maintain functional capability in school, at home, and in their community.***
- ***disabled children receive services that support their ability to remain at home and in their community, rather than being hospitalized or institutionalized.***
- ***lower rates of adolescent substance abuse, school-age parenting; and mental health problems.***

As State Medicaid recipients (of which 50% are children) move into managed care systems, the development of child-specific quality assurance parameters is critical to guide the provision of care and services. In addition, State Medicaid programs should be required to: (a) collect data and monitor specific pediatric diagnosis, including asthma, ear infections, urinary tract infections, and developmental disabilities; and, (2) collect data and monitor specific pediatric services, including

therapies, immunizations, respiratory care, durable medical equipment purchases/leases, and other services available under the home and community-based waiver.

## CONCLUSION

In full recognition of the need to control and manage the existing Medicaid program, it is the recommendation of the Department of Education that the administration support a guaranteed basic health benefit program that meets the needs of all low income and disabled children with strong quality assurance provisions. Low income and disabled children are our most vulnerable population and deserve the right of appropriate health care to achieve healthy and productive adult lives. Low income children have the following relative frequency of health issue that cannot be left up to state discretion for resolution:

- ❑ low birth weight . . . . . double
- ❑ delayed immunization . . . . . triple
- ❑ lead poisoning . . . . . triple
- ❑ accidental death . . . . . double/triple
- ❑ severe disability . . . . . double/triple
- ❑ severe iron deficiency anemia . . . . . double
- ❑ 60% of children in foster care have diagnosable moderate to significant mental health problems.
- ❑ 40% of children in foster care have physical health problems with a significant number having asthma, neurological conditions and growth disorders.

Guaranteed basic health benefits provided under Medicaid, when delivered in a timely and cost-effective manner, continue to be a critical safety net for poor and disabled children in this Country. If these benefits are inadequate or eliminated, children and families in this Nation will suffer.

# Consortium for Citizens with Disabilities

**Kathy McGinley (202) 785-3388**
**Peter Thomas (202) 466-6550**

To: ChrisJ
JenK
Debbie Fine
Marilyn Yager
Nancy-Ann Min
Fr: Diana Fortuna
They want a meeting. Maybe Friday's meeting w/ disability advocates would suffice.

November 22, 1995

**VIA TELEFAX**

The Honorable William Jefferson Clinton
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

Re: **Disability Community's Recommendations on Medicaid and Medicare Reform**

Dear President Clinton:

On behalf of the Health and Long Term Services Task Forces of the Consortium for Citizens with Disabilities (CCD), comprised of over 50 national associations interested in disability policy, we request a meeting with you and your staff to discuss the attached Medicaid and Medicare recommendations from a disability perspective. We are currently drafting a detailed analysis of the Congressional leadership's reform proposals which we intend to forward to you within the next week.

We strongly support your position that the current version of the budget bill must be vetoed in order to protect these two vital programs. We welcome the opportunity to discuss with you and your Administration substantive alternatives to the current proposals to reform these programs that will be acceptable to all Americans, particularly people with disabilities.

CCD representatives are available at any time to meet and discuss these important issues. Thank you for your consideration.

Sincerely,

Peter W. Thomas

Peter W. Thomas, J.D.
Health Task Force Co-Chair

Marty Ford

Marty Ford, Ph.D.
Long Term Services Task Force Co-Chair

cc: Marilyn Yeager
Chris Jennings
Diana Fortuna

Consortium for
Citizens with
Disabilities

Kathy McGinley (202) 785-3388
Peter Thomas (202) 466-6550

# CCD's MEDICAID AND MEDICARE RECOMMENDATIONS

## I. MEDICAID RECOMMENDATIONS

Recommendation No. 1: The Consortium for Citizens with Disabilities strongly recommends maintaining the current individual federal entitlement to Medicaid and not block granting this vital program to the states. If any significant changes are made in the Medicaid program, they must be phased-in to ensure a smooth transition for Medicaid beneficiaries and must include public participation in the development, preparation, implementation and monitoring of state plans.

Recommendation No. 2: The Consortium for Citizens with Disabilities recommends a significant reduction in the level of proposed Medicaid cuts over the next seven years in order to ensure the continued vital assistance that Medicaid provides to people with disabilities.

Recommendation No. 3: To control the rate of growth in Medicaid spending, the Medicaid reforms should adopt alternatives to the current proposals such as a per capita cap on federal Medicaid dollars and the creation of incentives for home and community-based care in appropriate circumstances--and disincentives for the use of institution-based care.

Recommendation No. 4: The Consortium for Citizens with Disabilities recommends that the Medicaid reforms include specific provisions to ensure the active participation of persons with disabilities at every level of decision-making in the Medicaid program. In addition, the Medicaid reforms should include a declaration of principles regarding valued outcomes for persons with disabilities including, but not limited to, empowerment, choice, independence, self-sufficiency, and community inclusion.

Recommendation No. 5: The Consortium for Citizens with Disabilities recommends that federal oversight and minimum standards of consumer protection and quality assurance be maintained in Medicaid-funded programs such as nursing homes, ICFs-MR, community-based programs, and in all Medicaid-funded managed care. Managed care should be an "option" and not the only choice for Medicaid beneficiaries with disabilities. Any use of managed care should include strong protections for timely and appropriate access to all necessary services, supports, and providers.

Recommendation No. 6: The Consortium for Citizens with Disabilities recommends that the Medicaid reforms maintain the existing federal private right of action against states to enforce compliance with the Medicaid statute and regulations and to ensure that state Medicaid programs fully comply with the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973.

