

2010

# ***The Fundamentals of Care Coordination within the Medical Home***

Module 1 in a series of 5



**North Dakota Center for Persons with Disabilities**  
*Minot State University*

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## **The Fundamentals of Care Coordination within the Medical Home**

This training manual was developed by the North Dakota Center for Persons with Disabilities at Minot State University to be used by providers of coordinated medical care services for children and youth with developmental disabilities and special healthcare needs. Requests for use of this publication for any other purpose should be submitted to Minot State University, NDCPD, Attn: Executive Management, 500 University Avenue West, Minot, ND 58707.

### **SUGGESTED CITATION**

Dockter, K. & Ressler, K. (2010). The Fundamentals of Care Coordination within the Medical Home. Minot, ND: North Dakota Center for Persons with Disabilities, a University Center of Excellence at Minot State University.

### **PRODUCTION OF THIS PUBLICATION SUPPORTED BY FUNDING FROM:**

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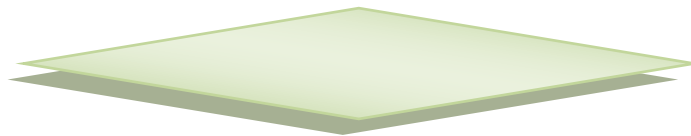
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## INTRODUCTION

Care Coordination for Children with in a medical home setting is the first learning module in a series of eight. Thank you to the Medical Home Grant Project for funding the curriculum for care coordination for <sup>1</sup> children and youth with developmental disabilities and/or special health care needs. In addition, thank you to North Dakota Department of Health-Children's Special Health Services, Early Childhood Comprehensive Systems Program. North Dakota Department of Human Services- Medical Services Division, Family Voices of North Dakota and care coordinators in the pilot sites for taking time from their busy schedules to share the practical aspects of care coordination in their settings. The opportunity to review resource materials and speak with staff associated with care coordination greatly assisted with the research phase of developing this curriculum.



## MODULE OBJECTIVES

1. Participant will be able to verbalize understanding of care coordination and related terms.
2. Participant will be able to discuss when care coordination would be valuable.
3. Participant will be able to describe various settings that care coordination could be done.
4. Participant will be able to verbalize who can do care coordination.
5. Participant will describe the benefits of care coordination for children with special healthcare needs.
6. Participant will describe the barriers of care coordination for children with special healthcare needs.

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<sup>1</sup> DD/SHCN- Children and youth with developmental disabilities and or special health care needs.

## WHAT IS CARE COORDINATION?

Care coordination is a patient and family centered, assessment-driven, team based activity designed to meet the needs of children and youth (Antonelli, et. al, 2009). Another definition of care coordination as defined by the National Quality Forum (NQF) is “A function that helps ensure



patients’ needs and preferences for health services and information is met”. Care coordination and case management have similar functions but the focus or center of the care is different. Case management according to the Tabers Cyclopedia Medical Dictionary is defined as an *individualized* approach to coordinating patient care services for individuals with complex health care needs or chronic medical problems. Care coordination is a *patient –and-family centered* approach for care delivery. Although a single “recipe” for care coordination does not exist, similar characteristics and competencies are noted.

Care coordination within the medical home for children and youth with developmental disabilities and/or special health care needs are comprehensive. The strengths of the family are incorporated into the development of the care plan or in some settings the service plan. The patient and family centered approach to care coordination links patients and families to the primary care medical home. Within the medical home, the family and care coordinator work as a team along with the medical provider. The team is the parent(s), child, care coordinator and provider. As the care plan<sup>2</sup> evolves a broader range of stakeholders may be included in the care plan. The additional stakeholders that may participate in the continuum of care for the child or youth with DD/SHCN could be additional family members, community organizations,<sup>3</sup>Title V program staff, durable medical equipment companies, health insurers, school staff or daycare providers. The list of stakeholders will vary from case to case depending on the need of the child/ youth. As a result of working with a care coordinator within the medical home, the process of obtaining health services should be more seamless.

Care Coordination is a proactive approach to obtaining health care whether well visits or symptomatic treatment. In addition, the care coordinator assists the family and child/youth with navigating the complicated health care system so that health needs are met in an efficient and timely manner at the appropriate level of care. For example, a clinic visit is scheduled for the same day if needed to prevent an unnecessary emergency room visit. When the family-patient unit, care

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<sup>2</sup> Action steps or instructions used by the team in providing patient centered care.

