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WHITE HOUSE BRIEFING DOCUMENT ON MEDICARE AND MEDICAID FOR PEOPLE WITH DISABILITIES

November 13, 1995

WHITE HOUSE BRIEFING DOCUMENT ON MEDICARE AND MEDICAID FOR PEOPLE WITH DISABILITIES

Contents Page

OVERVIEW

Medicare and Medicaid provide critical health care services and long-term supports to people with disabilities of all ages:

- Medicaid serves more than 6 million people with disabilities.

- Medicare serves 4 million people under age 65 with disabilities.

Medicaid payments for people with disabilities totaled $52.8 billion in fiscal year 1995.

Medicare payments for people eligible for Medicare because of a disability totaled $18.5 billion in fiscal year 1995., although many more Medicare dollars are spent on behalf of elderly people with disabilities.

MEDICAID AND PEOPLE WITH DISABILITIES: WHO MEDICAID COVERS

Do we know this?

- Medicaid is the primary insurer of people with disabilities because private insurance is not affordable for people with pre-existing conditions. People with disabilities are more likely to be low-income, use more health and long-term care services, and incur higher health costs than people without disabilities.

- Medicaid covers people with disabilities if they:
  - Are poor enough to qualify for Social Security Income (SSI)
  - Reside in an institution and cannot afford the full cost of care [check]
  - In some states, people impoverished by medical expenses
  - Meet state criteria for home and community-based care
  - Are poor and elderly (Medicaid pays for their Medicare premiums and cost sharing)

MEDICAID SERVICES FOR PEOPLE WITH DISABILITIES

- All states cover a minimum set of services, including:

  - Hospital and physician services
  - Nursing home services
  - Institutions caring for people with mental retardation (ICFs/MR)

- States have the option of covering many services that people with disabilities need, including:

  - Prescription drugs
  - Physical, occupational, and speech therapy and other rehabilitation services
  - Assistive devices and equipment, such as wheelchairs and communication devices
  - Home and community-based care which enables people with disabilities to live in communities, attend school, participate in family life, and for some, work

How?

MEDICARE COVERAGE FOR PEOPLE WITH DISABILITIES

- Medicare covers people with disabilities if they:
  - Receive Social Security disability benefits (after a waiting period of two years)
  - Have a kidney failure
  - Are adult disabled children of individuals receiving Social Security benefits, if the parent has died and was the sole source of support for the child

Are Elderly and [illegible] on MC

- People with disabilities on Medicare qualify for the same services as other Medicare beneficiaries, including hospital services, physician services, laboratory services, skilled nursing facilities, home health care, and durable medical equipment.

CHILDREN WITH DISABILITIES

- Medicaid serves over 913,000 children with disabilities, according to the Department of Health and Human Services.

- Children may experience a range of disabling conditions, such as mental retardation, severe speech and language problems, developmental delays, cerebral palsy, emotional disorders, cystic fibrosis, and seizure disorders.

[INSERT CASE EXAMPLES]

CHILDREN WITH DISABILITIES: HOW THEY QUALIFY FOR MEDICAID

- Medicaid covers children with disabilities if:
  - The family's income is low enough to meet AFDC guidelines
  - The child is disabled and poor enough to qualify for Supplemental Security Income (SSI)
  - The child qualifies for a state home and community-based waiver program, based on the nature of the disability, family income, or the need for certain services
  - The family qualifies for a "medically needy" program offered in many states for families with large medical expenditures but incomes that are too high to qualify for Medicaid under normal circumstances. Medical costs for a child with a disability can easily impoverish a middle class family

CHILDREN WITH DISABILITIES: MEDICAID SERVICES

Medicaid provides children with disabilities services and supports, including:

- Basic health services
- Special therapies
- Long-term care services
- Family training and support
- Special education
- Home modifications

Under the Medicaid Early and Periodic Diagnosis, Screening and Treatment Program (EPSDT), states must cover all needed treatment identified under a child's EPSDT screening -- regardless of whether the state Medicaid program would otherwise cover the services.

Medicaid provides health coverage that makes it possible for many disabled children to be legally adopted by families. Without Medicaid some adoptive parents would be unable to get needed health care coverage for their disabled children.

- [ADD COORDINATION WITH OTHER PROGRAMS]

PEOPLE WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES (MR/DD)

Medicaid provides health coverage for approximately 734,000 adults, aged 21–64, with mental retardation or other developmental disabilities (MR/DD).

Many of these individuals also receive some health coverage under Medicare as “adult disabled children" of Medicare beneficiaries.

Medicaid acute and long–term care services enable people with MR/DD to live in their homes and communities, as well as in institutions. Medicaid enables many people with MR/DD to take care of themselves and their homes, get around in their communities, work, and meaningfully contribute to society.

While the MR/DD population is not a large segment of all Medicaid users, MR/DD spending accounts for 10% of all Medicaid spending or $__ billion [CHECK].

MEDICAID SERVICES FOR PEOPLE WI' 'H MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES

- Medicaid provides long-term support to many people with MR/DD:

  1. Intermediate Care Facilities for the Mentally Retarded (ICFs/MR): 120,000 people receive 24-hour services in ICFs/MR at a cost of about $9 billion. ICFs/MR are federally regulated and monitored group living situations, ranging from 4 to over 500 individuals.

