



Complex Medical Needs

Service Delivery Guidelines

Intervention guidance for service providers and families of young children
with complex medical needs



State of Alaska • Department of Health & Social Services • Office of Children's Services
Alaska Early Intervention • Infant Learning Program

ALASKA EARLY INTERVENTION / INFANT LEARNING PROGRAM

Service Delivery Guidelines

CHILDREN WITH COMPLEX MEDICAL NEEDS

EARLY INTERVENTION GUIDANCE FOR SERVICE PROVIDERS AND FAMILIES
OF YOUNG CHILDREN WITH COMPLEX MEDICAL NEEDS

JUNE 2011



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

–Alaska Early Intervention/ Infant Learning Program

CHILDREN WITH COMPLEX MEDICAL NEEDS

Alaska Early Intervention/Infant Learning Program

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INTRODUCTION

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. While some interventions are short-term, others may continue into adulthood.

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. Often a family's financial, emotional and psychological resources have already been tested and stretched by the time they obtain a diagnosis or diagnoses.

Providers of early intervention and infant learning services work closely with each family to support them and build capacity to take on the additional tasks and roles of caring for a child with complex medical needs. Even after they become confident in these new roles, the family may need help to see how much they have accomplished, what skills they have developed, and to plan for the future. Acknowledging these new skills is important because parenting a child with complex medical needs can be an overwhelming and emotional process.

Providing early intervention services in an area as large as Alaska is challenging. Medical evaluation, treatments and therapies may require a family to travel far from familiar surroundings, cultures and traditions. It may also require parents or caregivers to leave a child in the hands of medical professionals while they return home to attend to other priorities such as children, work, etc. This makes the role of Alaska early intervention providers even more significant, coordinating between the family, medical professionals, and development experts to make certain the family is getting the information and support they need to be the best advocates for their child.

PURPOSE OF THE GUIDELINES

The purpose of these service delivery guidelines is to provide parents and service providers with an overview of the best practices for early intervention and support for children with complex medical needs in Alaska. These include those approaches shown to result in the best outcomes for children from birth to three.

While most of the recommended practices in the guidelines do not carry the force of

regulation, they are intended to guide parents and early intervention providers in making informed decisions about the most appropriate assessment procedures and intervention practices.

Not all practices will be appropriate in all cases. The guidelines are intended to be flexible, not prescriptive or limiting, and to set the tone for the family to be an instrumental part of early intervention. An Individualized Family Service Plan (IFSP) should be developed for each child based on his or her particular needs, the resources available, and input from the family and the early intervention provider or team.

The guidelines also aim to increase understanding of the needs of families with young children with complex medical needs in Alaska and the many resources available to them.

EARLY INTERVENTION SERVICES IN ALASKA

Early intervention services are federally mandated under Part C of the Individuals with Disabilities Education Act (IDEA), a federal law passed in 1986. IDEA requires states to ensure that young children who may have disabilities or developmental delays receive an evaluation to identify the potential need for early intervention.

Alaska's early intervention services are administered by the Department of Health and Social Services, Office of Children's Services, Early Intervention/Infant Learning Program (EI/ILP). They include a flexible array of services for children birth to 3 years of age who experience disabilities or developmental delays, or who are at risk for developmental delays.

EI/ILP partners with grantees to provide services directly to families at a local and regional level. In 2010, services were provided to children throughout the state by approximately 115 highly qualified staff employed within 17 regional grantee agencies. Programs vary widely by staff and region size. Service may include:

- Developmental screening and evaluation
- Individualized Family Service Plans to outline goals for the family and the child
- Child development information
- Home visits
- Infant mental health services
- Physical, occupational or speech therapy
- Specialized equipment
- Referrals to other needed services

EI/ILP APPROACH TO SERVICE DELIVERY

Because no single professional can meet all the needs of a child with developmental delays, EI/ILP encourages the use of a *transdisciplinary* approach, with a primary service provider assigned to each child and a team of professionals from different disciplines who share their expertise with the parents and other team members as needed to support the child's progress and participation in daily activities in the family's home and community.

In addition to taking a team approach to service delivery, the core values of the EI/ILP support services that are *evidence-based* and *family-centered*. By listening to the family throughout the process, intervention techniques can be modified on a continual basis to match the child's and family's unique needs and strengths.

MORE INFORMATION

More information and resources for early intervention services in Alaska are available at the EI/ILP website. The site includes a statewide directory of EI/ILP programs that cover all regions of Alaska.

 www.earlyintervention.alaska.gov

UNDERSTANDING COMPLEX MEDICAL NEEDS

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

These guidelines describe tools and services to assist families of children with such needs. The tools provided in Appendix 2 should be used to determine the level of complexity of care required for a child, not the complexity of the diagnosis or condition, in order to assist families and providers in meeting the specific care needs for a child. Specific scores on the index should not be used as definitive “qualifiers” for a type or intensity of service.

WHO DELIVERS INTERVENTION SERVICES FOR YOUNG CHILDREN WITH COMPLEX MEDICAL NEEDS?

THE ROLE OF HEALTH CARE PROVIDERS IN EARLY INTERVENTION

A child’s primary health care provider can play an important part in the delivery of early intervention services to children who have complex medical needs. This role may include referral to needed services, participation in the development of the child’s IFSP, and assistance with coordinating changes in the child’s care. Ideally for children with complex medical needs enrolled in EI/ILP programs, linkage to a strong *medical home* with a care coordination component allows the family and EI/ILP service coordinator to partner with a child’s health care provider, who can then assist in many of the activities, roles, and concerns outlined in this guideline.

SERVICE DELIVERY IN A MEDICAL HOME MODEL OF CARE

A medical home model of primary care promotes partnerships between health care providers, families, EI/ILP providers and other community agencies to assure that all of the medical and non-medical needs of the child are met. Through a medical home model of care, families and early intervention providers can access coordinated health care that places the child and family at the center of care.

A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective (1). A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. The medical home becomes the place where children receive ongoing, routine health care in their community as well as coordination with a broad range of other specialty providers and related services. Ideally, a medical home provides after hours and weekend access to medical consultation about the child.

What Can Families Expect from their Medical Home?

The child and family can expect to regularly see the same primary care provider and office staff who know them. They can expect their primary care provider to be a partner with them in coordinating care for their child. This partnership should be based on mutual trust and respect, including respect for the family's cultural and religious beliefs.

The family should feel supported in finding resources for all stages of growth and development of their child. Some of those resources may include being connected to information and family support organizations. The medical home partnership promotes health and quality of life as the child grows and develops into an adult.

How Can EI/ILP Help?

"I really needed someone to help me organize all the specialists, the appointments, the paperwork. I felt like I had to keep telling my story over and over."

The EI/ILP family service coordinator works with the medical home care coordinator to ensure access to appropriate care and support. The EI/ILP service coordinator can assist families who have children with complex medical needs to find and link with their medical home. If care coordination is available through the primary care provider, then the EI/ILP service coordinator can assist the family in identifying the needs and issues that should be included in a medical home care coordination plan.

