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## SERVICE GUIDELINE 7

### Children with Complex Medical Needs

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

September, 2007



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*The Committee would also like to thank the parents from the Family Support Network who gave us their insights and comments which are reflected throughout the document.*

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## Preface

*Our biggest priority is helping him be a kid who is doing age-appropriate things.*

*CT Family Support Network 2007 Survey*

Children with complex medical needs represent a small percentage of the children served in Birth to Three, but their parents or caregivers may face many challenges. Their priorities are not that different from other parents. They want their children to be happy, have friends, and be a valued part of their community. However, in order to achieve their priorities, these parents are faced with the difficult tasks of accessing services from multiple health care specialists, allied health services, multiple public and private payment sources and family supports, as well as Birth to Three services. Birth to Three service providers can assist these families by developing an Individualized Family Service Plan that addresses their unique needs and priorities as a family while linking with the larger circle of health care providers and with their medical home. While these outcomes may include assistance in accessing a vast array of services, information, and supports, the mission of the Birth to Three system remains the same:

“To strengthen the capacity of families to meet the developmental and health-related needs of their infants and toddlers who have delays or disabilities.”<sup>1</sup>

The purpose of the guideline is to ensure that:

- All children with complex medical needs who are eligible for Birth to Three services have access to and receive quality early intervention.
- Birth to Three providers have an awareness of the unique needs of families who have children with complex medical needs and will offer appropriate support.
- Parents who have a child with complex medical needs will understand the ways that Birth to Three can support and assist them in meeting their child’s unique needs.
- Birth to Three providers can build the competence of families in meeting their child’s unique care needs, and share their skills and knowledge about existing resources and supports available to these children and families.

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<sup>1</sup> Mission Statement. Connecticut Birth to Three System, 1996 to present

This guideline should be adapted or tailored to suit the individual needs of children and families. It provides suggestions to assist providers in delivering Birth to Three services that are appropriate and sensitive to the needs of each family. While this guideline offers ideas on how to support and assist families, it is critical for Birth to Three providers to remember two critical concepts:

1. The focus of good service coordination is to build capacity and skill in the family. This includes assisting families in understanding how to access a variety of services and supports in their community. In some instances this may mean accompanying the family to appointments, assisting them in contacting other services, or providing other relevant information and support.
2. There are many other programs that can also offer these families care coordination, assistance, and support. It is the role of the Birth to Three service coordinator to ensure that families have access to the array of services and supports outlined in this document. In some instances, this simply means checking in with the family to ensure that another agency or individual is assisting the family and to periodically check to make sure that these needs are still being addressed. In other instances it may mean providing more intense service coordination if the family is unable to access care coordination through another agency.

We would like to thank the members of the Children With Complex Medical Needs Task Force and the parents who took the time to share their insights, and whose quotes are featured throughout the document.

## Who Are the Children With Complex Medical Needs and Their Families?

We all come from families. A family is the basic unit in our communities. At the center of a family are one or more persons who consistently serve as the care givers for a child. This could be a parent, foster parent, guardian, brother or sister. In some cases other members of the extended family, such as an aunt, grandparent or close friend may be part of the basic family unit.

Children with complex medical needs are children who have a serious and/or ongoing illness 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. Children with complex medical needs can include (but are not limited to):

- Children who require mechanical ventilation (respirator) for at least part of each day
- Children who need prolonged intravenous nutrition
- Children who need tracheotomy support such as suctioning, oxygen, or tube feeding through g-tubes or j-tubes
- Children who need cardio-respiratory monitoring, kidney dialysis, ostomy care
- Children who require multiple medications

This guideline includes several tools to assist in the identification of children with complex medical needs. The tools provided in Appendix 1 should be used to determine the complexity of care required for a child, *not the complexity of the diagnosis or condition*. These are guides to assist families and providers in meeting 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.

### Tools to Use in the Identification of Children with Complex Medical Needs Appendix 1

- Children and Youth With Special Health Care Needs Complexity Index

## Health Care Providers and the Birth to Three System

Pediatricians and other health care providers have always played a role in Birth to Three. This role includes referral, participation in the development of the child's IFSP (a physician signature is required on all IFSPs) and assistance with transition. In addition to these roles, a child's primary health care provider can play an important role in the delivery of Birth to Three services to children who have complex medical needs. Through a medical home model of primary care, families and Birth to Three providers can access support through coordinated health care that places the child and family at the center of care, promoting partnerships between physicians, families, Birth to Three providers and other community agencies to meet the unique care needs of each child. For children with complex medical needs enrolled in Birth to Three, linkage to a strong medical home with a care coordination component allows the family and service coordinator to partner with a professional who can assist in many of the activities, roles, and concerns outlined in this guideline.

### The Doctor - Parent Partnership

*What is a Medical Home?* "In a medical home, a pediatric clinician works in partnership with the family and child to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family and child access and coordinate specialty care, educational services, out of home care, family support, and other public and private community services that are important to the overall health of the child and family. A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective."<sup>2</sup> 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 and related services. Thus the medical home becomes a place in which providers and families work as partners to meet the unique needs of children and families.

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<sup>2</sup> American Academy of Pediatrics. (2004) National Center on Medical Home Initiatives.

### **A Medical Home**

- A partnership between the family and their child's primary care clinician
- A relationship based on mutual trust and respect
- Connections to supports and services to meet the child's and family's need
- Respect for the family's cultural and religious belief
- After hours and weekend access to medical consultation about the child
- Families feel supported in caring for their child
- A primary care clinician working with a team of other care providers

### **What Can Families Expect From Their Medical Home?**

- The Birth to Three service coordinator and the Medical Home care coordinator will partner in ensuring access to appropriate care and support;
- The child and family regularly see the same primary care clinician and office staff who know the child and family;
- Primary care providers partner with families in coordinating care for their child;
- Providers exchange information with families honestly and respectfully as they learn from one another;
- The family feels supported in finding resources, for all stages of growth and development of their child;
- The family is 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.

## The Role of the Birth to Three Service Coordinator in a Medical Home

*Our Birth to Three experience was invaluable because of the relationship that we developed with our [Birth to Three] provider. The [IFSP] plan helps determine the next steps for the child, ... The help we received with making decisions on things both in and outside Birth to Three are also part of the big picture. Our [Birth to Three] provider helped with decisions on surgeries and outside specialists, and sometimes even came to appointments with us. This support was crucial to our family. CT Family Support Network 2007 Survey*

Birth to Three service coordinators 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 physician, then the service coordinator can assist the family in identifying the needs and issues that should be included in the Medical Home care coordination plan.

Not every primary care medical home practice will have access to care coordination. In those settings, the role of the service coordinator is more crucial in assuring access to appropriate supports. It is important for Service Coordinators to assist families in building partnerships with their primary care providers. This can include coaching families prior to a doctor visit and even accompanying families to appointments so that they have an “extra set of ears” when they are hearing new information. It is also helpful to take notes for the parent at those visits, so that they capture all the information given. Service coordinators can be of assistance in helping the family access needed information about their child’s diagnosis, treatment and equipment needs. They can help ensure that families are understood and that their concerns are addressed at each appointment.