  2. Home and Community-Based Supports: Over 122,000 people receive home and community-based supports under a Medicaid waiver program, at a cost of approximately $3 billion.

  3. Other Medicaid Long-Term Care Services: These include personal care, clinic and rehabilitation services, supported living, supported employment, and case management.

- Medicaid also provides acute health services to people with MR/DD, including doctor and hospital care, physical therapy, eyeglasses and dental care, and assistive technology and equipment like communication devices and wheelchairs.

WORKING-AGE ADULTS W TH DISABILITIES

Medicaid covers health _____ [care?] and long-term supports for approximately 3.2 million adults with disabilities other than MR/DD.

1.4 million disabled individuals under age 65 receive both Medicare and Medicaid (e.g., poor people who are eligible for Medicare because of a disability).

Vital services for this population include: physician and hospital services, home health care, personal care, therapies, assistive devices and equipment, nursing home care, and prescription drugs.

Under current law, many people with disabilities are able to work and earn some income and still receive Medicaid coverage, so that people do not have to choose between health care coverage and employment.

SEPARATE PAGE ON PEOPLE WITH HIV AND AIDS

ELDERLY PEOPLE WITH D SABIL T ES

- Medicaid provides a safety net for over 4 million low- and middle-income elderly individuals, many with disabilities, and their families:
  - **1.4 million older Americans received nursing home care**, at a cost of $23.5 billion in 1993.
    - Medicaid is the largest insurer of long-term care for all Americans, including the middle class. Medicaid covers 68% of nursing home residents and over 50% of nursing home costs.
    - Nursing home care costs average $38,000 per year.
  - **500,000 people received home and community-based care**, at a cost of $3.8 billion in 1993.
  - **Prescription drug coverage.** Medicaid pay approximately $872 per elderly beneficiary for prescription drugs.
- Medicaid covers Medicare premiums and cost-sharing for people with incomes below 100% of poverty (known as "Qualified Medicare Beneficiaries") and premiums for people with incomes between 100% and 120% of poverty. In 1995, 5.4 million low-income people had their

Add MC??

Medicare premiums and cost-sharing covered by Medicaid.

QUALITY STANDARDS

As a condition of Medicaid financing, nursing homes must comply with strict federal quality standards. These standards require facilities to provide all needed services, limit the use of physical and chemical restraints, and ensure that nurse aides are trained and qualified.

- Since these standards have been in place, there has been a 50% reduction in dehydration among residents, a 31% reduction in hospitalization rates, and a 25% reduction in the use of physical restraints. [Source: Research Triangle Institute and HCFA.]

Medicaid has also set standards and monitored care in institutions caring for the mentally retarded since 1971. Because of these standards, people with mental retardation can live in safe, healthy institutions rather than in the deplorable conditions of the past.

The House Republican budget repeals federal quality standards for nursing homes. Senate Republicans allow states with "equivalent or stricter" standards and enforcement to receive waivers from the federal requirements. However, the federal government would have no way to ensure that states enforce these standards. Budget constraints, combined with the elimination of federal standards and monitoring, could threaten quality of care. *[change to reflect conference bill]*

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

SPOUSAL IMPOVERISHMENT PROTECTIONS

Medicaid protects spouses of nursing home residents from having to become impoverished in order for their spouse to qualify for Medicaid. States must let spouses keep income equal to 150% of the national poverty level -- about $15,000 per year. States must also allow spouses to keep a minimum amount of the couple's assets -- ranging from $15,000 to $75,000 -- in addition to their house and car.

Since this law went into effect in 1989, it has protected about 450,00 spouses of nursing home residents. Most of the spouses are women.

Initially Republicans repealed these protections. In response to criticism that spouses could be forced to use all their income and assets to pay for nursing home care, Republicans modified their plans. But their protections are hollow. Both bills make it more difficult for the federal government to ensure that states comply with any spousal protections. And under the House bill, people can no longer sue the State to enforce these protections.

HOME AND COMMUNITY-BASED CARE

People with disabilities of all ages, and their family members, often prefer to receive services and supports at home and in the community. Medicaid financing has followed this preference, especially over the past 15 years.

The Medicaid home and community-based waiver program allows states to provide home and community care to people who would otherwise need to be in an institution, as long as the cost of the care does not exceed the cost of institutional care.

49 states operate a total of over 200 home and community-based waiver programs, using Medicaid dollars to provide a range of supports to subsets of people eligible for Medicaid, such as adults with mental retardation, the frail elderly, or people with HIV/AIDS. Waivers may also be designed to serve people in targeted areas within a state (e.g., certain counties).

In addition to waiver programs, states provide home and community-based care to people with disabilities by offering optional Medicaid services like personal care services or case management.

IMPACT OF THE REPUBLICAN MEDICAID CUTS ON PEOPLE WITH DISABILITIES

4 es

SUBSTITUTE THIS GENERIC PAGE FOR ALL THE IMPACT PAGES?

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

About 1.3 million people with disabilities would lose coverage in 2002 under the House Republican plan.

