

# CSHCN Orientation Notebook

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# Introduction

## Welcome to the Children with Special Health Care Needs Program

Our purpose of this Notebook is to provide useful information for new and experienced Children with Special Health Care Needs (CSHCN) Coordinators and other Public Health Nurses working with children and their families.

All of the information has been contributed by CSHCN Coordinators throughout Washington State to share with other Coordinators. Inclusion of these materials does not constitute an endorsement of the organizations, their materials, or websites by the Department of Health (DOH), Children with Special Health Care Needs Program and should not be inferred. DOH is not responsible for the content of the individual organization's materials or information found at their websites.

This notebook is intended to be a companion to both the [Children with Special Health Care Needs Policy and Procedure Manual](#) ("the Manual") and [Nutrition Interventions for Children with Special Health Care Needs](#), both available on the DOH website.

Information and resources are intended to be used as they fit your needs. Everything printed and placed in this Notebook can be copied without any copyright infringements. We encourage you to add information specific to your county and any other helpful materials you have accumulated along the way so this notebook becomes a practical guidebook for your day-to-day use.

## Acknowledgements

This notebook was the combined effort of many CSHCN Coordinators throughout the state and the Children with Special Health Care Needs Program staff. The Southwest CSHCN Coordinators originated the idea of an Orientation Notebook for new CSHCN Coordinators and contributed many hours to its formation.

## Mission

Our mission is to promote integrated systems of care that assure that children with special health care needs have the opportunity to achieve the healthiest life possible and develop to their fullest potential. We promote access to integrated, family centered, culturally competent and community based programs and services.

## Definition

The Children with Special Health Care Needs Program serves children who have serious physical, behavioral or emotional conditions that require health and related services beyond those required by children generally. In Washington State, children who participate in this program must be under the age of 18 years at initial enrollment and have, or be at risk of developing a serious or chronic condition including but not limited to: diabetes, neuromuscular disorders, cancer, AIDS, sickle cell anemia, asthma, cystic fibrosis, hearing or visual impairments, cleft palate, kidney disease, ventilator dependency, or metabolic disease. Some children who are already part of the program may be able to continue services until the twenty- first birthday for purposes of transition to adult care.

## Website

<http://www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds.aspx>

# CSHCN Frequently Asked Questions

## Where do I get the answers to questions about the CSHCN Program?

There are several places to find answers about the CSHCN Program. Looking in your CSHCN Manual or this Orientation Notebook, talking to other CSHCN Coordinators in your region through personal contact or regional meetings <http://www.doh.wa.gov/Portals/1/Documents/Pubs/970-141-CoordinatorList.pdf>, or calling or emailing any staff member at the CSHCN Program at DOH would be good places to start.

## Where do I find forms and places for documentation?

If you can't find the forms you need in the Manual or Notebook, talk to your agency about agency-specific forms you may need. Once again, contacting other CSHCN Coordinators or the DOH CSHCN staff may be helpful.

## How do I access Diagnostic and Treatment Funds? What are the eligibility requirements?

The process to access these funds is outlined in the CSHCN Manual, Section 6000. Eligibility is tied to the family's resources. Two phrases should be kept in mind whenever you are considering providing an item to a child: "medically necessary" and "payor of last resort". If you can't find all the answers in the Manual, you may also call a CSHCN staff member for help.

## When do I CHIF?

A CHIF (Child Health Intake Form) should be completed on any child you serve and submitted to the CSHCN Program. Information on the definition of "serve" and other details are explained in the Manual, Section 5000.

## What services does my client qualify for?

There are many services available for children with special health care needs and their families. Different families qualify for different services. You will need to begin by finding out basic information on your client, such as the age, diagnosis, whether they qualify for Medicaid as well as the needs of the family. You can then begin the process of finding appropriate services. Consider calling the Answer for Special Kids (ASK) Line at WithinReach (1-800-322-2588) or going to the WithinReach website, [www.parenthelp123.org](http://www.parenthelp123.org). They have a broad list of available services that can help you decide what to offer the child and family.

Children birth to three with developmental concerns warrant a call to a Family Resources Coordinator (FRC) who can help with the evaluation process for the Early Support for Infants and Toddlers (ESIT) at the Department of Early Learning (DEL), [www.del.wa.gov](http://www.del.wa.gov). If the child qualifies for ESIT, the FRC can arrange the appropriate services. If the need is for financial help paying bills, this Notebook contains a chapter on financial resources and how to access them. The Manual also contains financial information.

If the concern is feeding issues, you may want help from a registered dietician. Your agency will have the name of a registered dietician or you may call the DOH CSHCN Program for information on the CSHCN Nutrition Network. The CSHCN Program works closely with Neurodevelopmental Centers and the Maxillofacial Teams. Their information is available in the Manual. Connecting the family with parent groups such as Washington State Parent to Parent and Washington State Father's Network is a great way for families to discover other services and resources. Once again, other CSHCN Coordinators and the CSHCN staff at DOH will be able to help you. For more information on Head Start and Early Childhood Education and Assistance Program (ECEAP), go to their website at [www.del.wa.gov](http://www.del.wa.gov).

**Who should be the care coordinator for a child between birth and 3 years of age if the child has developmental delays? What is the difference between the FRC's role and that of a public health CSHCN Coordinator?**

Each community should have an integrated and collaborative system in place to make sure children and families are served well and with a minimum of confusion. Each child's special needs must be considered, and the family must be an equal partner in decision-making for all aspects of their child's care, including who they want to act as their care coordinator. Legal requirements for eligibility vary between programs and need to be considered, as well.

Hopefully, the following training and job criteria for each of these important community partners will be helpful in considering the best fit for the child's and family's needs:

## **Family Resources Coordinator**

Family Resources Coordinators (FRC) are trained through the Early Support for Infants and Toddlers Program and learn the skills needed to work with families and with other providers in their communities. The focus of the FRC is to ensure that children with developmental delays are given access to early intervention programs which enable the child to develop to his fullest potential.

FRC processes may include:

- ✿ Coordinating all services across agency lines;

- ✿ Serving as a single point of contact in helping parents to obtain the services and assistance they need;
- ✿ Assisting parents in gaining access to early intervention services and other services identified in the family service plan developed for each child;
- ✿ Coordinating the provision of early intervention services and other services that the child needs or is being provided; and/or
- ✿ Facilitating the timely delivery of available services; and continuously seeking appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.

## Children with Special Health Care Needs Coordinator

Children with Special Health Care Needs Coordinators are formally trained in a health care field and often, though not always, are Registered Nurses. The goal of CSHCN Coordinator intervention is to facilitate access to care. In addition, Coordinators may identify potential problems, prevent secondary complications for children who are at high risk, and identify early health and developmental problems. Their focus is not only on the child with a special health or developmental needs but also on the impact of the child's needs on the family and on the services needed within the community to support the family.

Interventions may include focused screening to:

- ✿ Identify a child's potential/actual health or developmental needs; and/or
- ✿ Identify family strengths, concerns, priorities, and resources.

And provide information about:

- ✿ Child's health or developmental status;
- ✿ How to reduce risk factors for poor health, nutritional, or developmental outcomes;
- ✿ Developmentally appropriate experiences to promote growth and development;
- ✿ Typical family responses and feelings;
- ✿ Available therapeutic and family support services; and/or
- ✿ How to find and obtain services.

## Where do I find more information about Special Education and 504 Plans?

Call your local Educational Service District (ESD) for information or look on the website of the Office of the Superintendent of Public Instruction (OSPI), Special Education at <http://www.K12>.

[wa.us/specialed/](http://wa.us/specialed/) or call them at (360) 725-6075. The school nurses at your local schools have information about the 504 Plans.

Section 504 of the Rehabilitation Act of 1973 guarantees accommodations for children with special needs at school. This Act also applies to adults in the workplace. A 504 Plan is a legal document that falls under the provisions of Section 504 of the Rehabilitation Act of 1973. A student with a physical or emotional disability or one who has an impairment that restricts his or her ability to walk, see, hear, speak, or learn may be considered for a 504 Plan. A 504 Plan is not an Individualized Education Program (IEP). IEPs are for students enrolled in a Special Education Program. There are lots of statutes and rules that govern 504 Plans and IEPs. Consult the OSPI website for more information.

## Where do I find growth charts?

Growth chart are found on the CDC website [www.cdc.gov](http://www.cdc.gov). More growth chart references are in the Nutrition Section of this Notebook.

## Where do I find disease-specific information?

Disease-specific information can be found in a number of places. The “Resource” chapter of this Notebook gives you links to easily accessed sites such as [www.cshcn.org](http://www.cshcn.org) and others.

## What is a Medical Home?

A Medical Home (also known as Health Home) is an approach to providing health care in a high-quality and cost-effective manner through a partnership between families and providers. Children receive the care they need from a primary care provider with referrals and access to other health care professionals.

According to the 2005-6 National Survey of CSHCN, 14.3% of children have a special health care need in Washington State and less than 50% of those have a medical home. The questions asked of parents in the National Survey of CSHCN serving as indicators of a medical home were around the following:

- ✿ Their child’s usual source of care
- ✿ Their child’s personal doctor or nurse
- ✿ Referrals for specialty care
- ✿ Coordinated care
- ✿ Family-centered care

The state CSHCN program is charged with developing strategies to improve the Maternal Child Health Bureau’s (MCHB) Performance measure on Medical Home which states “all children

with special health care needs in Washington State will receive regular ongoing comprehensive care within a Medical Home.” The State CSHCN Program works on this performance measure through leadership, contracts and other program activities.

## What is the history of Medical Home?

- 1967 1<sup>st</sup> known documentation of the term “medical home” was written by the American Academy of Pediatrics (AAP) Council on Pediatric Practice in Standards of Child Health Care, which says “For children with chronic diseases or disabling conditions, the lack of a complete record and a “medical home” is a major deterrent to adequate health supervision.”
- 1974 Council on Pediatric Practice held a meeting to begin developing a policy statement to address the delays and gaps in healthcare for children; the AAP made a commitment to the “Every child deserves a Medical Home” principle. Interesting to note, there was a discussion at that time about the term “Medical Home” replacing “family physician” and “pediatrician” but the AAP Board of Directors rejected the idea.
- 1977 AAP Board of Directors published a statement noting “Quality care is also best provided when all the child’s medical data are together in one place (a medical home), readily accessible to the responsible physician or physicians.”
- 1979 Medical Home concept began to evolve from a repository for medical records to a method of providing primary care which would address the total needs of the child and family.
- 1980’s Dr. Calvin Sia from Hawaii developed a method for delivering care in his practice which involved the inherent relationship between the parent and the pediatrician. He led the movement in Hawaii to have the medical home concept adopted into Hawaii’s Child Health Plan. He suggested that the pediatrician is the point of first contact for the child and family; linkages for resources and services must be ensured.
- 1989 MCHB awarded a grant to Hawaii Medical Association to develop a medical home curriculum for pediatricians caring for children with special health care needs. Four other states, including Washington, developed a similar curriculum.
- 1999 Shriners Hospitals, AAP, MCHB, NACHRI (National Association of Childrens Hospitals and Related Institutions), Family Voices all endorsed a curriculum promoting Medical Home.
- 2000 Medical Home becomes MCHB National Performance Measure

The above information has been taken from several articles in the Supplement to the journal, Pediatrics, vol. 113, no 5, The Medical Home.

## Where does the CSHCN Coordinator fit into a Medical home?

Not all providers have a practice that meets the criteria of a medical home. In 1999 the AAP outlined the components of a medical home with the understanding that the family is the primary source of strength and support for each child and that the family is the primary care coordinator for their own child. A medical home must:

- 1) Provide preventive care
- 2) Assure ambulatory and inpatient care 24 hr/day
- 3) Offer continuity of care for infants through adolescents
- 4) Offer appropriate use of subspecialty consults and referrals
- 5) Have interaction with schools and communities
- 6) Have central medical records and database

Bonnie Strickland in Pediatrics, Vol 113, No 5, May 2004, noted that “Care coordination may be the element that most distinguishes medical home from a traditional pediatric practice.” The CSHCN Coordinator often acts as a care coordinator for the children with special needs in her community and is in the unique position to know and understand the needs of each family, advocate for family-centered care, and promote each child’s need to have a medical home.

The Coordinator has the opportunity to:

- ✿ meet with the pediatricians in the community to promote medical homes
- ✿ explain the purpose and services of the local and state CSHCN Program
- ✿ provide resource information
- ✿ become part of the child’s medical home by providing care coordination for the family

For more information on the promotion of Medical Homes in Washington State and how you can become involved, contact the Medical Home Leadership Project at <http://www.medicalhome.org> or go the DOH website on Patient-Centered Health Homes at <http://www.doh.wa.gov/PublicHealthandHealthcareProviders/PublicHealthSystemResourcesandServices/LocalHealthResourcesandTools/HealthyCommunitiesWashington/HealthHOMe.aspx>.

# CSHCN Companion Volumes

## Children with Special Health Care Needs Manual

- Section 1000 Mission and Philosophy
- Section 2000 Legal Authority
- Section 3000 Organization
- Section 4000 Program Eligibility
- Section 5000 Client Intake Management
- Section 6000 Authorization and Payment
- Section 7000 Fiscal and Contract Management
- Section 8000 Information and Data Management
- Section 9000 Service System Development
- Section 10000 Early Identification Services
- Section 11000 Intervention
- Section 12000 Resource Information
- Appendices

## Nutrition Interventions for Children with Special Health Care Needs

- Section 1 Determination of Nutrition Status
- Section 2 Problem-Based Nutrition Interventions
- Section 3 Condition-Specific Nutrition Interventions Appendices (Includes Growth Charts)



# The Role of the CSHCN Coordinator

If you are new to the CSHCN Program, you may have many questions on what you should be doing as the Coordinator of the CSHCN Program. If you are from a smaller county, you may have many other duties as well as the CSHCN Program. Start with the Children with Special Health Care Needs Manual for orientation to the Coordinator's responsibilities as well as the policies and procedures of the CSHCN Program. The information in this section will briefly review the role of the CSHCN Coordinator with regard to community involvement and care coordination.

The role of the CSHCN Coordinator varies depending on the local health jurisdiction (LHJ). They must, to some degree, assure care coordination or resource coordination occurs for the children with special health care needs in their community. How they do this will depend on the resources available. Some Coordinators are conducting home visits, assessing the child and family's needs and connecting them to needed resources. Others are providing care coordination through a one-time telephone call or clinic visit. The CSHCN Coordinator may work closely with the local school district to assure services are in place for school age children in their community. Please note—the level of care coordination may range from very simple (assuring through a telephone call that the child is enrolled in managed care or has a medical provider and transportation to the provider) to very complex (including a home visit). If the agency does not have the resources to do a minimal amount of CSHCN care or resource coordination, they should contact the CSHCN Program for help in deciding how to use the consolidated contract dollars for the children with special health care needs in your community. There might be a more appropriate organization to provide CSHCN services.

The terms “care coordination” is often used interchangeably with “case management” or “patient navigation” or even “resource coordination.” A review of the literature shows slight variations in the definitions, adds even more terms (care management, care navigation, disease management) and demonstrates that experts in the care coordination field have not agreed upon a standardized definition. Care coordination may be performed in a provider office or a community setting and includes the concept of connecting children and their families to comprehensive health care and community resources.

Child Health Intake Form (CHIF): A minimum amount of interaction must be done with families of children with special needs in order to complete the required elements in the Child Health Intake Form (CHIF). This information may be obtained through a telephone interaction or a clinic visit as well as the more complex home visits. Please refer to the CSHCN Manual for information on how to complete and submit a CHIF. It is one of the three activities required by the consolidated contract between the LHJ and Department of Health. The three activities are:

- (1) Complete a Child Health Intake Form (CHIF) on each child served and submit it to the CSHCN Program
- (2) Administer and track the Diagnostic and Treatment Funds
- (3) Adhere to the CSHCN Policy and Procedure Manual, including participation in the CSHCN Regional System

There are other activities described in the consolidated contract focus of work that may be undertaken to the extent allowed by each LHJ. Please see the Department of Health website for the consolidated contract information on the CSHCN Focus of Work.

The CSHCN Coordinator has the opportunity to be part of the CSHCN Regional Network of Coordinators who meet regularly to discuss mutual issues and brainstorm solutions to problems. Each year one of the Coordinators from each region takes a turn as a Regional Representative at the Communication Network meetings. These are opportunities for the Coordinator to meet and form partnerships with other community professionals who interact with children with special health care needs and their families. Examples of community professionals include, but are not limited to, Family Resources Coordinators, registered dietitians, social workers, representatives from Parent to Parent and Fathers Network, and managed care organizations. A description of the Regional System and Communication Network as well as the importance of parent involvement in regional meetings follows. For more information, see CSHCN Manual, Section 3000.

Family-centered care is a key ingredient to providing excellent health care and coordination of services for children with special needs. Part of the process of developing our capacity at the local level is to create meaningful opportunities for parents to provide input at regional meetings, and also simply to encourage their attendance. The CSHCN Program has increased their capacity to involve parents in a meaningful way in program planning and implementation of programs over the last decade. Your partnership at the local level to promote inclusion of the family perspective in meetings will lead to the best possible innovations in program planning for your community. Some examples of family-centered care are included at the end of this chapter.

Involvement in your local community is dependent on the needs and capacity of your local health jurisdiction. Many coordinators find themselves participating on the Interagency Coordinating Council, Medical Home Team, Safe Kids Coalition, Oral Health Coalitions, as well as providing organization and input to care coordination meetings, schools, and child abuse or neglect teams that may be present in your community. There is no “right way” to become involved and participate in these meetings. Check with your supervisor about their expectations and budget. CSHCN Regional meetings are also a great place to exchange ideas on what other coordinators are doing. The state CSHCN Program has Power Point presentations on the background of CSHCN and Title V that can be shared when you participate in community meetings and need information on the Title V program. A more detailed discussion on the

mission and philosophy of the State CSHCN program is available in your CSHCN Manual, Sections 1000 and 2000. Section 3000 contains a list of clinical and administrative activities as well as involvement in your local community.

# Developmental Screening

Developmental Screening is a brief, objective, and validated test that is performed at specific points in time. It may also be performed whenever a caregiver expresses concern about a child. Generally, developmental screening tests are performed at ages 9, 18, and 20/30 months.

A validated screening tool generally takes a short time to perform and increases the ability to identify a developmental delay at an early age. With a screening tool, identification of a developmental disability is about 70-80% compared to 30% without a screening tool. Additionally, identifying a mental health problem using a screening tool increases from 20% without a tool to 80-90% with a tool.

Children who are screened early are identified early. They are then referred to an early intervention program early and have improved outcomes in development, behavior, and school readiness. Many resources for early screening are available including the [MCH Learning Network](#) (aka MCH Compendium)

The role of the CSHCN Coordinator in assuring developmental screening is performed for all children, whether they have an identified special health care need or not, will vary from county to county. You may be doing developmental screening on children yourself if you still do home visits or provide some direct care. Or, you may work with others to assure a comprehensive system of universal developmental screening system is present in your community.

LHJs can choose to be a part of a statewide initiative to promote universal developmental screening through funding in the MCH Consolidated Contract. The Universal Developmental Screening Partnership was formed in 2009 and is an active committee committed to promoting developmental screening for all children. More information, including the history and partners of the Universal Developmental Screening Partnership can be found at [MCH Learning Network](#) (aka MCH Compendium).

## Adverse Childhood Experiences (ACES)

According to the Centers for Disease Control and Prevention (CDC), the Adverse Childhood Experiences (ACE) Study is one of the largest studies ever done to look at the relationship between experiences in childhood and adult health and well-being. The ACES study was a collaboration between the CDC and Kaiser Permanente's Health Appraisal Clinic in San Diego.

Over 17,000 Kaiser Permanente members who were having a physical exam had the opportunity to provide detailed information about their childhood experiences of abuse, neglect, and family dysfunction. The information obtained suggests certain experiences are major risk factors for the leading causes of illness and death as well as poor quality of life. Understanding the problems from childhood may help prevent and/or improve health problems later in life.

The CSHCN Coordinator has a role in understanding and using the information from the ACES study. LHJs can choose to implement activities in their community that relate to ACES in their Consolidated Contract. For more information including literature and web resources, see [MCH Learning Network](#) (aka MCH Compendium).



# The CSHCN Statewide Outcome Project

From 2008-2011, the CSHCN Program worked with the CSHCN Coordinators statewide to agree upon common goals, desired outcomes, and a methodology for collecting outcome data. The result of this collaborative process was the decision to develop a standardized care plan based on the language of the Omaha System. The Omaha System is a research-based standardized documentation system designed to meet the needs of public health nurses for assessment, intervention, and outcomes. The Coordinators who participated in the Outcomes Project completed an Omaha System care plan on the children with special health care needs in their local health jurisdiction and sent it to the state DOH Program for one year. The type and severity of the children who received an Omaha System care plan varied from county to county, depending on county capacity to participate. The data was compiled and a report was completed in 2012. A copy of the Omaha System care plan is attached here. The website to the Omaha System is <http://omahasystemmn.org/>

Name: \_\_\_\_\_ CHIF # \_\_\_\_\_ Child's DOB \_\_\_\_\_ CV/OV  HV  TV

Primary Caregiver/Guardian (ie parent/grandparent/foster parent): \_\_\_\_\_ Date: \_\_\_\_\_ Initial  Interim  Final

The following three boxes indicate whether the child has a Medical Home. Please mark all that apply.

Usually goes to a specific place or provider for medical treatment/advice when ill.

Has a personal doctor/nurse who the family states knows them well and is familiar with their child's health history.

Medical provider usually makes referrals and coordinates health services as needed.

**Growth and Development (Child)**

K 1 2 3 4 5					B 1 2 3 4 5					S 1 2 3 4 5					Not Applicable or Unable to Address Today (circle one)					
Signs and Symptoms					Category	Target					Client Specific Information					Notes				
<input type="checkbox"/> Abnormal results of developmental screening tests					S	Bonding/attachment					Parent/Child interaction									
					S	Dietary Management					Feeding methods/adequate intake/supplements/solids/WIC									
<input type="checkbox"/> Abnormal weight/height/head circumference in relation to growth/age standards					S	Growth/Devel. Care					Developmental tasks for age, developmental test scores									
					S	Rest/Sleep					For age/condition, consistent patterns									
					S	S/S physical					Physical growth/variations									
<input type="checkbox"/> Age-inappropriate behavior					S	S/S physical					Voiding and stooling									
					S	S/S mental/emotional					Behavior concerns									
<input type="checkbox"/> Inadequate achievement/maintenance of developmental tasks					S	Communication					Expression of needs/receptive & expressive language									
					S	Education					Appropriateness of grade level/program: client's attitude re progress; parent's/caregivers attitude to grade level/progress									
<input type="checkbox"/> Other					S	S/S mental/emotional					Intervention programs for behavioral health									
					S	S/S physical					HC provider, WIC, Lactation Consultant, community support group									
					S	Growth/Devel. Care					Education/developmental resources									

**Abuse (Child)**

K 1 2 3 4 5					B 1 2 3 4 5					S 1 2 3 4 5					Not Applicable or Unable to Address Today (circle one)					
Signs and Symptoms					Category	Target					Client Specific Information					Notes				
<input type="checkbox"/> Harsh/excessive discipline					S	S/S mental/emotional					Behavioral extremes									
<input type="checkbox"/> Attacked verbally					S	S/S physical					Unexplained injuries; evidence of abuse									
<input type="checkbox"/> Welts/bruises/burns/questionable injuries					CM	Legal system					Child Protective Services, law enforcement									
<input type="checkbox"/> Fearful/hyper vigilant behavior																				
<input type="checkbox"/> Violent environment																				
<input type="checkbox"/> Consistent negative messages																				
<input type="checkbox"/> Assaulted sexually																				
<input type="checkbox"/> Other																				

County: \_\_\_\_\_

Name: \_\_\_\_\_ CHIF # \_\_\_\_\_ Child's DOB \_\_\_\_\_ CV/OV  HV  TV

Primary Caregiver/Guardian (ie parent/grandparent/foster parent): \_\_\_\_\_ Date: \_\_\_\_\_ Initial  Interim  Final

Neglect (Child)																								
K 1 2 3 4 5					B 1 2 3 4 5					S 1 2 3 4 5					Not Applicable or Unable to Address Today (circle one)									
Signs and Symptoms					Category					Target					Client Specific Information					Notes				
<input type="checkbox"/> Lacks adequate physical care					S					S/S physical					Hygiene, skin condition, medical/dental conditions									
					S					S/S mental/emotional					Affect/behavior									
<input type="checkbox"/> Lacks emotional support					S					Safety					Environment/supervision									
					S					Sickness/Injury Care					Awareness of need									
<input type="checkbox"/> Inappropriately left alone					CM					Legal system					Child Protective Services, law enforcement									
<input type="checkbox"/> Inadequate/delayed medical care																								
<input type="checkbox"/> Lacks necessary supervision																								
<input type="checkbox"/> Other																								

Health Care Supervision (Child)																								
K 1 2 3 4 5					B 1 2 3 4 5					S 1 2 3 4 5					Not Applicable or Unable to Address Today (circle one)									
Signs and Symptoms					Category					Target					Client Specific Information					Notes				
<input type="checkbox"/> Fails to obtain routine/preventive health care					S					Continuity of care					Medical home/access to care									
					S					Medical/dental care					Follows/receives when scheduled									
<input type="checkbox"/> Fails to seek care for symptoms requiring evaluation/treatment					S					Wellness					Immunizations/routine preventive health care									
					S					Sickness/injury care					Follows/receives when needed									
<input type="checkbox"/> Fails to return as requested to health care provider					CM					Medical/dental care					Coordinate/schedule services									
					CM					Sickness/injury care					Refer to HC provider									
<input type="checkbox"/> Inability to coordinate multiple appointments/treatment plans																								
<input type="checkbox"/> Inconsistent source of health care																								
<input type="checkbox"/> Inadequate source of health care																								
<input type="checkbox"/> Inadequate treatment plan					CM					Medication coordination/ordering					Assistance accessing/obtaining medications									
<input type="checkbox"/> Other																								