**Tips For Families:  
Building Medical Home Partnership**

- Bring a list of questions or concerns to discuss
- Share information on how your child is changing (progressing, regressing, etc.)
- Ask about resources that may help your child and family
- Ask about how to get care after hours if needed
- Ask to meet the office staff that will be working with you and your child (nurses, referral coordinator, billing person, etc.)
- Share successes

For more medical home information for families, tools, brochures, and presentations, go to:

<http://www.medicalhomeinfo.org/tools/familyindex.html>

### **First Contact With Families**

In most instances, children who have complex needs will be referred to Birth to Three (by their parents, doctors, hospital staff of other providers) shortly after the diagnosis is made. Parents may refer or the hospital, doctor, or other health care provider may make the referral. This first contact is therefore often at a difficult time for families. Parents are struggling to understand the diagnosis and access a broad array of medical services from a variety of specialists. They are dealing with the challenge of trying to incorporate all this information into their own family and meet the special needs of this child while dealing with all the other needs and priorities in the family. For many families this will be the beginning of a long road in a new world - a world of specialized medical care, special equipment and treatment, and special programs. In order to help them through this process, the Birth to Three programs should focus on building a strong partnership with the family and support them through this very difficult and confusing time, while providing quality Birth to Three 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 that they have available, this may contain diagnostic or other information in the notes section. Whenever possible, 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 scheduling the first visit. Lastly, families may have had to spend long periods of time with doctors, specialty care, and in hospitals with this child. Sometimes, as they are gaining skills and knowledge about their child's unique medical needs, they lose the vision of their child as just a child.

One of the best services Birth to Three can offer is assistance to let the family connect with their child as a person, not just as a list of medical conditions and treatments. The interaction modeled at the first contact, and continued throughout the time the child is in Birth to Three 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 their child is just as important as knowing about the medical care. Providers can help the family re-connect with their child as a person and assist them to describe their child's personality, likes, dislikes, who else the child might resemble in their family, and all the other descriptors that we often take for granted when a child does not have complex medical needs. 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 begin to see their child as a child first.

## Evaluation

Birth to Three eligibility is determined by an evaluation team using a multi-domain standardized instrument as well as parent report and observation. The child with a confirmed medical condition that is expected to lead to a developmental delay is automatically eligible. Many children with complex medical needs will fall into this category. If the child does not have one of these conditions, then the child is evaluated by professionals from at least two different disciplines (for example, early childhood special education and physical therapy) who can determine that there is significant developmental delay. Additional information about evaluation can be found in the Birth to Three Procedures manual in the evaluation procedure. In addition to assessing areas of development, the evaluation team may need to learn more about:

- The child's prenatal history and birth. This is sometimes difficult for a parent to discuss, since the prenatal history may have been a time of concern and is painful to discuss. Some of this information may be found in the child's medical records and may not be readily available at the time of evaluation. It may be obtained later if the child is found eligible for Birth to Three services.
- The child's health, current diagnoses and conditions and any information available about those diagnoses and conditions. The medical history and list of diagnoses may be somewhat lengthy, depending on the

intensity of the child's medical needs. As suggested in the section on First Contacts, evaluators should make an effort to learn a little about the diagnosis before arriving for the evaluation. Additional information may be available from the family or may be in the medical record.

- Information on the child's developmental history. In instances in which the child has been hospitalized for a long period of time, the family may not have had an opportunity to observe a lot of developmental milestones due to the constraints of a hospital setting.

The team will review results from this testing, the information provided by the family about this child's medical history and condition, and any reports received from medical providers to arrive at an eligibility decision. The family will be given a written draft copy of the results and eligibility decision to review prior to a final report.

### **Before the Evaluation**

Families are the experts on their child's strengths and needs and they may be able to provide valuable information regarding the child's medical condition. However, it is important for the evaluators to have an understanding of the child's medical diagnosis, precautions, and medical needs prior to arriving at the home. 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.

### **Scheduling Considerations**

Occasionally, families are able to provide a substantial amount of information at the first contact, prior to the initial visit. When this is not possible, the family and evaluation team may want to allow more time for the intake visit in order to discuss all relevant medical information. Since intake for these children is often close to the time of the diagnosis, it may be very painful for families to share this information with the team and the family may become overwhelmed during the intake process. While at the home, the Birth to Three providers should be sensitive to the family and offer to schedule a second intake visit if the family appears to be fatigued or overwhelmed or if life circumstances make it challenging to complete the scheduled visit. This information is often difficult for families to discuss, and should be carefully documented in the child's file so that the family does not have to repeat it, as new providers are added over time.

### **Helpful Tips For Providers in Planning the First Contact With Families**

- An experienced Birth to Three provider may bring a newer staff person with them to mentor and support them as they learn about the unique needs of children with complex medical needs.
- Families may want to have current information on the diagnosis available to share with Birth to Three staff at the first visit and to assist with the evaluation/assessment process.
- Many children with complex medical needs are vulnerable to colds and other infections. Birth to Three providers should check with the family if they are not feeling well and determine the appropriateness of making the visit.

### **Sharing the Evaluation/Assessment Results with the Family**

Once the evaluation is completed 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. 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 Birth to Three program staff understand the child's strengths and needs.

Prior to sharing the evaluation/assessment results, the Birth to Three 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.

When discussing results, it is important to begin with the child's strengths and to discuss the parenting strengths of the family as well. Examples of these can be letting the parents know they are doing a good job, that their child seems happy, well cared for, and cute. Sometimes parents get so pre-occupied with meeting their child's unique and often demanding care needs that they lose sight of the fact they have acquired substantial skill in meeting such complicated needs, keeping track of appointments and 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 evaluation 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.

### **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.* CT Family Support Network 2007 Survey

Throughout the evaluation/assessment process it is important to keep in mind that families of children with complex medical needs often feel that they have little control over what is happening to their child. As part of the family assessment, families should be encouraged to talk about their priorities and what they would like to see for their child, as well as stating their concerns. Encourage families to let Birth to Three staff know how they can help support the family and what the next steps will be to reach a family outcome.

Families may have many questions and heightened anxiety about the future. They may raise questions that providers do not feel comfortable or qualified to answer. Birth to Three staff may not have medical expertise. However, staff can assist families to formulate questions and help them identify the appropriate person to ask, as well as assist families to access support from other parents who may have experienced similar feelings.

Here are some examples of family priorities/outcomes for families who have children with complex medical needs.

- Understanding more about their child's diagnosis/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

In addition to medical/health information, families can share other important information about their child such as:

- What does your child like? Dislike?
- What frustrates your child?
- What does your child do during the day?
- What things do you like to do as a family? With friends?
- Which people and agencies do you find helpful?
- What are your family's strengths in meeting your child's needs?
- What else do you want the team to know about your child or family?

