



Shared Decision-Making and Children With Disabilities: Pathways to Consensus

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Shared decision-making (SDM) promotes family and clinician collaboration, with ultimate goals of improved health and satisfaction. This clinical report provides a basis for a systematic approach to the implementation of SDM by clinicians for children with disabilities. Often in the discussion of treatment plans, there are gaps between the child's/family's values, priorities, and understanding of perceived "best choices" and those of the clinician. When conducted well, SDM affords an appropriate balance incorporating voices of all stakeholders, ultimately supporting both the child/family and clinician. With increasing knowledge of and functional use of SDM skills, the clinician will become an effective partner in the decision-making process with families, providing family-centered care. The outcome of the process will support the beneficence of the physician, the authority of the family, and the autonomy and well-being of the child.

INTRODUCTION

Families of children with disabilities face many decisions about medical treatment. These choices may be added stressors for the child, family, and the clinicians involved. The nature and complexity of decisions are highly variable and may involve diagnosis, evaluation, treatment, care management, and support services. Shared decision-making (SDM) promotes family and clinician collaboration, with ultimate goals of improved health and satisfaction. This clinical report provides the following: (1) a basis for a systematic approach to implementation of SDM; (2) a narrative overview of the literature for application of SDM techniques; (3) exemplars and guidance for use of SDM for children with intellectual, physical, and/or neurodevelopmental disabilities and their families; and (4) information on tools available for clinical or research use. The decision-making process related to acute management of life-threatening conditions or end-of-life care is outside of the scope of this clinical report.

abstract



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BACKGROUND

Concepts of SDM have been described in publications over the past 2 decades. Although multiple definitions of SDM have been offered,¹⁻³ key features include the following: (1) at least 2 parties are involved, (2) information is exchanged in both directions, (3) all parties are aware of treatment options and what they are, and (4) all bring their knowledge and values-related priorities equally into the decision-making process. For this clinical report, the following working definition is used: SDM 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.^{2,4,5}

SDM is best characterized as a process that actively uses words or phrases such as “collaborative,” “patients and health professionals,” “together,” “informed,” “best scientific evidence available,” “patient’s values and preferences,” “family/patient centered,” “options,” and “supports needed.” The construct of SDM is founded in ethics, law, clinical care, cultural tenets, and standards within public and private health care delivery systems¹ and is the basis of patient-centered care.⁶ This process sets the stage for consensus about routine decisions building up to more significant decisions.

Too often, in the discussion of treatment plans, gaps exist between the child’s/family’s values, priorities, and understanding of perceived “best choices” and those of the clinician. An “either-or” approach to decision-making supposes 1 approach “wins out” with acquiescence of the other. However, when conducted well, SDM affords an appropriate balance incorporating all voices, ultimately

supporting both the child/family and clinician⁷ (Fig 1).

Much of the evidence for SDM comes from adult medicine, with fewer pediatric studies available. Nonetheless, there are many opportunities for its application in pediatric care, particularly for children with disabilities. SDM is applicable for chronic and acute care encounters. Added complexity occurs in the SDM process in children who have made developmental progress and have the skills to become an active participant.⁸ Presenting children with information (appropriate for their developmental age) can help their understanding of their condition and treatments, reduce fear, and enhance self-confidence.⁹ A recent review underscores the need for studies that support active participation of the child, along with the family and clinician,¹⁰ and that assist in decisions focused on acute or long-term concerns and future planning.

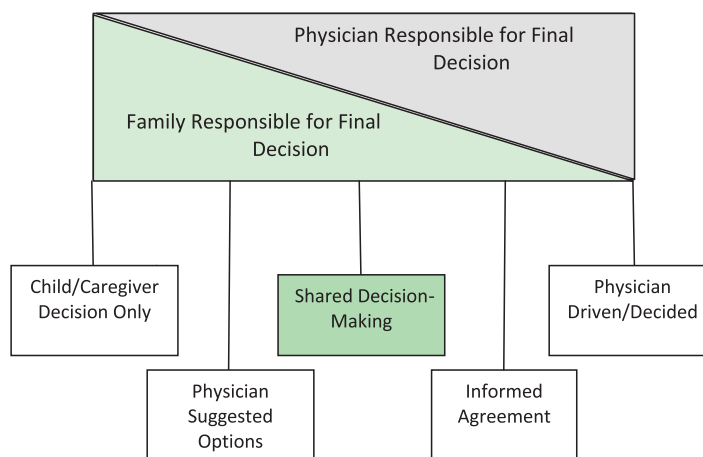
The timing of SDM is important, because it must be implemented for routine decisions and well in advance of predictable (or unpredictable) crises, such as those requiring intensive care or do-not-resuscitate

decisions. Crisis and emergency situations change the process to accomplish SDM. In children who require complex care management, such as those with chronic illness requiring teams of professionals, additional complexity exists where teams must integrate SDM among all members.¹¹

