

**SB**

**5**



**ALASKA STATE LEGISLATURE**  
SENATE

**SS SB 5 — The Brianna Hurley Bill — by Sen. Johnny Ellis**

**SPONSOR STATEMENT**

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.

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 over two 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. Brianna's parents chose to keep Brianna at home, which forced them to quit their jobs to meet the federal requirements (poverty income levels). The strain caused the breakup of the Hurley's marriage.

Today, as a single parent, Elaine Hurley can earn just over \$900 per month, before taxes, to keep her daughter qualified for Medicaid. Elaine cannot purchase health care for Brianna because her medical problems are considered a "pre-existing condition" by health insurance companies. At this time, Medicaid is the only option for Brianna.

In December of 1992, Brianna was diagnosed as terminal by doctors at the Mayo Clinic in Rochester, Minn. Her mother, Elaine Hurley, has been a leader in the fight to get last year's bill passed and to work with the state DHSS to get better services for children with disabilities. She agrees that this legislation may be too late for her daughter but hopes, as I do, that the state can make sure that health care is available for other children with disabilities in a way that keeps families together.



ALASKA STATE LEGISLATURE  
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**SS SB 5 FACT SHEET**

***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. Seventeen states have the TEFRA Option, 28 states have regular waivers that serve kids and six have both as of Sept. 1, 1989

***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 consider supporting 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. This legislation will provide services to only those families who cannot be covered with a Medicaid waiver.



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.

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.

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.

*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.*

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.



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



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

# HOME COMING: Youngster may celebrate Christmas outside hospital

Continued from Page F-1

open-heart surgery. Then, during the medevac flight, his stomach filled up with air and burst like a balloon.

Somehow little Zachary held on, though barely.

Larry McKenzie, a Kenai auto mechanic just managing to make ends meet, couldn't begin to afford an intensive-care baby. Some estranged fathers would have shucked the responsibility. McKenzie bought a plane ticket to Seattle.

Four months later, after extensive surgery and two visits from his dad, Zachary was back in Alaska. But his first year was a shaky one. He'd be home in Kenai for a week or two with his mother, Daughn Carpenter, then he'd catch pneumonia or some other bug and be medevaced to Anchorage. His mother could never relax. The last time it happened, he'd been home only 24 hours.

Since then, for the past three years, "home" has been a room in the pediatric intensive care unit at Providence Hospital, a room decorated with stuffed toys, colorful posters and high-tech equipment.

Behind him trails a tangle of tubes and hoses. He must eat through a tube in his stomach. He must breathe through a tube in his throat. Because of a hearing impairment and a tracheotomy, Zachary cannot speak; when he cries, no sound comes out.

That first year, McKenzie drove up from Kenai every Friday night after work to spend the weekend with his son. In 1989, he gave up his job, home, relatives and friends on the Kenai Peninsula and moved to Anchorage to be closer. Eventually he received physical custody (they share legal custody), since Zachary's mother still lives in Kenai and has two other children of her own to raise.

Virtually every night since, McKenzie has spent at Providence, keeping Zachary company and tucking him in at bedtime. Around 9:30 p.m., he puts his boy in a clean diaper, lays him in his crib, closes the curtains and turns out the lights.

"Good night, Bud," he says softly, nose to nose. "See you tomorrow."

"He's pretty much here every single night," says Anita Schief, a registered nurse on the unit. "We're talking about seven days a week. He's so devoted. It's a real joy to watch."

Lately, members of Zachary's extended hospital family have been keeping their fingers crossed for Zachary and his dad. If all goes



Zachary cries as nurse Shari Whitehorn and respiratory therapist Sheila Van Cuyk clear his intensive care room of equipment and belongings. Zachary was moved to the pediatric floor as a step toward his release.

the way they hope, this father-son relationship won't be confined to a hospital room much longer. A team consisting of Zachary's doctor, nurses, home health-care coordinators and others are working hard to bring Zachary home before Christmas.

McKenzie has been preparing for this day for more than a year. Last fall, he moved into a bigger, two-bedroom apartment and started getting Zachary's room ready. He built him a little pine bed and a matching toy chest. He hung curtains, pictures and a couple of nets to hold Zachary's bulging collection of stuffed creatures. A quilt made by Larry's mother is draped across the bed, and a supply of shiny toy trucks waits in a corner. A pair of miniature cowboy boots sits atop the dresser.

But McKenzie and the home health care team know from experience not to get too excited about all this until it happens.

"We started on this last year," Schief said. "Our date was Jan. 1. Then it got moved to May 1. Then we went to July. It's just being continually set back."