The Senate claims to have preserved coverage, but it has not. The Chafee Amendment guarantees that people with disabilities will be covered by Medicaid, but does not guarantee any services. Because the Medicaid cuts reach nearly 30% in 2002, the Chafee amendment may provide a guarantee to little, if anything.

People with disabilities would no longer be guaranteed coverage of even the minimum set of services now covered by all states (known as "mandatory services"), such as doctor and hospital care.

Prescription drug and long-term care coverage -- which are not covered by Medicare -- could be eliminated.

IMPACT OF THE REPUB ICAN M D CAID C JTS ON PEOPLE WITH DISABILITIES

The deep funding cuts could force States to eliminate coverage for many services important to people with disabilities, such as assistive devices and equipment, home and community-based supports (such as personal assistance services), prescription drugs, and home modifications.

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

Adults with MR/DD who live independently in community settings with Medicaid supports might be forced to enter state institutions or return to the homes of their aging parents, who would have to provide care formerly covered by Medicaid.

Working age people with disabilities might be forced to give up their job in order to qualify for Medicaid benefits.

Family members and friends would have to pay for or provide much of the care for people with disabilities that is today covered by Medicaid.

IMPACT OF THE REPUBLICAN MEDICAID CUTS ON PEOPLE WITH DISABILITIES

- Costs would increase significantly for elderly people with disabilities:

  - Medicare premiums would increase dramatically, disproportionately affecting people with disabilities who already pay high out-of-pocket costs, are less likely to have private insurance, and are more likely to be poor. The Republican Medicare plan increases premiums by $20 a month in 2002, compared with the President's plan [CHECK].

  - Medicaid would no longer cover premiums and cost-sharing for low-income Medicare beneficiaries. The Republican Medicare plan sets aside only 44% of the funding needed to cover their premiums in 2002 and does not set aside any funding for their cost-sharing.

MISSING PAGE ON TOUGH CHOICES THAT STATES WOULD BE FORCED TO MAKE BETWEEN POPULATIONS AND SERVICES/HOW LONG TERM CARE COULD BE THE FIRST TO GE BECAUSE EXPENSIVE

MISSING PAGE ON PROBLEMS FOR PEOPLE WITH DISABILITIES OF MANAGED CARE

THE PRESIDENT'S BALANCED BUDGET PLAN PROTECTS PEOPLE WITH DISABILITIES

The President's Medicaid plan includes savings of $54 billion over seven years. This is less than one-third of the $170 billion cut proposed by the Republicans.

The President's plan limits the growth in federal Medicaid payments to States on a per person basis, so that states do not need to reduce coverage to achieve savings.

The President's plan guarantees coverage to people currently eligible for Medicaid, including the disabled. Under the Republican plan, 1.3 million people with disabilities would lose coverage in 2002.

The President's plan also maintains mandatory services for people on Medicaid. The Republican plan would leave states free to decide not to cover any service.

The President's plan protects quality of care in nursing homes and other facilities and ensures that spouses of nursing home residents are not driven into poverty by the costs of nursing home care.

END OF DOCUMENT

WHO ARE PEOPLE WITH DISABILITIES?

I dropped this page to shorten the document

People with disabilities live with a range of chronic conditions, including physical disabilities (e.g., spina bifida), blindness, developmental disabilities (e.g., delayed speech), AIDS, mental retardation, chronic mental illness, and Alzheimer's disease.

People with disabilities are more likely to be low-income, use more health and long-term care services, and incur higher health costs than people without disabilities.

People with disabilities are often unable to buy private health insurance because of high costs, pre-existing condition exclusions and other restrictions. They are therefore much more likely to use Medicare and Medicaid to meet their more extensive health care needs.

CHI _DREN WITH DISAB LITIES: MPACT OF MED CA D CUTS

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

Children with disabilities would no longer be guaranteed Medicaid coverage.

For those children still covered by Medicaid, states would no longer have to provide the minimum set of services covered today (known as "mandatory services"), such as doctor and hospital services.

The deep funding cuts might force States to eliminate "optional services" important to children with disabilities, including therapies, assistive devices and equipment, home and community-based supports, and home modifications.

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

PEOPLE WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES: IMPACT OF MEDICAID CUTS

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

People with MR/DD would no longer be guaranteed Medicaid coverage.

For those people with MR/DD still covered by Medicaid, States would no longer have to provide the minimum set of services covered today ("mandatory services"), including doctor and hospital services.

The deep funding cuts might force States to eliminate coverage for other services important to people with MR/DD, including personal care, therapies, assistive devices and equipment, home and community based-supports (such as personal assistance services), prescription drugs, and home modifications.

Adults with MR/DD who live independently in community settings with Medicaid supports might be forced to enter state institutions or return to the homes of their aging parents, who would have to provide care formerly covered by Medicaid.

WORKING–AGE ADULTS WITH DISABILITIES: IMPACT OF MEDICAID CUTS

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

Working–age adults with disabilities would no longer be guaranteed Medicaid.

For those adults with disabilities still covered, States would no longer have to provide the minimum set of services covered today (known as "mandatory services"), including doctor and hospital services.

The deep funding cuts might force States to eliminate coverage for other services important to adults with disabilities, including personal care, therapies, assistive devices and equipment, home and community–based supports, prescription drugs, and home modifications.