RESEARCH ABOUT SDM

Research in pediatric SDM is in its early stages.¹²⁻¹⁹ Most published studies are observational and/or qualitative in nature. Descriptive studies have focused on the evolution of commonly accepted definitions of SDM, facilitators or barriers to the use of SDM, and the impact on families. Few studies exist on efficacy and effectiveness of decision aids or other SDM interventions.²⁰

Studies of parental decision-making on behalf of their child reveal a diversity of influences. Parental or family factors include cultural norms, community standards, impact on siblings or extended family, previous experiences, religious faith, and impact of acuity and stability of the child’s health status.²¹⁻²³ Descriptions of cultural influences



(Consumerism) ← Autonomy ← ----- → Beneficence → (Paternalism)

FIGURE 1
Continuum of decision-making.

on the physician-patient interaction continue to inform the process of decision-making.^{6,24–29}

Barriers and facilitators may be divided into categories of knowledge, attitudes, agreement, lack of expectancy/hope, and behaviors.³⁰ Barriers to SDM include patient (family) characteristics, health system constraints (time for consultation, lack of continuity of care with physician, reimbursement issues, inadequate environmental conditions), power imbalance in a relationship, language barriers between families and clinicians, lack of availability of evidence and tools for decision support, attitudinal biases, knowledge deficits of clinicians,³¹ and lack of applicability (eg, patient characteristics or situations of unusual life-threatening events requiring intensive emergency intervention).³²

Common facilitators for the use of SDM include provider motivation, positive impact on the clinical process, and patient outcomes.³³ Pediatric clinician motivation may include the consideration of cost-effectiveness of the additional time. To address cost-effectiveness, American Academy of Pediatrics' resources on coding/billing are available and continually updated. Information on face-to-face and time-based billing and other avenues of support can be found at <https://www.aap.org/en-us/professionalresources/practice-support/Coding-at-the-AAP/Pages/Evaluation-and-Management.aspx>. Data from the National Survey of Children with Special Healthcare Needs and the Medical Expenditure Panel Survey describe the frequency of SDM, associations with the likelihood of its use, characteristics of providers using SDM, and impact on quality and satisfaction with care.^{34,35} Studies of effectiveness have been rare and have examined the impact of different tools to implement SDM. Standardized tools available

for clinical use and/or research are listed in Supplemental Table 5. Tools included in Supplemental Table 5 and Supplemental Fig 2 might be useful to inform clinicians of the anticipated components by which they are likely to be measured and to use as a template for designing the SDM conversation(s) needed.

Decision aids have been designed to provide education about specific disorder(s), outline treatment options, exchange evidence about treatment risks and benefits, and support families' values and priorities. A 2014 Cochrane review reported that decision aids improve patients' knowledge of options, expectations of benefits and harms, and participation in SDM.³⁶ Other benefits include reduced decisional conflict, increased active participation by families, and fewer undecided patients.³⁷

Clinical tools to measure patient preferences, clinician behaviors, frequency of use of decision aids and/or patient educational materials, and satisfaction and comfort (family or clinician) with decisions³⁸ have been studied. A Cochrane Collaboration review of interventions to improve the adoption of SDM by clinicians described 2 studies meeting strict criteria for quality and effect size.²⁰ No studies have reported measures related to medical/surgical outcomes.

As interest in SDM has increased, tools to promote its use, such as decision aids, have been constructed. Historically, these tools were related to specific conditions (acne, diabetes medication regimen, prostate cancer, and others) and were for adult patients/conditions. Some tools focus on patients' perceptions of physicians' performance in support of the decision-making process. Others encompass theory, practical guidance, and clinical use.^{39,40} Toolkits are available online through the Agency for Healthcare Research and Quality and the Dartmouth-Hitchcock Center for Shared Decision

Making. See Supplemental Table 5 for examples of tools and toolkits.

