LINKING AND ALIGNING CARE COORDINATION TOOLKIT

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JFK Partners Linking and Aligning Toolkit Development Committee

For JFK Partners’ Linking and Aligning Project

March 16, 2009
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Upon completion of the 2007-2008 supplemental funding for the Linking and Aligning project from the Substance Abuse and Mental Health Services Administration (SAMHSA) to, in part, develop a behavioral and physical health integration care coordination plan for Colorado stakeholders, additional funding from JFK Partners was secured to create an accompanying comprehensive toolkit. The following toolkit was developed based on the same foundation of principles of the Linking and Aligning Care Coordination Plan: integrating the Medical Home and System of Care approach.

**JFK Partners** is a multifaceted Interdepartmental Program of the Departments of Pediatrics and Psychiatry of the University of Colorado Health Sciences Center. Designated as Colorado's University Affiliated Program by the Administration on Developmental Disabilities and as Colorado's LEND Program (Leadership Education in Neurodevelopmental Disabilities) by the Maternal Child Health Bureau, JFK Partners has strong collaborative relationships with numerous organizations that are a part of Colorado's developmental disability and special health care needs communities.

**The mission of JFK Partners** is to promote the independence, inclusion, contribution, health, and well-being of people with developmental disabilities and special health care needs and their families through consumer, community, and university partnerships. At the core of our mission is a commitment to family and person-centered, community-based, culturally competent programs and services. This mission is accomplished through the pursuit of excellence in education and training, consultation, technical assistance, direct service, research, program development, policy analysis, and advocacy.

The development of this toolkit was supported by the following federal grants:

1. University Center on Developmental Disabilities Research, Education, and Service (UCEDD), PI: Cordelia Robinson, PhD, RN, US Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities, Award #: 90DD0632/02, 7/1/07-6/30/11.

2. Leadership Education in Neurodevelopmental and Related Disorders Training (LEND), PI: Cordelia Robinson, PhD, RN, Health Resources and Service Administration (HRSA), Maternal Child Health Bureau (MCHB), Award #:T73 MC11044, 9/1/08-8/31/11.

[YOUR AGENCY’S NAME]’S MISSION, VALUES, AND PRINCIPLES

Please use this space to include your agency’s mission, values, principles, etc.

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INTRODUCTION

On behalf of the Colorado Family Leadership Task Force, I am delighted to endorse the Linking and Aligning Care Coordination Toolkit. Developed through a collaborative partnership with various stakeholders in Colorado, including family leaders, this toolkit serves as a resource to guide and connect providers with valuable information.

Promoting authentic partnerships between families and providers is a core value of the Colorado Medical Home/Systems of Care Initiatives. Families throughout Colorado have consistently expressed their desire and readiness to be active partners in their child’s health care. Coordinating care between many providers and disciplines has proven to be challenging for families, and yet, families understand how important it is! As you utilize the resources found in this toolkit we encourage you to continue to engage the individual and their family in all levels of care planning. It is the shared vision of many families and agencies across Colorado that services will be coordinated, comprehensive and culturally respectful and this toolkit is a resource to support this vision.

Thank you for your ongoing commitment to partner with individuals with special health care needs and their families to deliver quality, family-centered health services.

Eileen Forlenza
Colorado Family Leadership Task Force

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BACKGROUND

For families of children with special health care needs, the current health care system offers fragmented care, with limited access to a single provider who can coordinate the necessary multiple sources of care.¹ This often results in an inefficient use of resources, as well as the loss of quality services and spiraling health care costs for both families and providers.² Because compromised social, emotional or behavioral health places children at high risk for short- and long-term problems, families of children with special health needs can benefit from the coordination of physical and behavioral health care. Care coordination has been identified by the Institute of Medicine as one of the key strategies for potentially addressing the aforementioned challenges.³ Similarly, according to the Colorado Health Care Foundation, one of the four components of integrated care is care coordination, which should occur “across all elements of the health care system and the patient’s community including family, public and community-based services”.⁴ Figure 1 below, from the Substance Abuse and Mental Health Services Administration’s (SAMHSA) System of Care, illustrates this concept.

The Linking and Aligning project identifies care coordination as “a dynamic process that is value-driven and crosses systems.” To that end, the five essential qualities of care coordination involve relationship-building; the provision of culturally competent, family-focused and strengths-based care; active interagency collaboration that includes information and referral processes; and process and outcomes evaluation.