The reason is a frustrating one for people who value quality-of-

life issues over financial ones. As hard as Zachary's advocates have been working to get him free, snags in the system have been working to keep him put.

Zachary's medical care has been costing well over \$1 million a year, his father says. Medical insurance pulled him through the first year; then, because he's disabled, Medicaid picked him up.

But now that it's time to go home, Medicaid won't follow. It would pay for Zachary to go into a nursing home, but not his own home.

Medicaid simply won't cover 24-hour nursing care outside an institution, and Zachary is a 24-hour job. This youngster is tethered to a ventilator that needs constant attention. There's no way McKenzie can do it alone. Nobody could.

Zachary and his dad must rely on a patchwork of services to make this work. Medicaid will cover medications, equipment and a limited amount of nursing care, and several agencies — Providence Home Health Care, the Division of Mental Health and Developmental Disabilities, the Anchorage School District and others — are piling

together a plan that should provide the necessary nursing, respite and transportation coverage, according to Marchelle Hanson, health care coordinator for the state Division of Mental Health and Developmental Disabilities.

The plan includes 24-hour nursing care assistance for the first couple of weeks, until Zachary and his dad can get settled into their new routine. After the transition period, nursing assistance would be tapered off to about 16 hours a day. If this works as well as everyone hopes, Zachary should be able to start preschool in January.

McKenzie had to quit his job at Grand Auto Supply to do this. He's not thrilled about going on welfare. But he'll do whatever it takes to be there for his boy. And once Zachary gets adjusted, he figures he can start job hunting again.

"I'm getting kind of nervous about quitting work," McKenzie said. "How am I going to support myself? It will be hard. But I know I'm quitting for a cause. I know I have to do this."

While all this is being sorted out, the home health team is plow-

ing ahead with homecoming plans. On Monday, Zachary moved from the intensive care unit to the regular pediatric floor. The same day, his father moved into the room with him and took over his health care routine.

McKenzie feels confident in his ability to care for his son, and Zachary's nurses agree he's plenty competent. McKenzie has taken extensive courses on all the equipment it takes to keep his son alive. For the past year, he has been Zachary's primary caregiver during his evening visits — feeding him and giving him medications as well as his respiratory therapy. At the end of this trial run, Zachary's nurses believe the two will be more than ready to go home.

Zachary is stronger now than he's ever been. But he still has a long way to go.

His esophagus has been connected through surgery, but, as Dr. Dion Roberts says, "It's not a perfect piece of plumbing." To prevent scar tissue from closing it off, doctors have run a string through Zachary's body that goes in a hole in his stomach and comes out his nose. Should the esophagus start to squeeze shut, a device can be attached to the string and pulled through to stretch it out.

But the biggest obstacle Zachary faces is with his lungs. Both have been severely damaged by pneumonia, as well as aspirated stomach acids and saliva.

Nevertheless, Roberts is hopeful for Zachary. It is conceivable that someday he could learn to swallow without gagging. And he could very well learn to breathe on his own. As long as he's growing, his lungs are, too, they could grow strong enough to compensate for some of the damage.

"He has a long, long road to rehabilitation," Roberts says. "It won't be weeks or months. It will be years."

Meanwhile, Zachary's nurses are trying to figure out what they're going to do once their charge really goes home for good.

"You're so happy he finally gets to go home and be with his dad and have the life of a child," one of his nurses, Anita Schief, says. "But what's he going to do without all his moms?"

"We watched him learn how to crawl. We watched him learn how to walk. We watched him learn sign language. We watched him grow up."

"But no child deserves to grow up in a hospital. He's got a home and a loving father, the most devoted I've ever seen. He needs to go home."



FRAN DURNER / Anchorage Daily News

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

# 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 \$75 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

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 current policy needlessly impoverishes working families trying to care for a disabled child at home.

Responding to the problem, the council has examined the Medicaid system and recommended improvements to make home care more available to persons with disabilities.

In 1990, the legislature required a similar study by an independent commission known as Project Choice whose final report will be presented in January. Both the council and Project Choice recommend that the state act for a waiver from federal Medicaid rules.

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

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

In 1981 Katie Beckett, a 3-year-old girl from Iowa who, like Brianna, suffered from viral encephalitis, was granted a federal waiver by President Ronald Reagan. He cited the case as overregulation.

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

Medicaid's Ashenbrenner says Alaska has never applied for this particular waiver or option because the state already has an adequate welfare program, with the most generous eligibility standards in the country.

