



Early Intervention: A Powerful Investment

Alaska Infant Learning Program 2010

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Our Mission

To promote positive development and improved outcomes for Alaska's Families by creating a culturally responsive, comprehensive and accessible service delivery system that links service providers, empowers families and engages communities.



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Alaska Infant Learning programs are:

Locally administered ILP contracts with agency grantees statewide to ensure services are available across Alaska.

Family centered respecting parents' natural leadership role in care giving and decision making for their children.

Flexible recognizing the diversity of Alaska families' strengths, needs, roles, values, and cultures.

Committed to partnerships facilitating a dynamic partnership between families, agencies, providers and their communities.

Delivering services in natural settings natural home and community settings promote the inclusion of the family, and help to maximize a child's development.

How We Fulfill Our Mission

- **Educating Alaskans** — Outreach
- **Connecting with Families** — Referral
- **Partnering with Families** — Setting Goals, Achieving Goals
- **Supporting Families** — Service Delivery, Forming a Support System
- **Taking the Next Step** — Planning for a Successful Transition



Jonah's Story



People sometimes get confused about which biblical icon Kama Gregory's son was named after. Was it Noah, the guy with the ark?

"It was Jonah, the one in the whale," his mother tells them.

Jonah Ryan Gregory's tumultuous story "begins in utero," she explains.

In her child's 30th week of gestation...

Kama expected to have a routine sonogram.

Kama, CEO of a non-profit agency which provides ultrasounds to underserved populations around the world, had a bad feeling when the man doing the sonogram suddenly said he needed to go get a doctor.

“I thought, oh, something’s not right.”

It wasn’t. After a clean bill of health just a few days before, suddenly the left ventricle of the baby’s brain was hemorrhaging.

“It was a fetal anomaly,” Kama says. “To this day, there’s not a reason it happened.”

But the longer the bleeding went on, the more damage occurred. Jonah developed hydrocephalous. No one knew what this meant for the baby’s future — or if he even had a future.

The value of intervening – early!

Kama said doctors told her to be prepared for the baby not to make it, or for his development to be severely stunted because of the ongoing brain damage. The prognosis was “pretty ugly,” she recalls.

But when doctors suggested delivering the baby early — too early to ensure his survival — all of Kama’s protective instincts kicked in. She was crying nightly and completely baffled as to why this had happened to her, but she was going to be a mom. Kama, who says her faith is “a big deal to me,” held on to that.

“I just wasn’t giving up hope. I mean, he was my child.”

And so Kama became an advocate for her son before he was even born. And once that happened, the pieces came together to help her care for him, including services and experts and practitioners and therapy for Jonah — provided by the Alaska Early Intervention/Infant Learning Program (EI/ILP).

“Once doctors realized I wasn’t giving up on my child, he became a child, not an anomaly.”

An 8 pound 7 ounce son who would breathe on his own and receive highly respectable scores of 8 and 9 on his one- and five-minute Apgar tests.

But a son who also received a shunt to lessen the pressure on his brain at only 3 days old, which he will have for the rest of his life. And who was paralyzed on his right side.

“He still has brain damage,” Kama says. “It’s like a stroke. Jonah came into the world with us knowing he would need every service under the sun.”



Fortunately, the services were there within weeks, Kama and Jonah were signed up for the Infant Learning Program (ILP) through the Program for Infants and Children in Alaska (PIC). A system of services designed for families of children birth to three; delivered through a network of provider agencies across Alaska.

“It’s for birth to 3, and we took full advantage of that,” Kama says.

As a result, despite the partial paralysis, called hemiplegia, Jonah now walks. Kama says her son knew he didn’t want to be on the ground, so for a year he walked on his knees. Now he can even run. “It’s not pretty, but he can do it,” Kama says.

“I think parents can do anything with the support and encouragement of people who believe in their child’s potential.”