## II. MEDICARE RECOMMENDATIONS

**Recommendation No. 7: The Consortium for Citizens with Disabilities recommends a significant reduction in the proposed level of spending cuts to be taken out of the Medicare program in order to maintain access and quality of health care services for people with disabilities.**

**Recommendation No. 8: The Consortium for Citizens with Disabilities recommends that the premium collected by Medicare managed care plans be limited to the government contribution—adjusted for the age and health status of the enrollee--for the individual beneficiary. The CCD further recommends that the Medicare reforms include provisions related to guaranteed issue and renewability of Medicare managed care plans and continue the prohibition against balance billing throughout the entire Medicare program.**

**Recommendation No. 9: The Consortium for Citizens with Disabilities opposes the creation of Medicare Medical Savings Accounts. If Medicare MSAs are authorized, however, the Medicare reforms should risk adjust the capitated government contribution toward MSAs and strictly limit the use of MSA funds to health, long-term care, and independent living expenses only.**

**Recommendation No. 10: The Consortium for Citizens with Disabilities recommends that the 30-day disenrollment provision be maintained in Medicare managed care and expanded to Medicaid managed care plans in order to ensure access, quality, and accountability to all Medicare and Medicaid beneficiaries. In addition, Medicare and Medicaid managed care plans should ensure access to out-of-network providers through an affordable point-of-service option.**

**Recommendation No. 11: The Consortium for Citizens with Disabilities recommends the inclusion in the Medicare and Medicaid proposals of federal standards for managed care plans. These standards should address the critical issues of access and quality of care for Medicare and Medicaid beneficiaries with disabilities and chronic illnesses who enroll in managed care plans. Without adequate quality assurance standards, managed care is likely to be discriminatory against people with disabilities in the near term and against all people in managed care over time.**

# Friendship Services Center, Inc.

P.O. Drawer 2109 • Russellville, Arkansas 72811 • Phone 967-2322 • FAX 967-2876

Cindy Mahan
*Administrator*

Tom Hill
*Operations Director*


December 1, 1995

Carol Rasco
Domestic Policy Advisor
The White House
Washington, D.C.

Dear Carol,

I am sorry I didn't get to see you; however, I knew you would love these wonderful letters and pictures.

We appreciate all of you so much and look forward to promising futures for Americans with Disabilities.

Sincerely,

Cindy Mahan

Jen K.

December 1, 1995

MEMORANDUM FOR DISTRIBUTION

FROM: Debbie Fine

SUBJECT: Meeting with Disability Groups on the Budget

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

**AGENDA:**

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

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

**BACKGROUND**:

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

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

Attached are the following: a position paper on the Republican Medicare and Medicaid proposals from Consortium of Citizens with Disabilities, and a couple of examples of alerts going out from Justice For All, a disability grassroots network.

Thanks so much for your help.

**PARTICIPANTS:**

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

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

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

# Consortium for Citizens with Disabilities

**CCD HEALTH TASK FORCE CO-CHAIRS:**

**Peter Thomas** (202) 466-6550

**Kathy McGinley** (202) 785-3388

**PRESS STATEMENT** **FOR IMMEDIATE RELEASE**

**October 24, 1995**

## CCD STRONGLY OPPOSES MEDICAID AND MEDICARE PROPOSALS

Washington, D.C. The Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national disability-related organizations, announced today its strong opposition to the Congressional leadership's proposals to "reform" the Medicaid and Medicare programs, two of the most important government programs for children and adults with disabilities and chronic illnesses.

"Some cuts never heal," stated Kathy McGinley, Ph.D. "Congressional leaders would have you think this is merely a budget issue. But the proposed changes in Medicaid will put all children and adults with disabilities on that program at genuine risk of losing their health and long term services and supports, the kinds of services that enable them to live healthy, independent lives in their homes and communities. In short," warned Dr. McGinley, "we could be taking a quantum leap backward to the time when people with disabilities were warehoused in institutions receiving custodial care at best."

"The Medicare proposals are just as threatening to people with disabilities and chronic illnesses," stated Peter W. Thomas, J.D., "when you consider the dismal track record that most managed care plans have in serving enrollees with significant health needs. There are very few

federal standards in the Medicare and Medicaid proposals that will protect consumers--and the providers who serve them--in managed care plans." Stated Mr. Thomas, "these proposals will be a windfall for insurance companies and managed care organizations at the expense of people with disabilities and chronic illnesses and all consumers of health care."

**Medicaid**

The Congressional leadership proposes to decrease Medicaid spending by $182 billion over seven years by eliminating (in the House) and limiting (in the Senate) the federal entitlement to the program, block granting the program to the states, and capping the federal share to be contributed to the program over the coming years. States would be able to determine their own eligibility criteria and benefit package available under Medicaid, possibly eliminating all mandatory health services currently available to Medicaid-qualified children and adults with disabilities.

**The Disability Set-Aside:** The House and Senate proposals create a set-aside for people with disabilities where states will be required to spend in the future on this population at least 85% of what they spent in prior years on mandatory services for people with disabilities. This set-aside provision does not require states to consider the amount spent on optional services for this population, the kinds of services most likely to be of critical importance to children and adults with disabilities.

**Optional Services Not Counted in Set-Aside Amount:** Optional services include rehabilitation therapies and devices, psychological services, prescription drugs, home and community based services, services of Intermediate Care Facilities for persons with Mental Retardation (ICF-MR), personal care services and case management. The proposed funding formula for the disability set-aside, therefore, will vastly underestimate the level of disability services currently provided by states and will likely lead to dramatic reductions in health and long term services and supports for children and adults with disabilities in future years.

**Loss of Federal Standards:** The House and Senate Medicaid proposals would eliminate all federal standards for nursing homes and ICF-MRs, as well as the minimal requirement that federal funds be spent on active treatment for individuals in institutional settings, rather than merely custodial care. This represents a major setback for vulnerable people with disabilities and for all Americans who one day may reside--or have loved-ones who reside--in these or similar institutions.

