SB

5

JOHNNY ELLIS
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ALASKA STATE LEGISLATURE
SENATE

MEMORANDUM

TO: Sen. Loren Leman, Chair
Senate State Affairs Committee

FROM: Sen. Johnny Ellis JE

RE: Scheduling CS SS SB5 — The Brianna Hurley Bill

DATE: March 26, 1993

Please consider scheduling CSSS SB5 (HES) -- The Brianna Hurley Bill. This bill is a repeat of my bill from last year, HB 438, which failed to reach the Senate floor for a vote in the last few hours of the session. It is named after Brianna Hurley, now nearly three years old, who was born with cerebral palsy.

Current eligibility requirements for Medicaid allow parents to give up their child to the care of an institution — which is often much more expensive to the State — but will not allow parents to keep their child at home and still qualify for health coverage.

The sponsor substitute reflects changes which will delay the effective date of this legislation in order to allow the Department of Health & Social Services (DHSS) to implement federally-approved Medicaid waivers for home and community-based health care. Waivers are better than options in that they provide habilitation, environmental modifications and respite care — services greatly needed by children and families. The CS changes give DHSS the flexibility to fill waiver slots as they are needed.

So why have the option? Because there may not be enough waiver slots for all the children needing services. Studies have shown that the cost of institutionalization can be up to three times as expensive as the cost of home and community based care.
Since Alaskans are paying for those children in institutions and foster care anyway, why not allow them to come home and be with their families?

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SENATE

MEMORANDUM

TO: Sen. Loren Leman, Chair
Senate State Affairs Committee

FROM: Sen. Johnny Ellis

RE: Scheduling CS SS SB5 — The Brianna Hurley Bill

DATE: April 6, 1993

Thank you for scheduling CSSS SB5 (HES) — The Brianna Hurley Bill. This bill is a repeat of my bill from last year, HB 438, which failed to reach the Senate floor for a vote in the last few hours of the session. It is named after Brianna Hurley, now nearly three years old, who was born with cerebral palsy.

This new group of people — children with severe disabilities who want to live at home — to the optional list of Medicaid-eligibles in Alaska. Alaska's current eligibility requirements for Medicaid allow parents to give up their child to the care of an institution — which is often much more expensive to the State — but will not allow parents to keep their child at home and still qualify.

The sponsor substitute reflects changes which will delay the effective date of this legislation in order to allow the Department of Health & Social Services (DHSS) to implement federally-approved Medicaid waivers for home and community-based health care. The CS changes give DHSS more flexibility to fill waiver slots *and* use the option, so that children who *only* need medical care (which is what CS SS SB 5 provides) — don't fill up valuable and limited waiver slots.

Why do we need the option? There may not be enough waiver slots for all the children needing services. Studies have shown that the cost of institutionalization can be up to three times as expensive as the cost of home and community-based care. Since Alaskans are paying for those children in institutions and foster care anyway, why not allow them to come h

SPONSOR STATEMENT

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ALASKA STATE LEGISLATURE
SENATE

SS SB 5 the "Brianna Hurley Bill"

SECTIONAL ANALYSIS

SECTION 1
AS 47.07.020 is amended by adding a new section, (10), which describes a new group of people to be eligible for Medicaid assistance.

10(A) Is under the age of 19 and qualifies as a disabled person under Social Security

10(B) Requires or is at risk of needing an "institutional" level of care
The care is appropriately provided outside the institution
The cost of providing the care is no more than the cost of institutional care

10(C) If in an institution, the person would be eligible for Medicaid under other provisions in this chapter

10(D) Home and community-based services are not available to them under a waiver (yet to be approved by the federal government)

SECTION 2
AS 47.07.030 is amended to add a new subsection (c) which allows DHSS to offer a service with waivers because they were directed to apply for waivers by a *concurrent or joint resolution of the legislature.*

(usually new services are authorized through *legislation* passed by the legislature. The waivers for home and community based services, which DHSS applied for last year, were an exception)

SECTION 3
AS 47.07.035 is amended by adding a new section, (23), which places the group of individuals described in section 1 in the priority order of groups served by Alaska's Medicaid program. It is placed in this particular position because this is where the services end and the groups of people to receive services begin.

SECTION 4
Sections 1 and 3 take effect 180 days after the effective date of Medicaid plan amendments (*Medicaid waivers for home and community-based services)* approved by the federal government. We want to get the waivers up and running before implementing the Medicaid option.

SECTION 5
Section 2 takes effect immediately.

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ALASKA STATE LEGISLATURE
SENATE

WHAT SERVICES DOES SS SB 5 — THE BRIANNA HURLEY BILL — OFFER?

The Brianna Hurley Bill (SS SB5) adds a new Medicaid optional eligibility group consisting of those persons under age 19 who reside at home and who would be Medicaid-eligible if they were residing in medical institutions. It places this group of people in the priority order of groups served by Alaska's Medicaid program. Children who qualify would be eligible for basic hospital doctor care, health services, hospice for kids, case management — everything in normal EPSTD coverage.

DOES THIS BILL HAVE ANY MEANS OF COST CONTAINMENT?

Yes. It only applies to kids under the age of 19 who meet the requirement for an institutional level of care *and* their care is more cost-effective if provided at home.

WHO IS ELIGIBLE FOR THE SERVICES PROVIDED BY THE BRIANNA HURLEY BILL?

- Is under the age of 19 and would be eligible for Medicaid in an institution
- Requires or is at risk of needing an "institutional" level of care
- The cost of providing care is no more than the cost of institutional care
- Home and community based services are not available to this person under a waiver

WHAT GROUPS OF CHILDREN DOES THE BRIANNA HURLEY BILL COVER?

The DH&SS estimates about 100 children (listed below) would be eligible for the option as of June 1990 — Families & advocates estimate there are more children.

- 20 children in Hope Cottages, one of Alaska's two ICF-MR's
- 5 children in hospitals
- 11 children in foster care
- 9 children in nursing homes
- Estimated 55 children at home (paid through private insurance from parents or Medicaid)

CONCLUSION

Please support both the Brianna Hurley Bill (SS SB 5) and the Department of Health and Social Services budget amounts needed to implement Medicaid waivers (will be included in a supplemental budget). The effective date of this legislation is 180 days after the federally-approved effective date of the waivers.

Alaska C.O.P.E. Coalition of Parents Educating for the Disabled & Medically Complex

P.O. Box 220584 Anchorage, AK 99522-0584 • Elaine Hurley, Chair

Dear Legislator's;

YOU MUST PASS SENATE BILL # 5 THIS YEAR !!!

Somewhere before you lays Senate Bill 5, the Brianna Hurley Bill. This bill is calling for a Medicaid Option for disabled children who are eligible for an institutional level of care. If passed this option would allow children to remain at home with their parents instead of forcing them into expensive institutions or medical foster homes as an only "option" to accessing Medicaid coverage. Removing children from their families and communities is not only more expensive for this State, but it is also inhumane.

Senate bill 5 is a repeat of last year's House bill 438 which passed through the House and both the Finance and HESS committees before simply running out of time before it could get a vote. This was not only a disappointment, but to the families that need this option and are waiting, it was a disgrace! Are we going to run out of time again this year? Are our children going to have to wait until next year or the year after? How long must we wait? Some of these children are very sick and may not have another year, like Brianna Hurley whom the bill is named after and is suffering from a terminal brain disease. How much longer must she and other children wait?

Alaska is now the only State that does not offer a Medicaid waiver or option to children who experience disabilities, WHY? Why has every other State except Alaska been able to recognize this need and allow for it?

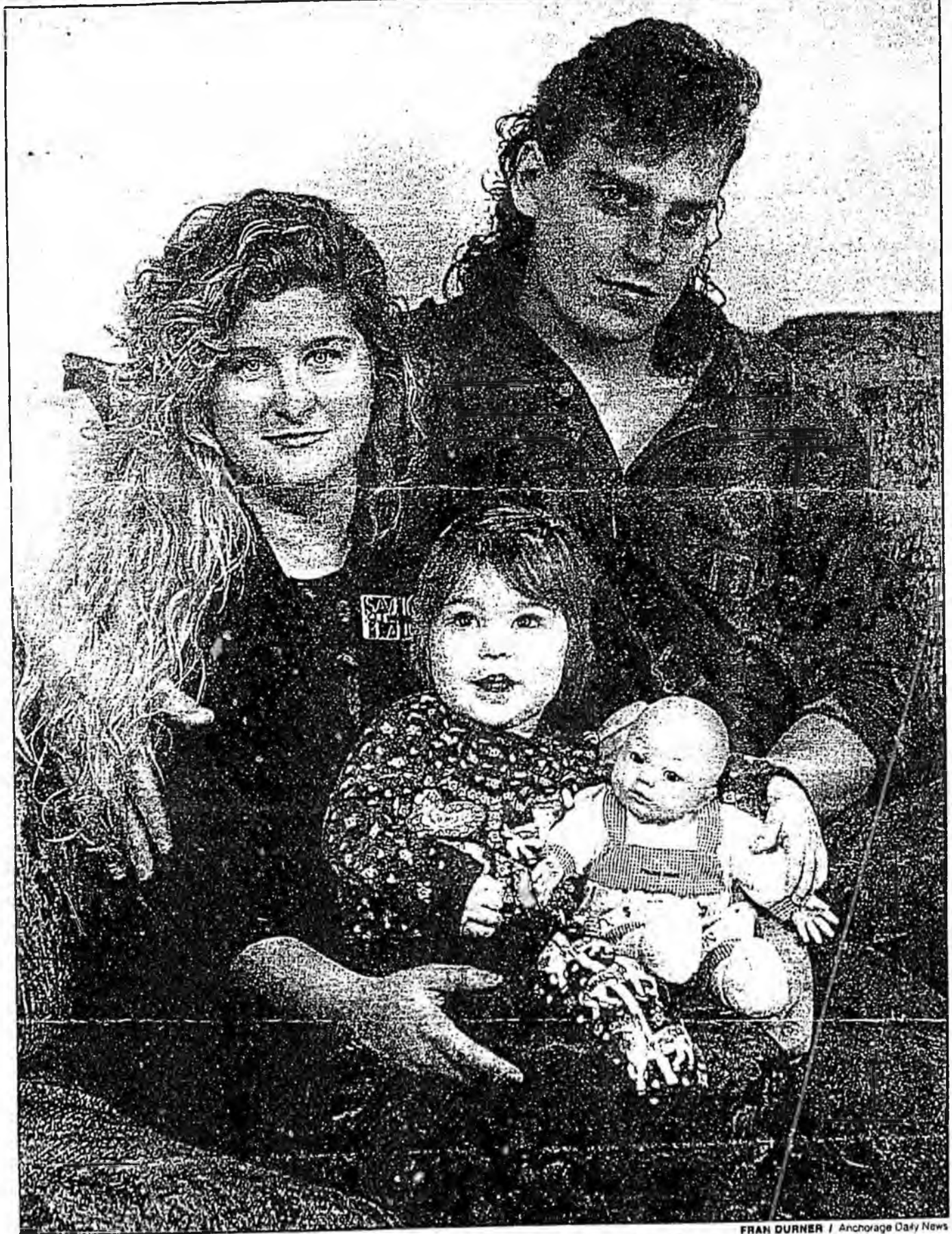
There's a lot of controversy over what this Legislature is doing or not doing. Send a message to all Alaskans that you care about your Alaskan families and children who experience disabilities. Don't let another year go by. THIS BILL MUST GO THROUGH THIS YEAR!!!