Kama believes so strongly in Early Intervention she’s testified to legislators about the need to fund it, and the need for more practitioners. “This is how much it costs, and this

“There’s a limited amount of time,” Kama notes. “They aren’t birth to 3 forever.”



is how much it serves you,” she tells them. It helps that her son testifies with her.

Jonah just graduated from speech therapy. That’s graduated — he won’t need to go back.

“He’s very independent now,” his mom says. “He’s doing things he never would have done without Early Intervention.”

All of which means Kama is starting to have a little more time herself. Which is very good, considering there’s a new little Gregory baby in the house.

So now Jonah gets to try out another role: big brother. His mom says he’s ready.

She encourages other parents to move quickly to get their own children the help they need.

“There’s a limited amount of time,” Kama notes. “They aren’t 0 to 3 forever.”



Gains during the **first 3 yrs**
are critical and will continue to
benefit a child ...

throughout their lifetime



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Educating Alaska

Why is Early Intervention Critical?

The early years of a child's life are critically important: From birth through age three rapid learning and brain development takes place. During this time, children form the foundation for future learning, problem solving, relationship building, and independence. When a child experiences a developmental delay, early intervention can help guide them through this extraordinary time of growth to maximize their development.

Statewide outreach efforts educate families, providers and the general public about early intervention services available to children ages birth to three, including:

- Developmental Screenings and Evaluations
- Hearing and Vision Screening
- Family Service Coordination
- Early Education Services
- Play Groups, Support Groups, and Social Services
- Developmental, Physical, Occupational and Speech Language Therapy
- Early Childhood Mental Health Services

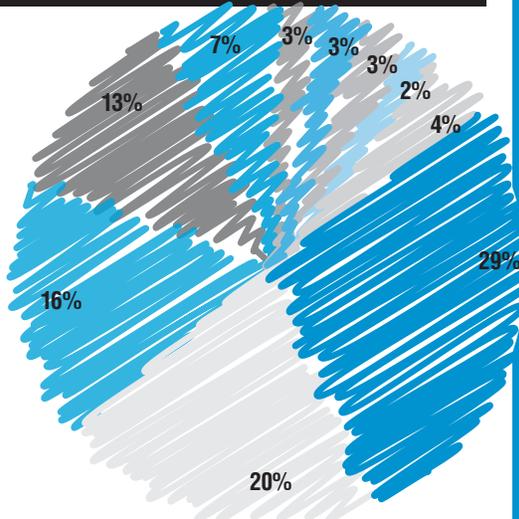


Kama found out about the Infant Learning Program through the Neonatal Intensive Care Unit.

"I was one of the 'fortunate' ones where Jonah's condition was diagnosed in-utero, so we hit the ground running."

How did families learn about the Infant Learning Program?

- 29% Child Find Publicity
- 20% Infant Learning Program
- 16% Physician
- 13% Other/Unknown
- 7% Friend/Family
- 3% Public Health Nurse
- 3% Child Care/Preschool
- 3% Child Protection Services
- 2% Clinic/Hospital
- 4% Community Health Aide/Other Health Provider



Children Referred to EI/ILP

*Fiscal Year	Referrals
2006	2,331
2007	2,557
2008	2,657
2009	2,503
2010	2,548

* Fiscal year begins July 1 and ends June 30 of the year noted
Referral source: Referrals by Status for ILP FY09 (Analyst Reports)

Children screened by EI/ILP

*Fiscal Year	Referrals
2006	1185
2007	1220
2008	1316
2009	1230
2010	1149

Screened source: Service Summary FY09 (Analyst Reports)

Children newly evaluated by EI/ILP

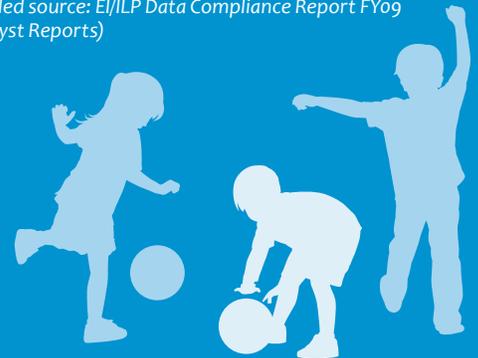
*Fiscal Year	Referrals
2006	1078
2007	1152
2008	1278
2009	1120
2010	1138