County: \_\_\_\_\_

Revised 07/19/2011

Name: \_\_\_\_\_ CHIF # \_\_\_\_\_ Child's DOB \_\_\_\_\_ CV/OV  HV  TV   
 Primary Caregiver/Guardian (ie parent/grandparent/foster parent): \_\_\_\_\_ Date: \_\_\_\_\_ Initial  Interim  Final

Income (Adult)																			
K	1	2	3	4	5	B	1	2	3	4	5	S	1	2	3	4	5	Not Applicable or Unable to Address Today (circle one)	
Signs and Symptoms					Category	Target					Client Specific Information					Notes			
<input type="checkbox"/>	Low/no income				S	Finances					Income versus expenses; use of available resources								
<input type="checkbox"/>	Uninsured medical expenses				S	Finances					Health insurance								
<input type="checkbox"/>	Difficulty with money management				S	Education					Access educational resources/Follows educational plan								
<input type="checkbox"/>	Able to buy only necessities				TGC	Finances					Crisis intervention/short-range planning; budgeting; community resources								
<input type="checkbox"/>	Difficulty buying necessities				CM	Finances					All available resources: food bank, clothing bank, energy assistance								
<input type="checkbox"/>	Other				CM	Legal system					Office of Support Enforcement, Guardian, free legal assistance								
<input type="checkbox"/>					CM	Education					Educational options, financial aid								

Caretaking/Parenting (Adult)																			
K	1	2	3	4	5	B	1	2	3	4	5	S	1	2	3	4	5	Not Applicable or Unable to Address Today (circle one)	
Signs and Symptoms					Category	Target					Client Specific Information					Notes			
<input type="checkbox"/>	Difficulty providing physical care/safety				S	Bonding/attachment					Mutual responsiveness; eye contact								
<input type="checkbox"/>	Difficulty providing emotional nurturance				S	Caretaking/parenting					Infant/child care								
<input type="checkbox"/>	Difficulty providing cognitive learning experiences and activities				S	Growth/development					Realistic expectations								
<input type="checkbox"/>	Difficulty providing preventive and therapeutic health care				S	Coping skills					Parents stressors, ability to manage care giving functions								
<input type="checkbox"/>	Expectations incongruent with stage of growth and development				S	Support system					Availability of support network								
<input type="checkbox"/>	Dissatisfaction/difficulty with responsibilities				S	Safety					Appropriate supervision; safety hazards, infant sleep, emergency/disaster plan in place								
<input type="checkbox"/>	Difficulty interpreting or responding to verbal/non-verbal communication				S	Legal system					Hx/status of legal issues e.g. paternity, CPS, incar.								
<input type="checkbox"/>	Neglectful or abusive				S	Discipline					Methods, appropriate for age/condition								
<input type="checkbox"/>	Other				S	Medication admin					Schedule, technique, safe medication storage								
<input type="checkbox"/>					TGC	Bonding/attachment					Activities to promote								
<input type="checkbox"/>					TGC	Caretaking/parenting					Infant/child care, feeding techniques, bathing and hygiene								
<input type="checkbox"/>					TGC	Growth/development					Realistic expectations, toileting								
<input type="checkbox"/>					TGC	Growth/development					Activities to promote optimal development								
<input type="checkbox"/>					TGC	Screening Procedures					Results of screening/assessments; significance								
<input type="checkbox"/>					TGC	Safety					Car seats/seat belts, safe sleep, shaken baby								
<input type="checkbox"/>					TGC	Medical/dental care					Preventive care								
<input type="checkbox"/>					TGC	Day care/respite					How to choose, appropriate care givers								
<input type="checkbox"/>					TGC	Discipline					Appropriate for age								

County: \_\_\_\_\_

	TGC	Dietary management	Food choices intake/supplements/solids/WIC	
	TGC	Medication admin	Method and dose	
	TGC	Coping skills	Stress reduction	
	TGC	Stimulation/nurturance	Tummy time, age appropriate dev information`	
	CM	Caretaking/parenting	Parenting classes	
	CM	Safety	Car seat checks, CPR and first aid	
	CM	Continuity of care	Coordination among providers	
	CM	Day care/respite	Referrals given for services	

**Communication with Community Resources (Adult)**

K 1 2 3 4 5      B 1 2 3 4 5      S 1 2 3 4 5      Not Applicable or Unable to Address Today (circle one)

Signs and Symptoms	Category	Target	Client Specific Information	Notes
<input type="checkbox"/> Unfamiliar with options/procedures for obtaining services <input type="checkbox"/> Difficulty understanding roles/regulations of service providers <input type="checkbox"/> Unable to communicate concerns to provider <input type="checkbox"/> Dissatisfaction with services <input type="checkbox"/> Language, cultural, educational, transportation barriers <input type="checkbox"/> Limited access to care/services/goods <input type="checkbox"/> Unable to use/has inadequate communication devices/equipment <input type="checkbox"/> Other	S	Communication	Ability to communicate with service providers/resources	
	S	Transportation	Availability and mode	
	TGC	Communication	Procedures to communicate with service providers/resources	
	TGC	Interpreter/translator services	Procedures to obtain services	
	CM	Other community resources	Culturally specific services and groups	
	CM	Legal assistance	Client advocacy related to refugee/immigration/documentation	
	CM	Transportation	Refer to transportation services	

Residence (Adult)																								
K 1 2 3 4 5					B 1 2 3 4 5					S 1 2 3 4 5					Not Applicable or Unable to Address Today (circle one)									
Signs and Symptoms					Category					Target					Client Specific Information					Notes				
<input type="checkbox"/> Structurally unsound; inadequate heating/cooling <input type="checkbox"/> Steep unsafe stairs/inadequate/obstructed exits & entries <input type="checkbox"/> Cluttered living space <input type="checkbox"/> Unsafe storage of dangerous objects/substances <input type="checkbox"/> Unsafe mats/throw rugs/inadequate safety devices <input type="checkbox"/> Presences of lead based paints/unsafe equipment/wiring <input type="checkbox"/> Structural barriers <input type="checkbox"/> Homeless <input type="checkbox"/> Other					S					Home					Condition of residence, access									
					S					Home					Stability, homelessness									
					S					Safety					Home safety assessment									
					TGC					Safety					Home safety recommendations, home modifications, access									
					TGC					Home					Long range planning/decision making									
					CM					Home					Housing resources, home modifications, access									
					CM										Safety supplies and equipment									

# Tier Systems

The following pages are examples of Tier Systems (Acuity Systems) contributed by Snohomish County, the CaCoon (CAre COordinatiON) Program, and Tacoma Pierce County.

NOTE: You may not need or use a tier system but the information about asking questions and prioritizing work may be helpful.

Permission was given to share these examples of Tier Systems by Anne Mitchell in Snohomish County, Nancy Lowry with the CaCoon Program in Oregon, and Rhonda Fry and Sue Whalen from Tacoma Pierce County.



# SNOHOMISH HEALTH DISTRICT

## ACUITY SCALE

Head of Household Name: \_\_\_\_\_

The Acuity Scale is to be completed for each head of household at the initial assessment and then once per quarter, or more often if it is obvious that a significant event has occurred in that family since the last visit. During the three initial assessment visits "S" may be used as the acuity score.

Scoring Instructions: Indicate the date at top of appropriate column. Put a check in the low, medium or high box for each acuity factor. When completed, add the number of checks for each column, multiply by the number of the acuity weight: 1 for LOW, 2 for MEDIUM and 3 for HIGH. Then total the scores in all three columns and place the total acuity scores in the indicated box. Complete the date and total acuity score, circle the appropriate acuity level for the client, and sign your name.

		Levels of Acuity													
		LOW				MEDIUM				HIGH					
Date completed:															
Activity Factors															
Physical Environment	Living situation is stable					Living situation is temporary					Family is homeless - living in a shelter or on the street				
	Neighborhood appears safe; housing adequate with no safety hazards					Neighborhood poorly kept up; presence of some delinquency and/or gangs; substandard housing and/or safety hazards present					Neighborhood unsafe with high crime rate, gangs and/or high levels of pollution; home has major safety hazards				
Financial Resources	Family has adequate resources to meet needs					Family has inadequate resources to meet basic needs					Family has no money to meet basic needs				
	All family members have health insurance					One or more family members have no or inadequate insurance					Family has no insurance				
Coping Skills	Family is able to cope emotionally with problems and identify solutions					Family minimally copes with problems and has difficulty identifying solutions					Family unable to cope with problems and is unsafe; unable to use problem solving skills				

	Levels of Acuity											
	LOW				MEDIUM				HIGH			
Psychosocial	No family members have serious emotional or behavioral problems				One or more family members exhibit inappropriate emotional behavior which interferes with ADL, such as depression or inappropriate anger				One or more family members exhibit abnormal emotional behavior. Hospitalization for mental illness and/or attempted suicide or homicide, within past year			
Support	Has a supportive network				Family does not have a readily identifiable support network				Family has no support network			
	Utilizes support network appropriately				Family willing to utilize people and agencies for support with minimal intervention				Family is distrustful of support, people and agencies and refuses to utilize them			
Family Interactions	Parent/Caregiver shows attachment or bonding				Parent/Caregiver shows minimal attachment or bonding				Parent/Caregiver is critical and negative; exhibits open hostility			
Family Account-ability/ Compliance	Family appropriately follows through with appointments/ recommendations				Family minimally follows through with appointments/ recommendations				Family fails to follow through with appointments/ recommendations; family placing child or individuals at risk			
Resources Access	Community resources are available and family can access them				Community resources are available, but family has one or more barriers to accessing them				Community resources are available but over 10 miles from family; family does not have resources or transportation to access them			
Language	Family members can understand, speak and read English				Household members have minimal English-speaking and reading skills; requires use of translator				Household members do not understand, read or speak English and/or resistant to the use of a translator			
Culture	Cultural barriers do not exist				Cultural barriers exist but are not a significant problem				Cultural barriers exist and are a significant problem			
Client Concerns/PHN Diagnosis	Single client concern/ nursing diagnosis				Two or more client concerns/ nursing diagnoses				Multiple, complex client concerns/ nursing diagnoses			
Medical Diagnosis	Single diagnosis				Two or more medical diagnoses				Multiple, complex medical diagnoses			

	Levels of Acuity											
	LOW				MEDIUM				HIGH			
Substance Abuse	Family shows no high risk behavior as evidenced by substance abuse				Family shows minimal high risk behavior as evidenced by one or more family members with a current or recent history of substance abuse and/or no formal treatment				Family shows significant high risk behavior as evidenced by one or more family members abusing legal and/or illegal substances			
Risk Behaviors; i.e., smoking, eating disorders	Does not engage in high risk behavior				Engages in one or two risk behaviors				Engages in multiple risk behaviors			
SubTotals												

Date Completed												
Subtotals:	Low:	x 1 =										
	Medium:	x 2 =										
	High:	x 3 =										
Grand Total												

If any one of the categories is rated HIGH: Psychosocial, Family Interactions, or Substance Abuse, the family is automatically placed in the HIGH acuity level, i.e., total score may be increased to 40, if necessary.

Date \_\_\_\_\_ Total Acuity Score: \_\_\_\_\_ LOW: 17-24 MEDIUM: 25-39 HIGH: 40-51 Signature \_\_\_\_\_

Date \_\_\_\_\_ Total Acuity Score: \_\_\_\_\_ LOW: 17-24 MEDIUM: 25-39 HIGH: 40-51 Signature \_\_\_\_\_

Date \_\_\_\_\_ Total Acuity Score: \_\_\_\_\_ LOW: 17-24 MEDIUM: 25-39 HIGH: 40-51 Signature \_\_\_\_\_

Date \_\_\_\_\_ Total Acuity Score: \_\_\_\_\_ LOW: 17-24 MEDIUM: 25-39 HIGH: 40-51 Signature \_\_\_\_\_

# Acuity

GOAL: All clients will have accurate documentation of their individual acuity level. Home visit intensity and interventions will support the acuity level.

Standard	Activities	Evaluation
Acuity level will be assessed on the initial face-to-face visit.	Document acuity level at the initial face-to-face encounter with the client. Assess client for each of the fourteen acuity classification factors. Rate each of these factors as low, medium, or high.	An Encounter form review will show documentation of the acuity classifications and total acuity score.
Acuity level will be reassessed every three months or sooner if significant events have occurred.	Assess the current acuity level at each visit and update, if needed. Update the acuity level every three months. Document any change on the Encounter form.	The Encounter form will show an updated acuity level every three months or more often if significant changes have occurred.
Each home visit encounter will have acuity level documented.	Document the acuity level on the nursing encounter form in the space provided.	An Encounter form review will show documentation of the acuity level.
Interventions will reflect the acuity level.	At each visit, document interventions that reflect the acuity level.	An Encounter form review will show interventions reflecting the acuity level.

# CaCoon Program Tier Level Assessment Protocol

The Tier Level Assessment is a tool designed to assist the CaCoon (CAre COordinatiON) Nurse Coordinators in developing appropriate caseload standards and to help set priorities and plan for coordination of services for families.<sup>1</sup> The tier level is based on child health issues and on family functioning issues.

The Tier Level is to be completed for each family after the initial nursing assessment and then once per year, or more often if a significant change has occurred in the family since the last evaluation.

1. Using the Tier Level Assessment form, place a score (1, 2, or 3) in the score column that best represents the health care needs and level of family functioning.
2. Tabulate the total score and assign a tier level based on the score breakdown.
3. A score of 2 or 3 in any category with an asterisk may indicate the family should be assigned the higher tier level regardless of their total score. (As an example, the family who is usually capable of taking care of their own needs may require a period of intense support from professionals while the child's health or developmental condition is critical. Or a family whose child has only mild or moderate health issues but the family members are inexperienced in utilizing resources, necessitating a higher level of assistance until the family can perform those skills.)
4. Record the tier level assignment at the top of the form.
5. Subsequent reassessment scores may be recorded on the Tier Level Summary sheet. The Family Follow Up Guidelines section provide suggestions for the type of service or intervention appropriate for families at each tier level.

<sup>1</sup>This tier level system and accompanying guide was developed using research and works from Kay Guirl, RNC, MN with the Washington State Bureau of Parent-Child Services (1988), Alameda County Public Health Dept., Public Health Nursing (2003), and from Family Resource Network, Santa Cruz, CA, in collaboration with Institute for Community Collaborative Studies, California State University, Monterey Bay (2002).

# CaCoon Program Family Follow up Guidelines by Tier Level

## Tier Level I

### Frequency and Type of Contact

- ✿ An appropriate schedule for visits may include monthly to quarterly visits, with follow up phone contacts.
- ✿ A yearly contact for re-assessment after the child's condition becomes stable and the family is connected with appropriate resources.
- ✿ Monitoring of the progress of long-term therapy/medications and contact at milestones may be adequate. (E.g., contact family to provide anticipatory guidance related to issues such as pre and post hospitalizations/surgeries, entrance to childcare or school, and when child approaches their next developmental stage, etc.)

### Care Coordination Activities and Advocacy

- ✿ Families may be very capable of coordinating care and advocating for services, but in order to do this they need accurate medical and resource information.
- ✿ They will be able to follow through when given numbers of agencies and contact persons. Handouts at the appropriate reading and cognitive level will be helpful.
- ✿ When information is provided by PCP/specialists, the family requires little or no interpretation of instructions and medical information.
- ✿ The family will ask questions, request information or assistance with coordination of appointments with minimal prompting.
- ✿ The family will participate in creating a care plan for their child. They may feel confident in sharing the written recommendations from treating physicians.
- ✿ The PHN should provide periodic assessment of available information, as well as parental skill level and emotional strength to advocate for the needs of their child and family.
- ✿ Obtain a release of information for providers and service agencies with whom there needs to be professional communication.

### Child Health and Development

- ✿ The PHN should perform periodic health assessment and developmental monitoring, especially if the child's condition carries a risk for delay in any domain. A referral for further evaluation should be made when deviations become apparent.

- ❖ The PHN should provide anticipatory teaching to help the parents feel confident in their child's progress and recognize deviations from expected norms as early as possible. Use of a parent questionnaire, such as the Ages and Stages, is an appropriate first-stage screening tool for determining developmental status.
- ❖ Consult with other professionals doing developmental assessment to coordinate follow up and services.

## Health Teaching and Anticipatory Guidance

- ❖ Families are usually self-directed and actively participate in obtaining information about their child's health care and prognosis.
- ❖ They need minimal reinforcement of information related to their child's medical and preventative care.
- ❖ They will initiate contact with the CaCoon Coordinator or other health professional for information and questions with minimal prompting.
- ❖ The PHN may provide websites, books and written materials to help parents anticipate issues for their child and the confidence to direct the care of their child.

## Family and Community Resources

- ❖ Families typically have adequate resources to meet the needs of their child. (Health insurance, income, etc.)
- ❖ Families will be able to follow through on initiating services and completing the application process (including gathering supporting documents).
- ❖ They will call with questions or if they meet barriers to accessing services.
- ❖ The PHN needs to provide information on specialty resources. (Examples would include SSI, Early Intervention, Developmental Disabilities services, support groups, etc.)
- ❖ Follow up regarding the outcome of referral for services can be confirmed at the next scheduled contact.

## Family Development and Coping Patterns

- ❖ Families need normalization and validation of feelings and experiences.
- ❖ The PHN needs to prepare the family for how their child's special health condition will impact their family.

- ✿ Encourage use of parent-to-parent network or support groups if perceived helpful by the family.

## TIER Level II

### Frequency and Type of Contact

- ✿ An appropriate schedule for contacts may include visits once per week to monthly with follow up phone calls to check on progress or additional needs.
- ✿ Families may need more frequent follow-up at the time of diagnosis and during times and crises.
- ✿ As the child's condition and family environment stabilizes, visits or phone contact once per month to quarterly may be adequate.

### Care Coordination Activities and Advocacy

- ✿ Families will need assistance coordinating their child's care and/or advocating for services.
- ✿ They will need coaching in order to assure success in obtaining services and verbal explanations, written instructions and reinforcement of information in order to follow through on recommendations for their child's care.
- ✿ The PHN should be familiar with eligibility requirements and scope of service when referring to resources.
- ✿ The PHN may need to initiate contacts with professionals or agencies on behalf of the family during crises.
- ✿ Obtain a release of information for providers and service agencies with whom there needs to be professional communication.
- ✿ Assist families to request written care recommendations from all treating physicians.

### Child Health and Development

- ✿ Children usually receive health and developmental monitoring from their pediatrician and/or specialists.
- ✿ The nurse should perform health and developmental assessments between these visits to monitor progress and provide anticipatory guidance when appropriate.
- ✿ It is important for children with developmental delays to have a differential diagnosis from a physician. Many conditions causing delay have health implications for the child. Sometimes children receive intervention services from EI or special education prior to a diagnosis and families feel less need to continue exploring the cause.

- ✿ When delays are not significant enough to qualify for an intervention program, the nurse should collaborate with the PCP to refer the family for private treatment or assist the family with activities to promote development at the level the child is capable of attaining.

## Health Teaching and Anticipatory Guidance Activities

- ✿ Families are likely to need some assistance with interpreting medical information and understanding recommendations.
- ✿ Health teaching and anticipatory guidance may need to be reinforced, especially during times of high stress or crisis.
- ✿ The PHN will need to check in with families periodically to see if they have further questions or information needs.

## Family and Community Resources

- ✿ The family's personal resources may not always be stable or adequate.
- ✿ They may need community resources and a moderate amount of care coordination from professionals to meet the needs of their child.
- ✿ They may need coaching on how to contact resources and some assistance filling out applications.
- ✿ The PHN should follow up after appointments or at the next scheduled visit to see if families received the assistance they needed, determine if further referral is necessary and/or to assist with care recommendations.

## Family Development and Coping Patterns

- ✿ Families need normalization and validation of feelings and experiences.
- ✿ The PHN needs to prepare the family for how their child's special health condition will impact their family.
- ✿ Families may benefit from professional counseling or support resources when their personal support network is unavailable.
- ✿ Encourage use of parent-to-parent network or support groups if perceived helpful by the family.

## Tier Level III

### Frequency and Type of Contact

- ✿ An appropriate schedule for contact at this will include frequent visits and phone follow-up during times of crises or high stress, and monthly or quarterly contacts when the child's condition and family environment is stable.

### Care Coordination Activities and Advocacy

- ✿ The family may need an advocate to attend significant appointments with them and/or communicating with other providers about their child's condition and recommendations for treatment.
- ✿ They will also need assistance from professionals to advocate for services for their child.
- ✿ Families need multiple verbal explanations, clearly written step-by-step instructions and frequent support from professionals in order to follow through with recommendations for their child's care.
- ✿ The PHN may need to act on the family's behalf to coordinate care and resources for their child.
- ✿ Obtain a release of information for providers and service agencies with whom there needs to be professional communication.
- ✿ The nurse should request written care recommendations from all treating physicians for the family.

### Child Health and Development

- ✿ Children receive health and developmental care from multiple providers and specialists.
- ✿ They will need significant support to live in their community, such as home health, Developmental Disabilities in-home support services or specialized equipment and assistive devices.
- ✿ Families will need reinforcement of information on child development and assistance to support their child's progress.
- ✿ They may also need adaptations to their home environment such as wheelchair access ramps, widened doors, roll-in showers, etc.

- ✿ Along with close monitoring of health, the PHN should assist the family to access appropriate developmental activities.

## Health Teaching and Anticipatory Guidance Activities

- ✿ Families are likely to need significant assistance with interpreting medical information and understanding recommendations, as well as health teaching and anticipatory guidance related to their child's development and medical condition.
- ✿ Families may not be ready for health teaching or anticipatory guidance if their social environment is not stable.
- ✿ The PHN will need to check back with families frequently to see if they have further questions or additional needs.

## Family and Community Resources

- ✿ The family's personal resources are usually not stable or adequate.
- ✿ They will need significant resources and a high level of care coordination from health or community resources to access services for their child.
- ✿ Families will likely need assistance filling out applications.
- ✿ The PHN may need to initiate contact with resources until the family has the skills to do this activity for themselves.
- ✿ Follow up immediately after appointments to see if families received the assistance they needed, to determine if further referral is necessary or to assist with care and recommendations.

## Family Development and Coping Patterns

- ✿ Families need normalization and validation of feelings and experiences.
- ✿ Families at this level may need crisis intervention and/or referral for counseling and support.
- ✿ Encourage use of parent-to-parent network or support groups if perceived helpful by the family.
- ✿ The PHN may need to help with basic problem solving skills to prevent crises.
- ✿ The PHN needs to prepare the family for how their child's special health condition will impact their family.

--CaCoon Program

# CaCoon Program Care Coordination

TIER LEVEL ASSESSMENT (To be assigned AFTER initial assessment)

Tier Level Assignment \_\_\_\_\_

Tier Level I = 13 -18 points Tier Level II = 19-28 points Tier Level III = 29-36 points

Client Name: \_\_\_\_\_ BD: \_\_\_\_\_

Date: \_\_\_\_\_

Diagnosis/Risk Codes: \_\_\_\_\_

Initials: \_\_\_\_\_

DRAFT COPY

\*\*A score of 2 or 3 in any category with an asterisk may indicate the family should be assigned the higher tier level regardless of their total score.