## Service Coordination for Children With Complex Medical Needs

*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.*  
CT Family Support Network 2007 Survey

### Service Coordinator Roles Under Part C of IDEA

The service coordinator is the single point of contact for a family. For children with complex medical needs this is a significant and challenging role, because there may be many disciplines and providers involved in the care of this child. Part C of IDEA Federal Regulations clearly states the responsibilities of a service coordinator. These include: “The activities carried out by a service coordinator to assist and enable a child eligible under this part 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.”<sup>3</sup> These roles are specified as follows (The bolded word are from federal regulations.):

- *Coordinating all services across agency lines.* For a child with complex needs this could include services from the Title V program at the Department of Public Health, Medicaid and insurance services, services through clinics, and specialty care providers. The service coordinator is responsible for making sure the services are delivered in a timely fashion but the responsibility for implementing these services is shared with others. For example, when a family is applying for Title V for their child, the service coordinator is not responsible for filling out the forms but can greatly assist the family by coaching them in obtaining or completing the application or by helping them identify a family support resource to assist them.
- *Serving as a single point of contact in helping the parents to obtain the services and assistance they need.* These children are part of a fragmented and sometimes difficult to access system. The service coordinator can play a valuable role in providing resource information. Some resources are listed in Appendix 7.
- *Assisting parents of eligible children in gaining access to Birth to Three services and other services identified in the IFSP.* Other services could include accessible child care, specialty services, family support, health financing, or medical vendors.

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<sup>3</sup> 34.C.F.R. Part 303 Early Intervention Program for Infants and Toddlers with Disabilities. Sec. 303.23 Service Coordination (case management).

- *Coordinating the provision of Birth to Three services and other services that the child and family needs.* This includes assisting the family in communicating and linking with other supports, services and programs as listed on the IFSP and ensuring that these services are being provided.
- *Facilitating the timely delivery of available services.* This may include assistance in coordinating the scheduling of medical appointments by working with care coordination in the hospital settings or within the medical home.
- *Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.* As the child's medical and developmental needs change, additional services may need to be added. For example, if a child's developmental and medical needs change following a hospitalization, the services to be coordinated may also change, such as family supports, home nursing, or other specialists.
- *Facilitating the development of a transition plan to preschool services.* 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.

### **Service Coordination Activities**

Service coordination may involve assisting the family in accessing a variety of supports to meet the demands that they encounter in caring for their child with complex medical needs. The service coordinator can offer a significant amount of assistance and support to families. This includes the following types of activities:

- Interpret evaluation results and observations for the family
- Assist the family in setting priorities for their child and family
- Help coordinate services and information from different sources including medical information and services.
- Help the family find answers to questions they may have about their child and their child's medical condition.
- Assist families in connecting with other families who may have a child with similar needs or diagnosis.

- Help families talk with other specialists involved such as medical providers and childcare staff
- Offer information on helpful state and community resources.
- Coach the family on ways to teach their child new skills during regular routines and activities.

### **Coordinating Medical Information**

Working with the child’s primary care provider and other specialists involved with the family is an important aspect of Birth to Three. At the time of the evaluation/assessment, evaluators should list all of the providers the child sees and list follow up appointments. The service coordinator should discuss with the family which doctors they would like to receive developmental information. If the family is in agreement, it is also important for the Birth to Three providers to have permission to speak directly with physicians, 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 release of information for any physicians with whom the Birth to Three provider needs 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. A “blanket” permission for “ongoing dialogue” is not acceptable. Additionally, the service coordinator and the family should develop:

- A communication plan that details how parents and Birth to Three staff will communicate with other providers.
- An emergency plan (this is an example of a good family outcome). A sample emergency planning form is in Appendix 3.

#### **Coordination Tools for Providers and Parents**

*Directions:* A guide to assist families in maintaining records of medical information, appointments and providers. Information about Directions and how to access a copy may be found in Appendix 4.

*Ecomapping:* An ecomap is a diagram of a social “solar system”, in which a family is placed in the position of the sun, at the center, and other important people and institutions in their life space are depicted with circles around the center, like planets around the sun. More information on Ecomapping is in Appendix 5.

**Checklist for Service Coordinators/Providers  
Working with Families of Children with Complex Medical Needs**

<b>Pre-Contact Planning</b>	✓	<b>Notes</b>
Review information from the NOTES section on the referral form		
Review information on the child's diagnosis		
Understanding of the diagnosis, precautions and concerns		
<b>First Contact: Information from the family</b>		
Medical equipment being used in the home		
Environmental assessment to accommodate medical equipment: electrical, space, etc.		
Precautions		
Relevant birth history		
Medications		
Time/scheduling considerations		
Develop a list of health care professionals, other program personnel, and family who should receive information and need releases.		

<b>Service Coordination Suggested Activities</b>		<b>Notes</b>
Develop an eco-map of providers, supports, resources with the family		
Coordinate appointments		
Develop a Communication Plan		
Development of an Emergency Medical Plan and assistance in notifying Emergency Medical Personnel in the town		
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		
<p>Locate and access financial assistance programs and coordinate financial benefits from public and private sources</p> <ul style="list-style-type: none"> <li>▲ HUSKY A (Medicaid)</li> <li>▲ HUSKY B (S-CHIP)</li> <li>▲ Insurance</li> <li>▲ Title V</li> <li>▲ Medicaid waivers</li> <li>▲ Social Security</li> <li>▲ Other resources</li> </ul>		

<b>Service Coordination Suggested Activities</b>	✓	<b>Notes</b>
Access to services to adapt the home to support special technology such as a ventilator or a motorized wheelchair.		
Access to child care		
Transition		
Assist in accessing home nursing supports		
Address sibling supports		
Encourage the family to use the DIRECTIONS manual to organize information		
Other		

## IFSP/Program Development

*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.*

*CT Family Support Network 2007 Survey*

Supports and services are designed around each family's needs, concerns, and priorities. The focus of Birth to Three services is the whole family, not just the eligible child. The outcomes are the skills the team will work on together. Services are delivered in the home and community and may be delivered in the hospital with appropriate permissions and attention to restrictions. The frequency and intensity of services will depend on the family's choice, child's medical condition, stamina and any medical restrictions and must be related to the evaluation and outcomes on the IFSP. As these change over time, the IFSP can be modified.

Team members work together to develop the IFSP by reviewing information, making choices, and developing IFSP outcomes. During these discussions, they will reach agreement on the strategies, activities and Birth to Three services that will support the goals for this child and family. All Birth to Three team members need to actively participate in sharing information and making decisions about services for this child, considering all information in the development of the IFSP. The IFSP for a child with complex health care needs could include discussion of the following:

- Absences and special concerns -- in the notes section;
- 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; and
- Ramping up services. Pay attention to stamina and look at gradual increase of services over time.