Evaluated source: Service Summary FY09 (Analyst Reports)

Children enrolled by EI/ILP

*Fiscal Year	Referrals
2006	1777
2007	1834
2008	1892
2009	1831
2010	1788

Enrolled source: EI/ILP Data Compliance Report FY09 (Analyst Reports)



Kama was referred to an Anchorage agency, Programs for Infants and Children, who completed an evaluation of Jonah in his home. Kama says "I did not prepare for his needs really before he was born, as it was not determined how long he would live after birth, if he made it that long, and how much he might need."



Connecting with Families

The Earlier the Referral is Made the More Successful the Outcome

Children and their families are referred to regional Infant Learning Programs via fax, phone and email. Most referrals are made by those who know the child best: their families or health care provider.

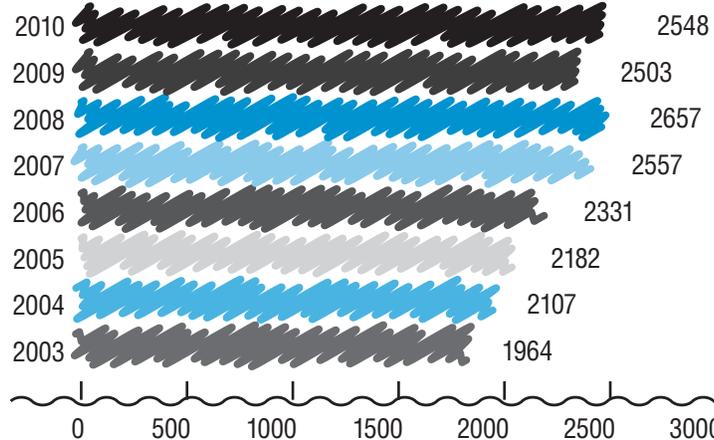
"Parents are often the first to know their baby needs a helping hand"

Referrals to the Infant Learning Program exceeded 2500 in FY2010, representing an increase of more than 25% since 2003.

During FY 2009, 2503 children were referred to an Infant Learning Program and 1756 children enrolled. During FY2010, Infant Learning Programs served 5% of all Alaskan children aged birth to three.

Total Number of Children Referred

* Fiscal Yr



* Fiscal year begins July 1 and ends June 30 of the year noted
Referral source: Referrals by Status for ILP FY09 (Analyst Reports)

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The earlier a referral is made, **the better.**

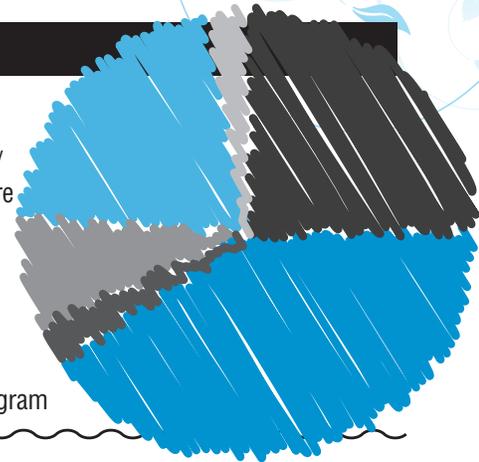
“Research shows us that starting early has more impact than starting late. As brain circuits are built up and stabilize over time, they become increasingly more difficult to alter.”

(Sam Meisels, Ph.D., EdWeek (vol 25:20, pages 36-44) January 25, 2006)



Referral Source

-  25% Parents
-  41% Physician/Clinic/
Other Health Care
-  3% Infant Learning
Program
-  8% Other/Unknown
-  21% Friend/Family
-  3% Community Program



Referrals to the Infant Learning Program can be made by contacting the state office:

**1-877-HSS-FMLY (477-3659), in Anchorage 269-8442
or by contacting a regional provider
[hss.state.ak.us/ocs/InfantLearning/program/
program_dir.htm](http://hss.state.ak.us/ocs/InfantLearning/program/program_dir.htm)**



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Intake

Assessing Growth & Development

Alaska's Infant Learning Programs serve children across the state from diverse backgrounds.

