EVERY CHILD DESERVES A MEDICAL HOME

Component Four: Comprehensive, Coordinated, Collaborative Care

Facilitator Manual

In Collaboration With
American Academy of Pediatrics
Family Voices
Maternal and Child Health Bureau
National Association of Children's Hospitals and Related Institutions
Shriners Hospitals for Children

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Component Four: Comprehensive, Coordinated, Collaborative Care

Slide 1	**Comprehensive, Coordinated, Collaborative Care**
Slide 2	**Learning Objectives** • Understand the essential component of care coordination in the medical home concept and how it supports the provision of comprehensive, collaborative care. • Acknowledge strategies to enable chronic care management within the primary care office setting. • Recognize the role of community within a medical home and the importance of the primary care practice establishing linkages to it. • Understand different community-based service systems and how to access them for care coordination. • Identify effective strategies for collaboration and communication among families, children and youth with special health care needs (CYSHCN), providers, and community-based services in the provision of quality, comprehensive care. • Apply the learning objectives to the given case study.
	Section One: Why Provide Comprehensive, Coordinated, Collaborative Care?

Slide 3	**What Is Comprehensive Care?** • Continuous care (24 hours a day, 7 days a week, 365 days a year) • Requires the physician and medical staff to be knowledgeable and competent to participate in the care of CYSHCN • Involves medical, developmental, educational, recreational, vocational, psychological, and financial issues
Slide 4	**Why Is Comprehensive Care Important?** CYSHCN and their families/caregivers typically have multiple needs - Medical and health - Developmental and educational - Psychosocial - Financial - Family support service
Slide 5	**How Is Care Coordination a Part of Comprehensive Care?** • Physicians can't "do it all" - Not much training - Not much time • Families may have unmet needs - Information, coordination of services - Unvoiced needs - Needs may be more than physician perceives
Slide 6	**Why Is Care Coordination Important?** Families spend 11+ hours/week coordinating care for CYSHCN, which has consequences for • Emotional/mental/behavioral health of family and CYSHCN • Finances • Employment MCHB/NCHS. National Survey of Children with Special Health Care Needs. 2002

Notes:	
	The article “Effects of Providing Comprehensive Ambulatory Services to Children With Chronic Conditions” is available in **Appendix A.**
Slide 7	**Care Coordination** • Is a collaborative process • Involves families, educational, social service, and medical providers • Ensures access to appropriate community-based services • Advocates for the comprehensive, community-based service systems Donati B, Passerello T, Stille C. Coordination of Care in the Medical Home. Presented at: National Association of Pediatric Home and Community Health Conference; October 3, 2003; Mystic, CT
	The AAP policy statement, “Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs” is available in **Appendix B.**

Slide 8	**Goals of Care Coordination** To promote the well-being of families and CYSHCN through • Information and referral • Consultation • Training • Outreach • Collaboration • Service coordination • Optimization of insurance and public benefits
Slide 9	**Care Coordination: The Medical Home Physician's Role** • Gathering information, triage: medical, non-medical, "in-between" • Interpret medical information, integrate it all into care plan • Teach CYSHCN and families • Learn from CYSHCN and families • Mediate any potential conflicts Donati B, Passerello T, Stille C. Coordination of Care in the Medical Home. Presented at: National Association of Pediatric Home and Community Health Conference; October 3, 2003; Mystic, CT
Slide 10	**Care Coordination: What Does It Look Like?** • A plan of care developed by the physician, CYSHCN, and family • A central record/database containing all pertinent medical information (ie, hospitalizations, specialty care) is maintained in the primary care office. This information is confidential, yet accessible • When CYSHCN are referred for a consultation or additional care, the medical home physician assists CYSHCN and families in communicating clinical issues • The medical home physician evaluates and interprets the consultant's recommendations for CYSHCN and families • The written care plan is coordinated with other community agencies

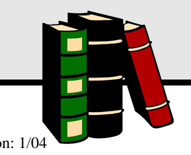
Section Two: How Do You Coordinate Care From a Primary Care Perspective?