## **Frequency And Intensity Of Services For Children With Complex Medical Needs**

The decision on how much service to provide a child with complex medical needs is made by the IFSP team. The team should consider stamina and medical concerns, recommendations from the child's doctors, information from evaluations and the priorities and concerns of the family when making this decision. As with all children in Birth to Three the services provided should be directly related to specific outcomes on the IFSP. A child with complex medical needs who is enrolled in Birth to Three 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. More intense services should not be confused with medical therapy simply because the child has a complex medical need. Strategies may include direct, hands on therapies which demonstrate techniques that the family can employ when the Birth to Three team is not present. Hands on therapy is also not considered a medical intervention. However direct therapy should not replace coaching and supporting the family in meeting their child's developmental needs. The decision on which strategies to use is the professional judgment of the interventionist in consideration of the specific goals and outcomes identified by the team. Supplemental rates for services which will exceed 13 hours per month will need approval of the Birth to Three Service and Support Office, using a Contract Supplement request, Form 2-7a.

## **Helpful Hints in Developing an IFSP for a Child With Complex Medical Needs**

- **No matter how complex the medical need, every child has strengths.** 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 doctor 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.

## **The Child Who Is Terminally Ill**

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

- Palliative care (care or treatment that concentrates on reducing the severity of disease symptoms rather than providing a cure)
- Children who are receiving intense medical care, either at home or in a hospital or other facility
- Keeping services family driven
- Working with the primary care physician
- Developing DNR (Do Not Resuscitate) orders
- Conversations on end of life decisions and planning

## **Children in Hospitals**

### **First Contact When A Child Is In The Hospital**

For some children and families, Birth to Three services may begin prior to discharge from the hospital. If a child is expected to be hospitalized for a prolonged period prior to discharge, it is helpful to begin developing a relationship between families and Birth to Three providers while the child is still at the hospital. This can ensure that the transition to home and the start of Birth to Three services is smooth.

During a hospitalization, Birth to Three services could include contact with a service coordinator and interaction with other hospital staff such as a physical therapist, occupational therapist, speech language pathologist, social worker, or nursing and child life staff. While hospitals generally do not allow direct Birth to Three services to be provided during hospital stays, this is a time when parents and providers can get to know each other and when parents can learn about the Birth to Three System. This may be a time when the family receives service coordination only. In order to communicate with hospital staff, service coordinators will be required to have the family sign a consent form provided by

the hospital. For more information on hospital policies, check with the social worker or other administrator at the specific hospital. When possible, providers should encourage the hospital staff to partner with Birth to Three in order to address the developmental and support needs of the child and family during the hospitalization and to ensure a smooth discharge. This is especially important if the child is expected to be hospitalized long term. The hospital staff should not expect Birth to Three providers to augment hospital services, such as physical therapy, occupational therapy or other services being provided as part of the child's medical care in the hospital.

It should be noted that early intervention for children who are receiving Birth to Three services while at a long term care facility, such as the Hospital for Special Care, may be carried out with little contact with the family. Family members often live at a distance from the hospital and face significant challenges in accessing transportation or time away from work in order to visit at the hospital. In these situations, Birth to Three providers may relate more frequently to hospital staff, and much less frequently with family members. Under no circumstances should Birth to Three services be planned or delivered without contact and participation from the care-giving staff at the hospital. Phone contact and visits when the family members are able to attend should be scheduled on a regular basis.

### **Service Coordination When a Child Is Hospitalized**

Service coordination during this period 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 can also include:

- *Collaborating with hospital personnel* (i.e. social workers, child life staff). 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. It is important for Birth to Three providers to remember to use understandable language with hospital staff since they may not be familiar with Birth to Three and will not know about IFSPs, certain evaluations, etc.;
- *Attending discharge planning meetings* and other meetings as appropriate;
- *Developing a relationship with the child and family;*
- *Minimizing isolation:* Assist families in accessing supports while they are in the hospital. These can include social services, child life, parent to parent support, and any available assistance with meals for the parents and parking/phone expenses while they stay at the hospital to care for their child.

Sometimes a child is hospitalized for a long period and the stay may be out of state or in a hospital which is located in an area of the state not served by the child's current Birth to Three provider. In these instances the provider and parent should discuss the options for continuation of services from Birth to Three during the hospital stay. These could include:

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

### **Children With Complex Medical Needs in Child Care Settings**

Some families of children with very complex medical needs will not choose to use child care. However, some children may participate in home child care settings, relative child care or even a community child care center. Considerations for children with complex health care needs include:

- Assessing the staff skill and supports
- Developing appropriate emergency plans
- Identifying staff and protocols for administering appropriate treatments and medications
- Assessing the safety of all staff and children if equipment is in use
- Assessing attendance policies for other children and staff when they are ill
- Assessing the physical accessibility of all areas of the center
- Discussing liability issues

In some instances, the needs of the child may exceed the capabilities of the staff and child care facility. In other circumstances, accessing a child care setting poses some challenges and may require accommodations and training with the child care staff. Connecticut has several regulations pertaining to children with

complex medical needs in child care settings. Connecticut 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. Connecticut also prohibits licensed centers and group family child care 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. Centers that serve infants and toddlers full time are required to have weekly visits by a health consultant, with specific tasks defined in state regulation. Part-day programs for infants or toddlers must have monthly visits.<sup>4</sup> Centers serving preschool or older children have no such licensure requirement. 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 child care venues if they are receiving public funds.

## Transitions

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 Birth to Three 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 of this information can be found in the book "Directions" available from the CT Department of Public Health.(Appendix 4) which can be used to assist the family in identifying and organizing the information that will be needed.

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<sup>4</sup> CGS Section 19a-79

### **Helpful Hints for Families and Birth to Three Providers in Transitioning Children With Complex Medical Needs to Preschool Programs**

- **Prior to the 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 Planning and Placement Team (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.

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## **Appendices Index**

- 1. *CSHCN Complexity Index***
- 2. *Health Care Financing Resources***
- 3. *AAP Emergency Plan for CSHCN***
- 4. *Directions: A Guide for Families***
- 5. *Ecomapping***
- 6. *Glossary***
- 7. *Resources***
- 8. *Federal Poverty Guidelines 2007***

# APPENDIX 1

## CONNECTICUT MEDICAL HOME CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS COMPLEXITY INDEX

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

**CONNECTICUT MEDICAL HOME  
CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS  
COMPLEXITY INDEX GLOSSARY**

*A complexity score for each identified child will help providers/staff prepare and budget time more effectively for each child. It will also help administrators justify essential extra time spent by the practice in the care and support of the children and their families.*

**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 US 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 one 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 & 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 medial 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.

**Care Coordination Activity Examples:**

- Providing assessments and monitoring of child and family needs
- Participating in parent/professional practice improvement activities
- Offering supportive services including counseling, education and listening
- Facilitating communication among PCP, family and others
- Developing, monitoring, updating and following up with care planning and care plans  
organizing wrap around teams with families

- Supporting meeting recommendations and follow-up
- Coordinating inter-organizationally
- Advocating with and for the family (e.g. to school, daycare, or health care settings)
- Finding, coordinating and promoting effective and efficient use of current resources
- Monitoring outcomes for child, family and practice and other activities needed and/or requested by the child and family.

