

CARE COORDINATION: DEFINITION & PRINCIPLES

**Prepared by the Care Coordination Work Group of the
Massachusetts Consortium for Children with Special Health Care Needs**

June 2, 2005; revised October 6, 2005

Definition of Care Coordination

Care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families. Care coordination engages families in development of a care plan and links them to health and other services that address the full range of their needs and concerns. Principles of care coordination reflect the central role of families and the prioritization of child and family concerns, strengths and needs in effective care of children with special health care needs. Activities of care coordination may vary from family to family, but start with identification of individual child and family needs, strengths and concerns, and aim simultaneously at meeting family needs, building family capacity and improving systems of care.

Principles of Care Coordination

- **Accessibility**
 - Universal source; available/accessible for all CYSHCN
 - Continuous across service systems and across transitions as important to family
 - Is housed within medical home but with family, rather than practice, as “client”
 - Integrated with community resources to assure access for all linguistic and cultural groups

- **Individualization** based on family circumstances, needs and strengths
 - Maximizes family care-giving capacity
 - Looks to family to define needs, rather than offering family what the system happens to provide
 - Builds, and builds on, family strengths
 - Provides anticipatory guidance to prepare family and child for future
 - Respects and engages with family culture and custom

- **Aligned with the family** in its interactions with broader community
 - Promotes inclusion of child/youth in all settings
 - Promotes autonomy of child/youth towards and through transition
 - Serves as advocate for family when systems with challenging or unresponsive systems
 - Elevates status of family and legitimizes family concerns to broader community

- **Promotes solution of systemic problems** through network of CCs guided by clear standards and ethics
 - Ties individual CC to broader network for quality assurance, accountability and support
 - Draws on knowledge base and resources of multiple disciplines, while not focused on providing any one specific therapeutic or curative service
 - Promotes appropriate use of services and resources (from family and system perspectives) based on needs of child, family and system
 - Reduces fragmentation and connects services across systems
 - Identifies and tracks systemic gaps and barriers

Outcomes of Care Coordination

- Satisfaction, well-being and autonomy of child
- Satisfaction and well-being of family
- Satisfaction and capacity of providers
- Effectiveness and efficiency of system/s

Stages of Care Coordination Process and Associated Activities

The following activities are components of an effective care coordination process.

1. Conduct and update community and environmental scan
 - a. Develop census of community programs and agencies
 - b. Acquire or develop community resource guide
 - c. Gather written and electronic program descriptions and application
 - d. Establish person-to-person contact with agency staff
 - e. Join or initiate community coalition
2. Enhance capacity for early and ongoing screening and identification
 - a. Collect and synthesize screening tools reflective of different conditions, needs, languages
 - b. Establish mechanisms for referral including self-referral by families
 - c. Conduct outreach and education regarding availability of CC services
3. In-depth needs assessment
 - a. Interview family to determine full array of needs related to care of child
 - b. Identify family strengths and resources
 - c. Review family circumstances, needs and concerns on an ongoing basis
 - d. Conduct home visit as setting for needs assessment
4. Development of individualized family support plan
 - a. Review needs, concerns and strengths with family
 - b. Define priority issues
 - c. Identify resources, programs, benefits to address priority issues
 - d. Provide or carry out referrals to relevant services and programs
 - e. Intercede with or for family when systems fail to respond

5. Implementation and monitoring of care plan
 - a. Carry out activities with or for family as prioritized
 - i. Identify family versus CC tasks incorporated in plan
 - ii. Contact referrals
 - iii. Initiate meetings as needed
 - iv. Send information to family
 - v. Identify resources to meet specific family needs
 - vi. Follow-up with services and family as needed
 - vii. Act as proxy/advocate for family as need
6. Review and revision or completion of plan as needed
 - a. Conduct regular, periodic global review of plan with family
 - b. Revise plan as needed and return to stages 4 and 5
7. Link information on unmet needs and continuing barriers to system level assessment and planning efforts

*Kathy Ryan, Debby Allen
Care Coordination Work Group*

*MA Consortium for CSHCN
c/o New England SERVE
info@neserve.org
www.neserve.org*