Category	Score	MINIMAL NEED (1 pt)	MODERATE NEED (2 pts)	HIGH NEED (3 pts)
Medical Needs**		<ul style="list-style-type: none"> <li>▫Medical diagnosis with limited effects on health and/or</li> <li>▫Condition is stable and the course and treatment predictable</li> </ul>	<ul style="list-style-type: none"> <li>▫Medical diagnosis has complex or long-term effects on health</li> <li>▫Condition usually stable, however illness or crisis exacerbates condition</li> </ul>	<ul style="list-style-type: none"> <li>▫Medical diagnosis/condition is severe enough to impair major body systems (may require technological support) and/or health status</li> <li>▫Condition frequently becomes unstable or has an unpredictable course</li> </ul>
Medical Management		<ul style="list-style-type: none"> <li>▫Routine preventative care with PCP</li> <li>▫May see specialist annually for consultation</li> </ul>	<ul style="list-style-type: none"> <li>▫Regular physician visits</li> <li>▫Condition requires medical management from one or more specialists to maintain health.</li> <li>▫Periodic consultation with or treatment from one or more specialists</li> </ul>	<ul style="list-style-type: none"> <li>▫Condition requires medical management from one or more specialists to maintain health.</li> <li>▫Frequent hospitalizations or visits to ER</li> <li>▫Frequent consultations with or treatments from one or more specialists</li> </ul>
Health Teaching and Information Needs		<ul style="list-style-type: none"> <li>▫Minimal information and health teaching needs</li> </ul>	<ul style="list-style-type: none"> <li>▫Needs periodic interpretation of information</li> <li>▫Needs health teaching around specialty care and/or treatments</li> </ul>	<ul style="list-style-type: none"> <li>▫Needs significant interpretation/reiteration of information</li> <li>▫Needs health teaching and monitoring around specialty care and/or treatments</li> </ul>
Development**		<ul style="list-style-type: none"> <li>▫Child meets developmental benchmarks in all areas or</li> <li>▫Has questionable development in one domain</li> </ul>	<ul style="list-style-type: none"> <li>▫Child does not meet developmental benchmarks in one or more domains</li> </ul>	<ul style="list-style-type: none"> <li>▫Child has serious developmental delay affecting ability to function in one or more areas</li> </ul>
Parent/Child Interaction		<ul style="list-style-type: none"> <li>▫Child's health condition has potential to interfere with attachment and/or parent/child interaction</li> <li>▫Current relationship appears intact</li> </ul>	<ul style="list-style-type: none"> <li>▫Child's health condition and/or parent behavior interferes with the development of bonding and/or positive parent/child interaction</li> </ul>	<ul style="list-style-type: none"> <li>▫Child's health condition and/or parent behavior presents significant barrier to achieving bonding and/or positive parent/child interaction</li> </ul>
Education (including EI/ECSE)		<ul style="list-style-type: none"> <li>▫Does not need EI/ECSE services</li> <li>▫Attends regular classroom with minimal support</li> <li>▫Progress in school is age appropriate</li> </ul>	<ul style="list-style-type: none"> <li>▫Has IFSP, IEP or 504 plan</li> <li>▫Attends regular classroom with one special health consideration/protocol at school</li> <li>Other related services</li> </ul>	<ul style="list-style-type: none"> <li>▫Attends specialty classroom or requires full-time aide for most of day</li> <li>▫Requires health related protocols and/or delegated procedures in order to attend school</li> </ul>
Environment		<ul style="list-style-type: none"> <li>▫No adaptation required to home or community environment in order to accomplish ADL/access community environment</li> </ul>	<ul style="list-style-type: none"> <li>▫Condition will require some adaptation in order to accomplish ADL/access community environment</li> </ul>	<ul style="list-style-type: none"> <li>▫Condition will require use of multiple adaptive devices and/or specialized services to accomplish ADL/access community environment</li> </ul>

Category	Score	MINIMAL NEED (1 pt)	MODERATE NEED (2 pts)	HIGH NEED (3 pts)
Housing		<input type="checkbox"/> Housing and neighborhood is safe and not overcrowded <input type="checkbox"/> Family owns home or tenancy will be long-term <input type="checkbox"/> No safety hazards present	<input type="checkbox"/> Housing substandard and/or frequent moves <input type="checkbox"/> Neighborhood suggests possible presence of delinquency or gangs <input type="checkbox"/> Safety hazards present	<input type="checkbox"/> Family history of being evicted <input type="checkbox"/> Has been or currently homeless <input type="checkbox"/> Neighborhood has high crime rate and poorly kept <input type="checkbox"/> Home has major safety hazards
Resource Utilization**		<input type="checkbox"/> Specialty resources available locally <input type="checkbox"/> Knowledge of resources <input type="checkbox"/> No assistance needed to access <input type="checkbox"/> Family comfortable asking for help when needed	<input type="checkbox"/> Specialty resources available; not all locally <input type="checkbox"/> Some awareness of available resources <input type="checkbox"/> Limited means to access resources <input type="checkbox"/> Needs coaching or support to access and utilize resources <input type="checkbox"/> Family not always comfortable asking for help when needed	<input type="checkbox"/> Specialty resources available; none are local <input type="checkbox"/> No knowledge of available resources <input type="checkbox"/> No means to access resources <input type="checkbox"/> Needs direct assistance to access and utilize resources <input type="checkbox"/> Family resists accepting help when needed

Tier Level I = 13 -18 points

Tier Level II = 19-28 points

Tier Level III = 29-36 points

# Pierce County Tier System for CSHCN Nursing Case Management/Coordination of Services

## Tier I (those meeting medical criteria and not psychosocial/ environmental risk criteria)

Involvement:

- ✿ Nursing Screening provided on the phone to identify needs.
- ✿ Send family a resource packet and/or provide community resources over the phone without nursing case management enrollment.

## Tier II (determined after initial home visit)

- ✿ Family able to cope, but with support and encouragement.
- ✿ Family has difficulty identifying problems and solutions.
- ✿ Needs help to use community resources.
- ✿ Disorganized in several areas.
- ✿ Inconsistent follow-up, needs encouragement to carry out recommendations.
- ✿ Struggles to meet financial needs.

Involvement:

- ✿ Special or limited intervention.
- ✿ Ongoing support/encouragement.
- ✿ Assistance in coordinating services.

Level of family contact: Every two month (minimum of 3 home visits/year and 3 phone/clinic contacts/year).

## Tier III (determined after initial home visit)

- ✿ Family disorganized, unable to cope.
- ✿ Unable to recognize problems or identify solutions.
- ✿ Resistant to recommendations, fails appointments.
- ✿ Unwilling to use resources.

- ✿ Unable to meet financial needs.

Involvement:

- ✿ Supervision frequent.
- ✿ Case Manager assume role of coordinating services.
- ✿ Intensive intervention.

Level of family contact: Monthly (minimum of 6 home visits/year and 6 phone/clinic contacts/year).

NOTE: Families may weave in and out of the various tier levels depending on their needs.

# CSHCN Tier Assessment Summary Sheet

(For case management clients)

Client Label

Date							
Medical Needs							
Medical Management							
Education/Training Needs							
Resource Utilization							
Finances							
Problem Solving Skills							
Support System							
Coping							
Total Tier 2							
Total Tier 3							
Tier Assigned							

Tier 2: Every two months (3 home visits/year and 3 family phone contacts, clinic visits and/or team meeting contacts/year)

- ✿ Special or limited intervention
- ✿ Ongoing support/encouragement
- ✿ Assistance in coordinating services

Tier 3: Monthly (4 home visits/year and 8 family phone contacts, clinic visits and/or team meeting contacts/year)

- ✿ Supervision frequent
- ✿ Case Manager assume role of coordinating services
- ✿ Intensive intervention

---Mary Bridge Children’s Hospital and Health Center

MultiCare

# CSHCN Program

## Health Care and Family Functioning Guidelines:

(To be used as a guideline for the Tier Assessment Summary Sheet)

	Tier II (2 points)	Tier III (3 points)
Medical Needs	Complex; long term	Complex; lifelong (requiring technology)
Medical Management	Requires periodic medical specialty consultation	Requires complex multidisciplinary team
Education/Training Needs	Requires moderate education/training needs	Requires extensive education/training needs
Resource Utilization	Requires assistance in identification/utilization of resources	Unwilling to utilize resources; resists recommendations
Finances	May have difficulty meeting financial needs	Unable to meet financial needs
Problem Solving Skills	Requires assistance in identifying problems/problem solving	Unable to recognize problems/identify solutions
Support Systems	Support systems present; may need encouragement utilizing support systems	Support systems absent; not utilized
Coping	Family able to cope with support and encouragement	Family unable to cope

Following focused nursing screen, score two points for tier II and three points for tier III for each indicator that pertains to the family. The tier with the most points indicates Tier assigned (indicating level of contact and case management provided).

---Mary Bridge Children's Hospital and Health Center

# Helpful Prompts for Intake

Hello,

First, thank you for calling the Pierce County Children with Special Health Care Needs Program. How did you hear about us? How can I assist you?

Our program offers three distinct services depending on your needs. Resources by phone or mail, Community Health Nursing Case Management and the Hearing Impaired Program.

We can start by reviewing the new eligibility criteria for nursing case management:

- ❖ Is your child 17 or younger?
- ❖ What is your child's special health care condition? Has a medical provider diagnosed your child formally? What is his/her diagnosis?
- ❖ What services do you receive from other agencies?
- ❖ Are you the primary caregiver? Are you over 18 years of age?
- ❖ Who do you turn to for support? Do you have nearby supportive relatives or friends?
- ❖ What type of barriers have you found in getting the care needed for your child? Some families have experienced domestic type violence as a barrier; has this been an experience for you within the past two years?
- ❖ With whom do you live and what are the ages of your children?
- ❖ What is the highest grade level you achieved?
- ❖ If you are the primary caregiver, are you challenged by your own disability (physical or mental)?

From these guidelines, you Do/Do Not meet the criteria for nursing case management.

If meet: “If you are interested in receiving assistance from a community health nurse, the nurse will schedule between 2-4 home visits with you and your child a year and provide phone contact every one-three months in between. The nurse can assist you identifying needs, linking to appropriate services, coordinating services with medical and non-medical providers and providing support. Are you interested in this assistance?”

If yes, “What is the best time and number for a nurse to contact you?”

If no, “Thank you for calling and please give us a call if you have future questions about resources for your child.”

If does not meet: “If you need information about resources, we will be more than happy to provide resource information over the phone or by mail. Would you like a nurse to call you?”

If no, “Thank you for calling and please give us a call if you have future questions about resources for your child.”

For non-English speaking, “When you call please tell us your name, phone number and language you speak and we will forward your message to a nurse to call back using an interpreter.”

---Pierce County Children With Special Health Care Needs Program

# Helpful Prompts for Reviewing Eligibility Criteria with Families

“Hello, may I speak with\_\_\_\_\_. This is \_\_\_\_\_. I’m a community health nurse working with the Pierce County Children With Special Health Care Needs Program. Your child is currently enrolled in this program and I would like to discuss new eligibility criteria for nursing case management that may effect continued enrollment for your child.”

- ✿ First, how is \_\_\_\_\_doing? Have there been any changes to your child’s condition?
- ✿ What services do you receive from other agencies?
- ✿ Is your child receiving Medicaid as the primary insurance? Do you know if this is a Healthy Options plan or straight/open coupon? If you are not sure, if you have a current coupon handy, can you tell me if there is writing under the section “HMO”?
- ✿ Is your current address: \_\_\_\_\_?

To review the new eligibility criteria, I’ll need to ask you the following questions:

- ✿ Who can you count on for support? Do you have nearby supportive relatives or friends?
- ✿ What type of barriers have you found in getting the care needed for your child? Some families have experienced domestic type violence as a barrier; has this been an experience for you within the past two years? Do you worry about somebody mistreating you or your child?
- ✿ With whom do you live and what are the ages of your children?
- ✿ What is the highest grade level you achieved?
- ✿ If you are the primary caregiver, are challenged by a physical disability of your own? Do you have any concerns about your mental or emotional health?

From these guidelines, you Do/Do Not meet the criteria for nursing case management.

If meet: “If you are interested in receiving case management assistance, I could schedule between 2-4 home visits with you and your child a year and provide phone contact every one- three months in between. I can assist you with identifying needs, linking to appropriate services, coordinating services with medical and non-medical providers and providing support. Would you like this case management assistance?”

If yes, “I need to review a little more information and then we can set up a home visit.”

If no, “Thank you for calling and please give us a call if you have future questions about resources for your child.”

If does not meet: “If you need information about resources, I’d be more than happy to provide resource information over the phone or by mail. If you do not have a current need for resources, please keep our number available for any future questions you might have.”

For non-English speaking, “If you have questions about resources, please call us and tell us your name, phone number and language you speak and we will forward your message to myself or another nurse to call back using an interpreter.”

---Pierce County Children With Special Health Care Needs Program

# CSHCN Telephone Family Needs Assessment and Recommendations

## CHN Tier 1 Consulting Worksheet

### Medical/Dental:

PCP \_\_\_\_\_ Dentist \_\_

Specialists \_\_\_\_\_

Do you receive home health services? \_\_\_\_\_

If yes, who provides? \_\_\_\_\_

Does your child use adaptive equipment? \_\_\_\_\_

Is there any equipment you need now or expect to need in the near future? \_\_\_\_\_

What medical supplier do you use? \_\_\_\_\_

Notes \_\_\_\_\_

### Insurance:

How are you covering your medical expenses? \_\_\_\_\_

Are you being covered for things like diapers, pediasure? \_\_\_\_\_

### DSHS

Healthy Options \_\_\_\_\_

Open Coupon \_\_\_\_\_

DDD Cap Waiver \_\_\_\_\_

Private \_\_\_\_\_

Basic Health \_\_\_\_\_

Needs Insurance

Notes \_\_\_\_\_

## Community Resources currently in place:

(be sure to discuss services with family if they do not have)

- WIC
- SSI
- DDD
- FRC
- CSO Services: TANF, Food Stamps
- Section 8 housing
- Support/Parent Group
- Family Support Center
- Childcare ....Are you satisfied with the ability of daycare to work with your child?

- 
- Behavioral health
  - MSS/MCM
  - Transportation
  - Family Interested in Additional Information regarding: \_\_\_\_\_

## Growth and Development:

- Family shared no concerns about growth/nutrition/feeding or appetite
- Screened for development using birth-six prescreen chart

Nursing concerns: \_\_\_\_\_

Family concerns: \_\_\_\_\_

- Hearing and vision testing within the last year
- Parents have no concerns about behavior
- Parents shared no concerns about education/early intervention resources

What services does your child receive at school? \_\_\_\_\_

Does your child receive an IEP?  Yes  No

If yes, are you satisfied? \_\_\_\_\_

Notes \_\_\_\_\_

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## Safety/Recreation

Uses car restraint          Child weighs \_\_\_\_\_

Family denied concerns or questions about safety

What type of recreation programs does your child participate in? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Does your child have the opportunity to attend camp over the summer? \_\_\_\_\_

Family interested in information regarding recreational activities/resources

Notes :

### Family Concerns:

What help is most important to you right now?

### Recommendations Shared With Family:

Parent verbalized understanding of recommendations

CHN

Date

# Family-Centered Care

## Building Partnerships with Families

How can professionals begin to lower the traditional barriers between themselves and the families they serve? Anne Perez, president and founder of The Family Center, Inc. in Somerville, Massachusetts, offers five strategies for meeting with families that can help build relationships of partnership and mutual trust:

**Offer Choices.** Encourage families to choose where you meet with them. Some may feel uncomfortable meeting in their homes or at your center, especially at first. Inviting your client out for a cup of coffee, a meal, or even a movie can foster the sense that you are offering friendship, respect, and acceptance.

**Learn the Language.** Every family has its own way of describing and understanding their experiences. Discover the family's unique language patterns and terminology, and be sure to explain your own.

**Ask for the Family's Help.** By asking your clients to teach you how to help them, you empower them to define their strengths and their needs and to work with you as equal partners. Every family has its strengths, and professionals need to know about them before they can help the family address its needs and problems.

**Pitch In.** Sometimes the most obvious needs are very concrete—a house to be cleaned, a bed to be made, a diaper to be changed, a meal to be prepared. Your willingness to help out with these basic tasks builds trust and conveys your commitment to working together, whatever needs to be done.

**Exchange Experiences.** As you learn about the family's experiences, share some of your own. Equal give and take builds mutual trust, caring, and a sense of partnership.

Adapted from the Institute for Patient and Family-Centered Care

<http://www.ipfcc.org/>

# Family-to-Family Support

When families who have children with similar needs share information, concerns, and strategies with each other they find essential comfort and support and learn new ways of coping. The following questions offer a framework for thinking about how to facilitate family-to-family support.

Do we...

- ✿ Routinely offer families opportunities to meet and talk with other families sharing similar experiences?
- ✿ Help families who have newly-diagnosed children meet families who are more experienced?
- ✿ Routinely offer opportunities for family-to-family support to all family members: Fathers? Brothers and sisters? Grandparents or other extended family? Families who speak other languages?
- ✿ In a variety of settings: Hospitals? Schools, childcare, and early intervention programs? Through referral to community-based groups and family-to-family networks?
- ✿ Hire family members as staff to facilitate family-to-family support?
- ✿ Offer families opportunities to communicate with each other in a variety of ways? These may include: Family-to-family newsletters, phone networks, social gatherings such as coffee hours or pizza nights, spaces in hospitals, clinics, and community programs for informal conversations, such as outdoor areas and family lounges, family-to-family bulletin boards
- ✿ Provide meeting space and logistical support including child care and transportation for family support groups?

Information based on Institute for Patient and Family-Centered Care

<http://www.ipfcc.org/>

# A Checklist for Attitudes

## Families as Advisors

- ✿ Do I believe that families bring unique expertise to our relationship?
- ✿ Do I believe in the importance of family participation in decision making at the program and policy level?
- ✿ Do I believe that families' perspectives and opinions are as important as professionals?
- ✿ Do I believe that families bring a critical element to the team that no one else can provide?
- ✿ Do I consistently let others know that I value the insights of families?
- ✿ Do I work to create an environment in which families feel supported and comfortable enough to speak freely?
- ✿ Do I listen respectfully to the opinions of family members?
- ✿ Do I believe that family members can look beyond their own child's and families experience?
- ✿ Do I clearly state what is required and expected of families in their advisory role?
- ✿ Do I help families set clear goals for their role?
- ✿ Do I understand that a child's illness or other family demands may require parents to take time off from advisory responsibilities?
- ✿ Do I feel comfortable delegating responsibilities to parents?

# Four Family Approaches

Family Centered Approach	Family Focused Approach	Family Involved	Professional Centered
View child's development within the context of family and community (total system approach).	View child in a whole systems approach.	Understand that other systems impact child but this is not an intervention concern.	Not family systems oriented.
See the family as the expert on their child and their family. Families are active participants in all aspects of services and the ultimate decision makers.	Believe that professionals are the experts on children and family issues. Families can be helpful to professionals.	Professionals are experts on all issues. Families are receivers of services.	Professionals are experts on all issues. Families are passive receivers of services.
Have all families and all professionals bring different strengths and resources to the working relationship.	See the family as having important information about the child and family to share with professionals.	View the family as an "aid" to the professional to carry out child activities at home. Families may be involved in some aspect of the agency or service, such as fund raising, publicity, being on board or helping in a classroom, etc.	Whole family often viewed as causing or contributing to child's or individuals' problem. Families are told by professionals what the child needs and how these needs should be taken care of.
The helping relationship is set up as a partnership based upon trust, respect, honesty and open communication. Parent and professional work together collaboratively in getting needs/concerns accomplished.	Professionals are friendly and respectful to parents and want to have a positive working relationship. "Parent training" is a focus of intervention.	Professionals have little contact with families except for formal meetings. Parents can watch intervention session or visit classroom.	Professionals have little or no contact with families.
The purpose of intervention is family empowerment which in turn benefits the child.	The purpose of intervention is child and/or family progress.	Focus of intervention is to correct child's problems or deficiencies.	Focus of treatment is a child's illness or problem.
Intervention begins with first contact.	Intervention doesn't begin until intake, eligibility, and assessment take place.	Intervention doesn't begin until intake, eligibility, assessment and placement occur.	Treatment does not begin until diagnosis and treatment plans are completed by professional.
The ongoing identification of concerns and needs, family strengths, and resources from various sources of support are continually linked as the ongoing "work" of the partnership.	Program solicits parental input about long range goals and plans but professionals assume primary responsibility for planning interventions. Plans are made yearly and reviewed quarterly.	Families are asked if they agree or disagree with assessment finding and treatment plan. Families are told what interventions and services will be provided by professionals. Plans are made yearly.	Family's role is to consistently bring child or individual to scheduled appointments with one or more professionals.
A broad-based perspective of family needs permits flexibility for planning outcomes as well as for seeing different options for addressing outcomes.	Families can choose from existing services and agencies.	Child is "placed" with family's permission in assigned services.	Service delivery is not flexible. A prescribed treatment is provided.

Family Centered Approach	Family Focused Approach	Family Involved	Professional Centered
Each helping interaction is an opportunity for families to use their abilities, capabilities (strengths) or to learn new skills and abilities.	Family strengths are identified through an assessment process, but not utilized in on- going helping interactions.	Helping interactions are not planned to build family strengths. “Help” is given to family.	Family strengths are not acknowledged.
Efforts are made to use and build families’ informal support systems rather than rely solely on professional services.	Professionals make information available on a variety of community services or assign a staff person to take care of family needs and support as identified during assessment.	Family needs are not a programmatic concern. Family support may be provided by global services such as a parent group meeting.	Family needs are not addressed. Family support not a concern.

--Family Enablement Messenger; Spring 1994

# Promoting Family-Centered Child Care

In February 1996, the Child Care Bureau, Administration for Children and Families, Department of Health and Human Services convened a national Leadership Forum focusing on promoting family-centered child care. This Forum provided an opportunity for approximately 150 participants to “paint” the picture of what family-centered programs should look like.

Family-centered child care begins with the premise that families are the center of children’s lives. Programs that are family-centered reflect and respect the unique characteristics of all members of a child’s family. This includes not only the child and the child’s mother and father, but also all other significant adults who are involved in caring for the child.

Historically, parent involvement in child care programs has been viewed from a program perspective. In family-centered settings, parent involvement is viewed from the families’ perspective. Many children today live in homes in which all adults are working outside of the home. Families are a major part of the workforce, and they are working longer shifts and often during non-traditional hours, such as nights and weekends. Programs which are open for less than a full day, or those which expect parent participation at events held during the day or at the conclusion of a long workday may need to re-evaluate such practices in light of today’s family realities.

Family-centered programs form close collaborations with other community agencies, so that a broad array of comprehensive services are available. It is from this foundation that the families’ goals and needs become the stimulus for program design and practice.

## Family-Centered Child Care: What Does It Look Like?

Family-centered child care is flexible by definition and may look different in different settings. However, there are some common characteristics.

- ✿ Family-centered child care supports the connections between children and their families. It recognizes that children draw their identities from the family. A basic belief in the value of families permeates program policies and practices. All family members are included and treated with respect and warmth. Programs are welcoming and non-judgmental, and all staff are readily available to family members.
- ✿ A family-centered program speaks the languages and respects the cultures of families in the program. Staff members are drawn from the community the program serves.
- ✿ Family-centered child care programs build on family strengths. Such programs recognize various stages of development in family members and work with them to meet their needs. There is a natural give-and-take in these programs that empowers parents to make contributions to the program in ways that are not pre-determined.

- ✿ Family-centered child care forges true partnerships with families. Unlike traditional partnership models, in which parents are in a passive role of being informed or educated, parents in family-centered child care programs are in a creative role of establishing goals and making decisions. Efforts are made to build inclusiveness and to welcome all family members as partners in the program. In family-centered programs, families know that their feedback will effect change.
- ✿ Family-centered child care meets the basic requirements of families. This means that families have real choices when it comes to child care, and they are able to locate care that is affordable, close to home or work, and which provides care consistent with their working hours. Such programs are inclusive of all children regardless of age or abilities, and offer flexibility in scheduling and payment mechanisms. These are the primary needs of families--care for their children, offered at the times and places that they need it.
- ✿ Family-centered child care supports and trains caregivers. It is important to provide training for staff on the basic principles of family-centered care. Preservice and in- service training, peer coaching, and mentoring opportunities are provided on a continuous basis on topics such as relationship building and communication skills. Joint training is also provided for staff and families.

## Partnerships with Families

The partnership relationship is at the heart of family-centered child care. The family is viewed as part of the program and the program is viewed as part of the family's life. A system exists for families to be part of the program's planning process and policy-making. The partnership

between family members and program staff is based on cooperation, respect, and the mutual goal of doing their best for the children in their care.

## Family-Centered Child Care: What Are Its Guiding Principles?

In family-centered programs, all policies and practices are based on an underlying set of principles regarding their relationships with families.

- ✿ Families are the primary influence in the lives of their children. Families are the center of children's lives. Programs should create an environment which reflects the culture, strengths, and desires of families for their children.
- ✿ It is not possible to accurately generalize about families. Professional caregivers take the time to get to know family members individually and to support them in their goals for their children.
- ✿ Families have a great deal to offer child care providers. Traditionally, exchanges between parents and child care professionals have been viewed as a means of informing families

about their child. However, in family-centered programs it is recognized that, while professionals bring information to parents about child development and about their experiences with many children, families provide information about the individual child, across time and in a variety of settings.

- ❖ Contemporary families experience multiple demands. Employment, housing, health care, and transportation are some issues facing families, whose possible lack of involvement with the child care program should not be mistaken for lack of concern for their child.
- ❖ There are many ways for a family to be “involved.” It is important to provide a range of options for families to participate in this aspect of their child’s life, and to allow families to choose the type and level of participation which suits them.
- ❖ Family-Centered Child Care includes fathers and other male family members. The relationship of children to their fathers and other male figures is of vital importance and growing concern. Research demonstrates that children are better off when their relationships with fathers (as well as mothers) are close and warm. At the same time, evidence is emerging of both fathers’ increasing participation in their children’s care and the growing sense of exclusion felt by some fathers.

## Family Support

Families are dynamic, and engaged in a process of development. Throughout this process, they may need resources and support. Child care is an essential family support. As we consider efforts to reform systems of family support, we recognize that child care is critical for stable employment and is a catalyst for children’s healthy development, a touchstone for parent growth, and a potential hub for an array of family programs.

## Shared Care: Welcoming Fathers

In today’s world, the terms parent and family must become more than code words for mother. As mothers enter the workforce in greater numbers, the traditional role of fathers and other male figures has greatly expanded. Fathers, as well as mothers, are the nurturers and caregivers of their children, and play a critical role in their development. This has real implications for child care programs, as language, expectations, and overall program climate are re-evaluated in terms of their inclusion of men as full partners.

Washington State Fathers Network has information for father as well. (<http://www.fathersnetwork.org>)

# Home Visiting

Not all CSHCN Coordinators visit children and families in their homes. Much of the work of the Coordinator is now done by telephone in many counties. If you still do home visiting, this section introduces you to the challenges and rewards of home visiting and includes a perspective by Public Health Nurse, Debra Means. Many new CSHCN Coordinators have not had more than an introduction to home visiting and have asked for some basic guidelines. This chapter also has safety guidelines from the Tacoma Pierce County Health Department. If you need more information than this chapter provides and have been unable to find information at your agency, please contact us.

