Report is guide to shared decision-making when child has a disability

by Richard C. Adams M.D., FAAP

Whether working with the family of a newborn infected by Zika virus, a 12-year-old with cerebral palsy considering a major surgical procedure or a family navigating information about alternative therapies, the pediatrician often is a central player in the many decisions that arise among children with disabilities. At times, such decisions can be fraught with anxiety, hesitation and confusion.

The associated stress often is shared by the child, the family and the physician. For many families of children with disabilities, this process of decision-making is a recurrent one. The pediatrician, likewise, often is a core participant throughout these episodes.

Shared decision-making (SDM) provides a framework for the pediatrician participating in such decisions. The framework promotes family and clinician collaboration, with the ultimate goals of improved health and satisfaction for all those involved.

Too often, the emotions, stress and perceived gravity of the situations surrounding decisions needed in this complex group of children can stymie the process and create a sense of avoidance by those involved. The new clinical report Shared Decision-Making and Children With Disabilities: Pathways to Consensus provides guidance for use of SDM for children with intellectual, physical and/or neurodevelopmental disabilities and their families, and offers information and tools for clinical application.

The report, from the AAP Council on Children With Disabilities, is available at https://doi.org/10.1542/peds.2017-0956 and will be published in the June issue of Pediatrics.

While definitions can differ, a working description of shared decision-making is "an interactive process in which patients (families and children, especially more cognitively able children) and physicians (and other involved professionals) simultaneously participate in all phases of the decision-making process and together arrive at a treatment plan to be implemented."

Core elements of a SDM process include:

- reflecting on and considering the impact of alternative options and decisions;
- guiding the process with sensitivity to the family's values and lifestyles;
- looking at choices and arriving at a decision;
- reflecting on and considering actions to be taken based on the above; and
- arranging for follow-up to assure support and assistance.

Much of the research and published studies on SDM come from the internal medicine literature. The clinical report provides a review of the pediatric experiences with SDM and offers suggestions for future use across various clinical settings: primary, specialty, quality improvement and clinical research endeavors. Functional tools and links to web-based learning sites are provided.

By increasing pediatricians’ comfort level in using these techniques, children and their families will come to further appreciate the guidance and should derive a greater confidence in their various (and too often recurring) decisions. Awareness of specific practical steps improves the clinician's efficient use of consultation time and effective leadership and support to the family. When SDM is used routinely and confidently, the ultimate outcomes should be to support the beneficence of the physician, the authority of the family and the autonomy and well-being of the child.
Dr. Adams, a lead author of the report, is an immediate past member of the AAP Council on Children With Disabilities Executive Committee.