<sup>3</sup> Title V-Americans with Disabilities Act provisions defined to assist individuals with mental or physical impairment.

coordinator and provider work together, self-care skills and independence can be gained. Effective communication among the team members has a positive impact on developing relationships across the organization and with schools and community partners. The entire team works collaboratively in achieving the same goals keeping in mind that the patient and family are the center of the team.

**Example of Criteria for Care Coordinator from Washington State:**

Guide to Care Coordinators in Washington State

**Children with Special Health Care Needs (CSHCN) Coordinator**

Job Requirements for Care Coordinators Working in Public Agencies	Agency Definition of Care Coordination and Client Eligibility	Services Provided
<p><b>Agency:</b> Children with Special Health Care Needs (CSHCN) Program, Washington State Department of Health</p> <p>CSHCN Coordinators are public health nurses located in the thirty-four local health departments throughout the state.</p> <p><b>Education requirement:</b> Bachelor of Science degree in nursing with specialization in public health nursing, or graduation from a state-accredited school of nursing supplemented by public health training. Current Washington State registered nursing license.</p>	<p><b>Definition:</b> Care coordination promotes the effective and efficient organization and utilization of services for children with special health care needs and their families.</p> <p>Care coordination is a process for:</p> <ul style="list-style-type: none"> <li>• Identifying a child’s health or developmental needs, family strengths, concerns, priorities, and resources.</li> <li>• Assisting families to find and establish services they want and need.</li> <li>• Facilitating on-going identification of needs and coordination of resources.</li> </ul> <p><b>Client Eligibility:</b> Children age birth to 18 years who have or are at risk of having a serious physical, developmental, behavioral or emotional condition; who require health and related services of a type and amount beyond what is generally required, and who reside in Washington State.</p>	<p><b>The CSHCN Coordinator is responsible for:</b></p> <ul style="list-style-type: none"> <li>• Helping families access needed services for their child such as medical care and other intervention.</li> <li>• Referring families to health insurance programs and information, both private insurance and the state funded Medicaid Program.</li> <li>• Helping families help each other through parent support organizations.</li> <li>• Helping with concerns such as feeding nutrition, growth, development and behavior.</li> <li>• Providing screening and assessment.</li> </ul> <p>To learn more visit <a href="http://www.doh.wa.gov/cfn/mch/cshcnhome2.htm">www.doh.wa.gov/cfn/mch/cshcnhome2.htm</a></p> <p>Source: Case Management/ Service Coordination Matrix prepared by the WISE grant Care Coordination Committee, 2002 and Children with Special Health Care Needs Program brochure, Washington State Department of Health Publication #970-108</p>

**WHEN WOULD CARE COORDINATION BE VALUABLE?**

A better question might be when wouldn’t care coordination be valuable? As the US government strives to make healthcare more accessible and affordable to all Americans, having a medical home with a knowledgeable care coordinator would be a positive step in that direction. Care Coordination is vital for patient’s that have complex medical and non-medical needs. The time consuming nature of coordinating and organizing all of the activities necessary for the child with special healthcare needs can be overwhelming for the family. When the patient-and-family are ready to embark on a high performance approach that fills in the gaps and links the patient with the needed services or programs, care coordination encompasses specific functions to accomplish that goal. According to (Antonelli, et al, 2009), “The goal of care coordination is to help link patients and families to services that optimize outcomes articulated in a patient-centered care.”

## MAKING THE MOST OF THE CLINIC VISIT

Care coordinators have the ability to coach and mentor families by assisting the family or care giver with making the **most** of the clinic visit. The care coordinator can encourage the family or care giver to:

- Plan ahead for the clinic visit
- Write down questions prior to the clinic visit
- Be open and honest about concerns
- Keep written records
- Use a care notebook
- Ask what to in the case of an emergency

## FOUR QUALITIES OF SUCCESSFUL FAMILY/PROFESSIONAL RELATIONSHIPS

*Adapted from Steven Covey: 7 Habits of Highly Effective People*

1. Be Proactive: Adapt an attitude that is collaborative and responsible
2. Begin with the end in mind: Be able to envision the future
3. Put first thing first: Prioritize needs for the upcoming year
4. Seek first to understand then to be understood: Listen; you do not have to agree

