



**A Public Health Model for Health Care
Coordination Services
For Children and Youth with
Special Health Care Needs**

March 20, 2006 DRAFT, DRAFT

Colorado Department of Public Health and Environment

7th Edition
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**CARE COORDINATION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS
A Public Health Model**

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THE HEALTH CARE PROGRAM FOR CHILDREN WITH SPECIAL NEEDS

Overview of HCP

The Health Care Program for Children with Special Needs (HCP) is a unique resource for families, health care providers, and communities. Our goal is to help improve the health, development, and well being of Colorado's children with special health care needs and their families. HCP serves children from birth to age 21 that have, or are at risk for, serious physical, behavioral, or emotional conditions.

HCP works with families, health care providers, communities, and policy makers to strengthen our state's capacity to meet the needs of children and their families.

The HCP program is funded by federal Maternal and Child Health Bureau Title V funds as well as state and local funding. Through contracts with private insurers, community agencies, and local public health agencies, the program assists families in understanding and coordinating the resources available for care and support including:

- Medicaid
- Social Security Income (SSI)
- Child Health Plan Plus (CHP+)
- Early Childhood Connections (Part C)
- Special education and developmental disabilities services
- Access to health care providers

Definition of Children and Youth with Special Health Care Needs

The Maternal and Child Health Bureau defines children and youth with special health care needs (CYSHCN) as "those who have, or are at increased risk for having, a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." (McPherson, et al., 1998).

INTRODUCTION TO CARE COORDINATION

Background

There are approximately 9.4 million -- or 12.8% of all children in the United States under the age of 18 – that have special health care needs (HRSA, 2004). Meeting the complex needs of children and youth with special health care needs (CYSHCN) and their families often requires special assistance in the form of care coordination. Children and youth with special health care needs require access to treatment and special services that take into account their overall growth and development. The challenge for families is in accessing these services in an often-fragmented system of care (AMCHP, 2002). Care coordination helps families identify and enroll in programs and services and promotes efficiency by increasing access to care and eliminating duplication of services (AMCHP, 2003).

History of Care Coordination

Public and private agencies involved in human services have historically helped families determine their needs and gain access to services (AAP, 1999). Beginning in the early 20th century, community service coordination began and evolved into the concept of “case management,” which appeared in the early 1970s. In the 1980s, commercial insurers used case managers as a way to coordinate care and manage costs in “catastrophic cases” (AMCHP, 2000). Today comprehensive “care coordination” enables people to navigate through complex systems (Rosenbach and Young, 2000).

Case Management vs. Care Coordination

Historically, case management programs rely on a medical model focused on the patient’s health care needs only, while care coordination programs tend to use a broader social service model that considers the patient within a psychosocial context as well. Case managers tend to coordinate services within a single managed care plan, and focus only on covered services. In contrast, care coordinators may work with a full range of medical and social support services offered within and outside the managed care plan, therefore often arranging both covered and non-covered services (Rosenbach and Young, 2000). Refer to Appendix A for a more detailed comparison of these two distinct services.

Part C Early Childhood Connections Service Coordination

Part C Early Childhood Connections program, provides service coordination for children birth to 3 years of age. This is defined as “those activities carried out to assist and enable a child, eligible under Part C, and the child’s family to receive the rights, procedural safeguards, and services that are authorized to be provided under Colorado’s early intervention program.” Service coordinators are responsible for assuring that individual children and families receive multidisciplinary evaluation and assessment, individualized family service plans, and the provision of services in natural environments (Early Childhood Connections, 2004).

HCP's Definition Of Care Coordination

HCP's definition of care coordination is the facilitation of access *to* and coordination *of* medical and social support services for high-risk populations across different providers and organizations. It includes both public and private, covered and non-covered, services (Rosenbach and Young, 2000) resulting in improved health and quality of life. Care coordination is multifaceted and involves needs identification, assessment, prioritizing, and monitoring. A care coordinator is required to communicate, network, and educate as well as advocate for resources to meet a family's needs for their child (AAP Committee on Children with Disabilities, 2005). (Additional definitions and information used in describing care coordination can be found in Appendix B.)

Purpose of Care Coordination

The Association of Maternal and Child Health Programs (AMCHP 2000; 2002) outlines specific goals of care coordination, recommendations, roles and training of care coordinators, and research and evaluation issues.

Care coordination is considered a standard of care for children and youth with special health care needs due to the following:

- The need to plan beyond the medical needs of the child (social, developmental, educational, vocational, and financial).
- The complexity of the service system with its different entry points and eligibility criteria.
- The importance of the family's role in the center of care coordination; families are the most knowledgeable about their child's condition and they become effective leaders and partners in the care coordination process as their skills and strengths are supported, and their opinions valued and respected (AAP, 1999).
- Children and their families benefit from understanding their options of services and resources that meet their unique needs.
- Partnerships with families among providers, agencies, programs, specialists, and primary care providers are essential to effective care that truly serves families.

Goals for care coordination are described as follows:

- Improving and sustaining the quality of life for the family and the child.
- Assuring access to optimal care.
- Improving systems of care for children with special health care needs.