Slide 11	**Chronic Care Management: 6 Actions** • Proactive decision to provide chronic care management to identified CYSHCN • Provision of care intertwines management of chronic condition with other areas of primary care services • Continuous communication with family; engages them as partner • Establishes necessary procedures in the primary care office • Initiates continuous management of chronic condition (monitoring, evaluation) • Develops and maintains collaborative relationships among CYSHCN community agencies and providers
Slide 12	**Chronic Care Management: Making the Decision** A primary care office staff should acknowledge the need for chronic care management strategies when a child's or youth's health condition meets the following criteria: • Significantly impacts daily living and family life • Impacts school performance • Impacts development • Involves ongoing specialty care • Involves several providers and agencies • Causes new predicament/emergency
Slide 13	**Chronic Care Management: Creating a Plan** • Developed in concert with the primary care physician (PCP), family, CYSHCN (if developmentally appropriate), care coordinator (if appropriate) • Addresses goals, concerns, interventions, services, referral contacts for medical and non-medical needs • Includes medical information, visit schedules, communication strategies, other agencies services, etc • Continuously updated and assessed • Family/CYSHCN provided with copies of care plan

	Gifford Medical Center, Randolph, VT, developed a medical care plan, which is located in **Appendix C.**
Slide 14	**Chronic Care Management: The Provider's Role With the Family/CYSHCN** • Communicate office procedures that the family/CYSHCN will frequently experience • Discuss what family/CYSHCN support resources are available; assist the family/CYSHCN in accessing those services • Identify roles and expectations for all (PCP, office staff, family, CYSHCN) • Discuss time lines and possible agendas for provision of care
Slide 15	**Chronic Care Management: The Family's/CYSHCN's Role** • Act as a partner • Communicate directly and honestly with providers • Responsibly manage care notebooks to assist in communicating needs to provider(s) • Bring notebook to provider appointments • Continuously assess care plan and its integration into CYSHCN/family's life activities
	The Center for Children with Special Needs—a program of the Children's Hospital & Regional Medical Center of Seattle, WA—developed a care notebook for families of CYSHCN. This notebook helps families/CYSHCN manage documents involved with health care, as well as assist in facilitating communication with provider(s). It is located in **Appendix D.** The article "Continuity of Care Is Associated With High-Quality Care by Parental Report" is located in **Appendix E.**

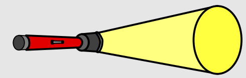
Notes:	
Slide 16	**Chronic Care Management: Putting the Office Systems in Place** • Establish a system to "flag" or "identify" the medical chart of CYSHCN • Establish a system that will alert front office staff to schedule longer visits for identified CYSHCN • Identify a primary office contact person for the family

Slide 17	**Chronic Care Management: Putting the Plan to Work** • Assess the plan • Monitor involvement of specialists • If service gap, conflict, or concern is identified, review and revise the plan • Use direct communication strategies between physician and family/CYSHCN
Slide 18	**Chronic care management: Co-management Between PCP and Specialists** • The Institute of Medicine (IOM) and AAP have identified PCP-specialist communication as an important element in the medical home • Specialists communicate assessment results to 51% of PCPs • Specialists outline co-management of the CYSHCN care plan in only 31% of cases Stille CJ, Primack WA, Savageau JA. Generalist-subspecialist communication for children with chronic conditions: a regional physician survey. *Pediatrics.* 2003;112:1314–1320
Slide 19	**Co-management Between PCP and Specialists: Barriers** • Timeliness of communication • Telephone difficulties • Specialists referring to other specialists without PCP involvement • Families seen as central method of communicating between providers Stille CJ, Primack WA, Savageau JA. Generalist-subspecialist communication for children with chronic conditions: a regional physician survey. *Pediatrics.* 2003;112:1314–1320