When a child is referred to an Infant Learning Program, a developmental screening or evaluation is administered to assess the child's growth and development in several areas, including:

- Using large muscles, moving around (*Gross Motor*)
- Using hands and fingers (*Fine Motor*)
- Thinking, learning (*Cognitive*)
- Understanding, talking (*Communication*)
- Getting along with others (*Social/Emotional*)
- Doing things for themselves (*Adaptive*)

A multidisciplinary assessment will gauge if a child is developing at a similar rate as children of the same age. If a child experiences a delay they may be eligible for early intervention services.

"A multidisciplinary assessment will gauge if a child is developing at a similar rate as children of the same age."

Age at Referral (Enrolled Children)

52%	Birth to 11 Months	903
31%	12 to 24 Months	549
17%	24 to 36 Months	304



Referral by Ethnic Background

	28%	American Indian/Alaska Native	522
	3%	Asian	55
	3%	Black or African American	62
	3%	Hispanic/Latino	62
	25%	Unknown or Other	451
	37%	White/Caucasian	680



By far most children qualify due to a developmental delay, children also qualify if they have a diagnosed physical condition likely to result in developmental delay.

Most Frequently Diagnosed Delays

Down Syndrome	38		13%
Cleft Palate	36		12%
Hearing Impairment	34		11%
Complex Seizure Disorder	22		7%
Cerebral Palsy	20		7%
Vision Impairment	19		6%
Autism	13		4%
Spina Bifida	11		4%
Hydrocephaly	10		3%
Heart Disease, Congenital	8		3%
Microcephaly	8		3%
Fetal Alcohol Syndrome	7		2%





Partnering with Families

Setting goals, educating families

Early intervention services are designed to assist families to help their infants/toddlers maximize their development. The child's family plays a crucial role in both planning and delivering early intervention services. Infant Learning Programs embrace each family's unique capacity to support and promote their child's development.

"Knowing what to expect, how to support my child's development helped me be less afraid..."

Individualized Family Services Plan
Alaska Early Intervention / Infant Learning Program

Referral Information

Child's Name: _____ Child Previous Name or Alias: _____

Gender: Female Male Birth Date: _____

Referral Date: _____ Referral Follow Up Date: _____ (letter/call)

Referral Source: _____ Phone: _____

If parent is referral source, how did parent hear: _____

Reason for Referral (include any important notes): _____

Parents decide if they would like their children to participate in early intervention assessments and services, and help set the developmental goals for their children.

Through the Infant Learning Program, families partner with providers to develop a written Individual Family Services Plan (IFSP). The IFSP outlines the child's strengths and current levels of functioning; the plan clearly outlines the developmental goals for the child and the specific early intervention steps that will be taken to help the child achieve their goals.

Jonah's early intervention team of doctors, therapists, and ILP staff joined with his family to begin the service plan. Kama remembers feeling overwhelmed and not knowing what concerns to focus on. "He was my first child. Having ILP was reassuring... they or the doctor answered any question I had, if they could."

Kama and Jonah attended many weekly therapy sessions (including speech, occupational, physical therapy), and also did exercises at home. As Jonah grew, Kama recalls, "the therapy changed to make Jonah learn functional things like how to manipulate objects, hold a cup and survive in the world."



Infant Learning Programs educate families about the developmental steps they will see their child move through.

Families learn specific techniques they can use daily to support the developmental goals of their child. When a child reaches a goal, the family will receive additional training to support them as they work towards the next developmental goal.

“Parents are a child’s first and most important teacher.

Early intervention services are most effective when the family is directly involved in their delivery.”