**“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.).

## **Appendix 2 Health Care Financing Resources**

There are a number of public sources of funding to assist some families with their child's medical expenses. Additionally there are resources to assist families in clarifying their insurance coverage. The following table is designed to give Birth to Three providers and parents an overview of these resources. The table includes web sites and/or 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.

Program	Eligibility Criteria	Resources/services provided	Application/Contact/Information
HUSKY A (Medicaid, Title 19)	<ul style="list-style-type: none"> <li>➤ For children: 185% of the Federal Poverty Limit <sup>5</sup></li> <li>➤ Resident of CT under 19 years of age or primary caregiver with a child under 19</li> <li>➤ Eligible if pregnant</li> <li>➤ U.S. citizen, legal alien or permanent resident</li> </ul>	<p>This is a program for low income groups. Children under 21 are eligible for EPSDT (Early Periodic Screening Diagnosis And Treatment), which is a comprehensive child health benefit package in addition to the covered services under CT Medicaid including:</p> <ul style="list-style-type: none"> <li>➤ Inpatient hospital</li> <li>➤ Outpatient hospital</li> <li>➤ Labs and x-rays</li> <li>➤ Nursing facilities for age 21 and older</li> <li>➤ Physician services</li> <li>➤ Home health services</li> <li>➤ Nurse mid-wife services</li> <li>➤ Pediatric and family nurse practitioners</li> <li>➤ Medical and surgical services of a dentist</li> </ul>	<ul style="list-style-type: none"> <li>➤ Apply by phone or mail</li> <li>➤ 45 day limit to process HUSKY A</li> <li>➤ HUSKY A coverage may begin up to three months prior to application.</li> <li>➤ Eligibility is renewed every 12 months.</li> <li>➤ Same day determination for children seen at qualified health centers</li> <li>➤ Must select and use a managed care network.</li> </ul> <p><b>1-877-CT-HUSKY</b>  <a href="http://www.huskyhealth.com/">http://www.huskyhealth.com/</a></p>

<sup>5</sup> The Federal Poverty Limit Table can be accessed at:  
<http://www.cms.hhs.gov/MedicaidEligibility/Downloads/POV07ALL.pdf>.  
The FPL Table for 2007 is in Appendix 8. These limits change in April of each year.

Resources	Eligibility Criteria	Resources/ services provided	Contact Information
Katie Beckett Waiver	<p>This program looks only at the income and assets of the child for purposes of eligibility determination. The application itself will ask for parental/household income, but does not count this income towards eligibility.</p> <p>Child must have a medical condition that requires a skilled level of care: home health aide, LPN or RN</p> <p>The cost of care must be less than or equal to placement in a skilled facility.</p>	Provides the full range of Medicaid services including home health/nursing service	Call <b>800-445-5394 or (860) 424-4904</b> . The program is administered through the Connecticut Department of Social Services, the agency that administers the state Medicaid programs.

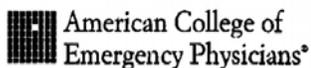
Program	Eligibility Criteria	Resources/ services provided	Contact/ information
SSI: Supplemental Security Income through Social Security	<p>Available to children ages birth to 18 when they meet the definition of disability for children and income and resources of parents are within allowable limits. 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 state agency needs more information, they will arrange an examination for the child, which SSA will pay for. Call SSA at 1-800-325-0778 for current income eligibility information. Income is typically at or below the eligibility for Medicaid and is therefore a low income program. Some assets are allowed.</p>	<p>A monthly payment to assist in meeting the care needs of the child with a disability in the household</p>	<p><a href="http://www.ssa.gov/d&amp;s1.htm">http://www.ssa.gov/d&amp;s1.htm</a></p> <p>Call <b>1-800-772-1213</b> (TTY <b>1-800-325-0778</b>) or contact your local Social Security Office to set up an appointment to complete the SSI application form in person or over the phone. You can locate your local office online at <a href="https://s044a90.ssa.gov/apps6z/FOLO/fo001.jsp">https://s044a90.ssa.gov/apps6z/FOLO/fo001.jsp</a></p>

Program	Eligibility Criteria	Resources/ services provided	Contact/ information
Title V	<p>This program is administered through the Department of Public Health. The program is for Children and Youth up to age 21 who meet the definition of special health care needs: "Children &amp; Youth with Special Health Care Needs (CYSHCN) 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. The household income must be less than or equal to 300% of the Federal poverty level. The program primarily covers underinsured families.</p>	<p>The Title V program extended services funds provide medically necessary and appropriate durable medical equipment and approved extended services. Clinical services will not be covered through these funds. The services must be related to the condition that qualified the child for the program. The list of specific extended services that are covered under this program can be obtained from the Department of Public Health at 860-509-8057.</p> <p>The program also offers limited access to respite funds for eligible families. Please note that due to the limited availability of funds, there is a \$500 per family maximum per year for Respite funds, including camp within the availability of funds.</p>	<p>Child Development Infoline (CDI) serves as the access point for the Connecticut Children and Youth with Special Health Care Needs (CYSHCN) Initiative Program. CDI Care Coordinators can provide general information and referrals to community based services for the families of these children. Call toll free at 1-800-505-7000." Connecticut Lifespan Respite Coalition provides information on extended services and respite funds. They can be reached by calling 860-513-0172 or toll free at 1-877-737-1966.</p>

### Appendix 3

## AAP Emergency Plan for Children with Special Health Care Needs

# Emergency Information Form for Children With Special Needs



American Academy  
of Pediatrics



Date form  
completed  
By Whom

Revised  
  
Revised

Initials  
  
Initials

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: _____
_____	_____
_____	_____

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

<b>Management Data:</b>	
<b>Allergies: Medications/Foods to be avoided</b>	and why:
1. _____	_____
2. _____	_____
<b>Procedures to be avoided</b>	and why:
1. _____	_____
2. _____	_____

<b>Immunizations (mm/yy)</b>											
Dates											
DPT											
OPV											
MMR											
HIB											
Dates											
Hep B											
Varicella											
TB status											
Other											
Antibiotic prophylaxis:				Indication:				Medication and dose:			

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

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

**Appendix 4**  
**Directions: A Guide For Families**

# Directions: Resources for Your Child's Care

Third Edition

For information and to obtain this book, visit:  
[Hhttp://www.dph.state.ct.us/Publications/publications.htm](http://www.dph.state.ct.us/Publications/publications.htm)

*Directions* was created for parents of a child with special health needs. It can assist parents to plan and coordinate care for a child with special health care needs.

The notebook contains:

- Ways to organize a child's health information
- Information about caring for a child who has special needs
- Resources
- Tips from parents of children with special health care needs

*Directions* has many forms and a lot of information to read through. This notebook can be very helpful to parents, early intervention providers and health care providers.