MODEL OF HCP CARE COORDINATION

HCP Network

The Colorado Department of Public Health and Environment’s Health Care Program for Children with Special Needs (HCP) offers care coordination services through 14 regional and 41 local public health agencies that serve all 64 counties in Colorado. HCP provides a range of care coordination services for individual families. HCP also provides a second vital public health service to all families. Through HCP’s care coordination experience with families, HCP identifies areas of the health system that need to be changed and then advocates and brings together local and state agencies to put these changes in place.

Professionals and paraprofessionals representing nine distinct disciplines implement HCP care coordination services. Team members bring their medical and professional training to address the myriad health needs of children and youth with special health care needs. These multidisciplinary HCP care coordination teams include community health nurses, registered dietitians, speech pathologists, occupational and physical therapists, hearing specialists and audiologists, social workers, visual specialists, and family advocates. The team also focuses on coordination with other systems and organizations.

Training of Care Coordinators

The literature suggests that care coordinators who work with families should have key qualities and skills (CMSA, 2002; Novak, 1998; Wayman, 1999; Gilbert, 1997; Tahan, 1999; Huston, 2002; Nichols, 1997; Peterson, 2004). HCP assures that its care coordinators are provided with training materials and have ongoing training and supervision to assure that they can offer these qualities and skills.

Key Qualities and Skills of HCP Care Coordinators	
<ul style="list-style-type: none"> • Clinical expertise in child and family health assessment 	<ul style="list-style-type: none"> • Skilled in collaborating with community partners and in infrastructure building to address gaps in services
<ul style="list-style-type: none"> • Clinical knowledge and expertise in the health care needs of CYSHCN 	<ul style="list-style-type: none"> • Knowledge of funding sources for CYSHCN
<ul style="list-style-type: none"> • Knowledge and expertise in assisting families in the development of their child’s health care plan. 	<ul style="list-style-type: none"> • Knowledge of community agencies and resources for CYSHCN
<ul style="list-style-type: none"> • Capable of supporting and assisting families in implementing their child’s care plan. 	<ul style="list-style-type: none"> • Organizational skills
<ul style="list-style-type: none"> • Expertise in providing ongoing care plan evaluation and revisions 	<ul style="list-style-type: none"> • Written and verbal communication skills

Essential HCP Care Coordination Activities

- **Relationship Building** – Identify and support family strengths, culture and values.
- **Assessment** –Collect and review medical and educational information, and family input to identify strengths, needs and available resources
- **Planning** – Assist the family to develop a care coordination plan with specific objectives, goals and actions to meet identified needs.
- **Implementation** – Initiate and facilitate specific activities and interventions that lead to accomplishing the goals set forth in the care plan.
- **Monitoring and Evaluation** – Gather information about the care plan’s activities, interventions, and services to determine the plan’s effectiveness in reaching desired goals and outcomes, and modify the plan as needed. Look at the overall effectiveness of the care coordination plan to achieve positive outcomes for families and improve the system of care for CYSHCN.
- **Partnering with Families** – to connect with community resources and parent support.

Levels of HCP Care Coordination Services

HCP provides three levels of care coordination services. The need to identify and define different levels of care coordination services evolved for three reasons. First, there was a desire to provide health information and resource identification to all children and youth birth to 21 years of age who are at risk for or have special health care needs. At the same time, the ability to provide in-depth care coordination is limited by decreasing availability of resources and increasing demand for them. As a result, it was necessary to seek reimbursement for the more in-depth care coordination services and thus define those services for insurers and community agencies. Lastly, it was necessary to differentiate HCP care coordination services from the coordination services provided by other community agencies or providers.

Level 1 services are available to all families. Level 2 and Level 3 services are available to limited numbers of families and clients where there is capacity to provide the services within the local region or when there is a third- party payer.

HCP’s three Levels of Care Coordination services are defined below:

➤ Level I Care Coordination Services

HCP’s Level I care coordination services are available to all families. HCP staff provides information, resources, and referrals as needed to all families living in Colorado who have children with special health care needs from birth to age 21. HCP staff also provides this same service to health care providers, as requested,

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for their clients' medical and health concerns, specific medical information, and community resources. This service usually consists of a brief, short-term, encounter. For more detail about Level I services, refer to the HCP Care Coordination Flow Chart on page 9 and further descriptions in Appendix B.

Examples of Level I services follow:

- A family requesting assistance in obtaining food and clothing was referred by the HCP social worker to local agencies that assist families needing food and clothing. She also referred the family to LEAP (for energy assistance) and low-income housing.
- An audiologist who had recently become a Medicaid provider needed information on correct coding for billing. The HCP staff referred her directly to the appropriate person at the state Medicaid office for further assistance and she was able to have her question answered in a direct and timely manner.
- A family contacted HCP with questions concerning cleft lip and palate. They were considering adopting a child with this condition and needed more information before making this decision. The HCP nurse was able to provide them with contact information for the Cleft Palate Foundation as well as inform them about local resources.