Also included in this section are examples of interview questions and Home Visiting Forms, which have been collected from several health departments. These examples have been contributed by CSHCN Coordinators throughout Washington State to share with other Coordinators. Inclusion of these forms does not constitute an endorsement of the organizations or their forms by the Department of Health, Children with Special Health Care Needs Program and should not be inferred. DOH is not responsible for the content of the individual organization's forms or materials shared here. Many of the examples are based on the Region X Standards. The Region X Standards are not included here and may be still available in your health department. These are guidelines only.

Many screening tools, such as NCAST, Ages and Stages Questionnaire (ASQ), and the Ages and Stages Questionnaire: Social and Emotional (ASQ: SE) are available and widely used but must be purchased. Check with your supervisor, or other CSHCN Coordinators for those that may already be available in your local health jurisdiction.

# Home Visiting: A Public Health Nurse Perspective

*Deb Means, Lincoln County Health Department*

Home visiting affords you as the nurse, social worker or parenting aide a unique opportunity. That of meeting the child and family in their natural environment. It is here that you need to set aside all pre-conceived notions, judgments, and feelings about how a house “should be kept”.

The only time that clutter or uncleanliness in a home should be addressed is when it threatens the well being of the child and/or family in an impending manner. The more that you can put aside your values and feelings about the situation, especially in the early visiting period when you are establishing trust and rapport, the quicker that trust will come to you from your client. You are probably making visits for a specific purpose (i.e. parenting instruction & observation, prenatal care, breastfeeding issues, etc). These purposes need to be the focus of your visit—not what the home appears like. As you continue to establish trust you may be able to guide and support some changes in household care, or you may not.

When preparing to contact a new client/family for a home visit try to schedule in advance by phone. Tell them how you received the referral, what the purpose of your visit is and about how long you plan to be there. Be considerate of their time schedules (naptimes w/small children, meals, school hours, etc) in requesting an appointment. If you are not able to schedule in advance because no phone is available and the appointment can wait a week or so consider mailing out a notice explaining briefly why you are coming and a phone number they can call if that date/time is not going to work for them. If you aren't able to schedule in advance because of urgency expect that the client may not appreciate you just showing up expecting them to let you in. Be sure to offer them some hope and advocacy even though the reason you were sent may not be a positive one. You have an opportunity to offer honesty with some guidance and possibly concrete steps to take to make a change in their lives.

Being prepared for your visit is another important factor in your success in home visiting. That means have a topic to discuss during the time of your visit prepared (i.e. the initial intake, home safety, 2<sup>nd</sup> trimester fetal growth and development along with anticipatory guidance, etc.). Include handouts, maybe even a short video, as most home seem to have video players before phone and other necessities. In being prepared as part of your initial and first follow up visits, ask the client/family to identify personal goals & dreams that you can work on with them. Whether this is a plan in writing, using the cardsort method or similar methods remember to allow the client to have some control. Without their direct participation you will not reach your goals either (which should coincide with theirs).

However, be prepared for a crisis that may push your plan right out the window and in fact, cause you to schedule an additional visit if your topic is of vital importance. Keep on hand for all visits (in your bag of tricks!) emergency information such as phone numbers for the electric company, phone company, housing authority, legal aid services, etc. These numbers along with

a pad of plain paper for you to write step-by-step instructions are sometimes the most valuable part of your visit. Don't hesitate to make the first call for the client as you have the opportunity to model appropriate phone etiquette when dealing with a difficult situation. Most clients will value that you took the time to help them deal with an urgent issue and be more willing to participate in what you have to present during that same visit or at another visit time. It is often helpful during the initial visit to inform the client of the purpose of your visits and get them to share or think about what their goals might be. Working toward a mutual goal will be much more satisfying for both you and your client. As often as possible be the primary contact for the client. If you know that you will be leaving a position and no longer seeing the same clients in home, it is advisable to contact the client by phone, send a note in the mail, or inform them at your last home visit with them. Be sure to tell them who their next contact will be (if you know) and whom they can contact if they have concerns in the interim.

Safety in home visiting is of utmost importance. You would be wise to leave a schedule of visits with a central person in your office and check out at the end of the day if you are not returning to the office. Several things to consider when doing home visits:

1. Be aware of weapons. Place a note in the file to alert others working in the home and consider discussing the weapon with the client or family and asking them to remove it or relocate it (This could be a teachable moment if children are in the home). Unlocked guns in a home with children are a CPS issue and they should be notified.
2. If you see a crime or suspicious situation, do nothing different at the time (other than leave as soon as possible!). When you are safe, always report to your supervisor and then report to the authorities. There does not need to be a crime to report a suspicious situation.
3. If you find yourself in a danger, unable to leave the situation, but can access a phone call 9-1-1 or the office with a statement similar to: "Hello this is MR/MRS/MS (your full name) checking for my messages." Your full name will immediately alert the person (usually a receptionist) that there is a problem. Next say: "I'm on schedule at (Clients Name) home or I'm off schedule and am still at (Clients Name) home"—so that your location is known and appropriate help can be sent. Repeat this statement until reception understands.
4. If you are going into a potentially risky situation and can take a cellular phone with you —that is advisable.
5. If possible pre-program the phone for 9-1-1.
6. If you are still concerned about safety but feel strongly that the visit needs to be made consider asking someone to go with you on a joint visit. You can advise your client that this will be happening as a routine follow-up of one another or you can just arrive with an extra person.

I know that most of this information may seem like common sense, however, seeing it in writing validates it for you. You have a unique opportunity and not all of you will decide that this is “your cup of tea”. Home visiting is a method for client/family-centered care and you should feel free to make a change when needed for you or the client.

## The Do's and Don'ts on Home Visits

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### Do

Call before you go  
Tell a co-worker where you are going  
Be aware of your surroundings  
Trust your gut feelings  
Assess the neighborhood before visit  
Take someone with you  
Park your car in view of the house  
Have your keys accessible  
Wear your identification badge  
Identify yourself  
Be polite

### Don't

---

Go in the dark  
Take weapons  
Enter if there is a crowd  
Enter unless you feel safe  
Sit in your car  
Leave your car unlocked  
Sit in front of a window or door  
Take valuables with you  
Challenge behavior  
Rely on a cell phone  
Be a hero

# Guidelines To Safety For Community Health Nurses

## Preparation at Home and Office

- ✿ Always be aware of your surroundings; use good common sense and think prevention.
- ✿ Be familiar with the location of public telephones. You don't need money to call 911.
- ✿ Get sufficient rest to remain alert for your work day.
- ✿ Dress appropriately. Select bright colored clothing with pockets. Wear clothes that make it easy for you to move fast. Leave expensive jewelry at home. Wear a simple watch.
- ✿ Carry a noise-making device such as a whistle.
- ✿ Make sure personal electronic equipment (pager, cell phone, etc.) is working properly and have a fresh or charged power supply.
- ✿ Have all emergency numbers posted at home.
- ✿ Have available extra keys to your home and car. Don't put names tags on key rings.
- ✿ Carry the extra keys on your person at all times.
- ✿ Travel light – do you really need a purse? Carry only what you really need, avoid having to make repeated trips to your car.
- ✿ During the work day, listen occasionally to a local all-news radio station, if available.
- ✿ Make note of the weather reports, travel restrictions, and any unusual police or fire activity in the area where you will be working.
- ✿ Organize your day well. Check your schedule, read unfamiliar charts or records, check with your supervisor on anything questionable.
- ✿ Call every client and confirm your visit and expected time of arrival. Listen to the client, listen for problems.
- ✿ Take only what supplies you will need for the day. Organize your nursing bag according to your visit schedule prior to leaving for visit.
- ✿ Keep your purse locked in the trunk of your car. Place it there when you are at home, not in the public's view. It is best not to take it into the clients' homes.
- ✿ Finalize your schedule. Place current schedule information into Outlook calendar and allow others to view. Include client name, address and phone on calendar.
- ✿ Do not carry large sums of money. Do not wear expensive jewelry.

## Community Travel

- ✿ If uncertain about location, use a map book or ask someone who knows. Never guess location or access. Know where you are going before leaving for visit. Assure correct location is entered on Outlook calendar.
- ✿ Know the area you are going into – read the charts, have a good map source, or access directions in the computer. Clarify with client when setting up appointment, or ask others familiar with the area. Develop a rapport with the community.
- ✿ If you use a map, it must be current and quality issue. Map books with a scale of 1 inch equal to 2,000 feet are ideal. Map Quest or Microsoft Streets & Maps are examples of electronic resources.
- ✿ Avoid alleys and unsafe short cuts. Stay on the main thoroughfares.
- ✿ If you are lost, never follow anyone. Instead, you should: (a) accept verbal directions; (b) call the office; or (c) ask a police officer, firefighter, letter carrier, business owner, or gas station attendant to assist you.
- ✿ Never enter a residence that appears unsafe. If the situation appears unsafe, go to a safe area and notify your first line supervisor.
- ✿ Make the time of your visits as early as possible. Arrange work schedule so new or questionable visits are early in the day. You'll be less likely to find loiterers congregating on street corners. A good rule is to conduct visits during the same time as school hours. Anticipate weather and road conditions.
- ✿ If using public transportation, know the schedules, alternate route(s), and stops before and after your stop. Sit in the front half of buses, if possible. Have extra fare available. Have backup transportation available (e.g. taxicab, family or friend with a car). Travel light. Consider having a portable cell phone.
- ✿ Show authority in your walk, talk, and look. Routinely make eye contact. When appropriate, use informal greetings with strangers. Your actions say two things: "I belong here," and "I'm in control."
- ✿ Look around you when entering immediate neighborhoods. Check street activity.
- ✿ Avoid walking where there are shrubs and tall hedges.
- ✿ Park close to the client's home. Choose a parking space that is in the open and near a light source that offers the safest walking route to the dwelling. If possible, try to park where you can see your car from inside the home and try to watch it periodically during the home visit. Allow sufficient space for quick pull-out if needed. It is always better to park on the street than in a driveway. That way, there is no danger of being blocked in when you want to leave.
- ✿ If you have to park in visitor parking a long distance from the apartment you are planning to visit, be sure that you know where the manager's office is located.

- ✿ Watch for rubble and broken glass that can flatten a tire or a ditch that can immobilize your car.
- ✿ Park in the direction you want to go when leaving the home visit. Beware of dead-end streets.
- ✿ If you suspect that a car is following you while you are walking, cross the street and go in the opposite direction.
- ✿ If someone is walking behind you, and you think you are being followed, enter a business establishment.
- ✿ Listen and observe while on the street.
- ✿ As much as possible, keep your strong hand free of items. Whenever possible wear cross-strap bags with straps over your shoulder with the flap opening against you.
- ✿ If approaching a group, move to the outside and pass by quickly. If necessary and possible, cross to the other side of the street without attracting attention. Remember, maintain that demeanor of I belong here, - I'm in control.
- ✿ If confronted, react! Approaches such as "Do you know the time," "Are you lost," "Do you have change for..." etc. may very well be a prelude to an attack. If you must answer, do so in the negative and remain on the move. Do not stop and become distracted (e.g. looking at your watch or checking the change you have).
- ✿ If your car is surrounded by loiterers, approach with caution and ask them to leave, or return to the client's home and call building security or 911.
- ✿ TRUST YOUR GUT!

## Environmental Transition

- ✿ Remember: you are the most vulnerable at times of transition (e.g. leaving or entering your car, waiting for client to answer the door, leaving the client's house).
- ✿ Homes may appear innocent but in reality they may be a methamphetamine lab.
- ✿ Signs like Neighborhood Watch are indicators that others in the community have an increased awareness of crime.
- ✿ Pay attention to what's happening around you. If unfamiliar territory, drive around the area and block of the home visit looking for fences, bushes, or other hiding places.
- ✿ Look for places to go in case of emergency: Block homes, pay phones, gas stations, any business, fire department, buses.
- ✿ When exiting public transportation, know what direction you are going to go in before you leave the vehicle. Look outside before leaving; if it does not look safe, stay in the vehicle. Once out, avoid being or looking confused or lost. Walk with authority and maintain that I belong here, in control look. Don't give anyone time to size you up.

- ✿ When leaving your car be L-E-S-S of a target: Look before getting out; check all mirrors. Exit the car quickly. Never remain in your car in the client's neighborhood to conduct business, such as reading, completing records, or calling on the cell phone. Secure the car. Step away quickly and proceed to the client's home. Note: Avoid working out of your trunk. If you must keep equipment in your trunk, organize it so that you can quickly open and retrieve what you need with minimum exposure time. Do not bend over into the trunk space rooting for something that should have been better positioned.
- ✿ Enter the client's home with caution. While waiting to be admitted, do not turn your back entirely to the street. Stand at an angle so that you can observe both the door and the street. Observe and listen as you enter.
- ✿ When leaving the client's home, know who is behind you. Look outside before exiting if possible. Have car keys ready and in your hand before leaving. Never stand by your car fumbling around for your keys.
- ✿ When re-entering your car, remember L-E-S-S: Look before getting in; check under and inside the car. Enter quickly. Secure (lock) the car doors. Start out quickly. Do not sit in your car to conduct business.
- ✿ Try to coordinate your client visit with transportation schedules. Wait in a conspicuous spot. Stand tall; keep items you're carrying close to you. If the situation deteriorates, have options (e.g. move to another stop, cross and take the opposite direction transport, go back to the client's home, walk off and call a taxicab).
- ✿ Pay attention to signs like NO Trespassing, Beware of Dog, Beware of Owner, as they may be an indicator of the resident's attitude towards strangers.
- ✿ TRUST YOUR GUT!

## Client's Residence

- ✿ Never enter a building that appears vacant (i.e., apartment doors open; no curtains on windows; boarded up windows, etc.) If you feel unsafe making a visit, go to a safe location and notify your first-line supervisor.
- ✿ Pause at the door before knocking and listen. If you hear loud quarreling, sounds of fighting or some other disturbance leave immediately.
- ✿ You are an invited guest in the home. Although the client and family control the environment, you must manage or control the visit. Be polite but firm if you need an adjustment in the environment. Focus on the client's well-being.
- ✿ Be cautious of pets; protect your feet and ankles with your bag. Make a note with the directions to the home where there is a pet in the area you need to be wary of.

### General safety guidelines with dogs:

- ✿ Dog owners are seen by their dogs as the dog pack leader.

- ✿ Visitors usually pose no threat to the dog as they are not members of the pack and thus remain friendly.
- ✿ Precautions should be taken to avoid dogs that are unleashed and unfamiliar.
- ✿ When calling a new client prior to the initial visit, inquire about aggressive dogs.
- ✿ Let the client/family member know the arrival time for the visit and request the dog's confinement.
- ✿ Lower your hand to the side of your leg and "wag one finger." This is a universal friendly sign from one dog to another. This action lets the dog know that he does not have to defend himself, his territory, his food, or his toys or get rid of competition for a mate.
- ✿ Assess the stance of the animal. If the dog approaches in an aggressive manner, shout "Go lie down" loudly and make as much or more fuss than the dog is making. Usually, if your voice and action show no fear, the dog will not actually attack. Throw large stones just close enough to the dog to bounce near but not actually hit it. Several rocks thrown in rapid succession may assist in warding off the dog.
- ✿ Remember: never try to run away from an aggressive dog. This will encourage it to attack. Move slowly to the house or car. Carry a large stick and sweep it through the air. This deters aggressive dogs.
- ✿ Avoid distractions in the home. Select a good area in which to perform the required clinical assessment. If possible sit as close to the door as possible.
- ✿ Always have a clear path to an exit.
- ✿ Before going into another part of the dwelling or using the phone, ask permission. Remember you are a guest in their home. Follow them, never lead.
- ✿ Safeguard your supplies and personal belongings at all times.
- ✿ If the situation ever becomes out of hand or uncertain, leaving is recommended.
- ✿ Document anything unusual in the record or visit report and bring it to the attention of your immediate supervisor.
- ✿ Do not get on an elevator if you feel uncertain about the other occupants. Feel free to exit the elevator if you feel uncomfortable, even if it is embarrassing. Wait for another elevator. Do not use the stairs. When you are on the elevator, stand next to the control panels by the emergency button. Do not push the stop button.
- ✿ If the apartment building hallways have men or teenagers loitering, do not enter, or have a family member meet you at the outside entrance and escort you to the apartment.
- ✿ If someone is about to threaten you, scream loudly, "Fire!"

- ✿ If you are threatened by a purse snatcher, do not attempt to resist him or her. Give him or her purse or wallet.
- ✿ If an assailant does not have a weapon and attempts to physically harm you: (a) Run to a location where there are people; (b) Strike using your bag, a fingernail file, a comb, a pen, etc; (c) Bite the assailant's arm or hand if he or she covers your mouth to prevent you from screaming; (d) Scratch his or her face and eyes; (e) Scream "Fire!" and attempt to free yourself; (f) Kick male assailants in the groin; (g) Don't panic!
- ✿ Do not give out your home telephone number to clients. Do not carry yours or your family's home address with you.

**If you are in a tight situation:**

- ✿ Don't show fear. Try not to show any facial expression.
- ✿ Control your breathing.
- ✿ Speak slowly and lower the pitch of your voice, talk from your diaphragm. Watch your hands so they don't move nervously.
- ✿ Maintain eye contact, but don't try to stare anyone down.
- ✿ Don't challenge, but be assertive, especially if lewd comments are made.
- ✿ Check your watch, say you need to call your office because they are waiting for your call. Don't tolerate nonsense or crazy behavior, rudeness, or name calling.
- ✿ Repeat what you are there for. Stand up and leave.

**Methamphetamine Lab**

- ✿ Many residences are the locations of drug activity or meth labs. Be alert to homes whose view to the interior is obstructed in some manner by blinds, or the windows are boarded over, etc.
- ✿ Meth labs can be identified by their strong smell, similar to stale cat urine.
- ✿ Chemicals and glassware are typically found dumped outside of a lab on the ground.
- ✿ The cooking is done in a three-necked reaction flask with foil chips in the bottom. They can be placed on a heat source like a chafing dish (which has inadequate heat control, making it dangerous). Foil chips are commonly used in the manufacturing of meth. It is part of the reaction process. It is the uncontrolled heating process and the products used in the production of meth (like ether) that make the "cooking" of meth dangerous for the cooks and innocent bystanders alike.
- ✿ Typical containers found at a meth lab location look like common household glassware.

- ✿ The “sludge” residue of the cooking process closely resembles used crank case oil. Its hazards are unknown. Chemicals can be stored in marked or unmarked containers. You may see a “separating funnel” which is used to separate the meth (a whitish substance) from the meth oil.
- ✿ Be careful when walking in yards with discarded glassware and containers that could have been used in a meth lab operation because the chemicals they contained can contaminate you and filter down through the soil and into the water table resulting in contamination of the water.
- ✿ Be alert to stripped batteries, Sudafed containers, multiple propone containers.
- ✿ If lab glassware and chemical containers are present leave immediately. Don’t touch anything at the location. Call 911 at the first safe opportunity; your anonymity can be maintained. State that you are reporting a possible meth lab operation so proper emergency response procedures will be used.
- ✿ TRUST YOUR GUT! Do not enter homes when you suspect that an unsafe situation exists.

## Personal Transportation

Your car is your field office. It must be reliable, safe, and easy for you to drive. Consider the following points:

- ✿ Maintenance is a must. A poor battery or badly worn brakes will let you down at the most inconvenient times. Have your car inspected regularly, especially the battery, ignition, cooling, and tires.
- ✿ Keep the fuel level reasonable – fill up when the tank is between one-half and one-quarter filled. In cold climates, keeping the tank at least half filled will help prevent moisture buildup.
- ✿ Check the windshield washer fluid, wipers, all lights, and horn.
- ✿ Carry safety items such as a flashlight, jumper cables, tow strap, “Call Police” sign, duct or electrical tape, flat tire repair, highway warning devices, and standard hand tools. The two best safety items are your cell phone and a reliable auto club.
- ✿ Keep the interior clear of all items that may attract attention. Do not keep money, a cell phone, or purse in plain view or on seats. Keep the doors locked and windows up at all times. Use a heater and air conditioning for climate control.
- ✿ Drive with doors locked, and if possible car windows up.
- ✿ TRUST YOUR GUT!

# Sample Interview Questions

## For Nurses to Conduct a Structured Interview Completing the Region X Newborn to 36 Months Standards

### Screen and Assessment

As a response to requests from field nurses, these SAMPLE questions are provided as ideas for client interview. The Region X Screening tool is organized around questions that the nurse asks herself when analyzing data to determine client outcome. The Region X Screening Tool is not an interview guide. Nurses have requested sample questions that would assist in client interview to gather client data by functional pattern. These questions are also NOT an interview guide. These questions, if asked in sequence, would be overwhelming for the client and the Public Health Nurse. Instead, use these questions as a review to think about asking some of them when the timing is appropriate. Some questions may be suitable for screening, and others suitable for assessment.

Every Public Health Nurse will be using individual styles and will prioritize interview questions and techniques according to the situation and client. The interview should be comfortable and paced appropriately for the nurse and the client. It is always best to try for an open-ended “conversation” with the parent or caregiver. First ask, “Tell me about your child and how your day is spent together.” Encourage a “free-flow” discussion as much as possible. Remember to interject POSITIVE statements about the child and family OFTEN in the interview. This is the chance for the caregiver to really BRAG about the child!!

Most of the questions are stated so that the parent is encouraged to describe WHO, WHAT, WHERE, WHEN and HOW. Try to avoid WHY question. They are much more difficult and often the answer is “I don’t know.” Some questions, especially in the physiological areas, allow the client a yes or no response. IT is always better not to ask a question that is answered yes or no.

These examples are in question format; however, parents often volunteer information about their child, and these concrete examples may:

- ✿ Cue your thinking about which functional pattern the parent is describing
- ✿ Help you think of ways to respond or words that would encourage the parent to describe the issue more precisely.
- ✿ Assist you to open topics that the parent has not volunteered.

## Nutrition/Metabolic

### Birth to 2 Months

- ✿ How does your baby let you know when she is hungry? What is different about her hunger “cues” and the “cues” she gives to let you know she wants something else? Does she become excited as you are getting her into a feeding position?
- ✿ Breast feeding? How often? Each breast at each feeding? How long on each breast? Are you in a comfortable position? Is baby latching on well? Does baby root at your breasts when you hold him? Do you have any breast tenderness or nipple problems?
- ✿ Formula feeding? What kind? How often? How many ounces at each feeding? About how many ounces in a 24 hour period? How are you preparing the formula? What temperature? How are you storing formula that has been mixed and open? How long do you let formula in the bottle when baby does not finish all the formula at one time?
- ✿ How does your baby let you know he has had enough food? Does he seem satisfied at the end of the feeding? Does he fall asleep right after feeding?
- ✿ How do you hold your baby while she eats? Can you show me the position she likes best? Do you know why she likes that position? (Trunk to trunk? En face?) Who else has the opportunity to feed your baby? Family? Friends? Sitters?
- ✿ How do you let the person who will feed your baby know about all the things your baby likes during feeding?
- ✿ Do you feed your baby anything besides breast milk or formula? (Water? Juice? Cereal? Fruits? Teas? Herbs?) How much? How often?
- ✿ To whom do you turn to for advice about feeding your baby? Or if you have questions or concerns about feeding your baby?
- ✿ Is your baby burping well? How often does your baby spit up? (After each feeding? When you lay him down?) Describe how your baby spits up? (Dribble out of mouth? Projectile?) How much does your baby spit up each time? (Almost all of the feeding? Just enough to wipe off her mouth? A few teaspoons?)

### 3 to 9 months

- ✿ When do you think it is time to add solids? Which solids will you start first? What is important about this solid being first? When will you add the next new solid? How will you know that the baby is having no difficulty with his new solid? What kinds of things may indicate that the baby is having difficulty?
- ✿ How is your baby getting more involved with his feeding situation? Does he recognize his bottle? Does he bring his hands to midline to try to cuddle with it? Try to hold it?
- ✿ How is your baby initiating feedings? Reaching and pointing at the breast or bottle? Trying to be “in charge” of starting and pausing during feeding? Reaching for the spoon?

- ♣ What does your baby do when you give him a spoon? Describe how your baby tries to feed himself (Spoon? Fingers?)
- ♣ How is your baby doing with a cup? Does she drink well when you hold it? Does she like to hold it herself? Does she have a Tommy-Tippy?
- ♣ When does your baby like to keep his bottle close? At bedtime? Naps? Does he go to sleep holding his bottle in his bed? Are you still holding your baby for all bottle feedings?
- ♣ What time of the day can all family members sit down to eat together? How does baby participate in family meals?
- ♣ How do you make sure you have enough food for you and your children? Does your child take vitamins? Fluoride?