If you had to walk into an institution or foster home and tell a child "I'm sorry little one maybe next year you can go home, maybe next year you can live with those that love you instead of this home" could you do it? Well if you don't pass Senate bill 5 this year, essentially that's what your saying.

PLEASE PASS SENATE BILL 5 AND BRING OUR CHILDREN HOME!!!

Sincerely,
Your Alaskan Families

TESTIMONY



FRAN DURNER / Anchorage Daily News

Elaine and Douglas Hurley with 18-month-old daughter Brianna.

January 1992 Article / Anch. Daily News

NEWS ARTICLE

Caught in a Health Care Trap

Medicaid rules push middle- class family toward poverty

By JAY BLUCHER
Daily News reporter

Douglas and Elaine Hurley had it all — a new marriage, good jobs, a promising future. The only thing that would have made their lives perfect, they thought, was a child.

But when their daughter, Brianna, was born with severe medical problems, the Hurleys were forced to surrender much of what they had so Medicaid would pay for her care.

Eighteen months ago, before Brianna's birth, the Hurleys were a two-income family earning more than $40,000 a year. Douglas, 24, was working full time as a baker and commercial fisherman, and Elaine, 26, was holding down three part-time jobs as a secretary and bookkeeper. They had been married for just two years.

"We scrimped, saved and planned for this baby and thought we had what people think of as the American dream — money for a down payment on a house, college funds, savings accounts — if not attainable, then at least in sight," says Douglas.

Brianna was born with cerebral palsy and epilepsy. She also has severe brain damage caused by viral encephalitis contracted in the womb. The disease, often fatal, causes paralysis.

At 7 months old, Brianna also suffered a stroke.

Some doctors tell the Hurleys that Brianna might learn to walk by age 6 or 7. Others, such as Dr. Jerome Mednick, a pediatric neurologist in San Francisco, say she will never walk or talk.

Now, when other children her age are toddling, Brianna has only recently been able to muster the muscle coordination to wave her right hand. She cannot support herself upright or crawl, and the entire left side of her body is impaired. She is like a limp rag doll, with the motor skills of a 2-month-old.

While the Hurleys accept Brianna's special needs, the cost of caring for her at home was unexpected.

"We thought to ourselves, 'OK, we'll deal with it; there's help available for families like us,' " says Elaine.

But little did they realize that their decision to care for Brianna at home would force them to cash in their lives for a welfare check.

Since birth, Brianna has required extensive medical attention ranging from emergency hospitalizations — as when her seizures caused a semi-comatose state for 30 days — to regular visits with pediatricians, neurologists, nutritionists and other specialists. As a disabled infant, she also receives regular occupational, physical and speech therapy services through the state's Infant Learning Program.

She's had every manner of diagnostic test, and these continue. At a big price.

The specialized infant formula she needs to gain weight costs $7[illegible] a case, and lasts only a week because Brianna still cannot eat solid foods. The medications needed to control her seizures cost $700 per month. Her medical bills average $4,000 a month. And in Brianna's future looms extensive orthopedic surgery and probably an expensive liver transplant. (The drugs that help control her seizures have damaged her liver.)

The Hurleys estimate Brianna's medical bills will cost $60,000 annually for the next five years. More than $20,000 remains unpaid now.

At first, the couple had reasonably good medical insurance through Douglas' employer. It paid 80 percent of the family's medical costs. But after just three months in which Brianna's total medical costs topped $60,000, Blue Cross of Washington and Alaska reduced its coverage to 50 percent.

Douglas' employer at the time, William Pargeter, who owns Harry's restaurant and owned the now-defunct Kayak Club, could have continued the higher coverage, but at greater cost.

Pargeter says he was acutely aware of the Hurleys' high medical expenses because the Kayak Club was in the midst of a bankruptcy reorganization at the time and he

Please see Page D-2, TRA

• Continued from Page D-1

was looking for a new health insurance plan for his employees.

"But this family's high medical costs made the insurance companies leery of accepting the whole group," he says. "In fact, one carrier flatly refused to carry us as long as Douglas was employed with us."

Rather than offering his employees a health plan that excluded the Hurleys, Pargeter instead opted for a less comprehensive Blue Cross plan for all.

Blue Cross officials would say only that the company opted for a less expensive health plan.

Other insurance companies wouldn't accept the family because Brianna's medical needs were "pre-existing."

The Hurleys soon owed thousands of dollars with no hope of ever repaying it on their existing incomes. Threatening phone calls from bill collectors now punctuate their days. Their credit ratings are ruined.

We were taking food out of our own mouths in order to send $10 here, $20 there, for medical bills left unpaid by our insurance, but we were falling hopelessly behind," says Elaine.

The couple realized their only option was Medicaid, the federal health-care program administered by individual states to help the poor. But Medicaid has a strict income limit, and the Hurleys exceeded it.

This family of three, to qualify for Medicaid, would have to begin living on $1,334 a month, before taxes. Or, as they were told by Medicaid officials, they would have to "spend down to 133 percent of the federal poverty level."

This meant Douglas had to quit his job in September and go on unemployment, which pays him $760 a month. Elaine could bring in only $574 a month to stay under Medicaid's limit, so she could accept only part-time work as a bookkeeper.

"I despise living this way, feeling like I'm on the dole looking for a handout, but it's the only way my daughter's medical bills can be paid," says Douglas.

"It's frustrating to be a capable and willing-to-work father who wants to be the provider for my family, and yet be forced by bureaucratic rules to *not* work," says Douglas.

Income wasn't the only thing they had to cut. The Hurleys were required by Medicaid rules to deplete their savings accounts, college funds for Brianna, certificates of deposit, individual retirement accounts, and to trim their possessions to one car of no more than $1,500 value, household goods of $500 value, and $250 worth of baby furniture.

Every three months, state public assistance officials grill the family about new sources of income — inheritances, church donations or money from other family members.

"It makes me feel so demeaned, like

> *"I despise living this way, feeling like I'm on the dole looking for a handout . . . It's frustrating to be a capable and willing-to-work father who wants to be the provider for my family, and yet be forced by bureaucratic rules to not work."*
>
> — Douglas Hurley

I have no worth, no self-esteem," says Douglas.

Since he's been unemployed, he's gotten several good job offers at considerably more salary.

"I've been reduced to turning down good jobs in order to care for my daughter," he says. "Now isn't that a perverse situation?"

Elaine is just as frustrated.

She worries that the couple may never be able to afford a home, have other children or excel in a career that could provide the security every family seeks.

They could do all that, however, if they did just one thing: Put Brianna in an institution or make her a ward of the state. Then Medicaid would pay for her care and release her parents from income limits.

Unacceptable, say the Hurleys.

"We want to be able to look at ourselves in the mirror and say that we did everything we possibly could to help her, no matter the sacrifice," says Elaine.

Equally distasteful is a third option — for the couple to legally separate. Elaine could accept public assistance as a single parent and Douglas would be free to return to work and pay child support.

"So the state would actually reward the breakup of a loving family," says Douglas sarcastically.

Chris Ashenbrenner, program officer for the state's medical assistance office, says the Hurleys are not alone.

"Because there's no nationwide health plan in this country, people such as the Hurleys are among the gap group, people caught in the middle-class health crisis," she says.

But she also says it's unfair to blame Medicaid.

"It's the whole health care mess in this country and insurance companies that are allowed to drop coverage when claims get too high or certain limits are reached."

David Maltman, executive director of the Governor's Council for Handicapped and Gifted, says it happen to anyone.

He agrees that Alaska's currenc needlessly impoverishes wo families trying to care for a dis child at home.

Responding to the problem, council has examined the Med system and recommended imp ments to make home care more able to persons with disabilities.

In 1990, the legislature requir similar study by an independent mission known as Project Ch whose final report will be present January. Both the council and Pr Choice recommend that the state a for a waiver from federal Med rules.

This would let Medicaid waive income limits for families like Hurleys.

Alaska is one of only a handf states that have not adopted a w program or something known as "Katie Beckett option."

In 1981 Katie Beckett, a 3-yea girl from Iowa who, like Bria suffered from viral encephalitis, granted a federal waiver by Presi Ronald Reagan. He cited the cas overregulation.

Since then, a majority of U.S. st have adopted either waiver prog or Katie Beckett options.

Medicaid's Ashenbrenner says A ka has never applied for this partic waiver or option because the s already has an adequate welfare gram, with the most generous eligi ty standards in the country.

This rationale, however, does consider people like the Hurley family caught in precisely the regul ry paradox that such waiver prog were intended to address.

The Hurleys see a waiver or Bec option as their only relief fro poverty sentence.

"Sometimes, you get the impres these Medicaid people think of i their own money," says Elaine.

She glances lovingly at Bria who responds with a curious l When all the frustrations become much, the Hurleys focus on wh most dear.

They shower Brianna with at tion. The tiniest of achievements, s as a simple wave of her hand, br them renewed hope for her future

"Her wonderful disposition thro all of this really makes it easy on hearts, knowing that as difficult a gets for us sometimes, her love rem unconditional," says Douglas.

He marvels at his daughter's re ience as she sleeps in his arms.

"She's so beautiful, so innocent She has no idea any of this is happ ing, no idea that she's . . . diffe . . . or how difficult all of this been for her parents," he says.

Brianna stirs.

"Ssshhh, little one. It's OK. Dad here."

Daily News - 12/31/92

BRIANNA HURLEY: CATCH-22

In January, we wrote about Elaine and Douglas Hurley's struggles to care for their 18-month-old daughter, Brianna, born with cerebral palsy and mysterious seizures. Her severe medical problems and the accompanying medical bills forced her parents to exist at the federal poverty level to qualify for Medicaid.

Nearly one year later, they are still caught in a medical Catch-22.

Legislation that might have helped the Hurleys — a waiver from federal Medicaid parental income rules — failed to pass in the state's last legislative session.