➤ **Level 2 Care Coordination Service**

Level 2 care coordination services also include all Level I services. At this level, HCP staff are available to discuss health concerns with families and to review medical records and/or consult with primary care providers and/or specialists as needed. HCP staff also consult or collaborate with other agencies to help meet and focus on health and/or educational goals. Individual HCP team members are available to provide more in-depth consultation than for Level 1 service. Level 2 services generally are completed within a short, distinct, time period and the family is not expected to require on-going care coordination. This service is available on a first-come, first-served basis depending on the resources available at the local HCP office. Third-party payers such as managed care plans or public agencies may also contract for this service through our HCP office(s). For more detail about Level 2 services, refer to the HCP Care Coordination Flow Chart on page 9 and further descriptions in Appendix B.

Those interested in exploring contracts with HCP for Level 2 services should contact their local HCP Regional Office and review Appendix C: Package Pricing for One Year of Care Coordination. You can find the closest HCP Regional Office by going to the HCP Web site at <http://www.hcpcolorado.org>.

Examples of Level 2 services follow:

- A teenager with questionable seizure activity and an immediate need for oral surgery contacted an HCP office. This individual did not have insurance and was not living at home. The HCP team provided consultation with the teenager and his parent which resulted in referrals to the Medicaid program for children (EPSDT), the Colorado Indigent Care Program (CICP), a primary care physician, and a local public health nurse.

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- A family with a child with a speech delay due to a medical condition requested assistance because their request for speech therapy was denied by a public insurance plan. The word “delay” was included in the medical diagnosis and this had automatically caused a denial for authorization in the insurance system. The mother contacted the HCP staff requesting information about other possible resources to help continue the therapy while she proceeded through the appeal system. The HCP nurse encouraged the mother to continue with the appeal and to talk with the school speech therapist to see what could be done at school. The mother stated that the school speech therapist told her she does not know how to deal with the child’s specific problem. The HCP Speech/Language team member contacted the school therapist and offered the guidance and technical assistance she needed to provide supportive services to the child until private therapy sessions could resume.

➤ **Level 3 Care Coordination Service**

Level 3 care coordination services also include all Level 1 and Level 2 services.

Level 3 is the most intensive level of HCP care coordination services. An HCP Primary Care Coordinator is assigned to the child and family and has regular, direct contact with family and child. HCP Care Coordinators are available to consult with the child or youth’s primary care provider (PCP) and specialty care providers. The HCP multidisciplinary team assesses the child’s health and medical needs with the family and together they develop a care coordination plan that is monitored and evaluated regularly. For more detail about Level 3 services, refer to the HCP Care Coordination Flow Chart on page 9 and further descriptions in Appendix B. HCP Level 3 care coordination is available on a first-come, first-served basis depending on the capacity and resources available through the individual HCP offices. Priority consideration for Level 3 care coordination is given to families with no other source of care coordination or for families that qualify for specific programs that reimburse HCP directly for their care coordination services. Third-party payers such as managed care plans or public agencies can contract for this service through our HCP offices. Those interested in exploring contracts with HCP for Level 3 services should contact their local HCP Regional Office and refer to Appendix C: Package Pricing for One Year of Care Coordination. You can find the closest HCP Regional Office by going to the HCP Web site at www.hcpcolorado.org.

Examples of Level 3 services follow:

- A family had a son diagnosed with Duchenne’s muscular dystrophy. Over the winter, his muscle strength began to deteriorate rapidly. In November he had been able to manage his own self-care; however, by May, he was completely dependent on his mother for assistance with all activities of daily living. The HCP care coordinator helped the family obtain an appointment with a pediatric orthopedic specialist. A referral was made to obtain a power wheelchair and an evaluation of the family’s home was completed for possible renovation to allow for the installation of a lift system. The child developed cardiac problems, requiring numerous visits to the PCP and several hospitalizations. The HCP care coordinator helped arrange for homebound education when the youth became too weak to attend school. The family became socially isolated because they only had a car for transportation, which was not capable of transporting the child’s power wheelchair. Discussions with the Muscular Dystrophy Association resulted in the donation of a van from another family. The HCP care coordinator and the

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HCP social worker accompanied the family when they received the van, providing interpretation services and emotional support to both families. As the young man's health status continued to deteriorate, hospice services were set up with the help of the HCP Care Coordinator. The HCP Social Worker contacted the family's church and arranged for additional support services. The HCP social worker provided support to the entire family in numerous ways – food bank referrals, transportation arrangements, and emotional support in dealing with the situation. The HCP nurse and social worker worked with the older brother who was missing school and at risk for associating with gangs. The younger sister received emotional support as well as she experienced her brother's deteriorating condition.

