



Early Intervention: A Powerful Investment

Alaska Infant Learning Program 2013



A special thank you to Karli and Ernesto Lopez for opening their home and family to us. All of the beautiful images in this book were taken of the family in Anchorage, Alaska.



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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 caregiving 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



Karli's Story

Everything about the birth of Karli Lopez's first baby was a surprise. First, the timing: Little Corbin arrived four weeks early and, as Karli recalls, "he came very fast."

Next, soon after birth the baby received an unexpected diagnosis. Doctors suspected Corbin had Down syndrome, a possibility that had never come up during Karli's pregnancy.

Continued on page 4



“Everything changed from that point forward,” she says.

When they left the hospital with Corbin, Karli and her husband received a giant packet of informational papers and brochures. A social worker from the hospital went through the pile once with Karli, but she found the whole process overwhelming. Karli and her husband knew they had to fill out some of the forms to have the baby certified as disabled, but what that meant and how to do it was another story.

“The ‘disabled’ label really threw me for a loop,” Karli remembers. “Here I am, sitting in the NICU, trying to feed my tiny 5-pound baby, and I am given this stack of paperwork and referrals: Call here, these people will call you, here’s this, but you need to apply for SSI first, but before that, you’ll need to have him certified as disabled ...”

“Wait,” she remembers thinking. “WHAT?”

‘Madness’

By the time Karli got home, she had her referrals and contacts and agency brochures, but no recollection of who she needed to call or when.

“All of that information, it was just madness. My brain stopped processing instructions when she told me my little not-even-1-week-old baby would need to be certified as ‘disabled’ to qualify for some services. I didn’t want to say what he could and couldn’t do so early!”

Karli managed to sort it out over time, she says. “But wow. That’s not something you should tell a new mom.”

Plus, there was the matter of letting go of the way Karli and her husband thought things were going to be with their first child.

“There’s a grieving process you go through, grieving the loss of the child you thought you were going to have,” Karli says.

“It gets better,” she learned, “even though you don’t think it will.”

But not right away.

“You can get to a very dark place and that’s OK. You have to go through that process to get to the point of acceptance.”

Reaching out

Adjusting to their new normal was something Karli and her husband did alone — at first.

But less than a month after Corbin was born, a representative from PIC (Programs for Infants and Children, part of the state of Alaska’s Early Intervention/ Infant Learning Program) came to visit.

That first visit clarified things for Karli and let her see just how much help was available for families like hers.

Learning what PIC could do helped his parents set Corbin on a healthy path and inspired Karli to reach out even more. Soon she was connected to an entire network of support. PIC continued to supply knowledge and know-how and Karli learned about other resources of the Early Learning Program.

“They helped us apply for TEFRA (Medicaid), so we don’t have to worry about the copays for all of his medical care,” Karli says of PIC and others. “And when it was time, they referred us to different therapies for Corbin.”

She even made new friends.

“It’s hard to meet other parents” coping with similar challenges, Karli says. “It’s so nice to make those connections when you’re ready to make them. That’s something else that Early Intervention helped with.”

Becoming an advocate

Once Karli was on her own path of receiving necessary information and support, she began to do the same for others in similar situations.

“Not enough parents of little ones are out there doing advocacy work,” she says.

So Karli began helping wherever she saw a need.

“She really has a lot going on,” says Amy Simpson, who worked with Karli at PIC. “But now she’s someone who’s really involved. She’s decided she’s going to make a difference for all children with disabilities.”

Among the things Karli has going on is serving on several

statewide boards and committees — Stone Soup Group and the Governor’s Council on Disabilities, among others — not to mention her new baby Mia.

‘Exhausted but good’

These days Karli describes herself as “exhausted but good.” And Corbin, who turned out to be her “easy baby” compared to the equally beautiful but more demanding Mia, is too.

“He’s been a very happy and healthy baby,” Karli says of her 2-year-old. “He’s so mellow and independent.”

And even though it took Corbin a while to start walking, his mom didn’t rush him. The hard-won knowledge Karli has gained over the past couple of years, with the help of PIC and other resources, has taught her to relax and trust.

“He’ll do things in his own time,” she says.

PIC’s Simpson knows both Corbin and Karli are going to be just fine. And more than that, Karli is seeing to it that other parents and children with challenges will be too.

“I’m just in awe of her,” Amy says, “of her energy and her willingness to jump in and make a difference for others.”