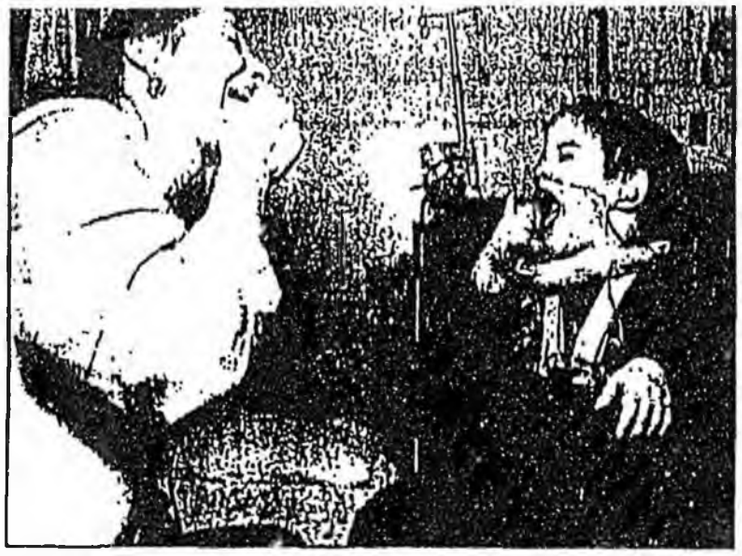
The strain of caring for Brianna and fighting both state and federal bureaucracies proved too great for the Hurleys' marriage; the couple divorced earlier this year.

As a single parent, Elaine Hurley can earn $963 per month, before taxes, to keep her daughter qualified for Medicaid. Because her daughter's severe medical problems are considered to be a "pre-existing condition" by private health insurance companies, Elaine can't buy health insurance of any kind for Brianna; Medicaid is her only option.

Earlier this month, the state's Division of Mental Health and Developmental Disabilities paid for Brianna to go to the Mayo Clinic in Rochester, Minn., for more specialized diagnosis and care. The Mayo Clinic doctors say her condition is terminal.

Elaine Hurley is considering a move to Seattle or elsewhere in the Lower 48, hoping to locate near a pediatric center that may offer opportunities to prolong Brianna's life.

— Jay Blucher



Therapist Gale Andrus trains Zachary to eat normally

YOUNGSTER MAY FINALLY SPEND CHRISTMAS OUTSIDE HOSPITAL

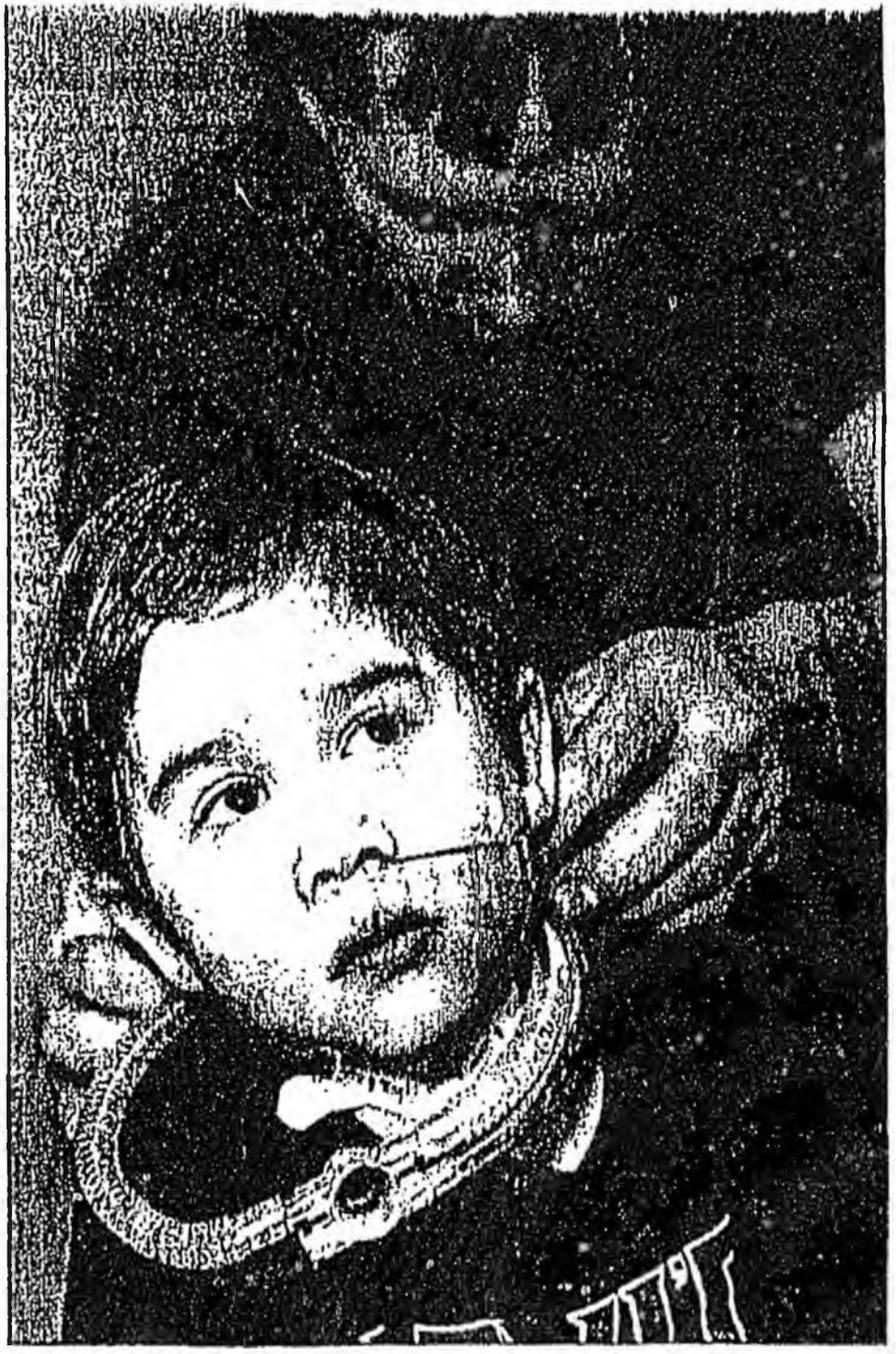
By DEBRA McKINNEY
Daily News reporter

Life would have been far easier for Larry McKenzie had he just walked away. He and his wife had split up when she was two months pregnant, and hadn't seen each other since. He didn't even know the baby had been born until the hospital called him with insurance questions.

Zachary McKenzie arrived two months early on Dec. 29, 1987. Within hours of his birth, the 3-pound boy was moved to a Seattle hospital with problems so severe he wasn't expected to last the day.

The upper end of his esophagus led to a dead end, not his stomach, and the lower end detoured into his lungs. He couldn't swallow without choking. And acids and other stomach fluids threatened to flow into his lungs and drown him. On top of that was a heart problem for which he needed

Please see Page F-2, HOMECOMING



Larry has become his son's primary caregiver during the evenings.

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ADN 1/7/92

Medicaid reform

Start with a waiver, but do more

In photographs, Brianna Hurley looks like any healthy, happy 18-month old. The picture that ran in Monday's Daily News showed her sitting on her mother's lap. Her pink sweat shirt had white ponies on it, and her straight brown hair was swept back with a matching pink barrette. She shared the couch with her father and a doll.

But the photograph doesn't tell you the whole story. Yes, Brianna is as sweet looking as they come. And it's obvious her parents, Elaine and Douglas Hurley, love her. But their daughter can't hug her doll, or even sit upright on the couch by herself. Born with cerebral palsy and epilepsy, brain damaged from viral encephalitis, felled by a stroke, Brianna can't walk or talk, and may not ever.

There's something wrong with a system that pays for institutional care but won't help a family that wants to care for its loved one at home. There's something wrong with a system that takes two people with good work histories and tells them they can't work.

Elaine and Douglas Hurley's life is like that photograph: It turned out different than it looked. It's not just that their daughter was born with the problems she has; they have found the personal strength to deal with that. But their financial resources — their jobs, insurance and savings — proved wholly inadequate in the face of $60,000-a-year medical bills.

Had they put their daughter in an institution, Medicaid would have paid for her care without restricting the Hurleys' income. But the couple wants to take care of their daughter, at home, themselves. So they've had to quit their jobs, deplete their savings and sell off household goods to meet Medicaid's income limitations.

There's something wrong with a system that pays for institutional care but won't help a family that wants to care for its loved one at home. There's something wrong with a system that takes two people with good work histories and tells them they can't work.

The state of Alaska can help the Hurleys and families like them by applying for an option — used by other states — that would let Medicaid waive the income limits for families who want to care for disabled members outside of an institution.

But while that's a quick fix — and a necessary one — there is more wrong here than simply Medicaid.

There's something wrong with an insurance company that can reduce coverage just when it's needed most, as happened to the Hurleys. There's something wrong with an insurance industry that can refuse to cover prior conditions or high-risk people. There's something wrong with a system that doesn't address catastrophic illnesses. And there's something very wrong with a system that leaves some 90,000 Alaskans with no insurance coverage at all.

The Alaska legislature can ask for a Medicaid waiver. But that's only a stopgap measure toward ensuring everyone the right to medical care. It's only a reminder of how desperately this country needs to reform its health care system.

Remember, the family in the photograph could be yours. If this could happen to the Hurleys, it could happen to you.

Helping Kids, Helping Families

While the new Clinton administration hammers out its version of health care reform, states continue to struggle with universal coverage for their own citizens. Among the most vulnerable populations are children with special health care needs.

Mimi Bodel and Martha King

Two-year-old Justin Smith's body doesn't produce the human growth hormone, a condition that costs $3,000 a month to treat. Although father Brad's employer-based insurance covers a large portion of the treatment, the premiums are escalating rapidly and the family is afraid it will lose its coverage. Justin's parents struggle to pay their share of the costs as it is. "Our whole life is devoted to paying medical bills. We can't afford to do more," says mother Cindy. When she sought state assistance, Cindy found no program for which her family was eligible because they made too much money. State health officials told her she apparently had three choices:

- Buy private insurance for Justin (at $1,000 a month, due to his "pre-existing" condition);
- get divorced and go on welfare; or
- move to Canada.

"This sounds more like an American nightmare than the American dream," exclaims Cindy, who says she cannot pay for a private insurance policy, and she refuses to leave her husband or country. And so the Smiths wonder whether Justin will be able to continue receiving hormone treatments or have to quit and be lucky to reach three feet in height on his own.

John, a healthy full-term baby at birth, got sick when he was 5 months old. It seemed like the flu—but within 12 hours, parents Carol and Curt Terwilliger knew they had serious trouble. The baby had spinal meningitis. He slipped into a coma and sustained damage to every part of his brain. His life, and that of his parents, was irrevocably altered.

This sounds more like an American nightmare than the American dream.

Now, at seven, John has multiple problems: spastic quadriplegia, cortical blindness, mental retardation and a convulsive disorder. John also has two parents who love him, two healthy younger siblings and colored beads on the spokes of his wheelchair. But it takes 45 minutes to feed John a small bottle of liquid, and 45 minutes to spoon feed him a single meal. Carol, an MBA, gave up her career as a fiscal operations officer in a Medicare program to become full-time mom and caretaker for a child with special needs.