While there are little data available regarding the benefits of care coordination, available research suggests that it does have a positive impact on the well-being of both the child and family. Specific benefits include:

- Ongoing health promotion and disease prevention consultation;
- Appropriate use 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; and
- Active participation in child’s Individual Family Service Plan (IFSP) and Individual Education Plan (IEP).⁵

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For a list of Community-Based Resources organized by these categories, click here.
TOOLKIT PURPOSE

This toolkit, developed as an accompanying document to the Linking and Aligning Care Coordination Plan, is primarily intended for care coordinators and providers of services1 (hereafter referred to as providers) who are beginning to build, or want to evaluate their capacity to provide care coordination. Thus, the toolkit is designed to be used as a comprehensive resource guide when working directly with families in a variety of settings across Colorado. However, families/consumers can use this toolkit as a guide for developing expectations about their care and as an advocacy tool when interacting with their care coordinators or health care providers. Systems-level agencies can also use this toolkit as a document to make policy and programmatic decisions based on the included recommendations.

NOTE: This toolkit includes examples of tools that providers may find useful in their work with families. In using this toolkit, it is not a requirement to use any particular tool. It is the expectation that providers may use any of the tools as a new implementation to the care they provide and/or that some tools may provide a useful question(s) that could be added to the tools currently being used. Please keep in mind that the reliability and validity of a tool is compromised if it is not used with fidelity.

How is the toolkit organized?

The Toolkit is divided into five main sections:
(1) Assessment;
(2) Quality Assurance;
(3) Permission for Information Sharing;
(4) The Care Plan; and
(5) Community-Based Resources & Referrals.

Included resources have no hierarchy within the toolkit, but are listed in alphabetical order.2 Following this collection of resources are recommendations for system-level agencies and recommended next steps, by the Toolkit Development Committee, for the progression of this work.

1 Examples of the types of providers for whom this toolkit would be useful include: mental health specialists, physical therapists, occupational therapists, substance abuse specialists, family physicians, pediatricians, nurses, licensed social workers, as well as care coordinators, service coordinators, navigators, and family advocates.
2 The Linking and Aligning Project recognizes that there are a variety of available resources related to the components of this toolkit, yet 3-5 resources per section were chosen at this stage of toolkit development so as not to overwhelm the user.
How was the toolkit developed?

In October 2008, a 13-person committee, including four staff, was convened to assist in the development of this toolkit. Committee members were invited to attend based on their experience and role within care coordination initiatives across Colorado. It was the intention of the staff to have the voices of families, service providers, and administrative agencies represented on the committee.

Two in-person meetings were held to discuss the focus and format of the toolkit, as well as to identify resources to be included in the toolkit. The committee, joined by additional colleagues, participated in a review of the toolkit. During this process, the toolkit was reviewed for content, organization and grammar.

JFK Partners acknowledges and appreciates the time and effort that the Toolkit Development Committee members and external reviewers spent on developing this document. These individuals are:

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The developers of this toolkit recognize that the term care coordination and care coordinator, while referring to a similar concept and role, respectively, differ across disciplines and systems, examples of which are noted below. This toolkit is meant to be all-inclusive to those providers working with families who have children with special health care needs who are in need of a variety of services, regardless of the level of intensity of need. This wide variety of terms illustrates the need for collaboration among existing and future care coordination-related initiatives. Thus, one intention of this toolkit is to foster communication and partnerships between service providers working with the same families.

- 360°
- Care guides
- Case management/case managers
- Coaches
- Continuum of care
- Early Periodic Screening, Diagnosis, and Testing (EPSDT)
- Family Service Plan (Child Welfare)
- Holistic care
- Individual Education Plan (IEP) – Individual Family Service Plan (IFSP/IEP) - 504 (Education system
- Individual treatment plan
- Integrated care
- Medical Home
- Navigation/Navigators
- Service coordination
- System of Care
- The nursing process
- Wraparound/Facilitators

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A. ASSESSMENT

Assessment, identified by Colorado’s Health Care Program for Children with Special Needs (HCP) as an essential care coordination activity, is to “collect and review medical and educational information, and family input to identify strengths, needs and available resources.”vi Conducting an assessment is not exclusive to other care coordination activities, yet is part of a process that leads the way to the development of an appropriate care plan.vii Assessments are most effective when conducted by skilled professionals.

This section includes five suggested resources for conducting an assessment.

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1. **Colorado Family Support Assessment**

   Used by the Colorado Family Resource Centers, the purpose of the *Colorado Family Support Assessment* is to learn about the level of support needed by families across various areas of life through discussion and dialogue initiated by a family advocate. Both the family and the family advocate provide input into the assessment. This assessment is intended for families who are receiving more intensive and long-term family support services, and includes 16 domains, some of which are *Health Care Access, Housing, Food, and Mental Health*.

   The complete assessment, as well as the Colorado Family Support Example Interview Guide, can be found as Appendix A below. The assessment is available in both English and Spanish.

2. **Cultural Competence Health Practitioner Assessment**

   The *Cultural Competence Health Practitioner Assessment* (CCHPA) was developed by the National Center for Cultural Competence (NCCC) at the request of the Bureau of Primary Health Care, Health Resources and Services Administration, U.S. Department of Health and Human Services. The CCHPA is intended to enhance the delivery of high quality services to culturally and linguistically diverse individuals and underserved communities. It is also intended to promote cultural and linguistic competence as an essential approach for practitioners in the elimination of health disparities among racial and ethnic groups.