This rationale, however, does not consider people like the Hurleys, a family caught in precisely the regulatory paradox that such waiver programs were intended to address.

The Hurleys see a waiver or Beckett option as their only relief from poverty sentence.

"Sometimes, you get the impression these Medicaid people think of it as their own money," says Elaine.

She glances lovingly at Brianna who responds with a curious look. When all the frustrations become too much, the Hurleys focus on what's most dear.

They shower Brianna with attention. The tiniest of achievements, seen as a simple wave of her hand, bring them renewed hope for her future.

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

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

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

Brianna stirs. "Sshhhh, little one. It's OK. Dad's here."

**BRIANNA HURLEY:**

**CATCH-22**

Daily News - 12/31/92

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

# FISCAL NOTE

STATE OF ALASKA  
1993 LEGISLATIVE SESSION

BILL NO. SS SB 5

Revision Date: 3/19/93 Dept. Affected: Health and Social Services  
 Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ... BRU: Medical Assistance  
 Component: Medicaid Facilities  
 Sponsor: Ellis, Salo, Lincoln, Duncan  
 Requestor: Senate HESS Committee 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						
<b>TOTAL OPERATING</b>	<b>499.6</b>	<b>296.6</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

CAPITAL						
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REVENUE FUND SOURCE						
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**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						
<b>TOTAL</b>	<b>499.6</b>	<b>296.6</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**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:	
$\$102.2 \times 21 \times 50\% =$	<u>\$1,073.1</u>

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:	
$\$32.9 \times 36 \times 50\% =$	<u>\$592.2</u>

Total FY 94 cost of Medicaid services for all new recipients:	
$\$1,073.1 + \$592.2 =$	<u>\$1,665.3</u>

## 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:	
$\$111.1 \times 6 \times 100\% =$	<u>\$666.6</u>

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:	
$\$35.8 \times 9 \times 100\% =$	<u>\$322.2</u>

Total FY 95 cost of Medicaid services for all new recipients:	
$\$666.6 + \$322.2 =$	<u>\$988.8</u>

## Component Breakout:

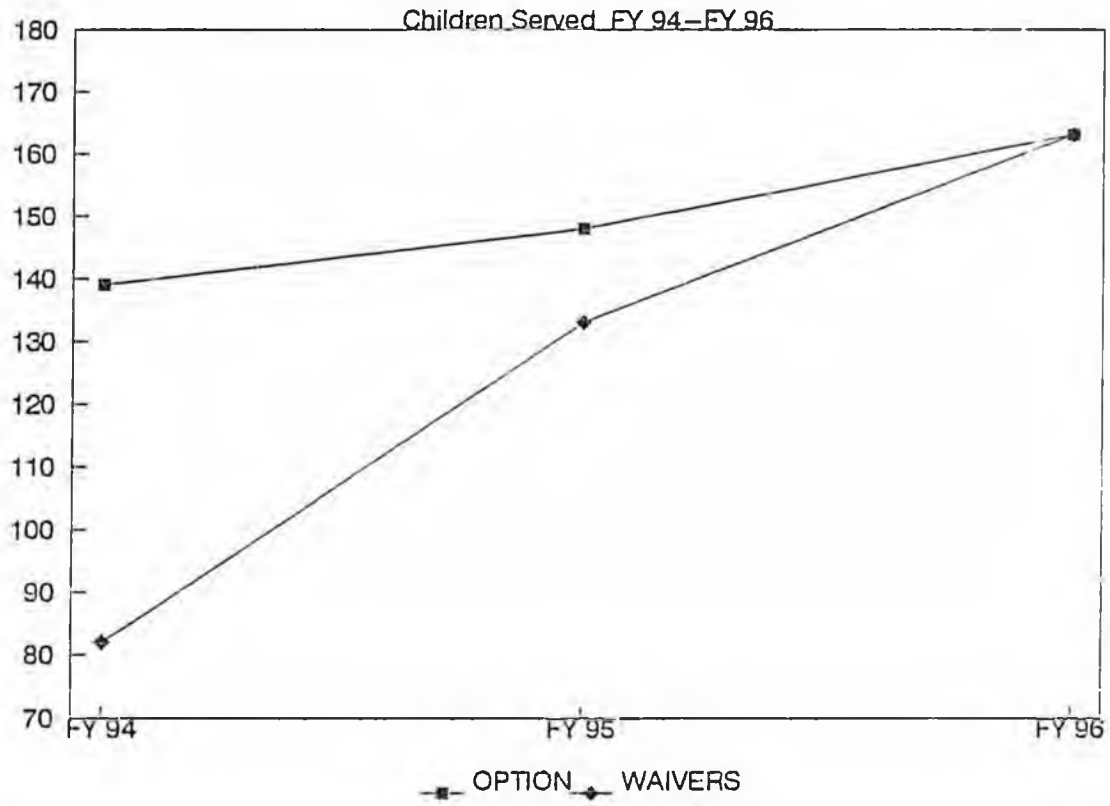
Medicaid Non-Facility (70 percent of total costs)	\$692.2
Medicaid Facility (30 percent of total costs)	\$296.6

