

Involving Your Child in the Decision-Making Process: AAP Report Explained

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Treatment should never be a process done to your child. Rather, decisions about care should be implemented with your child's input—as much as possible—with support, guidance, and assistance from you and other care team members.

The American Academy of Pediatrics (AAP) clinical report, *Shared Decision-Making and Children with Disabilities: Pathways to Consensus* (<http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2017-0956>), states that children, when cognitively able, should be involved in decisions about their care. Parents and professionals too often look to this process for "the big decisions," however smaller decisions can have a significant impact over time.

Presenting children with information—appropriate for their developmental age—can help in their understanding of their condition and treatments, reduce fear, and enhance self-confidence.



Shared Decision-Making Tips for Parents of Children with Disabilities:

- **Educate your child about his or her condition.** Find out what your child understands and/or wants to know. Work with your child's doctors and others in your community to identify books, videos, websites, and other resources to help your child learn about his or her condition.
- **Identify future goals.** Have a discussion with your family and your child's doctors. Start picking out goals for your child's future—short-term (e.g., within the year) and long-term (e.g., as an adult).
- **Have quick check-ins with your child.** Once you have identified the goals for your child and their priority, make sure he or she understands them as fully as possible given his or her level of understanding—especially if things don't make sense or just don't feel right.
- **Have your child present.** Your child should be present whenever possible for at least part of meetings concerning his or her condition or treatment. Parts of the discussion should address your child directly at his or her level of understanding.
- **Consider who else should be present.** Some decisions are relatively straightforward (e.g., antibiotics for strep throat) and may not require long or difficult discussions, but others (e.g., starting a psychotropic medication for behavior) may be tougher. In addition to having your child present for these decisions—if he or she is able—it is also a good idea to have another family member(s) there. For example, grandparents, siblings, or child care providers involved in day-to-day care may have input and even act as a scribe in the meeting. Sometimes, it can be difficult to hear and process information correctly after the fact. The other family member there can help recall the conversation later and clarify for questions.
- **Ask about breaking up appointments.** Sometimes, it can be helpful to separate long, complex discussions into shorter, topic-based meetings. This also gives everyone—including the doctors and other professionals—more time to prepare. Having a set time limit for the discussion can be helpful, as well.
- **Be aware that this is a "process."** There are situations where a "yes" or "no" decision is needed immediately. Considering data, reflecting on choices, and coming to a consensus can be accomplished either quickly (if needed) or within a longer timeframe if shared decision-making techniques are used regularly.
- **Know teens need time alone with the doctor.** Adolescents may benefit from time alone with their doctor(s) or other health professionals without parents present. The shared decision-making process allows for more input from your child. Ask your child about what he or she would like to talk about and arrange a separate meeting if he or she would like one.
- **Realize participation prepares your child for adulthood.** Your child's prioritizing of his or her condition-related problems should be taken seriously. Teach your child to consider his or her strengths, obstacles, and abilities to function in different situations and to monitor any changes. It's never too early to start talking about these topics. Ask your child's doctors for more ideas on how to include your child in this process, as well as any additional resources.

About Crisis & Emergency Situations:

Shared decision-making should be implemented for routine decisions and well in advance of predictable (or unpredictable) crises, such as those requiring intensive care or do-not-resuscitate decisions. Complex or serious decisions are often easier to make if a foundation of trust was already built through prior experiences in the shared decision-making process.

Crisis and emergency medical situations (</English/family-life/health-management/Pages/Is-It-a-Medical-Emergency-or-Not.aspx>) can also change the process to accomplish shared decision-making. Components of shared decision-making can and should be used if possible, but the AAP report acknowledges that it may not always be possible or allowed in an acute (</English/family-life/health-management/Pages/Nonemergency-Acute-Care-AAP-Policy-Explained.aspx>) or serious emergency.

Additional Information & Resources:

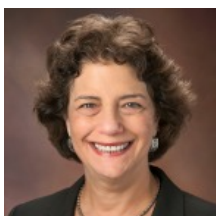
- [Common Coping Styles of Teens Who Are Chronically Ill or Disabled \(/English/health-issues/conditions/chronic/Pages/Common-Coping-Styles-of-Teens-Who-Are-Chronically-Ill-or-Disabled.aspx\)](/English/health-issues/conditions/chronic/Pages/Common-Coping-Styles-of-Teens-Who-Are-Chronically-Ill-or-Disabled.aspx)
- [Reproductive Health in Teens with Chronic Health Conditions \(/English/health-issues/conditions/chronic/Pages/Reproductive-Health-in-Teens-with-Chronic-Health-Conditions.aspx\)](/English/health-issues/conditions/chronic/Pages/Reproductive-Health-in-Teens-with-Chronic-Health-Conditions.aspx)
- [The Stresses Faced by Teenagers Who Are Chronically Ill or Disabled \(/English/health-issues/conditions/chronic/Pages/The-Stresses-Faced-By-Teenagers-Who-Are-Chronically-Ill-or-Disabled.aspx\)](/English/health-issues/conditions/chronic/Pages/The-Stresses-Faced-By-Teenagers-Who-Are-Chronically-Ill-or-Disabled.aspx)
- [For Families and Caregivers \(https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx\)](https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx) (National Center for Medical Home Implementation)
- [Fostering Partnership and Teamwork in the Pediatric Medical Home: A "How-To" Video Series \(https://medicalhomeinfo.aap.org/tools-resources/Pages/How-To-Videos.aspx\)](https://medicalhomeinfo.aap.org/tools-resources/Pages/How-To-Videos.aspx) (National Center for Medical Home Implementation)
- [Family-Centered Care Self-Assessment Tool \(http://www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf\)](http://www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf) (Family Voices)
- [Health Care Transition for Youth with Disabilities and Chronic Health Conditions \(http://health.ri.gov/publications/policybriefs/HealthCareTransitionForYouthWithDisabilitiesAndChronicHealthConditions.pdf\)](http://health.ri.gov/publications/policybriefs/HealthCareTransitionForYouthWithDisabilitiesAndChronicHealthConditions.pdf) (Rhode Island Department of Health)
- [Youth & Families: What Is Health Care Transition? \(http://www.gottransition.org/youthfamilies/index.cfm\)](http://www.gottransition.org/youthfamilies/index.cfm) (GotTransition.org)

About Dr. Adams:



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About Dr. Levy:



Susan E Levy, MD, MPH, FAAP, is a member of the Center for Autism Research and Vice Chair, Committee for Protection of Human Subjects at the Children's Hospital of Philadelphia, and Professor of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania. Within the AAP, Dr. Levy is a member of the following Sections: Epidemiology, Public Health & Evidence, Obesity, Developmental & Behavioral Pediatrics, and Integrative Medicine. She is a current member and past Executive Committee member of the AAP Council on Children with Disabilities (COCWD) and Chairperson of the COCWD Autism subcommittee.

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