Early intervention services are most effective when delivered in a child’s natural settings such as: home, preschool, childcare or other community settings. Delivery in these natural settings helps to educate everyone who interacts with the child, and strengthens the community’s ability to support the child’s growth and development.



For Kama, Jonah's journey brought out a myriad of emotions. "Watching him grow was a combination of excitement, confusion, and some disappointment." Kama reflects, "Considering that he continued to move forward is what I started to define as success, not milestones, just the progress. The individual therapists were amazing, supportive, and also encouraging...we had a great team."



Supporting Families

Advocacy, support groups

Raising a young child with special needs presents both joys and challenges. Alaska's ILP believes supporting the family is a critical component to supporting the child's development.

Alaska's Infant Learning Programs endeavor to:

- Ensure families feel respected and in control of their child's participation in the Infant Learning Program
- Educate families about the unique developmental steps they can expect their child to move through
- Teach families specific skills and techniques to promote their child's development
- Assist families to develop a strong support system including: extended family, neighbors, other families with special needs children and community resources
- Support families to become effective, life-long advocates for their children

As a child enters each new learning opportunity, the family will need to advocate and educate on behalf of their child.

Research shows that family education and support can directly reduce the incidence of child abuse.

Families will guide their children through a lifetime of growth and learning. All parents benefit from a strong network of support, especially parents raising children with special needs.

Taking the Next Step

When a child reaches his or her third birthday, or no longer needs early intervention services, it is time for the child to transition out of the Infant Learning Program.

Most children will continue to receive services at home or in a preschool setting. Great care is taken to plan for a graceful and effective transition. Transition meetings will bring the family together with the child's current and future service providers to plan for the child's continued growth and development.

Reasons for Leaving ILP

36%	Turned Age 3 (Part B Eligible)	307
14%	Attempts to Contact Unsuccessful	112
14%	Withdrawal by Parent/Guardian	109
12%	Completion of IFSP Prior to Age 3	108
8%	Turned Age 3, (Part B Elig Not Deter)	73
7%	Moved Out of State	64
5%	Not Part B Eligible, Exit No Referrals	40
3%	Not Part B Eligible, Exit Other Program	26
1%	Deceased	6

Where do children go after ILP?

42%	Home	366
36%	Preschool Special Education	308
9%	Child Care/Preschool	76
6%	Other Settings	52
4%	Head Start	37
2%	Outpatient Therapy	19
1%	Transfer to Another ILP in Alaska	6

Jonah moved from his Infant Learning Program into a private preschool. "The transition phase was rough." Kama answers honestly, "ILP was used to handing families off to the school district." (School districts often provide preschool for children with special needs). "Jonah's preschool did not have information at hand; it was mostly me providing that. His physical therapist did attend one session to help him on the playground." Jonah recently completed his first preschool year. Kama reports that Jonah loves school and learning.





Jonah has grown into a boy who “loves school and being a big brother, as long as his sister doesn’t play with his toys,” Kama shares. “He has exceeded most all of the ‘unwritten’ and written

expectations since his birth. He officially graduated from speech and continues to get stronger each month in his weak areas. I have to believe that his early intervention played a huge role in his development. I know it did, I can’t imagine not receiving those services.”

Celebrating Success

Early Intervention: A Powerful Investment

Most children enrolled in an Infant Learning Program measurably improved their functioning to levels nearer their same aged peers:

- 79% of enrolled children improved functioning in the area of positive social-emotional skills.
- 83% of enrolled children improved functioning in the area of acquisition and use of knowledge and skills (including early language/communication).
- 79% of enrolled children improved functioning in the area of using appropriate behaviors to meet their needs.
 - Reducing the need for special education services provided by school districts
 - Reducing the incidence of grade retention, class disruption, teen pregnancy
 - Reducing the incidence of child abuse
 - Increasing independence and reducing the need for institutionalization
 - Increasing families’ skills and confidence to support their child’s growth
 - Increasing potential contribution to society