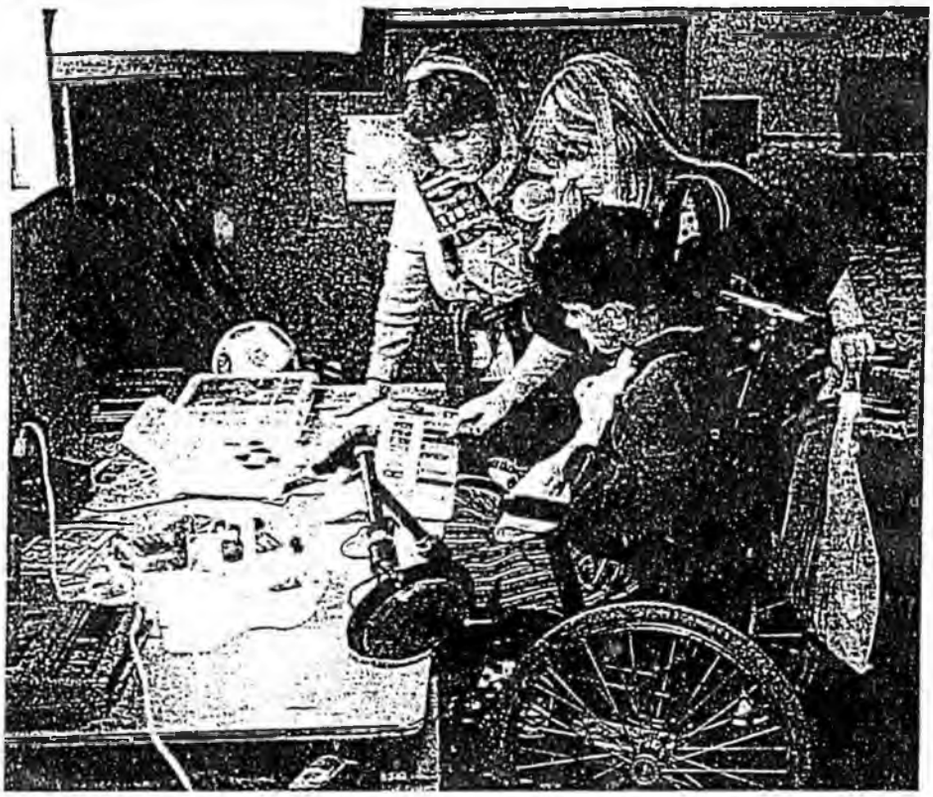
"Luckily I can stay home," says Carol, "because we can cover our expenses with Curt's salary and his employer's excellent insurance program." Nonetheless, the family is well aware that any change of job or company insurance carrier could put them in jeopardy of discontinuing John's coverage.

Donald Penzenik did have bad luck with employer-based insurance and was forced to "spend down" his family's resources to qualify his "uninsurable" son for Medicaid. Michael, who has cerebral palsy, mental retardation, scoliosis and a seizure disorder, was dropped by the insurance company that had covered him. In the meantime, Donald's new employer would not include Michael in the health coverage for his other family members. Desperate to provide for their son, the Penzeniks turned to Medicaid, but at great cost to the family's security.

"I impoverished my family," says Penzenik. "This was our reward for raising our child with severe disabilities at home. To qualify for Medicaid, *all* family assets, including our savings, individual retirement accounts and life insurance policies were 'spent down,' leaving my family unprotected and vulnerable to financial disaster." Now Donald and his wife, a nurse, are restricted in the amount they may earn, and they may not save for their other children's college or for retirement in order to keep Michael covered under Medicaid.

Today, serious illness and chronic conditions affect children from all sectors of the American population. Estimates of the numbers of children vary, but several surveys of different conditions (developmental disabilities, diabetes, cystic fibrosis, childhood cancers and other chronic medical needs) suggest that between 10 percent and 15 percent of American children have a chronic health condition; about 5 percent have serious health care needs; and 1 percent to 2 percent, or about 1 million children,

Mimi Bodel recently completed a graduate internship at NCSL. Martha King manages the NCSL Maternal and Child Health Project, which is funded under a grant from the federal Maternal and Child Health Bureau.



Conrad delaParra, 11, can't walk or talk, but he manages to communicate with his school friends. His middle class family is determined that he live at home, even though they would get more financial assistance if he was institutionalized.

have severe chronic impairments.

These children and families have a large stake in the national health care reform debate. The Clinton administration backs "managed competition," and may endorse a "minimum package" of benefits for all Americans. The insurance industry now supports an "essential package" of health benefits for everyone. Whether a "minimum package" or "essential benefits" would meet the extensive needs of children with chronic ailments and serious disabilities is a million-dollar question. Advocates remain hopeful in light of the federal ruling against Oregon's health reform and cost containment initiative. The Bush administration rejected Oregon's proposal, saying it discriminates against people with disabilities and conflicts with the Americans with Disabilities Act. But now there's a new ballgame in town.

In the meantime, families look to states for assistance in the immediate future. Thousands of families who are not poor enough to qualify for Medicaid, but are neither well-insured nor independently wealthy, struggle daily to provide care for their children and to make ends meet. Look at the problems such families face: obtaining and keeping private insurance for children who are considered high-risk by insurance companies; paying for expensive care not covered by insurance policies, such as various therapies, in-home nursing help, high-tech medical equipment and van lifts; staying within the lifetime expenditure caps of insurance policies (virtually impossible for families who have children with severe and chronic health problems); getting the support needed to keep their families intact, such as respite care, parent education, home modifications, cash assistance and special equipment; fighting public policies that will assist them only if they institutionalize their children; and dealing with barriers and public attitudes that make it difficult to get a baby-sitter, or take a child to a restaurant, a movie theater or to school.

In addition to high costs and insurance problems, families face extreme emotional stress. For example, Carol Bennet, whose twins were 10 weeks premature, says her marriage suffered and eventually broke up from the strains created by the boys' need for constant care and attention. She struggled as a waitress to care for Trevor and Travis, both of whom have special health care needs. Travis has cerebral palsy, cannot walk and takes seizure medication. Trevor, who also cannot walk and just began talking at age 6, is mentally retarded. After wearing herself out trying to be a breadwinner and caretaker, Carol reluctantly placed Trevor in a group home for children with multiple disabilities.

"I couldn't afford to keep both of them at home without help, but I'm not poor enough to qualify for Medicaid to help me at home. But Medicaid would pay for institutional care," Carol explains. "Both boys had savings accounts, and I had to give the money back to our families so I could meet the eligibility requirements."

Rhonda delaParra faced pressure to institutionalize her son Conrad after he suffered severe brain damage at age 2. As a happy, seemingly healthy infant, Conrad walked, talked and laughed. Then something happened and he went into a coma. The family is still not sure what caused it, maybe an asthma attack.

"'If you take him home, you're on your own' they told me," reports Rhonda. Ironically, the state would have paid for the expensive institutional care. Now, at age 11, Conrad is mentally retarded, his vision is poor, he can't walk or talk. Conrad's new step-dad, Joe, would like to adopt him, but adoption might jeopardize Conrad's eligibility for Supplemental Security Income, a federal cash assistance program. Joe works seven days a week as it is to support them, and the family doesn't think it could make it without the assistance.

"There's a gap between the needs and the distribution of services," says Rhonda. "They don't offer services that people really need, like counseling, and they don't offer anything for the middle class. With a little assistance, families could cope with keeping their child at home—nobody wants their child to live with strangers, and we don't want to be indigent before we can get some help."

The bias toward institutional care in most states stems from Medicaid reimbursement policies. Many of the extensive services needed by children with severe health problems or disabilities are reimbursable under Medicaid only if the child is in a facility such as a state insti-

Dollars and Sense: Federal Assistance

Children with disabilities qualify for help under the following major federal programs: Medicaid, the Maternal and Child Health (MCH) Block Grant, and the Individuals with Disabilities Education Act.

Medicaid

Medicaid is a major source of funding for low-income families of children with special health care needs. Medicaid programs cover children age 5 and under who come from families with incomes up to 133 percent of the federal poverty level (states have the option of covering infants up to 185 percent of the poverty level). By 2002, those up to age 19 with family incomes up to the poverty level must be covered.

States must also provide "medically necessary" treatment for children up to age 21 to correct or ameliorate physical or mental problems. This requirement applies to all services reimbursable under federal guidelines, including optional services not covered under a state's regular Medicaid plan.

Waivers allow states to cover certain nonmedical services for Medicaid-eligible people who otherwise would be served in an institutional setting at an equal or higher cost. As of 1991, through this option, 46 states offered home- and community-based services to about 50,000 people with developmental disabilities and other special health care needs. Although most are adults, Medicaid-eligible children with disabilities also benefit from this option.

A state may also cover optional services that are not in its Medicaid plan for a small targeted group of people, such as children who depend on a ventilator. The waiver allows Medicaid reimbursement for home care services for a limited number of people who otherwise would need institutional care.

Under the Tax Equity and Fiscal Responsibility Act (TEFRA), states may offer Medicaid services without regard to family income, to certain children with severe disabilities who are living at home.

Maternal and Child Health Block Grant

Thirty percent of the federal money coming to states through this program must be earmarked for children with special health care needs. States provide $3 for every $4 in federal funds. States determine eligibility requirements for receiving services and may charge fees, except to low-income women and children.

State health agencies usually provide MCH block grant services, which may include case management and counseling, home nursing, respite care, hospitalization, surgical care, therapy and training for families.

Grants for special projects of regional and national significance are available to states through the MCH block grant to help implement the family-centered, community-based approach to services and care for children with special health care needs.

Individuals with Disabilities Education Act (IDEA)

Under IDEA, all eligible children with disabilities, beginning at age 3, must receive a free and appropriate public education. The law provides funds to local schools to help pay the excess costs of educating students with disabilities, including funds for special therapies and adaptive equipment. States must meet this requirement to receive federal funds for children in preschool under federal formulas for special education grants.

The act also provides funds to help states develop early intervention services for infants and toddlers with developmental disabilities and other problems. IDEA requires an interagency coordinating council, composed of representatives from many federal agencies, to work on behalf of such children.

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tution or a licensed group home. Exceptions are possible, most notably under the federal "Home- and Community-Based Services" waiver. This waiver allows Medicaid payment for certain nonmedical services, such as respite care or habilitation services, for eligible children who otherwise would be served in an institutional setting at an equal or higher cost. But children who are not certified as needing institutional care, in most cases, do not qualify for such community services.

In addition, many children at home do not qualify for Medicaid because their family's income is too high. But if they move to an out-of-home setting, their income as children may be considered separately, thereby qualifying them for assistance. Again, exceptions exist, such as a state's option to serve a small number of children dependent on a ventilator. But the relative numbers are small. These public policies exclude thousands of families who would benefit from community services.

State legislators asked to help fill the gaps for these families, face their own problems. State coffers are empty, revenues continue to shrink and new federal mandates require more services for more people. Advocates pressure lawmakers to fund community services to assist families in need, arguing that community care is cheaper than institutional care. In many cases it is. But budget watchdogs fear the "woodwork" effect: Those people not currently eligible for state assistance would "come out of the woodwork" if states expand eligibility criteria for community services.

