Shared Decision Making Can Enhance Care of Children with Autism or Other Disabilities

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Pediatric primary care practices are grappling with the needs of children with developmental delays or disorders, who may make up five to 10 percent of their patients. Practices are working to ensure that families are connected to appropriate community- and health care-based services for evaluation and treatment, as these children may have diagnoses such autism, attention-deficit/hyperactivity disorder (ADHD) or learning disorders. Unfortunately, decision making that could facilitate these connections may be one-sided; physicians or families may make treatment decisions with minimal input from the other. What we should strive for is decision making that engages both the family and clinician to bridge this gap.

During an interview for our qualitative study on parent and pediatrician perspectives of decision making and treatment decisions for children with autism spectrum disorder (ASD), the mother of a four-year-old boy with ASD talked about her views of the pediatrician's role and actions. She told us "[there] was no back and forth conversation … which is huge, so … I guess it doesn't seem like he [the clinician] is very interested because he is not engaging me in conversation … so I'll just figure this out on my own." Shared decision making (SDM) helps to bring families and pediatric clinicians together by providing an interactive process of information exchange, discussion of treatment and care preferences and agreement on a treatment plan.

Can We Leverage Shared Decision Making (SDM) in Pediatrics?

In a recent clinical report, the American Academy of Pediatrics (AAP) emphasized the need to incorporate SDM into family-centered care in the medical home and across the care continuum. The AAP noted that choices related to the diagnosis, evaluation, treatment and services in the community may add to the stress that families experience. SDM can help reduce those stressors, but if we are to see it realized in pediatrics, we need to address barriers in three key areas: providers, health systems and families.

Providers

Unfortunately, not all providers appreciate how important their families' values and preferences may be to effective care and may misjudge families' preferences and goals. Additionally, pediatricians may not be comfortable discussing possible treatments with families of young children with ASD if they do not feel informed about details of the disorder, its treatment and available community resources. In our study, one pediatrician noted, "to be honest, I don't feel like I have been trained well enough to be able to do that [*make treatment recommendations*]. Everybody gets referred to Early Intervention … [*and an*] evaluation, but sort of making recommendations to have this type of behavioral therapy versus this type of medication, I don't make those recommendations."

In reality, SDM embraces both of these common barriers by combining the pediatrician's professional expertise with the family's values and pragmatic knowledge of family circumstances. One strategy to promote the use of SDM in pediatrics is to educate and train primary care providers about evidence-based treatments for ASD, addressing gaps in knowledge and comfort treating the condition.

Health Systems

Alongside providers, health systems must overcome barriers to using SDM, which may mean making changes at the local, regional and federal levels. Many health systems are not set up to promote SDM for children with special health care needs because this approach may be time consuming, has the potential to increase costs of providing care and is perceived as not practical for implementation into daily care. Access to specialized care for children with ASD and other disabilities is a problem because there are not enough specialists to treat all affected children, and families may have to rely on a primary care provider who may not know have adequate training to deliver a diagnosis or inform treatment. Thus, there may be delays in diagnosis or care unless steps are taken to address these gaps. Health systems should collaborate with providers and take steps to promote SDM, including establishing teams to champion implementation, training and support for staff, access to evidence-based resources and streamlining SDM processes into daily operations.

Families

Families may have incomplete knowledge about treatments and their evidence, both beneficial and harmful, may have different cultural norms regarding interactions with providers and language barriers. Some families have extensive support within their family and the community and others are more isolated. By integrating SDM into daily practice, physicians can not only educate families about evidence for treatment options, but also connect them with community resources.

Hope for SDM on the Horizon

As pediatricians who have dedicated themselves to seeking better solutions for families, we think there is hope on the horizon for SDM. While the clinical use of SDM might appear to be in its early stages, there is emerging data that SDM and its techniques contribute to improved knowledge, increased family satisfaction, decreased decisional conflict, improved health and decreased health care costs – things we strive for every day. While this data is promising, we still need more research to fully understand SDM's effectiveness in pediatrics, support the development of SDM facilitation technologies and build systems for physicians to connect families to community resources. Additionally, we need public policy changes to promote health system change and innovation, with funding to develop and implement training programs for subspecialist physicians and other providers and mechanisms to provide fiscal support for the implementation of SDM in daily care.

These are some large steps to get us over the finish line, but we know it is possible because SDM has large potential benefits not only for children with ASD, but for all children we encounter across our health systems. It's promise for providers and their empowerment is simple, according to our interviews: "[SDM] means that we are not just the experts prescribing the treatment, we don't have all the answers and have to sort of listen to families and discuss options with families and give them the information and decide together to make a plan." With an environment that supports SDM, we can reduce the burden of diagnosis, treatment and community connections on the family and, ultimately, build the best systems of care to ensure the best outcomes for children.

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