Gains during the **first three**
years are critical and will continue
to benefit children ...

throughout their lifetime



Educating Alaska

Why is early intervention critical?

The early years of a child's life are critically important: From birth through age 3, rapid learning and brain development take place. During this time children form the foundation for future learning, problem solving, relationship-building and independence. When children experience a developmental delay, early intervention can help guide them through this extraordinary time of growth to maximize their development.

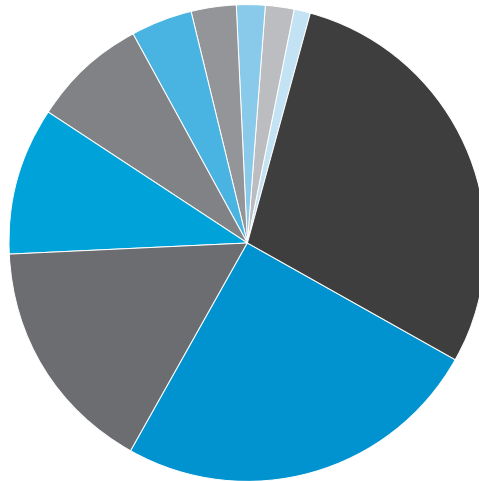
Statewide outreach efforts educate families, providers and the general public about early intervention services available to children ages birth to 3 including:

- Developmental screenings and evaluations
- Hearing and vision screening
- Family service coordination
- Early education services



How did families learn about the Infant Learning Program?

- ♥ 29% Physician
- ♥ 25% Other
- ♥ 16% EI/ILP
- ♥ 10% Child Find Publicity
- ♥ 8% Friend/Family Member
- ♥ 4% WIC
- ♥ 3% Clinic/Hospital
- ♥ 2% Child Care/Preschool
- ♥ 2% CPS
- ♥ 1% School District



- Play groups, support groups, and social services
- Developmental, physical, occupational and speech language therapy
- Early childhood mental health services

Children Referred to EI/ILP

*Fiscal Year	Referrals
2006	2331
2007	2557
2008	2657
2009	2503
2010	2548
2011	2668
2012	3008
2013	2643

Service Summary ILP FY13 (Analyst Reports)

Children screened by EI/ILP

*Fiscal Year	Referrals
2006	1185
2007	1220
2008	1316
2009	1230
2010	1149
2011	1287
2012	1063
2013	923

Screened source: Service Summary FY13 (Analyst Reports)

Children newly evaluated by EI/ILP

*Fiscal Year	Referrals
2006	1078
2007	1152
2008	1278
2009	1120
2010	1138
2011	1289
2012	1786
2013	2055

Evaluated source: Service Summary FY13 (Analyst Reports)

Children enrolled by EI/ILP

*Fiscal Year	Referrals
2006	1777
2007	1834
2008	1892
2009	1831
2010	1788
2011	1873
2012	1952
2013	1923

Enrolled source: EI/ILP Data Compliance Report FY11 (Analyst Reports)

* Fiscal year begins July 1 and ends June 30 of the year noted



Connecting with families

The earlier the referral is made, the more successful the outcome

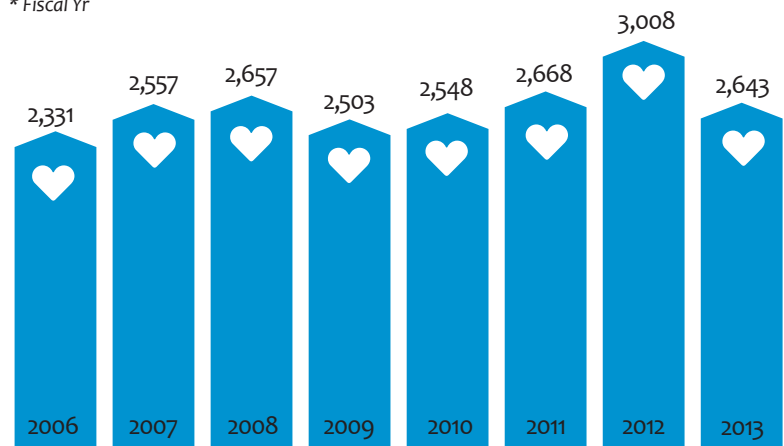
Children and their families are referred to regional Infant Learning Programs via fax, phone and email. Most referrals are made by those who know the child best: their families or health care provider.