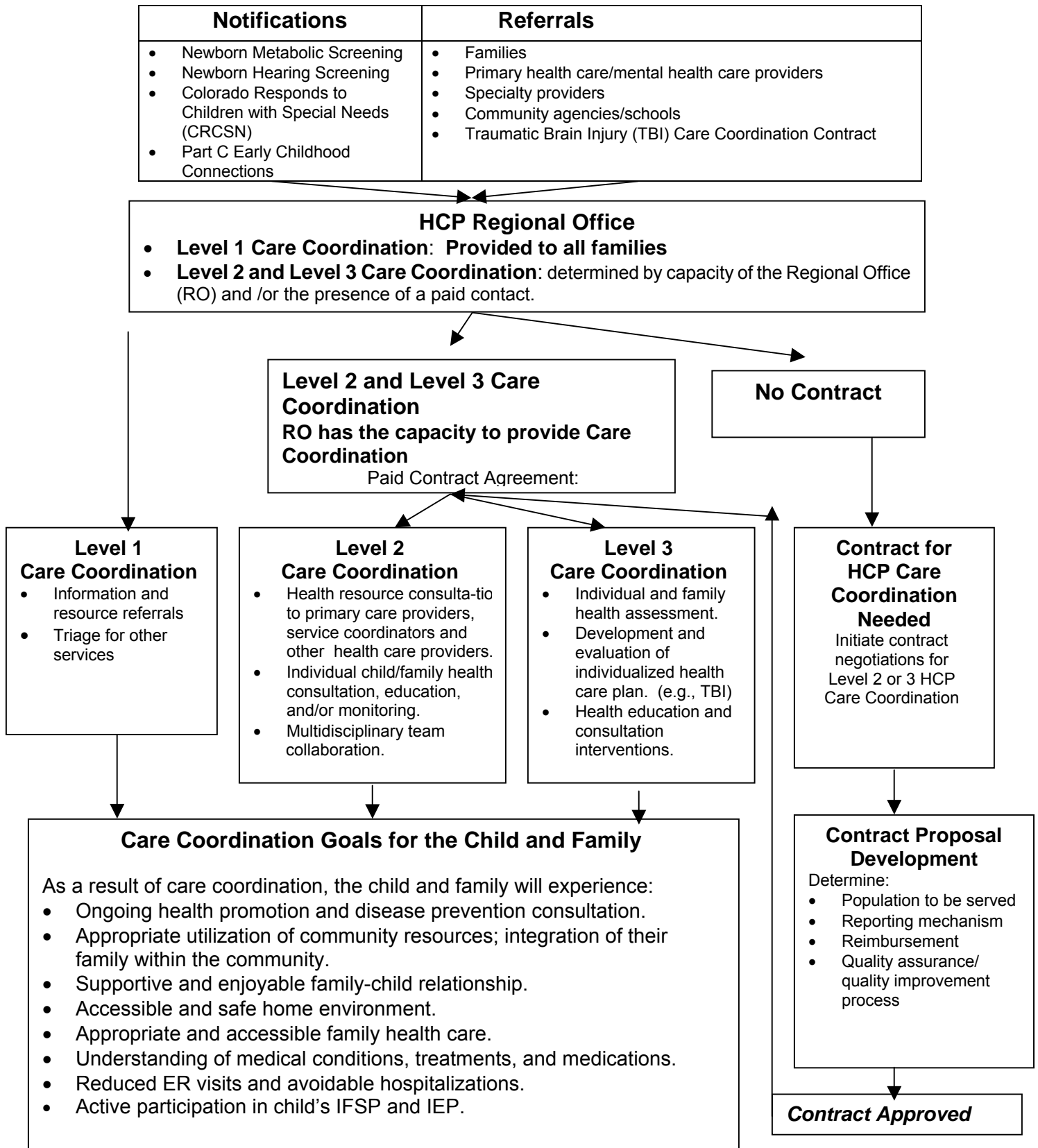
- A family contacted the HCP office because their 18-month-old child had multiple medical problems and they didn't know what services were available to help their child. HCP provided consultation to the family and linked them with their local Early Childhood Connections Program through Part C (a program serving children from birth to age three who are at risk for developmental delay), a Public Health nurse, the Medicaid program for children (EPSDT), and a nutritionist. HCP staff also assisted the family in working with their primary care physician and obtaining referrals for the child to be seen in HCP Cardiac and Neurology clinics for diagnostic and treatment assessments.

REFERRALS FOR HCP CARE COORDINATION

Referrals for care coordination services are made to the HCP Regional Office or the local Public Health Office. Sources of referrals include national, regional, and local public health agencies, HMOs, primary care and specialty health care providers, Child Health Plan +, Medicaid, Early Childhood Connections Part C, Child Find, families, and other community partners. Families, agencies, and providers can find and contact their local HCP Regional Office by going to the HCP Web site at www.hcpcolorado.org.

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HCP CARE COORDINATION FLOW CHART



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Evidence regarding specific outcomes of care coordination and direct benefits to the lives of individuals and children with special needs and their families is beginning to appear in the literature, but is inconclusive due to the variability in sample sizes, study designs, and study outcome evaluations. However, it is clear that professionals in the health care field and those that work closely with children and youth with special health care needs feel strongly about the impact that care coordination has on improving the child's well being and making the lives of family members easier as well (Barrett, 2000; Grupta, 2004; Jablonski, 2003).