Progress Data for Children Exiting 2008-2009		
Positive Social Emotional Skills: Including Social Relationships	Number of Children	Percentage of Children
Did Not Improve Functioning	5	2%
Improved Functioning: Not Sufficient to move nearer same aged peers	46	19%
Improved Functioning: Nearer same aged peers, but did not reach	51	21%
Improved Functioning: Reached level comparable to same aged peers	53	22%
Maintained Functioning: At level comparable to same aged peers	89	36%

Data Source: Part C State Annual Performance Report FFY 2008 (OMB NO: 1820-0578/
Expiration Date: 11/30/2012

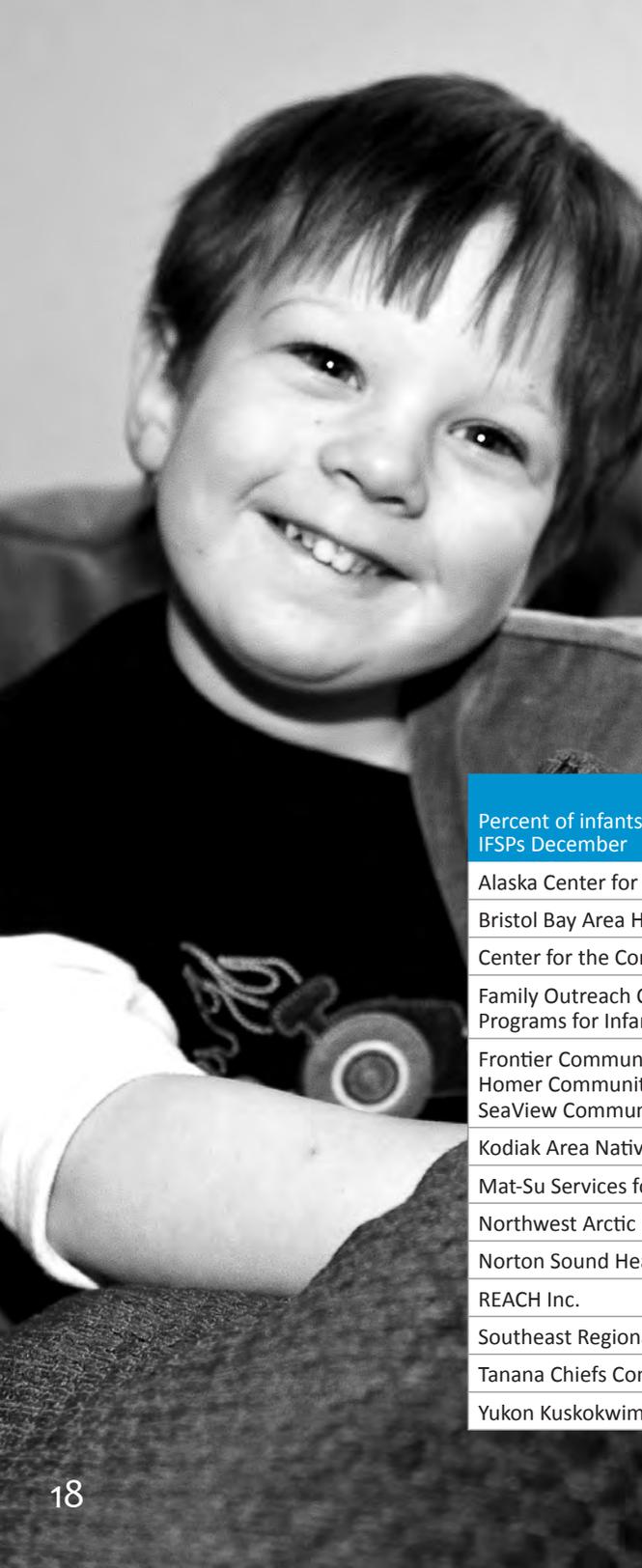
Progress Data for Children Exiting 2008-2009		
Acquisition and Use of Knowledge and Skills: Including Early Language/Communication	Number of Children	Percentage of Children
Did Not Improve Functioning	3	1%
Improved Functioning: Not Sufficient to move nearer same aged peers	39	16%
Improved Functioning: Nearer same aged peers, but did not reach	63	26%
Improved Functioning: Reached level comparable to same aged peers	83	34%
Maintained Functioning: At level comparable to same aged peers	56	23%