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

Referrals to the Infant Learning Program exceeded 2,600 in FY2013.

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 FY13 (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)

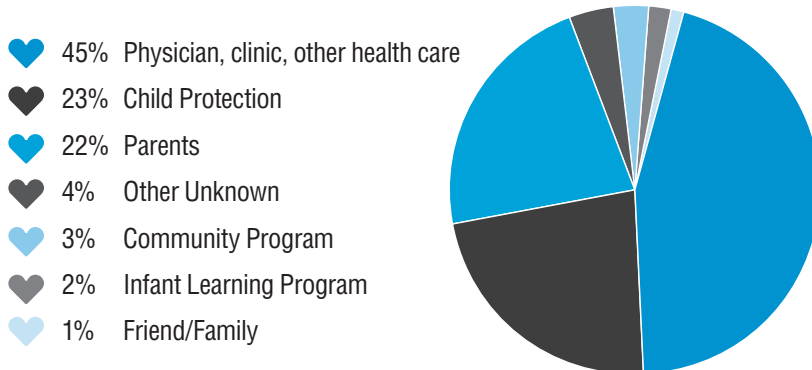
**Referrals to the Infant Learning Program can be made
by contacting the state office:**

1-877-HSS-FMLY (477-3659)

**in Anchorage
269-8442**

or by contacting a regional provider:
www.earlyintervention.alaska.gov

Referral Source





Intake

Assessing growth and 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.

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, he or she may be eligible for early intervention services.

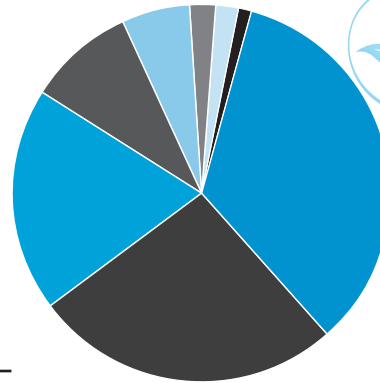
Age at referral (enrolled children)



Average age at referral: 15 months

Referral by ethnic background

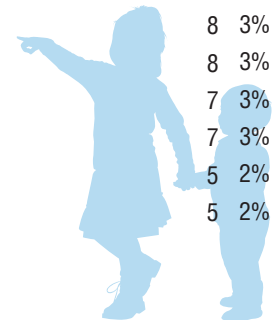
♥	White	897	34%
♥	American Indian or Alaska Native	698	26%
♥	Unknown	514	19%
♥	Two or more races	228	9%
♥	Hispanic/Latino	146	6%
♥	Black or African American	62	2%
♥	Asian	59	2%
♥	Native Hawaiian or Other Pacific Islander	39	1%
Total		2,643	100%



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	40	17%
Hearing Impairment, Significant/Progressive	36	16%
Vision Impairment, Significant/Progressive	24	10%
Heart Disease, Congenital	21	9%
Cleft Palate with or without Cleft Lip	20	9%
Complex Seizure Disorder	19	8%
Cerebral Palsy	17	7%
Hydrocephaly	13	6%
Autism	8	3%
Microcephaly	8	3%
Bronchopulmonary Dysplasia (BPD)	7	3%
Cytomegalovirus (CMV), Congenital	7	3%
Fetal Alcohol Syndrome (FAS)	5	2%
Spina Bifida	5	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 Program embrace each family's unique capacity to support and promote their child's development.

**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 his or her goals.



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 support as the child works toward 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.





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 Program strives to: *Families will guide*

- 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, lifelong advocates for their children

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.

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.

Taking the next step

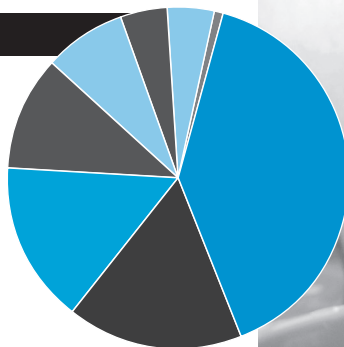
When a child reaches his or her third birthday, or no longer needs early intervention services, it is time for the child to transition out of the Infant Learning Program.