Not every health care facility will offer care coordination. In those settings, the role of the EI/ILP service coordinator is more crucial in ensuring access to appropriate supports. It is important for the service coordinator to assist families in building partnerships with their primary care providers. This can include coaching families prior to a medical visit and even accompanying families to appointments so they have an "extra set of ears" when they are trying to take in new information.

Parents may find it helpful to take notes during appointments in order to capture all the information given. The EI/ILP service coordinator can be of assistance in helping the family access needed information about their child's diagnosis, treatment and equipment needs. The service coordinator can also help ensure that families concerns are understood and addressed at each appointment.

In summary, there are many ways EI/ILP can help support families as they travel through the maze of services and programs designed to help children with complex medical needs:

- Interpreting evaluation results for the family
- Helping the family find answers to questions they may have about their child and their child's medical condition
- Assisting the family in setting priorities for their child and family
- Helping coordinate services and information from different sources including medical information and services
- Assisting families in connecting with other families who may have a child with similar needs or diagnosis
- Helping families talk with other specialists involved such as medical professionals and childcare staff
- Offering information on useful state and community resources

GUIDELINES FOR FIRST CONTACT WITH FAMILIES

In most instances, children who have complex needs will be referred to EI/ILP by their parents, primary care providers, hospital staff or other providers shortly after the diagnosis is made. Therefore, the first contact is often at a difficult time for families. During the initial diagnosis and referral, parents may struggle to understand the diagnosis and access a broad array of medical services from a variety of specialists. Parents may face the challenge of incorporating all this new information into their own family, meet the special needs of the child and also meet the other needs and priorities in the family.

In order to support the families through the long road ahead and navigating through a world of specialized medical care, equipment and treatment, the EI/ILP provider should focus on building a strong partnership with the family while providing early intervention services to their child.

This first contact may be difficult for the provider as well. Providers may have had little or no experience with children who have complex medical needs. They may be anxious or intimidated by the care needs of the child. They can minimize these challenges by being well prepared prior to contacting the family.

Although information from a referral form may be all they have available, this may contain diagnostic or other information in the notes section. Whenever possible, EI/ILP providers should get some background information on the diagnosis, any

equipment the child may be using, or other treatments or concerns. When the call is made to the family, the caller should discuss precautions, schedules and time constraints, and any other considerations prior to setting a time for the first visit.

Lastly, families may have had to spend long periods of time with medical professionals and specialty care providers and in hospitals with their child. As they are gaining skills and knowledge about their child's unique medical needs, they may lose the vision of their child as just a child. The interaction modeled at the first contact by EI/ILP staff, and continued throughout the time the child is receiving services can have a lasting impact on the way a family will view their child.

Playing with their child, laughing, and getting to know the personality of the child is just as important as knowing about the medical care. Even though the child may be fragile, parents need to be reassured that these normal interactions, play times and fun are as important as their child's medical care. This allows them to look beyond all the medical care and enjoy their child as a child first.

Tips for Families Building Medical Home Partnership

- Bring a list of questions or concerns to discuss
- Come prepared so you can make the most of your visits
- Consider bringing a support person with you
- Share information on how your child is changing (progressing or regressing)
- Ask about resources that may help your child and family
- Ask about how to get care after hours if needed
- Ask to meet the other staff who will be working with you and your child (nurses, referral coordinator, billing specialist, etc.)
- Share successes

For more medical home information for families, tools, brochures and presentations, go to:
www.medicalhomeinfo.org/tools

ASSESSING CHILDREN WITH COMPLEX MEDICAL NEEDS

DETERMINING ELIGIBILITY FOR SERVICES

A child with a confirmed medical diagnosis that is expected to lead to a developmental delay is automatically eligible for EI/ILP services. Other children with complex medical needs will be evaluated to determine eligibility for services.

The evaluation process includes professionals from at least two different disciplines. Families are the experts on their child's strengths and needs and they provide valuable information regarding the child's medical condition. It is important for the evaluators to have an understanding of the child's medical diagnosis, precautions, and medical needs. They can supplement this information with information the family provides as they discuss parent concerns, diagnostic information, relevant birth history, surgeries, and medications with the family.

In addition to evaluating areas of development, the multi-disciplinary team will need to learn more about:

- The child's prenatal history and birth
- The child's health, current diagnoses and conditions and any information available about those diagnoses and conditions
- Information on the child's developmental history
- The family's priorities and their concerns for their child

The information that a family shares is often very personal. Providers should be aware of the sensitivity of the information and receive it with empathy and understanding. In instances in which the child has been hospitalized for a long time, the family may not have had an opportunity to observe many developmental milestones due to the constraints of a hospital setting. Team members should always check with the family to make sure the timing is good, before making a visit to the hospital or to the family's home.

At the evaluation, information that will be written into the summary should be shared with the family. Families should know that the evaluation is not a test and there is not a pass or fail score. Rather, the information helps the early intervention program staff understand the child's strengths and needs.

SHARING RESULTS WITH THE FAMILY

The team will review results from the evaluation, the information provided by the family about the child's medical history and condition, and any reports received from health care providers to arrive at an eligibility decision.

Once the evaluation is complete and the team is ready to discuss the information, it is important to consider what information will be shared and what supports the family may need when this information is shared with them.

Prior to sharing the evaluation results, the EI/ILP service providers should discuss with the family who they would like to have present, both to hear the information and to support them through this process. They can then plan a time when other family members can be present for support, and as an extra set of ears to absorb the information.

Within the report and when discussing results, it is important to begin with the child's strengths and to discuss the parenting strengths of the family as well. Parents may be pre-occupied with meeting their child's unique and often demanding care needs, and they may lose sight of the fact they have acquired substantial skill in meeting such complicated needs, keeping track of appointments and in managing the demands of the rest of the family.

Many families have stated that hearing the results of an evaluation or assessment is not the most difficult part of the process, but rather it's sharing the news with other family members. If only one caregiver can be present when the evaluation results are shared, try and arrange a time to speak by phone to other family members. Help both parents to think of ways to explain information to other children or other members of their extended family. Brothers and sisters can often feel left out of the process and it is important to answer their questions and give suggestions on how they can be involved.

DEVELOPING AN IFSP

The IFSP is the written plan for providing early intervention services to eligible children and families. The IFSP is developed jointly by the family and the appropriate professionals. The IFSP:

- Is based on a multidisciplinary evaluation and assessment of the child and family
- Has a family directed statement of resources, priorities and concerns
- Includes services necessary to enhance the development of the child and enhance the family's capacity to meet the child's developmental needs
- Includes a plan for transitioning the child to school- and community-based services after age three

IDENTIFYING FAMILY PRIORITIES

“My child has no siblings. She has no one her age to play with. We are always at home where she is medically safe, but being confined to your home is incredibly taxing. We really need more parent-to-parent connection.”

Once a child is determined eligible for EI/ILP services, an assessment of the child and of the family’s priorities, concerns, and resources is completed. This assessment process helps the family identify what outcomes will be addressed in the IFSP and the supports necessary to achieve these outcomes. As part of the IFSP process, it is important to keep in mind that families of children with complex medical needs often feel they have little control over what is happening to their child. Families should be encouraged to talk about their priorities and concerns for their child and needs for support.

