

Chapter 3

Elements of Care Coordination

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I. ELEMENTS OF CARE COORDINATION

INTRODUCTION

Children with special healthcare needs and their families utilize a myriad of services from health, education, social services, developmental, and other arenas. It can be difficult, time consuming, and confusing to identify, locate, access, and coordinate services. In an effort to assist children and families to gain access to needed services and assure that they are provided in a coordinated fashion, care coordination services are provided. Care coordination is defined by the Maternal Child Health Bureau as "services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special healthcare needs and their families (MCHB, 1977)."

This service should involve:

- # Working with the child and family to identify needs, concerns, and priorities
- # Locating, accessing, and evaluating needed services and resources
- # Working to assure that services are coordinated among interdisciplinary team members and across programs and agencies
- # Evaluating the effectiveness of service delivery in meeting client and family needs.

Care coordination services can be provided by professionals, lay staff or parents, depending on the nature and complexity of the child's needs and family preferences. In CSH the PHN is the person responsible for coordinating services which is an important component in the care of children with special healthcare needs. The PHN Care Coordinator is needed as the client/family interacts with a number of systems which provide services for acute and chronic problems. Families and providers should be able to anticipate a set of processes and measurable outcomes which help define a successful care coordination program.

The children with special healthcare needs are those who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (MCHB, 1997). In addition to these services, these children have the same needs as children in general to have services and programs that promote optimal health and development. This will require coordination of services to avoid gaps and duplications.

The guiding elements of care coordination are:

- # Families are at the center of the care coordination process. Families receive this service by choice and direct the goals of care coordination. This family directive is neither imposed on families nor taken from families against their wishes. As age and development allows, children should be active participants in the care coordination process. This is especially important as they approach the transition to adult services.
- # To have family-centered care, the service delivery must be flexible and provided with regard to the family's cultural beliefs and values. A culturally competent system of care goes beyond the provision of services in the family's preferred language to encompass a program's ability to honor and respect beliefs, interpersonal styles, attitudes, and behaviors of families who are clients as well as the multi-cultural staff who are providing services. It incorporates these values at the levels of policy, administration, and practice.

Utilizing these principles, the following outcomes should be achieved to have quality family-centered care:

- Families are given information about: Appropriate and available care coordinated services, the process by which the care coordinator is selected and assigned, the role of the care coordinator, and options for changing care coordinators; families then make choices that best meet their needs.
- Families receive care coordination services appropriate to their needs and preferences.
- Families receive care coordination services which are consistent with their ethnic and cultural beliefs and values, and in the families' preferred language.
- Families receive care coordination services in their communities whenever quality and appropriateness allow.
- Families receive timely and responsive initial and ongoing care coordination services.
- Families receive care coordination services which support the child's and family's developmental needs.
- Families serve as their own care coordinators, with support, appropriate training and collaboration with others, when they so choose. This role may be shared with the agency, in part or fully, as requested by families.
- Families choose their goals for care coordination services and revise their goals and plans based on ongoing evaluation of needs and progress.
- Families participate in the development of a plan, based on identification of needs, concerns and priorities, which promotes access to and coordinates needed services, and supports optimal outcomes for their children.
- Families are informed about and have access to appropriate, available, and comprehensive resources and supports optimal outcomes for their children to promote optimal health and well being. Families choose services and supports to meet their needs and are supported in accessing those services.
- Families experience continuity of care among and between community based and tertiary health, educational, developmental, social and other support services.
- Families receive information, assistance, and support in planning for transition including those related to age/development, systems/programs, health, family needs and concerns, and care coordinator changes.
- Families are informed about and supported while exercising their rights to appropriate care coordination services and services within the delivery system at large.
- Families are satisfied with their care coordination services.