**A Quantum Leap Backward:** CCD asks Congress to recognize the well-warranted and deep-seeded fears of the disability community that the loss of minimum federal standards represents. Coupled with intensifying fiscal pressures, CCD believes that some states will return to institutional-based custodial care with the consequent loss of individual freedom, rights, and quality of life of people with disabilities. This is, of course, if these people with disabilities receive any Medicaid services at all.

**Medicare**

The Congressional leadership proposes to reduce spending in the Medicare program by $270 billion over the next seven years by shepherding large numbers of beneficiaries into managed care plans, cutting the growth of provider fees, and imposing additional costs on Medicare beneficiaries through increased Medicare Part B premiums and the allowance of balance billing. The Medicare program currently serves the health care needs of 4.2 million people with disabilities and chronic illnesses below 65 years of age.

**The Proposed Level of Medicare Savings Must be Reduced:** Gouging an unprecedented $270 billion out of the Medicare program over the next seven years for the purposes of budget balancing and tax cutting is just plain wrong. All beneficiaries, particularly those who remain in the Medicare fee-for-service system will be forced to pay more out-of-pocket for health care services. The rate of growth of provider fees will be sharply reduced, leading to decreases in quality care, health benefits, and access to the provider of one's choice. CCD believes the reduction in the rate of growth of Medicare should be commensurate with the amount needed to strengthen the Medicare Part A Trust Fund, not the amount needed by Congressional leadership for non-medical issues.

**Managed Care Often Fails People with Disabilities:** Because managed care often reduces costs by limiting access to specialists and treatments, managed care plans often fail people requiring significant health services, particularly people with disabilities and chronic illnesses. CCD supports the Congressional leadership's provisions requiring Medicare managed care plans to guarantee issue and renewability to all Medicare beneficiaries, but remains deeply concerned with the potential for "cherry picking" and adverse selection through experience-based premium rating.

Because of this problem, CCD believes that insurance companies and managed care organizations may reap windfall profits under the Medicare proposals while more costly beneficiaries stay in the Medicare fee-for-service system. CCD is also concerned that the proposed Fail-Safe and "BELT" mechanisms will only serve to increase the costs of remaining in the Medicare fee-for-service program, thereby eliminating this as a viable option for low and moderate income Medicare beneficiaries.

**Federal Standards Needed for Managed Care to Ensure Access and Quality:** CCD believes a reasonable response to shifting large numbers of Medicare beneficiaries into managed care plans is the maintenance of existing standards and the creation of additional federal standards that will safeguard the interests of consumers and providers in managed care plans. These standards include consumer and provider due process procedures, grievance and appeals mechanisms to challenge benefit denials, inclusion of a point-of-service option in every managed care plan, ensuring access to specialists, allowing beneficiaries with disabilities to choose specialists as primary care "gatekeepers," and establishing utilization management protocols to ensure informed determinations of medical necessity.

**For more information, please see the enclosed position papers on the Medicaid and Medicare proposals or contact one of the Co-Chairs listed on the first page of this release.**

Consortium for Citizens with Disabilities

**FOR MORE INFORMATION CONTACT:**

**Kathy McGinley (202) 785-3388**
**Marty Ford (202) 785-3388**
**Peter Thomas (202) 466-6550**

# A MESSAGE TO CONGRESS

## Congressional Medicaid "Reform" Proposals Will Harm Children and Adults with Disabilities and their Families

Member organizations of the Consortium for Citizens with Disabilities Health and Long Term Services Task Forces are extremely concerned about the impact the House and Senate Medicaid "reform" proposals will have on the lives of children and adults with disabilities and their families. We strongly urge you not to support these proposals and to carefully reconsider how to "reform" the Medicaid program so that children and adults with disabilities and other individuals with low and very low incomes are not harmed.

The proposals reported out of the House Commerce and Senate Finance Committees make harmful, fundamental changes to the Medicaid program -- a program which now is the largest source of federal and state funding for services and supports for individuals with disabilities. It has been access to critically needed health and related services and to essential community-based long term services and supports -- provided through the Medicaid program -- that have enabled families to stay together and children and adults with disabilities to live fuller and more productive lives in their communities.

**Specific CCD concerns relate to the following issues.**

- **While the Senate proposal maintains a guarantee of health care coverage for low income individuals with disabilities, the House proposal completely eliminates the current individual entitlement status of Medicaid for people with disabilities.**

- **Neither the Senate or House proposals would require states to provide any specific services, except for childhood immunizations.**

If Medicaid is no longer an entitlement and if there is no requirement for the provision of a full range of services, people with disabilities will lose access to critical health and long term services and supports. For people with disabilities and serious health conditions, the lack of access to health and health-related services and supports will lead to an exacerbation of existing health problems and/or disabilities, as well as the emergence of additional health problems and secondary disabilities.

For people with long term care needs, the lack of Medicaid coverage will lead to the loss of services and supports that help them to live more independent lives in the community, in some cases leading to homelessness and inappropriate institutionalization. In addition, families of children with disabilities will have their economic security undermined as they try to pay for essential health and long term services. It is important to remember -- especially in a nation where the number of individuals insured through their employer continues to decrease -- that for many people with disabilities, Medicaid has been the only health care coverage available.

- **The House and Senate proposals include state level "set-asides" for certain vulnerable populations, i.e. families with pregnant women and children, elderly individuals, and low income people with disabilities under age 65. The proposed funding formula for these set-asides would mean that states could not continue to provide the full range of services and supports that they now provide for children and adults with disabilities.**

States would be permitted within these broad categories to determine what services to provide. According to the House proposal, for each set-aside category states would have to spend 85 percent of the average percentage of the state's Medicaid spending from FY 1992 through FY 1994 devoted to mandatory services (what the state now must cover) for people in that category. According to the Senate proposal, for each set-aside category states would have to spend 85 percent of the state's Medicaid spending in FY 1995 on mandatory services for people in that category.