Here are some examples of family priorities and concerns from families who have children with complex medical needs.

- Understanding more about their child’s diagnosis and prognosis
- Supporting siblings
- Developing an emergency plan
- Finding a family support group
- Health care financing: Dealing with their health insurance, SSI, Medicaid
- Creating a Special Needs Trust
- Coordinating schedules, treatments and care needs
- Taking a break—find respite or home nursing

DESIGNING SUPPORTS AND SERVICES AROUND THE FAMILY’S NEEDS

“Having care come into my home brings all the team support in, for the child and the family, rather than having care at a hospital. They help us in our own environment, with our own equipment, every day.”

Supports and services are designed around each family’s needs, concerns, and priorities. The focus of EI/ILP services is the whole family, not just the eligible child. The outcomes are the skills and capacity building that the team will work together with the family. Services are delivered in the home and community, and may be delivered in the hospital with appropriate permissions and attention to restrictions.

EI/ILP believes it is the best practice to use a transdisciplinary approach for all early intervention and support services. Transdisciplinary means the parent and professionals from two or more disciplines teach, learn and work together across traditional disciplines or professional boundaries. The team, with the child’s family as integral members, will develop the IFSP collaboratively by reviewing information, making choices, and identifying outcomes. During these discussions, they will reach agreement on the strategies, activities and early intervention services that will

support the goals for this child and family. All EI/ILP team members need to actively participate in sharing information and making decisions about services for the child and consider all information in the development of the IFSP.

The IFSP for a child with complex medical needs could include discussion of the following:

- A thorough discussion of who to list as part of the team
- A discussion of the frequency of reviews as health status changes
- Scheduling team meeting time
- Accompanying parents to appointments (this may be a family outcome)
- Linkage to the nursing care plan when appropriate
- Ramping up services (pay attention to stamina and look at gradual increase of services over time)

How Much Intervention Should A Child Receive?

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.

The decision on how much service to provide is made by the IFSP team. In determining the frequency and intensity of intervention, the team should consider a child's medical condition and stamina, any medical restrictions or recommendations from the child's health care providers, and the priorities and concerns of the family.

What Intervention Strategies May be Used?

Intervention services must be related to the child's evaluation and the specific goals and outcomes on the IFSP (though the IFSP should be modified as the child's and family's needs and conditions change). The decision on which strategies to use is the professional judgment of the early intervention practitioner. The team may choose to designate one member as the primary service provider.

Strategies may include direct, hands-on therapies, such as physical, occupational or speech therapies, respiratory treatments, counseling or other therapeutic interventions. Direct therapy should be paired with coaching and supporting the family in meeting their child's developmental needs when the early intervention team is not present. Therapists should demonstrate techniques the family can use within the context of daily routines. Hands-on therapy is not considered a medical intervention.

Tips for Developing an IFSP for a Child with Complex Medical Needs

Every child has strengths, no matter how complex the medical need. For example, a child may be soothed by or respond to music, may have good tolerance for tactile experience, or may respond to familiar voices.

Identify goals that have potential for some progress. For example, the family and the child's medical team may be encouraging the development of a particular skill, such as head control. This may be a goal that holds significant challenges for the child, with limited promise for progress. It is important for everyone involved to be able to note developmental benefit in outcomes. Therefore, in addition to the head control outcome, the team could add one for tolerance to sensory experience, response to visual and auditory stimulation or other areas of developmental benefit like feeding, bath time, tolerance for a position, etc.

Look for daily routines to build upon. In addition to medical procedures and treatment, which may occupy a significant portion of a child's daily routines (during hospitalization and during home care), there may be naturally occurring social and play opportunities, bathing, feeding, moving and positioning that can be used in developing outcomes embedded in daily routines. A head control goal should be functional, such as having head control during feeding or activities, and could also address increased tolerance during an activity.

Focus on the interaction of the child with the environment. Use assistive technology to promote seating mobility and interaction with the environment. This can include low tech items like switch activated toys, or high tech positioning devices that promote interaction with the environment as part of developmental benefit.

Always respect family goals. It is easy to discount family goals when they are experiencing significant challenges with their child's health, citing unrealistic goals as part of a coping strategy. In most instances, families who are coping with a child with complex medical needs are keenly aware of their child's challenges and should be supported in pursuing their goals for their child just like any other family.

Use as many members of the team as possible when planning goals. This includes the physician, home care agency, and other community providers who may have valuable insight into appropriate outcomes and strategies.

SERVICE COORDINATION

“Our experience was invaluable because of the relationship we developed with our EI/ILP provider. Our service coordinator helped with decisions on surgeries and outside specialists, and sometimes even came to appointments with us. This support was crucial to our family. The help we received with making decisions on things both in and outside the program was also part of the big picture. The IFSP plan helped determine the next steps for our child.”

ROLE OF THE SERVICE COORDINATOR

The EI/ILP service coordinator is a primary point of contact for a family. Federal regulations under Part C of IDEA state that the responsibilities of a service coordinator are to assist and enable an eligible child and the child’s family to receive the rights, procedural safeguards, and services that are authorized to be provided in the state’s early intervention program (2). For children with complex medical needs this is a significant and challenging role as there may be many service providers, from many disciplines, involved in a child’s care, and families may need a variety of supports to meet the demands they will encounter in caring for their child’s needs.

To fulfill this role, the activities of a service coordinator include:

- **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 childcare, specialty services, family support, health financing or medical vendors.
- **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.
- **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 this child.

COORDINATING MEDICAL INFORMATION

Receiving a diagnosis that a child has a serious or chronic medical condition can be traumatic for families. Families are vulnerable particularly right after diagnosis. EI/ILP can help family members with the daunting task of understanding the diagnosis, coordinating between medical experts, and accessing community supports. Sometimes they may, with family permission, attend medical appointments with the family to act as another set of eyes and ears, as active participant or as note taker.

Working with the child's medical team and other specialists involved with the family is an important aspect of EI/ILP services. The service coordinator is responsible for gathering medical information, including a current list all of the services the child receives. The service coordinator should discuss with the family which health care providers they would like to share developmental information with.

If the family is in agreement, it is also important for EI/ILP providers to receive written permission to speak directly with medical providers, especially if there are concerns about stamina, types of activities that may be contra-indicated or other questions regarding intervention strategies. The service coordinator should ensure that the parent signs a release of information for any health care providers with whom the EI/ILP service providers need to communicate. This release should specify the type of information that will be discussed, the purpose of the contact and the duration of the permission. "blanket" permission for "ongoing dialogue" is not acceptable.

Additionally, the service coordinator and the family may want to develop:

- **A communication plan** that details how parents and EI/ILP staff will communicate with other providers.
- **An emergency plan.** Developing an emergency plan is an example of a good family outcome. See Appendix 4 for a sample emergency planning form.

SERVICE COORDINATION WHEN A CHILD IS HOSPITALIZED

During the period that a child is hospitalized, service coordination can include regular visits to the hospital to support the family and caregiver. It provides an opportunity to participate in the development of the care plan that will be in place when the child is discharged, and gives a good framework for the development of an IFSP.