The 9-item Shared Decision Making Questionnaire (SDM-Q-9) was developed by Kriston et al.³ This tool can be used (1) to investigate the effectiveness of interventions aimed at the implementation of SDM, (2) as a quality indicator in health services assessments (eg, for Maintenance of Certification projects), and (3) as a guide for use in the "real world" clinical setting for structuring the "practical steps" in support of SDM. A copy of the SDM-Q-9 is included in Supplemental Fig 2.

PEDIATRICIANS AND THE SDM PROCESS

For children with disabilities and their families, issues of health-related quality of life occur at different and repeating periods. Variables such as developmental stage and the ability of the child or adolescent and timing, context, severity, acuity or chronicity of primary conditions, and comorbidities present unique challenges to child/family-physician interaction. Family-centered care is a valuable construct for all children, but especially for those with special health care needs. Family-centered care serves as a good foundation when questions arise and the application of an SDM process is needed.⁴¹

As difficult decisions need to be made (such as those in the case examples described later), focused leadership by the clinician will assist the family's arrival at a confident decision. Too often, as the clinician engages in conversation about options for care, the efforts are met with a lack of decisional closure, a "stalling out" of the process. Table 1 outlines needed steps and components of SDM.^{42,43} Items bulleted in Table 1 also offer potential "sticking points." If there appears to be a lack of consensus for action, the answer may be found at any of several

TABLE 1 A Guide to Pediatricians' Active Listening: Considering Context and Family Values in SDM

Context: Unique Family Characteristics Affecting the Decision-Making Process	Values: Unique Child/Family Attitudes and Belief Systems Affecting the Decision-Making Process	Pediatrician's Ability to Inform and Clarify in the SDM Process
<ul style="list-style-type: none"> ● Family's understanding of diagnosis ● Child's involvement based on developmental status ● Adolescent's capability, values, and preference for involvement ● Family's understanding of the child's physical, social, emotional status/prognosis ● Family's understanding of implications of intervention being considered <ul style="list-style-type: none"> ○ Parents' previous experiences in difficult decisions ○ Decision-making process: parents' styles/preferences ○ Decision-making process: extended family influence/support ○ Decision-making process: external influences (school, finance, others) ○ Health literacy of the family, including the patient ● Health professionals' understanding of barriers to the family's/child's full participation in the SDM process 	<p>Quality-of-life considerations:</p> <ul style="list-style-type: none"> ● Child's enjoyment of activities of daily living is addressed (self- and proxy report) ● Child's comfort is addressed (self- and proxy report) ● Financial considerations (cost/benefits) are addressed ● Emotional status and social interactions are addressed ● Unique ethnic, cultural characteristics affecting health beliefs <p>Health-related quality-of-life considerations</p> <ul style="list-style-type: none"> ● Personal competence and self-directed skills are addressed ● Educational planning is addressed ● Participation in recreation/leisure activity ● Family or significant-other personal support (caregiver's perceived roles/investment) ● Personal rights and social inclusion are optimized ● Healthy weight and growth attained ● No food insecurity or unaddressed nutritional issues ● Concerns of medical/surgical complications 	<ul style="list-style-type: none"> ● Adequacy of information is addressed ● Accuracy and quality of information is addressed ● Timing of information is appropriate ● Support of "peer-to-peer" interactions is addressed ● Clarifications are continually addressed: <ul style="list-style-type: none"> ○ Health team is seen as listening, understanding, supportive ○ Family does not feel "pressured" to decide ○ Support team seems present and will be over time

“sticking points.” For example, if the family’s understanding of the underlying diagnosis (or potential complications) is unclear, if financial stressors are not addressed, if cultural traditions are not acknowledged, or if the adequacy of support systems for the child/family is not explored, the decisional process may feel “stuck.” Although conversations with a specific child/family may not require a point-by-point inclusion of all components of Table 1, the clinician’s access to such an outline may help direct the decisional discussions.

“Practical steps”³ that are common to any SDM process are outlined in Table 2. Awareness of these steps improves the clinician’s efficient use of consultation time and effective leadership and support to the family. At times, the process will seem smooth and natural, with a relatively quick consensus. Other times, the complexities of the individual situation may require that the steps in Table 2 be explored more deeply.