These benefits include:

- Ongoing health promotion and disease prevention consultation.
- Appropriate utilization of community resources; integration of their family within the community.
- Supportive and enjoyable family-child relationship.
- Accessible and safe home environment.
- Appropriate and accessible family health care.
- Understanding of medical conditions, treatments, and medications.
- Reduced ER visits and avoidable hospitalizations.
- Active participation in child's Individual Family Service Plan (IFSP) and Individual Education Plan (IEP).

Quality Assurance

Quality-based outcomes of care coordination include indicators such as: improved clinical status, improved functional status, enhanced quality of life, client satisfaction, adherence to the treatment plan, improved client safety, cost savings, and client autonomy (CMSA, 2002). In addition, care coordination programs must have mechanisms to include sustained family involvement in systems improvement – through surveys, advisory committees, family consultants, and regular forums. Care coordination programs must be involved in system

improvement efforts with the participation of coordinators in other systems and organizations, particularly within the child's medical home (AMCHP, 2002).

HCP monitors its care coordination program services through various systems that include, but are not limited to:

- Written policies, procedures, and standards
- Family satisfaction surveys
- Systematic family participation in policy and program decisions at both the regional and state levels
- Ongoing training of HCP staff including topics such as resources development, system and organizational coordination and collaboration, medical home initiatives, and care coordination and planning
- Reporting requirements to contracted third parties utilizing data from our electronic client database

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HCP Care Coordination Pilot Study

HCP conducted a care coordination pilot study between May 1, 2001 and April 30, 2002 to research the outcomes of HCP care coordination services. A total of 77 children were enrolled into the pilot project. Overall, the care coordination pilot study results showed:

- *Lower acuity scores for a significant proportion of participants.* Of the families categorized as high acuity at the beginning of the pilot project, 47.6% reduced their acuity category to moderate or less. Of the families categorized as moderate acuity at the beginning of the project, 36.6% were categorized as having low acuity by the end of the project. Only 15.4% demonstrated increasing need to the high acuity category. Of the families categorized as low acuity at the beginning of the pilot project, only 9% demonstrated any increase to the moderate acuity range by the end of the project.
- *High rates of resolution for specific and frequent family concerns.* There were 10 frequently occurring concerns identified by families. The percentage of resolved concerns varied with the type of concern, but 13% to 60% were resolved.
- *High proportion of families with completed health referrals.* Almost half of the participants completed 75% of the health referrals. That rate was higher than referrals completion rates in the community generally.
- *Community referral rates.* Almost a quarter of the participants completed 100 % of their referrals.

Lower acuity scores, resolution of specific concerns, and completion of referrals may decrease overall health care costs and improve health outcomes for children and their families. Overall, the data indicate that HCP care coordination may be a cost-efficient method to provide effective services to children and youth with special needs and their families.

Families were asked to indicate their satisfaction with the following health care components of HCP and other health care services:

Outcome Criteria	Percentage indicating “very satisfied”
Friendliness of the staff	100%
Timeliness of services	100%
Availability of translation services if needed	100% of those for whom the question was applicable
Sensitivity of the staff toward the needs of your child and family	95.7%
Overall services received through HCP and other HCP team members	95.7%
Overall health care services your child is receiving?	91.3%

In addition to these questions, families were asked to rate the helpfulness of HCP services. Over ninety-five percent (95.7%) indicated HCP services were “very helpful.” Families also indicated that their children are participating in their communities and that for some children HCP services not only improved the health of the children, but also their self-

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esteem. Comments indicated that families are grateful for the coordination of services.

CONTRACTING FOR HCP LEVEL 2 AND LEVEL 3 CARE COORDINATION SERVICES

As mentioned in previous sections, HCP can be contracted to provide Level 2 and Level 3 care coordination services. Currently, HCP has care coordination contracts with one major Colorado managed care organization (MCO) and with the Colorado Department of Human Services (see Appendix C). For more details contact your local HCP Regional Office. You can find your local HCP Regional Office by going to the HCP Web site at www.hcpcolorado.org.

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APPENDIX A

**HCP CARE COORDINATION
COMPARED WITH CASE MANAGEMENT**

Features	Case Management	vs.	Care Coordination
Objective	Contain Cost		Facilitate Access
Target Population	High cost/High use patients		High-risk populations
Functional Orientation	Prior authorization		Problem solving
Context	Health care context		Psychosocial context
Nature of Coordination	Promote coordination and communication across disciplines within the organization providing medical care		Promote coordination of social support and medical services across different organizations and providers

Table taken and adapted from “The Faces of Medicaid”, 2000, (p. 46).

APPENDIX B

HCP CARE COORDINATION DEFINITIONS

Care coordination is a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of the children and provide them with optimal health care. (AAP, 1999).

A process designed to facilitate timely access to services and resources; promote continuity of care; provide family support and enhance family well being; improve health, developmental, educational, vocational, psychosocial, and functional outcomes; and maximize efficient and effective use of resources (Presler, 1998).