Service coordination activities in a hospital setting may include:

- Collaborating with hospital personnel
- Attending discharge planning meetings and other meetings as appropriate

- Developing a relationship with the child and family
- Minimizing isolation

It is important to work with the family and hospital staff to develop a collaborative plan to implement while the child is in the hospital, so that there is a clear understanding of roles. EI/ILP providers should remember to use understandable language with hospital staff since they may not be familiar with early intervention services and will not know about IFSPs, certain evaluations, etc.

Providers can help minimize isolation by assisting families in accessing supports while they are in the hospital. These can include social services, parent-to-parent support, and any available assistance with meals for parents or parking and phone expenses while they stay at the hospital to care for their child.

When Hospitalization Occurs far from Home

Frequently hospitalization occurs far away from the child's current EI/ILP provider. In these instances the provider and parent should discuss options for continuation of early intervention services during the hospital stay. These could include:

- **Transferring to a provider in that area** for the period of hospitalization and then back to the provider nearer to their home upon discharge
- **Continuing to implement the IFSP, if allowed by the hospital**, and if the program is willing and able to travel outside their catchment area
- **Receiving just those EI/ILP services available at no cost**, including service coordination, evaluation and IFSP development. The service coordinator may be able to visit monthly at the hospital to meet with the parents and hospital staff, and can maintain phone contact with the family.

THE CHILD WHO IS TERMINALLY ILL

When a service coordinator is working with a child who has a terminal illness, some of the intervention roles will be related to activities that promote comfort, feeding and sleeping routines. Family support will be a critical component of EI/ILP services, ensuring that the family has adequate supports through this difficult time. It is also critical for service providers to make sure they are supported in dealing with this issue. The service coordinator's ability to support the family will require the establishment of a comfort level in dealing with terminally ill children.

Some issues to consider discussing with the family:

- Palliative care (care or treatment that concentrates on reducing the severity of disease symptoms rather than providing a cure)
- Keeping services family driven
- Working with the primary care physician
- End of life decisions and planning
- Developing DNR (do not resuscitate) orders

CHILDREN WITH COMPLEX MEDICAL NEEDS IN CHILDCARE SETTINGS

Some families of children with very complex medical needs will not choose to use childcare. However, some children may participate in home childcare settings, childcare provided by a relative, or even a community childcare center. When childcare is being considered for a child with complex health care needs, there are a variety of issues that should be discussed:

- The staff skill and supports
- Appropriate emergency plans
- Which staff and protocols to use for administering appropriate treatments and medications
- The safety of all staff and children if equipment is in use
- Attendance policies for other children and staff when they are ill
- The physical accessibility of all areas of the center
- Liability issues

In some instances, the needs of the child may exceed the capabilities of the staff and childcare facility. In other circumstances, accessing a childcare setting poses some challenges and may require accommodations and training with the staff.

Alaska has several regulations pertaining to children with complex medical needs in childcare settings:

- Alaska requires documentation that any center-based staff member giving medications shall have been trained by a registered nurse, physician's assistant or doctor. Approval by the medical professional must be renewed every year.
- Alaska prohibits licensed centers and group family childcare homes from refusing enrollment to children who have allergies or carry Epi-pens. Procedures adopted for other medications are applicable to the administration of pre-filled injectable cartridges as well.

Additionally, the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability and requires "reasonable accommodations" in several arenas, notably in public facilities, which covers most childcare venues if they are receiving public funds.

Coordination Tools for Parents & Service Providers

The Paper Trail Notebook: An organizational tool to assist families in maintaining records of medical information, appointments and providers. Available at no charge to families of children with special health care needs through EI/ILP providers or directly from the Stone Soup Group at (907) 561-3701 or at: www.stonesoupgroup.org/papertrail.html

Ecomapping: A way to diagram family and community systems. Ecomaps can provide a picture of family support, services, needs and priorities. Service coordinators can use the eco-map to support or confirm outcomes and as part of family assessment. It can also be used to show changes in needs and supports over time, and can be a useful picture to use in the transition process. Tools for ecomapping are included in *Routines-based Early Intervention: Supporting Young Children and Their Families* by R. A. McWilliams (5).

Find more information on ecomapping in Appendix 5.

Where to Turn: An online listing of service agencies in Alaska designed to help locate resources that may be needed for children and adults who experience physical, mental, or emotional disabilities. Find it at: www.hss.state.ak.us/gcdse/Publications/Wheretoturn/wttindex.htm

PLANNING FOR TRANSITION

Transitions are one of the most difficult times for any family, including families who have a child with complex medical needs. Careful attention to providing necessary support through this process can minimize the stress and make the transition as smooth as possible.

Children with complex medical needs experience many transitions in addition to the transition out of EI/ILP and into preschool. These include transitions into and out of hospital settings and transitions among specialty care providers. In addition to the emergency medical care plan, it is helpful for the family to have a complete medical history, current list of diagnoses and treatments and a basic description of daily routines, such as bathing, feeding, etc, with a description of any specific protocols for their child. Some transition planning tools are listed in the box on page 24.

TIPS FOR TRANSITIONING CHILDREN WITH COMPLEX MEDICAL NEEDS

- Prior to the planning and placement team (PPT) meeting, plan a meeting with the school nurse to discuss the medical care the child will need at school. You may want to include home care agency staff in this meeting.
- When appropriate, and with parental consent, involve the medical director for the school district prior to the PPT meeting. This is in addition to others who may be involved in the PPT process, such as the special education director or the preschool coordinator.
- Develop an individualized health care plan for the child which would include medications, treatments, scheduling concerns, meal time accommodations, the location of any equipment to be stored and the emergency plan for this child.
- Determine the role of home care staff at school. If the home care staff will be accompanying the child to school, then it is critical that they develop a good working relationship with the school nurse, have access to the nursing office, and are clear about the role they will play at school.
- Discuss transportation needs. Include an emergency plan, any special seating during transport and necessary personnel to accompany the child during transport.
- Discuss social opportunities. It may be helpful to meet with the teachers and students to answer any questions or fears they may have about equipment and medical needs of this child. Use this as a time to talk about similarities with other children as well as differences.