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

♥ Part B eligible	36%	326
♥ Attempts to contact unsuccessful	15%	136
♥ Withdrawal by parent/guardian	14%	126
♥ Completion of IFSP prior to age 3	10%	89
♥ Part B eligibility not determined	10%	64
♥ Not Part B eligible, exit to other program	7%	37
♥ Not Part B eligible, exit with no referrals	4%	36
♥ Unknown	4%	5

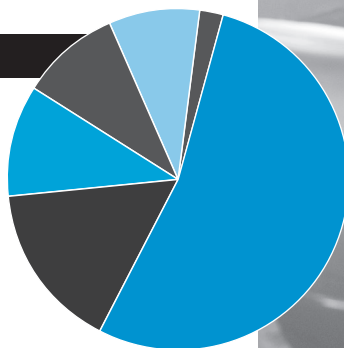
Total 909



Where do children go after ILP?

♥ Preschool Special Education	41%	298
♥ Other Setting	35%	88
♥ Unknown	10%	59
♥ Head Start	6%	53
♥ Child Care/Preschool	6%	48
♥ Outpatient Therapy	1%	12

Total 909





Celebrating success

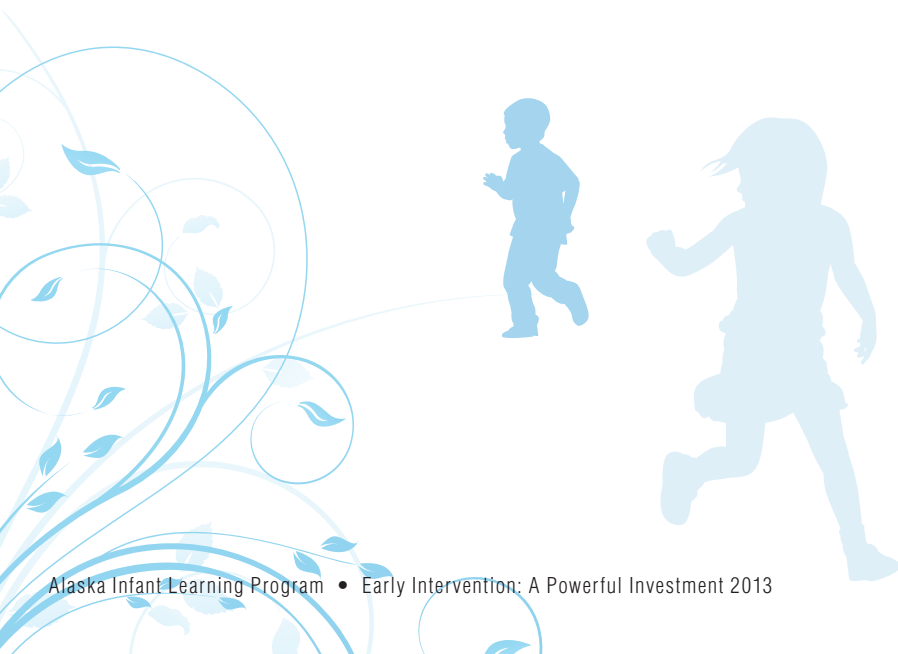
Alaska Early Intervention/Infant Learning Program measures child outcomes by comparing how children are functioning before and after receiving early intervention services. The child outcomes focus on children’s abilities to be successful in everyday activities and routines, and skills children need to be successful in future school settings. Three outcome areas are measured:

- Children have positive social relationships.
- Children acquire and use knowledge and skills.
- Children take appropriate action to meet their needs.

Percentage of Part C Children falling in each of five OSEP Categories FY13 7/1/2012-6/30/2013			
OSEP Improvement Category	Emotional	Knowledge	Action
Percent			
Number of Children	487	487	487
e. Children who maintained functioning at a level comparable to same-age peers	26.49%	15.81%	18.28%
d. Children who improved functioning to reach a level comparable to same-age peers	27.31%	30.39%	30.60%
c. Children who improved functioning to a level nearer to same-age peers but did not reach it	20.53%	26.28%	24.85%
b. Children who improved functioning but not sufficient to move nearer to functioning comparable to same-age peers	25.26%	27.31%	25.87%
a. Children who did not improve functioning	0.41%	0.21%	0.41%