TO PROVIDE CARE COORDINATION IN THE COMMUNITIES, THREE ELEMENTS NEED TO BE CARRIED OUT, THEY ARE:

**PROGRAM REPRESENTATION
CHILD AND FAMILY ASSESSMENT, AND THEN,
THE COORDINATION OF THE CARE**

II. PROGRAM REPRESENTATION

INTRODUCTION

Program representation is the first core element of the care coordination system. It includes activities performed in the community to inform prospective clients, healthcare providers, educators, social service agencies, and the community at large about the services provided by the CSH program. Information about other local, county, state, and tertiary care centers that serve children with special healthcare needs is given to the client and family.

Program representation leads to early identification of children with special healthcare needs and their families who might be referred to CSH, Early Intervention Programs, and other community resources. It also facilitates and encourages interagency collaboration. An informed community can better coordinate services and avoid duplication of services. No one agency or discipline can meet the diverse and complex needs of these children and their families. Mutual respect and recognition of each agency's unique contribution is essential to the success of the CSH Program.

GOAL

The long-term goal for CSH program representation is to assure that eligible children in the community will be identified and offered CSH services. Strengthening communication with other agencies is essential in finding eligible children, referring them for needed services, providing optimal comprehensive community-based services, and coordinating these services as needed. This is systems development for children with special healthcare needs.

ACTIVITIES

Activities include: community assessment, program education, case finding and advocacy at the community level.

A. Community Assessment

1. Purpose

The community assessment is to familiarize the PHN Care Coordinator with both the needs and resources of the community which forms the basis for planning. It helps to identify cultural differences, strengths, concerns, and motivation. Community assessment is important in designing programs. Traditions in each community vary so it is essential to design programs to meet the consumer needs. Programs appropriate for one community or group within a community may be effective in meeting the needs of other community populations.

2. Plan

There are a variety of strategies the PHN Care Coordinator can use in identifying community strengths and needs for children with special healthcare needs population. It is important to first determine what agencies are assessing community

needs and working collaboratively to identify and evaluate community intervention activities.

- a. Assess and identify needs resources in the community and participate in developing absent or deficient services. The local PHN Care Coordinator will assist with service development as needed.
 - b. It may be useful to utilize the expertise of the local Interagency Coordinating Council (ICC), Public Health Advisory Committee, or Healthy Community Planning Board (PATCH) when obtaining information for the assessment.

B. Program Education

1. Purpose

Program education is to provide current information of changing policy and services/resources regarding the CSH program, specialty clinics and other secondary and tertiary services serving children with special healthcare needs, as well as local providers who accept children with special healthcare needs or have special skills (i.e., a local engineer who can repair wheelchairs or dentists who will see children with developmental disabilities).

Target groups may include:

- **Public and Private Community Care Providers**
 - Hospitals, Nurses, Physicians, Therapists
 - Indian Health Services
 - School Nurses
- **Education/Social Services Agencies**
 - Local School Board, Early Intervention Council
 - Head Start, Child Developmental Centers, schools
 - Vocational rehabilitation centers
 - Division of Developmental Disabilities Area Resources Specialists and Individually Selected Case Managers
 - Medical foster parents
 - Protection and Advocacy
 - Diabetes Program
- **Parents/Families Groups**
 - Parent Advocacy Groups i.e., PTO, Parent Information Center (PIC), Wyoming Family Support Network (WFSN), WYNOT Council, UPLIFT, Wyoming Independent Living Rehabilitation (WILR), Western Wyoming Council for Independent Living (WWCIL), local ARC groups
- **Interagency**
 - Local advisory groups
 - Community Coalitions
 - Local Interagency Coordinating Committees (ICC)

2. Plan

- **Require** annual personal contact with pediatricians, family physicians who see children with special needs, child developmental centers and school nurses. Include other groups as time allows.

- Distribute CSH pamphlets to private providers, clinics, and local agencies at a minimum, annually. (Public service announcements and local TV and radio talk shows are good opportunities for raising awareness.)
- Submit information about CSH to agency or organization newsletters, and press releases to local newspapers and radio stations.
- **Require** a visit to new providers within three months of starting their practice in your community to provide information about CSH. Give them an orientation of community services, if needed. Children's Special Health staff are available to attend those meetings with you!
- Participate in the update of the local ICC resource directory every two years.