Transition Planning Tools

EI/ILP Transition Planning Handbook

A detailed, step-by-step guide for parents going through the transition process with a timeline of steps as a child gets older and an overview of the process to create an Individual Education Plan (IEP). Available at:

www.hss.state.ak.us/ocs/InfantLearning/afterage3/ilp_StepAhead.pdf

Alaska Transition Training Initiative

A consortium of early childhood programs and providers in Alaska, ATTI helps address transition issues for special needs children moving from Part C to Part B at age three. Learn more at:

www.alaskaearlytransitions.org/trainers.html

Stone Soup Group: Transitions

Information and resources for parents and caregivers transitioning someone with special needs from one phase of care to the next, including medical and legal issues, guardianship, Medicaid, and transitions into postsecondary programs. Links to parent groups, behavioral supports and assistance programs specifically for kids transitioning from an early intervention to early education can be found at:

www.stonesoupgroup.org/transitions.html

The Paper Trail Notebook can assist the family in identifying and organizing the information that will be needed for transition from EI/ILP to preschool. See page 22 for more information. Request a copy at:

www.stonesoupgroup.org/papertrail.html

Emergency Information Form for Children with Special Needs. Provided in Appendix 4, this tool can be used to transfer critical information about a child's medical history and needs. Download additional blank forms at:

www.aap.org/advocacy/blankform.pdf

REFERENCES

1. **American Academy Of Pediatrics.** *National Center on Medical Home Initiatives.* 2004.
2. *34.C.F.R. Part 303 Early Intervention Program for Infants and Toddlers with Disabilities. Sec. 303.23 Service Coordination (case management).*
3. **Connecticut Birth to Three System.** *Service Guideline 7: Children with Complex Medical Needs.* September 2007.
4. **Georgetown University Child Development Center.** Supporting Families with Children with Disabilities. *Serving Children with Disabilities, A Video Series For Child Welfare Workers.* [Online]
<http://gucchd.georgetown.edu/products/72791.html>.
5. **McWilliams, R.A.** *Routines-based Early Intervention: Supporting Young Children and Their Families.* s.l. : Paul H. Brookes Publishing Co., 2010. ISBN 978-1598570625.

APPENDICES

1. Service Coordination Checklist
2. Complexity Index
3. Health Care Financing Resources
4. Emergency Information form
5. Eco-mapping
6. Glossary
7. Resources

Service Coordination Checklist for Working with Children with Complex Medical Needs		
Precontact Planning	✓	Notes
Review Information from the NOTES section of the referral form		
Review information on the child's diagnosis		
Understanding of the diagnosis, precautions and concerns		
First Contact Information from the Family	✓	Notes
Medical equipment being used in the home		
Environmental assessment to accommodate medical equipment; electrical, space, etc.		
Precautions		
Relevant birth history		
Medications		
Time/Scheduling considerations		
List of health care professionals, other program personnel, and family who should receive information and need releases		
Service Coordination Suggested Activities	✓	Notes
Coordinate appointments		
Develop a communication plan		
Develop of a Emergency Medical Plan and assistance in notifying Emergency Medical Personnel in the community		
Develop an eco-map of providers, supports, resources for the family		
Assist in identifying and accessing services and resources in the community		
Discuss with family the need for additional in-home supports, including identifying the need for nursing services and assisting with access to those service		
Gain access to appropriate transportation		
Support family in acquiring assistive technology devices		
Locate and access financial assistance programs and coordinate financial benefits from public and private sources (Medicaid, Denali Kid Care, Insurance, Title V, Medicaid Waivers, Social Security, other resources)		
Access to services to adapt the home to support special technology such as a ventilator or a motorized wheelchair		
Access to childcare		
Transition planning		
Assist in accessing home nursing supports		
Encourage the family to use the Paper Trail manual to organize information		
Other		

Adapted from Connecticut Birth to Three Systems. *Service Guideline 7: Children with Complex Medical Needs*. September 2007 (3)

COMPLEXITY INDEX

A complexity index can be useful for supporting children with complex medical needs in a medical home environment. Having a complexity score for each identified child will help providers and staff prepare and budget time more effectively for each child.

The purpose of this index is to identify the level of complexity/intensity involved in supporting children and youth with special health care needs in a Medical Home practice.		
Score each category 0, 1, or 2 (0 means no service, activity or concern)		
Category	Criteria	Score
H ospitalizations, ER Usage and Specialty Visits (in last year)	0 = No service, activity or concern 1 = <i>One hospitalization</i> , ER or specialist visits for complex condition 2 = <i>Two or more hospitalizations</i> , ER or specialist visits for complex condition	
O ffice Visits and/or Phone Calls (in last year, over and above well-child visits, +/- extra charges)	0 = No service, activity or concern 1 = <i>One - two office visits</i> or MD/RN/care coordinator phone calls related to complex condition 2 = <i>Three or more office visits</i> or MD phone calls for complex condition	
M edical Condition(s): One or more diagnoses	0 = No service, activity or concern 1 = <i>One – two conditions</i> , no complications related to diagnosis 2 = <i>1-2 conditions with complications or 3 or more conditions</i>	
E xtra Care & Services at PCP office, home, school or community setting (see Services)	0 = No service, activity or concern 1 = <i>One service</i> from the list below 2 = <i>Two or more services</i> from the list below: <u>Services:</u> Medications, medical technologies, therapeutic assessments/ treatments/procedures and care coordination activities	
S ocial Concerns	0 = No service, activity or concern 1 = <i>“At risk” family/school/social</i> circumstances are present 2 = <i>Current/urgent complex family/school/social</i> circumstances are present	
Complexity Scores will range from 0-10: 0-3 (low), 4-6 (medium), 7-10 (high)	Child’s Name: _____ Total Score _____	
	Primary Care Provider: _____ Date: _____	

Source: Connecticut Birth to Three Systems, 2007 (3). Adapted from a similar tool developed by Exeter Pediatrics Associates and the Center for Medical Home Improvement.

DEFINITIONS FOR USE WITH COMPLEXITY INDEX

Medical Home. Community-based primary care provided by the practice which is: accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent (American Academy of Pediatrics definition).

Children and Youth with Special Health Care Needs (CYSHCN)/ (Complex Condition). Children and youth with special health care needs are defined by the U.S. Maternal and Child Health Bureau as those children who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions. The condition must be present for at least 1 year. These children require health and related services of a type or amount beyond that generally required by children.

Specialist Visit. Includes visits to MD's, audiologists, feeding specialists and similar others.

MD Phone Calls. Includes time on phone with family, physicians, agencies/organizations, schools and others.

Complications. Medical, emotional, or social concerns related to the complex condition. For example, conditions which prove particularly difficult to manage, like depression or behavioral issues secondary to the complex condition, or learning difficulties and/or falling behind in school as a result of the condition (missed school or missed parent work days).

Medical Technologies. Some examples include G-tubes, infusions, tracheotomies, communication devices, or the need for other medical equipment and supportive technologies.

Therapeutic Treatments. Some examples include physical, occupational or speech therapies, respiratory treatments such as postural drainage or regular nebulizer use, counseling or other therapeutic interventions.

“At risk” circumstances. Children/adolescents living in poverty, in a foster home, with parents or guardians who are alcohol or drug dependent, depressed or ill, or living with domestic violence. Also at risk are pregnant teenagers and teens who demonstrate health risk behaviors (e.g. smoking, drugs, alcohol, firearms, dangerous driving habits, etc.)

HEALTH CARE FINANCING RESOURCES

The table on the following pages gives EI/ILP providers and parents an overview of some of the public resources that may be available to assist families with medical expenses and insurance questions. The table includes websites and phone numbers that can be accessed for applications, application assistance or more information.

The role of the service coordinator in this process is to ensure that families have access to the information, to assist them in understanding the information and to ensure that they have supports in completing applications and accessing resources.

Service Coordinators *do not* have to become familiar with each set of eligibility criteria, but *do* need to possess a basic understanding of the programs and the eligibility and application procedures as well as the types of support these programs will provide.