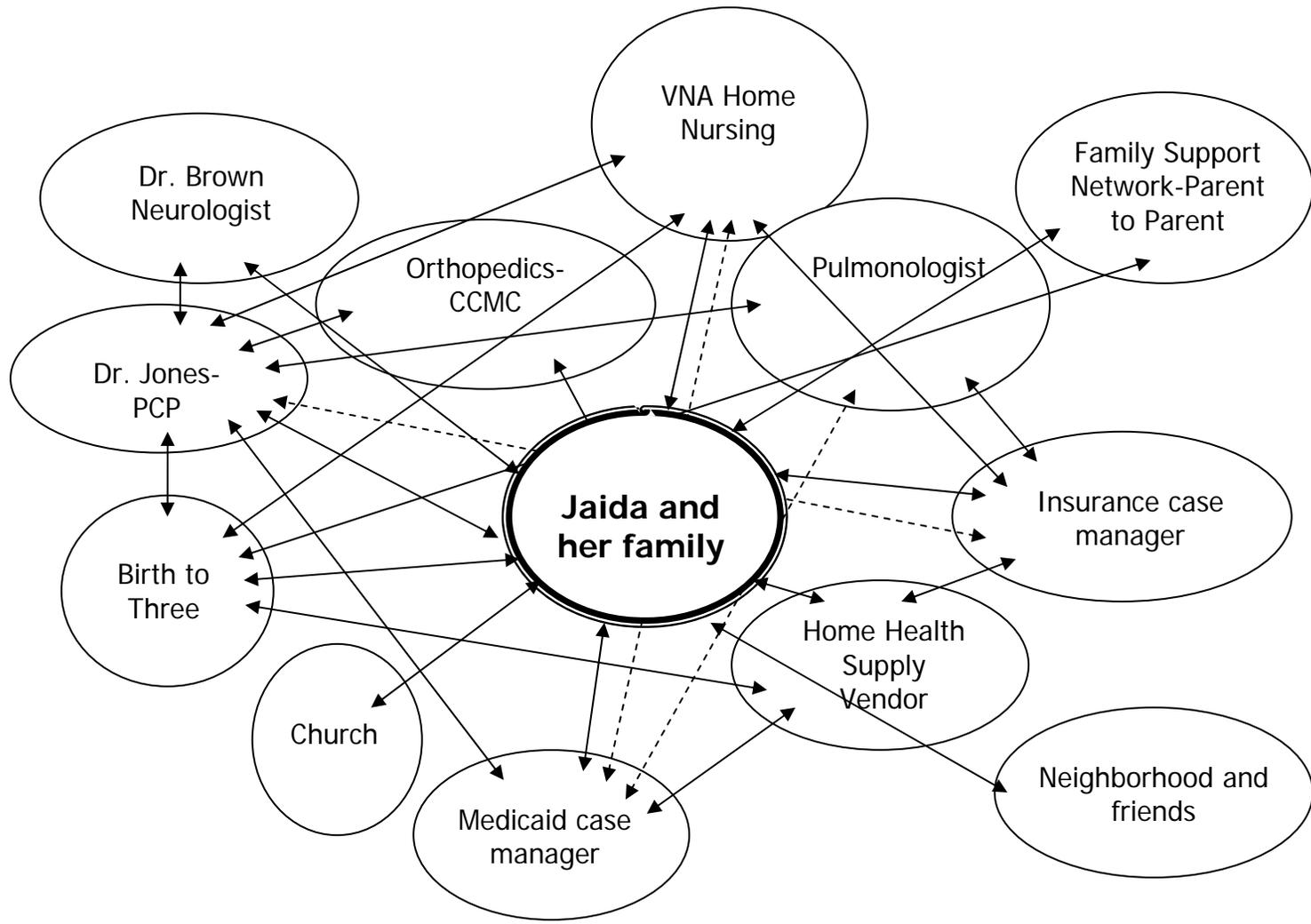
## Appendix 5 Ecomapping

### ECO-MAPPING

An eco-map is a diagram that maps **family** and **community** systems. It can provide a picture of **family support** and **services**.

- Service coordinators can use the eco-map to support or confirm outcomes and as part of family assessment.
- It can be used as a pictorial representation of changes in services/supports needs and priorities over time.
- It is also a useful picture to use in the transition process.

# ECO-MAPPING



**How do all these circles relate to one another and to the child and family?**

For each circle, list the individuals with whom you have contact and draw arrows among the groups they relate with.

## Appendix 6 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.
Birth to Three 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.
CSHCN	Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs
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; cannot be shared without the parent/ legal guardian permission
Consent	The approval that the parent gives for someone to do something; consent in Birth to Three is always voluntary and may be cancelled at any time. Permission to share medical information is given through a written consent form.
Continuity of Care	Complete care that is provided during all transition, such as hospital to home, home to hospital, etc. Planning ensures 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. The amount of the deductible varies by the benefit package or the health insurance program.
DME	Durable Medical Equipment; equipment that is not disposable such as wheelchairs, walkers, oxygen concentrators, ventilators.
Early Intervention	Programs of services designed to meet the developmental needs of infants or toddlers, ages Birth to Three and their families
EPSDT	<b>Early and Periodic Screening, Diagnosis and Treatment:</b> These are mandatory Medicaid benefits and services for Medicaid eligible children and youth under age 21. The services are designed to provide preventative care and treatment.

ERISA	Employee Retirement Insurance Security Act a federal act that allows businesses to develop self funded health insurance programs without control by the state insurance regulations.
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 and reflects this in the way services are planned and delivered. It promotes family/professional partnerships and 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. Those medications not on the list 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 <ul style="list-style-type: none"> <li>1) is developed jointly by the family and the appropriate professionals;</li> <li>2) is based on a multidisciplinary evaluation and assessment of the child and family;</li> <li>3) has a family directed statement of resources, priorities and concerns and</li> <li>4) includes services necessary to enhance the development of the child and enhance the family's capacity to meet the child's developmental needs.</li> </ul>

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. In Connecticut, the Department of Social Services is the Medicaid agency.
Medical home	Refers to 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.
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. This 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; assist in selection or service of assistive technology devices and may provide training in the use of the selected device(s)
Outcomes	Statements of changes as a result of early intervention services. These statements are part of the Individualized Family Service Plan.
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 that provides primary, preventative and non-specialty care, generally from family practice, internal medicine and pediatrics.
SSI	Supplemental Security Income 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 the Birth to Three program who will assist the family to make connections with the people on their team, understand the information given to them, and assists and enables the family to connect to community resources outside of Birth to Three 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	The federal funding from 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.

## Appendix 7 Resources

### National Resources

#### American Academy of Pediatrics

The 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.

141 Northwest Pontre Boulevard, Elk Grove IL 60007 847.434.4000 [www.aap.org/](http://www.aap.org/)

#### Family Village

Family Village is a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support. The website includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more. This is a user friendly website.