Slide 20	**Co-management Between PCP and Specialists: When Communication Is Essential** • The PCP and family make the initial decision to refer • The Specialist has conducted an assessment and outlines the plan for diagnosis/treatment • Follow-up care by either provider is significant to a managed care plan Stille CJ, Primack WA, Savageau JA. Generalist-subspecialist communication for children with chronic conditions: a regional physician survey. *Pediatrics.* 2003;112:1314–1320
Slide 21	**Co-management Between PCP and Specialists: Possible Strategies** • Send a referral letter and supporting materials from the PCP prior to specialist consultation • Create a list of providers being seen by each CYSHCN to note who the PCP should be sharing communication • Establish common procedures for all providers to use when e-mail is the frequent medium to communicate • Identify strategies for specialists to educate the PCP on certain chronic conditions Stille CJ, Primack WA, Savageau JA. Generalist-subspecialist communication for children with chronic conditions: a regional physician survey. Pediatrics. 2003;112:1314–1320
Slide 22	**Chronic Care Management: How Can the Practice Be Supported Financially?** • Use of appropriate *Current Procedural Terminology (CPT)* codes is essential • Establish proper documentation of use and consultation • Understand the different type of applicable codes for care coordination (prolonged services, case management, care plan oversight)
	Receiving appropriate reimbursement for effective chronic care management is a huge barrier for primary care providers.

	More information and resources regarding this topic are available in the ***Practices, Policies, and Procedures*** component of the curriculum. The fact sheet "Proper Use of Coordination of Care Codes with CSHCN" is available in **Appendix F.**
	Section Three: How Do You Provide Coordinated and Comprehensive Care Within the Community?

Slide 23	**Barriers to Accessing Community-based Services** • The need to navigate several systems of care, each with its own rules, procedures, personnel, and eligibility criteria • Rarely no single point of entry • No single agency responsible for all services • HIPAA often seen problematic to sharing information
Slide 24	**Additional Barriers** • Fragmented and categorical service systems • Service systems and health care systems often not linked • Different systems, different terminology • Service systems often geographically dispersed, increasing time and transportation challenges
Slide 25	**Advantages of Community-based Care for Providers** • Provider more likely to be familiar with a community's health and social issues • Provider able to promote the health and well-being of all children in a community • Provider more likely to be accessible to a community's service systems
	The AAP policy statement, which outlines a pediatrician's role in the community, can be found in the appendix of ***Common Elements*** (Component One).

Slide 26	**Advantages of Community-based Care for Families** • Minimizes disruption of family life, work, and school • Keeps family connected with community and its natural support systems • Supports family and community values • Encourages healthy, stable relationships • Builds on family's strengths, maximizes their decision-making power
Spotlight Example 	An example of a community-based initiative around medical home is the Pennsylvania Medical Home Project. This community-based initiative is composed of representatives from families, health care professionals, the AAP Pennsylvania Chapter, Title V CSHCN, and early intervention programs. They began carrying out activities related to medical homes for CYSHCN in 1999 with the planning process for the *Every Child Deserves a Medical Home* training program. From the beginning of their planning, this community-based committee developed a train-the-trainers model to bring medical home educational programs to their entire state. This model is known as Educating Physicians in Community Integrated Care (EPIC IC). It has since been funded by the Maternal and Child Health Bureau (MCHB). Since 1999, 21 primary care practice teams across the state have been recruited to engage in quality improvement processes to ensure provision of quality care to their patients with special health care needs. Teams are composed of a clinician, staff member, and a family representative. To support integration of medical home into these primary care settings, these teams attend a 2-day training conference and participate in monthly conference calls on a medical home concept. As a recent accomplishment to this community-led initiative, 11 participating practices now have care coordinators, and multiple office tools have been developed to help with the identification of CYSHCN, documentation and billing for services, and communication with families. Tools include evaluation and management codes (*CPT*), progress note template, fax back referral form, tip sheet for parents, and a list of state and national Web sites/resources. For more information on the Pennsylvania Medical Home Project, contact *Molly Gatto, Project Coordinator, AAP Pennsylvania Chapter* at mgatto@paaap.org.