This proposes formula does not take into consideration spending on optional services (what the state now chooses to cover). For people with disabilities, this is a major blow. Current optional services are the ones most likely to be of critical importance to children and adults with disabilities and dollars currently spent towards them would not be counted towards the disability set-aside. Optional services include the following: speech, physical, and occupational therapy, psychological services, clinic services, prescription drugs, dental services, eyeglasses, prosthetic devices, rehabilitative services, home and community based services, ICF-MR services, personal care services, respiratory care services, and case management.

- **In addition to the loss of the personal entitlement to specific required services and the weak funding formula, both the House and Senate proposals eliminate consumer and quality assurance protections and federal oversight in Medicaid services and in Medicaid funded facilities.**

This includes the elimination of federal nursing home and ICF/MR regulations and even the minimum requirement that funds be spent on active treatment for individuals in institutional settings rather than merely custodial care. While Congress continues to speak of the value of devolution and state's rights, the CCD remembers when states could not or would not provide needed services and supports for children and adults with disabilities and their families.

There are well warranted and deep-seeded fears in the disability community that the loss of minimum federal standards coupled with intensifying fiscal pressures will mean that some states return to institution-based custodial care with the consequent loss of individual freedom, rights, and quality of life. The public policy and the original intent behind federal oversight requirements currently attached to funding for certain Medicaid long-term services must be remembered and respected. The proposals also permit the states to move more people into managed care plans with very few consumer protections related to access and quality in these plans.

- **The CCD strongly urges you to carefully reconsider how to "reform" the Medicaid program and not to support the passage of the provisions in the Medicaid Transformation Act of 1995 as part of the budget reconciliation bill.**

We ask you not to eviscerate a program that has allowed millions of children and adults with disabilities to live fuller and more productive lives in the community because they now have access to both acute health care and needed long term services and supports. The CCD does not support the status quo on Medicaid. We do believe, however, that there are changes to the program that can be made that will not penalize those who now benefit from the program. These changes include the elimination of the current incentives for institutional care and the provision instead of incentives for home and community-based long term services and supports.

Finally, the CCD supports efforts to reduce the federal deficit. However, the CCD strongly believes that it is unfortunate that most of the programs on the table for deficit reduction are those of importance to children and adults with disabilities, such as Medicaid, children's Supplemental Security Income, housing, social services, jobs, and education. It is also unfortunate that Congress is endeavoring to balance the budget using only 48% of the federal budget and that 48% comes at the expense of programs of critical importance to the lives of people with disabilities.

**Summary Recommendations**

- **The CCD asserts that the individual entitlement status of Medicaid to a mandated set of benefits for children and adults with disabilities must be maintained.**
- **The CCD asserts that federal reimbursement should be maintained for the full range of acute and long term services and supports that are presently available, including optional services which states now choose to provide through their Medicaid programs. In addition, the states should be required to continue to contribute at least their current share of funds to finance Medicaid services and supports.**
- **The CCD asserts that the federal requirements that states meet certain standards of care and continue appropriate quality assurance measures, as well as due process and other consumer protections must be maintained.**
- **The CCD asserts that managed care should be an "option" and not the only avenue of service for people with disabilities and that strong consumer protections, including timely and appropriate access to all necessary services, supports, and providers must be ensured.**
- **The CCD asserts that current incentives for institutional care built into the Medicaid program must be eliminated and replaced with incentives for the provision of home and community-based long term services and supports.**

For more information, contact the CCD Co-Chairs listed on the first page of this document.

Consortium for Citizens with Disabilities

CCD HEALTH TASK FORCE CO-CHAIRS:
Kathy McGinley (202) 785-3388
Peter Thomas (202) 466-6550

# CCD Health Task Force Position on Medicare Reform

The CCD Health Task Force, comprised of over sixty-five national disability-related organizations, agrees that aspects of the Medicare program are in need of reform, but strongly opposes key elements of the House and Senate leadership's reform proposals. While Medicare serves the health care needs of nearly 40 million senior citizens, the program also covers 4.2 million people with disabilities below 65 years of age. Coupled with the dramatic dismantling of federal protections in the current Medicaid program, these reforms constitute a serious threat to the health, independence, and dignity of all Americans with disabilities.

## Reform for the Wrong Reasons

If Medicare and Medicaid are growing at unsustainable rates of increase, it is largely because the private sector has failed to adequately provide for the health care needs of the populations covered by these programs. In this respect, the Medicare and Medicaid programs represent enormous high risk pools that skew rates of medical inflation in publicly subsidized versus privately funded health programs.

Comparing the growth in Medicare spending to the recent decline in the growth of private insurance spending fails to recognize that the number of Medicare beneficiaries is growing and these persons tend to use more health care services, while employer-sponsored health care is declining and those who are covered tend to be less frequent users of health services. In fact, over one million people under age 65 become uninsured each year which currently represents over 41 million people.

## CCD Supports Medicare Reform for the Right Reasons

The CCD Health Task Force ("CCD") supports constructive change in the Medicare program and acknowledges the importance of fiscal responsibility. Medicare and Medicaid reform should be driven by the goals of enhanced coverage and quality, increased efficiency, decreased waste and abuse, and delivery of benefits that meet the health care needs of the elderly and disabled populations. CCD, however, opposes efforts to dramatically overhaul these programs for the purposes of budget balancing or tax cutting.

## CCD's Concerns with the Congressional Leadership's Medicare Reform Proposals

CCD has five major areas of concern that Congress must consider and address if it is to truly protect and strengthen the Medicare program.