   The CCHPA can be completed online at: https://www4.georgetown.edu/uis/keybridge/keyform/form.cfm?formID=277

3. **Health Care Program for Children with Special Needs (HCP) Care Coordination Acuity Tool**

   The *HCP Care Coordination Acuity Tool* offers the provider an opportunity to discuss a variety of issues to determine the level of care coordination a family needs. Sections are provided to track when referrals are made, when a parent and/or child are informed or taught information about a specific issue, and space is provided to develop a summary for developing a care plan.

   The complete assessment can be found as Appendix B below.

4. **Phases, Activities, and Skill Sets of the Wraparound Process: Strengths, Needs, Culture, and Vision Discovery (section 1.3a)**

   The *Phases and Activities of the Wraparound Process* represents the results of a research project intended to clarify the types of activities that must be included in a full wraparound process. It is one component among a set of materials produced by the *National Wraparound Initiative*, a project with a goal to clearly operationalize and define this important and innovative model for working with families. This document focuses on what needs to happen in wraparound and how the work is accomplished. Merely accomplishing the tasks is insufficient unless this work is done in a manner consistent with the 10 principles of wraparound WHAT ARE THE 10 PRINCIPLES? The Strengths, Needs, Culture, and Vision section in this process is an example of a comprehensive assessment. Following this model would allow the care coordinator or provider of services to engage in a dialogue with the family about their
experiences, thus enabling the ability to identify appropriate community resources to meet the family’s needs.

The complete assessment can be found as Appendix C below.

5. **Traumatic Brain Injury Care Coordination: Health Screening Questionnaires for Parents**

The *Traumatic Brain Injury Care Coordination: Health Screening Questionnaires for Parents* tool, designed by Colorado’s HCP, is a two-page, parent-completed assessment that assists the care coordinator in identifying necessary care coordination services. The worksheet also offers space for the care coordinator to track referrals and services requested for the family.

The complete assessment can be found as Appendix D below.

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B. QUALITY ASSURANCE

For the purposes of this toolkit, quality assurance refers to the capacity by which a practice, clinic, or program has the infrastructure and ability to provide care coordination services. HCP identifies several indicators as quality-based outcomes of care coordination, including “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.” Additionally, HCP recommends that care coordination programs have the capacity to include “sustained family involvement in systems improvement – through surveys, advisory committees, family consultants, and regular forums.”

This section includes five suggested resources for assessing a practice, clinic, or program for its ability to provide quality care coordination services. Resources are available to be completed by both the practitioner and the family.

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1. **Cultural and Linguistic Competence Policy Assessment (CLCPA)**

The *Cultural and Linguistic Competence Policy Assessment* (CLCPA) was developed by the National Center for Cultural Competence (NCCC) at the request of the Bureau of Primary Health Care (BPHC), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Service (DHHS) to assist community health centers to advance and sustain cultural and linguistic competence. The CLCPA is intended to support health care organizations to improve health care access and utilization, enhance the quality of services within culturally diverse and underserved communities, and promote cultural and linguistic competence as essential approaches in the elimination of health disparities. The NCCC has also developed a companion *Guide for Using the Cultural and Linguistic Competence Policy Assessment Instrument* that provides step-by-step instructions on how to conduct an organizational self-assessment process.

The CLCPA can be accessed online at:

https://www4.georgetown.edu/uis/keybridge/keyform/form.cfm?formID=277

2. **Family-Centered Care Self-Assessment Tool: (1) Family Tool and (2) Provider Tool**

The *Family-Centered Care Self-Assessment Tool*, developed by Family Voices, is not designed to provide a score, but is meant as an opportunity for reflection and quality improvement activities related to family-centered care within outpatient health care practices. It can also be used by families to assess their own skills and strengths, the care their children and youth receive, and to engage in discussions within health care settings and with policy makers in organizations, health plans and community and state agencies about ways to improve health care services and supports.

The tool is intended to assess care for all children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. Questions on the tool address the ten components of family-centered care and the key aspects of family/youth/provider partnerships.

Both tools, along with a User’s Guide, can be accessed online at:


3. **National Initiative for Children’s Healthcare Quality: (1) Medical Home Index and (2) Medical Home Family Index**

The *Medical Home Index* (MHI) is a validated self-assessment and classification tool designed to translate the broad indicators defining the medical home (accessible, family-centered, comprehensive, coordinated, etc.) into observable, tangible behaviors and processes of care within any office setting. It is a way of measuring and quantifying the "medical homeness" of a primary care practice. The MHI is based on the premise that "medical home" is an evolutionary process rather than a fully realized status for most practice settings. The MHI measures a practice's progress in this process.
The *Medical Home Family Index* is a companion survey intended for use with a cohort of families of children and youth with special health care needs who receive care in a designated practice. This tool gives the practice a valuable consumer perspective while allowing family corroboration of the practice’s self-assessment (as reported on the Medical Home Index).