Summary Statements for Part C Children FY13 7/1/2012-6/30/2013			
Summary Statement 1	Emotional	Knowledge	Action
Of those children who entered the program below age expectations in the Outcome Area, the percent who substantially increased their rate of growth by the time they exit the program.	64.08% 233 of 358	67.32% 276 of 410	67.84% 270 of 398
Summary Statement 2			
The percent of children who are functioning within age expectations in the Outcome Area by the time they exit the program.	53.80% 262 of 487	46.20% 225 of 487	48.47% 238 of 487



Percent of infants and toddlers enrolled birth to 3 with Individualized Family Service Plans (IFSPs) December 1, 2012		Community	%CC Pop Enrolled 0-1	%CC Pop Enrolled 0-3
Alaska Center for Children and Adults	ACC	Fairbanks, Copper River, Delta Junction, North Slope Borough	2.2%	3.0%
Bristol Bay Area Health Corporation	BBA	Dillingham, Bristol Bay, Lake and Peninsula Region	7.1%	5.7%
Center for the Community	CCK	Sitka, Kake, Angoon	2.3%	3.1%
Community Connections Ketchikan	CFC	Ketchikan, Prince of Wales Island and Metlakatla	0.8%	3.6%
FOCUS Inc. Program for Infants & Children	FOC/PIC	Eagle River, Chugiak, Cordova, Valdez Anchorage, Whittier, Girdwood	1.7%	2.2%
Frontier Community Services Homer Community Services SeaView Community Services	FCS/SCS	Soldotna, Kenai, Sterling, Nikiski, Tyonek Homer, Anchor Point, Nikolaevsk, Ninilchik, Clam Gulch, Port Graham, Nanwalek, Seldovia, Vosnesanka, Kachemak Selo, Razdolna Seward, Hope, Moose Pass	2.2%	3.2%
Kodiak Area Native Association	KAN	Kodiak City, USCG Support Center Kodiak, Kodiak road system, villages: Akhiok, Karluk, Larsen Bay, Old Harbor, Ouzinkie, Port Lions	1.3%	1.8%
Mat-Su Services for Children and Adults	MSU	Big Lake, Buffalo/Soapstone, Butte, Chase, Chickaloon, Farm Loop, Fishhook, Gateway, Glacier View, Houston, Knik-Fairview, Knik River, Lake Louise, Lakes, Lazy Mountain, Meadow Lakes, Palmer, Petersburg, Point MacKenzie, Skwentna, Susitna, Sutton-Alpine, Talkeetna, Tanaina, Trapper Creek, Wasilla, Willow	1.3%	1.5%
Northwest Arctic Borough School District	NWA	Kotzebue, Ambler, Buckland, Deering, Kiana, Kivalina, Kobuk, Noatak, Noorvik, Selawik, Shungnak, and Point Hope	1.3%	1.6%
Norton Sound Health Corporation	NSH	Nome, Brevig Mission, Diomedea, Elim, Gambell, St Michael, Savoonga, Shishmaref, Stebbins, Teller, Wales, White Mountain	0.8%	1.6%
REACH Inc.	REA	Juneau, Haines, Skagway, Hoonah, Yakutat, Gustavus, Pelican, Tenakee Springs. Our Petersburg office serves Petersburg and Wrangell	1.5%	2.7%
Southeast Regional Resource Center		Aleutian, Pribilof Islands	0.4%	2.6%
Tanana Chiefs Conference	TCC	Allakaket, Bettles, Hughes, Kaktovik, Manley, Minot, Nenana, Rampart, Stevens Village, Tanana, Arctic Village, Beaver, Ft. Yukon, Chalkyitsik, Circle, Venetie, Dot Lake, Eagle, Healy, Northway, Tanacross, Tetlin, Tok, Metasta, Galena, Hulsia, Kaltag, Koyukuk, Nulato, Ruby, McGrath, Nikolai, Takotna, Anvik, Grayling, Holy Cross, Shageluk	3.2%	3.6%
Yukon Kuskokwim Health Corporation	YKH	Akiachak, Akiak, Alakanuk, Aniak, Anvik, Atmuauuluak, Chefornak, Chevak, Chuathbaluk, Crooked Creek, Eek, Emmonak, Grayling, Holy Cross, Hooper Bay, Kasigluk, Kipnuk, Kongiganank, Kotlik, Kwethluk, Kwigillingok, Lime Village, Lower Kalskag, Marshall, Mekoryuk, Mountain Village, Napaskiak, Newtok, Nightmute, Nunapitchuk, Oscarville, Pilot Station, Pitka's Point, Quinhagak, Russian Mission, St. Mary's, Scammon Bay, Shageluk, Sheldon's Point, Sleetmute, Stony River, Toksook Bay, Tuluksak, Tuntutuliak, Tununak, Upper Kalskag	1.9%	1.8%
Statewide Average			1.9%	2.5%
Statewide Target			1.5%	2.6%