The Family Village, [Waisman Center, University of Wisconsin-Madison](http://Waisman Center, University of Wisconsin-Madison), 1500 Highland Avenue, Madison, WI 53705-2280 [www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

#### Family Voices

Family Voices, a national grassroots network of families and friends, advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision makers at all levels of health care; and supports essential partnerships between families and professionals. The website will direct you to the Connecticut contacts, or the national office will provide the information by phone.

Family Voices, Inc., 2340 Alamo SE, Suite 102, Albuquerque, NM 87106 505.872.4774 Toll Free: 888.835.5669 Fax: 505.872.4780 [www.familyvoices.org](http://www.familyvoices.org)

#### Medical Air Transport Services

Patient Travel.Org (Formerly the National Patient Air Transport HELPLINE)

This helpline offers information and referrals regarding air transport options for patients and their families.

4620 Haygood, Suite 1, Virginia Beach, VA 23455 TOLL FREE 1.800.296.1217 [www.patienttravel.org](http://www.patienttravel.org)

## **NICHY: National Dissemination Center for Children with Disabilities**

NICHY stands for the *National Dissemination Center for Children with Disabilities*. They serve as a central source of information on:

- Disabilities in infants, toddlers, children, and youth,
- IDEA, which is the law authorizing special education,
- No Child Left Behind (as it relates to children with disabilities), and
- Research-based information on effective educational practices.

*P.O. Box 1492 Washington, DC 20013 800. 695.0285 · v/tty202. 884.8441 · fax*  
[www.nichy.org](http://www.nichy.org)

## **NORD: National Organization for Rare Disorders**

The 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.

*NORD, 55 Kenosia Avenue, PO Box 1968, Danbury, CT 06813-1968 203.744.0100 Toll free: 800.99.-6673 (voicemail only) TDD Number: 203.797.9590 Fax 203.798.2291* [www.rarediseases.org](http://www.rarediseases.org)

## **Parent to Parent USA (P2P-USA)**

Parent to Parent-USA is a national non-profit 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'. The website will direct you to local contacts in Connecticut. [www.p2pusa.org/](http://www.p2pusa.org/)

## **Prescription Drug Assistance**

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

*NeedyMeds.com 120 Western Ave, Gloucester MA 01930* [www.needymeds.com/](http://www.needymeds.com/)

## **State Resources**

### **CT Academy of Pediatrics**

The Connecticut chapter of the AAP strives to promote the good health of children via its working committees, lobbying efforts, and the dissemination of information to families and those who care for children.

*Hezekiah Beardsley Connecticut Chapter American Academy of Pediatrics*  
*135 Broad Street Hartford, CT 06105 860.525.973 Fax: 860.524.1092*

### **Connect CT—Official Website for the State of CT**

This website provides on line access to all branches, agencies and offices of Connecticut State government including executive, judicial and legislative and all state agency web sites.

[www.ct.gov](http://www.ct.gov)

## **CT Department of Public Health Children and Youth With Special Health Care Needs Program**

The State of Connecticut Department of Public Health, Bureau of Community Health, Family Health Division strives to enhance the quality of care and services provided to Children & Youth with Special Health Care Needs (CYSHCN) and their caregivers and families.

*Department of Public Health, 410 Capitol Avenue, MS #11MAT, PO Box 340308*

*Hartford, CT 06134-0308, Phone: 860-509-8057, Fax: 860-509-7720*

[www.ct.gov/dph](http://www.ct.gov/dph) Click on "Programs and Services" at the top and then click on "Children and Youth With Special Health Care Needs".

## **CT Department of Public Health, Office of Oral Public Health, "OPENWIDE"**

OPENWIDE is a statewide oral health training program for non-dental health and human services providers, including physicians, nurses, nutritionists, childcare and outreach workers, and others. OPENWIDE TRAINING IS DESIGNED TO:

- Educate, build awareness and integrate oral health into existing health systems
- Enable non-dental providers to recognize and understand oral diseases and conditions
- Enable non-dental providers to engage in anticipatory guidance and prevention interventions and make appropriate referral for improved oral health
- Make a positive impact on overall health and well-being through improved oral health.

*CT Department of Public Health, Office of Oral Public Health, 410 Capitol Avenue, MS #11ORH, PO 340308, Hartford, CT 06134-0308, Phone 860-509-8203 [www.ct.gov/dph](http://www.ct.gov/dph) Click on "Programs and Services" at the top and then click on "Oral Health".*

## **The Connecticut Family Support Council AND The Connecticut Family Support Network**

The CT Family Support Network is a network of families who have children with disabilities. They are parents interested in helping other parents to find the supports they need. The Network was created by the Connecticut Family Support Council, a legislatively established partnership of parents and professionals working to improve supports for families of children with disabilities.

[www.ctfsc.org](http://www.ctfsc.org) 1-877-FFN@day

## **Connecticut Family to Family Health Information Network**

The Family to Family Health Information Network can assist families with resource information on health care, and direct advocacy and support in accessing health care and health financing resources.

*Joy Liebeskind, Coordinator, 2138 Silas Deane Highway, FAVOR, Inc., Suite 100 Rocky Hill, CT 06067. 860-563-3232, ext 108*

## **Connecticut Parent Advocacy Center, Inc. (CPAC)**

The Connecticut Parent Advocacy Center (CPAC) is a statewide nonprofit organization that offers information and support to families of children with any disability or chronic illness, age birth through 26. The Center is committed to the idea that parents can be the most effective advocates for their children, given the confidence that knowledge and understanding of special education law and its procedures can bring.

338 Main Street, Niantic CT 06357 860.739.3089 V/TDD Toll Free 800.445.CPAC  
Fax: 860.739.7460 E-mail [cpac@cpacinc.org](mailto:cpac@cpacinc.org) [www.cpacinc.org](http://www.cpacinc.org)

## **Connecticut Office of the Healthcare Advocate**

The mission of the Office of the Healthcare Advocate is to assist consumers with health care issues through the establishment of effective outreach programs and the development of communications related to consumer rights and responsibilities as members of managed care plans. The Office provides consumer-friendly assistance to those who may be confused about health care in general and need help in working through various managed care issues. The Office of the Healthcare Advocate can assist Connecticut residents who belong to managed care/HMO health plans. They can answer questions about managed care, assist in understanding the referral or pre-authorization process or provide assistance with the appeal/grievance procedures.

Office of the Healthcare Advocate, P.O.Box 1543, Hartford CT, 06144  
Toll Free 866.HMO.4446 FAX: 860.297.3992  
E-mail: [Healthcare.advocate@ct.gov](mailto:Healthcare.advocate@ct.gov) [www.ct.gov/oha](http://www.ct.gov/oha)

## **Connecticut Lifespan Respite Coalition**

The Connecticut Lifespan Respite Coalition seeks to establish quality respite services in Connecticut. They can assist in locating respite resources in the state.