Both tools can be accessed online at:
C. PERMISSION FOR INFORMATION SHARING

As discussed above, children with special health care needs often require multiple service providers. In order to provide care efficiently and effectively, it is important that the various providers coordinate referrals and services provided, as well as participate in the creation and evaluation of the care plan. However, the family must agree to the sharing of their child’s health information.

This section includes two examples of forms that give permission for the sharing of personal information, as well as information about The Health Insurance Portability and Accountability Act (HIPAA).

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1. **Behavioral/Physical Health Coordination**

This form, developed by the State of Indiana’s Office of Medicaid Policy and Planning, Family & Social Services Administration, contains a section on the first page, entitled *Patient Consent*, which may be used as an example of obtaining permission for sharing a child’s health information among providers.

This form can be accessed online at: [http://in.gov/icpr/webfile/formsdiv/51856.pdf](http://in.gov/icpr/webfile/formsdiv/51856.pdf)

2. **The Health Insurance Portability and Accountability Act (HIPAA)**

HIPAA is a federal law that protects the privacy of personal health information. The Office for Civil Rights, under the U.S. Department of Health & Human Services, enforces HIPAA. Families must give permission before personal health information can be shared with the following:

- Employers
- Health care providers
- Hospitals
- Insurance companies
- Schools
- State and federal agencies
- Any other entity requesting health information

Information about HIPAA can be accessed online at: [http://www.hhs.gov/ocr/privacy/index.html](http://www.hhs.gov/ocr/privacy/index.html)

The Colorado Department of Human Services, Alcohol and Drug Abuse Division HIPAA Workgroup, and Colorado Mental Health Services published a HIPPA manual “to inform providers about HIPAA and assist them in their efforts towards HIPAA compliance.” This manual can be accessed online at: [http://www.cdhs.state.co.us/dmh/PDFs/providers_HIPAA_Manual_and_Attachments.pdf](http://www.cdhs.state.co.us/dmh/PDFs/providers_HIPAA_Manual_and_Attachments.pdf)

3. **Information Release Form: Family Education Rights and Privacy Act**

The Family Educational Rights & Privacy Act (FERPA) is a federal law that protects the privacy of student education records, both financial and academic. For the student’s protection, FERPA limits release of student record information without the student’s explicit written consent; however, it also gives the student’s parent(s)/guardian the right to review those records if the parent(s)/guardian claim the student as a dependent on their federal income tax return. This form may be necessary when collaborating with a child’s educational services.

An example of this form can be accessed online at: [http://orientation.wooster.edu/ferpa.pdf](http://orientation.wooster.edu/ferpa.pdf)
D. THE CARE PLAN

Planning, identified by HCP as an essential care coordination activity, is to “assist the family to develop a care coordination plan with specific objectives, goals and actions to meet identified needs.”vi The development of a care plan allows both the practitioner and the family to continually monitor and evaluate the effectiveness of the services provided to the family.vi Care plans are a dynamic document that can capture the changing needs of the family that occur over time. The ultimate goal of a care plan is to achieve positive outcomes for the family.

This section includes five examples of how a care plan can be organized. Care plans for both practitioners and parents are included.

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1. Care Plan for Children with Special Health Care Needs
This three page template, developed by the State Government of Victoria, Australia, Department of Human Services (September 2008), is designed to supplement the Universal Child Health Record (UCHR, CH-14). It is intended to be used for children with special health needs. The UCHR is designed to be concise and does not provide sufficient space for detailed instructions that a CSHN might need. This Care Plan should be used when instructions for the child’s care cannot be fit on to the UCHR. This Care Plan can be utilized as a template and be adapted as needed. Not all parts need to be completed for some children, but other children may require extra pages to be attached to fully explain the instructions for the child’s care. In order to facilitate communication between the health care provider and the parent, it may be best to complete this form with the parent/guardian present.

The Care Plan for Children with Special Health Care Needs can be found as Appendix E below.

2. Care Plan and Services Template
This two page plan, developed by the United Kingdom’s National Children’s Bureau (2006), allows the practitioner or family to document contact information and an outcomes timeline for each provider contributing care within nine domains, note the type of care plan, and record a contingency plan.

This resource can be accessed online at: http://www.ncb.org.uk/careplanning/pdf/Care-plan-and-services-template.pdf

3. Colorado’s Individualized Family Service Plan (IFSP)
The Individualized Family Services Plan (IFSP) is the process and document that guides and directs the provision of early intervention services. The IFSP is based on the individualized, functional needs of the infant or toddler and the concerns and priorities of the parents. The IFSP is routinely reviewed and changed as needs, concerns and priorities change.