Poor, disabled working–age individuals eligible for both Medicare and Medicaid could lose their Medicaid coverage and with it critical benefits –– such as prescription drugs –– that are not covered by Medicare.

- Family members and friends would have to pay for or provide much of the care for people with disabilities that is today covered by Medicaid.

ELDERLY INDIVIDUALS WITH DISABILITIES: IMPACT OF MEDICAID CUTS

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

Elderly people with disabilities would no longer be guaranteed Medicaid coverage.

Prescription drug and long-term care coverage -- which are not covered by Medicare -- could be eliminated.

Costs would increase significantly for elderly people with disabilities:

- Medicare premiums would increase dramatically, disproportionately affecting people with disabilities who already pay high out-of-pocket costs, are less likely to have private insurance, and are more likely to be poor. The Republican Medicare plan increases premiums by $20 a month in 2002, compared with the President's plan [CHECK].

- Medicaid would no longer cover premiums and cost-sharing for low-income Medicare beneficiaries. The Republican Medicare plan sets aside only 44% of the funding needed to cover their premiums in 2002 and does not set aside any funding for their cost-sharing.

voted to retain nsg home q stds; with some wiggles; one change was to create possibility of waiver, state stds at least as stringent; a lot of controversy yesterday; elim. annual resident review; still do preadmission, but not annual;

but left intact obra 87 nursing home reforms;

jen: pryor: but no enforcement; Roth amendment came after Cohen/Pryor;

susan hill: 3-933-1454

don J; 7-241-0528

Chafee passed, SSI minimum;

Tom G 3-587-5756

Susan Hill: Pryor/Cohen: OBRA 87 is nsg homes; dereg:

icf/mr's still blast
pryor/cohen passed - state reinsttatement; Roth: waivers; we don't like them:

IMPACT OF MEDICAID CUTS ON PEOPLE WITH DISABILITIES

People with disabilities will be among those hit hardest by the Republican Medicaid proposals. Medicaid provides a safety net for people with disabilities of all ages -- children, people with mental retardation, people with AIDS, and the frail elderly and their families. Many families, both lower-income and middle class, receive support from Medicaid.

- More than 6 million people with disabilities are now served by Medicaid, including over 1 million children. Under the Republican budget proposals, up to 1.4 million individuals with disabilities could lose Medicaid coverage.

- Cuts in Medicaid would be particularly devastating to people with disabilities because they are often shut out of the private health insurance market.

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

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

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

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

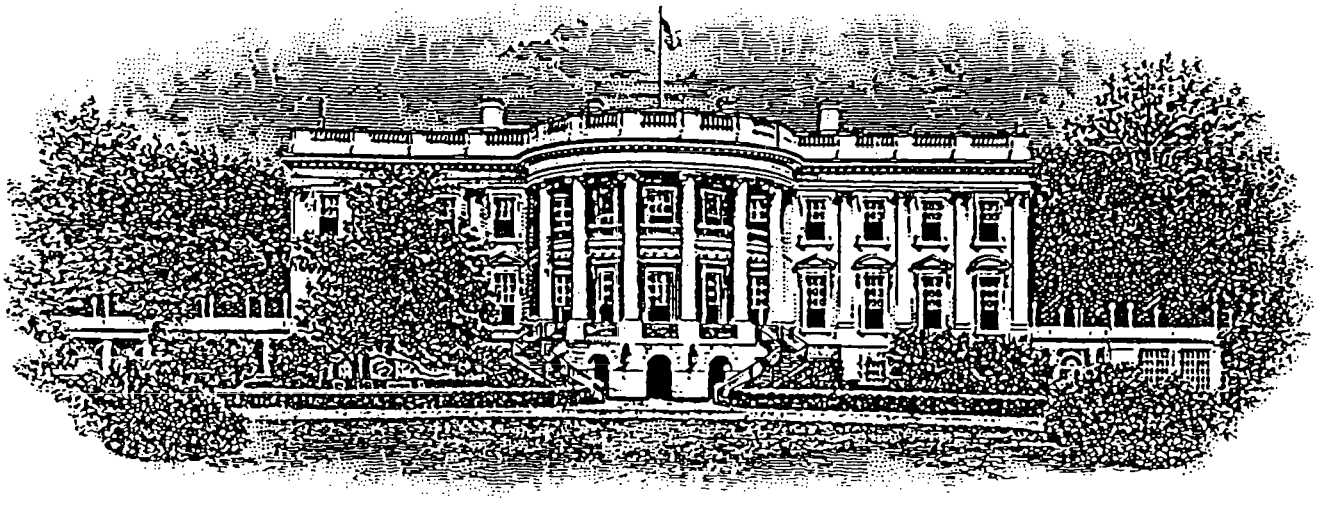
- States often use Medicaid funding to provide early intervention services for infants and toddlers with disabilities. Early intervention and therapies for these very young children is critical to maximize what they can later accomplish in school. Under a block grant, states would be under severe pressure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

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

- The block grant proposal threatens quality standards at nursing homes and at intermediate care facilities for the mentally retarded. Not that long ago, most people with mental retardation were relegated to large institutions with substandard conditions. Federal standards have greatly improved conditions in institutions and have created a wider range of choices for families, including services at home and in the community.