For example, when Arizona recently expanded its services for people with developmental disabilities, the number of consumers more than doubled, from 5,000 to 11,500. Caseloads suddenly jumped from 47 to as high as 80 families per case manager, although federal guidelines advise a caseload of no more than 30.

Deborah Meintel, a case supervisor in the Arizona Division of Developmental Disabilities, says that the size of such caseloads detracts from the time and attention given to each family. "I'm not trying to get away from being account-

Help for Families That Can't Get Medicaid

A few state insurance plans help cover citizens who either can't afford or don't qualify for private insurance. While most of the plans don't cover many of the services needed by children with special health care needs, they help. Such programs include:

Massachusetts: CommonHealth
✔ Sells health care benefits on a sliding scale to qualifying families.
✔ Provides broad benefits—therapy, equipment and mental health services.
✔ Funded by state appropriation ($15 million in 1992).

Minnesota: Children's Health Plan
✔ Sells inexpensive basic health services to low-income families.
✔ Funded by annual $10 million state appropriation.

Florida: Healthy Kids Corporation
✔ Sells liberal health coverage on a sliding scale through public schools.
✔ Funded by grants and limited state funds.

Florida: Developmental Evaluation and Intervention
✔ Catches problems early through evaluations in neonatal intensive care units.
✔ Provides family support.

New Jersey: Catastrophic Illness in Children Relief Fund
✔ Assists families with catastrophic medical expenses.
✔ Funded through annual surcharge on certain employers.

Texas: Early Intervention
✔ Provides support, therapy, equipment and transportation through 75 local programs.

Wisconsin: Family Support
✔ Supplies up to $3,000 in extensive services a year to families and children.

About half the states: High-risk Pools
✔ Expensive, but available to those uninsurable through private insurance.
✔ Most have a waiting period before covering pre-existing conditions.

able, but I feel we're meeting the needs of the system, and we need to get back to meeting the needs of the family."

Patti, an Arizona school teacher whose 1-year-old son Ben has Down syndrome, recalls that it took six weeks to be assigned a caseworker, becoming number 60 in her caseload. Patti received the paperwork to apply for services, but was told of an indefinite state freeze on funds and services due to budget constraints. Ben was put on a waiting list, and was ineligible for federal services until he had state services first. "It's a Catch-22," Patti declares.

Advocates insist that home care is better for the child than out-of-home placement, and is preferred by most families. The key, they say, is to provide adequate financial support and a comprehensive array of services to meet the individual family's needs.

Most states provide at least some support for families caring for children with disabilities at home. Services most commonly offered include case management, respite care, parent education, home adaptations, special equipment and transportation. Other services may include information and referral, parent and family counseling, peer support groups, homemaker services, attendant care, in-home nursing, future planning and cash assistance.

In addition to family support, many states provide other forms of assistance, but often a gap exists between the intention and the reality.

"There's a theoretical system," says Carol Terwilliger, of California, "but it is so badly funded and understaffed that the only way it will work is if the parent is able to pour time into it. You're a coordinator, researcher, therapist. It's up to the families to keep on top of things, to get services and see that the service providers work together."

Budget watchdogs fear the "woodwork" effect: Those people not currently eligible for state assistance would "come out of the woodwork."

Although children with special health care needs are relatively few, their expenses can be enormous. These children consume an estimated 25 percent to 50 percent of all child health care expenses.

Carol Terwilliger explains, "Anything that's 'special needs' is extremely expensive because the market is so small. And the price for anything that goes through the medical market immediately gets kicked up. A standing frame costs $700; plastic foot braces are $1,400 a pair; a therapeutic foam wedge for sleeping runs $100. And these are all for a growing child, so they have to be replaced every two years or so. Just the growth adjustment to John's wheelchair cost $900 this year."

When the cost of their care is high, insurance companies drop families or raise premiums to prohibitive levels. Massachusetts addresses this problem through its CommonHealth plan. "The plan allows parents to make sure that their children's needs are met without going bankrupt, and it keeps families together," explains Representative John McDonough. "It's a humane, cost-effective, sensible way to address the needs of a vulnerable population. I wish we could do it for everyone."

Cheryl Gresek, the mother of a Massachusetts boy with a rare and costly heart condition, is a firm advocate of the CommonHealth program. It was a life-saver for the Greseks after they were priced out of their employer-based health plan. The Greseks had paid premiums for four years without

making a claim, but when they suddenly faced serious and expensive health care needs for their son Daniel, their premiums skyrocketed, first to $766 a month. They sold their condo, and paid. The next year, their premium jumped to $1,371 a month. They couldn't pay and had to drop out. After much expense, anguish and searching, the Greseks were referred to the new CommonHealth program, which insured Daniel for $58 a month, a premium determined by the family's income.

Even families whose employers offer excellent insurance benefits fear loss of coverage if they change jobs, get laid off, or if their employer changes health insurance coverage. They also face the possibility of exceeding their plan's total dollar limit, and most plans also limit the types of services covered. Insurance policies usually have pre-existing conditions clauses, which deny or restrict coverage for new enrollees of conditions that will be expensive to treat. A recent proposal by the Health Insurance Association of America (HIAA) recognizes problems in the current insurance system. HIAA's new position supports agreement among private insurers to provide unspecified essential benefits for everyone, regardless of medical history.

In the meantime, both the Massachusetts CommonHealth program and the Minnesota Children's Health Plan (CHP), to some extent, address these insurance issues for children.

"The idea is to get health care to kids who need it," says Minnesota Representative Lee Greenfield of the Children's Health Plan, which covers primary and outpatient health care. "We don't screen kids, we don't have any prior conditions clause—everyone's welcome." Nonetheless, Minnesota's program doesn't cover many of the services needed by children with special health care needs. CHP proponents had hoped to expand the program to cover acute care needs and inpatient hospital services, but policymakers found the costs prohibitive. The state's new MinnesotaCare plan, which builds on the success of the Children's Health Plan to cover uninsured adults, will eventually replace CHP and cover inpatient and acute care. Funding will come from a new tax on hospitals and other health care providers and a 5-cent increase in the state's cigarette tax.

In response to the growing outcry for help, the federal government assists states and families of children with special health care needs through changes and additions to Medicaid, the Maternal and Child Health Block Grant and the Individuals with Disabilities Education Act. But much of the financial burden under new federal mandates falls on states. Caught between added demands and limited resources, the states are in an increasingly awkward, and unsupportable, position.

A class action lawsuit under way in Pennsylvania (*Scott, et al. vs. Snider, et al.*) is a case in point. The lawsuit charges Pennsylvania with negligence for slow response to the federal mandate to actively seek out eligible children and enroll them in Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program. Under EPSDT, states must provide extensive treatment services to Medicaid-eligible children who need them. The lawsuit also requests Pennsylvania to set Medicaid payments for providers high enough to ensure children on Medicaid access to providers. A victory for the plaintiff on this provider payment issue would open the door to additional cost increases for states. As of mid-December, the plaintiffs and the state continued to work toward a settlement.

Although children with special health care needs are relatively few, their expenses can be enormous.

Pennsylvania Representative Ronald Cowell views the lawsuit as a potentially unifying force. "All in all, I think the outcome of this lawsuit will be very positive. It has prodded the state to re-examine the way it handles Medicaid, and by doing some reorganizing, we can probably improve the situation. We may even be able to draw down some additional federal money as well."

Senate colleague James Greenwood sees the additional federal support as critical. "Children who need health care should have health care, and we recognize that Medicaid's EPSDT program is a cost-effective way to provide services to children. However, it's unfortunate that we have been given a federal mandate without the time or the resources to implement it effectively. This is a well-intentioned policy, but it creates an impossible burden on the states."

A recent U.S. Supreme Court ruling, in *Sullivan vs. Zebley*, also has a major impact on Medicaid spending in most states for children with special health care needs. The court found that Supplemental Security Income (SSI) requirements for children were more restrictive than for adults and ordered the states to rectify the situation. As a result, many more children with disabilities will be eligible for SSI, and therefore Medicaid, in most states. This is good news for families of children with special health care needs, but expensive for states.

But for many parents, it's a question of paying now, or paying more later. "The sooner you get treatment and services to families of [these] children, the better," says Carol Bennet. "Doctors and pediatricians should have a lot more material on hand. My children were late being diagnosed, and there really is a need to start with these children early. There needs to be a set of guidelines, steps to follow, some package of information. You get little snips of things from here and there."

Numerous studies show that early intervention substantially enhances development in children with delays and disabilities, supports family-based care and uses public money efficiently. According to some estimates, for every $1 spent on early intervention states can save between $3 and $7 in future expenditures for institutionalization and special education.

Carol Terwilliger says the prevailing practices don't make sense. "If you don't invest in these children now, they will be institutionalized at great cost to the state. But they might be able to live differently if the money is spent in the early years, on support for the family and training and health care for the child."

Rhonda delaParra echoes her plea. "We care for Conrad at home because we love him. Conrad is a human being and he has a right to be here. And if legislators say, 'Why should we pay for services for a child who will wind up in an institution sooner or later,' I say, why not later rather than sooner?"

FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. CS SS SB 5 (HES)

Revision Date: 03/29/93
Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ...
Sponsor: Ellis, Salo, Lincoln, Duncan
Requestor: Senate State Affairs Committee

Dept. Affected: Health and Social Services
BRU: Medical Assistance
Component: Medicaid Non-Facility
COMPONENT SERIAL NO. 229

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS	1,165.7	692.2	0.0	0.0	0.0	0.0
MISCELLANEOUS						
TOTAL OPERATING	1,165.7	692.2	0.0	0.0	0.0	0.0
CAPITAL						
REVENUE FUND SOURCE						

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	582.8	346.1	0.0	0.0	0.0	0.0
1003 GF Match	582.9	346.1	0.0	0.0	0.0	0.0
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	1,165.7	692.2	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)
The fiscal impact of this bill results from adding new Medicaid recipients. Cost calculations are shown on attached page. Cost per recipient and number of new recipients are taken from home and community-based services waiver applications and supporting documents.

The Department of Health and Social Services has submitted a budget amendment for Medicaid home and community-based service waivers. The cost of serving new eligibles who would also be covered under a waiver is not included in this fiscal note. Some of the cost impact of SB 5 would be increased if that amendment is not fully funded.

The Department has limited experience identifying children living in the community who need an institutional level of care. Any variance with the predicted number of those eligible will impact costs.