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Providing Community-based Care: Provider's Role

- Establish office procedure for staying aware of community services
  - As part of care coordinator's responsibilities
  - Collate local resource directory, ensure accuracy
  - Establish regular meetings/consortiums with community providers and agencies
- Assess needs of family and CYSHCN for community services

To help providers assess the needs of the family/CYSHCN, a document titled "Notes to Providers" was developed to assist in facilitating that process. It can be located in **Appendix G.**

A fact sheet on community-based services is located in **Appendix H.**

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Accessing Community-based Care: Family's/CYSHCN's Role

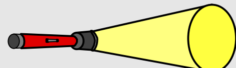
- Acknowledge needed supports and resources
- Provide an honest assessment of current services/resources (ie, access, eligibility, hours, payment)
- Be proactive in informing the physician and office staff of additional community-based resources and service systems

The following is a list preformatted letters for medical home providers to use when assisting families/CYSHCN in accessing community services that are available in the appendices:

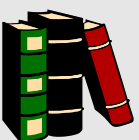
- Letter to electric or gas company: **Appendix I**
- Letter of necessity for diapers and wipes: **Appendix J**
- Letter of necessity for equipment: **Appendix K**
- Letter of necessity for formula and nutritional supplement: **Appendix L**

Slide 29 (Option 1)	**Considerations for Provision of Comprehensive Care: Medical Issues** • Is there a recent and comprehensive medical history available? • Has medical information been communicated in understandable terms to the family/CYSHCN? • What procedures are in place for discharge planning? • How does the family feel about managing medical needs at home? Has the definition of "medically-necessary" services been explained? • Has the care plan been reviewed by the family? Have medical contacts been clearly identified for the family? • What communication strategies are in place between the medical home physician and other providers to co-manage medical needs?
Slide 30 (Option 1)	**Community Resources and Agencies: Medical** • Books, articles, disease-specific handouts • Parent notebook of CYSHCN's condition • Mental health/Mental retardation/ Developmentally delayed/ Title V state programs • Respite programs • Child care facilities • Extended care facilities • Home care agencies • Durable Medical Equipment companies
	A list of questions parents should consider when electing if home health care is appropriate for their CYSHCN and their family is available in **Appendix M.**

Slide 29 (Option 2)	**Considerations for Provision of Comprehensive Care: Developmental Issues** • What early surveillance and screening procedures have been performed? • What therapies are needed (physical/ occupational /speech)? Where will they be provided? Are they accessible? • If necessary, has referral been made to early intervention? Has release of information been sent? What follow-up has been done? • What communication strategies between the medical home physician and other providers have been established to co-manage developmental needs?
Slide 30 (Option 2)	**Community Resources and Agencies: Developmental** • Early intervention • Head Start • Community-based therapies (PT/OT/speech) • School system
Notes:	

Spotlight Example 	Bright Futures is a set of tools that can be part of providing comprehensive care by medical home practitioners. Bright Futures, initiated by theMCHB, is a philosophy and approach that is dedicated to the principle that every child deserves to be healthy, and that optimal health involves a trusting relationship between the health professional, child, family, and community. As part of this initiative, *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* was developed to provide comprehensive health supervision guidelines, including recommendations on immunizations, routine health screenings, and anticipatory guidance. An example of a primary care physician who uses Bright Futures to assist in providing comprehensive care is Lance Chilton, MD, from Albuquerque, NM. His office uses the Bright Futures age-appropriate materials to develop questionnaires that parents complete in the waiting room. Parents answer questions about their child's development, eating habits, and safety, among others, and they can highlight issues of particular concern. The feedback from the questionnaires assists Dr Chilton in ensuring he is meeting the diverse needs of his patients and their families during the office visit. *For more information about Bright Futures, please visit: http://www.brightfutures.aap.org/web/*