C. Case Finding

1. Purpose

Early identification of children with special healthcare needs is important for a thorough evaluation, diagnosis, and treatment so they can receive maximum benefit and reduce/prevent secondary complications.

It is a goal that every child who receives services from a child developmental center has specific diagnosis(es) from appropriate medical specialists.

2. Plan

- Assist families in completing applications to facilitate processing and establishment of an appointment with a healthcare provider to determine if there are special healthcare needs.
- Foster interagency communication and collaboration for the purpose of direct service and facilitating access to noted resources, i.e. child developmental centers, special education departments.
- Work with Early Intervention Programs to implement the Health Screening Questionnaire as part of their intake process to facilitate referral to PHN.
- Refer for appropriate evaluation and intervention services and financial resources such as SSI, Kid Care A, Caring Program, Wyoming Health Insurance Pool, Kid Care B, Children's Waiver, etc.

D. Advocacy at the Community Level

1. Purpose

Public relations activities increase and maintain visibility of the CSH program and other programs for children with disabilities with the community and other providers. Periodic contact with them increases awareness of the needs of children with special healthcare needs and supports coordinated community services.

2. Plan

- Increase support by participating in community events (i.e., developmental center and Shriner's screenings, school health fairs, conference, etc.).
- Communicate with public officials and legislators by being involved in community events and/or personal contact with them as a client advocate.

III. CHILD AND FAMILY ASSESSMENT

INTRODUCTION

Assessment is the second core element of the care coordination system. When working with families of children with special healthcare needs, the focus is often on the child's health, level of functioning and development. However, it is not enough to simply define the child's requirements and the resources available in the community to accommodate them. Coordinators must address the needs, strengths, abilities and limitations of the family as well. The way in which a family defines healthcare and illness affects the healthcare plan and its success or failure. The family's perception of a healthcare related situation will usually be quite different from that of the professional. With accurate assessment, the PHN Care Coordinator will be better able to assist families to identify and understand the needs of their child and family, and to seek appropriate resources to meet those needs.

There are good resources available to assist the professional in obtaining an objective family assessment. Among them are standardized and un-standardized tools and questionnaires. It is important for the professional to be knowledgeable about how the tool was developed and its intended use. The CSH Program recommends using standardized tools for assessments such as Nursing Child Assessment Satellite Training (NCAST) and the Family Needs Assessment.

GOAL

The goal for the assessment process is to identify the health and developmental needs of the child, identify family strengths, and identify resources in the community which may assist in meeting child and family needs. The family is the most important part in the development of their overall family plan.

ACTIVITIES

Activities include: assessment of the child and family.

A. Assessment of Child

- Assess the health and developmental needs of the child to assure outcomes for growth commensurate with abilities.
- Screening/Assessment can occur in the home, clinic, or other setting, providing it allows for comfort of the child and reliability and confidentiality of the assessment. It may take several contacts to obtain all of the information the PHN Care Coordinator feels is appropriate and meets the needs of the family in establishing rapport and trust.
- The minimum services should include a physical assessment of the child as well as vision, hearing, and developmental screening. Screening tools such as the NCAST,

Family Needs Assessment, etc., may be used if appropriate. The PHN Care Coordinator is not expected to repeat any recent assessment or screening which has been completed by another qualified professional. It may be appropriate for the PHN Care Coordinator to collaborate with other resources in the community to complete a screening or assessment.

- Based on the screening and assessment data, determine with the child/family the areas in which intervention will be necessary to achieve optimal health and development of the child.
- If indicated, refer the child for further assessment, diagnosis, and/or treatment. Assist the family in setting up appointments, filling out applications, and supplying requested or other pertinent information, if appropriate.