The IFSP can be accessed online at:
http://www.eicolorado.org/index.cfm?fuseaction=Professionals.content&linkid=61

4. Service Coordination Plan
This two page plan, developed by Australia’s Victorian Department of Human Services (2006), allows the practitioner to record the individual care plans of all workers, practitioners, or agencies involved in a consumer’s care to allow a coordinated approach to service delivery.

This resource can be accessed online at:

5. What’s the Plan?
This one page worksheet, developed by the Washington State Department of Health’s Center for Children with Special Needs at Children’s Hospital and Regional Medical Center, is designed to help parents organize their questions and concerns. Completion of this plan can help families
plan for doctor visits. This worksheet is available in English, Spanish, Chinese, Vietnamese, Russian, and Korean.

This resource can be accessed online at:  http://cshcn.org/planning-record-keeping/care-plans-parents/parents-create-care-plan

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E. COMMUNITY-BASED RESOURCES & REFERRALS

Care coordination often requires some level of referral to comprehensively meet a family’s needs. Making appropriate referrals, especially for complex patients, requires being knowledgeable about medical and social resources available in your community.\textsuperscript{xii}

This section includes a list of statewide services that offer community-based resources throughout Colorado. Resources are organized according to the Substance Abuse and Mental Health Services Administration’s (SAMHSA) System of Care Model, Figure 1, illustrated on page 7 of this toolkit. The website, and in some cases a phone number, is included. Some resources maybe appear in more than one category.

What follows this list is a section that includes three suggested resources for navigating the referral process.

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1. Local Resources

**Educational Services**

**Child Find**

Child Find offers information and resources related to the earliest possible identification of young children and their families who may benefit from early intervention or education services.

Child Find is a component of [Individuals with Disabilities Education Act (IDEA)](http://www.childfindidea.org/) that requires states to identify, locate, and evaluate all children with disabilities, aged birth to 21, who are in need of early intervention or special education services. The below Child Find web site is mainly focused on Part C of the IDEA, the Early Intervention Program for Infants and Toddlers with Disabilities. However, much of the information and many of the links listed on the Child Find web site can be useful in conducting child find for all young children, not just child find for infants and toddlers.

Website: [http://www.childfindidea.org/](http://www.childfindidea.org/)

**Colorado Department of Education**

The Colorado Department of Education offers a variety of resources for educators, administrators, and parents and students. Parents and students can find information on performance & accountability, existing educational programs, and district-specific information.

Phone: 303-866-6600
Website: [http://www.cde.state.co.us/](http://www.cde.state.co.us/)

**Colorado Family Resource Centers**

The [Family Resource Center Association](http://www.cofamilycenters.org/) is a collaborative network of 24 community-based family resource centers that provide a comprehensive and proven approach to improving health, social, educational and economic outcomes for entire families, not just individuals.

The statewide Association (FRCA) unites stand-alone centers to strengthen programs and service delivery through advocacy and outreach, joint programming and evaluation, capacity-building training and technical assistance, and resource development.

Phone: 303-388-1001
E-mail: [info@cofamilycenters.org](mailto:info@cofamilycenters.org)
Website: [http://www.cofamilycenters.org/](http://www.cofamilycenters.org/)
**Early Childhood Colorado (Early Childhood Colorado Information Clearinghouse)**

This website is a one-stop-shop for all Coloradans to access services and resources related to young children and the people who care for them. Website users can search by county to see a complete listing of services and resources available in that county, or a keyword search can be conducted.

Website: [http://www.earlychildhoodcolorado.org/](http://www.earlychildhoodcolorado.org/)

**Early Intervention Colorado**

Early Intervention Colorado offers supports and services for infants, toddlers, and their families. Resources are available online for both families and professionals (providers, service coordinators, and system partners). Families can use the site to determine whether their child is eligible to receive Early Intervention (EI) services, how to get connected to services, etc. County contacts for EI services can also be found on this website, as well as information on the referrals process and related forms.

Website: [http://www.eicolorado.org](http://www.eicolorado.org)

**Parent to Parent of Colorado**

Parent to Parent of Colorado (P2P-CO) is a parent initiated, parent controlled, organized group that connects families of sons and daughters with disabilities or special healthcare needs in communities in Colorado.

Toll free information and referral line in English and Spanish: 877-472-7201
Email: info@p2p-co.org
Website: [http://www.p2p-co.org/](http://www.p2p-co.org/)

**United Way**

United Way is a national network of nearly 1,300 local organizations that work to advance the common good by focusing on education, income and health. These are the building blocks for a good life: a quality education that leads to a stable job, enough income to support a family through retirement, and good health.