### 1. The Proposed Level of Medicare "Savings" Must be Reduced

Gouging $270 billion out of the Medicare program over the next seven years would represent an unprecedented assault on the stability and effectiveness of the program. While Medicare and Medicaid spending represent 17% of the annual federal budget, 45% of the spending reductions necessary to balance the federal budget by 2002 will come from these two programs under the House and Senate leadership's proposals. Whether these deep spending reductions are characterized as "cuts" or reductions in the rate of growth, taking this magnitude of resources out of the health system will most assuredly cause decreases in quality care, health benefits, and access to necessary medical services.

In order to accomplish these dramatic savings, consumers will spend significantly more for health care than under current law through increased premiums, out-of-pocket expenses and through balance billing. Providers' fees will be sharply restricted, causing significant access and quality concerns for Medicare beneficiaries. Considering the fact that the majority of the proposed savings will not be dedicated to strengthen the Medicare Part A Trust Fund, the argument that these spending reductions are necessary to save and strengthen the Medicare program seem disingenuous.

**The Interaction of Medicare and Medicaid:** The effort to "reform" Medicare and Medicaid as separate programs fails to recognize the vital interaction of these programs on beneficiaries who are dually eligible. The House and Senate leadership's Medicare plan allows managed care plans to charge beneficiaries for deductibles and co-payments as high as traditional indemnity plans.

An open question remains whether low income Medicare beneficiaries will be able to receive the covered services they need when they cannot afford these deductibles or co-payments. This problem is crucial because the Congressional leadership intends to eliminate the Medicaid entitlement, thereby eliminating the guarantee of subsidies for low income elderly persons who cannot afford Part B premiums, deductibles, or co-payments.

### 2. Problems with the Managed Care Approach

**Choice:** Sheparding a greater percentage of Medicare beneficiaries into managed care arrangements and out of the fee-for-services system is a major component of the Congressional leadership's proposed reform. To suggest, however, that Medicare

beneficiaries will have more "choice" under the proposed reforms is to fail to acknowledge that the current Medicare program affords unrestricted choice of provider, the type of choice valued most by beneficiaries. Currently, Medicare beneficiaries may choose any provider and/or specialist they wish or can choose to enter into the Medicare risk contract program to receive health care through managed care plans.

**Managed Care Often Fails People with Disabilities:** As managed care continues to sweep the health care marketplace, dissatisfaction with these plans among people with disabilities and chronic illnesses becomes more and more apparent. Anecdotal and empirical data suggest that most managed care plans do not adequately meet the needs of high users of health care services. CCD believes that many Medicare beneficiaries with significant health conditions will opt to remain in the fee-for-service Medicare program in order to ensure access to appropriate specialty care and to avoid the dangers of underservice which often occurs with this population in managed care plans, particularly in capitated systems.

**A Potential Windfall for Managed Care Organizations:** CCD believes the costs to the fee-for-service Medicare program will proportionately increase as relatively young and healthy Medicare beneficiaries move to Medicare managed care plans. The average Medicare outlay per beneficiary was $4,020 in 1993, a figure similar to the probable amount that Medicare will pay managed care plans under the proposed system for each person each year. The healthiest 90 percent of Medicare beneficiaries, however, received only $1,340 of Medicare outlays in that same year.

As a result, Medicare managed care plans will have the potential for windfall profits by attracting the healthiest Medicare beneficiaries--and receiving inflated payments which reflect the health care expenditures for the most expensive Medicare beneficiaries, most of which will not enroll in managed care plans. Because of this, the shift to Medicare managed care may result in higher Medicare outlays for health services, not savings as are currently anticipated.

**Fee-For-Service Medicare Must Remain a Viable Option:** The costs of remaining in the fee-for-service Medicare system must not be so burdensome on beneficiaries as to effectively deny the option to choose between managed care and the traditional fee-for-service system. With burdensome costs in the fee-for-service program, Medicare runs the risk of becoming a two-tiered system, where affluent beneficiaries will be able to remain in fee-for-service while moderate and low income beneficiaries will be forced into managed care plans.

CCD believes that increased numbers of Medicare beneficiaries with significant health care needs will join Medicare managed care plans if adequate federal safeguards are established to ensure access and quality to high users of care and to protect against

underservice. (See section 5 of this document). CCD strongly supports two provisions in the House and Senate proposals that begin to address CCD's managed care concerns:

- CCD supports the guaranteed issue and renewal requirements on all managed care plans servicing Medicare beneficiaries so that young and healthy beneficiaries will be less apt to be "cherry picked" by managed care plans.

- CCD supports adjustments in the Medicare managed care premium based on age. CCD suggests that these premiums should also be adjusted based on health status and disability, enhancing the protections against adverse selection.

Medical Savings Accounts Will Drain the Medicare Trust Fund: The House and Senate proposals allow a Medicare beneficiary to establish a Medical Savings Account (MSA) in conjunction with a high deductible catastrophic insurance plan which is designed to increase the Medicare beneficiary's sensitivity to the price of health services. Medicare would pay the premiums for the catastrophic insurance plan and deposit in the beneficiary's MSA the difference between the average Medicare outlay (per person per year) and the premium for the catastrophic plan.

Medicare beneficiaries would be expected to pay a high deductible--probably between $3,000 to $10,000--out of their MSA and their own funds before the catastrophic plan would begin paying for their care. The Medicare MSA option will likely appeal to relatively young and healthy beneficiaries who are currently at low risk of using significant health services. Under the House and Senate proposals, beneficiaries who have funds remaining in their MSAs at the end of the year could use these funds for non-medical purposes, as long as taxes on this income are paid.