Prepared by: Kimberly B. Busch
Division: Division of Medical Assistance
Phone: 465-3355
Date: 04/02/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
Agency: Department of Health & Social Services
Date: 4/6/93

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ANALYSIS (cont.):

Cost Estimate (thousands of dollars)

FY 94:

FY 94 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$102.2
Number of new recipients, not on waivers, in FY 94 needing hospital or NF level of care:	21
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$102.2 x 21 x 50% =	$1,073.1
FY 94 Medicaid service costs per recipient needing ICF/MR level of care:	$32.9
Number of new recipients, not on waivers, in FY 94 needing ICF/MR level of care:	36
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$32.9 x 36 x 50% =	$592.2
Total FY 94 cost of Medicaid services for all new recipients:	
$1,073.1 + $592.2 =	$1,665.3
Component Breakout:	
Medicaid Non–Facility (70 percent of total costs)	$1,165.7
Medicaid Facility (30 percent of total costs)	$499.6

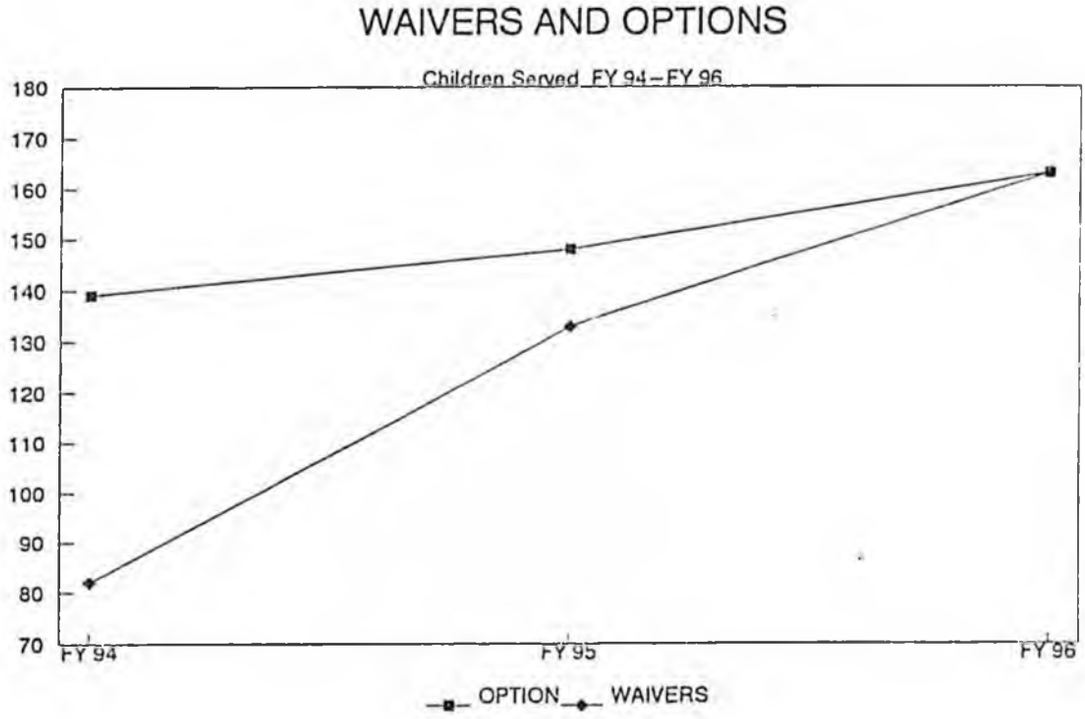
FY 95

FY 95 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$111.1
Number of new recipients, not on waivers, in FY 95 needing hospital or NF level of care:	6
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$111.1 x 6 x 100% =	$666.6
FY 95 Medicaid service costs per recipient needing ICF/MR level of care:	$35.8
Number of new recipients, not on waivers, in FY 95 needing ICF/MR level of care:	9
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$35.8 x 9 x 100% =	$322.2
Total FY 95 cost of Medicaid services for all new recipients:	
$666.6 + $322.2 =	$988.8
Component Breakout:	
Medicaid Non–Facility (70 percent of total costs)	$692.2
Medicaid Facility (30 percent of total costs)	$296.6

FY 96 – FY 99:

It is assumed that all new eligibles covered under this bill in FY 96 or after would receive coverage under waivers if this bill did not pass.

ANALYSIS (cont.):



FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. CS SS SB 5 (HES)

Revision Date: 03/29/93
Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ...
Sponsor: Ellis, Salo, Lincoln, Duncan
Requestor: Senate State Affairs Committee

Dept. Affected: Health and Social Services
BRU: Medical Assistance
Component: Medicaid Facilities
COMPONENT SERIAL NO. 230

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS	499.6	296.6	0.0	0.0	0.0	0.0
MISCELLANEOUS						
TOTAL OPERATING	499.6	296.6	0.0	0.0	0.0	0.0
CAPITAL						
REVENUE FUND SOURCE						

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	249.8	148.3	0.0	0.0	0.0	0.0
1003 GF Match	249.8	148.3	0.0	0.0	0.0	0.0
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	499.6	296.6	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)
The fiscal impact of this bill results from adding new Medicaid recipients. Cost calculations are shown on attached page. Cost per recipient and number of new recipients are taken from home and community-based services waiver applications and supporting documents.

The Department of Health and Social Services has submitted a budget amendment for Medicaid home and community-based service waivers. The cost of serving new eligibles who would also be covered under a waiver is not ncluded in this fiscal note. Some of the cost impact of SB 5 would be increased if that amendment is not fully funded.

The Department has limited experience identifying children living in the community who need an institutional level of care. Any variance with the predicted number of those eligible will impact costs.

Prepared by: Kimberly B. Busch
Division: Division of Medical Assistance
Phone: 465-3355
Date: 04/02/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
Agency: Department of Health & Social Services
Date: 4/6/93

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ANALYSIS (cont.):

Cost Estimate (thousands of dollars)

FY 94:

FY 94 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$102.2
Number of new recipients, not on waivers, in FY 94 needing hospital or NF level of care:	21
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$102.2 x 21 x 50% =	$1,073.1
FY 94 Medicaid service costs per recipient needing ICF/MR level of care:	$32.9
Number of new recipients, not on waivers, in FY 94 needing ICF/MR level of care:	36
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$32.9 x 36 x 50% =	$592.2
Total FY 94 cost of Medicaid services for all new recipients:	
$1,073.1 + $592.2 =	$1,665.3
Component Breakout:	
Medicaid Non–Facility (70 percent of total costs)	$1,165.7
Medicaid Facility (30 percent of total costs)	$499.6

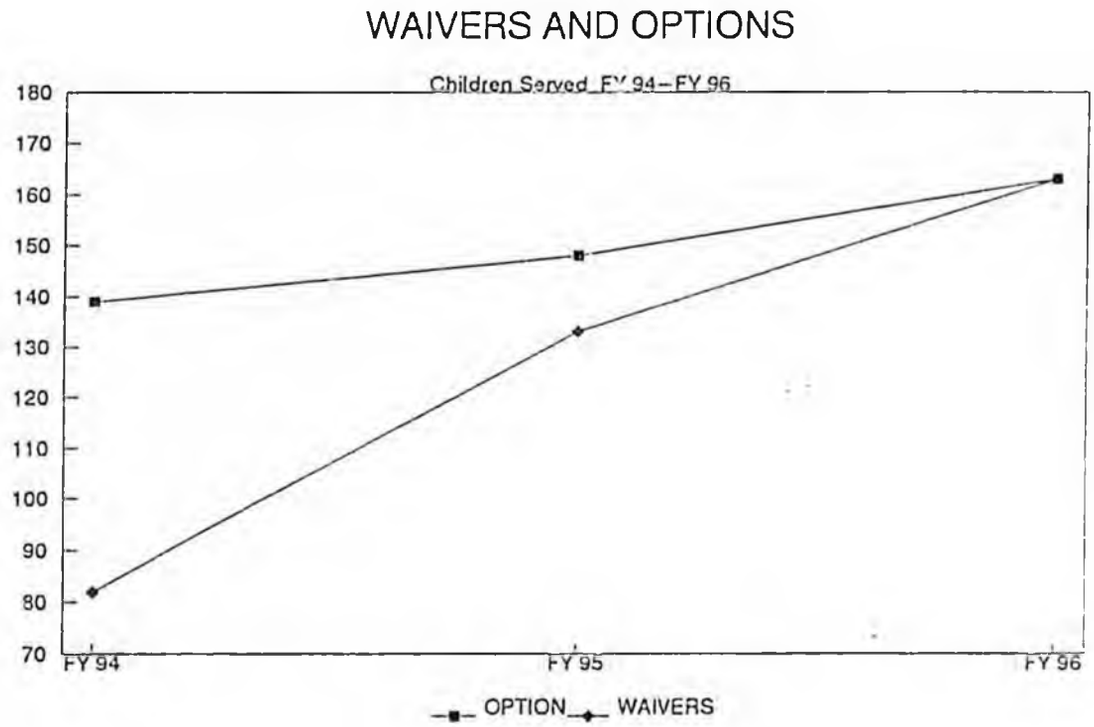
FY 95

FY 95 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$111.1
Number of new recipients, not on waivers, in FY 95 needing hospital or NF level of care:	6
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$111.1 x 6 x 100% =	$666.6
FY 95 Medicaid service costs per recipient needing ICF/MR level of care:	$35.8
Number of new recipients, not on waivers, in FY 95 needing ICF/MR level of care:	9
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$35.8 x 9 x 100% =	$322.2
Total FY 95 cost of Medicaid services for all new recipients:	
$666.6 + $322.2 =	$988.8
Component Breakout:	
Medicaid Non–Facility (70 percent of total costs)	$692.2
Medicaid Facility (30 percent of total costs)	$296.6

FY 96 – FY 99:

It is assumed that all new eligibles covered under this bill in FY 96 or after would receive coverage under waivers if this bill did not pass.

ANALYSIS (cont.):



FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. CS SS SB 5 (HES)

Revision Date: 03/29/93
Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ...
Sponsor: Ellis, Salo, Lincoln, Duncan
Requestor: Senate State Affairs

Dept. Affected: Health and Social Services
BRU: Medical Assistance Administration
Component: Claims Processing
COMPONENT SERIAL NO. 243

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL	25.1	9.0	0.0	0.0	0.0	0.0
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	25.1	9.0	0.0	0.0	0.0	0.0
CAPITAL						
REVENUE FUND SOURCE						

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	12.5	4.5	0.0	0.0	0.0	0.0
1003 GF Match	12.6	4.5	0.0	0.0	0.0	0.0
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	25.1	9.0	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)
The fiscal impact of this bill results from an increase in claims processing charges due to increasing new recipients. Cost calculations are shown on the attached page. In addition, FY 94 impact include one-time changes to the Medicaid Management Information System to add a new category of eligibility.

The Department of Health and Social Services has submitted a budget amendment for Medicaid home and community-based service waivers. Failure to fully fund this amendment would increase the cost of SB 5.