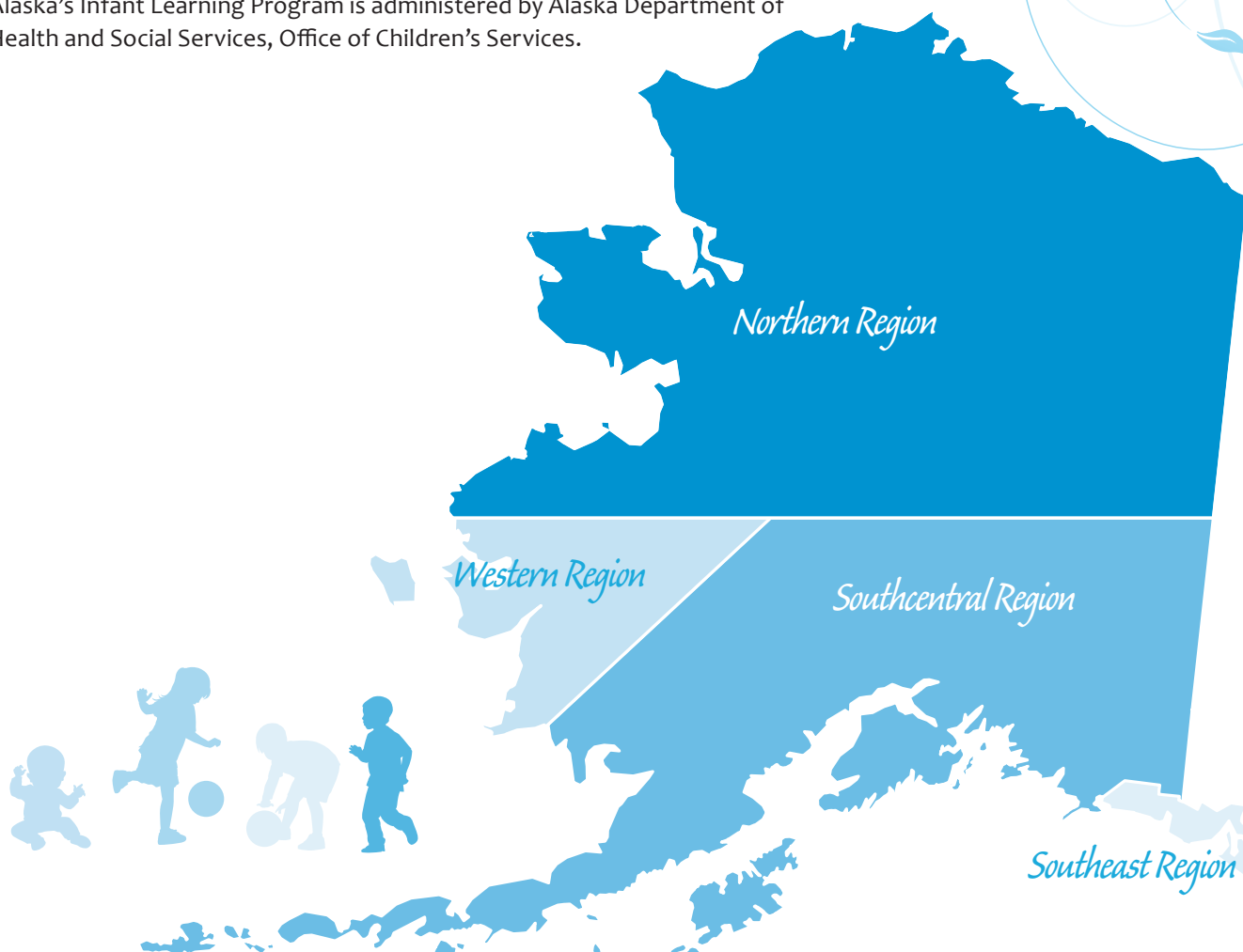
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Collaboration

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.





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January 2014

*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
www.earlyintervention.alaska.gov

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twitter.com/AlaskaILP/

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, contact 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.