CCD believes this proposal will have the profound effect of draining precious medical dollars out of the Medicare Trust Fund at a time when the long term solvency of this Fund is at genuine risk. In fact, the Congressional Budget Office (CBO) estimates that the MSA option would cost the federal government $2.3 billion if only 1% of Medicare beneficiaries choose to establish MSAs. If Congress is to move forward with the establishment of Medicare MSAs, at the very least, it should strictly limit the use of MSA funds to qualified medical expenses only.

## 3. The "BELT" or "Fail Safe" Provision Could Seriously Harm the Fee-For-Service System

Because the Congressional Budget Office (CBO) recognizes that Medicare's shift to managed care may not be the cost saver that the proposals envision, the Congressional leadership has included a "Fail Safe" or "BELT" mechanism in their plan. This mechanism allows the Secretary of Health and Human Services in future years to review the savings

actually achieved-- from the Medicare program (in the Senate) and from Medicare managed care (in the House)--and, if the savings is less than expected, to further decrease provider fees under the fee-for-service Medicare program.

**The Fail Safe/BELT Mechanism is Inequitable:** CCD strongly opposes this provision for two primary reasons: It penalizes fee-for-service providers for the failure of managed care plans to achieve the savings they have projected, and it further negatively impacts people with disabilities and chronic illnesses (and the providers who serve them) who remain in the fee-for-service program to avoid underservice in Medicare managed care plans. This again raises grave concerns related to access and quality. High users of care will be effectively forced into managed care plans as their out-of-pocket costs continue to rise and as the number of providers accepting fee-for-service Medicare patients continues to decline.

## 4. Quality Assurance Must be Maintained

One of the key consumer protections for Medicare beneficiaries with disabilities and chronic illnesses currently enrolled in risk contract managed care plans is the ability to disenroll from the plan with 30-days notice if the beneficiary's health care needs are not being adequately met. The Medicare leadership's reform proposals eliminate this important protection and only allows disenrollment during an annual open enrollment period.

CCD believes the 30-day disenrollment provision must be maintained in order to ensure that Medicare managed care plans provide access, quality, and accountability. At the very least, every Medicare managed care plan should be required to offer an affordable point-of-service option to beneficiaries in order to ensure access to out-of-network services when medically necessary and appropriate.

## 5. Shifting to Managed Care Requires Federal Standards to Ensure Access and Quality

The point-of-service option is just one of the many federal standards that managed care plans servicing Medicare and Medicaid beneficiaries should be required to meet. The tradeoff for shifting large numbers of Medicare and Medicaid beneficiaries into managed care plans should be that such plans adhere to certain minimal standards that will safeguard the interests of consumers and the providers who serve them.

Examples of these important safeguards can be found in several pieces of legislation including **H.R. 2400**, introduced by Congressman Norwood (R-GA) and Congressman Brewster (D-OK); **H.R. 2350**, introduced by Congressman Coburn (R-OK), and **H.R. 2329**, introduced by Congressman Brown (D-OH). CCD strongly supports application of the provisions of these bills to Medicare and Medicaid managed care plans, particularly the following requirements:

- consumer and provider due process standards
- adequate grievance and appeals mechanisms for denials of benefits and access to specialists
- inclusion of a point-of-service option in every managed care plan
- allowing beneficiaries with disabilities and chronic illnesses to choose a specialist as a primary care "gatekeeper"
- allowing direct and ongoing access to specialists when medically indicated
- ensuring access to centers of specialized treatment expertise
- prohibition of physician incentive plans that reward physicians for not making referrals to specialists
- establishing utilization management protocols to ensure informed determinations of medical necessity

## Conclusion

CCD strongly urges Congress to assess in detail the far-reaching impact of the decisions it will make over the next few weeks and months on Medicare and Medicaid issues. We recognize that reform is necessary in both our publicly-supported and employer-based health care programs, but CCD strongly believes that the Medicare and Medicaid proposals offered by the Congressional leadership to date have the potential to devastate the quality of and access to health care services for people with disabilities and chronic illnesses in this country.

For more information on CCD's positions on Medicare, Medicaid, and private insurance reform, please contact Peter W. Thomas (202) 466-6550 or Kathy McGinley (202) 785-3388.

Revised October 23, 1995

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

24-Nov-1995 05:33pm

TO: justice

FROM: owner-justice

SUBJECT: Alert: Budget Battle Escalates!

jdart@tsbbs02.tnet.com

JUSTICE FOR ALL

TRUTH TEAM '95

BECKY OGLE: CHAIR, MARK SMITH: TRUTH TEAM COORDINATOR, 754 NORTH PRESIDENT STREET, SUITE 2, JACKSON, MS 39202, 601/969-0601 V/TDD, 969-1662 FAX, JUSTIN DART: 907 6TH STREET, S.W., #516C, WASHINGTON, DC 20024, 202/488-7684 V/TDD, 863-0010 FAX, FRED FAY: justice@tnet.com E-MAIL

* * * * * ALERT!!!

BUDGET BATTLE
ESCALATES!

THE NEXT THREE WEEKS WILL BE DECISIVE.
FLOOD THE MAIL, THE PHONES, THE FAXES,
THE FORUMS, THE MEDIA WITH TRUTH.

To the President:

Congratulations! Hang tough! We are with you!

To the Congress, the Governors and the media:

- A balanced budget, yes! A weakening budget, no!
- No weakening of the federal role in guaranteeing the rights of U.S. citizens to the basic services of civilized society.
- No weakening of federal or state guarantees of Medicaid and Medicare for low income Americans. Strengthen community based long term care and personal assistance services.
- No weakening of the basic educational transportation, job and other services that empower people with and without disabilities to achieve a prosperous, balanced-budget economy.
- No cuts in taxes for the well-to-do. No increases in taxes for low income workers.
- No cuts in SSI benefits for children with disabilities.