Prepared by: Kimberly B. Busch
Division: Division of Medical Assistance
Phone: 465-3355
Date: 04/02/93

Approved by Commissioner: Theodore A. Matt, MD, MPH
Agency: Department of Health & Social Services
Date: 4/6/93

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ANALYSIS (cont.):

Cost Estimate (thousands of dollars)

FY 94:	
Number of new recipients in FY 94:	57
x claims processing charges per recipient	$0.6
Percent of time in FY 94 recipients are covered	50%
FY 94 claims processing charges (57x$0.6x50%)	$17.1
One–time MMIS modification costs	$8.0
Total FY 94 Claims Processing	$25.1
FY 95:	
Number of new recipients in FY 95:	15
x claims processing charges per recipient	$0.6
Total FY 95 Claims Processing (15 x $0.6)	$9.0

FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. CSSSSB5(HES)

Revision Date: 03/29/93
Title: An Act relating to Medicaid eligibility

Dept. Affected: Health and Social Services
B U: Public Assistance Administration
Component: Eligibility Determination

Sponsor: Ellis
Requestor: Senate State Affairs

COMPONENT SERIAL NO. 270

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES	46.8	48.2	49.7	51.1	52.7	54.3
TRAVEL	0.0	0.0	0.0	0.0	0.0	0.0
CONTRACTUAL	5.0	5.0	5.0	5.0	5.0	5.0
SUPPLIES	0.5	0.5	0.5	0.5	0.5	0.5
EQUIPMENT	3.5	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES	0.0	0.0	0.0	0.0	0.0	0.0
GRANTS, CLAIMS	0.0	0.0	0.0	0.0	0.0	0.0
MISCELLANEOUS	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL OPERATING	55.8	53.7	55.2	56.6	58.2	59.8
CAPITAL	0.0	0.0	0.0	0.0	0.0	0.0
REVENUE FUND SOURCE	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	27.9	26.8	27.6	28.3	29.1	29.9
1003 GF Match	27.9	26.9	27.6	28.3	29.1	29.9
1004 GF	0.0	0.0	0.0	0.0	0.0	0.0
1005 GF/Program Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1006 GF/MHTIA	0.0	0.0	0.0	0.0	0.0	0.0
Other	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL	55.8	53.7	55.2	56.6	58.2	59.8

POSITIONS:

FULL-TIME	1	1	1	1	1	1
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: NONE

ANALYSIS: (Attach a separate page if necessary)

CSSSSB5 (HES) expands Medicaid eligibility to cover severely disabled children in home and community-based care. The Division of Medical Assistance estimates that 139 disabled children who do not currently receive Medicaid would become eligible in FY94 under CSSSSB5 (HES) and the Governor's amended budget. This caseload would grow to 148 in FY95 and 163 in FY96.

Additional public assistance field eligibility staff would be required to process applications and maintain Medicaid cases for these additional clients. One additional Eligibility Technician I/II would be necessary to cover the increased caseload.

Prepared by: Jan L. Hansen, Director
Division: Division of Public Assistance
Phone: 465-2680
Date: 4/2/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
Agency: Department of Health & Social Services
Date: 4/6/93

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Position Title			No. of Positions	Range/Step	Bargaining Unit
Eligibility Technician II			1	14B	GGU
Time Status	Staff Months		Location		Election District
PFT	12.0		Anchorage		House 15

TYPE of EXPENDITURE		AMOUNT
Salary		32.8
Benefits		14.0
Premium Pay		
Other		
Total Personal Services		46.8
Travel		
Contractual		5.0
Commodities		0.5
Equipment		3.5
Other		
Total Cost		55.8
FUNDING SOURCE for TOTAL COST		
1002 Federal Receipts		27.9
1003 GF Match		27.9
1004 General Fund		
1005 GF/Program Receipts		
1006 GF/Mental Health Trust		
1007 I/A Receipts		
1061 CIP Receipts		
Other		

Justification

CSSSSB5 (HES) expands Medicaid eligibility to cover severly disabled children in home and community-based care. The Division of Medical Assistance estimates that 139 disabled children who do not currently receive Medicaid would become eligible in FY94 under CSSSSB 5 (HES) and the Governor's amended budget. This caseload would grow to 148 in FY95 and 163 in FY96.

Additional public assistance field eligibility staff would be required to process applications and maintain Medicaid cases for these additional clients. One additional Eligibility Technician I/II would be necessary to cover the increased caseload.

REQUEST for NEW POSITION

AGENCY: Health and Social Services

BRU: Public Assistance Administration

COMPONENT: Eligibility Determination (270)

Revised Date:

FY94

FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. SS SB 5

Revision Date: 3/19/93
Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ...
Sponsor: Ellis, Salo, Lincoln, Duncan
Requestor: Senate HESS Committee

Dept. Affected: Health and Social Services
BRU: Medical Assistance
Component: Medicaid Non-Facility
COMPONENT SERIAL NO. 229

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS	1,165.7	692.2	0.0	0.0	0.0	0.0
MISCELLANEOUS						
TOTAL OPERATING	1,165.7	692.2	0.0	0.0	0.0	0.0
CAPITAL						
REVENUE FUND SOURCE						

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	582.8	346.1	0.0	0.0	0.0	0.0
1003 GF Match	582.9	346.1	0.0	0.0	0.0	0.0
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	1,165.7	692.2	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)
The fiscal impact of this bill results from adding new Medicaid recipients. Cost calculations are shown on attached page. Cost per recipient and number of new recipients are taken from home and community-based services waiver applications and supporting documents.

The Department of Health and Social Services has submitted a budget amendment for Medicaid home and community-based service waivers. Some of the cost impact of SB 5 would be increased if that amendment is not fully funded.

The Department has limited experience identifying children living in the community who need an institutional level of care. Any variance with the predicted number of those eligible will impact costs.

Prepared by: Kimberly B. Busch
Division: Division of Medical Assistance
Phone: 465-3355
Date: 03/22/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
Agency: Department of Health & Social Services
Date: 3/23/93

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ANALYSIS (cont.):

Cost Estimate (thousands of dollars)

FY 94:

FY 94 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$102.2
Number of new recipients, not on waivers, in FY 94 needing hospital or NF level of care:	21
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$102.2 x 21 x 50% =	$1,073.1
FY 94 Medicaid service costs per recipient needing ICF/MR level of care:	$32.9
Number of new recipients, not on waivers, in FY 94 needing ICF/MR level of care:	36
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$32.9 x 36 x 50% =	$592.2
Total FY 94 cost of Medicaid services for all new recipients:	
$1,073.1 + $592.2 =	$1,665.3
Component Breakout:	
Medicaid Non-Facility (70 percent of total costs)	$1,165.7
Medicaid Facility (30 percent of total costs)	$499.6

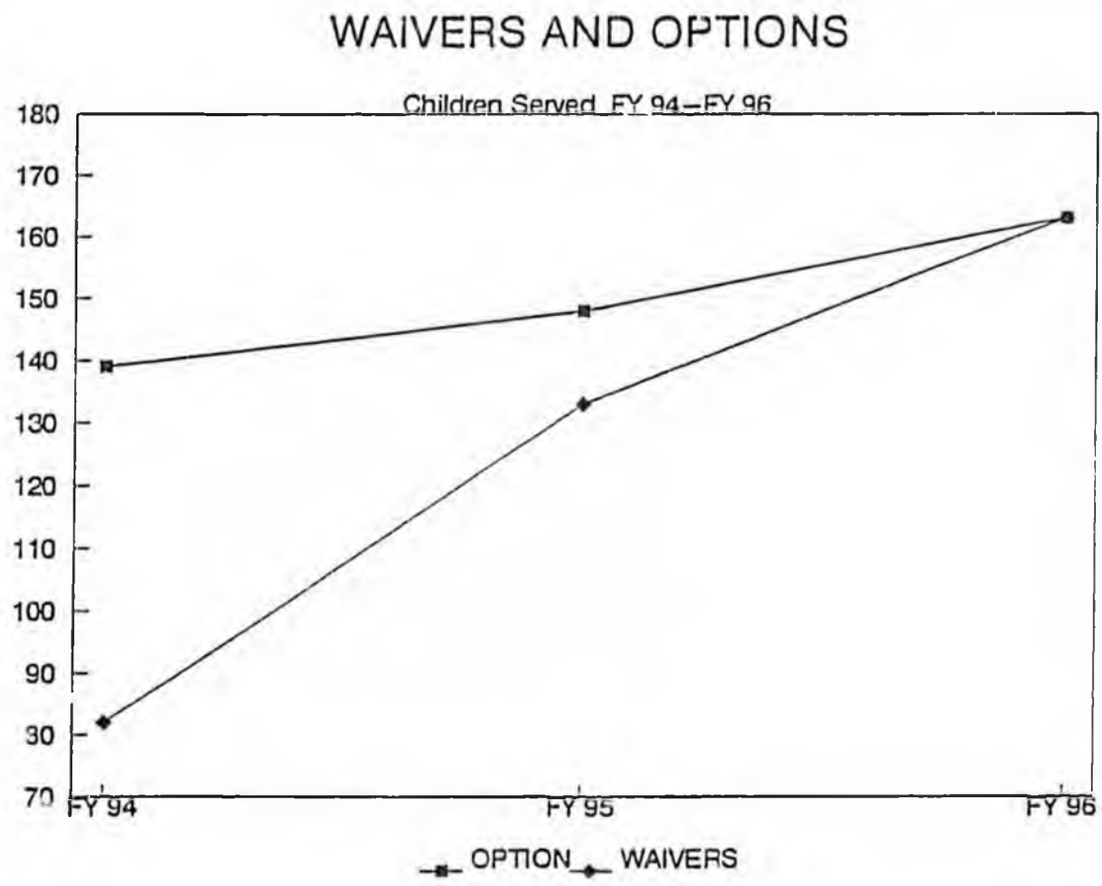
FY 95

FY 95 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$111.1
Number of new recipients, not on waivers, in FY 95 needing hospital or NF level of care:	6
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$111.1 x 6 x 100% =	$666.6
FY 95 Medicaid service costs per recipient needing ICF/MR level of care:	$35.8
Number of new recipients, not on waivers, in FY 95 needing ICF/MR level of care:	9
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$35.8 x 9 x 100% =	$322.2
Total FY 95 cost of Medicaid services for all new recipients:	
$666.6 + $322.2 =	$988.8
Component Breakout:	
Medicaid Non-Facility (70 percent of total costs)	$692.2
Medicaid Facility (30 percent of total costs)	$296.6

FY 96 – FY 99:

It is assumed that all new eligibles covered under this bill in FY 96 or after would receive coverage under waivers if this bill did not pass.

ANALYSIS (cont.):



FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. SS SB 5

Revision Date: 3/19/93
Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ...
Sponsor: Ellis, Salo, Lincoln, Duncan
Requestor: Senate HESS Committee

Dept. Affected: Health and Social Services
BRU: Medical Assistance
Component: Medicaid Facilities
COMPONENT SERIAL NO. 230

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS	499.6	296.6	0.0	0.0	0.0	0.0
MISCELLANEOUS						
TOTAL OPERATING	499.6	296.6	0.0	0.0	0.0	0.0
CAPITAL						
REVENUE FUND SOURCE						

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	249.8	148.3	0.0	0.0	0.0	0.0
1003 GF Match	249.8	148.3	0.0	0.0	0.0	0.0
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	499.6	296.6	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)
The fiscal impact of this bill results from adding new Medicaid recipients. Cost calculations are shown on attached page. Cost per recipient and number of new recipients are taken from home and community-based services waiver applications and supporting documents.