## WHERE WOULD CARE COORDINATION BE DONE?

Care coordination is a value added service that can be conducted in various settings such as clinics, hospitals, outpatient settings, public health, mental health or home health services. This curriculum will elaborate on care coordination within the medical home. To better understand the medical home as a setting to provide care coordination, an understanding of a *medical home* is necessary. The term medical home can also be referred to as the patient-centered medical home or health care home. Various authors and websites refer to a medical home as an approach for providing comprehensive patient centered care that will increase satisfaction with care, allow better access and improve the health of the individuals participating. Patient satisfaction is improved because the primary care provider has an ongoing relationship with the patient and takes the lead or the responsibility for the care of the entire person. Any referrals made to specialists, home health agencies, mental health agencies, hospitals, nursing homes or other stakeholders are done so by the provider within the medical home. Improved access to care is within the medical home can be accomplished by same day scheduling, expanded hours or new options for communication.



The care coordinator is the link that connects the patient and family with services within the practice, with community based services, inpatient and outpatient settings and between various specialty settings. Effective care coordination functions efficiently when provided in the context of the team setting within the medical home with an identified care coordinator. The team can meet face to face, conference call or virtual depending on the format the group chooses. At the team meeting, goals and objectives, planned interventions and measurable outcomes are some of the topics that should be discussed. The outcomes of the team meetings should be documented according to the policy of the organization.

## WHO CAN DO CARE COORDINATION?

The majority of the care provided and coordinated for children and youth with DD/SHCN is done by the family. In addition, little information is available about how medical practitioners might better coordinate patient care, both within and across practice settings (O'Malley et. al., 2009). Since the responsibilities of the care coordinator is varied in different settings, family, nurses, social workers, nurse practitioners or any knowledgeable individual can work as a care coordinator. A care coordinator can have dedicated hours allotted for the activities of care coordination or incorporate the activities into the daily workload. A family member of a child with special health care needs has firsthand experience and could work very effectively as a care coordinator. Social workers have traditionally worked with linking people with appropriate services



which is a vital part of care coordination. Nurses and nurse practitioners have the clinical experience and assessment skills in addition have experience in care planning and continuous monitoring. No matter the perspective whether family, nursing, social work or other, the major qualification is to be instrumental in resolving fragmentation in the healthcare delivery system. In A Workbook by, (McAllister, et.al, 2007) titled Medical Home Practice –Based Care Coordination, a worksheet described the responsibilities of a care coordinator that could be customized to suit your practice.

## WHY DO CARE COORDINATION?

The needs of children and youth with DD/SHCN often require complex care from numerous agencies. Without a care coordinator within the medical home to assist with navigating the maze of services and programs, disconnects in services occur resulting in duplication or elimination of needed services. There are benefits and barriers to care coordination, examples from varying perspectives are listed below.

### **BENEFITS OF CARE COORDINATION: A PATIENT/FAMILY PERSPECTIVE**

Increased wellness resulting from comprehensive care is one of many benefits for patients and family that work with a care coordinator within a medical home. The improved patient outcomes can be a direct impact on the improvement in absenteeism from school or a reduction in use of the emergency room. Parents of children and youth with DD/SHCN are often bombarded with added responsibilities, having a care coordinator within a medical home to assist with coordinating referrals, communicating with other agencies or schools, interpreting medical reports or managing continuous communication improves parent satisfaction ([www.medicalhomeinfo.org/health/general.html](http://www.medicalhomeinfo.org/health/general.html)).

### **BENEFITS OF CARE COORDINATION: PHYSICIAN/PROVIDER PERSPECTIVE**

Palfrey et al., (2004), reported that patients who have a stronger relationship with providers reported greater satisfaction with services. Reduction in family needs, caregiver strain, decreased school absences. Improved professional satisfaction was also noted related to improved communication and an established forum for problem solving.

### **BENEFITS OF CARE COORDINATION: SYSTEMS FACTORS**

An integrated care coordination infrastructure is an important component needed to create a high performance pediatric healthcare system. The high performance healthcare system promotes the efficient use of limited resources. In addition decreased inpatient days result in a cost savings for the health insurer stakeholders.