Types of Care Coordination Services

Level 1 Information and Referral

(Available to all families, providers, and community agencies)

- Provide information about health and social services available in the community
- Consultation is available with the HCP multidisciplinary team for health information and resources (nursing, social services, nutrition, family advocacy, speech, OT/PT, and audiology)
- Connecting families to community agencies depending upon their needs

Level 2 Care Coordination Consultation (Includes Level 1 Services)

(Available depending upon Regional Offices capacity and/or contract status)

- Consultation, collaboration, and monitoring of health needs with the family.
- Consultation and education with families and providers for health concerns.
- Training, consultation, and education for health for providers and community agencies. (For example: consultation with Part C Service Coordinators.)

Level 3 Intensive Care Coordination (Includes Level 1 and Level 2 Services)

(Available depending upon Regional Offices capacity and/or contract status)

- Provide assessment of the child's health, education, and social needs with the family to assist family in setting health care goals.
- Consult with HCP multidisciplinary team to identify appropriate strategies to meet the child/youth's needs. (For example: transition needs for youth)
- Consult with the PCP regarding the child/youth's plan for health care.
- Develop an individualized health care plan for the child/youth.
- Monitor the child/youth's health care plan for changes or need for further assessment and evaluation.
- Provide anticipatory guidance related to health, safety, injury and illness prevention, and management of minor acute illnesses.
- Support advocacy efforts related to health care needs.

APPENDIX C

HCP CARE COORDINATION PACKAGE PRICING FOR ONE YEAR

For more information about package pricing contact the nearest Regional HCP Office, contact the State HCP Offices at 303-692-2370 or refer to the CDPHE web site at <http://www.cdphe.state.co.us/ps/hcp/regoff.html>.

As a Public Health service, resource and referral information regarding children with special health care needs and care coordination is available on request to all families and/or community partners.

- Families with needs of low acuity
Resource and Referral Information
1 moderate consultation
4 limited consultations
\$155.00 *

- Families with needs of moderate acuity
Resource and Referral Information
1 extensive consultation
2 - 3 moderate consultations
1 moderate home visit
1 moderate team conference
2 - 3 limited consultations
\$359.00 **

- Families with needs of high acuity
Resource and Referral Information
1 extensive consultation
1 extensive home visit
2 moderate home visits
1 extensive or 2 moderate team conferences
4-5 moderate consultations
6 limited consultations
\$850.00 **

* Includes completion of Care Coordination Acuity Level

** Includes completion of Care Coordination Acuity Tool, and Child and Family Care Plan

APPENDIX C (continued)

Package Pricing for One Year of Care Coordination

Services:

Consultations limited (30 minutes or less)
 moderate (31 to 60 minutes)
 extensive (61+ minutes)

Home Visits limited (60 to 90 minutes or less)
 moderate (91 to 120 minutes)
 extensive (121+ minutes)

Multidisciplinary Team Conferences and/or Staffings
 professional/hour (121+ minutes)
 limited (90 minutes or less)
 moderate (91 to 120 minutes)
 extensive (121+ minutes)

* Includes all contacts, correspondence, phone calls related to care coordination, as well as including all preparatory/support & documentation time.

APPENDIX D

HCP CARE COORDINATION ACUITY TOOL

GENERAL INSTRUCTIONS FOR ACUITY DETERMINATION

1. On the Concern List mark "**Assessed**" column if there are questions asked and/or discussion about the issue.
2. Mark the "**Referred**" column if a referral will be made.
3. Mark "**Counseled**" if the parent and/or child is informed or taught information about the issue.
4. On the Acuity Tool add up the total number of factors checked for care coordination and mark the acuity level as indicated.
5. On the Acuity Tool "Summary of Need Identified", "Health Referrals", and "Community Referrals" sections will help to develop a structure for developing a Child and Family Care Plan.

**CARE COORDINATION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS
A Public Health Model**

APPENDIX D (continued)

**HCP ACUITY TOOL FOR LEVEL 3 CARE COORDINATION
HEALTH CARE PROGRAM FOR CHILDREN WITH SPECIAL NEEDS (HCP)**

Date _____ Assessment completed by _____

Client Name _____ B.D. _____

Primary caregiver (parent/guardian/foster parent) _____

Diagnosis _____ SSI _____ Model Waiver _____

Insurance _____ HMO _____

PCP _____

Specialty _____

Provider(s) _____

Referral date _____ Source _____ Reason _____

ACUITY SCORES:

Health

Development

Family

Community

ACUITY

Acuity Level: Low (1-5 CC Indicators) Moderate (6-10 CC Indicators) High (Over 10 CC Indicators)

SUMMARY OF NEEDS IDENTIFIED

HEALTH REFERRALS NEEDED (If child is enrolled in an HMO, referral must be obtained from The Primary Care Provider)