### 9 to 36 Months

- ♣ How does your child let you know when he wants to eat? How much does your child eat from these groups every day?  
 Dairy\_\_\_\_\_ Vegetables\_\_\_\_\_
   
Cereals/Bread\_\_\_\_\_ Meat\_\_\_\_\_ Fruit\_\_\_\_\_
- ♣ What does your child eat for snacks?
- ♣ What beverages does your child drink through the day? How much water does your child drink every day?
- ♣ When does your child drink from a bottle? Does he like to walk around with his bottle and keep it close? Does he like his bottle at bedtime? Naps? How many a day?
- ♣ How well does your child use a cup? Does he play with his cup and pour out the liquid? How well does your child feed herself? Finger foods...spoon...fork?
- ♣ What foods does your child choose when he wants to eat? Does he like to help plan family meals?
- ♣ Does your child help with food preparation? Stirring? Setting the table? Clean up? What table manners is your child learning?
- ♣ What time of the day can all family members sit down to eat together? How do you make sure you have enough food for you and your children? Does your child take vitamins \_\_\_\_  
 Fluoride\_\_\_\_\_

## Health Perception/Health Management

### General/All Ages

- ✿ Another part of the chart contains health history; family history; medical records; growth grids and physical exam. Use an interview to gather information about functional patterns.
- ✿ Does your family have a primary health care provider? Appointment for next wellness exam?
- ✿ Last well child exam? Immunizations up to date? Dental care provider? Last dental check up?
- ✿ Has transportation: Car \_\_\_\_\_ Bus \_\_\_\_\_ Relies on Others \_\_\_\_\_
- ✿ Has financial ability for health care?
- ✿ How do you know when your baby is sick?
- ✿ What are your plans in case your child has an emergency? Do you know first aid or CPR? Do you have a phone? Do you have a way to call for help?
- ✿ What have you done to make your home safe for your child? Do you have Ipecac on hand? Do you have the poison control number handy? What is the temperature of your hot water?
- ✿ Does anyone smoke in your home? Do you have a smoke alarm? What are your plans in case of a fire?
- ✿ Do you use a seat belt in the car? Do you have a car seat for your child? Does your child see you “buckle up” every time you get into the car?
- ✿ What things do you think will keep your child healthy? Does your family have any traditions to keep your child healthy? To treat her when she is sick?
- ✿ Whom do you rely upon for help and advice when you have questions or concerns about your child’s health? Illness?

## Health Maintenance/Management

### 9 to 36 Months

- ✿ How are you teaching your child about good health habits? Brushing teeth? Washing Hands?
- ✿ Good food choices? Exercise?
- ✿ How are you teaching your child about safety? “Hot things”? Sharp objects? Crossing streets?

- ✿ People who will help you...neighbors? Family? Policement? Firemen? Doctors? Nurses? Teachers?
- ✿ Is your neighborhood safe to play outdoors? Fenced yard? Hazards in the yard? Borken glass?
- ✿ Refrigerators? Supervised play?

## Elimination

### Birth to 9 Months

- ✿ How many wet diapers does your baby have in a 24 hour period? Can you see any color in the urine? Brown? Dark yellow?
- ✿ How many bowel movements does your baby have in a 24 hour period? Describe his stool? (Hard and dry: firm “balls.” Soft and firm: formed but easily flattened. Soft and unformed: squishy. Thick liquid: like thin oatmeal. Thin liquid: like water. What color? Any distinctive odor?
- ✿ Do you see mucus or blood in your baby’s stool?
- ✿ Does your baby sweat? When? Only when wrapped warmly? Is his skin normally warm and dry?
- ✿ What changes in your baby’s urine and bowel movements would concern you? Can you tell me what changes in your baby’s urine and stool would let you know he may be sick?

### 9 to 36 Months

- ✿ Does your child have problems with constipation or diarrhea? Does your child urinate without complaining?
- ✿ How many bowel movements per day? Urinations per day?
- ✿ What are your expectations about toilet training? How will you know your child is “ready” to begin toilet training? Is your child toilet trained? At what age do you expect him to have control of his urine? Of his bowels?
- ✿ Does your child have “accidents” during the day? At night?

## Sleep/Rest

### Birth to 2 Months

- ✿ How does your baby let you know that she needs to sleep? In what position do you put your baby to sleep?
- ✿ What time do you usually put her to sleep for the night? Does she awaken in the night? How often, at what times? When does she awaken in the morning?

- ✿ How often does she sleep in the day? What times are her naps? How long are her naps?
- ✿ Where does your child sleep at night? For naps? Does she have her own crib? Sleep in which room?
- ✿ Are his night sleeps increasing? Awakenings less often? Is his schedule conforming to the family's schedule?

### **3 to 9 Months**

- ✿ When your child first awakens, does he play and make happy noises for a while before he cries for you to come?
- ✿ What special routines do you use before bedtime? Holding for a bottle feeding? Rocking in a chair? Singing a special song? Reading a story? Do you put your baby to bed when he is already asleep? Will he go to sleep if you put him in his bed while he is sleepy, but still awake?

### **9 to 36 Months**

- ✿ How does your child let you know he needs to sleep? What time is bedtime? What time does your child get up in the morning? What do you do to awaken your child? Does your child usually awaken refreshed and alert?
- ✿ What activities do you do with your child before bedtime? Any night routines? Bath? Brushing teeth? Story time? Bedtime toys? Can she go to sleep easily? Sleep through the night?
- ✿ Where does your child sleep at night? Does he sleep with others? Where does your child take naps? What time are naps?

## **Activity/Exercise**

### **Birth to 2 Months**

- ✿ Describe how your baby plays actively. Does she like to kick and move a lot? Does she move her arms and legs equally on both sides?
- ✿ Can he suck vigorously and long enough to finish his feeding? Does he show signs of fatigue during feeding?
- ✿ Does your baby like active and movement play? Rolling on a pillow? Having you move his arms and legs?

### **3 to 9 Months**

- ✿ How is your baby reaching out to his world? Pointing to objects? Throwing objects out of his crib? Onto the floor?
- ✿ Describe how your baby is increasing his activity level. Getting stronger? Likes to bear weight and “jump” while on your lap? What does he do while he has “floor time.” How

is he increasing the space in which he can move around? Rolling over? Working for toys out of reach?

- ✿ What kinds of new playthings are you offering him? Which ones does he like?

### **9 to 36 Months**

- ✿ Is your child as active as other children her age? Can she play actively, jump, run, climb without fatigue?
- ✿ What indoor and outdoor games/toys/activities does your child play? Same age friends/older children?
- ✿ Can your child play alone for a while with his toys? Focus in on a game and play quietly while coloring, using a puzzle, playing with cars?
- ✿ Does your child prefer quiet or active play?
- ✿ When do you read stories, look at pictures together? How often can you read together? Who else reads stories to your child? Grandparents? Older siblings?
- ✿ What does your child do when he goes shopping for groceries with you? Describe how he explores the new, colorful objects in the store. How would you like him to behave while you are shopping?
- ✿ What does the family do together for fun? Go to the park? Movies? Fishing? Camping? Rent videos? Cook together? Visit family? Invite guests? Work in the yard? Rake leaves?

## **Cognitive/Perceptual**

### **Birth to 2 Months**

Use an agency approved STANDARDIZED DEVELOPMENTAL SCREENING TOOL And then do an interview to determine functional patterns:

- ✿ How does your baby respond to different kinds of touch? Stroking? Massaging? Light tickles? Water?
- ✿ How does your baby respond to different kinds of sounds? Loud noises? Singing? Crooning talk? Music?
- ✿ How does your baby respond to different kinds of visual stimulation? Your face? Lights? Patterns? Colors?
- ✿ What kinds of toys do you have for your baby?

### **3 to 9 Months**

- ✿ Does your child like to play in her bath? Play with her food? Make a mess? Spit out her food? “Blow bubbles”?

- ✿ How does your child respond to cuddling? Touching? Different textures and temperatures? Does she have a favorite blanket or an object she likes to hold, feel and suck on?
- ✿ How does your baby respond to non-verbal language (smiles, stern looks, body posture changes?) Is she exposed to hearing more than one verbal language on a regular basis?
- ✿ What are your child's favorite TV programs? What other programs does your child watch?
- ✿ How much TV does your child watch?

## 9 to 36 Months

- ✿ What do you observe about your child's learning style? How does he learn? Hear and tell stories? Sing songs? Copy what you do?
- ✿ Describe your child's special talents/interests. Music? Art? Dancing? Acrobatics? Performing for others?
- ✿ Where do you display your child's art work in your home?
- ✿ How does your child respond to or touch different textures? Put things in his mouth? Rub them on his face or head? Bang objects on the floor? Make things move?
- ✿ How does your child play in her bath? Play with mud, clay, finger paints?
- ✿ How does your child let you know she wants to be touched and to cuddle? How does she let you know she does not want to be touched or to cuddle? Does she have a favorite blanket or object she likes to carry, feel and/or suck on?
- ✿ Does your child speak/understand more than one verbal language? If so, describe how he is learning words for both languages. Is he aware and does he respond to non-verbal language (smiles, stern looks, body posture changes?)
- ✿ What are your child's favorite TV programs? What other programs does your child watch?
- ✿ How many hours of TV does your child watch?

## Self Concept/Self Perception

### Birth to 2 Months

- ✿ How does your child let you know what he needs?
- ✿ How would you describe your child's personality or temperament? Is he happy? Content? Stubborn? Curious? Funny? Sweet? Shy? Nervous? Sad?
- ✿ How is your baby like you? How is your baby different from you? Is your baby like anyone you know?

- ✿ What names are you calling your baby? Her real name? Nickname? Baby names? What do those names mean to you? What do you think they will mean to your baby?

### **3 to 9 Months**

- ✿ How does your child act in new situations? With new people? With new toys? What does your child do when you leave her with a babysitter?
- ✿ What does your baby do when you call his name?

### **9 to 36 Months**

- ✿ How does your child refer to herself? Is she starting to say “good girl” or “bad girl”?

## **Role/Relationship**

### **General/All Ages**

- ✿ How long have you lived in this area? What family members live here or close by?
- ✿ What friends or neighbors live close by? Do you get the kind of support you want from:  
Family\_\_\_\_\_ Friends\_\_\_\_\_ Others\_\_\_\_\_
- ✿ What is your child’s position in the family? Oldest\_\_\_\_\_ Youngest\_\_\_\_  
Middle\_\_\_\_\_
- ✿ What kinds of parenting skills did your parents have that you think were helpful and you want to use with your child?
- ✿ What things did your parents do that you think were not helpful and you do not want to do?
- ✿ What parenting tips do you get from others? Whom do you go to for advice about parenting and questions about your child’s behavior and your response?

### **Birth to 2 Months**

- ✿ What does your baby do that pleases you? Smiles? Cuddles? Looks at your face? Eats well?
- ✿ Sleeps well? How do you let her know that you are pleased? How does she respond?
- ✿ What does your baby do that displeases you? Crying? Not sleeping well? Not eating well?
- ✿ How do you help him to stop that behavior? How does he respond?
- ✿ Where does your baby spend most of the day? Crib? Playpen? Couch? Swing? Car seat?
- ✿ Where do you spend your day?

- ✿ What do you expect your child will be doing at his next stage of development? What will you do to help him enter this next stage?

### **3 to 9 Months**

- ✿ Describe how your child plays with: siblings? Peers? Extended family?

### **9 to 36 Months**

- ✿ Does your child like to play with toys that represent the adult world? Dress-up? Trucks? Dolls?
- ✿ What does your child do that pleases you? How do you let her know that you are please? How does she respond?
- ✿ What does your child do that displeases you? How do you help him to stop that behavior? How does he respond?
- ✿ What chores or “helping activities” does your child do? Pick up toys? Fetch articles for you? Do you have a pet? How does your child help to care for the pet? Feed, exercise, groom?
- ✿ What do you expect your child will be doing at his next stage of development? What will you do to help him enter this next stage?

## **Sexuality/Reproductive**

### **Birth to 2 Months**

- ✿ Did you expect your daughter/son to be a girl/boy? Did others in your family have wishes for a boy or girl? How are they reacting to you baby’s gender?
- ✿ What are your plans to teach your child about sexuality? Are you and your child’s co-parent in agreement about teaching sexuality?

### **3 to 9 Months**

- ✿ What do you do when your child refuses to be cuddled, kissed or touched?

### **9 to 36 Months**

- ✿ How does your child describe herself as a girl? Like Mommy? Himself as a boy? Like Daddy? Describe how your daughter plays with trucks and balls.
- ✿ Describe how your son plays with stuffed animals and dolls. Describe how your child plays in messy things like mud and water.
- ✿ What do you do when your child refuses to be cuddled, kissed or touched.

- ✿ What body parts can your child point to and name? Eyes? Ears? Toes? Vagina? Penis? How much does your child like to touch her genital areas? How do you and others respond to your child when she is touching herself in private areas?
- ✿ What are your plans to teach your child about sexuality? Are you and your child's co-parent in agreement about teaching sexuality?
- ✿ What have you said or plan to tell your child about safe touch and unsafe touch?

## Coping/Stress Tolerance

### Birth to 9 Months

- ✿ How does your baby let you know when she is stressed? What kinds of things make your baby stressed?
- ✿ How does your baby adapt to changes in temperature? Diaper changes? Position? Bright lights? Loud noises?
- ✿ How does your child let you know when she is: Happy? Afraid? Sad? Angry?
- ✿ Describe how your baby changes from sleeping to waking? From being drowsy to being alert? From quiet to cry? From cry to content?
- ✿ What does your baby do to calm herself? Suck on her hand? Stare at the wall? Listen to a voice? Change her position? What do you do to soothe your baby when she is upset?
- ✿ What are your methods to soothe yourself when you are stressed? What causes your stress?

### 9 to 36 Months

- ✿ How long does it take for your child to recover from one mood to another? How often does your child go to bed crying, angry or afraid?
- ✿ What are the fears your child tells you about? What fears do you observe him displaying? Dark? Animals?
- ✿ What does your child do to soothe herself? What do you do to soothe your child when she is upset?
- ✿ What are your methods to soothe yourself when you are stressed? What causes your stress? Does your child display behaviors that concern you? Temper tantrums? Screaming? Breath-holding? Head-banging? Hitting others? Biting other? Tics? Picking nose or skin?
- ✿ Biting nails?

## Value/Belief

### Birth to 9 Months

- ✿ Are there special ceremonies or rituals that you or your family practice when a new baby is born? Did you have a chance to have those celebrations?
- ✿ What brings you joy and happiness?
- ✿ When you think about your child becoming an adult...what kind of person do you want him to be?
- ✿ What ways will you teach your child right from wrong?
- ✿ Do you and the significant adults in your child's life generally agree on how to raise your child?
- ✿ When you do not agree, how do you resolve your differences? Do you usually present one decision to your child?
- ✿ What religious upbringing did you have? What are your religious beliefs now? What do you want your child to experience in his upbringing?

### 9 to 36 Months

- ✿ What brings joy and happiness to your child?
- ✿ Has your child experienced any deaths or separations of people/pets that she has been close to?
- ✿ How did you talk with your child about this loss?
- ✿ What opportunities do you find to talk with your child about his cultural heritage? Does your family have the opportunity to practice traditions? Holidays? Food? Group meetings?
- ✿ What do you do to be sure that your child is treated fairly and sensitively by community services and agencies? How do you advocate for your child?

# Nursing Plan of Care—Child

Date	Problem	Desired Outcome	Intervention	Date/ Outcome
	I. Health Perception/ Management: Actual/potential problem	<ul style="list-style-type: none"> <li>• Child maintains optimal health/hygiene</li> <li>• Immunization/well child checks UTD</li> <li>• Good dental hygiene</li> <li>• Uses car seat/seatbelt appropriately</li> <li>• Child's environment modified to minimize hazards, 2nd hand smoke</li> <li>• Has working smoke alarm</li> <li>• Child with disabilities functions at optimal level</li> <li>• Services available and coordinated</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Child</li> <li>• Signs of health/illness</li> <li>• Immunization/well child schedule</li> <li>• Dental care &amp; development</li> <li>• Age appropriate safety, child- proofing</li> <li>• Safety r/t environmental toxins/ 2nd hand smoke/ guns</li> <li>• Importance of smoke alarm</li> <li>• Provide emergency numbers</li> <li>• Refer to DDD services</li> <li>• Refer to community resources</li> </ul>	
	II. Nutrition/Metabolic Actual/potential problem	<ul style="list-style-type: none"> <li>• Can state age appropriate nutrition requirements</li> <li>• Caregiver demonstrates appropriate feeding techniques</li> <li>• Reports adequate intake</li> <li>• Growth WNL</li> <li>• Aware of community resources</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Age appropriate nutritional requirements</li> <li>• Monitor wt/ht/ofc</li> <li>• BF techniques, position, frequency, duration, pumping, storage &amp; weaning</li> <li>• Bottle weaning</li> <li>• Refer to community resources</li> </ul>	
	III. Elimination Actual/potential problem	<ul style="list-style-type: none"> <li>• Voiding pattern WNL for age/intake</li> <li>• Stools=frequency and consistency appropriate for age/intake</li> <li>• Caregiver expresses age appropriate expectation for toilet training</li> <li>• Self care toilet training beginning (18-36 months)</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Age appropriate elimination patters</li> <li>• S/Sxs dehydration, inadequate intake</li> <li>• Toilet training guide</li> <li>• Refer to WIC, Nutritionist, Dr. prn</li> </ul>	
	IV. Sleep/Rest Actual/potential problem	<ul style="list-style-type: none"> <li>• Age appropriate</li> <li>• Has safe place to sleep</li> <li>• Environment contributes to sleep, rest, relaxation</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Normal ranges of sleep patterns</li> <li>• Safety concerning sleep area, surface &amp; position</li> </ul>	
	V. Activity/Exercise Actual/potential problem	<ul style="list-style-type: none"> <li>• Fine/gross motor skills &amp; develop milestones WNL</li> <li>• Has age appropriate toys</li> <li>• Activities contribute to G&amp;D</li> <li>• Child free to participate in activities</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Normal development of motor skills</li> <li>• Age appropriate child stimulation &amp; activities</li> <li>• Safe &amp; age appropriate toys</li> <li>• Perform Denver Developmental Screen</li> <li>• Refer to community resources</li> <li>• Refer to parenting groups</li> <li>• Developmental need to explore environment, play</li> </ul>	

Open Date: \_\_\_\_\_ PHN: \_\_\_\_\_

Client Name: \_\_\_\_\_ Client ID# \_\_\_\_\_ Client DOB \_\_\_\_\_

Child Name: \_\_\_\_\_ Child DOB \_\_\_\_\_

Date	Problem	Desired Outcome	Intervention	Date/Out- come
	VI. Cognitive/ Perceptual Actual/potential problem	<ul style="list-style-type: none"> <li>• Communication/hearing/ vision WNL for age</li> <li>• Has developmentally appropriate toys</li> <li>• Child communication &amp; language development WNL for age</li> <li>• Caregiver interacts with child, provides adequate stimulation</li> <li>• Child has access to formal education</li> <li>• School performance WNL</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Child Stimulation</li> <li>• Communication/language development</li> <li>• Importance of reading &amp; talking to child</li> <li>• Importance of nurture B-3 yrs for brain development</li> <li>• Perform Denver Developmental Screen</li> <li>• Refer to educational resources</li> </ul>	
	VII. Self Perception/Self Concept Actual/potential problem	<ul style="list-style-type: none"> <li>• Child/child develops + self concept</li> <li>• Caregiver demonstrates + response to child</li> <li>• Caregiver recognizes/ understands child temperament and responds appropriately</li> <li>• Child participates with peers</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Importance of caregiver responses to child's development of + self-concept</li> <li>• Individual temperament differences</li> <li>• Importance of healthy peer relationships</li> <li>• Refer to community resources</li> </ul>	
	VIII. Role/ Relationship Actual/potential problem	<ul style="list-style-type: none"> <li>• Caregiver-child attachment</li> <li>• Caregiver responds appropriately to child cues</li> <li>• Child's emotional/ physical need met by caregiver</li> <li>• Free from abuse/neglect</li> <li>• Child thrives physically</li> <li>• Caregiver physically &amp; emotionally available to child</li> <li>• Any childcare used is safe &amp; appropriate</li> <li>• Child displays + social interaction</li> <li>• Housing and transportation adequate to meet child's needs</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Importance of caregiver-child attachment, cues to meet child's emotional/physical needs</li> <li>• Prevention of/resources for CAN</li> <li>• How to find/screen for childcare</li> <li>• Importance of social interaction</li> <li>• Appropriate/adequate housing/ transportation</li> <li>• + effect of caregivers working toward education &amp; career goals</li> </ul>	
	IX. Sexuality/ Reproductive Actual/potential problem	<ul style="list-style-type: none"> <li>• Demonstrates + gender ID</li> <li>• Free from physical, sexual, emotional abuse</li> </ul>	Teach: <ul style="list-style-type: none"> <li>• Importance for fostering + feelings regarding gender</li> <li>• Personal safety</li> <li>• Refer to resources for CAN prevention</li> </ul>	

Date	Problem	Desired Outcome	Intervention	Date/Outcome
	<p>X. Coping/Stress Tolerance Actual/potential problem</p>	<ul style="list-style-type: none"> <li>• Caregiver attends to child's signs of stress/emotional needs</li> <li>• Caregiver reinforces positive coping skills</li> <li>• Caregiver understands discipline vs. punishment</li> <li>• Caregivers agree on how to discipline child</li> <li>• Environment free of DV/unhealthy relationships of caregiver</li> <li>• Caregiver does not abuse substances</li> </ul>	<p>Teach:</p> <ul style="list-style-type: none"> <li>• Signs of stress in child</li> <li>• Coping skills &amp; stress reduction measures</li> <li>• Positive discipline vs. punishment</li> <li>• Importance of responding to child's emotional needs</li> <li>• Shaken Baby Syndrome &amp; safe coping methods</li> <li>• Neg. effects of DV in environment</li> <li>• Neg. effects of parental substance abuse</li> </ul>	
	<p>XI. Value/Belief Actual/potential problem</p>	<ul style="list-style-type: none"> <li>• Child has secure/routine environment</li> <li>• Caregiver has age-appropriate expectations for child's behavior</li> </ul>	<p>Teach:</p> <ul style="list-style-type: none"> <li>• Importance of routine, feelings of security</li> <li>• Respect cultural &amp; spiritual practices</li> <li>• Reinforce healthy values, beliefs</li> </ul>	

--Thurston County

# Plan of Care—Child

Date

Client Signature

Date	Problem	Desired Outcome	Intervention	Date/Outcome
	Nutrition/metabolic: Potential/actual problem, R/T	Parent provides adequate nutrition appropriate for age/ development. Child beginning to learn healthy food choices. Ht/Wt profile WNL.	Teach: age appropriate nutrition, healthy food choices/ ADA Pyramid, sx of eating problems/disorders. Provide community resources.	
	Elimination: Potential/actual problem, R/T	Has voids/stools WNL. Has no sx of complication/ infection. Teaching initiated/ accomplished @ appropriate age/developmental readiness w/out anxiety/ parental pressure.	Teach: normal bowel/bladder patterns. Alterations/sx of infection. Toiler teaching/ developmental readiness, bed wetting.	
	Sleep/Rest: Potential/actual problem, R/T	Child receives appropriate sleep/rest for age. Has appropriate/safe place for sleep. Environment conducive to sleep/rest. Has + bedtime routines.	Teach: developmental requirements for sleep/rest. Methods to promote sleep/rest. Naptime/bedtime routines.	
	Activity/Exercise: Potential/actual problem, R/T	Child demonstrates normal development of motor skills. Has safe/developmentally appropriate toys. Participates in healthy activities.	Teach: teach age appropriate activities that promote G&D. Good choices for developmentally appropriate toys. Refer to community resources for child activities.	
	Cognitive/Perceptual: Potential/actual problem, R/T	Child's vision/hearing WNL. Language & communication skills WNL. Parent reads & talks to child. Learning (informal & schooling) WNL &=reinforced by parent.	Teach: normal development of vision/hearing, language/ communication skills. Importance of reading/talking to child. Encourage parental involvement in school/ learning.	
	Health Perception/Mgmt: Potential/actual problem, R/T: Inadequate health/ dental care. Environ risk 2 <sup>nd</sup> hand smoke. Parent abuses substances. Other:	Child maintains optimum health/hygiene. Immunizations/well child checks & dental care UTD. Uses carseat/seatbelt appropriate for age. Environment safe, clean & free of toxins or 2 <sup>nd</sup> hand smoke. Has working smoke alarm.	Teach: sx of health/illness, illness care, immune./well child schedule. Importance of general & oral hygiene, fluoride (prn), & dental care; Need for carseat/seat belt use. Need for safe/clean environment. Effect of environmental toxins/2 <sup>nd</sup> hand smoke. Importance of smoke alarm.	

Parent name: \_\_\_\_\_ Name of child: \_\_\_\_\_

Thurston County

Date	Problem	Desired Outcome	Intervention	Date/Outcome
	Self Concept/Perception: Potential/actual problem, R/T	Child develops + self concept. Parent interaction conducive to child's self esteem. Parent respects child as an individual.	Teach: importance of parent responses in child's development of + self concept/healthy self esteem. Individual differences in temperament.	
	Role/Relationships: Potential/actual problem, R/T	Child is nurtured. Parent demonstrates + interaction/communication with child. Child is not abused or neglected.	Teach: child's emotional need for attention, affection & nurturing. Reinforce + interaction/communication. Prevention of/resources for CAN.	
	Sexuality/Repro- ductive: Potential/actual problem, R/T	Child demonstrates + gender ID. Reproductive/sexuality knowledge healthy & appropriate for age.	Teach: importance of fostering + gender ID. Age appropriate knowledge of reproduction/sexuality.	
	Coping/Stress Mgmt: Potential/actual problem, R/T	Child free of stress. Demonstrates + coping methods. Able to discuss stressful events/feelings with parent. Parent aware of shaken baby syndrome.	Teach: signs of stress in child. Methods to comfort/console & discuss feelings. Shaken baby sx & safe coping methods.	
	Values/Beliefs: Potential/actual problem, R/T	Environment/parent interaction contributes to sense of security, autonomy, hope & confidence. Uses appropriate non-physical methods to deal with undesirable behaviors.	Teach: importance of routine, instilling family beliefs/ traditions. Providing environment conducive to security. Appropriate/ effective ways to deal with undesirable behavior.	
	Psycho/Social: Potential/actual problem, R/T	Attends school regularly (school age children). Parent involved in activities with child. Child has + interaction with siblings/ peers. Housing & transportation adequate to meet child's needs. Parent working toward education/ career goals. Environment free of DV/unhealthy social relationships of parent. Parent does not abuse substances.	Teach: how to find/screen for childcare. Methods to deal with sibling rivalry/ adjustment. Importance of peer interaction. Child's need for appropriate/ adequate housing/transportation to have needs met. + effect of parents working toward education/career goals. - effect of exposure to DV/ unhealthy social relationship of parent. Effect of parental substance abuse.	