**Family Advocates**

**Colorado Department of Public Health and Environment, Health Care Program for Children with Special Needs (HCP)**

At the Health Care Program for Children with Special Needs (HCP), professionals and families work as a team. HCP provides information, referral to services and support. Families make choices and take action. Together, we help children with special health needs get what they need and grow to be their healthiest, as well as reach the full potential of their independence.
HCP can help you find:
- Screenings and clinics
- Medical Home, health, transition and community services
- Financial assistance
- Family support groups
- Respite care
- Answers to questions...and more

Phone: 303-692-2370
Website: http://www.cdphe.state.co.us/ps/hcp/

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Phone: 303-388-1001
E-mail: info@cofamilycenters.org
http://www.cofamilycenters.org/

Family Voices of Colorado
Family Voices Colorado is a chapter of the national, grassroots organization composed of families and friends who care for and about our children with special health care needs. The primary goal of the organization is to ensure that our children's health is addressed amidst change in public and private health care systems.

Family Voices Colorado provides:
- Information and Referral
- Advocacy Support Information
- Private Health Insurance Advocacy
- Training
- Systems Change/ Policy Work

Phone: 1-800-881-8272
Website: http://www.familyvoicesco.org/
The Federation of Families for Children’s Mental Health – Colorado Chapter
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Phone: 303-572-0302
Website: http://www.coloradofederation.org/

Parent to Parent of Colorado
Parent to Parent of Colorado (P2P-CO) is a parent initiated, parent controlled, organized group that connects families of sons and daughters with disabilities or special healthcare needs in communities in Colorado.

Toll free information and referral line in English and Spanish: 877-472-7201
Email: info@p2p-co.org
Website: http://www.p2p-co.org/

Health Services

Colorado American Academy of Pediatrics
The mission of the Colorado Chapter American Academy of Pediatrics is “to provide an active voice promoting the optimal health and welfare of infants, children, adolescents, and young adults in Colorado; to support the continuing education of health care providers in matters of child and adolescent health; and to encourage participation and fellowship in these areas by Pediatricians throughout the state.” This membership organization is active in legislation related to the health of young children, endorses several public health programs across the state, and provides CME opportunities.

Website: http://www.coloradoaap.org/

Colorado Department of Public Health and Environment, Health Care Program for Children with Special Needs (HCP)
At the Health Care Program for Children with Special Needs (HCP), professionals and families work as a team. HCP provides information, referral to services and support. Families make choices and take action. Together, we help children with special health needs get what they need and grow to be their healthiest, as well as reach the full potential of their independence.

HCP can help you find:
- Screenings and clinics
- Medical Home, health, transition and community services
- Financial assistance
- Family support groups
- Respite care
- Answers to questions...and more

Phone: 303-692-2370
Website: http://www.cdphe.state.co.us/ps/hcp/

Colorado Family Resource Centers
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The statewide Association (FRCA) unites stand-alone centers to strengthen programs and service delivery through advocacy and outreach, joint programming and evaluation, capacity-building training and technical assistance, and resource development.

Phone: 303-388-1001
E-mail: info@cofamilycenters.org
Website: http://www.cofamilycenters.org/

Colorado Medical Home Initiative
A Medical Home is not a building, house or hospital, but a team approach to providing health care. A Medical Home originates in a primary health care setting that is family-centered and compassionate. A partnership develops between the family and the primary health care practitioner. Together they access all medical and non-medical services needed by the child and family to achieve maximum potential. The Medical Home maintains a centralized, comprehensive record of all health related services to promote continuity of care.

Children with special health care needs may have many professionals invested in their physical and emotional well-being. Coordination of care is an essential activity to assure communication and planning amongst team members, including family, primary health care practitioners, specialists, community programs and insurance plans.

Website: http://www.cdphe.state.co.us/ps/hcp/medicalhome/index.html

Early Childhood Colorado (Early Childhood Colorado Information Clearinghouse)
This website is a one-stop-shop for all Coloradans to access services and resources related to young children and the people who care for them. Website users can search by county to see a complete listing of services and resources available in that county, or a keyword search can be conducted.
Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

EPSDT is a health care benefit package for all Medicaid enrolled children ages 20 and under and pregnant women. EPSDT services include:

- All Medicaid benefits and dental benefits, hearing aids and limited orthodontia
- Case management services with an EPSDT Outreach Coordinator in your community help you: EPSDT Outreach Coordinator
- Locate providers that accept Medicaid
- Obtain non-emergency medical transportation
- Childcare
- Food or shelter
- Part C Head Start
- The Women, Infants and Children (WIC) program
- The Health Care Program for Children with Special Needs (HCP) program

Most counties have an EPSDT Outreach Coordinator who can help a client navigate the Medicaid system, as well as non-Medicaid community systems. To access contact information for the EPSDT Outreach Coordinator in your county, click on this website: https://hcpf.cdhs.state.co.us/HCPF/EPSDT/CountyAddressEPSDT.doc

Website: https://hcpf.cdhs.state.co.us/HCPF/EPSDT/EPSDTindexnew.asp

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1. Assist pediatric practices with resources they may not be aware of for treating children and youth with special health care needs;
2. Identify case management services for families who may not know they are available;
3. Identify gaps or shortages in services through the data collected.

The Provider Resource Hotline is 1-877-731-6017.