Therapy (type) _____ Prenatal Care _____

EPSDT Screen _____ Mental Health _____

Primary Care _____ HCP Clinic _____

Specialty Care (type) _____ CO-Hear _____

Nutrition _____ Other _____

COMMUNITY REFERRALS

- | | | |
|---|--|--|
| <input type="radio"/> Medicaid | <input type="radio"/> Employment | <input type="radio"/> Child Care |
| <input type="radio"/> Medicaid Waivers | <input type="radio"/> Vocational Rehab | <input type="radio"/> Parent Support Network |
| <input type="radio"/> EPSDT Case Management | <input type="radio"/> CCB | <input type="radio"/> Advocacy |
| <input type="radio"/> CHP+ | <input type="radio"/> BOCES | <input type="radio"/> Respite |
| <input type="radio"/> SSI | <input type="radio"/> Child Find | <input type="radio"/> WIC |
| <input type="radio"/> Human Services | <input type="radio"/> School-Part B | <input type="radio"/> Family Planning |
| <input type="radio"/> Housing | <input type="radio"/> Part C | <input type="radio"/> Legal |
| <input type="radio"/> Food Resources | <input type="radio"/> Head Start | <input type="radio"/> Other _____ |
| <input type="radio"/> Transportation | | <input type="radio"/> Other _____ |

Notes/Preliminary Plan

Parent/Guardian consent to send the above information to: PCP HMOs Other
Parent Signature _____

Verbal Consent Given: Initials: _____ Date: _____ Revocation Date: _____

APPENDIX E

HCP CARE COORDINATION CONCERN LIST (DRAFT)

HEALTH CARE PROGRAM FOR CHILDREN WITH SPECIAL NEEDS (HCP)

Client _____

Date Completed _____

CHILD/YOUTH	Assessed	Referred	Counseled	DEVELOPMENT	Assessed	Referred	Counseled
Current Health: <input type="checkbox"/> Medical condition/s & knowledge <input type="checkbox"/> Mental/emotional health <input type="checkbox"/> Behavioral status/temperament <input type="checkbox"/> Environment/Safety <input type="checkbox"/> Immunizations Treatments <input type="checkbox"/> Medications <input type="checkbox"/> Equipment/DME <input type="checkbox"/> Therapies <input type="checkbox"/> Home Accessibility Past Med History <input type="checkbox"/> Birth history <input type="checkbox"/> ER/Hospitalizations <input type="checkbox"/> Accidents/injuries <input type="checkbox"/> Procedures/test <input type="checkbox"/> Allergies <input type="checkbox"/> Other: Rev. of Systems <input type="checkbox"/> Growth <input type="checkbox"/> Nutrition <input type="checkbox"/> Hearing <input type="checkbox"/> Dental care/orthodontia <input type="checkbox"/> Vision <input type="checkbox"/> Other				Educ. Services <input type="checkbox"/> Part C/ECC (IFSP) <input type="checkbox"/> Part B (IEP) <input type="checkbox"/> Child Find <input type="checkbox"/> Community Center Board Development <input type="checkbox"/> Mobility/gross motor skills <input type="checkbox"/> Fine motor <input type="checkbox"/> Communication skills <input type="checkbox"/> Cognitive skills/status <input type="checkbox"/> Personal-social emotional skills Self care: <input type="checkbox"/> Feeding <input type="checkbox"/> Sleep/Regulation <input type="checkbox"/> Dressing <input type="checkbox"/> Bathing <input type="checkbox"/> Dental hygiene School Progress <input type="checkbox"/> Peer Activities <input type="checkbox"/> Handling transitions Employment <input type="checkbox"/> Other:			
FAMILY STATUS	Assessed	Referred	Counseled	COMMUNITY	Assessed	Referred	Counseled
Family Well-Being: <input type="checkbox"/> Physical health status <input type="checkbox"/> Emotional/mental health status <input type="checkbox"/> Caregiving concerns Financial: <input type="checkbox"/> Employment concerns Health Insurance <input type="checkbox"/> Medicaid/ Medicaid Waiver <input type="checkbox"/> CHP + <input type="checkbox"/> SSI <input type="checkbox"/> Private <input type="checkbox"/> Self Pay Family Relationships <input type="checkbox"/> Health beliefs/values/ practices <input type="checkbox"/> Family learning style <input type="checkbox"/> Parent child relationship <input type="checkbox"/> Parenting skills <input type="checkbox"/> Other:				Health Care <input type="checkbox"/> Primary care providers <input type="checkbox"/> Specialty Providers <input type="checkbox"/> Therapies/therapists Community services <input type="checkbox"/> Family support systems <input type="checkbox"/> Child care <input type="checkbox"/> Respite <input type="checkbox"/> Faith based resources <input type="checkbox"/> Emergency plans Basic Needs: <input type="checkbox"/> Housing <input type="checkbox"/> Clothing <input type="checkbox"/> Food <input type="checkbox"/> Electricity <input type="checkbox"/> Phone Transportation Legal issues Other			

APPENDIX F (underdevelopment)