# Children with Special Health Care Needs

Child's Name: \_\_\_\_\_ B.D. \_\_\_\_\_

Medical Diagnosis: \_\_\_\_\_

Parent(s) Name: \_\_\_\_\_ tc \_\_\_ ov\_\_\_ hv\_\_\_\_\_

## Areas of Concern Form

Please check areas that are of concern to your family:

FAMILY	CHILD
Housing	Medical (including immunizations)
Job/Education	Medications
Transportation	Dental
Telephone/Heating	Therapy (OT, PT, Speech)
Clothing/Food	Special Equipment
Financial	Special Clothing
Legal	Child Care/Respite Care
Medical/Health Care	Educational Needs
Dental	Counseling
Counseling	Recreational
Interpreter	Growth & Development
Immigration/Naturalization	Nutrition/Feeding
Family Planning	Behavior
Support Group	Support Group
Other	Other

What are your special concerns? \_\_\_\_\_

Do you have resources to help with these concerns?

Do you wish to have further assistance to access resources for any of these concerns? Yes No

Signature

Date

--Thurston County Health Department





# Social and Emotional Well-Being

CSHCN Coordinators consider social and emotional factors with each contact they have with families. Your agency probably has quite a bit of information about these topics because it is general information for Public Health Nurses and is not specific to the CSHCN Program. This section will cover specific situations or requirements suggested or requested by Coordinators. The list is not exhaustive, but will provide a good start. With the advent of internet resources, many more sites are available with information. A general consideration when selecting a topic to research on the internet is to utilize .edu, .gov, and .org sites rather than .com sites. Inclusion of these materials does not constitute an endorsement of the organizations, their materials, or websites by the Department of Health, Children with Special Health Care Needs Program and should not be inferred. DOH is not responsible for the content of the individual organization's materials or information found at their websites.

## Child Protective Services Mandatory Reporting

All health professionals are mandated to report any Child Abuse or Neglect to their local Child Protective Services (CPS) agency within DSHS. Please refer to RCW 26.44.030: “When any practitioner...registered or licensed nurse...has reasonable cause to believe that a child has suffered abuse or neglect, he or she shall report such incident, or cause a report to be made, to the proper law enforcement agency or to the department provided in RCW 26.44.040.”

Most Local Health Jurisdictions have a contract with DSHS to provide Early Intervention Services to families amenable to intervention. See the attached example of one such program.

There is a video tape available called “Making a CPS Referral: A Guide for Mandated Reporters” that is available through the Children’s Administration, CPS Program Manager/Risk Assessment Trainer. Each Local Health Jurisdiction should already have a copy of this video.

# About the Grieving Process: How Do We Tell the Children

When you confront the problem of telling your children about death.

1. Accept that it is not easy. You may:

- ✿ Be upset and stressed.
- ✿ Lack energy.
- ✿ Feel unable to concentrate.
- ✿ Worry about how your emotions will affect your child.
- ✿ Be concerned about the effect of the death on your child.
- ✿ Not know how much your child understands about death.

2. Be prepared for resistance from others. People may say of your children:

- ✿ They don't know what's going on.
- ✿ Wait until later to tell them.
- ✿ Make up a story.
- ✿ Don't say anything.
- ✿ Send them away until the funeral is over.
- ✿ Why do you want to put them through this?

Consider saying to these people:

- ✿ I really could use your help. I believe that what I am doing is the right thing for my children and me.
- ✿ You can help me by reinforcing what I am telling them, or by saying nothing. Don't undermine my effort.

Parents should know that children will:

- ✿ Read emotions around them.
- ✿ Respond to body language.
- ✿ Overhear conversations.
- ✿ Ask questions directly or indirectly.

Your children will receive some kind of message. No matter what you do, it is impossible not to communicate. They will see your grief and if you have not explained what's going on it will signal them that something is the matter. They will be confused and anxious.

Control the message instead by giving them accurate information, geared for the age of the child, in language he or she can understand.

## Understanding Sadness

1. Your children need to know:

- ✿ Why you are sad.
- ✿ Why others are sad.
- ✿ Why they are sad.

Acknowledging this lets your children know that it's okay to be sad. Tell them, "This is how we feel when someone dies."

2. Children must be told that it is the death that has made you sad. Without an explanation, they may think your sadness is caused by something they did or didn't do. Start by saying:

- ✿ "This is a very, very sad time..."
- ✿ "A very, very sad thing happened..."
- ✿ "Mommy and Daddy are sad because..."

## Understanding "Dead" and What it Means

1. Explain that dead means that:

- ✿ A person's body has stopped working and won't work anymore.
- ✿ The body won't do any of the things it used to do: it won't talk, walk, move, see, or hear, none of the parts work.
- ✿ The person won't feel any of the feelings he or she used to feel, such as sad, mad, happy, hurt, hot or cold.
- ✿ The person will not eat, drink, or go to the bathroom (urinate and defecate) anymore.

2. Refer back to this explanation when answering questions that arise, such as:

- ✿ Will Grandpa ever move again? (No, his body has stopped working.)
- ✿ Why can't they fix him? (Once the body stops working, it can't start again.)

- ✿ Why is he cold? (The body only stays warm when it is working, like ours.)
- ✿ Why isn't he moving? (He can't move because his body isn't working anymore.)
- ✿ When will he come back? (He won't. People who die don't come back.)
- ✿ Is he sleeping? (No, when we sleep our body is still working, just resting.)
- ✿ Can he hear me? (No, he could only hear you if his body was working.)
- ✿ Can he eat after he's buried? (No, a person eats only when his body is working.)

3. Don't use words like "passed away," "left us," "gone on." To a child, this sounds like the person is taking a trip. His parents' trips may become a source of anxiety if the child thinks that some people never return from them. Don't hold out any hope of return. Death is a form of abandonment.

## Special Characteristics to Keep in Mind

### **Newborn to Age Three**

1. No matter how young the child, he or she can sense when things in the family routine are different. However, they will not be able to figure out why they are different. Among the changes in the daily routine that children might sense are:

- ✿ Excitement at home.
- ✿ Sadness or anxiety.
- ✿ Presence of new people.
- ✿ Parents being gone at odd time.
- ✿ A significant person in their lives is missing.

2. Watch your child to see if he or she starts acting differently. Among the changes you might note are:

- ✿ Stopped or altered nursing patterns (in infants).
- ✿ Crankiness
- ✿ Altered sleep patterns.
- ✿ Change in eating habits.

3. Children in this age group cannot comprehend the concept of death, however, they can understand your sadness. When you know what changes to look for in your children, you can respond more sensitively to their needs.

### **Age Three to Six**

1. Children in this age group think death is reversible, people will come back, death isn't forever. E.T. came back from the dead, so did Jesus and Lazarus. The coyote on the Roadrunner cartoon program gets right back up again after being squashed.

They will ask questions about the dead person's return, also. They may not be really affected by the death, since they expect the person to come back soon. They cannot understand the concept of "finality" at this age.

2. They will connect events that don't belong connected:

- ✿ Does this mean someone else is going to die?
- ✿ Grandpa died from a headache, mommy says she has a headache too...
- ✿ Old people die, daddy is very old, daddy may die too...

Be prepared for indirect questions, aimed at finding out if someone else might die: "How old are you? How old is daddy?"

You must explain the difference between:

- ✿ Very, very sick and just "sick."
- ✿ Very, very old and over 20.
- ✿ Very old and very sick, and very old and not sick.

3. It's important that your child not assume he is responsible in any way for the death.

4. Explain about the emotions your child may be feeling of observing:

- ✿ Crying is okay for everyone (boys too).
- ✿ Feeling bad inside is okay. After a while, you'll feel better.
- ✿ Being mad is okay.
- ✿ People in the family might have trouble sleeping or eating. This is a natural reaction.

### **Age Six to Nine**

1. Most children in this age group will understand that death is final, but some might still think that the dead person will come back.

2. Children in this age group need a more detailed explanation of why the person died. It's important to distinguish fatal illness from just being sick ("It's not like when your stomach hurts, or when mommy gets a cold...") They may have a greater fear of their parents' dying, particularly if they see them as vulnerable (often ill, etc.). This concern is even greater when they are being raised by a single parent.
3. They see death as a taker, something that comes and gets you. Or they may see it as something you catch, like a cold. They also may not want to go to a house where someone has died.
4. Explain about the emotions your child may be feeling or observing:
  - ✿ Crying is okay for everyone (boys, too).
  - ✿ Feeling bad is okay.
  - ✿ Feeling frightened is okay.
  - ✿ Being angry is okay.
  - ✿ Feeling that something is missing is okay.

Parents often find it helpful to share some of their own feelings with their children; it helps start discussion.

5. Because children in this age group connect death with violence, they may ask when being told about a death, "Who killed him?"
6. Make sure your child does not feel responsible for the death in any way.

### **Age Nine to Twelve**

1. Children in this age group are more aware of the finality of death and of the impact that a death may have on them, even to the point where it affects family security and economic security.

These feelings are quite close to those experienced by adults, and parents say it helps to share their own thoughts and feelings with their children.

2. Children may show anger, guilt and grief.

### **Teenagers**

1. The older your children, the greater the temptation to assume they can handle themselves and their problems. Don't assume this; they need your help and support to understand their feelings at this time.

## **Describing How/Why the Death Occurred (to Young Children)**

1. Old Age

✿ “When a person gets very, very, very old, his body wears out and stops working...”

## 2. Terminal Illness

✿ “Because the disease couldn’t be stopped, the person got very, very sick, his body wore out and stopped working.”

## 3. Accident

✿ “A terrible thing happened (car crash, etc.), his body was badly hurt and couldn’t be fixed. It stopped working...”

## 4. Miscarriage

✿ “Sometimes when a baby is just starting to grow, something happens that makes it stop. We don’t know what it was, it wasn’t anything anyone did...”

## 5. Stillborn

✿ “Sometimes something makes a baby die before it is born. We’re not sure why, but it’s nothing anybody did or didn’t do...”

## 6. Sudden Infant Death Syndrome (SIDS)

✿ “Sometimes with little babies something makes their bodies stop working. It’s nothing anybody did or forgot to do. Doctors are not sure why it happens...”

## 7. Suicide – Absolute (when there is no doubt the person killed himself)

✿ “Some people’s bodies get sick and just don’t work right and sometimes a person’s mind doesn’t work right. They can’t see things clearly and they feel the only way to solve their problems is to take their lives—to kill themselves. However, this is never a solution to problems. The only reason they thought of it is that they weren’t thinking very clearly...”

## 8. Suicide—Questionable

✿ “Sometimes people take pills to relax or sleep. Sometimes they forget how many they took and think they need more. These pills make a person’s body slow down. Too many of them make the body stop working. We don’t think the person wanted to die, but that’s what happened...”

## 9. Homicide

✿ “Sometimes very bad people do very bad things...”

## After the Death—What Will Happen Now

1. Children should be told what is going to happen and what they are going to experience. Should they be brought to the funeral home and/or service? Definitely, if they are well prepared

in advance. Tell them what will happen, then give them the choice of going or not. Fit the following explanation around your family's plans and special traditions.

“will be taken from \_\_\_\_\_, where he died, to the funeral home. At the funeral home \_\_\_\_\_ will be dressed in clothes that he liked and put into a casket. A casket is a box we use so that when \_\_\_\_\_ is buried, no dirt will get on him. Because \_\_\_\_\_'s body isn't working any more, it won't move or do any of the things it used to do. But it will look like \_\_\_\_\_ always did.

People will come and visit us and say how sorry they are that died. After days, the casket will be closed and taken to church, where people will say prayers that picked out.

If you like, you can come to the funeral home and visit for a while, even go to the cemetery. You could bring something to leave with \_\_\_\_\_ if you want. That would be nice.

We have to go to the funeral home to make plans, and we will let you know all about them when we come back. We will be gone \_\_\_\_\_ hours.”

For a cremation, use this additional information:

“After we leave the funeral home, \_\_\_\_\_ will be taken to a crematory, a place where his body will be turned to ashes. Then we will take those ashes and (scatter them, keep them in an urn). Since \_\_\_\_\_'s body doesn't work and doesn't feel anything, being cremated doesn't hurt.”

If the dead person has changed because of illness or accident, it's important to describe some of this change. (“It's still Grandpa, but you know he was sick and lost a lot of weight—so he will look thinner.”)

2. Describe the room in the funeral home where the person will be. Be very detailed and specific for younger children.

- ✿ Color of rug.
- ✿ Color of walls.
- ✿ Whether there are plants and paintings.
- ✿ Where the casket will be.
- ✿ Color and type of casket (wood, metal).
- ✿ Color of the suit and tie, or dress, that the person will be wearing.
- ✿ Color of flowers.

3. Explain that the person will be:

- ✿ Lying down.

- ✿ Not moving.
- ✿ Whether the whole body will be visible or not.

If you plan to have a closed casket, when possible I suggest the children be allowed to briefly look at the whole body so they'll realize that the person is, in fact, dead and in the casket. If the casket is going to be half open, children may think that only half of the person is there, show them that this is not so. You might say, "Some children think that only half of the person is there—so if you want, we can ask the funeral director to open the bottom and show you his legs." When there is a full open casket, children will see the whole person and know that he or she is there.

4. Ask your child whether he or she wants to come to the service or not. Some children do, other's don't. Remember that:

- ✿ If a child is left out there is no next time, no going back.
- ✿ The child remembers not being able to say goodbye, not being included, not being given the choice.

Telling a child what is happening and making him part of things, or asking him if he wants to be a part of things, draws him in. He makes the decision.

## How Children May React

Children may:

- ✿ Be very upset, picking up on the family's emotion.
- ✿ Be upset about not knowing what is happening.
- ✿ Not be upset at all, or be upset only for a little while (they may think that the person will be dead only for a time, then come back).
- ✿ Act out difficult behaviors.
- ✿ Seek attention.
- ✿ Sulk or withdraw.
- ✿ Become angry or hostile.
- ✿ Not want to believe the person is dead.
- ✿ Not want to go to the funeral, which would confirm the death.
- ✿ Not want to talk about it.
- ✿ Want to join the deceased (suicide).

- ✿ Romanticize the death.

### **Anger**

Anger is common at the time of a death; it can be very damaging to the family. Understanding it and anticipating it helps parents deal with both their own and their children's anger.

Children may be angry at their parents for:

- ✿ Not telling them that the person who died was so sick.
- ✿ Spending so much time with the sick person.
- ✿ Just because they need someone to be angry with.

Children may be angry at themselves for:

- ✿ Not intervening earlier (not taking the car keys away before an accident, etc.).
- ✿ Wishing the person would die.
- ✿ Not visiting or helping the dying person.
- ✿ Not saying goodbye, or "I love you."

Children may be angry at others for:

- ✿ Not taking care of the person who dies (the bartender for serving him drinks, the doctors for not treating him adequately).
- ✿ Hurting or killing the person (in the case of accident or homicide).

Children may be angry at the person who died for:

- ✿ Not taking care of himself or putting himself in danger.
- ✿ Leaving, dying, abandoning them.
- ✿ Causing the family upset.
- ✿ Using up the family money.
- ✿ Not telling anyone he was sick.
- ✿ Committing suicide (causing family pain and stigma).
- ✿ Not fighting harder against death.

Children may be angry at their brothers and sisters for:

- ✿ No apparent reason.

- ✿ Grieving differently (some children cry, some don't).
- ✿ Not seeming to care.
- ✿ Not wanting to talk about the death.
- ✿ Seeming more privileged (others can go to the funeral, but they can't).

## **Guilt**

Many people feel guilt about a death. This might stem from anger:

- ✿ How can I be angry at the person who died?
- ✿ How can I be alive when he's dead?

From the feeling that you didn't do enough:

- ✿ I should have told the rest of the family that he was sick.
- ✿ I should have visited him before he died.

And from all the "shouldn't haves:"

- ✿ I shouldn't have left the hospital.
- ✿ I shouldn't have let him drive.
- ✿ I shouldn't have left him alone (suicide).

## **Responsibility**

Guilt and a feeling of responsibility go hand-in-hand. Children can feel responsible for a person's death for a number of reasons:

- ✿ They may have been told something that they misunderstood and took to heart ("you're driving me crazy," "you'll be the death of me yet," "you're killing your father").
- ✿ Because they often see God as a rewarder or punisher, they may feel God has punished their bad behavior by causing the person's death, also they may feel if they had prayed harder the person wouldn't have died.
- ✿ They connect events that don't belong together ("If I had sent a 'get well' card maybe he wouldn't have died").
- ✿ They indulge in magical thinking ("If I wish hard enough, he'll come back," "I got mad and wished that he would die").

This is why it is so important that children understand why the person died. Remember, your child may think he is responsible for the death. Tell him this is not so.

In the case of actual responsibility for a death, parents cannot make a child believe what he or she knows to be false. Parents of children directly responsible for the death of another should strongly consider professional help.

--From How Do We Tell The Children, by Daniel J. Schaefer

Bridges...A Center for Grieving Children

310 North K Street, Tacoma, WA 98403

# Children's Perceptions of Death According to Age

- 1-3 Years      Very little or no understanding of the idea of death.
- 4 Years      Very limited concept of death.  
Uses the word with some vague notion of its meaning.  
No particular emotion related though may verbalize a rudimentary notion that death is connected with sorrow or sadness.
- 5 Years      Concept becoming more detailed, accurate and factual.  
May still think of death as reversible.  
Bodily actions may come in associated with death. Avoids dead things or may enjoy killing.
- 6 Years      New awareness of death. Beginning of emotional response to the idea of death.  
Worries that the mother will leave him.  
Idea of death as result of aggression or killing. Some preoccupation with graves, funerals, burial. Does not believe that he/she will die.
- 7 Years      Similar to six years, but more detailed and realistic; better understanding.  
Interest in causes of death, old age, violence, disease. Interest in visiting cemeteries.  
May complain, "I wish I were dead."  
Suspects that he himself will die. Denies that he/she will die.
- 8 Years      Progresses from an interest in graves and funerals to interest in what happens after death.  
Feels that he understands the concept better.  
Still has some magical thinking regarding death.
- 10 Years      Reference now made to logical or biological essentials. "Not living is when you have no pulse and no temperature and can't breathe."  
Now looks straight at death, not just at the peripherals; i.e. coffins, graves. Accepts quite realistically the fact that when he/she is old that he/she will die.

--Adapted from: Cesell, A. (1941). *Development Schedules.*, New York; Psch. Corp. and Wolfelt, A. (1983), *Helping Children Cope With Grief.* Mucnie, Indiana: Accelerated Press.

## Helping Your Grieving Adolescent

Parenting teenagers...it's a rough job under the best of circumstances. But when a teenager is grieving as well, four dynamics place additional stress on the situation:

First, grieving families often feel a need to pull together for support. Since adolescence is increasingly a time for breaking away and relying on peer support, these conflicting needs can place parents and teens at odds with one another.

Second, adolescents are keenly aware of parental reactions and, when parents are grieving, often try and protect them from further pain. Most commonly, this takes the form of not talking about it.

Third, simply because they've experienced the death of a loved one, grieving teens tend to feel different from their peers. In an attempt to fit in, they may try to ignore their own grief reactions. Nevertheless, their normal grief reactions seethe beneath the surface, waiting for expression...healthy or unhealthy, at appropriate or inappropriate times.

Fourth, the stress of bereavement adds to the physical and emotional swings already common in adolescence.

So what's a caring parent or caregiver to do? Here are four strategies for helping your adolescent through bereavement:

1. Provide an environment the adolescent perceives as safe. Like adults, if they don't feel safe, young people can't do the necessary grief work. They need to know that they can trust themselves as having grief reactions that are normal, their peers and adults to be supportive, and parents to be a dependable safety net.

You can help through structure, discipline, and education. Structure and maintaining routines provide adolescents with a subtle, daily sense of continuity and permanence at a time when everything else seems up for grabs.

Discipline...reasonable and caring but consistent and firm...reassures adolescents that someone is in control and will save them from serious harm.

Education can transform a neutral environment into a healing one for your teen. Make sure the adults in his or her world (school personnel, coaches, bosses, clergy, etc.) know that a death has occurred. Share with them printed materials about normal grief responses and what grieving people need. Use health classes and all-school assemblies to educate peer groups about bereavement.

And educate your child about normal reactions to grief so that he knows he is not going crazy and can trust the way his body, mind and emotions are responding. If he pulls back from discussion, provide books or movies that will illustrate normal grieving.

2. Encourage your teen to express what the grief experience is like for him or her. Recognize and affirm that her experience is likely to be different from everyone else's in the family. Provide "emotional coaching" for your child by modeling appropriate emotional reactions to loss.

If your teenager is a quiet or private person, encourage other methods of expression. Helpful ways of expressing emotion include playing music or musical instruments, writing (songs, poetry, diaries, letters to the person who died), sports (including the martial arts and punching bags), and art and photography.

3. Facilitate an ongoing connection with the person who died. Tell stories about the person who died. Give your adolescent a photo of him or her with the person. Support him in visiting the gravesite if that is meaningful to him. Make sure he has a memento of the person who died...a book, a sweater or robe...by which to stay connected.

And make sure you remember (in discussion, in prayer, by way of a small gift) to include the memory of the person who died in your celebration of important events in your child's life, events such as graduations, getting a driver's license, participating in his or her first school play or first varsity sporting event.

4. Encourage your teenager to participate in normal adolescent life as she feels able. Grieving takes enormous energy, so your child may need to slow down a bit while she works on her grief. However, it's important for her to know that you don't expect her to take on an adult role now that someone important has died. Let her know you love and accept and support her...just as she is now, with all the normal living and loving and learning she has yet to do.

# Welcome to Holland

The experience of raising a handicapped child feels like this...

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans--the Coliseum, Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"HOLLAND?!" you say. "What do you mean, Holland? I signed up for Italy. I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in flight plans. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you just go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips and Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I planned."

And the pain of that will never, ever, ever go away because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

--Emily Perl Kingsley



# WorkFirst—Public Health Children with Special Needs Initiative

The goal of the Children with Special Needs Initiative is to provide DSHS WorkFirst staff with an assessment of families that have children with special needs who are currently receiving Temporary Assistance to Needy Families (TANF) and are required to enter the work force to reduce poverty. This program is a working partnership between the DSHS WorkFirst staff and Local Health Jurisdictions. A professional nursing evaluation will provide input to DSHS WorkFirst staff on the following:

- ✿ determining the child's special medical, developmental, or behavioral needs; the impact of those special needs on the ability of the parent to participate in WorkFirst activities; and
- ✿ assisting parents to access appropriate community resources and programs for special needs children, including childcare services.

Referrals for this program are from DSHS WorkFirst staff only.

If your Local Health Jurisdiction has a contract with the local DSHS Region to provide Public Health Nursing home visits and assessments, become familiar with the process through <http://www.workfirst.wa.gov/>



# Children and Families Safety Information

This section contains information and links on safety for children with special health care needs and their families. There is also information here on safety devices and installation, firearm safety, car seat safety and website links.

# EMERGENCY INFORMATION



I. GENERAL		
A. PARTICIPANT'S NAME		LIKES TO BE CALLED
B. CAREGIVER'S NAME		TELEPHONE NUMBER (INCLUDE AREA CODE) (      )
C. STREET ADDRESS OF HOME/APARTMENT		
D. DIRECTIONS/CROSS STREETS		
II. EMERGENCY		
A. PHYSICIAN'S NAME	TELEPHONE NUMBER (      )	OTHER TELEPHONE NUMBER (      )
OFFICE ADDRESS		
HOSPITAL PREFERENCE		
B. What is your medical plan in case of emergency? Where is your documentation kept? Is a living will in place?		
C. EMERGENCY CONTACTS		
1. NEARBY NEIGHBOR/FRIEND/RELATIVE	TELEPHONE NUMBER(S)	
ADDRESS	RELATION TO PARTICIPANT	
2. OTHER NEIGHBOR/FRIEND/RELATIVE	TELEPHONE NUMBER(S)	
ADDRESS	RELATION TO PARTICIPANT	
3. EMERGENCY TELEPHONE NUMBERS:		
<b>Police, Fire, or Emergency Medical Help, Call 911</b>		
E. OTHER		
III. INSURANCE/ SUPPORT		
A. MEDICAL COVERAGE		
1. MEDICARE NUMBER	LOCATION OF CARD	
2. MEDICAID NUMBER	LOCATION OF MEDICAL COUPONS	
3. MEDICAL INSURANCE NUMBER	CARRIER	
LOCATION OF CARD		

# Injury Prevention Resources

## Injury Prevention Resources for Children with Special Health Care Needs

Many injury prevention resources are available on the Seattle Children's Center for Children with Special Needs website: [www.cshcn.org](http://www.cshcn.org). All materials may be downloaded to share with families. Other websites with safety information are also available through a web search.

*The inclusion of any website link (or resource accessed through a link) does not imply endorsement by Seattle Children's Center for Children with Special Needs. Seek the advice of your child's health care provider before you act or rely upon any information from these resources.*

# Safety Devices and Installation

*Article contributed by Thurston County CSHCN Coordinator*

This document provides an overview of currently available safety devices intended to protect children from injury in and around the home. With any product, look for the Juvenile Product Manufacturers Association (JPMA) safety certification seal, or see if devices comply with Consumer Product Safety Commission standards.