## 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.):

### WAIVERS AND OPTIONS



# FISCAL NOTE

STATE OF ALASKA  
1993 LEGISLATIVE SESSION

BILL NO. SS SB 5

Revision Date: 3/19/93 Dept. Affected: Health and Social Services  
 Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ... BRU: Medical Assistance  
 Component: Medicaid Non-Facility  
 Sponsor: Ellis, Salo, Lincoln, Duncan  
 Requestor: Senate HESS Committee 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						
<b>TOTAL OPERATING</b>	<b>1,165.7</b>	<b>692.2</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

CAPITAL						
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REVENUE FUND SOURCE						
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**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						
<b>TOTAL</b>	<b>1,165.7</b>	<b>692.2</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**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:	
$\$102.2 \times 21 \times 50\% =$	<u>\$1,073.1</u>

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:	
$\$32.9 \times 36 \times 50\% =$	<u>\$592.2</u>

Total FY 94 cost of Medicaid services for all new recipients:	
$\$1,073.1 + \$592.2 =$	<u>\$1,665.3</u>

## 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:	
$\$111.1 \times 6 \times 100\% =$	<u>\$666.6</u>

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:	
$\$35.8 \times 9 \times 100\% =$	<u>\$322.2</u>

Total FY 95 cost of Medicaid services for all new recipients:	
$\$666.6 + \$322.2 =$	<u>\$988.8</u>

## Component Breakout:

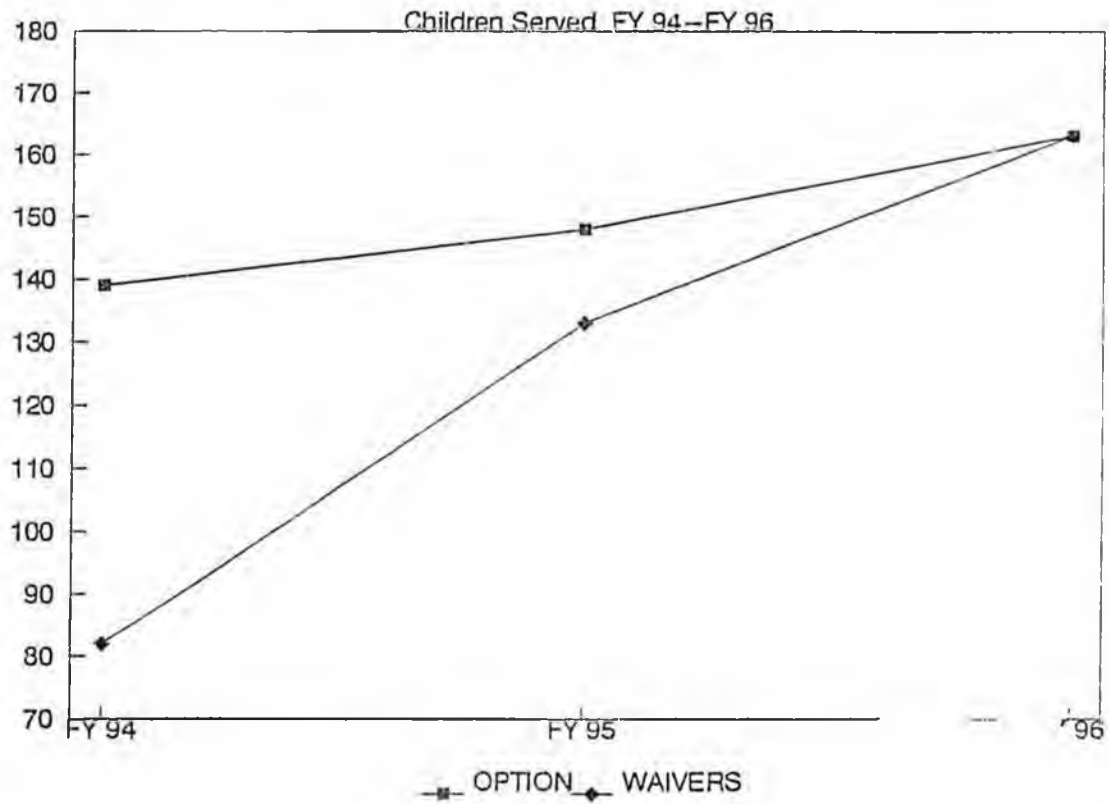
Medicaid Non-Facility (70 percent of total costs)	\$692.2
Medicaid Facility (30 percent of total costs)	\$296.6