CONGRATULATIONS COLLEAGUES! Your messages have made a difference. The President has made Medicaid and disability much more visible in his budget battle dialogue. He has taken a strong stand for principle. He has won apparent pledges from Congress that programs for the poor will not be devastated. The Istook, "Silence America" amendment was defeated. The public seems increasingly aware.

BUT THE CONGRESSIONAL STEAMROLLER ROARS ON. In spite of their pledges to the President and the people, Congressional leaders indicate no intention to modify any of their disastrous tax and program cuts, or any of their transfers of American citizenship rights to the states.

WASHINGTON POST, November 22, "Republican Governors and House Speaker Newt Gingrich vowed today to resist any Clinton administration efforts to impose limits on state discretion in welfare programs during the coming negotiations on a balanced budget."... "Gingrich offered repeated promises that the final version of the seven-year budget, to be hammered out by Dec. 15, will retain virtually unlimited powers for the states to reshape Medicaid and welfare programs when they take over from Washington."

Senator Chafee's effort to include a uniform federal definition of disability for Medicaid eligibility was defeated. Each state will be able to create its own definition. The Istook amendment probably will be brought up again. The ADA and the IDEA continue in danger.

Communicate!

The President *

Your Senators

Your Representative

Your Governor

Senator Bob Dole *

Senator Tom Daschle *

Speaker Newt Gingrich

Rep. Dick Gephart *

Senator John Chafee *

Senator Bill Frist *

Senator James Jeffords *

Senator Tom Harkin *

Senator Paul Wellstone *

Local TV, Radio and Newspapers

Address For All Senators:
U.S. Senate
Washington, D.C. 20510

Address For All Representatives:
U.S. House of Representatives
Washington, D.C. 20515

Address For The President:
The White House
Washington, D.C. 20500

* Has earned our thanks.

Advocate as if your life depends on it. It does!
And the lives of your children and grandchildren!/

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

28-Nov-1995 01:38pm

TO: justice

FROM: owner-justice

SUBJECT: FYI: Budget Showdown Update

Justice For All

beckyo@names.org

Budget Showdown Update

The White House and congressional Republican leaders are expected to begin deliberations this week on budget and tax cut issues. There is definitely a shadow of doubt concerning a resolution by both parties, but despite these sentiments both sides will proceed for the time being.

There are two major tasks that have to be completed before December 15th to avert another government shutdown when the short term spending bill expires. First, work needs to be finished on seven of the 13 spending (appropriations) bills for fiscal 1996 or agree to a long term continuing resolution that would keep the government up and running. Beyond that the two parties need to negotiate their way through the 'precarious long-term budget reconciliation'(Medicaid/Medicare....etc.).

What will happen to these negotiations is unknown at this time. Will there be a compromise? Will there be a stalemate of sorts? Some suggest that the differences between priorities of the Clinton Administration and the GOP balanced budget goal are unreachable within a seven year period, and no compromise will be achieved. If that happened, Medicaid, Medicare and others would continue as status quo, but it is reported that President Clinton would work toward an agreement on welfare reform. As priorily mentioned, it is anybody's guess what will happen.

The grassroots message should remain consistent regardless of the mess here in Washington. We should all be stressing that the cuts are too severe to Medicaid, Medicare, education and many others and some cuts never heal.

We support a balanced budget, but oppose a $245 billion dollar tax cut while attempting to achieve this worthy goal,(According to projections by the Joint Commission on Taxation, Congress's nonpartisan tax analysis group, the GOP plan would lower federal revenue by an average of about $35 billion annually between 1996 and 2002).

Priorities, principles and morality should be our guide through the labryinth political battle currently being debated. It is our job and responsibility to raise the debate off the dollar and back to the people where it belongs.

JUSTICE FOR ALL!!!!!!!!!!!!!!!!!!!!!!

Keep up the fantastic grassroots work and we will continue to keep everyone alerted to the developments as they occur.

Becky Ogle
E-mail: beckyo@names.org
Voice: 703-836-6263

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-Ellyn, 27, homemaker.

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

**Annual income:** $32,000.

**Lauren's primary diagnoses:** 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 fiancee, Meri-Ellyn 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*

WITH 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 standards."

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.

## 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.

## TROUBLE 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*

ON 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. Smeltzer**
*Dispatch Staff Reporter*

**Photos by Eric Albrecht**
*Dispatch Staff Photographer*

AMID 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

## Father discovers inflammatory file during hearing

By Michael J. Berens
*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 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 fiancee, 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.

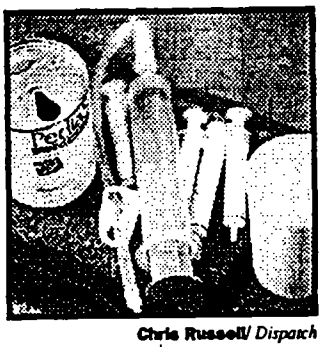
Still, Carter remained uneasy about the allegations — fearful that, though baseless, they might be used against him.

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.



Chris Russell/ *Dispatch*

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 |
| **Total medically fragile children** | | 2,239 |

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

*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 Susan 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 gunfighter 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*

SOMETIMES 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**

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

**J income:** $50,000

**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

**cost of waiver:** $105,000

**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 fiancee, 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 have Lauren reinstated to its Medicaid waiver program.

*Please see* **HOPE** *Page* **2A**

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 Services 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 or 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 fiancee 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*

SHARE 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, Mommmmmy!"

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*

TWO-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

# A new life for Lauren

**By Michael J. Berens**
*Dispatch Staff Reporter*

WITH 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 fiancee, 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.

"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 fiancee. "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.