## Baby Gates

Baby gates are used to block doorways, to prevent children from entering certain areas of the home, and at the top and bottom of stairs to protect from falls. Baby gates should be used once infants begin to crawl, usually around the age of six months.

Baby gates come in many different styles, shapes and sizes. Some can be fixed width gates, or expansion gates adjustable from 24" to 96" wide. Gate heights can vary from 24" to 32" high. Gate materials range from plastic, wood, mesh to tubular steel. Many models swing in either direction, have easy one-hand latching systems, and can retract to smaller sizes when opened.

The most common baby gates are ones that are permanently mounted and pressure gates. Regardless, all baby gates should be checked for the JPMA Certification seal, which signifies compliance with ASTM F 1004 standard. Never use accordion style gates. Gates without the JPMA-Certified seal can be hazardous.

Safety gates installed at the top of stairs should be permanently mounted directly to wooden frames. For all other situations, moldings (either 1x2" or 1x3") are required to properly secure gates. Gates should be attached to banisters or walls with mounting hardware attached to moldings. All gate types and installation instructions vary, such as gate latching systems that require the gate to be square with the wall or banister. Check with the manufacturer's recommendations before attempting to install any gate.

If attaching to banisters, moldings can be secured with four or five cable ties. Gates should be mounted no more than 3 ½ inches from the floor to prevent entrapment of children. Permanent installation gates require a drill or screw driver, and the hardware or mounting brackets provided by the manufacturer.

Pressure gates are ideally suited for a door frame between rooms and do not require permanent installation or hardware. Pressure gates with expanding pressure bars should be installed with the bar side away from the baby and anchored securely in the doorway. Pressure gates can also be used as portable travel gates.

## Latches, Locks and Door Safety Devices

Latches are used for doors, cabinets and drawers, or anywhere to prevent entry or access by children. Most locks and latches only function when they are set, although some automatically reset or close. These safety devices should be installed as soon as infants start crawling.

### **Doors**

Every door that opens outside, to a balcony, porch, deck or stairway should be kept closed and locked or latched. This includes attic, basement, garage, workshop, kitchen, bathroom, laundry room, sewing room, closet, cabinet and storage room doors.

Every door to an off-limits area should be equipped with a back up safety latch, positioned no less than five (5) feet high and out of children's reach. The most practical locks are the kind that can be opened by adults from either side of the door, such as door top locks. This door latch rests on top of the door and there is a peg that mounts on the door frame. To lock, slide the latch around the peg. To release, slide the latch in the opposite direction. The lock fits most interior doors measuring up to 1 5/8" thick. Installation requires a drill and screwdriver. When installing, check to make sure the device moves freely when the door is closed. To properly align the peg, place the device over the door, close the door and determine the best location where the latch will work. Place a mark, pre-drill the hole and then attach the peg with hardware provided. The latch should be placed as close as possible to the edge of the door opening side.

A door knob cover prevents children from turning the door knob to enter, or locking themselves in a room. The cover fits most standard style doorknobs. Adults can open doors by tightly gripping the cover and pushing the two points on each side of the cover while turning. Children cannot open the door because it requires more strength than most have to grip the cover and turn. No tools are required for installation, but the attaching device must be securely fastened.

Glass sliding doors should be made of safety glass and should be equipped with a baby-proof bar or latch. Screen doors may also need a safety latch.

A flip lock allows closet doors or any door which swings into a room to remain closed. The flip lock needs a 1/8" space between the door frame and the door. The lock is attaches with a drill, screwdriver and hardware provided.

Door locks can be used to prevent children from opening bi-fold doors, thus preventing the doors from opening. No tools are required for installation.

A plastic door positioner keeps the door firmly positioned and prevents it from closing on children's fingers. To use, place the device on the floor, push the door over the stop to lock the door into place, then step on the lock to release the door. No tools are required for installation.

A safety door stop fits over the top or side of the door, leaving a space so fingers don't get

caught between the door and the frame. The device prevents the door from closing. No tools are required for installation.

An emergency door lock release prevents children from being locked inside the bathroom or bedroom. The door lock release keeps the door locked with normal use. If a quick entry to a room is required, a strong, forceful push will open the door. This device works only on wooden doors with a standard inner door catch. To install, remove old door catch and hollow out area where the latch will be placed, using caution not to break out the area where the latch will be placed. This can be accomplished with a screwdriver or chisel and hardware provided.

### **Drawer and Cabinet Latches**

All cabinets and drawers accessible to children, containing cleaning products, alcohol, toiletries, medicines, plant supplies, knives, and other sharp tools and utensils must be locked or secured.

Drawer latches can be a simple spring loaded, push-button one-piece design that prevents toddlers from accessing drawers or cabinets, or a two-piece latch that allows the drawers or cabinets to open about 1", then locks them in place so they won't close on children's fingers.

Most latches require installation with a drill and/or screwdriver.

Locks can also be used on side-by-side closet and cabinet doors. These locks secure cabinets with double doors or with side-by-side pulls. By sliding the lock over door handles or through door pulls, the latch is then moved to its tightest position. To release, push in on the lock's side buttons. No tools are required for installation.

Medicine cabinet locks prevent glass or mirrored doors from sliding. To open, flatten the curved ends, and the sliding door simply slides over the lock. When the sliding doors are closed, it locks automatically. Sliding doors must have a space of less than 3/8" between them. The lock attaches to the glass mirrors with double-sided adhesive. The latch does not adhere well to certain painted wood surfaces. For other style medicine cabinets, an all purpose safety locking strap can also be utilized to prevent the opening of doors that open outward.

### **Appliance Latches**

All purpose locking straps can also prevent children from opening appliances such as refrigerators, freezers, microwave ovens, trash compactors and washing machines. The two- piece latch has a one handed adult release that attaches with two-sided adhesive to the sides or tops of appliances. However, it is not intended for ovens or appliances which give off heat. No tools are required for installation, but the surfaces must be clean and dry before applying the device.

## **Electrical Devices**

The only outlet plate designed which meets an Underwriters Laboratory standard is a sliding outlet cover that closes automatically when a plug is removed. The outlet is always covered,

preventing children's fingers or other objects from entering the electrical socket. To use the outlet, insert a plug slightly and then slide the spring-loaded cover over the socket to the right. The covers come in 2-prong, 3-prong and decora (two hole plate with bottom and top screw) styles. To install, remove existing cover and install new outlet cover with a screwdriver, checking to make sure the sliding outlet cover snaps shut automatically.

Shock locks are outlet caps connected to a flexible strap that attaches onto outlet plates. This device eliminates children's access to dropped or misplaced caps. One device covers a standard two receptacle outlet by simply removing the existing screw, placing the attachment hole of the strap over the outlet cover and reinserting the screw with a screwdriver. Once installed, place the caps of the device into the empty outlet sockets.

If an outlet has appliances in use, a plug guard provides a cover that completely encloses outlets and plugs, and allows threading of the cords through a bottom opening. To install, remove the existing screw, place the frame over existing plate and insert the screw provided. Plug in the power cords and place the cover box on the installed frame by squeezing the sides together. No other installation is required.

A power strip safety cover is a solution for cords from computers, answering machines, kitchen appliances and power tools. The device holds any standard single row power strip and can accommodate many types of plugs, including most transformers and heavy duty three-pronged plugs. The cover snaps shut with four child-resistant latches, and a separate latchable door allows adult access to the on/off switch. No tools are required for installation.

Other electrical safety devices include cord concealers which store up to 8' of electrical cord inside a durable plastic case. The cord winds up around an inside reel and is held in place by tension. No tools are required for installation.

A cord control kit is flexible plastic tubing which organizes cords and wires and conceals them from children. The tubing is available in 1' or 1 1/2" diameter, and has a full length opening so wires and cords can easily be inserted. Tubing can be cut to appropriate size with scissors. No tools are required for installation.

Other devices to protect against electrical shock include a VCR lock and VCR guard to prevent fingers or objects entering the VCR. The lock fits snugly into the VCR tape deck opening. The guard covers the front panel of the VCR and installs by simply sliding the guard under the VCR. No tools are required for installation.

## Bathroom Devices

The bathroom is potentially one of the most dangerous rooms in the home. Keep the bathroom door latched when not in use, and never leave an infant alone in the bathroom.

## **Toilets**

Keep toilet lids closed and use toilet latches to guard against drowning. Toilet or potty latches may have either one or two point latching systems. The one point latching system simply rotates the latch out of the way to open the lid. Lower the lid and the latch snaps back automatically.

This device is installed by using the double-stick tape provided and cannot be used on padded lids. The two-point system requires adults and older children to push in the side and bottom at the same time to lock. To release, push up on two buttons on the side of the latch. These devices mount easily to standard and padded toilet seats.

No tools are required for installation, but the area should be disinfected and allowed to dry prior to adhering adhesives to the toilet.

## **Bath Mats and Decals**

Use non-slip mats or non-slip decals to prevent falls in bathtubs and showers. When not in use, hang the mat on the side of a tub to minimize development of mold and mildew.

## **Bath Thermometer**

Set the water heater thermostat to 120° F or below. Bathtub thermometers (floating or cards) measure the temperature of bath water, usually around 98° F.

## **Bathtub Spout Cover**

A cushion on the tub spout protects children from bumps. The sleeve fits securely over the tub spout and has a top opening for the shower diverter switch. The device can be used for just about any tub spout. If the bath is too small, attach or tighten with a cable tie.

## **Stove Devices**

A stove guard is a heat resistant polycarbonate plastic shield that fits on the stove to prevent children from pulling down hot pots, control hot grease splatters, and touching hot burners. The device installs on the front, side or top of standard stoves with a high-temperature adhesive. No tools are required for installation, but all surfaces must be cleaned with a degreaser and allowed to thoroughly dry. Once clean and dry, remove backing of double sided adhesive and press the device onto the stove surface. Follow manufacturer's instructions and observe the 24-hour adhesive bonding time.

Stove knob covers prevent children from turning on stove burners. These clear plastic covers fit on both gas and electric stove knobs up to 2 ¼" diameters. To install, remove stove knobs and place the bottom of the device over the stove knob area. Replace the stove knob and place the clear plastic cover over the stove knob and squeeze to lock the cover into place.

An oven lock helps prevent children from opening conventional and microwave ovens. It attaches to the front and side of the oven with a special heat-resistant adhesive. To unlock, squeeze the two prongs and swing out the front part of the latch. No tools required for installation, but clean surfaces (oven door and side) where the device attaches with a degreaser and allow surfaces to dry thoroughly. Remove backing of double sided adhesive and press the device onto the surface.

## Window Devices

Infants can fit through a small open gap in a window less than four inches high. Install simple window latches and guards on all windows, especially those above the first floor. Certain cities have laws concerning windows, so check city codes/ordinances.

### **Window Cords**

A cord wrap or cord cleat keeps long blind cords out of children's reach. The cord wrap or cleat is mounted to the wall or window frame, which allows the cord to be wrapped around the object at a minimum height of 5 feet. To install, attach wrap or cleat to the wall or window frame with the use of a screwdriver and/or drill.

A blind cord shortener is commercially available to roll window blind cords up or down. An interior spool draws out or retracts the cord at the push of a button. The device fits vertical and horizontal blinds. No tools are required for installation. Follow manufacturer's instructions.

Blind cord windups are made of plastic and store excess blind cord inside a plastic case. To install, separate the two parts of the device and wind the cord around the inside spool. Reattach the two parts of the case and store the cord out of children's reach. No tools are required for installation.

Safety tassels are installed by cutting the cord above the end tassel (the item that looks like a small wooden or plastic thimble). Remove the equalizer buckle, then add new tassels for each cord, or replace it with a safety break away tassel. Do not retie the cords in a knot, as this only recreates a new loop.

### **Window Guards**

Window guards come in a variety of sizes for double hung and sliding windows. Mount the device in the frame beneath the upper window panel or vertically for sliding windows. To install, align the guard so that it is placed no more than 3½" from the bottom of the window sill. Using a drill and screwdriver, attach with the screws provided.

Stopping devices can also be installed on the inside of window frames to prevent the window from opening more than 4 inches. Requires the use of a drill and screwdriver for installation.

## Other Safety Devices

### **Furniture**

Furniture braces prevent injuries from furniture tip-overs. These devices can be either durable nylon straps with a heavy duty metal buckle or metal brackets that attach to the furniture and the wall.

It is recommended that two straps or metal connectors be used for each piece of furniture. Most straps hold more than 200 lbs. of pressure and can be removed for easy cleaning. Attach the devices to the wall studs and an area on the furniture. Installation requires the use of a drill and screwdriver.

### **Door Stop**

A one-piece door stop is safer than conventional door stops with springs or tips that can be hazardous to young children. Position the door stop in an appropriate location on the baseboard or bottom of the door. Installation requires a drill and wrench. To install, drill a pilot hole, insert the door stop and tighten in place using a wrench.

### **Fireplace**

Fireplace hearth gates include interlocking sections that prevent children from gaining access to the fireplace hearth. Most gates have a one-handed adult release and open in either direction. Follow manufacturers' instructions; installation varies depending on fireplace design, construction and layout.

Fireplace padding is a soft padded cushion to protect children from rough edges and sharp corners on hearths. With an adjustable, sturdy metal frame that's covered with fire resistant padding, the cushion stays in place when the fireplace is used. The device works best on brick or stone fireplaces with square corners. A screwdriver is required for installation. Follow manufacturer's instructions based on the type of fireplace design.

### **Protective Padding**

Protective padding devices include wrap around cushions to protect children from sharp corners and hard edges on dining room, coffee and end tables. Edge cushions and corner cushions attach with double-sided adhesive to glass, formica and tile. No tools required for installation, but clean surfaces with a degreaser and allow the surface to dry thoroughly.

### **Small Parts Tester**

A small parts tester ("choke tube") is an easy way to test the size of small toys and other objects.

16 CFR Section 1501 requires that toys and objects for children less than three years of age not have parts that fit completely into the tester. If any object fits completely in the tester, it is small enough to be a choking hazard. Dimensions are 1" x 2¼" with a 1¼" diameter opening.

### **First Aid Kit**

A first aid kit contains a complete assortment of products for emergency use. It should contain adult and child size bandages, alcohol cleansing pads, antiseptic cleansing wipes, aspirin, first aid tape, instant cold compresses, scissors, patch bandages, sponge dressing pads, sterile eye pads, stinging relief pads, trauma pads, triple antibiotic ointment packs, and tweezers.

### **Stairs, Balconies and Landings**

Clear banister shields made of shatter proof plastic are used for indoor balconies, lofts and landings. The material is flexible enough so it curves around a banister and can easily be trimmed to any length with scissors. Using a hole punch, attach one side of the plastic to a banister or wall using cable ties. Then unroll the plastic, punch holes and attach to the banister in approximately two to three foot increments, secure using cable ties. Make sure the plastic is stretched tight when making holes for attaching the cable ties. If a space exists at the bottom of the banister greater than 3 ½ inches off the floor, secure the plastic to the floor with eyelet screws and cable ties. This technique requires installation with a drill, screwdriver, pliers and hole punch.

Deck netting is made of plastic mesh that's designed for outdoor use. The netting can be attached with screw eyes and cable ties and can be easily trimmed to size with scissors. Attach to banisters in approximately two foot increments, making sure the netting is stretched tight before attaching the cable ties. If an opening exists at the bottom of the banister greater than 3 ½ inches off the floor, secure the netting to the deck with eyelet screws and cable ties. The netting requires installation with a drill, screwdriver and pliers.

Sheets of plexiglass 0.08 to 0.125 inches thick can be attached to a banister to create a solid barrier for balconies with openings more than 3 1.2 inches between banister railings. Measure banisters to determine size of plexiglass. Measure the length and height of the banister in several areas, as this distance may change over the length of the banister. To determine size of plexiglass sheets, subtract 0.25 inches from both the length and the height measurement of the banister. This spacing allows for expansion and contraction of materials. To mark holes for attaching the plexiglass, place the pieces in their approximate final positions. Use a magic marker to mark where the holes will be drilled. Use an acrylic drill bit to make the holes. Attach plexiglass with cable ties or screws.

## Warning Devices

### **Smoke and Fire Alarm**

New lithium-powered battery-operated smoke alarms last up to 10 years, and provide a new feature, a “hush button.” This special silencer button decreases sensitivity for 10 minutes to reduce nuisance alarms. The smoke alarm sounds a loud 85 decibel alarm that responds immediately to smoke or fire, and has an indicator light that flashes every 45 seconds during normal operations. A low battery signal beeps when the battery needs replacement.

A conventional smoke alarm uses the same principle, but only requires a regular 9-volt battery that should be replaced every year. It is recommended that when clocks are changed in the fall for daylight-savings time, smoke alarm batteries also be changed. All smoke alarms must be replaced every 10 years.

Smoke alarms should be installed on the ceiling or wall (not in the kitchen or bathroom), with the edge of the alarm no closer than 4” from the wall or ceiling. Do not place smoke alarms in direct line with air vents or near openings that could divert smoke away from the alarm. Depending on the wall or ceiling materials, a drill and screwdriver will be required for installation.

### **Carbon Monoxide Detector**

Carbon monoxide detectors operate on batteries or plug into a 120-volt electrical outlet. All CO detectors continuously monitor the air for carbon monoxide. CO detectors should be installed on the wall or ceiling in utility or sleeping areas.

Some detectors have a self-test feature, test/reset button and a digital readout of the highest CO levels detected. CO detectors must meet the requirements of Underwriters Laboratories Standard 2034. Detectors that meet the UL standards measure both high CO concentrations over short periods of time, sounding a loud 85 decibel alarm, and low CO concentrations over long periods, activating an intermittent warning alarm.

For devices that do not plug into an electrical outlet, wall or ceiling mounted CO Detectors require a drill and screwdriver for installation.

## Gun Locks

Gun locks are safety devices designed to prevent the unauthorized use of firearms. When correctly installed and secured on a firearm, a gun lock prevents that firearm from being discharged without the lock first being removed.

The Safe-T-Lock is designed to be used on semiautomatic pistols. Remove the magazine and empty the changer. Lock the slide back and insert the gun lock in the pistol’s ejection port. Lock in place with the turn of a key. Since the chamber can’t fully close, the firearm cannot be fired.

The Safe-T-claw is designed as a universal gun lock, for all types of guns, including long barrel (rifles and shotguns) and handguns (pistols and revolvers). Unload the firearm, insert the gun lock into the empty changer and lock in place with the turn of the key. Since the changer can't fully close, the firearm cannot be fired.



# Resources

## Local Community Resources

### Home Safety

Many agencies provide Home Safety Checks. An example of a Home Safety Check is provided here:

Prior to conducting a Home Safety Check:

- ✿ Compile a list of the most commonly used resources in the community and take it with you to the home visit. If a resource is needed, write it down or circle it and leave the list with the family.
- ✿ The resident may discuss other difficulties they may be having (i.e., a domestic violence situation). It is not a Home Safety Checker's responsibility to solve all of the family's problems. Provide referrals to other agencies that may be able to help. Limit help to referrals only.
- ✿ Have a contact person at a local public health or social service department to call if you are unsure of what resources are available for a specific problem.
- ✿ Keep in mind, there are not always resources for every problem encountered.

Many communities or local governments already have resource directories published or on-line directory assistance in locating community resources. Check the blue pages of the telephone directory for such services. Compile local contact information from the following resources to use as referrals for families prior to conducting a Home Safety Check:

- ✿ Protective services/child welfare/children and youth services
- ✿ Domestic violence assistance/shelters
- ✿ Crisis centers and hotlines
- ✿ Housing department/code enforcement agencies
- ✿ Social service agencies (private and public)
- ✿ Community action centers or agencies
- ✿ Health Departments
- ✿ Parent support groups
- ✿ Mental Health services
- ✿ Poison Control centers

## National Resources/Organizations

### American Society for Testing and Materials (ASTM)

ASTM is one of the largest developers of voluntary consensus standards systems in the world. ASTM is a non-profit organization that provides related technical information and services producers, users, ultimate consumers and standards for materials, products, systems and services. From the 132 standards-writing committees, ASTM publishes standard test methods, specifications, practices, guides, classifications and terminology. ASTM's standards development activities encompass metals, paints, plastics, textiles, petroleum, construction, energy, the environment, consumer products, medical services and devices, computerized systems, electronics and many other areas.

(620) 832-9585                      [www.astm.org](http://www.astm.org)

### American Academy of Pediatrics

The American Academy of Pediatrics is an organization of 55,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety and well being of children.

(800) 433-9016                      [www.aap.org](http://www.aap.org)

### American Burn Association

The American Burn Association is an international organization focused on burn and injury prevention. Members include firefighters, burn treatment specialists and other health care professionals.

(800) 548-2876                      <http://www.ameriburn.org/>

### American Red Cross

The American Red Cross is a volunteer organization known primarily for providing relief to victims of disasters. The American Red Cross also helps people prevent, prepare for and respond to emergencies. For more than 80 years, the American Red Cross has trained tens of millions of people of all ages in first aid and CPR.

(703) 207-7090                      [www.redcross.org](http://www.redcross.org)

### Building Department or Code Enforcement Department

The fire department and the local municipal building department work closely to ensure fire safety in buildings. The building department is most closely involved when the building is

being constructed and when major remodeling that requires a building permit takes place. The department is also responsible for notifying the fire department when new buildings (other than homes) are certified ready for tenants. The building and fire departments ensure that fire-related codes are enforced. If a fire code violation is suspected, depending on the municipal service, either the career fire department or the local building code official should be alerted.

## **Building Officials and Code Administrators, International, Inc.**

BOCA is the nation's original professional organization of code enforcement officials and publishers of the BOCA National Code Series of model construction codes. The BOCA code includes the National Building and Fire Prevention Codes. Most jurisdictions adopt model codes through ordinances. These codes may be adopted in part or in whole, as the local jurisdiction wishes and finds politically acceptable. The adoption of the fire prevention code usually designates the fire chief as the primary enforcement authority. The fire chief then delegates that authority to fire marshals and inspectors.

When a certificate of occupancy is issued on a new structure, that building must comply with all of the provisions of the jurisdictions' building and fire codes. After initial approval and for the life of the building, the code provides a mechanism for the periodic inspection and code enforcement process of the existing building.

## **Burn Prevention Foundation**

The Burn Prevention Foundation is committed to promoting safety by teaching the public how to recognize and avoid fire hazards and other burn risks. The Foundation offers numerous education programs and seminars as well as a wide variety of educational materials, audio-visual presentations and displays.

(610) 481-9810                      [www.burnprevention.org](http://www.burnprevention.org)

## **Centers for Disease Control and Prevention (CDC)**

The CDC, an agency of the Department of Health and Human Services, works to promote health and quality of life by preventing and controlling disease, injury and disability. The National Center for Injury Prevention and Control, a division of the CDC, works to reduce morbidity, mortality, disability and costs associated with injuries. This organization produces publications and information related to health and family safety. The Center also serves as a clearinghouse for lead poisoning prevention programs and related research in this area.

(703) 488-7330                      [www.cdc.gov](http://www.cdc.gov), or [www.cdc.gov/nceh/programs/lead/lead](http://www.cdc.gov/nceh/programs/lead/lead)

## Children's Safety Network (CSN)

The CSN National Injury and Violence Prevention Resource Center is located at the Education Development Center, Inc. It provides resources and technical assistance to maternal and child health agencies and other organizations seeking to reduce unintentional injuries and violence to children and adolescents. It is one of four Children's Safety Network Resource Centers funded by the Maternal and Child Health Bureau of the US Department of Health and Human Services. (617) 969-7101 [www.edc.org/hhd/csn](http://www.edc.org/hhd/csn)

## Coalition for Consumer Health & Safety

The Coalition is a partnership of consumer, health and insurance groups working together to promote safety.

(202) 387-6121 [www.healthandsafety.org](http://www.healthandsafety.org)

## Enterprise Foundation

The Enterprise Foundation is a national, nonprofit housing and community development organization. The Foundation works with more than 1,100 community-based organizations in more than 400 locations to improve America's low-income communities.

(410) 964-1230 [www.enterprisefoundation.org](http://www.enterprisefoundation.org)

## Fire Prevention or Inspection Bureau

Depending on the size and resources of a fire department or municipality, employees are usually fire department members or a mix of fire department and civilian members and fire/building inspectors and are assigned to the Fire Prevention Bureau. The Fire Prevention or Inspection Bureau inspects occupancies and enforces fire prevention codes and ordinances. Once the bureau identifies hazards, it works with property owners to eliminate them.

## I'm Safe! Network

An internet resource about child safety which has a bookstore, the latest recalled children's products (updated daily), child safety tips, newsletter and activities.

[www.imsafe.com](http://www.imsafe.com)

## Juvenile Products Manufacturers Association (JPMA)

The Juvenile Products Manufacturers Association has a certification program that has been guiding parents for more than 20 years. A JPMA Certification Seal on any product or its package

assures that the manufacturer designed and built it with safety in mind and ensures that the product was built to the very highest standards.

The Certification Program currently include high chairs, play yards, walkers, carriages and strollers, gates and enclosures, full-size cribs and portable hook-on chairs. JPMA is currently working on adding toddler beds, bath seats, bedding products, stationary activity centers, non-full-size cribs, infant carriers and infant swings to the program.

The American Society of Testing and Materials (see ASTM under Resources) publishes the voluntary standards used in the JMPA Certification Program. Industry members work together with the U.S. Consumer Product Safety Commission, consumer groups and other interested parties to develop the standards.