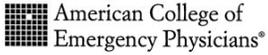
HEALTH CARE FINANCING RESOURCES			
PROGRAM	ELIGIBILITY CRITERIA	RESOURCES/SERVICES PROVIDED	CONTACT INFORMATION
Denali KidCare	Denali KidCare health insurance, delivered through the State of Alaska Department of Health and Social Services, is available for children and teens through age 18. For children with other health insurance, eligibility is based on a monthly income that is 150% of the Federal Poverty Guideline (FPG), and based on household size. For children or pregnant women with no health insurance, eligibility is based on 175% of the FPG	Denali KidCare provides health insurance coverage for children and teens through age 18, and for pregnant women who meet income guidelines, and is renewed on a yearly basis	AK DHSS Denali KidCare 3601 C Street, Frontier Building Anchorage, AK 99503 Local (907) 269-6529 Online www.hss.state.ak.us/dhcs/denalikidcare
Medicaid Waiver For Children with Complex Medical Conditions (CCMC)	Home and Community Based Services (HCBS) waivers allow people who would otherwise need an institutional level of care to live in their home or community and receive the care they need. To qualify for a waiver program, an individual must be both financially eligible for Medicaid and be assessed as needing an institutional level of care. Target population includes children who have a severe chronic physical condition which results in a prolonged dependency on medical care or technology to maintain health and well-being and who: 1) experience periods of acute exacerbation or life-threatening conditions; 2) need extraordinary supervision and observation, and 3) 3. need frequent or life-saving administration of specialized treatments, or dependency on mechanical support devices	Waivers provide regular Medicaid plus access to traditional home and community-based services including care coordination, respite, day habilitation, residential habilitation, environmental modifications, specialized medical equipment and supplies, intensive active treatment, meals, and transportation	HCBS Waiver Program 550 W 8th Ave. Anchorage, AK 99503 P. O. Box 110680 Juneau, AK 99811 751 Old Rich. Hwy, Ste 100-A Fairbanks, AK 99701 Toll-free (800) 478-9996 Anchorage (907) 269-3666 Online www.hss.state.ak.us/dsds/waivers.htm Online Application www.hss.state.ak.us/dsds/docs/HCBCCMC_waiver.pdf

APPENDIX 3

HEALTH CARE FINANCING RESOURCES			
PROGRAM	ELIGIBILITY CRITERIA	RESOURCES/SERVICES PROVIDED	CONTACT INFORMATION
<p>Title V Maternal and Child Health Services Block Grant Program</p>	<p>This program is administered through the Alaska Division of Public Health. The program is for Children & Youth with Special Health Care Needs (CYSHCN) from birth to age 21 who meet the definition of special health care needs: are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and require health and related services beyond that required for children in general.</p> <p>Services are provided to all on a fee for service model based with a sliding fee schedule.</p>	<p>Title V Enabling Services help families access and use health services and are usually targeted to families that have special needs or face specific barriers, such as providing parent navigation services to families of children and youth with special health care needs, through a grant with Stone Soup Group.</p> <p>Title V Direct Health Care Services are directly provided to individuals, by state or local agency staff or by grantees or contractors. Title V programs include support for specialty services for children and youth with special health care needs, including developmental/autism clinics, cleft lip/palate team clinics, metabolic genetics and pediatric genetic clinics.</p>	<p>Alaska Division of Public Health, Section of Women's Children's and Family Health 3601 C Street, Suite 322 Anchorage, AK 99503-5923</p> <p>Toll-free (800) 799-7570 Local (907) 269-3400 Fax (907) 269-3465</p> <p>Online www.hss.state.ak.us/dph/wcfh/tileV/activities.htm</p>
<p>SSI Supplemental Security Income through Social Security</p>	<p>Available to children ages birth to 18 when they meet the definition of disability for children and income and resources of parents are within allowable limits. Social Security has a strict definition of disability for children. The child must have a physical or mental condition(s) that seriously limits activities; and the condition(s) must have lasted, or be expected to last, at least 1 year or result in death. A state agency (DSS) makes the disability decision. If the agency needs more information, they will arrange an examination for the child, which SSA will pay for. Income is typically at or below the eligibility for Medicaid and is therefore a low income program. Some assets are allowed. Call for current income eligibility information.</p>	<p>A monthly payment to assist in meeting the care needs of the child with a disability in the household</p>	<p>Social Security Administration Toll-free (800) 772-1213 TTY (800) 325-0778</p> <p>Online www.ssa.gov/d&s1.htm www.ssa.gov/pubs/10026.html</p> <p>Or contact your local Social Security Office to set up an appointment to complete the SSI application in person or over the phone. Locate your local office online at: https://s044a90.ssa.gov/apps6z/FOLO/fo001.jsp</p>

EMERGENCY INFORMATION FORM

Emergency Information Form for Children With Special Needs



American Academy of Pediatrics



Date form completed
By Whom

Revised
Revised

Initials
Initials

Last name:

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1. _____	Baseline physical findings:
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs:
_____	_____
4. _____	_____
_____	_____
Synopsis:	_____
_____	Baseline neurological status:
_____	_____
_____	_____
_____	_____

*Consent for release of this form to health care providers

Last name:

Diagnoses/Past Procedures/Physical Exam continued:	
Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:	
Allergies: Medications/Foods to be avoided	and why:
1.	
2.	
3.	
Procedures to be avoided	and why:
1.	
2.	
3.	

Immunizations											
Dates											
DPT											
OPV											
MMR											
HIB											

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements		
Problem	Suggested Diagnostic Studies	Treatment Considerations