(even though The ICF/MR were not even

The White House



DOMESTIC POLICY

FACSIMILE TRANSMISSION COVER SHEET

TO: Don Johnson, Susan Hill

FAX NUMBER: 690-8168

TELEPHONE NUMBER:

FROM: Diana Fortuna

TELEPHONE NUMBER:

PAGES (INCLUDING COVER): C+5

COMMENTS: We are having a Conference Call at 1030 w/ John Spiegel to pursue

Coverage – particchildren undercovered
- could break thru.

Don't hit till Core's

Examples by disability

(Walk a few people thru)

Mrs Gore → network

Not opposed to event

Data vs. event

She does all the H/H's sheets on this.

~~What are we picturing~~

IMPACT OF MEDICAID CUTS ON PEOPLE WITH DISABILITIES

People with disabilities will be among those hit hardest by the Republican Medicaid proposals. Medicaid provides a safety net for people with disabilities of all ages -- children, people with mental retardation, people with AIDS, and the frail elderly and their families. Many families, both lower-income and middle class, receive support from Medicaid.

- More than 6 million people with disabilities are now served by Medicaid, including over 1 million children. Under the Republican budget proposals, up to 1.4 million individuals with disabilities could lose Medicaid coverage.

- Cuts in Medicaid would be particularly devastating to people with disabilities because they are often shut out of the private health insurance market.

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

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

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

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

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

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

- The block grant proposal threatens quality standards at nursing homes and at intermediate care facilities for the mentally retarded. Not that long ago, most people with mental retardation were relegated to large institutions with substandard conditions. Federal standards have greatly improved conditions in institutions and have created a wider range of choices for families, including services at home and in the community. A recent

Senate amendment purports to restore quality standards in nursing homes, but without Federal enforcement authority. In addition, this change does not restore quality standards in ICF/MRs.

MEDICAID AND CHILDREN WITH DISABILITIES
FACT SHEET

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

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

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

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

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

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

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

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

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

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

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

IMPACT OF MEDICAID CUTS ON EDUCATION PROGRAMS FOR CHILDREN WITH DISABILITIES

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

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

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

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

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

SSI FOR CHILDREN WITH DISABILITIES

- The Republican budget would severely cut back the Supplemental Security Income (SSI) program for children with disabilities. By 2002, the House approach would eliminate cash assistance for 755,000 children who would be eligible under current rules.

- Only children coming on the rolls who are at risk of institutionalization could get cash benefits. Other eligible children would have to apply for services from a new state block grant that is funded at only 75% of current spending.

- Both the House and the Senate would terminate benefits altogether for approximately 170,000 children with disabilities.

- The loss of cash assistance would be devastating to many low-income families struggling to care for a child at home. Cash benefits provide greater flexibility to meet the varied and changed needs of children with disabilities, and allow parents to determine the needs of their children, rather than a government agency.

- Families with children with disabilities rely on SSI to meet a wide variety of needs, including replacing lost income for a parent who can't work full-time or at all because of his or her child's disability, diapers, home modification, respite care, equipment, special dietary items, etc.

- While both the House and the Senate go too far, the Administration favors the Senate plan because it retains cash benefits. However, the Administration believes that the Senate's cut in eligibility should be applied only to new children joining the program, rather than retrospectively, in order to reduce hardship to families who have come to rely on this program.

IMPACT OF THE REPUBLICAN MEDICAID BLOCK GRANT PROPOSAL ON THE ELDERLY, PEOPLE WITH DEVELOPMENTAL DISABILITIES, PEOPLE WITH OTHER DISABILITIES

I. IMPACT ON THE ELDERLY AND THEIR FAMILIES

- ***The elderly and their families will suffer because of the Republican proposal to eliminate the Medicaid entitlement – there will no longer be guaranteed access to critical services.***

- ***Services needed by the elderly (e.g., prescription drugs, nursing home and community-based services) will no longer be required and many moderate and middle income families may be required to provide and/or pay for needed services.***

- Medicaid provides a critical safety net for over 4 million low and middle income elderly persons and their families. In 1993:

  - Medicaid covered nursing home services for 1.4 million elderly people at a cost of $23.5 billion.

  - 500,000 people received home and community based care, at a cost of $3.8 billion. Much of this care complemented care provided by family members.

  - Medicaid paid approximately $872 per elderly beneficiary for prescription drugs.

- ***Essential Medicaid coverage of Medicare premiums and cost sharing for low income persons will no longer be required. Adult children of elderly persons could be required to pay Medicare cost sharing for their parents.***

- In 1995, Medicaid paid Medicare cost sharing for approximately 2.4 million low income persons eligible for both Medicare and Medicaid and for 3 million persons who are ineligible for Medicaid but nonetheless have limited incomes. Many in the latter group are Qualified Medicare Beneficiaries (QMBs); today, states are required to pay their cost sharing.

- ***Federal nursing home quality standards and enforcement will no longer be required.***

- Due to deplorable conditions in nursing homes across America, comprehensive nursing home reforms were enacted in OBRA '87, a bipartisan agreement. These reforms included requirements that nursing homes provide all needed services so residents maintain their highest level of functioning, limit the use of physical and chemical restraints, and require that all nurse aides be trained and qualified.