Elwyn et al^{44,45} have outlined 3 types of “talks” that might help clinicians: “choice talk,” “options talk,” and “decisions talk.” This model works well alongside that of Kriston et al,³ discussed previously. Table 3 provides an outline of the 3 talks with an example narrative to serve as a guide for the clinician. These components support the steps of prioritization, negotiation, and finalization of the SDM process. If the family perceives “too many options” are in play, this can cause stagnation of the decision-making process.⁴⁶ The component talks can allow a natural but more gradual progression over time. As an example, a detailed discussion of SDM related to gastrostomy tube placement was central to a recent American Academy of Pediatrics’ clinical report, “Nonoral Feeding for Children and Youth With Developmental or Acquired Disabilities.”⁴² Specific SDM guidance for the pediatrician was outlined in that report.

Additional resources for clinicians and their partnering families

are provided in Supplemental Information 1. The SDM-Q-9 (Supplemental Fig 2) is a tool adapted for use in clinical practice; other measures may be better applied to outcomes review or research within a practice.³ For potentially unique considerations for SDM in specific cohorts, see Table 4.

Not uncommonly, the process of SDM requires more than 1 critical conversation. Notes can be entered into the medical record to assist with the “next step” meeting if one is needed. This process can either incorporate actual decision aid measures or can be documented by narrative summary. Summarization might include the following: people present, issues and concerns brought forward, pertinent comments and concerns expressed, perceived joint understanding, and status of the plan.

Finally, children with disabilities may be hospitalized for acute or chronic medical issues. Fox et al⁴⁷ outlined a structure for “family care conferences” to discuss

TABLE 2 Practical Steps Common to the SDM Process

- Acknowledge that a decision is at hand and needs to be made
- Identify salient stakeholders and formulate an equality of partners for the process
- Present, without bias, the spectrum of treatment options reasonably available
 - Review risks and benefits of the options being considered
 - Present at appropriate cognitive/developmental level for the child
- Investigate the child's/family's understanding and expectations of the decision
- Identify preferences and priorities of all parties actively involved
- "Negotiate" evenly and with sensitivity the aspects without early concordance
- Reach a decision for action
- Arrange follow-up or a revisiting of the decision to ensure closure
- See Supplemental Information 1 for tools and strategies to support discussions with families, such as "Ask-Tell-Ask," "Tell Me More," and others

Modified with permission from Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9): development and psychometric properties in a primary care sample. *Patient Educ Couns*. 2010;80(1):94–99.

TABLE 3 A Guide to Pediatricians' Conversations: "Choice Talk," "Options Talk," and "Decisions Talk"

Choice talk

- Step back
 - Summarize: "The issue is real. Do you consider it a problem? A major problem?"
 - What's next?
- Offer choice
 - "There is some information about this; I'm happy to share what I know."
- Justify choice
 - Respect preferences: "Treatments have different consequences; some will matter more to you than others; you will need to let me know."
 - Uncertainty: "Evidence may be lacking; outcomes vary at the individual level."
- Check reaction: information overload?
- Defer closure: "You've asked for and I'm happy to give an opinion, but first I wish to be clear ..."

Options talk

- Check knowledge: "What have you read or heard about _____?"
- List options
 - "Before we get into details and decisions, let me go through some options."
 - Note: observing and monitoring the child's present status is always 1 option
- Describe options
 - Using practical terms to ensure understanding
 - Potential order of treatments; postponement options
 - Is the intervention reversible?
 - "Chunks and checking": clarify re pros/cons, resume and clarify
- Provide decision support: informal/formal patient decision aids
- Summarize: list out and have patient/family "return" the information

Decisions talk

- Focus on preferences: "What, from your point of view, matters most?"
- Elicit a preference: offer more time to think/offer more guidance
- Moving to decision
 - "Do you have more questions?"; "How would you like to proceed?"; "Do you need more time to think about our decision?"
- Offer review: decisions can be revisited; can help with closure

Modified with permission from Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361–1367.

treatment decisions. Depending on the clinical situation, the SDM process should be used to help in the process. Unfortunately, time and circumstances can present constraints. But, as Fox et al⁴⁷ suggested, the primary care clinician (who knows the family and has been a part of the larger, longer SDM process) should be an invited participant to provide ongoing support to the family/child and to the hospitalist/specialists.

CONCLUSIONS

- *Future needs for pediatric research.* Three areas in need of further investigation include the following: (1) consensus definition of SDM, (2) measures specific to SDM-related constructs, and (3) selection of outcome measures (eg, child satisfaction, family satisfaction, and positive medical/developmental outcomes, particularly in chronic nonacute conditions).