Slide 29 (Option 3)	**Considerations for Provision of Comprehensive Care: Educational/Vocational Issues** • How will CYSHCN access the educational system (mainstream, special program, at home)? • Has an Individual Educational Plan (IEP) or 504 been developed? What was the medical home physician's role in that development? • How has the Individuals with Disability Education Act been incorporated into educational plans?
Slide 30 (Option 3)	**Community Resources and Agencies: Educational/Vocational** • Special education districts, boards, committees • Vocational rehabilitation programs • Easter Seals • Condition-specific associations
	Communication between the school system, primary care providers, and families can be complicated. To assist in facilitating clear and direct communication, the use of standard forms to share information has become a common practice. Templates of those forms are located in the following appendices: • Letter to school regarding CYSHCN condition: **Appendix N** • Release of information form: **Appendix O** The "When Your Child with Special Health Care Needs Goes to School" checklist was developed by Children's Hospital & Regional Medical Center in Seattle, WA. It is available in **Appendix P.**

	Many resources exist to assist in with the IEP process. An IEP checklist is available in **Appendix Q.** A classroom inclusion checklist is available in **Appendix R.** AAP policy "The Pediatrician's Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)" is available in **Appendix S.** An IEP pop-up tool was developed to assist families during the IEP meeting. To view this tool, please visit: **WWW.NCLID.UNCO.EDU/HVORIGINALS/ADVOCACY/POPUP/POPUP.HTML**

Slide 29 (Option 4)	**Considerations for Provision of Comprehensive Care: Recreational Issues** • What are CYSHCN interests regarding exercise/recreation? Goals? Dreams? • What are possible effects of medication on exercise/recreation? • What is current level of fitness? How can that relate to selecting which exercise/recreation to participate? • Has medical home physician been aware/involved in selection of exercise/recreation activity?
Slide 30 (Option 4)	**Community Resources and Agencies: Recreational** • Special programs, camps • A community's recreational department • A community's special education district • Transportation • Family resource centers
Slide 29 (Option 5)	**Considerations for Provision of Comprehensive Care: Psychosocial Issues** • Has a detailed psychosocial history been taken? • What is the impact of the CYSHCN's condition on the family? • What is the impact of the family's dynamics on ? • Has an Individual Family Support Plan (IFSP) been developed? What was the medical home physician's role in that development? • What current support groups and resources are used by the family/ CYSHCN? • Have "do not resuscitate"/comfort care issues been discussed? • Has guardianship or other legal issues been discussed? • Have there been discussions about possible death and bereavement?

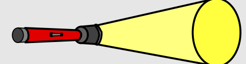
Slide 30 (Option 5)	**Community Resources and Agencies: Psychosocial** • Mental health community clinics • Behavioral health community clinics • Family resource centers • Foster care • Hospice
Slide 29 (Option 6)	**Considerations for Provision of Comprehensive Care: Financial Issues** • What are current payment options offered by your primary care practice? • If there are changes in the family's/CYSHCN's insurance, are they accommodated? How? • Is the billing process flexible to meet needs of different health plans? • Is there an office system established to continuously provide financial resource information to families/CYSHCN? • What is the medical home physician's and office staff's understanding of different health plans and financial resources?
Slide 30 (Option 6)	**Community Resources and Agencies: Financial** • Medicaid and Medicare • Title V CSHCN program • State Child Health Insurance Program • Waivers • ARC Family Resources • Utility programs • Social service agencies • Social Security Income
	"Managed Care and Children With Special Health Care Needs: The Medical Home Checklist" is available in **Appendix T.**

Slide 29 (Option 7)	**Considerations for Provision of Comprehensive Care: Oral Health Issues** • Has an oral health care provider been identified? Been used? • If oral health provider has not seen the child, what oral health risk assessments are available in the pediatric primary care setting? • Are medical home provider and office staff familiar with appropriate billing codes for oral health assessments? • What referral procedures are in place after conducting oral health assessment? • What resources are available to discuss dietary practices, fluoride exposure, oral hygiene, and the establishment of a consistent oral health care provider with families?
Slide 30 (Option 7)	**Community Resources and Agencies: Oral Health** • Community dentists • State Medicaid, SCHIP; Title V programs (some include oral health) • Dental schools
Notes:	