B. Assessment of Family

- Assess the ability of the family to meet their own needs as well as the special health and developmental needs of their child.
- A family assessment may be conducted in the home, clinic, or other setting in which the family is comfortable and which provides confidentiality. As with the child assessment, the family assessment may need to be done over a period of time and should keep the privacy and the needs of the family in mind at all times.
- Methods used to conduct a family assessment may include:
 - Interviews with family members (both structured and unstructured)
 - Observation
 - Surveys, questionnaires, and standardized tools (Family Needs Assessment, Bailey)
- It is important to select assessment methods/tools based on the needs of the family and use them only in their intended way so as not to make inaccurate generalizations or conclusions.
- Based on the screening/assessment, determine with the family the areas in which they wish to receive help.
- Provide intervention for identified areas of concern.
- Assess the resources available in the community to assist the family in meeting their needs and to coordinate care for their child. The PHN Care Coordinator may refer and may need to be an advocate for the family in obtaining appropriate and available resources. Families choose services and supports to meet their needs and are supported in accessing those services.
- Assign a tier level to the child/family and continue with appropriate care coordination activities.

IV. COORDINATING CARE

INTRODUCTION

Coordinating care is the third core element of the care coordination system. These children may have complex medical, educational, vocational, and social needs that require a wide range of services. All services are not usually available at the community level so families may need to travel some distance to a tertiary medical center. Fragmentation of care, duplication of services, gaps in services, and failure to involve the family in the decision-making process can create barriers and ongoing problems. Coordinating this care is an attempt to integrate services and deal with these problems.

GOAL

The goal for coordinating care is to help families locate and access resources needed to provide the best care for their child and to assist families in gaining the skills to manage the care of their child.

ACTIVITIES

Coordinating care includes five essential activities: assessment, planning, linking of services, monitoring and evaluating.

A. Assessment

The assessment is described in the preceding section of this manual (II. CHILD AND FAMILY ASSESSMENT).

B. Planning

Planning refers to the development and documentation of a service/care coordination plan that includes goals, interventions, expected or desired outcomes, and time frames for achieving the outcomes.

1. Develop the care coordination plan

- The plan should identify child/family needs, expected outcomes, planned interventions, name of individual or agency responsible for providing the service and time lines.
- Care coordination may be a multi-disciplinary effort. If coordination of care is being provided by another agency, the PHN Care Coordinator will work with the agency(ies) and family to clearly define each role and avoid duplication of services.
- The plan will be documented on the CSH Care Coordination Clinical Pathway (See Chapter Five, CSH-9 Form).

2. Determine the level of service by using the tier level assignment which is based on the child's healthcare needs and family's function. Tiering is designed to help the

coordinator determine priorities and the amount of assistance a family may need (See Chapter Five, CSH-2 Form).

3. Review, evaluate and modify care coordination plan based on assessed need at intervals consistent with the tier level.

C. Linking with Services

The objective of linking is to ensure that the child and family receive the special health services to which they are entitled. Linking includes five essential activities: referring, coordinating, educating, supporting, and advocating.

1. Referring

- Become knowledgeable about care providers, available services, and choices. Learn the various programs' eligibility criteria and identify contact point for each agency. It may be helpful to maintain a list of care providers for referral agencies.
- Assist the family to complete the necessary application forms and obtain releases of information or other pertinent information required by the referral agencies.
- Confirm that the child has a primary medical provider; if not, assist the family in locating one in their community.
- Link families/children with appropriate and needed services. This may be as simple as making a single referral or as complicated as arranging transportation, temporary lodging, respite care or securing the funding needed for the services, etc...
- Review and clarify recommendations of the care coordination plan with the family.

