Optimizing Care for Young Children with Special Health Care Needs

Knowledge and Strategies for Navigating the System

edited by

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Table 10.2. Recommendations for providers

1. Appreciate, acknowledge, and serve or refer
   - Welcome every child as a person before addressing possible health problems
   - Make initial diagnosis and begin care without delay
   - Keep and use a referral list for diagnosis of special conditions
   - Make all necessary referrals for the parents
     - Assist parents in understanding and determining who can help them understand their health plan options
     - Decide how case management will be handled
     - Continue to communicate across the continuum as needed
   - Present initial information slowly and incrementally
     - Ensure that information to be provided is accurate and up-to-date
     - Provide adoption information only after appropriateness has been determined
     - Provide timelines for care
   - Provide information on older children and adults with the condition
   - Keep and use a resource and referral list to help address families’ emotional needs
   - Conduct a series of follow-up calls with new parents

2a. Inform, empower, and communicate
   - Self-educate
     - Stay up-to-date on health care guidelines for CSHCN
     - Research the literature regarding the types of CSHCN served
   - Provide each parent with a notebook and calendar at the start
   - Distribute and discuss appropriate health care guidelines with parents
   - Keep and use a directory of providers with experience caring for CSHCN
   - Keep and use a directory of organizations and agencies supporting families with CSHCN
   - Keep and use a parent buddy list for linking new parents to experienced ones
   - Encourage dialogue between parents and providers
     - Encourage questions
     - Encourage families to share knowledge and information
   - Engage in and support provider–provider communication across the continuum of care for each CSHCN
     - Know who is case managing for the child and where the child’s medical home is and ensure that the parents have the same information
     - Stay informed about health insurance coverage policies for CSHCN
   - Encourage families to acknowledge the emotional and social aspects of having a CSHCN and refer to resources and referrals list as needed

2b. Participate and advocate
   - Ask more questions of parents
   - Realize (and remind parents as needed) that some conditions or behavioral situations are simply part of a normal childhood
   - Model destigmatization by practicing nonjudgmental care
   - Push for policy and program changes in support of provision of high-quality care
   - Continue to model nonjudgmental acceptance of/for CSHCN and their families
   - Use the power of one’s privileged provider position to advocate for policies and programs that support high-quality care
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