For assistance or more information:
- Call Monday - Friday from 8:00 a.m. to 4:00 p.m./ Voice mail 24/7
- E-mail providerhotline@familyvoicesco.org
- Fax information sheet to 303-691-0846

Website: http://www.familyvoicesco.org/hotline/index.htm
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Email: info@p2p-co.org
Website: http://www.p2p-co.org/

United Way

United Way is a national network of nearly 1,300 local organizations that work to advance the common good by focusing on education, income and health. These are the building blocks for a good life: a quality education that leads to a stable job, enough income to support a family through retirement, and good health

Find a local United Way Organization: http://www.liveunited.org/myuw/

Mental Health Services

Colorado Department of Human Services, Division of Behavioral Health

(This division encompasses the two divisions formally known as the Alcohol and Drug Abuse Division and the Division of Mental Health.) The Division of Mental Health website is provided as a resource for mental health providers, children, adolescents, adults and their families, policy makers, and all citizens of Colorado.

The Division of Mental Health administers non-Medicaid community mental health services for people with serious emotional disturbance or serious mental illness of all ages, through contracts with six specialty clinics and seventeen private, nonprofit community mental health centers. The Division of Mental Health strives to ensure high quality, accessible mental health services for Colorado residents, by reviewing community mental health programs; adopting standards, rules and regulations; providing training and technical assistance; and responding to complaints from non-Medicaid consumers.

Phone: 303-866-7400
Information for Providers: http://www.cdhs.state.co.us/dmh/

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Website: [http://www.earlychildhoodcolorado.org/](http://www.earlychildhoodcolorado.org/)

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Website: http://www.p2p-co.org/

**Operational Services**

None at this time.

**Recreational Services**

None at this time.

**Social Services**

**Colorado Department of Human Services, Division of Developmental Disabilities**

The Division for Developmental Disabilities (DDD) is the State office that provides leadership for the direction, funding, and operation of services to persons with developmental disabilities within Colorado. DDD services are administered under the Office of Adult, Disability and Rehabilitation Services (OADRS) of the Colorado Department of Human Services (CDHS).

State leadership and oversight includes: policy, planning, program development, budget development, program operation guidelines and technical assistance, training, determination of funding needs, setting priorities, contracting and allocation of resources, review of services and funding utilization, program quality, monitoring, and evaluation, and management information. These functions are performed in concert with service providers, advocacy groups, and consumers and their families.

Phone: 303.866.7450
Website: http://www.cdhs.state.co.us/ddd/

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Website: [http://www.earlychildhoodcolorado.org/](http://www.earlychildhoodcolorado.org/)

**Early Intervention Colorado**

Early Intervention Colorado offers supports and services for infants, toddlers, and their families. Resources are available online for both families and professionals (providers, service coordinators, and system partners). Families can use the site to determine whether their child is eligible to receive Early Intervention (EI) services, how to get connected to services, etc. County contacts for EI services can also be found on this website, as well as information on the referrals process and related forms.

Website: [http://www.eicolorado.org](http://www.eicolorado.org)

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Email: info@p2p-co.org
Website: http://www.p2p-co.org/

Substance Abuse Services

Colorado Department of Human Services, Division of Behavioral Health
(This division encompasses the two divisions formally known as the Alcohol and Drug Abuse Division and the Division of Mental Health.) The mission of the Alcohol and Drug Abuse Division (ADAD) is to reduce the health, social, and economic consequences of alcohol, tobacco, and other drug abuse and illegal use by fostering effective and efficient prevention services.

ADAD works in partnership with federal and state entities as well as with ADAD providers serving communities to encourage the use of multiple prevention strategies implemented through effective practices and ethical behavior. ADAD also licenses and monitors nearly 400 treatment provider agencies, with over 750 locations throughout the state; administers the Advocates for Recovery program, and develops and enforces regulations for Level I and Level II DUI education and treatment programs.
**Vocational Services**

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**United Way**

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**Other**

**2-1-1 Information & Referral Search**

Call 2-1-1 or visit the 211 website if you are in need of essential human services, including, but not limited to training, employment, food pantries, help for an aging parent, addiction prevention programs, affordable housing options, support groups, volunteer opportunities, etc.
Website: http://www.211.org/

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Find a local United Way Organization: http://www.liveunited.org/myuw/
2. This section includes three suggested resources for navigating the referral process.

   a. **Guide to Care Coordinators in Our Community**
   The *Guide to Care Coordinators in Our Community* was developed by the Center for Children with Special Needs, a Program of Children’s Hospital & Regional Medical Center in Seattle, Washington and the Washington State Department of Health Children with Special Health Care Needs Program. This guide may be helpful in noting contact information for the family/child’s various health care providers. (NOTE: Adaptation for state/local resources may be necessary as the form includes Washington State-specific websites.)