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.

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 fiancee 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.

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

**■ Camelot Lake**
Capacity: 36
Butler County
Fairfield

**■ Hattie Larlham Foundation**
Capacity: 130
Portage County
Mantua

**■ St. Joseph's Children's Home**
Capacity: 47
Hamilton County
Cincinnati

**■ Stillwater Center**
Capacity: 92
Montgomery County
Dayton

**■ 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 to , parents wouldn't have it any other way

**Story by Nancy J. Smeltzer**
*Dispatch Staff Reporter*

**Photos by Eric Albrecht**
*Dispatch Staff Photographer*

MARY 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."

# Sacrifices a daily part of son's care

**Story by Laurie Loscocco**
*Dispatch Staff Reporter*

**Photos by Lynn Ischay**
*Dispatch Staff Photographer*

NOT 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*

Martha 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."

# Consortium for Citizens with Disabilities

Marty Ford (202) 785-3388
Kathy McGinley (202) 785-3388
Peter Thomas (202) 466-6550


## CCD's MEDICAID AND MEDICARE RECOMMENDATIONS

### I. MEDICAID RECOMMENDATIONS

Recommendation No. 1: The Consortium for Citizens with Disabilities strongly recommends maintaining the current individual federal entitlement to Medicaid and not block granting this vital program to the states. If any significant changes are made in the Medicaid program, they must be phased-in to ensure a smooth transition for Medicaid beneficiaries and must include public participation in the development, preparation, implementation and monitoring of state plans.

Recommendation No. 2: The Consortium for Citizens with Disabilities recommends a significant reduction in the level of proposed Medicaid cuts over the next seven years in order to ensure the continued vital assistance that Medicaid provides to people with disabilities.

Recommendation No. 3: To control the rate of growth in Medicaid spending, the Consortium for Citizens with Disabilities recommends that Medicaid reforms should adopt alternatives to the current block-grant proposals such as a per capita cap on federal Medicaid dollars and the creation of incentives for home and community-based care in appropriate circumstances-and disincentives for the use of institution-based care.

Recommendation No. 4: The Consortium for Citizens with Disabilities recommends that the Medicaid reforms include specific provisions to ensure the active participation of people with disabilities at every level of decision-making in the Medicaid program. In addition, the Medicaid reforms should include a declaration of principles regarding valued outcomes for people with disabilities including, but not limited to, empowerment, choice, independence, self-sufficiency, and community inclusion.

Recommendation No. 5: The Consortium for Citizens with Disabilities recommends that federal oversight and minimum standards of consumer protection and quality assurance be maintained in Medicaid-funded programs such as nursing homes, ICFs-MR, community-based programs, and in all Medicaid-funded managed care. Managed care should be an "option" and not the only choice for Medicaid beneficiaries with disabilities. Any use of managed care should include strong protections for timely and appropriate access to all necessary services, supports, and providers.

Recommendation No. 6: The Consortium for Citizens with Disabilities recommends that. the Medicaid reforms maintain the existing federal private right of action against states to enforce compliance with the Medicaid statute and regulations and to ensure that state Medicaid programs fully comply with the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973.

## II. MEDICARE RECOMMENDATIONS

Recommendation No. 7: The Consortium for Citizens with Disabilities recommends a significant reduction in the proposed level of spending cuts to be taken out of the Medicare program in order to maintain access and quality of health care services for people with disabilities.

Recommendation No. 8: The Consortium for Citizens with Disabilities recommends that the premium collected by Medicare managed care plans be limited to the government contribution --adjusted for the age and health status of the enrollee-- for the individual beneficiary. The CCD further recommends that the Medicare reforms include provisions related to guaranteed issue and renewability of Medicare managed care plans and continue the prohibition against balance billing throughout the entire Medicare program.

Recommendation No. 9: The Consortium for Citizens with Disabilities opposes the creation of Medicare Medical Savings Accounts. If Medicare MSAs are authorized, however, the Medicare reforms should risk adjust the capitated government contribution toward MSAs and strictly limit the use of MSA funds to health, long-term care, and independent living expenses only.

Recommendation No. 10: The Consortium for Citizens with Disabilities recommends that the 30-day disenrollment provision be maintained in Medicare managed care and expanded to Medicaid managed care plans in order to ensure access, quality, and accountability to all Medicare and Medicaid beneficiaries. In addition, Medicare and Medicaid managed care plans should ensure access to out-of-network providers through an affordable point-of-service option.

Recommendation No. 11: The Consortium for Citizens with Disabilities recommends the inclusion in the Medicare and Medicaid proposals of federal standards for managed care plans. These standards should address the critical issues of access and quality of care for Medicare and Medicaid beneficiaries with disabilities and chronic illness who enroll in managed care plans. Without adequate quality assurance standards, managed care is likely to be discriminatory against people with disabilities in the near term and against all people in managed care over time.

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)*

November 15, 1995

The Honorable William J. Coyne
2455 Rayburn House Office Building
United States House of Representatives
Washington, DC 20515

Dear Representative Coyne:

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 that 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

Randall L. Rutta
Vice President,
Government Relations

Enclosure

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# WASHINGTON WATCH

DEPENDABLE, TIMELY INFORMATION FOR AMERICA'S DISABILITY COMMUNITY

Volume 1, Issue 32 December 5, 1995

## Clinton Responds to Disability Community on Medicaid

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

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

The letter went on to state:

*Ensure adequate funding for Medicaid by:*

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

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

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

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

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

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

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

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

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

*A popular government without popular information, or the means of acquiring it, is but a prologue to a farce or a tragedy or perhaps both. Knowledge will forever govern ignorance, and a people who mean to be their own governors must arm themselves with the power which knowledge gives. .. Madison, 1822*