2. Coordinating

- Coordinate services to prevent duplication and promote continuity of care.
- Facilitate communication between service providers to set common goals and identify responsibilities of the individuals involved. Obtain a signed release of information (See Chapter Five, PHN-51 Form) yearly from the family.
- Act as a liaison between CSH, other tertiary centers and local providers. Reports from specialty providers are obtained and shared with designated agencies/providers as indicated on the PHN-51. Review, clarify and follow-up on any clinic recommendations.
- Help coordinate medical and educational recommendations by taking part in the Local Interagency Coordinating Council and when appropriate, participating on the Multi-disciplinary Team, IEP and IFS meetings and school visits to discuss individual children.

- Promote continuity of care between the hospital and the home by participating in discharge planning.

3. **Educating**

- Provide general information to families and providers about the child's condition, diagnosis and treatment options which will allow them to make informed decisions.
- Provide instruction on special care techniques pertinent to the child's condition.
- Provide information to the family on how to access services.
- Assist families to learn how to coordinate their child's care.
- Educate the family on role and importance of a medical home and preventive care.
- Educate the family on importance of maintaining medical and educational records.

4. **Supporting**

Support is one of the most important activities the PHN Care Coordinator will provide. Often families and professionals are so engrossed in learning the specialized aspects of the child's care that little time is spent dealing with the emotional feelings that are ongoing for families. Beyond knowledge, families need the opportunity to express, clarify and receive validation for their feelings. Often the frequency and duration of services the PHN Care Coordinator provides depends more on the family functioning and ability to cope than on the severity of the child's disability.

- Provide emotional support and counseling when a child is initially diagnosed, during family crisis, or for grief counseling.
- Provide support to help the family reach the goals outlined in the CSH Care Coordination Clinical Pathway.
- Support families in the decisions they make regarding their child.
- Refer families to parent support groups or the MCH Parent Consultant at (1-800-438-5795).
- Encourage utilization of support persons already established with the family.

5. **Advocating**

- Become familiar with eligibility criteria, application processes and appeal procedures for programs and agencies.
- Become knowledgeable about the laws and regulations applying to the care of children with special healthcare needs. This includes programs such as Special Education, Early Intervention, Kid Care A or B, and Social Security.

- Provide resources to the family on legal rights and services. Refer to Protection and Advocacy (1-800-624-7648) as needed.
- Act as a family advocate to work toward removing barriers in accessing care.
- If necessary, participate with the family in negotiations to secure services.
- Assist families to gain skills in problem solving and self advocacy.

D. Monitoring and Evaluating

Monitoring and evaluating refers to the responsibility of the PHN Care Coordinator to follow-up with the family and providers. This involves periodic reassessment and modification of the plan to address new concerns. Evaluation is a critical piece of the care coordination process. Periodically, the PHN Care Coordinator and the family review the care plan and evaluate if the expected outcomes were met.

- Follow-up to decide if the child/family has received the services as noted on the CSH Care Coordination Clinical Pathway. For example, medical and educational plan, follow-through with referrals, appropriate educational services, etc.
- Monitor the family and child's progress in reaching the outcomes/goals as designated in the CSH Care Coordination Clinical Pathway.
- Evaluate the plan of care using the following as a guide:
 - Were the family/child expected outcomes met and the problems resolved?
 - When did the family achieve the expected outcome?
 - How realistic was the expected outcome?
 - Were the coordinator's interventions effective?
 - How instrumental were the interventions in assisting the family to achieve the outcome?
 - What happened when the intervention was not congruent with the expected outcome and/or the family's plan?
 - What variables influenced the attainment of the expected outcome?
 - Why were outcomes not attained? Wrong problems/needs identified? Interventions not appropriate? The care plan was incomplete? Team members did not complete their responsibilities?
 - What changes are needed in the plan?
 - Where should the coordinator and family refocus their efforts?
 - Is the coordinator no longer needed by the family?
 - Can the record be closed?
 - Is the family comfortable notifying the coordinator if new concerns arise?
- Update and modify the CSH Care Coordination Clinical Pathway as needed, i.e., tier level, family needs assessment.
- If the expected outcomes have been met, the PHN Care Coordinator has the option of closing the case.