- *Children, when cognitively competent, should be involved in decisions about their care.* Providing children information (on the basis of developmental age) can help them gain an understanding of the condition and treatments, reduce fear, enhance self-confidence⁹ as well as acceptance, and improve collaboration with treatment decisions. Providers should partner with adolescents and

TABLE 4 Considerations for SDM in Specific Cohorts

Children With	Considerations
Acquired and/or developmental disabilities	<ul style="list-style-type: none"> • Depending on age, etiology, and severity of the disability, families' experiences in decision-making may be greatly different. • Among families whose children have multiple congenital anomalies, decisions of great importance may have been made in the neonatal experience with little SDM. • Decisions often are required that address issues at hand but that have potential ramifications for the long-term. • Experiences in the past may well color the expectations for SDM in the future. • Inclusion of the child in the decision-making process is critical as he or she becomes cognitively aware and able to process options and priorities.
Intellectual disabilities	<ul style="list-style-type: none"> • Depending on the child's age and the severity of the intellectual disability, the young child is likely to be the passive recipient of the decisions made by others. • Depending on age and cognitive and executive function skills of the child, his or her involvement in SDM may require additional time and assistance (child life services, social worker, etc). • "Preference assessment" techniques may be needed (aided by professionals in the intellectual disability field). • Previous experiences (especially in the medical arena) need to be considered in light of the child's experiences, perceptions, and preferences. • Issues perceived traditionally as ethical dilemmas may be more frequent in this group. • Autonomy versus paternalism spectrum often shifts to the parents/caregivers/guardians.
Both severe neurodevelopmental and significant intellectual disabilities	<ul style="list-style-type: none"> • The combination of both intellectual and developmental disabilities lends itself to more interventions that might be considered alternative or complementary or unproven. • Issues perceived as quality-of-life considerations may be spoken of more frequently by families and professionals. • In visiting with parents about values or priorities or goals, these may seemingly shift over time as the child ages. Periodically revisiting the futures planning goals (particularly when no major decision is being required) can help families address future decisions.
Intellectual/developmental disabilities and who have been placed into the state foster care system	<ul style="list-style-type: none"> • Becoming familiar with state regulations under the agency charged with serving these children can better inform decisions, both large and small. • When major decisions need to be made (DNR designation, surgeries deemed nonemergency, and others), the information above can allow legal and ethical decisions to be made without unduly burdening family, staff, or physicians. • Involvement of CASAs and/or a guardian ad litem; as the person designated to advocate for the best interest of individual with intellectual disability, this individual will need to be involved in the process of SDM. • Often, multiple professionals (physical health, mental health, social workers, agency staff, others) have key roles in the overall care of the child; an efficient mechanism for sharing information is critical to addressing the ongoing and recurring issues that require broad input for the best decision-making.

CASA, court-appointed special advocate; DNR, do-not-resuscitate.

parents to solicit preferences about capacities and preferences for involvement as well as consent and confidentiality issues.^{48,49}

- *Development of SDM support technologies.* The development of better decision-support tools and technologies is needed. These tools should support validity in areas of information presentation, values clarification, and the decision deliberation process. Integration of decision-support tools into electronic medical records would support easier and more widespread use. In addition, means of promoting dialogue with families through the use of communication tools, such as patient portals and mobile applications, will support the use of SDM.

- *Implement the application of SDM into daily clinical care.* Three clinical cases are included as examples of complex decisions that many families face. Often, a family will set up a consultation with the hope/expectation that the clinician will answer the question "What would you do?" Offering a quick, prescriptive response negates the process of SDM and the values inherent in the process. The variations in issues addressed by families of children with disabilities are seemingly limitless; constructing SDM algorithms for each is not feasible. Standard questions may not apply. Rather, the elements of the process are key. Three examples have been chosen to allow the use of the

approaches and tools included in the report (see Supplemental Information 2, cases 1, 2, and 3).

With increasing knowledge of and functional use of SDM skills, the clinician will become an effective partner in the decision-making process with families, providing family-centered care. The outcome of the process will support the beneficence of the physician, the authority of the family, and the autonomy and well-being of the child.

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ABBREVIATIONS

SDM: shared decision-making
SDM-Q-9: 9-item Shared Decision
Making Questionnaire

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