HCP CARE COORDINATION CONCERN LIST HEALTH CARE PROGRAM FOR CHILDREN WITH SPECIAL NEEDS (HCP) CONCERN LIST DEFINITIONS

ITEM	DEFINITION
Child Health	
Current Health	Medical condition/s & knowledge; Mental/emotional health; Behavioral status/temperament; Environment/Safety; Immunizations
Treatments	Medications (dose, effectiveness, side effects); Equipment/DME (gastrostomy tube, feeding pumps, walkers, kid cart, hearing aides, glasses); Therapies (OT, Speech, PT, etc); Home Accessibility and Safety
Past Medical History	Birth history; ER/Hospitalizations; Accidents/injuries; Procedures/test; Allergies
Review of systems	Growth; Nutrition; Hearing and hearing tests; Dental care/orthodontia; Vision and vision evaluations
Development	
Educational Services	Part C/ECC; (IFSP); Part B (IEP); Child Find; Community Center Board
Development	Mobility/gross motor skills; Fine motor; Communication skills ((expressive and receptive); Cognitive skills/status; Personal-social emotional skills; psychological and behavioral status
Self Care	Adaptive Skills: Self Feeding; Sleep; Physical and Emotional Regulation; Dressing; Bathing; Elimination/toilet training; Dental hygiene; Handling transitions through out day and from one environment to another; Active and quiet play.
School Progress	Peer Activities; School transitions
Employment	Vocational Planning; Work experience
Family	
Family Health	Physical health status; Emotional/mental Health status: Caregiving concerns;
Financial	Employment; Financial concerns
Health Insurance	Medicaid/ Medicaid Waiver; CHP +; SSI; Private insurance; Self Pay
Family Relationships	Health beliefs/values/ practices; Family learning style; Parent child relationship; Parenting skills
Community	
Health Care Providers	Primary care providers; Specialty Providers; Therapies/therapists
Community Services	Family support systems; Child care; Respite care; Faith based resources; Emergency plans
Basic Needs	Housing; Clothing; Food; Electricity; Phone
Transportation	Reliable transportation; child care seat; knowledge of public transportation
Legal Issues	Ongoing legal concerns; previous legal problems.

APPENDIX G

ESSENTIAL HCP CARE COORDINATION ACTIVITIES

Care Coordination includes:

- **Relationship Building** – Identify and support family strengths, culture and values
 - Family Health: family member health status, health beliefs and values, primary care access, pregnancy/birth control, health risk behaviors (tobacco, alcohol, drugs).
 - Family Resources: educational level, employment, primary language, developmental and parenting knowledge, expectations, and perceptions, community life skills.
 - Family Support: safety (car/bus: seat belt use; environmental: fire & home safety plan and emergency planning; mobility), housing, food, transportation, insurance, family and friend support system, legal consultation.
 - Family Psycho-social: emotional/behavioral status, family relations, cultural and spiritual beliefs, family stress: family communication, domestic violence, finances, extended family.
- **Assessment** –Collect and review medical and educational information, and family input to identify strengths, needs and available resources (Assessment and evaluation of family and individual child's needs that support the child's transition from infancy, early childhood, middle childhood, adolescence and into adult life through the child's health care plan.)
 - Child/Youth's Health:
 - Child/Youth's Development:
 - Family Status
 - Community Connections and Resources

ESSENTIAL HCP CARE COORDINATION ACTIVITIES (continued)

Care Coordination includes:

- **Planning** – Assist the family to develop a care coordination plan with specific objectives, goals and actions to meet identified needs
 - Appropriate identification and referral to community resources and services for needs related to:
 - Health care providers: specialists, therapists, testing, procedures, durable medical equipment, dental services.
 - Nutrition services: WIC, nutrition counseling
 - Health Care Payment: Private insurance; public insurance (SSI, Medicaid, CHP+, Medicaid waivers, EPSDT services)
 - Transportation: van services, cab services
 - Social services: housing, food, and clothing
 - Mental health services: evaluations, consultations, counseling.
 - Education/Child care: early intervention services (Part B and Part B), respite care, child care, medically fragile resource care, family based child care.
 - Health education and health education materials provided:
 - Family centered
 - culturally sensitive
 - appropriate to learning style and reading level
 - supportive of increasing family problem solving and decision making skills
 - Assistance in reviewing, accessing, and appealing public and private insurance for needed services.
- **Implementation** – Initiate and facilitate specific activities and interventions that lead to accomplishing the goals set forth in the care plan. Facilitation of:
 - Collaborative partnerships between the health care provider and the family, and when

appropriate the youth, in the development and implementation of the health care plan, both short term and long term transition planning.

- Consistent communication between the pediatric specialists and the primary care providers on behalf of the child and family.
- Predictable and consistent communication from the hospital or ER and the primary care provider in order to provide appropriate follow up care.
- Communication and coordination of care and developmental needs in the child care and educational settings.

➤ **Monitoring and Evaluation** – Gather information about the care plan's activities, interventions, and services

- Determination of the plan's effectiveness in reaching desired goals and outcomes, and modify the plan as needed.
- Overall effectiveness of the care coordination plan to achieve positive outcomes for families and improve the system of care for CYSHCN.

➤ **Partnering with Families** – Connecting families to community resources, parent support systems.

- Determining parent/family needs and interests.
- Assisting families according to their unique needs and abilities to access services.
- Working with families to anticipate future needs and prioritize current activities.