The Department of Health and Social Services has submitted a budget amendment for Medicaid home and community-based service waivers. Some of the cost impact of SB 5 would be increased if that amendment is not fully funded.

The Department has limited experience identifying children living in the community who need an institutional level of care. Any variance with the predicted number of those eligible will impact costs.

Prepared by: Kimberly B. Busch
Division: Division of Medical Assistance
Phone: 465-3355
Date: 03/22/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
Agency: Department of Health & Social Services
Date: 3/25/93

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FISCAL NOTE

ANALYSIS (cont.):

Cost Estimate (thousands of dollars)

FY 94:

FY 94 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$102.2
Number of new recipients, not on waivers, in FY 94 needing hospital or NF level of care:	21
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$102.2 x 21 x 50% =	$1,073.1
FY 94 Medicaid service costs per recipient needing ICF/MR level of care:	$32.9
Number of new recipients, not on waivers, in FY 94 needing ICF/MR level of care:	36
Percent of time in FY 94 recipients are covered in FY 94	50%
Total FY 94 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$32.9 x 36 x 50% =	$592.2
Total FY 94 cost of Medicaid services for all new recipients:	
$1,073.1 + $592.2 =	$1,665.3
Component Breakout:	
Medicaid Non–Facility (70 percent of total costs)	$1,165.7
Medicaid Facility (30 percent of total costs)	$499.6

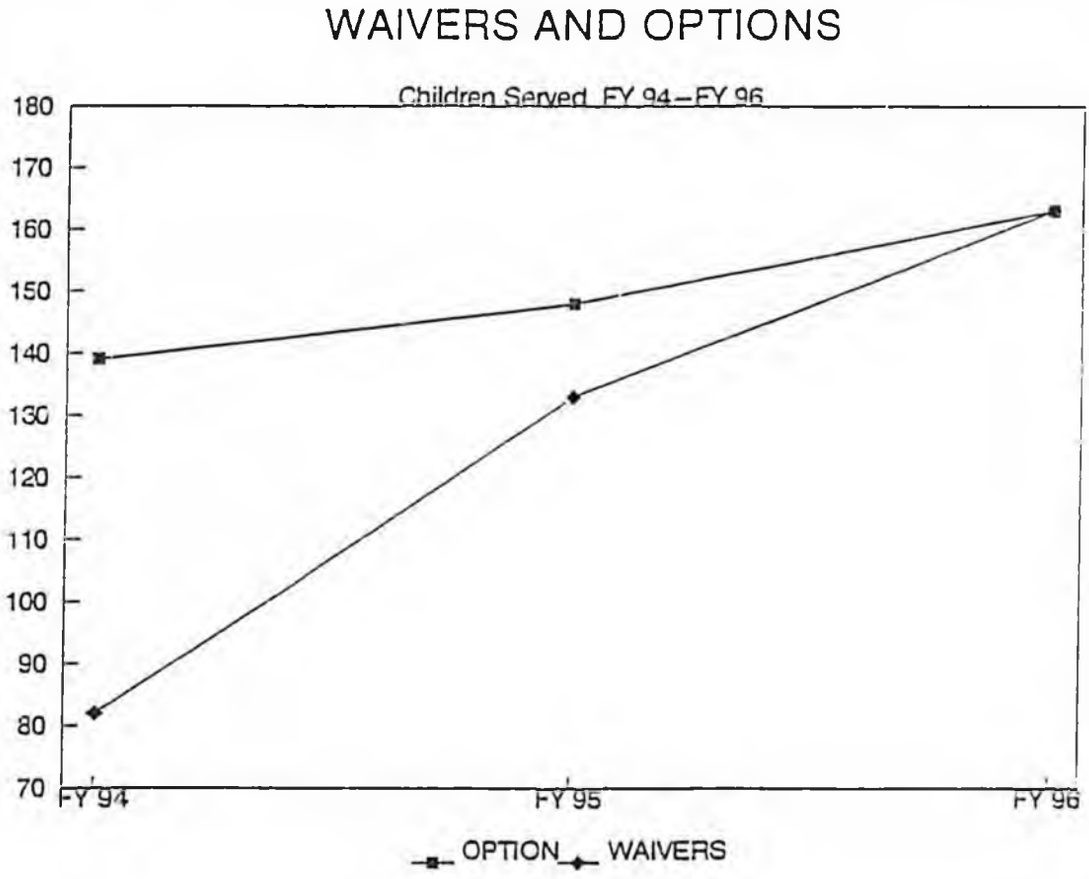
FY 95

FY 95 Medicaid service costs per recipient needing hospital or nursing facility level of care:	$111.1
Number of new recipients, not on waivers, in FY 95 needing hospital or NF level of care:	6
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing hospital or nursing facility level of care:	
$111.1 x 6 x 100% =	$666.6
FY 95 Medicaid service costs per recipient needing ICF/MR level of care:	$35.8
Number of new recipients, not on waivers, in FY 95 needing ICF/MR level of care:	9
Percent of time in FY 95 recipients are covered in FY 95	100%
Total FY 95 cost of Medicaid services for new recipients needing ICF/MR level of care:	
$35.8 x 9 x 100% =	$322.2
Total FY 95 cost of Medicaid services for all new recipients:	
$666.6 + $322.2 =	$988.8
Component Breakout:	
Medicaid Non–Facility (70 percent of total costs)	$692.2
Medicaid Facility (30 percent of total costs)	$296.6

FY 96 – FY 99:

It is assumed that all new eligibles covered under this bill in FY 96 or after would receive coverage under waivers if this bill did not pass.

ANALYSIS (cont.):



FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. SS SB 5

Revision Date: 03/19/93
Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ...
Sponsor: Ellis, Salo, Lincoln, Duncan
Requestor:

Dept. Affected: Health and Social Services
BRU: Medical Assistance Administration
Component: Claims Processing
COMPONENT SERIAL NO. 243

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL	25.1	9.0	0.0	0.0	0.0	0.0
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	25.1	9.0	0.0	0.0	0.0	0.0
CAPITAL						
REVENUE FUND SOURCE						

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	12.5	4.5	0.0	0.0	0.0	0.0
1003 GF Match	12.6	4.5	0.0	0.0	0.0	0.0
1004 GF						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	25.1	9.0	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)
The fiscal impact of this bill results from an increase in claims processing charges due to increasing new recipients. Cost calculations are shown on the attached page. In addition, FY 94 impact include one-time changes to the Medicaid Management Information System to add a new category of eligibility.

The Department of Health and Social Services has submitted a budget amendment for Medicaid home and community-based service waivers. Failure to fully fund this amendment would increase the cost of SB 5.

Prepared by: Kimberly B. Busch KBB
Division: Division of Medical Assistance
Phone: 465-3355
Date: 03/22/93

Approved by Commissioner: Theodore A. Mala, MD. MPH
Agency: Department of Health & Social Services
Date: 3/25/93

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ANALYSIS (cont.):

Cost Estimate (thousands of dollars)

FY 94:	
Number of new recipients in FY 94:	57
x claims processing charges per recipient	$0.6
Percent of time in FY 94 recipients are covered	50%
FY 94 claims processing charges (57x$0.6x50%)	$17.1
One-time MMIS modification costs	$8.0
Total FY 94 Claims Processing	$25.1
FY 95:	
Number of new recipients in FY 95:	15
x claims processing charges per recipient	$0.6
Total FY 95 Claims Processing (15 x $0.6)	$9.0

FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. SSSB5

Revision Date:
Title: An Act relating to Medicaid eligibility
Sponsor: Ellis
Requestor:

Dept. Affected: Health and Social Services
BRU: Public Assistance Administration
Component: Eligibility Determination

COMPONENT SERIAL NO. 270

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES	46.8	48.2	49.7	51.1	52.7	54.3
TRAVEL	0.0	0.0	0.0	0.0	0.0	0.0
CONTRACTUAL	5.0	5.0	5.0	5.0	5.0	5.0
SUPPLIES	0.5	0.5	0.5	0.5	0.5	0.5
EQUIPMENT	3.5	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES	0.0	0.0	0.0	0.0	0.0	0.0
GRANTS, CLAIMS	0.0	0.0	0.0	0.0	0.0	0.0
MISCELLANEOUS	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL OPERATING	55.8	53.7	55.2	56.6	58.2	59.8
CAPITAL	0.0	0.0	0.0	0.0	0.0	0.0
REVENUE FUND SOURCE	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

1002 Federal Receipts	27.9	26.8	27.6	28.3	29.1	29.9
1003 GF Match	27.9	26.9	27.6	28.3	29.1	29.9
1004 GF	0.0	0.0	0.0	0.0	0.0	0.0
1005 GF/Program Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1006 GF/MHTIA	0.0	0.0	0.0	0.0	0.0	0.0
Other	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL	55.8	53.7	55.2	56.6	58.2	59.8

POSITIONS:

FULL-TIME	1	1	1	1	1	1
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: NONE

ANALYSIS: (Attach a separate page if necessary)

SSSB5 expands Medicaid eligibility to cover severely disabled children in home and community-based care. The Division of Medical Assistance estimates that 139 disabled children who do not currently receive Medicaid would become eligible in FY94 under SSSB5 and the Governor's amended budget. This caseload would grow to 148 in FY95 and 163 in FY96.

Additional public assistance field eligibility staff would be required to process applications and maintain Medicaid cases for these additional clients. One additional Eligibility Technician I/II would be necessary to cover the increased case load.

Prepared by: Jan L. Hansen, Director
Division: Division of Public Assistance
Phone: 465-2680
Date: 3/23/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
Agency: Department of Health & Social Services
Date: 3/23/93

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Position Title	No. of Positions	Range/Step	Bargaining Unit
Eligibility Technician II	1	14B	GGU

Time Status	Staff Months	Location	Election District
PFT	12.0	Anchorage	House 15

TYPE of EXPENDITURE		AMOUNT
Salary		32.8
Benefits		14.0
Premium Pay		
Other		
Total Personal Services		46.8
Travel		
Contractual		5.0
Commodities		0.5
Equipment		3.5
Other		
Total Cost		55.8
FUNDING SOURCE for TOTAL COST		
1002 Federal Receipts		27.9
1003 GF Match		27.9
1004 General Fund		
1005 GF/Program Receipts		
1006 GF/Mental Health Trust		
1007 I/A Receipts		
1061 CIP Receipts		
Other		

Justification

Sponsor Substitute for Senate Bill No. 5 expands Medicaid eligibility to cover severely disabled children in home and community-based care. The Division of Medical Assistance estimates that 139 disabled children who do not currently receive Medicaid would become eligible in FY94 under SSSB 5 and the Governor's amended budget. This caseload would grow to 148 in FY95 and 163 in FY96.

Additional public assistance field eligibility staff would be required to process applications and maintain Medicaid cases for these additional clients. One additional Eligibility Technician I/II would be necessary to cover the increased caseload.

REQUEST for NEW POSITION

AGENCY: Health and Social Services

BRU: Public Assistance Administration

COMPONENT: Eligibility Determination (270)

Revised Date:

FY94