  - OBRA '87 achieved several positive outcomes for nursing home residents including reductions in the use of restraints, reductions in hospitalizations, and improved physical functioning.

II. IMPACT ON PEOPLE WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

- ***The Republican plan would eliminate all entitlements to health and long-term support services for people with mental retardation or other developmental disabilities.***

- Medicaid provides health coverage for approximately 734,000 working age adults with mental retardation or other developmental disabilities, aged 21-64.

  - People with MR/DD are more likely to be heavy users of health care, low income, and incur higher costs than others.

- Many of the 734,000 receive long-term care as well. 120,000 receive round the clock residential supports in "intermediate care facilities for the mentally retarded" (ICFs/MR) and 122,000 receive home and community based (HCB) waiver services.

  - In 1994, total spending on ICF/MR was $9.2 billion; on HCB waivers for the MR/DD it was $3.0 billion.

  - In addition to ICF/MR and HCB waiver services, other long-term supports used by this group include personal care, supported living arrangements, supported employment, and case management.

  - While the MR/DD population is not large, spending for MR/DD long-term care accounts for over 10 percent of all Medicaid spending.

- ***The array of mandatory and optional Medicaid health services now available to these individuals could be dismantled. States would have increased incentives to force them into managed care even though neither the public nor private sector has the experience to set adequate payment rates, arrange and provide appropriate services, or assure quality.***

- Typically, this population uses a range of Medicaid health services: physician, hospital, therapy services (physical, occupational, and speech), eyeglasses and dental care, and assistive technology and equipment, among others.

- ***The Medicaid long-term care system for the MR population could be eliminated or scaled back completely. The community system, which enables so many people to live productive lives, would be especially vulnerable to the budget axe, when states are faced with rationing shrinking resources across many types of people and services.***

  - ***Many elderly parents, whose adult children are living independently today, might be forced to care for those sons and daughters, even though the parents themselves may be in failing health.***

- With varying degrees of oversight, these residential supports enable people with severe

disabilities to live complete, valued lives in a range of settings. People with MR/DD, with help from Medicaid, make great strides in learning how to take care of themselves and their homes, get around in their communities, make friends, vocational supports, and make other meaningful contributions to society.

- ***The Republican block grant proposal would eliminate all federal regulation and monitoring of large and small institutional (ICF/MR) facilities.***

- People with mental retardation have come a long way in a short time. Until the 1960s, most people with MR were relegated to large state institutions, living in filthy, sordid conditions. Since Medicaid began supporting and regulating these institutions in 1971 they have become healthy, therapeutic environments. In addition, so much has been learned due to Medicaid support and federal intervention in quality of care, that MR/DD systems are today relying far less on institutional care and increasingly, offering people the choice of home and community based care.

III. IMPACT ON ADULTS WITH DISABILITIES (NOT MR/DD) AND THEIR FAMILIES

- ***Access to care for adults with disabilities would be extremely compromised under the Republican proposal.***

- Approximately 3.2 million adults aged 21-64 rely on Medicaid for health care, particularly for physician and hospital services. Other important services for this population include physical, occupational and speech therapies, assistive devices, and prescription drugs.

- Many also use Medicaid long-term supports, particularly home and community based waiver services, personal care, and nursing home services.

- Medicaid use among people with disabilities is high.

- ***In order to preserve their block grants funds, many states may offer only managed care systems to people with disabilities.***

- There is no experience on how to set adequate payment rates, provide appropriate services and referrals, or assure quality for people with disabilities under managed care.

- ***While the House Block Grant proposal appears to preserve some level of funding for elderly Qualified Medicare Beneficiaries, QMBs under age 65 have no such protections. Like the elderly, dually eligible individuals [not QMBs, but those who actually receive both Medicaid and Medicare] could lose their Medicaid coverage altogether, losing critical benefits that are not covered under Medicare, such as prescription drugs and nursing home care.***

- In 1993, 1.4 million individuals under age 65 received both Medicaid and Medicare.

Jen,

I've done two versions of the paper: one without any merged info from Education, and one with what look to me like the highlights of their stuff on the contribution of Medicaid to the IDEA program for disabled infants and toddlers. BOTTOM OF PAGE 2 + TOP OF P3 ON LONG VERSION

I've tried to emphasize that Medicaid--through its payment for health services--has allowed many community based programs to stay in business and take care of things Medicaid doesn't pay for. IDEA Part H for disabled kids is a good example. This kind of stuff will be a real loss for the middle class when Medicaid funding shrinks and the other funds that were perhaps going for services to middle (and sometimes upper) income families and kids must now be redistributed.

Call if you need more.