### **BARRIERS TO CARE COORDINATION: A PATIENT/FAMILY PERSPECTIVE**

Family members of children and youth with DD/SHCN have numerous concerns and may not be sure of the process. At times family members are unclear of the process and self refer to specialists which could result in a breakdown in care coordination. Family members of youth with developmental disabilities and special health care needs may engage in risky behavior such as tobacco use, illegal drugs or alcohol consumption which would affect his or her overall health and well being more severely than youth without healthcare needs. Noncompliance with a treatment plan could occur for various reasons as well as not understanding the recommendations made by the provider. After a review of literature and interviewing care coordinators in the medical home pilot sites, the lack of time was identified as major barrier that affects the ability to provide effective care coordination. The time constraints could be resolved by including a portion of the time during each clinic visit.

### **BARRIERS TO CARE COORDINATION: PHYSICIAN/PROVIDER PERSPECTIVE**

According to a recent review of literature, the barriers that physicians acknowledge include a lack of incentive in the reimbursement system for the activities of care coordination and the concern that primary care providers are responsible for filling the gaps in the health care system.

In one study, “A physician noted that some physicians are not aware of how to work within a team to accomplish the numerous coordination tasks required (O’Malley et.al, 2009). In addition, a culture of non-communication and non-ownership of coordination among providers exists (O’Malley et al., 2009).

### **BARRIERS TO CARE COORDINATION: SYSTEM FACTORS**

The fee for service does not reimburse for care coordination efforts in most cases. The expenses of care coordination activities are the financial responsibility of the practice or network. The more patients a physician can see during day, the greater the revenue for the practice. The face to face visits are billable time where as referrals or communicating with patients outside the office visit is not. However, according to recent literature, care coordination activities over time would likely lower overall costs to patients and health care systems; decrease emergency room visits and improve patient satisfaction. . An example of time protection tips and strategies has been outlined by McAllister et al (2007). The entire Medical Home Practice Based Care Coordination Workbook include in the Appendix.

### **ASSESSMENT AND DATA COLLECTION**

The exact forms that are used in the various sites can be individualized according to paper or electronic. The similarities would be in the data collected during the assessment. A suggested pediatric assessment would include:

- Family Status and Home Setting
- Medical/dental and behavioral health status
- Social or community support
- Financial concerns
- Family demands, relationships and functioning
- Cultural beliefs and family values
- Transportation needs
- School performance or needs
- Child development/progress/status

*“Families want and need a real time, accessible care coordinator, one who holds a key role within a practice or clinical team and possess the knowledge, skills, and desire to do what it takes helping families to meet the needs of their children and youth (McAllister,et al. pg. 493, September, 2009).*

## GOAL SETTING

A collaborative family/patient centered approach to goal setting is encouraged. The child with special health care needs may encounter school, daycare, healthcare and family member(s) in a 24 hour period, each having a different focus in the child's life. The goals must be flexible, measurable and realistic. The approach to goal setting might take place face to face during a clinic visit, a team meeting, email, telephone or video conferencing.



## CARE PLANNING

The care plan along with the measurable goals makes up the “recipe” or the written plan the entire team follows. The care plan does aid in communication among stakeholders. The exact format for documenting a care plan or action plan is facility specific. Medical home sites generally develop their own care plan document. There are several care plans that are available for adaptation through established medical home sites.

### NORTH DAKOTA SPECIFIC FORMS USED IN THE MEDICAL HOME PILOT SITES

- **MHMonthlyReportForm2 & Summary of Changes FormMar10** – We require the teams to fill out and submit this paperwork each month in order to receive reimbursement. This keeps track # of CYSHCN Identification, # of Care Plans developed, when the teams met and who was present, areas for technical assistance, # of school plans providers contributed, and # of hospitalizations or ER visits prevented. The summary of changes lets me know what the team is working on to improve the quality of care in their practice and increase their “Medical Homeness”
- **MHomeIndex** – This is an index developed by the Center for Medical Home Improvement. It is a self-assessment that measures the “Medical Homeness” of the practice based on 6 different domains. Practices should complete this index every 6 months to identify areas for improvement and what they are doing well.
- **Family Index with Notes** – This is completed by the Family Partners in each practice. It is a “family view” on the practice. This should also be completed every 6 months. In all honesty, I think this should be completed by all families whose child is considering a “Medical Home Patient”. Right now, the sample size of 2 is too small to really draw conclusive data.
- **ParentSurveyCoverMay2010** – This is the Parent Perception Survey. We complete these every 6 months. I don't think it would be a bad idea for practices to give this before or after each visit to families with CYSHCN.
- **NDIS Med Home Mtg FamilyFORM** – This is for family partner reimbursement.
- **NDIS Med Home Mtg PracticeFORM** – This is for practice reimbursement.