   This resource can be accessed online at: [http://www.cshcn.org/forms/CareCoordinator-BlankGuide.pdf](http://www.cshcn.org/forms/CareCoordinator-BlankGuide.pdf)

   b. **Referral Process for Infants and Toddlers 0-3 and Referral Process for Children 3-5**
   Following a *Colorado Leadership Workshop: Advancing a Collaborative Agenda to Improve the Health and Development of Young Children*[^3], a task force organized to address issues related to increasing screening for developmental delays in primary care provider’s offices including social and emotional delays. The task force consisted of 8 organizations including four state agencies, (The Colorado Departments of Human Services, Public Health and Environment, Health Care Policy and Financing, and Education) and some of the state’s preeminent experts in early childhood mental health, including the Colorado Children’s Hospital. The task force reviewed barriers to screening identified by primary care providers identified by Colorado Children’s Healthcare Access Program (CCHAP) and an EPSDT Screening Pilot funded by The Colorado Health Foundation. Knowing that primary care offices often did not know where to refer children once they were identified, the task force decided that an algorithm or flow chart that would outline the referral process for children from birth through age five would be helpful.

   After a year of work the task force developed two such algorithms, one for children from birth through three years of age and one for children ages three through five. The separation was developed because Part C organizes a different and more streamlined process for children 0-3.

   The *Referral Process for Infants and Toddlers 0-3* can be accessed online at: [http://www.eicolorado.org/index.cfm?fuseaction=Referral.referral&CFID=1115846&CFTOKEN=39140251](http://www.eicolorado.org/index.cfm?fuseaction=Referral.referral&CFID=1115846&CFTOKEN=39140251)

   The *Referral Process for Children 3-5* can be accessed on: [http://dev.civicore.com/cffc2/](http://dev.civicore.com/cffc2/)

   NOTE: Both flowcharts are color coded to identify responsibilities that are housed in the primary care office, outside resources or both. Behind many of the boxes on the flowchart are

[^3]: This workshop was co-sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services in 2006.
additional resources and forms that may be helpful to the provider. By clicking on the box this additional information can be accessed.

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RECOMMENDATIONS: SYSTEM-LEVEL AGENCIES

1. Develop core competencies and expectations for care coordination providers;
2. Provide core training for professionals who are doing care coordination and advocacy and families to include the following:
   a. Overview of key systems and services, including specific government programs (i.e., Health Care Program for Children with Special Health Care Needs [HCP]; Special Supplemental Nutrition Program for Woman, Infants, and Children [WIC]; Early Periodic Screening, Diagnostic, and Treatment [EPSDT]; Prenatal Plus; and Child Health Plan Plus [CHP+]);
   b. Relationship-building and assessment skills;
   c. Cultural competency; and
   d. Overview of the quality of life for those living with disabilities.
3. Establish communication pathways for coordination among education, and health and behavioral health systems;
4. Develop processes whereby the evaluation of outcomes and quality can be established;
5. Develop “comprehensive, consistently defined system-level measures on access, utilization and cost”\textsuperscript{xiii};
6. Create standards that allow for flexibility in the implementation of care coordination consistent with local resources and values;
7. Share accountability across agencies and pursue increased funding that will provide reimbursement for care coordination functions;
8. Develop a process for information sharing across systems; and
9. Identify existing care coordination programs, regardless of level, and their funding streams.

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RECOMMENDED
NEXT STEPS

The time available to develop this toolkit was short (3+ months). Therefore the Toolkit Development Committee recognized that additional strategies could be explored to enhance the design and impact of this document.

1. Assign the resources within each section to care coordinators and providers of services based on their level of providing care coordination services. TDC members suggested defining these levels according to the Department of Education’s 2007 Early Childhood Council grant process, i.e., (1) Emerging Care Coordination Agency; (2) Capacity-Building Care Coordination Agency; and (3) Model Care Coordination Agency.

2. Create accompanying toolkits for families/consumers and system-level agencies.

3. Continue to partner with the Colorado Family Leadership Task Force on toolkit review and development.

4. Adapt long care coordination templates for streamlining to appeal to agencies who seek to coordinate care for their families.

5. Pilot the toolkit within a community agency that services families with high needs and high-complexity cases in order to best determine the effectiveness of the included tools.

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APPENDICES

All Appendices can be access online at

http://www.jfkpartners.org/WorkShopItemInfo.asp>Type=2&Number=150

Assessment
A. The Colorado Family Support Assessment (available in both English and Spanish), and The Colorado Family Support Example Interview Guide
B. HCP Care Coordination Acuity Tool
C. Phases, Activities, and Skill Sets of the Wraparound Process: Strengths, Needs, Culture, and Vision Discovery
D. Traumatic Brain Injury Care Coordination: Health Screening Questionnaires for Parents

The Care Plan
E. Care Plan for Children with Special Health Care Needs

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i The Colorado Health Foundation
iii Ibid.
iv Ibid. i
vi Ibid.
ix Ibid. v
x Ibid. v
xi Ibid.