Data Source: Part C State Annual Performance Report FFY 2008 (OMB NO: 1820-0578/Expiration Date: 11/30/2012

Progress Data for Children Exiting 2008-2009		
Use of Appropriate Behavior To Meet Their Needs	Number of Children	Percentage of Children
Did Not Improve Functioning	6	2%
Improved Functioning: Not Sufficient to move nearer same aged peers	46	19%
Improved Functioning: Nearer same aged peers, but did not reach	58	24%
Improved Functioning: Reached level comparable to same aged peers	85	35%
Maintained Functioning: At level comparable to same aged peers	49	20%

Data Source: Part C State Annual Performance Report FFY 2008 (OMB NO: 1820-0578/Expiration Date: 11/30/2012





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Collaboration

Partners in Supporting Families

Alaska’s Infant Learning Program is grateful to the many partners who join together to serve Alaska’s children with special needs: the children and their families, regional grantee agencies, health care providers, early intervention service providers, and the communities that support them.

Alaska’s Infant Learning Program is administered by Alaska Department of Health and Social Services, Office of Children’s Services.

Percent of infants and toddlers enrolled birth to 3 with IFSPs December	Community	Percent Enrolled
Alaska Center for Children and Adults	Fairbanks/Barrow/Copper River	1.7%
Bristol Bay Area Health Corporation	Dillingham	2.8%
Center for the Community	Sitka	3.6%
Family Outreach Center for Understanding Special Needs Programs for Infants & Children	Eagle River/Chugiak/Cordova/Anchorage	1.7%
Frontier Community Services Homer Community Services SeaView Community Services	Kenai/Soldotna Homer Seward	1.9%
Kodiak Area Native Association	Kodiak	1.3%
Mat-Su Services for Children and Adults	Palmer/Wasilla	1.6%
Northwest Arctic Borough School District	Kotzebue	0.4%
Norton Sound Health Corporation	Nome	2.3%
REACH Inc.	Juneau/Haines	2.9%
Southeast Regional Resource Center	Aleutian/Pribilof Islands	2.5%
Tanana Chiefs Conference	Interior Alaska	1.3%
Yukon Kuskokwim Health Corporation	Bethel	1.7%

Data Source: Alaska Part C Data System (December 1 Child Count)

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Infant Learning Programs Throughout Alaska

Alaska's Infant Learning Program partners with the many agencies as regional grantees.





Sean Parnell, *Governor*
State of Alaska

William J. Streur, *Commissioner*
Department of Health and Social Services

Christy Lawton, *Director*
Office of Children's Services

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This publication was released by the State of Alaska, Department of Health & Social Services, Office of Children's Services, produced at a cost of \$2.62 per copy. Printed in Anchorage, statewide distribution. Limited numbers were printed in order to save the State funds. This report is available on the Web: www.hss.state.ak.us/ocs/InfantLearning/.

The Alaska Infant Learning Program
is administered by the Alaska Department of Health & Social Services, Office of Children's Services



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Collaboration

Alaska Infant Learning Program

This report, historical data and other publications available at hss.state.ak.us/ocs/InfantLearning

Call toll free in Alaska: 1 (877) HSS-FMLY (477-3659); In Anchorage 269-8442

INFANT LEARNING PROGRAMS THROUGHOUT ALASKA



The Alaska Infant Learning Program offers developmental services to families of children birth to 3. If you have concerns about your child's development make a referral to your local Infant Learning Program. Our Mission is to promote positive development and improved outcomes for Alaska's children birth to 3 by creating a culturally responsive, comprehensive and accessible service delivery system that links service providers, empowers families and engages communities.