# CARE PLAN 101: Important things to know about Your Care Plan

*Adapted from document retrieved from Merit Care Fargo North Dakota and Minnesota Learning Collaborative*

## WHAT IS A CARE PLAN?

- A valuable tool that is used to provide medical and education information regarding your child to health care providers, schools and child care providers.
- A quick reference with child-specific information needed in a medical emergency.
- Medical summary including current problem list, medications, past medical history and community resources that are being utilized.

## WHEN IS THE CARE PLAN USED?

In the emergency room: Especially when you are traveling! The care plan will define special instructions or an overview of your child's health care needs.

- At a specialist appointment: The care plan can be updated with any changes in medications or new diagnoses.
- Prior to your child's well child check: Review the care plan for any omissions or errors and add any information that you feel would be helpful. Example: All blood draws should be finger pokes if possible.
- If medications or equipment change, update the care plan.
- At school: For example, if your child has asthma, the care plan will document what treatment the school should administer. (Note: An asthma action plan may also be on file at school. Care plan and action plan should be consistent.)
- As a document you leave with your child's caregiver such as a babysitter or respite care provider.
- Have multiple copies of the care plan: in your car, your child's wheelchair, at mom's house and dad's house, etc.
- At your child's school meetings: Such as IEPs. The school is welcome to have a copy of the care plan if you chose.

### ***Components of Comprehensive Care Planning:***

1. *Medical Summary*
2. *Emergency Plan*
3. *Action Plan*

***[www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)***

## HOW DO I MAKE CHANGES TO MY CARE PLAN?

- Write on it? Make changes to your child's care plan by crossing out wrong information, old medication, etc. Bring the updated care plan to your child's medical appointments for discussion and review.
- Inform your care coordinator and/or medical home provider of any changes to the care plan so provider care plan can be updated.

## CONTINUOUS MONITORING

The child or youth with DD/SHCN should be monitored according to need or severity of his or her condition. For example, Antonelli, et al, May, 2009 recommends a framework that stratifies children into three levels:

1. *Level 1: Basic.* Families are informed of Care Coordination services and how to use them. For example, a parent of a 3 yr. old is inquiring about services in the community. Contact information is provided to the family.
2. *Level 2: Moderate.* Level 2 requires more coordination and contact than Level 1. Goals may include short and long term outcomes, additional monitoring is need, and collaboration among various stakeholders is required. For example, a 30 month old presents with language delays, the medical home team in conjunction with the family develop a care plan that includes referrals to audiology, Early Intervention, and community- based family support center. The communication among the various stakeholders is integrated and included in actions steps in the care plan, thus decreasing fragmentation of care.
3. *Level 3: Extensive.* At this level, care coordination needs to be far reaching. The care team and family determine methods of communication and intervals for the coordination of care. A mutual agreement on the method and frequency of communication should be established by the team. A child that needs extensive care coordination may be identified by the clinic or insurer based on the extensive needs of the child.



## CONCLUSION

Care Coordination within a medical home is a multifaceted approach to delivering quality, family centered patient care. The care coordinator has a very rewarding and integral role in being the pivotal point of the team. Communication is greatly improved when a care coordinator manages the team effort in addition the “go to” person is defined which literature states decreases use of ER visits and improves patient satisfaction. The US Department of Health and Human Services’ Healthy People 2010 goals and objectives state that “all CSHCN will receive regular ongoing comprehensive care within a medical home ([www.medicalhomeinfo.org/health/general.html](http://www.medicalhomeinfo.org/health/general.html)).

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## **APPENDIX A: WEBSITES**

[www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)

[www.medicalhomeinfor.org](http://www.medicalhomeinfor.org)

[www.medhomeportal.org](http://www.medhomeportal.org)

## **APPENDIX B: ATTACHMENT**

McAllister, JW, Presler, E., Cooley, CW., Medical Home Practice-Based Care Coordination: A Workbook: United States Maternal and Child Health Bureau, Integrated Services for CSHCN, HRSA.