	Section Four: The Role of the Community in Providing Collaborative Care

Slide 31	**Strategies for Effective Collaboration**
	
	• Develop an interdisciplinary, interagency advisory team to review and comment on office policies/procedures regularly
	• Establish means to facilitate continuous feedback
	  - Suggestion box
	  - Quarterly meetings that are open to families and CYSHCN
	  - Open e-mail list that families/CYSHCN can enroll
	• Have mutual respect for each other's expertise and role in supporting the family and caring for the child
	  - Include family representatives in office orientation for staff and new families/CYSHCN
	  - Provide continuous education opportunities for staff to learn about the family perspective

Slide 32	**Strategies for Effective Interagency Collaboration** • Identify your community partners • Identify a means to bring all community partners together OR facilitate communication among them • Once communicating, identify barriers and opportunities for systems improvement, reduced fragmentation, and duplication • Develop an implementation plan • What changes to be made? • Who will be responsible for which change? • Who will be affected by the changes? • How will others be educated about the changes? • How will the changes be evaluated? • Have a community-based agency representative(s) visit during a staff meeting

Spotlight Example 	The Illinois Title V CSHCN and the AAP Illinois Chapter have formed a strong collaboration to promote a statewide medical home initiative. Through regular meetings, co-sponsorship of local activities, and shared public relations efforts, these 2 agencies have been able to serve as a leading force in developing strategies to implement medical home throughout Illinois. For example, a continuing medical education medical home monograph was developed in 2000. This monograph is disseminated to Illinois pediatricians and family physicians to teach them about the medical home concept, and subsequently be eligible for enhanced reimbursement rates in Illinois. This interagency collaboration remains a constant in the Illinois medical home initiative, and was highlighted in 2002, as the then-governor George Ryan declared, "2002 as the year of medical home" in Illinois. *For more information on this interagency collaboration, please contact Chuck Onufer, MD, FAAP, director, IL Title V CSHCN Program, at cnonufer@uic.edu.*
Slide 33	**Strategies for Continuous Collaboration** • Keep communication honest, direct, and to the point; avoid repetition • Be open to change • Commit to the collaborative goals set by all involved (physician, family, CYSHCN, community partners, office staff) • Identify an appropriate method to facilitate ongoing communication (Web site, newsletter, e-mail list, quarterly meetings)
	Section Five: Case Study

Case Study	**Background of Family** • Mother, Tanya, is 17 years old, single, and a senior in high school • Father, Zach, is several years older, not in school, not committed to "providing for his family" • Mother lives in metropolitan suburb • Has intact family system (mother, father, siblings) • Average scholastic ability; labels herself "an underachiever" • Does not qualify for family insurance, but will for Medicaid
	At Birth • Daughter, Jennifer, is born and diagnosed with Down syndrome. • Jennifer spends a month in hospital due to congenital heart disease secondary to DS-GI • Jennifer requires ongoing medication and assisted feeding.
	Current Situation Jennifer is now 4 years old and in preschool. • Shows developmental delays in all areas • Has nutritional issues secondary GI/Cardio disease • Significant language delay; still nonverbal on indication Tanya is now 21 years old. • Lives on her own • Trying to balance school/job/child care • Dependent on public assistance, public transportation, and educational grant • No support or contact from Zach • Tanya's family is psychologically supportive, but physically removed • Has her GED

Discussion Questions ?	• What community resources will you help this family access? • What federal/state regulations apply to the child and mother at this time? • What is the role of the medical home physician in sharing information with this family? • What procedures should be established for the medical home to follow up on information/resources shared with Tanya? • What procedures could be put in place to keep the physician and office staff aware of community resources?
	Section Six: Wrap-Up
Slide 34	**Learning Objectives** • Understand the essential component of care coordination in the medical home concept and how it supports the provision of comprehensive, collaborative care. • Acknowledge strategies to enable chronic care management within the primary care office setting. • Recognize the role of community within a medical home and the importance of the primary care practice establishing linkages to it. • Understand different community-based service systems and how to access them for care coordination. • Identify effective strategies for collaboration and communication among families, children and youth with special health care needs (CYSHCN) and community-based services in the provision of quality, comprehensive care. • Apply the learning objectives to the given case study.