John Spiegel

PEOPLE WITH DISABILITIES AMONG THE HARDEST HIT BY THE REPUBLICAN MEDICARE AND MEDICAID PROPOSALS

- Medicare and Medicaid provide a basic safety net of health and long-term supports to people with disabilities of all ages, including children, people with mental retardation, people with chronic mental illness, people with AIDS and the frail elderly and their families.
  - In 1995, more than 6 million individuals with some form of disability will be served by Medicaid, and 4.1 million disabled people under age 65 will be served by Medicare.
  - at least 930,000 children with disabilities are covered under Medicaid.
- In fiscal year 1995, Medicaid payments for people with disabilities totaled $52.8 billion; for the same period Medicare payments for people who are eligible for Medicare because of disability were $18.4 billion.
- Medicaid provides coverage for approximately 734,000 working age adults (age 21-64) with mental retardation or other developmental disabilities (MR/DD). Of these, about 120,000 receive services in intermediate care facilities for the mentally retarded, and 122,000 receive home and community-based services.
- In 1994, total Medicaid spending on ICF/MR services was $9.2 billion; on Home and community-based services (including waivers, personal care, and other optional services)for the MR/DD it was $3.0 billion. **While the MR/DD population is not large, spending for MR/DD long-term care accounts for nearly 10% of all Medicaid spending.**
- People with disabilities are more likely to be low income, use more health and long term care services, and incur higher costs than people without disabilities.
  - because the disabled are less likely to have private health insurance, they are much more likely to use federal assistance--through Medicaid and Medicare--to meet their more extensive health care needs.
- The Republican response to the needs of people with disabilities would have three impacts: access would be compromised; out of pocket burdens would skyrocket; and quality of care would plummet.
- **Access would be compromised.**

- Medicaid as we know it disappears. Entitlements to basic health care (e.g., physician and hospital services)--**GONE.** Federal eligibility rules which guarantee low income people with disabilities access to Medicaid--**GONE.** Federal involvement in structuring managed care demonstrations to ensure that all Medicaid beneficiaries (including those with disabilities) are protected--**GONE.**

- States may have to ration care--deciding who among the most vulnerable citizens is more "deserving" of help. Even within the disability community, states would have to choose which groups to serve. **Up to 1.4 million individuals with disabilities could lose Medicaid coverage.**

- Community based long-term care services are essential for people with disabilities to be able to live independently. These services would be especially vulnerable as states attempt to cope with huge budget cuts. Years of progress in building home and community-based service systems would be negated. In 1994, over half a million people received home and community-based services, at a cost of $3.8 billion.

- Access to acute care services would decline as well, with more states attempting to preserve precious block grant funds by offering only managed care systems. States would have increased incentives to force disabled people into managed care even though neither the public nor private sector has the experience to set adequate payment rates, arrange and provide appropriate services, or assure quality.

- A $270 billion Medicare cut would disproportionately affect the disabled and chronically ill beneficiaries who are most in need of Medicare covered services.

- The House welfare reform proposal denies SSI cash to over three-fourths of eligible disabled children, but maintains their Medicaid eligibility.

  - In lieu of direct cash benefits, the Personal Responsibility Act establishes a block grant for states to use to cover services for these disabled children--services not otherwise provided under Medicaid. The SSI block grant is based on 75% of the cash benefits that would have been paid to these children.

  - This arrangement, in concert with the incentives created by the House Medicaid block grant proposal, allows states to determine that the needs of disabled children can be met totally by the SSI block grant. Consequently, these children could be cut out of the Medicaid block grant altogether. **In its extreme, it is possible that the total state spending for health and long-term care for children with disabilities could equal three-fourths of the former SSI cash payments to this group.**

o **Out of pocket burden for the disabled would skyrocket.**

- Medicare premiums would increase dramatically and an arbitrary ceiling on program growth would lead to additional cuts of $1700 per person by 2002. The combined burden of these cuts affects people with disabilities disproportionately.

  - These individuals already experience high out of pocket costs, are unable to obtain private insurance, and are more likely to be poor.

- The Medicaid entitlement to nursing home coverage for eligible individuals would disappear; families would be forced to pay all or part of the $38,000 annual cost of nursing home care. Sixty-eight percent of nursing home residents receive assistance from Medicaid.

- Under the Medicaid block grant proposal, states would be allowed to force adult children to pay for their parents' nursing home costs as a condition of receiving some public support.

- To the extent that states are forced to cut home and community-based services, there will be an increase in costs to those who sorely need and heavily rely on these services.

o **Quality of care will Plummet.**

- In lieu of widely heralded federal quality standards governing nursing home care, the lock grant proposal allows each state to set and enforce its own standards, survey rules and payment rates for nursing homes, leading to increased instances of abuse, neglect, and poor quality care.

- Federal ICF/MR standards would no longer apply. The states would be allowed to return to the days of substandard care in the back wards of large institutions for the mentally retarded.

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  - Medicaid funding has enabled a number of other programs to remain viable in their communities--for example, mental health centers,

community health centers, school health programs, and early intervention programs for disabled infants and toddlers. The availability of Medicaid funding has allowed these types of programs to use their otherwise scarce resources to serve people who are not eligible for Medicaid, and to fill in the gaps where needed.

- The coordination of Medicaid funding with the Individuals with Disabilities Education Act (IDEA) program created in 1986 under PL 99-457, has enabled states to provide needed services to disabled infants and toddlers with disabilities. In some cases, Medicaid has contributed more than 50% of the total budget for such state programs. **Severe reductions in Medicaid funding will devastate this and similar community-based programs.**

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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

Diana Fortuna
The White House
1600 Pennsylvania Avenue, Northwest
Washington, DC 20500

Dear Ms. Fortuna:

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

REPRINTED, WITH PERMISSION, FROM THE COLUMBUS (OHIO) DISPATCH

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?

