



Massachusetts Medical Home Network Well-Visit Guidelines

Assessing Comprehensive Care and Linking Families to Resources

A pediatric well-visit is an excellent opportunity for families caring for children with special needs discuss unmet service needs with their physician and to identify community resources and family support networks. Physicians and families are encouraged to discuss these “non-medical” needs during their child’s office visit. It may be necessary to schedule longer or more frequent visits to allow extra time to discuss these issues. Pediatricians typically receive fairly limited training in community resources, although this is starting to change in today’s residency programs. The following list of questions was originally developed to help pediatricians identify areas of needs they might be unaware of, and to help them to identify resources for families. This list was originally paired with the Family Ties resource guide (available on line at www.massfamilyties.org). We hope that the questions below help to increase discussion between families and physicians of non-medical needs and resources

The following set of guidelines offers an alphabetical listing of common topic areas or potential unmet needs for children with special health care needs and their families. Each topic includes a suggested query or conversational prompt.

Case Management/Care Coordination

- Do you have a Case Manager or Care Coordinator (through Department of Public Health (DPH); DMR; Mass Commission for the Blind; Mass Commission for Deaf and Hard of Hearing; your health insurer; other)?
- Do you receive any assistance in coordinating care for your child?

Clothing

- Do you need help finding specialized clothing -- shoes (e.g., to fit over braces), outerwear, helmets, clothing suited to g-tubes, wheelchairs?

Try this web site to find suppliers: www.familyvillage.wisc.edu

Daycare

- Are you satisfied with the ability of your child’s pre-school or daycare setting to work with your child?

Dental Needs

- Do you have a dentist for your child?

Durable Medical Equipment (DME)

- What equipment does your child now use?
- Is there any other equipment you need now or expect to need in the near future?
- Does any of your equipment need replacement or repair?

Family Support

- Are you involved in any family or parent support groups?
- How are the other children in your family doing? Do you think they could benefit from any programs for children who have a brother/sister with a special health care need?
- Would you like to be reaching out to help other families in similar circumstances?

Home Health

- What types of home health services does your child receive (skilled nursing, Personal Care Attendant or PCA)? Are there some needed which are not provided?
- Who provides these services? How often?
- Are these services enough?

Housing/Home Modifications

- Is your housing situation meeting your child's health care needs?
- Are there any adaptations or special equipment that would make daily living and care of your child easier for you and your family?

Information

- Would you like to have more information about your child's condition?
- Would you like to know about newsletters and other publications, which cover disability issues?
- Do you have access to the Internet? Would you like to know about disability-related web sites?

Insurance/Financing

- How are you covering your child's medical expenses? Do you have health insurance for your child?
- Do you have/know about CommonHealth? SSI?
- Do you need any help with Letters of Medical Necessity?
- Does your child's health insurance cover items like diapers, Peditasure?

Recreation and Social Activities

- What types of recreational programs does your child participate in?
- What kind of social connections does your child have --- with peers with and without special health needs?
- Does your child have an opportunity to attend camp or participate in a recreational program over the summer?

Respite

- Do you receive any respite (a break; a rest from direct childcare)? Who provides it?
- Are there any people available to help you with care for your child so that you can get a break?
- Is your family connected with the Department of Mental Retardation (DMR) to receive funds (when available) which can be used for childcare and equipment, etc.?

School/Education

- Is your child now, or did your child ever, participate in Early Intervention?
- Where does your child attend school now?
- Does your child have an Individualized Education Plan (IEP), or written plan for special educational services through the schools?
- Have you been satisfied with the Individualized Education Plan (IEP) and planning process at your child's school?
- Which special services (PT, OT, Speech, adaptive physical education, aide, nursing) does your child receive at school? Are you satisfied with these services?

Special Opportunities

- Are you aware of special programs available to families who have kids with special health care needs, such as Make a Wish Foundation, Starlight, Miracle Network, and Children's Wish?

Transitions

- Are you thinking about or planning for any major transitions for your child --- from Early Intervention to school; from one school to another; from adolescence to adulthood?

"Transition Planning for Adolescents with Special Health Care Needs and Disabilities" available free at <http://communityinclusion.org/transition/familyguide.html>.

Transportation

- Does your family have/need a handicapped placard or plate?
- Do you need any special assistance with transportation (e.g. PT 1 form completed if on CommonHealth)
- Have you ever had a need for specialized long-distance (i.e. air) transport to another medical facility?

Adapted from "How to Make Best Use of Resource Information", Freeman, L., Nazarian, B., Sherman, P. Medical Home Training Program Curriculum Materials, Boston, MA, November 2001.