## 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.):

### WAIVERS AND OPTIONS



# FISCAL NOTE

STATE OF ALASKA  
1993 LEGISLATIVE SESSION

BILL NO. SS SB 5

Revision Date: 03/19/93 Dept. Affected: Health and Social Services  
 Title: An Act relating to Medicaid eligibility of persons eligible to be institutionalized ... BRU: Medical Assistance Administration  
 Component: Claims Processing  
 Sponsor: Ellis, Salo, Lincoln, Duncan  
 Requestor: \_\_\_\_\_ 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						
<b>TOTAL OPERATING</b>	<b>25.1</b>	<b>9.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

CAPITAL						
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REVENUE FUND SOURCE						
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**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						
<b>TOTAL</b>	<b>25.1</b>	<b>9.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

**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: 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%)	<u>\$17.1</u>
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One-time MMIS modification costs	\$8.0
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Total FY 94 Claims Processing	<u>\$25.1</u>
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## 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)	<u>\$9.0</u>
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FISCAL NOTE

STATE OF ALASKA  
1993 LEGISLATIVE SESSION

BILL NO. SSSB5

Revision Date: \_\_\_\_\_ Dept. Affected: Health and Social Services  
 Title: An Act relating to Medicaid eligibility BRU: Public Assistance Administration  
 Component: Eligibility Determination  
 Sponsor: Ellis  
 Requestor: \_\_\_\_\_ 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
<b>TOTAL OPERATING</b>	<b>55.8</b>	<b>53.7</b>	<b>55.2</b>	<b>56.6</b>	<b>58.2</b>	<b>59.8</b>
<b>CAPITAL</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>
<b>REVENUE FUND SOURCE</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>

**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
<b>TOTAL</b>	<b>55.8</b>	<b>53.7</b>	<b>55.2</b>	<b>56.6</b>	<b>58.2</b>	<b>59.8</b>

**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 caseload.

Prepared by: Jan L. Hansen, Director *Jan Hansen* Phone: 465-2680  
 Division: Division of Public Assistance Date: 3/23/93  
 Approved by Commissioner: Theodore A. Mala, MD, MPH *Theodore Mala* Date: 3/23/93  
 Agency: Department of Health & Social Services

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Position Title Eligibility Technician II		No. of Positions 1	Range/Step 14B	Bargaining Unit GGU
Time Status PFT	Staff Months 12.0	Location Anchorage		Election District 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	2.9		
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				
<p>Justification</p> <p>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.</p> <p>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.</p>				

**REQUEST for  
NEW POSITION**

AGENCY: Health and Social Services

BRU: Public Assistance Administration

COMPONENT: Eligibility Determination (270)

**FY94**

Page 1 of 1

Revised Date:



03/24/93  
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LEGISLATIVE TELECONFERENCE NETWORK SYSTEM  
PARTICIPANT LIST (ALL PARTICIPANTS)

LTN1150  
BY:ANC  
FOR:ANC

TCN:30425

SCHEDULED FOR:03/24/93 13:30 TO 15:30

PUBLIC HEARING

SENATE HEALTH, EDUCATION & SOCIAL SERVIC

LOCATION: ANCHORAGE

SB 5  
SB 5

*see  
new  
sheet*  
MS.  
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LAUREL  
KAROL

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LIBBEY

TESTIFY  
TESTIFY

*J. Klawork*

*Brenda Trumble*

03/24/93  
13:42:07

TCN: 30425  
PUBLIC HEARING

LEGISLATIVE TELECONFERENCE NETWORK SYSTEM  
PARTICIPANT LIST (ALL PARTICIPANTS)  
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SENATE HEALTH, EDUCATION & SOCIAL SERVIC

LYN1150  
BY: ANC  
FOR: ANC

LOCATION: ANCHORAGE

SB 5  
SB 5  
SB 5

✓ MS.  
✓ MS.  
MS.

LAUREL  
KAROL  
ELAINE

PUTNAM  
LIBBEY  
HURLEY

TESTIFY  
TESTIFY  
TESTIFY

*Brian Hurley's mom*