Appendices

National Center for Medical Home Initiatives Web Promotion	
Effects of Providing Comprehensive Ambulatory Services to Children With Chronic Conditions	A
Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs	B
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Care Notebook for Families of CYSHCN	D
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Home Health Care—Choosing a Home Infusion Company: Questions for Parents	M
Letter to School Regarding CYSHCN Health Condition	N
Release of Information Form	O
Checklist: When Your Child with Special Health Needs Goes to School”	P
Checklist of Items for Consideration in Developing Individualized Education Plans (IEP) for Students with Physical Disabilities or Special Health Needs	Q
Classroom Inclusion Checklist	R
The Pediatrician’s Role in Development and Implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP)	S
Managed Care and Children With Special Health Needs: The Medical Home Checklist	T
Additional Resources	U

Additional Resources

Books

Search the Medical Home Bibliography at:
www.medicalhomeinfo.org/resources/bibliography.html

AAP Policy Statements

Search for any AAP Policy Statement at: http://aappolicy.aappublications.org/

Comprehensive, Coordinated, Collaborative Care Web Sites

- **American Academy of Pediatrics:** www.aap.org/
- **American Council of the Blind:** www.acb.org/
- **American Foundation for the Blind:** www.afb.org
- **American Society for Deaf Children:** www.deafchildren.org/
- **Birth Defect Research for Children, Inc:** www.birthdefects.org/
- **Commonwealth Fund Survey of Parents With Young Children:** www.cmwf.org/surveys/surveys_show.htm?doc_id=240205
- **CysticFibrosis.com:** www.cysticfibrosis.com/
- **Cystic Fibrosis Foundation:** www.cff.org/
- **Disaster planning information:** www.acep.com
- **Epilepsy Foundation:** www.efa.org/
- **The Interactive Guide to Learning Disabilities for Parents, Teachers, and Children:** www.ldonline.org/
- **KidNeeds:** www.kidneeds.com/
- **Muscular Dystrophy Association:** www.mdausa.org/
- **The National Association of Community Health Centers:** www.nachc.com/advocacy/
- **National Association for the Education of Young Children:** www.naeyc.org/
- **National Center for Education in Maternal and Child Health:** www.ncemch.org/
- **National Institute of Diabetes & Digestive & Kidney Diseases:** www.niddk.nih.gov/
- **National Down Syndrome Society:** www.ndss.org/
- **National Foster Parent Association:** www.nfpainc.org/
- **National Institute of Neurological Disorders and Stroke:** www.ninds.nih.gov/

- **National MCH Clearinghouse:** www.ask.hrsa.gov/
- **National Multiple Sclerosis Society:** www.nmss.org/
- **National Organization for Rare Disorders:** www.rarediseases.org/
- **National Organization on Disability:** www.nod.org/
- **National Organization for Rare Disorders:** http://nord-rdb.com
- **National Rehabilitation Information Center for Independence:** www.naric.com/
- **National Respite Locator Service:** www.respitelocator.org/index.htm
- **National Spinal Cord Injury Association:** www.spinalcord.org/
- **Office of Special Education and Rehabilitative Services:** www.ed.gov/about/offices/list/osers/index.html?src=mr
- **Online Mendelian Inheritance in Man:** www3.ncbi.nlm.nih.gov/omim
- **Parents Helping Parents:** www.php.com/
- **Pediatric Orthopaedic Surgery:** www.peds-ortho.com/
- **Project School Care information:** www.schoolhealth.org/
- **Rural Institute:** www.ruralinstitute.umt.edu/
- **Shriners Hospitals for Children:** www.shrinershq.org/
- **Social Security Administration:** www.ssa.gov
- **Spina Bifida Association of America:** www.sbaa.org/
- **Supplemental Security Income Program:** www.ssa.gov/notices/supplemental-security-income/
- **United Cerebral Palsy Association:** www.ucpa.org/

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