Chris Russell/ *Dispatch*

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

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

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

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

Total Ohio children under age 18	=	2,799,744
Formula percentage	x	.0008
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?"

Fam y 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

Home: Northwest Columbus

Father: Dale, 34, executive chef at Stouffer's Dublin Hotel

Mother: Martha Rose, 32, homemaker

Children: Dale Jr., 7; Amanda, 5; Ashley, 3

Annual income: $50,000

Dale Jr.'s primary diagnoses: Hydrocephalus, a condition characterized by an abnormal increase in fluid in the brain.

Difficulties: Among other brain-related disorders, the boy is mentally retarded and cannot walk, talk or use sign language. He eats through a tube inserted in his stomach

Annual cost of waiver: $105,000

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

Dale Jr. shares a hug and a nose rub with his mother, Martha Rose Sapp, after he reached out for her.

The Columbus Dispatch

SEPTEMBER 19, 1995

With appeal denied, father scrambles to find last-minute help

Hope running out

By Michael J. Berens
Dispatch Staff Reporter

Lauren Carter fumbled through her blindness before nestling into the perfect cuddling spot on her father's chest and shrieking, "Ca-caaa!"

"I think she knows that I'm her father," Greg Carter said softly, gently rocking his upper body. "I'll never know for sure, though."

There are times — such as this day in March — when he is grateful that his 7-year-old daughter's cerebral palsy and mental retardation make her oblivious to the world.

"Ca-caaa!" Lauren yelled again, wrapping her arms and legs tightly around her dad while struggling for control against spastic muscles.

"Damn, all I want to do is keep her at home," insisted Carter, sitting on the floor of his Cincinnati-area apartment with his 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.

"This facility was not designed for an active child like Lauren," social worker Linda McGuire said.

Founded in 1959 by Otto and Mildred Heinzerling, the original 34-bed children's facility — called Peck O'Wee Ones — was built on the city's East Side.

Today, Heinzerling — nestled among a quiet oasis of trees and grassy fields on the city's South Side — has facilities for adults and children.

The $4.5 million Heinzerling Developmental Center, built in 1982, houses 104 adults with severe mental retardation. Across the street, an equal number of similarly ill children live in the $2.9 million Memorial Foundation, built in 1979.

Heinzerling has no playgrounds, despite the open areas on the grounds. The small courtyard wasn't designed for play because few children can leave their wheelchairs.

My daughter does not belong here.

Carter could not rid himself of the thought, despite the friendly staff members who enthusiastically promised to change their routines so Lauren would get plenty of exercise.

The state had ruled that Lauren isn't sick enough to continue qualifying for Medicaid benefits under the Department of Human Services' Medically Fragile Waiver, which pays for home nursing care.

Now Lauren isn't sick enough to fit properly into Heinzerling.

Carter had crunched the numbers: Home care would cost the state about $45,000 annually; institutional care would cost at least $55,000 a year, according to conservative state estimates.

"It makes no sense," Carter said. "This is a system that destroys families."

THE UNAVOIDABLE FAREWELL

With Lauren, words were never necessary.

Carter squeezed his daughter in a giant hug, holding her at eye level, while gently rubbing his forehead against hers.

I love you.

His eyes spoke silently. He slowly twirled and nuzzled Lauren's body, hoping that she might know he is her father — and always will be.

Nurses quietly walked away, recognizing that the inevitable moment had arrived, just as it does for every parent on the first day.

Eubank stayed in the background, too, her eyes moistening as Carter and Lauren remained locked together.

"I feel so sorry for him right now," she said.

Carter carried Lauren to a recreation room, his eyes never leaving hers.

Goodbye.

His grip lingered as heart and mind clashed again, climaxing in a burst of pent-up tears as he handed Lauren to a waiting nurse. He dashed from the room back to where his 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.

"You know, I wonder if anyone really cares," he said. "Parents like us are really in the minority. It's easy just to ignore us."

Lauren is doing well at Heinzerling, where she celebrated her 8th birthday Sept. 12. She has been weaned off some medications and is working toward eating solid foods.

With major improvement, Lauren could be transferred to a residential facility, where patients require less medical supervision. A Medicaid waiver remains a distant option for the family because of the waiting list.

"I miss Lauren every day," Carter said. "I know she is fine, but not having her with me is very, very hard."

Lauren's absence doesn't go unnoticed by her stepbrother, either.

She and Dustin had spent many hours gently wrestling, forming a bond based on touch and movement.

The first night Lauren spent at Heinzerling, Dustin went into her old bedroom and climbed the walls of her special bed.

"I feel closer to her in the bed," he told his mother.

He plans to sleep there until Lauren comes home again.

Places for children

Institutional care is an alternative to home care, although most facilities have waiting lists. Many nursing homes offer some beds to children. Here are some of the largest facilities in Ohio that treat disabled children:

FRANKLIN COUNTY

■ Heinzerling Foundation Developmental Center
Capacity: 104
Columbus

■ Northland Terrace Medical Center for Subacute Care and Rehabilitation
Capacity: 260
Columbus

OHIO

■ Brookside
Capacity: 104
Warren County
Mason

■ 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 toll, 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."