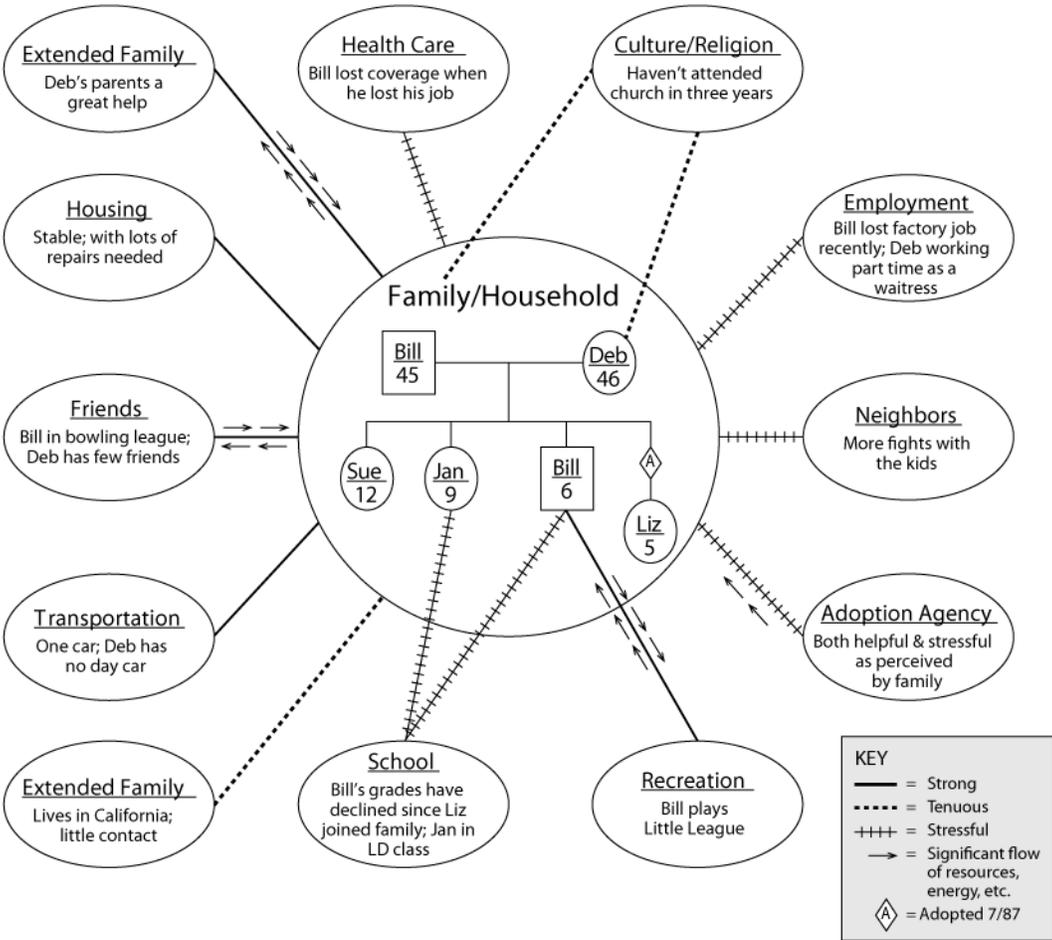
Comments on child, family, or other specific medical issues:	
Physician/Provider Signature:	Print Name:

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ECO-MAPPING

THE ECO-MAP

The Eco-Map diagrams a family's relationship with its environment. It can be used as a tool to help families identify sources of support in their community and areas of unmet needs and stress. For a family with a child with a disability the eco-map can show the relationships among various family members and community organizations. It may also show how different the relationships are from their expectations or how they have changed. (Sandmaier, 1988). Families are frequently unaware that outside interests, hobbies, and community and extended family supports have dwindled. In addition, eco-maps may help families discover that increased demands, such as medical and schooling needs of their child with a disability, have resulted in additional stress on the family. Eco-maps may prove helpful in discussing needed support and services.



Source: Georgetown University Child Development Center, *Supporting Families with Children with Disabilities*. Accessed online at: gucchd.georgetown.edu/products/72791.html (4)

GLOSSARY

Allowable Costs. Charges for services that the health plan will allow to be paid.

Assessment. Ongoing procedures used by qualified professionals throughout a child's early intervention experience to identify his or her unique needs, the family's resources, priorities and concerns related to his or her development, and the nature and extent of early intervention services required to meet these needs.

Assistive Technology. Devices Any item, piece of equipment or product system used to increase, maintain or improve a child's ability to do things.

Assistive Technology Services. A service that directly assists a child with a disability to get or use an assistive technology device.

Audiologist. Conducts audiological evaluations and assessments on the child's hearing, participates in IFSP development and implementation, monitors outcomes as part of a transdisciplinary team, and provides direct and/or consultative services to children and families.

Benefit Package. The services provided to the enrolled members of a health plan.

Early Intervention Team. People who have specialized knowledge about what works to reach developmental outcomes; always includes the child's family, and may include one or more therapists, a teacher, and other professionals who match the child/family goals and needs.

CCMC Waiver. An agreement between the State of Alaska and the Federal government to waive the usual eligibility requirement for Medicaid services for Children with Complex Medical Conditions. Waivers provide regular Medicaid plus access to traditional home and community-based services including care coordination, respite, specialized medical equipment and supplies, transportation, etc., for children from birth to 21.

CSHCN. Children with Special Health Care Needs.

CYSHCN. Children and Youth with Special Health Care Needs (Complex Condition) are children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions. The condition must be present for at least 1 year. These children require health and related services of a type or amount beyond that generally required by children.

Case Management. The process by which the services provided to a specific enrollee are coordinated and managed to achieve the best outcome in the most cost effective manner.

- Comprehensive Care.** A system of care that covers all health care needs and integrates health and health related services with early intervention, education, social services, and family support systems
- Confidential Private.** Information that cannot be shared without the parent/legal guardian permission
- Consent.** The voluntary approval the parent gives for someone to do something, such as using a written consent form to share medical information, and which may be cancelled at any time..
- Continuity of Care.** Complete care that is provided during all transition, such as hospital to home, home to hospital, etc., with planning to ensure linkages with early intervention, education, health and community resources
- Co-payment.** An agreement by which costs are shared with the covered person through their payment of a specified charge for a specified service
- Deductible.** The amount of health care expenses that must be paid for by the patient, out of pocket, before the insurance coverage applies, and which varies by the benefit package or the health insurance program
- Durable Medical Equipment (DME).** Equipment that is not disposable such as wheelchairs, walkers, oxygen concentrators and ventilators
- Early Intervention.** Programs of services designed to meet the developmental needs of infants or toddlers, ages birth to three and their families
- Early and Periodic Screening, Diagnosis and Treatment (EPSDT).** These are mandatory Medicaid benefits and services for Medicaid-eligible children and youth under age 21, and which are designed to provide preventative care and treatment
- Eligibility Evaluation.** Procedures used by qualified professionals to determine a child's initial and continuing eligibility which focuses on determining the status of the infant or toddler in an array of developmental areas: cognitive, social/emotional, physical (including vision and hearing, communication, and adaptive
- Explanation of Benefits (EOB).** Written, formal statement sent to enrollees that lists the services provided and costs billed by their health plan
- Family Centered.** The system of care that recognizes and builds upon the importance of the family, which reflects this in the way services are planned and delivered, and which promotes family/professional partnerships, responds to family-identified needs, builds upon family strengths, and respects the diversity of families

- Formulary.** List of approved prescription medications that a health plan will pay for, and which, by omission, indicates those medications that will not be covered
- Grievance Procedure.** A process in a health plan for consumers or providers to use when there is a disagreement about the plan's services, billing or general procedures
- IDEA.** Individuals with Disabilities Education Act
- Individualized Family Service Plan (IFSP).** The written plan for providing early intervention services to eligible children and families that is developed jointly by the family and the appropriate professionals
- Managed Care.** A system of care that manages the cost of health care while increasing and ensuring access to quality care
- Medicaid.** A federal health insurance program that provides payment for medical expenses for those who meet income limits
- Medical Home.** A relationship between the family and a primary care provider and clinic staff, supported by other community and specialty providers involved in the child's care of services, that describes community-based primary care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent
- Medical Necessity.** A legal term that the service is medically appropriate, necessary to meet the person's health needs, consistent with the person's diagnosis, and consistent with established standards of care
- Natural Environments.** Settings that are natural or normal for the child's age peers who do not have a disability, and which may include the home, neighborhood or community settings
- Natural Learning Opportunities.** The everyday routines and activities of life that can be used to teach and practice new skills (for example feeding time, diaper changing, bath time)
- Occupational Therapy (OT).** Activities designed to improve fine motor skills (finger, hand, or arm movements) and oral-motor (eating, swallowing) abilities
- Orientation and Mobility Therapists.** Completes assistive technology evaluations and assists the IFSP team to analyze needs of child with disabilities, and may also assist in selection or service of assistive technology devices and provide training in the use of the selected equipment
- Outcomes.** Statements of changes as a result of early intervention services, which are part of the IFSP