Joy Liebeskind, Coordinator, FAVOR, Inc. , 2138 Silas Deane Hwy. , Rocky Hill, CT, 06067 860.247-2572  
Fax 203.272.9058, [CTRespite@cox.net](mailto:CTRespite@cox.net) , [www.CTRESPITE.org](http://www.CTRESPITE.org)

## **HUSKY**

The **HUSKY** Plan is designed to help all children who don't have health insurance. It includes services under the traditional Medicaid program (now known as **HUSKY** Part A). It also provides health services for children in higher-income families (called **HUSKY** Part B).The program also offers also **HUSKY Plus**--a new coverage option for children who have intensive physical or behavioral health needs.

**HUSKY** Plan, P. O. Box 280747, East Hartford, CT 06108,  
Toll Free 1-877-CT-HUSKY (1-877-284-8759) [www.huskyhealth.com](http://www.huskyhealth.com)

## **Katie Beckett Waiver**

The Katie Beckett Waiver program is for children who have a skilled or complex level of care, and for whom the cost of care at home would not exceed the cost of care in a medical facility. The program waives the income/asset limits for the household and looks only at the income/assets of the child in determining eligibility for Medicaid. Eligible children receive a Medicaid card and access to all Medicaid services, including home health care, prescriptions, primary and specialty care, transportation and equipment. There is typically a wait (as long as several years) for this program, and families who believe their child would benefit from this program should call **800-445-5394 or (860) 424-4904**. The program is administered through the Connecticut Department of Social Services, the agency that administers the state Medicaid programs.

## **New England Assistive Technology NEAT Marketplace**

NEAT was established to provide information and access to equipment and devices that can change the lives of people of all ages, with all types of disabilities, both temporary and permanent. NEAT is a contracted provider of Assistive Technology services to Birth to Three. They can provide assessments, loan equipment for trial before purchase, and they house a used equipment bank. Families and providers can visit the center to try equipment.

*The New England Assistive Technology Marketplace, 120 Holcomb Street, Hartford, CT 06112  
860-286-3113 TTY, Toll Free in CT: 866-526-4492 or (860) 243-2869 in the Hartford area  
E-Mail: [info@neatmarketplace.org](mailto:info@neatmarketplace.org) [www.neatmarketplace.org](http://www.neatmarketplace.org)*

## **PATH Parent to Parent**

PATH is a network of families providing informational and emotional support to others who have a child with developmental or health related needs. PATH reaches out to help strengthen families coping with similar situations in Connecticut, and the organizations that serve them to reduce isolation, empower families as advocates for their children and reaffirm their values as parents and caregivers.

*Parents Available to Help, Inc., P.O. Box 117, Northford, CT 06472,  
1-800-399-PATH (CT only) or 1-203-234-9554 [www.pathct.org](http://www.pathct.org)*

## **Special Kids Support Center at Connecticut Children's Medical Center**

The Special Kids Support Center is a department at Connecticut Children's Medical Center dedicated to helping families who have children with special needs. The Center's goal is to provide assistance with care coordination, disability related information and community resources to families caring for a child with special needs. All families of children with special health care needs are eligible. The Center can offer expert medical guidance on disability related issues to parents, caregivers and community service providers. Our team includes a Physiatrist, a Developmental Pediatrician, a Nurse Practitioner, nurses, social workers, parent advocates, resource and benefits specialists and administrative staff that work together to help meet the family's needs

*146 Wyllys Street, Hartford, CT 06106 Phone: 860.545.9230 Toll-free at 1.877.743.5516  
Fax 860. 545.9201 [www.ccmckids.org/programs/ccsn.asp](http://www.ccmckids.org/programs/ccsn.asp)*

## Appendix 8 Federal Poverty Guidelines 2007

### FEDERAL POVERTY LEVELS (FPL) 4/1/07-3/31/08

Federal Poverty Levels are established by the U.S. Dept. of Health and Human Services. These guidelines are used to determine income eligibility for many local, state, and federal programs.

Annual income limits derived from U.S. Dept. of Health and Human Services,  
<http://aspe.hhs.gov/poverty/07poverty.shtml>

#### Annual Income Guidelines

Family Size	100%	125%	
<b>1</b>	10,210.00	12,762.50	
<b>2</b>	13,690.00	17,112.50	
<b>3</b>	17,170.00	21,462.50	
<b>4</b>	20,650.00	25,812.50	
<b>5</b>	24,130.00	30,162.50	
<b>6</b>	27,610.00	34,512.50	
<b>7</b>	31,090.00	38,862.50	
Family Size	130%	185%	
<b>1</b>	15,315.00	18,888.50	
<b>2</b>	20,535.00	25,326.50	
<b>3</b>	25,755.00	31,764.50	
<b>4</b>	30,975.00	38,202.50	
<b>5</b>	36,195.00	44,640.50	
<b>6</b>	41,415.00	51,078.50	
<b>7</b>	46,635.00	57,516.50	
<b>8</b>	51,855.00	63,954.50	
<b>Each add'l person, add:</b>	5,220.00	6,438.00	
<b>8</b>	34,570.00	43,212.50	
<b>Each add'l person, add:</b>	3,480.00	4,350.00	

Family Size	235%	250%	
1	23,993.50	25,525.00	
2	32,171.50	34,225.00	
3	40,349.50	42,925.00	
4	38,202.50	51,625.00	
5	56,705.50	60,325.00	
6	64,883.50	69,025.0	
7	73,061.50	77,725.00	
8	81,239.50	86,425.00	1
<b>Each add'l person, add:</b>	8,178.00	8,700	

### Monthly Income Guidelines

Family Size	100%	125%	
1	850.83	1,063.54	
2	1,140.83	1,426.04	
3	1,430.83	1,788.54	
4	1,720.83	2,151.04	
5	2,010.83	2,513.54	
6	2,300.83	2,876.04	
7	2,590.83	3,238.54	
8	2,880.83	3,601.04	
<b>Each add'l person, add:</b>	290.00	362.50	

<b>Family Size</b>	<b>235%</b>	<b>250%</b>
<b>1</b>	1,999.46	2,127.08
<b>2</b>	2,680.96	2,28
<b>3</b>	3,362.46	3,577.08
<b>4</b>	4,043.96	4,302.08
<b>5</b>	4,725.46	5,027.08
<b>6</b>	5,406.96	5,752.08
<b>7</b>	6,088.46	6,477.08
<b>8</b>	6,769.96	7,202.08
<b>Each add'l person, add:</b>	681.50	725.00

<b>Family Size</b>	<b>130%</b>	<b>185%</b>
<b>1</b>	1,276.25	1,574.04
<b>2</b>	1,711.25	2,110.54
<b>3</b>	2,146.25	2,647.04
<b>4</b>	2,581.25	3,183.54
<b>5</b>	3,016.25	3,720.04
<b>6</b>	3,451.25	4,256.54
<b>7</b>	3,886.25	4,793.04
<b>8</b>	4,321.25	5,329.54
<b>Each add'l person, add:</b>	435.00	536.50