## **Lowe's Home Safety Council**

Lowe's Home Safety Council channels funds into a variety of charitable and education projects. Members of the council include national safety-related organizations, manufacturers and notable donors. The Lowe's Home Safety Council works closely with local fire departments, school systems and other community organizations.

(800)SAFE-Home                      [www.lowes.com](http://www.lowes.com)

## **National Center for Education in Maternal and Child Health**

The National Maternal and Child Health Clearinghouse is funded by the Health Resources and Services Administration, Maternal and Child Health Bureau, a branch of the US Department of Health and Human Services. The National Sudden Infant Death Syndrome Resource Center is part of the clearinghouse. It produces and disseminates education materials on SIDS to public health and emergency medical practitioners and legal professionals, as well as to parents and families.

(703) 524-7802                      [www.ncemch.org](http://www.ncemch.org)

## **National Fire Protection Association**

The NFPA is a non-profit organization that creates scientifically-based consensus fire codes and standards. The NFPA also conducts research, develops educational materials about fire safety and produces the Fire Prevention and Life Safety Code.

(617) 984-7285                      [www.nfpa.org](http://www.nfpa.org)

## **National Program for Playground Safety**

The National Program for Playground Safety serves as a national clearinghouse for playground safety information.

(800) 554-PLAY                      [www.uni.edu/playground](http://www.uni.edu/playground)

## **National Safety Council**

The National Safety Council has home and community-based programs that provide information on health and safety.

(202) 293-2270                      [www.nsc.org](http://www.nsc.org)

## **National SAFE KIDS Campaign**

The National SAFE KIDS Campaign is the first and only national organization dedicated solely to the prevention of unintentional childhood injury—the number one killer of children ages 14 and under. More than 270 State and Local SAFE KIDS Coalitions in all 50 states, the District of Columbia and Puerto Rico comprise the Campaign.

(202) 662-0600                      [www.safekids.org](http://www.safekids.org)

## **National Swimming Pool Foundation (NSPF)**

The National Swimming Pool Foundation (NSPF) is a non-profit foundation that provides research and education to enhance aquatic safety.

(516) 623-3447                      [www.nspf.com](http://www.nspf.com)

## **National Spa and Pool Institute**

The National Spa and Pool Institute promotes the safe use and enjoyment of pools, spas and hot tubs. Members product information, education, technical training and certification, and standards for safe design, construction and installation.

(703) 838-0083 or (800) 323-3996                      [www.nspi.org](http://www.nspi.org)

## **Office of Lead Hazard Control**

The Department of Housing and Urban Development's Office of Lead Hazard Control provides millions of dollars in grants and state government agencies for lead hazard control activities. The Office has also funded critically important research to determine the effectiveness of lead hazard control strategies and is responsible for writing the regulations regarding lead safety for all federally assisted housing.

(202) 755-1805 or (202) 755-1785                      [www.hud.gov/lea/leahome.html](http://www.hud.gov/lea/leahome.html)

## Office of the State Fire Marshall

The Office of the State Fire Marshall enforces state fire laws. Specific responsibilities vary by state, but in general include reviewing and approving fire safety plans; investigating fires and fire-related deaths; and regulating storage and use of explosives and other hazardous materials.

## Underwriter's Laboratories, Inc.

Underwriters Laboratories Inc. is an independent, non-profit product safety testing and certification organization.

(847) 272-8800

[www.ul.com](http://www.ul.com)

## U.S. Consumer Product Safety Commission (CPSC)

The CPSC is an independent federal regulatory agency with jurisdiction over more than 15,000 types of consumer products, from automatic-drip coffee makers to toys and lawn mowers. The CPSC works to reduce the risk of injury and death from consumer products by developing voluntary standards with industry. The CPSC is also responsible for issuing and enforcing mandatory standards; banning consumer products if no feasible standard would adequately protect the public; recalling products or arranging for their repair; conducting research on potential product hazards; informing and educating consumers through the media; and responding to consumer inquiries. The CPSC also coordinates the efforts of the National Poison Prevention Council.

(301) 504-0580 (English/Spanish), (800) 638-2772

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



# Nutrition Resources

The following section contains some information provided through the WIC program and CSHCN Coordinators on special formulas. If the family is covered by private insurance you may need to help the family obtain formula through their insurance company. See if the insurance company has a case manager and work through them. There are times when the insurance will deny the first time and the family needs to be persistent and seek out the procedures that are in place for special consideration and requests. Occasionally a call to the formula company is helpful.

## Resources and Helpful Websites

Nutrition Interventions for Children with Special Health Care Needs <http://here.doh.wa.gov/materials/nutrition-interventions>

AAP Pediatric Nutrition Handbook Ordering Information

[https://www.nfaap.org/netForum/eweb/dynamicpage.aspx?webcode=aapbks\\_productdetail&key=9dfb8d31-2c44-4424-9a90-32ed96aa6e71](https://www.nfaap.org/netForum/eweb/dynamicpage.aspx?webcode=aapbks_productdetail&key=9dfb8d31-2c44-4424-9a90-32ed96aa6e71)

Medical Home website [www.medicalhome.org](http://www.medicalhome.org)

Starting Point Guide [www.cshcn.org](http://www.cshcn.org)

UW Nutrition <http://depts.washington.edu/cshcnnut/>

CDC Growth Charts [www.cdc.gov/growthcharts](http://www.cdc.gov/growthcharts).

Locating WIC offices: [https://resources.parenthelp123.org/resoure\\_finder](https://resources.parenthelp123.org/resoure_finder)

WIC approved formulas etc <http://www.doh.wa.gov/YouandYourFamily/WIC/WICFoods/InfantFormula>

Apply for WIC: <http://www.doh.wa.gov/YouandYourFamily/WIC/ApplyforWIC.aspx>

Breastfeeding support: <http://www.doh.wa.gov/YouandYourFamily/WIC/BreastfeedingSupport.aspx>

What is WIC?: <http://www.doh.wa.gov/YouandYourFamily/WIC.aspx>

Income Guidelines: <http://www.doh.wa.gov/YouandYourFamily/WIC/Eligibility.aspx>

Formula Locator

<http://similac.com/store-locator>

<http://www.enfamil.com/app/iwp/enf10/utility.do?dm=enf&id=-13507&iwpst=B2C&ls=0&csred=1&r=3524934287>

# Nutrition Frequently Asked Questions

## How do I monitor growth?

Two charts are available for plotting the growth of an individual child (WHO or CDC) [www.cdc.gov/growthcharts](http://www.cdc.gov/growthcharts). The CDC recommends using the WHO charts birth to 2 years and the CDC for > 2 years. Growth is assessed using serial measures of weight and length, plotted over time. A single measure of % provides a screen for nutritional risk requiring further assessment.

## How do I monitor growth of a preterm infant?

Although premie specific growth charts are available (IHDP, Fenton, and Olsen) they have some practical limitations and are used largely in hospital settings. Preterm infants can be plotted on CDC or WHO charts but growth measures (weight/length/OFC) should be corrected for prematurity.

## How do I correct for prematurity?

Corrected age is determined by subtracting the number of weeks or months premature from the infants chronological age. For example:

Baby J was born at 24 weeks and is now 6 months from his birthdate:

$40 \text{ weeks} - 24 = 16 \text{ weeks}$  or  $4 \text{ months}$  premature.  $6 \text{ months} - 4 \text{ months} = 2 \text{ months}$  corrected age. Growth measures would then be plotted at the 2 months age.

## How long do I correct?

Correct for prematurity until 2 years of age. A practical transition point from corrected to chronological age can occur when transition from one growth chart to another (ie 0-36 months to the 2 year-18 year chart).

## What do I do when a child screens at nutritional risk?

Screening identifies factors associated with actual nutritional problems or a high likelihood of having or developing a nutrition problem. Initial interventions might include education, monitoring and a rescreen. If the child continues to screen at risk, a referral for further assessment by an RD is appropriate. An RD assessment may be referred to as Medical Nutrition Therapy (MNT).

For example: Baby M is 5 months old. Her weight is as the 5<sup>th</sup>%. Mom provides some information on feeding and intake. Mom is instructed on formula preparation and feeding frequency and a follow-up appointment for weight check in 1 month is made (screened at risk-

---> education--->rescreen). Baby M continues to gain weight at a lower than expected rate. A referral for Nutrition assessment and Intervention (MNT) by an RD is made.

## What constitutes Nutritional risk?

Screening risk factors may include but are not limited to the following: 1) Weight, length and/or weight/length  $\leq 5^{\text{th}}$  percentile, 2) weight, weight/length  $\geq 90^{\text{th}}$  percentile, or BMI 85-95<sup>th</sup>% percentile 3) anemia or alteration in other nutrition related labs 4) feeding difficulties 5) weight gain greater than or less than expected, often seen as shifts across growth channels 6) inappropriate food choices, preparation or behaviors 7) disease specific: certain medical conditions such as cardio-respiratory, and malabsorbtive conditions are nutritional risk factors. Screening tools are available or you might consider working with an RD to develop a screening tool specific to you clinical and practice setting.

# Washington State Data on Children with Special Health Care Needs

Data on children with special health care needs can be found on the DOH CSHCN website. There is also a list of data sites that could provide data on the children in our state or specifically your county. <http://www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds/Publications.aspx>. On this site, you will find the newest data report on children with special health care needs. Another useful link is [www.cshcndata.org](http://www.cshcndata.org) for data on Washington State and nationally for children with special needs.

## What Can Data Do For You?

Provide information on children with special health care needs for the following purposes:

- ✿ Tool to guide local policy healthcare discussions
- ✿ Community planning
- ✿ Evidence for grant proposals
- ✿ Help present case for services to community leadership
- ✿ Describe the needs of your population in your county and Washington state



# Resources

There are many resources available for CSHCN Coordinators. Links to the resources are placed in this section for your convenience. County level resources are available at [www.cshcn.org](http://www.cshcn.org)

## Care Organizing Tools

The Care Notebook and Care Organizer are tools for families who have children with special health care needs. Families use Care Notebooks to keep track of important information about their child's health and care. This makes it easier to find and share key information with their child's care team.

### What are the Care Notebook and Care Organizer?

The Care Notebook is a 3-ring binder. It contains supplies that make it easier to find information quickly. These supplies include plastic pages that hold business cards and several pocket dividers that hold papers. The Care Notebook also contains forms that families may fill in. These 39 forms are available below.

The Care Organizer is a plastic expanding file folder with individual pockets labeled to help organize paperwork. Multi-lingual including English, Spanish, Vietnamese, Russian, Chinese and Somali.

### How can they help?

In caring for a child with special health needs, families may get information and paperwork from many sources. Families can use the Notebook or Organizer to help organize the most important information in a central place.

### How do I get them?

You can get copies of the forms included in the Care Notebook at [www.cshcn.org](http://www.cshcn.org). Families may use these pages to keep track of appointments and health care, to create a list of their care team and resources, and to create a summary of their child's abilities and care needs. Most families do not need or want every page. You can also find information on ordering the notebook or care organizer on [www.cshcn.org](http://www.cshcn.org). One notebook or organizer is available to every family of a child with special needs at no cost. Instructions for obtaining the tools are on the website. You can also get care plans and information for your teen as he/she transitions to adult health care at [www.cshcn.org](http://www.cshcn.org) or <http://depts.washington.edu/healthtr>.

# Nutrition and Growth

For general information regarding nutritional needs of CSHCN and how to accurately measure a child's growth:

Nutrition Interventions for Children with Special Health Care Needs, 2<sup>nd</sup> edition, Nardella, M; Campoll, Ogata B., editors. Washington State Department of Health, Olympia, May 2002 (see attached order form)

Maternal Child Health Bureau Health Resource and Services Administration; online at [www.MCHB.HRSA.Gov](http://www.MCHB.HRSA.Gov). Online module on nutrition, growth and accurate use of growth charts with specific information on CSHCN.

## Growth Charts

CDC Growth Charts for 0-36 months and 2-18 years. Online at [www.cdc.gov](http://www.cdc.gov). You can also order them through the American Academy of Pediatrics publication catalog 1-866-843-2271 or [www.qqp.org](http://www.qqp.org).

## Growth Charts for Premature Babies (Girls and Boys)

For "Very Low Birth Weight" and "Low Birth Weight." Order from Ross Pediatrics at 1-800-227-5767. They can also be downloaded from their online site, but it is slow and they may not print accurately. \$7.25/pkt of 25 charts or \$29.00 for 4 pkts of boys and girls VLBW & LBW.

## Growth Charts for Children with Down's Syndrome

Boys 0-3 yrs or 2-18 yrs, Girls 0-3 yrs or 2-18 yrs. Download from [www.growthcharts.com](http://www.growthcharts.com). Site: Growth Charts for Children with Down's Syndrome.

## Equipment

### Baby Scales

Seca Scales

West Coast Office

1300 South Valley Vista Drive, Suite 245

Diamond Bar, CA 91765

online: [www.seca.com](http://www.seca.com)

1-888-879-8582 email: [Info@seacorp.com](mailto:Info@seacorp.com)

They have portable, digital baby scales and the Seca "Measure Mat," which is a portable length board. It can be rolled up and carried in you baby scale bag. Seca also sells head circumference tapes.

Tanita Corporation of American

2625 S. Clearbrook Drive  
Arlington Heights, IL 6005  
1-847-640-9241      online: [www.tanita.com](http://www.tanita.com)

Portable digital baby scales.

AllHeart Professional Apparances, Inc.  
431 Calle San Pablo      online: [www](http://www)  
Camarillo, CA 93012      Email: [Customerservice@allheart.com](mailto:Customerservice@allheart.com)

This is a great site to purchase several different brands of baby scales, stethoscopes, etc. They seem to have very good prices.

### **Breast Pumps**

Check with local medical supply companies; local hospitals and/or WIC offices.

### **Haberman Feeders**

Medella, Inc. P.O. Box 660  
McHenry, IL 60051-0660  
1-800-435-8316

### **Mead-Johnson Cleft Palate Squeeze bottles**

Contact your local Mead-Johnson representative.

# Brochures and Publications for Children with Special Health Care Needs

## Parent information and support groups

- ✿ Adolescent Transition information for Children and Adolescents with Special Needs:  
<http://depts.washington.edu/healthtr/>
- ✿ Medical Homes: [www.medicalhome.org](http://www.medicalhome.org)
- ✿ Parent to Parent Support Programs: [www.arcwa.org](http://www.arcwa.org) (800) 821-5927
- ✿ Programas de Apoyo Padre a Padre: [www.arcwa.org](http://www.arcwa.org) (800) 821-5927
- ✿ Washington State Fathers Network (La Red de Padres del Estado de Washington): [www.fathersnetwork.org](http://www.fathersnetwork.org)
- ✿ Babies Sleep Safest On Their Backs  
1-800-505-CRIB (2742)  
Or Write to: Back to Sleep/NCHD  
31 Center Drive Room 2A32  
Bethesda, MD 20832-2425  
Website: [www.nichd.nih.gov](http://www.nichd.nih.gov)
- ✿ Crying (Please Never Shake A Baby)  
National Center on Shaken Baby Syndrome  
2955 Harrison Blvd. Suite # 102  
1.627.3399 [www.dontshake.com](http://www.dontshake.com) [mail@dontshake.com](mailto:mail@dontshake.com)
- ✿ Washington Sensory Disabilities Services (WSDS)  
Phone: 800/572-7000 V/TTY  
In King County call: 206/439-6937 V/TTY Web Address: [www.wsdsonline.org](http://www.wsdsonline.org)  
Email: [wsds@psed.wednet.edu](mailto:wsds@psed.wednet.edu)  
FAX: 206/439-6971

## Financial & Other Information

- ♣ ASK (Answer for Special Kids)  
WithinReach  
300 Elliott Ave West, Suite 300  
Seattle WA 98119-4118  
[www.withinreachwa.org](http://www.withinreachwa.org)
- ♣ Social Security. Benefits For Children With Disabilities  
Social Security Administration [www.ssa.gov](http://www.ssa.gov)

## Parenting and Child Care Information

- ♣ Choosing Child Care. A Consumer Guide for Parents Washington State Department of Social and Health Services Division of Licensed Resources  
Office of Child Care Policy  
DSHS 22-516(X) (Rev. 10-98)
- ♣ Child Care and the Americans with Disabilities Act  
Center for Children with Special Needs  
Seattle Washington <http://www.cshcn.org>
- ♣ Making Parenting A Pleasure  
A Group-Based Positive Parenting Curriculum. Birth To Three  
86 Centennial Loop Eugene OR 97401 (514) 484-5316  
FAX: (541) 484-1449 [www.birthto3.org](http://www.birthto3.org) BirthToThree@birthtothree.org

## Tips for Working on the Internet

### To print just part of the text on a page:

- ✿ Use your mouse to point to the beginning of the area you want to print.
- ✿ Click the left mouse button and hold down.
- ✿ Drag the mouse to the end of the text and let go.
- ✿ On the file menu, choose edit/copy.
- ✿ Then open a word-processing document and paste the text.

### When a page prints with just the header and not the text:

- ✿ Right-click with your mouse button on the text you want to print and choose print.

### To find a word on a web page:

- ✿ Hit “Ctrl” (control) on the keyboard and “F” at the same time. Then type in the word you want to search for. Or
- ✿ On the file menu, go to edit/find.

### To narrow your search:

Use quotes in the search box when searching for an exact phrase. For example:

- ✿ “Center for Children with Special Needs”
- ✿ Use the word “and” to find webpages with both search words on them.

### To download a file from the internet:

- ✿ Right-click on the file or link.
- ✿ Choose “Save Target as.”
- ✿ Choose a place to save the file and a name you will remember.

### To have the webpage address print in the header/footer:

- ✿ On the “File” menu go to “Page Setup”
- ✿ In the header or footer type “&u”

## Other Keyboard Shortcuts:

- ⌘ “Ctrl” and the letter “C” is Copy
- ⌘ “Ctrl” and the letter “V” is Paste
- ⌘ “Ctrl” and the letter “X” is Cut
- ⌘ “Ctrl” and the letter “Z” is Undo
- ⌘ “Ctrl” and the letter “P” is Print

# Evaluating Internet Resources

Abstracted from “Tips on Evaluating Web Resources” by the Greater Midwest Region of the National Network of Libraries of Medicine.

## Content

What is the purpose of the Web site? Is the site intended to educate or to sell? Is the information factual or opinion? Is the information accurate and verifiable? Is the resource detailed, or more general in scope?

## Audience

Is there an obvious intended audience for the Web site (children, teenagers, consumers, health professionals, etc.)? On what reading level is the information written?

## Authority/Source

Is the author of the Web site an individual, a university, a corporation, the government, or someone else? What expertise/authority does the author have to provide this information? Does the author list sources? Can the author be contacted with questions?

## Date/Timeliness - Currency

When was the site first produced? When was it last revised? How often is it updated? Are these dates evident? Does the information provided tend to change frequently, or is it more retrospective in nature?

## Structure/Access

Is the Web site designed well? Is it user-friendly? Does it contain images? If so, are they useful, or merely decorative? Do they load quickly? Would the page be useful to someone with a text-only browser? Does it offer a local search engine?

## Helpful Websites

AWRD—Access Washington Resource Directory	<a href="http://www.awrd.org/">http://www.awrd.org/</a>
*Center for Children with Special Needs	<a href="http://www.cshcn.org">http://www.cshcn.org</a>
*Seattle Children's	<a href="http://www.seattlechildrens.org">http://www.seattlechildrens.org</a>
Disability Resources Monthly WebWatcher	<a href="http://www.disabilityresources.org/">http://www.disabilityresources.org/</a>
*Healthfinder	<a href="http://www.healthfinder.gov/">http://www.healthfinder.gov/</a>
Internet Resources for Special Children—IRSC	<a href="http://www.irsc.org">http://www.irsc.org</a>
Kidshealth	<a href="http://www.kidshealth.org/index_noflash.htm">http://www.kidshealth.org/index_noflash.htm</a>
Merck Manual – Home Edition	<a href="http://www.merckhomeedition.com/home.html">http://www.merckhomeedition.com/home.html</a>
MEDLINEplus	<a href="http://www.nlm.nih.gov/medlineplus/">http://www.nlm.nih.gov/medlineplus/</a>
*NOAH	<a href="http://www.noah-health.org/">http://www.noah-health.org/</a>
NORD – National Organization of Rare Disorders	<a href="http://www.rarediseases.org/">http://www.rarediseases.org/</a>

## Information Clearinghouses

CHID	<a href="http://chid.nih.gov">http://chid.nih.gov</a>
Children's Health and Patient Education Database	<a href="http://www.seattlechildrens.org/parents/childcite/searchdb.asp">http://www.seattlechildrens.org/parents/childcite/searchdb.asp</a>
Maternal and Child Health Bureau Information Clearinghouse	<a href="http://www.ask.hrsa.gov/MCH.cfm?content=MCH">http://www.ask.hrsa.gov/MCH.cfm?content=MCH</a>
National Center for Education in Maternal and Child Health:	<a href="http://www.ncemch.org">http://www.ncemch.org</a>
*NICHCY	<a href="http://www.nichcy.org">http://www.nichcy.org</a>

## Pathways

### **A unique or specific diagnosis**

1. Make sure you have the correct spelling and terminology for the condition/disease.
2. Visit NORD—National Organization of Rare Disorders to find correct spelling, different names, a brief description and links to national foundations and support groups providing information. Use search of alphabetical listing <http://www.rarediseases.org/>

3. Visit <http://nlm.nih.gov/medlineplus/> and <http://www.familydoctor.org/> and [http://www.kidshealth.org/index\\_noflash.html](http://www.kidshealth.org/index_noflash.html) and try their search engine by the disease name.
4. Try an internet wide searching using a search engine with the disease name. Assess websites and look for national foundations or organizations.

For example: Galactosemia

# Cultural Competency Resources for Health Care Professionals

The following website is from the University of Washington Medical Center. It provides information specific to medical, illness and death beliefs for a variety of cultural groups in Washington State.

The website address is: <http://depts.washington.edu/pfes/CultureClues.htm>

The following are currently available:

- ✿ Albanian
- ✿ African American
- ✿ Chinese
- ✿ Deaf
- ✿ Hard or hearing
- ✿ Korean
- ✿ Latino (example follows this sheet)
- ✿ Russian
- ✿ Somali
- ✿ Vietnamese
- ✿ End of Life Care: The Russian Culture

## Birth Defects Resources on the Internet

**Alliance of Genetic Support Groups:** <http://www.geneticalliance.org/>

A national coalition of consumers, professionals and genetic support groups to voice the common concerns of children, adults and families living with, and at risk for, genetic conditions. This web site contains membership information and a searchable member directory, useful resources, newsletters and other publications.

**American Academy of Pediatrics:** <http://www.aap.org>

Provides online access to AAP's recommendations, research findings, and policy statements. Provides helpful tips and health information for parents and providers on all child health topics.

**Centers for Disease Control and Prevention (CDC):** <http://www.cdc.gov/nceh/ncehome.htm>

This web site provides information regarding various divisions, branches, and offices working in birth defects, genetics, and developmental disabilities. Other information includes publications, employment, and links to the CDC homepage and health topics A-Z. In addition, a kid's version and a Spanish version are also available.

**GeneClinics:** [www.geneclinics.org](http://www.geneclinics.org)

GeneClinics is a medical knowledge base relating genetic testing to the diagnosis, management, and genetic counseling of individuals and families with specific inherited disorders. The web site contains a database of genetic diseases with summary and diagnostic information, clinical description, management, resources, and references.

**HuGE Net:** <http://www.cdc.gov/genetics/hugenet/>

HuGE Net represents the collaboration of individuals and organizations from diverse backgrounds who are committed to the development and dissemination of population-based human genome epidemiologic information. The web site provides information about the HuGE Net and peer-reviewed synopses of epidemiologic aspects of human genes, prevalence of allelic variants in different populations, population-based disease risk information, gene-environment interaction, and quantitative data on genetic tests and services.

**March of Dimes Birth Defect Foundation:** <http://www.modimes.org>

This site contains a wealth of information about its organization, birth defects information, and infant health statistics in addition to numerous links to other birth defects data sources.

**Medical Genetics, University of Kansas Medical Center:** <http://www.kumc.edu/gec/geneinfo.html>

This website is jam-packed with information and hyperlinks; it is a resource for many birth defects and genetics/birth defects organizations, nationally and internationally. In addition, the site contains referral information for those wishing to see a health care professional about a birth defect or genetic disorder.

**National Institutes of Health: <http://www.nih.gov>**

Provides updates on the latest health and science research conducted by NIH researchers. The NIH Information Index has a subject-word guide to diseases and conditions under investigation at NIH. Also provides access to online catalogs, journals, and grant funding information.

**National Organization for Rare Disorders, Inc. (NORD): <http://www.rarediseases.org/>**

NORD is an organization of more than 140 not-for-profit voluntary health organizations serving people with rare disorders and disabilities. The web site contains organizational and services information, a rare disease database, an organizational database, an orphan drug database, newsletters, etc.

**National Society of Genetic Counselors: <http://www.nsgc.org>**

The National Society of Genetic Counselors (NSGC) is the leading voice, authority and advocate for the genetic counseling profession. The “What is?” section of their website explains the role of genetic counselors and the “resource link” lists genetic counselors nationwide and internationally, for those needing a referral.

**Spina Bifida Association of America: <http://www.sbaa.org/>**

The mission of the Spina Bifida Association of America is to promote the prevention of spina bifida and to enhance the lives of all affected. The web site contains organizational information and activities, facts about spina bifida, clinic directory, educational materials, etc.

**Teratology Society: <http://www.teratology.org/>**

The Teratology Society web site provides information on teratology, membership information, and links to numerous birth defects sites. Also has a teratology discussion forum.

