

A GUIDE FOR PARENTS OF INFANTS AND TODDLERS

CHILDREN WITH COMPLEX MEDICAL NEEDS

Many children with complex medical needs will deal with significant or prolonged medical intervention as a result of conditions and diseases that may once have been life threatening, but which medical discoveries have enabled us to treat more successfully. Children with cardiac anomalies, chronic lung disease, birth defects, and genetic disorders are living longer than ever before.

Often a family's financial, emotional and psychological resources have already been tested and stretched by the time they obtain a diagnosis or diagnoses. Families of children with complex medical needs are likely to require assistance in coordinating medical care, learning what services they are entitled to and what community supports are available. While some interventions are short-term, others may continue into adulthood.

What Is Considered a Complex Medical Need?

Children with complex medical needs are children who have a critical or chronic condition for at least a year. These children may require prolonged hospital stays or ongoing medical treatments and monitoring. They may require the use of medical technology, such as ventilators and oxygen.

Complex medical needs can include but are not limited to:

- Mechanical ventilation (respirator) for at least part of each day
- Intravenous nutrition
- Tracheotomy support such as suctioning, oxygen, or tube feeding
- Cardio-respiratory monitoring, kidney dialysis, or ostomy care
- Multiple medications

Who is Eligible for EI/ILP Services?

A child with a confirmed medical diagnosis that is expected to lead to a developmental delay is automatically eligible for services from Alaska's Early Intervention/Infant Learning Program (EI/ILP). Other children with complex medical needs will be evaluated to determine eligibility for services.

How Can EI/ILP Help?

EI/ILP offers support, assistance, and advice to families on how to best meet their child's unique needs, including access to a wide variety of information and resources.

EI/ILP supports a team approach for providing evidence-based, family centered services that take into account the child's and families unique strengths and needs. By continuing to listen to the family throughout the process, the intervention techniques can be modified on a continued basis to meet the child's and family's needs.



This parent guide is based on the *Service Delivery Guidelines for Alaska: Children with Complex Medical Needs*. The complete guidelines are available online at earlyintervention.alaska.gov

Providing early intervention services within the natural environment in which the child lives will provide the best circumstances for learning.

How Much Intervention Should My Child Receive?

Decisions about service are made by the early intervention team including the family. The team will consider stamina and medical concerns, recommendations from the child's health care providers, information from evaluations and the priorities and concerns of the family when deciding what, when and how often intervention services will take place.

A child with complex medical needs who is enrolled in EI/ILP should receive any services that the team feels are developmentally appropriate and which will lead to developmental benefit. For some children, this may involve a higher frequency of visits and intervention, while other children may have a very low tolerance for intervention and may only receive one or two visits a month.

Strategies may include direct, hands on therapies which demonstrate techniques the family can employ when the early intervention team is not present. Direct therapy should be paired with coaching and supporting the family in meeting their child's developmental needs within the context of daily routines.

What Does Early Intervention for Complex Medical Needs Look Like?

EI/ILP can help parents access a range of intervention services and family supports:

- **Coordinating all services across agency lines.** For a child with complex needs this could include Medicaid and insurance services, services through clinics, and specialty care providers.
- **Serving as a single point of contact in helping the parents to obtain the**

services and assistance they need.

The service coordinator can provide resource information and help the parents navigate the service system.

- **Assisting parents of eligible children in gaining access to services.** Services could include accessible child care, specialty services, family support, health financing, or medical vendors.
- **Continuously seeking the appropriate services and situations necessary to benefit the development of each child.** As the child's medical and developmental needs change, additional services may be needed. For example, if a child's needs change following hospitalization, the services like family supports, home nursing, or other specialists may be necessary.
- **Facilitating the development of a transition plan for services after age three.** This may include linkage with appropriate medical and emergency personnel, planning for scheduling and accommodations, and development of an individualized health care plan.

For More Information

Alaska Early Intervention/ Infant Learning Program

earlyintervention.alaska.gov
(877) HSS-FMLY. (907) 269-8442.0
TT Relay (800) 770-TYPE

Assistive Technology of Alaska/ AK Trading Post

www.atlaak.org
(800) 723-2852(ATLA). (907) 563-2599.
TTY (907) 561-2592

Stone Soup Group: Family-to-Family Health Information Center

www.stonesoupgroup.org
(877) 786-7327. (907) 561-3701

Family Voices

www.familyvoices.org
(888) 835-5669