Part C/IDEA. The part of the federal Individuals with Disabilities Education Act that authorizes grants to the states for early intervention services for infants and toddlers ages birth to three within each state's criteria for eligibility

Physical Therapy (PT). Activities designed to improve gross motor skills (leg, back, or whole body movements)

Primary Care Provider (PCP). The provider who provides primary, preventative and non-specialty care, generally from family practice, internal medicine and pediatrics

Supplemental Security Income (SSI) for children with disabilities administered through the Social Security Administration. This provides a monthly financial benefit.

Self-Funded Health Insurance. Insurance coverage in which actual medical bills are paid by an employee who contracts with an agency to manage those payments (rather than the more common type of health insurance in which an employer pays a flat fee per employee to a health plan).

Service Coordinator. A person from EI/ILP who will assist the family in making connections with people on their team, understand the information given to them, and assists and enables the family to connect to community resources outside of EI/ILP covering a wide variety of developmental, health, economic, and life quality issues

Speech and Language Pathologist. The person responsible for evaluation and treatment of speech and language disorders including auditory comprehension, cognitive, attention, writing, reading, and expression skills

Title V. Federal funding through the Social Security Act that supports public health services for women, infants, children, including those with special health care needs

Waiver. A process that allows state Medicaid agencies to apply for and receive permission from HCFA to provide services not otherwise covered by their Medicaid plan or to do so in ways not described by Title 19 of the Social Security Act

RESOURCES

ALASKA RESOURCES

Alaska Assisted Care Services, LLC, is a non-medical in-home care provider dedicated to enhancing quality of life by preserving independence in one's own home.

1399 West 34th Ave., Suite 101, Anchorage, AK 99503

Toll-free (866) 516-2687. Local (907) 929-2828

Email info@assistedcareak.com

www.assistedcareak.com

Alaska Early Intervention/Infant Learning Program (EI/ILP) is a division of the Alaska Department of Health and Social Services, Office of Child Services that partners with grantees around the state to provide services directly to children with special needs and their families at a local level.

P.O. Box 240249, 323 East 4th Avenue, Anchorage, AK 99501

Toll-free (877) HSS-FMLY (477-3659). Local (907) 269-8442

Fax (907) 269-3497

www.earlyintervention.alaska.gov

Find a complete list of EI/ILP providers in Alaska at:

www.hss.state.ak.us/ocs/InfantLearning/program/program_dir.htm

Alaska Governor's Council on Disabilities and Special Education (GCDSE) is one of four governor-appointed advisory boards to the Alaska Mental Health Trust. The Council plans, evaluates, and promotes programs for people with disabilities in the state of Alaska.

3601 C Street, Suite 740, P.O. Box 240249, Anchorage, AK 99524-0249

Toll-free (888) 269-8990. Local (907) 269-8990, Fax (907) 269-8995

www.hss.state.ak.us/gcdse

Assistive Technology of Alaska (ATLA). As the state's Tech Act Project, ATLA provides Alaska's most comprehensive assistive technology resources, including assessments, training, webinars, demonstrations, education and AT device loans, including technology for deaf and hard of hearing.

3330 Arctic Blvd., Ste.101, Anchorage, AK 99503

Toll-free (800) 723-2852(ATLA). Local (907) 563-2599. TTY (907) 561-2592.

Fax (907) 563-0699 | Email atla@atlaak.org

www.atlaak.org

Stone Soup Group: Family-to-Family Health Information Center (F2F HIC) is part of a national program that assists families of children and youth with special health care needs (CYSHCN) in finding the resources to provide and finance health care for their children, and to connect families statewide to other

families who are experiencing similar challenges. The Stone Soup Group is a grassroots, Anchorage-based, nonprofit founded by parents of children with special needs to provide information and advocacy and to build partnerships between families and healthcare professionals.

307 E. Northern Lights Blvd. #100, Anchorage, AK 99503

Toll-free (877) 786-7327, Local (907) 561-3701

www.stonesoupgroup.org/F2F.html

NATIONAL AND ONLINE RESOURCES

American Academy of Pediatrics is an organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. The Academy can provide general information related to child health as well as more specific guidelines concerning a pediatric issue.

www.aap.org

Family Village: Community of Disability-Related Resources is an international community that connects those with disabilities and their families and service providers to information and resources about specific diagnoses, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much more.

www.familyvillage.wisc.edu

Family Voices aims to keep families at the center of children's health care. A national grassroots network of families and friends, it advocates for health care services that are community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs. It promotes the inclusion of all families as decision makers at all levels of health care, and supports essential partnerships between families and professionals. Toll-free (888) 835-5669.

www.familyvoices.org

Learning Disabilities Online seeks to provide accurate and up-to-date information and advice about learning disabilities and ADHD. In addition to articles and multimedia content, the site hosts a comprehensive resource guide, very active forums, and a Yellow Pages referral directory of professionals and products.

www.LDOnline.org

Medical Air Transport Services. Formerly the National Patient Air Transport Helpline, this service offers information on air transport options for patients and their families, including referrals to programs that offer free air miles or transportation to eligible patients. Toll-free (800) 296-1217.

www.patienttravel.org

APPENDIX 7

National Dissemination Center for Children with Disabilities (NICHCY) serves as a central source of information on disabilities in infants, toddlers, children, and youth. It brings together information on IDEA, No Child Left Behind (as it relates to children with disabilities), and research-based information on effective educational practices.

www.nichy.org

NORD: National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

www.rarediseases.org

Parent to Parent USA (P2P-USA) is a national nonprofit organization committed to assuring access and quality in Parent to Parent support across the country. Parent to Parent programs provide emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained "Supporting Parent." There are currently no Parent to Parent programs in Alaska. Parents in Alaska are encouraged to contact a neighboring statewide P2P program or a Family-to-Family Health Information Center (see the Stone Soup Group listing under Alaska Resources)..

www.p2pusa.org

Needy Meds Prescription Drug Assistance is a source of information about assistance programs that help with the cost of medicine and other healthcare expenses.

www.needymeds.com

Additional Copies or Services

These guidelines are available online at www.earlyintervention.alaska.gov

To request additional copies or auxiliary aids and services, please contact:

Alaska Early Intervention/Infant Learning Program

P.O. Box 240249

323 East 4th Avenue

Anchorage, Alaska 99501

Toll-free (877) HSS-FMLY (477-3659)

Local (907) 269-8442

TT Relay (800) 770-TYPE (8973)



Alaska Infant Learning Program

This report, historical data and other publications available at www.earlyintervention.alaska.gov

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.