Published in final edited form as:

Am J Bioeth. 2018 March ; 18(3): 20–22. doi:10.1080/15265161.2017.1418923.

Optimizing Children's Involvement in Decision Making Requires Moving beyond the Concept of Ability

Victoria A. Miller, PhD¹

¹Department of Pediatrics, Children's Hospital of Philadelphia, and Department of Medical Ethics & Health Policy, Perelman School of Medicine at the University of Pennsylvania

In the target article, "The default position: Optimizing pediatric participation in medical decision-making," Olszewski and Goldkind present an important argument concerning involving children in medical decision making. The authors argue that children should routinely be given a voice and describe a step-wise approach to determining when and how a child should be involved. Their framework is informed by the regulatory requirements for research assent, case studies of adolescent refusal of clinical care, and guidelines for involvement of adults with impaired decisional capacity. They describe their application of this approach to two clinical cases, a 15 year-old with a malignant facial tumor and a 7 year-old with incurable metastatic rhabdomyosarcoma.

I commend the authors for outlining a framework for involving children and adolescents in decision making, especially because their framework assumes that children can almost always be involved. Involving children shows respect for their developing autonomy and may have additional benefits, discussed more below. Olszewski and Goldkind cogently underscore the complex dynamics of supporting both parents *and* children in a fluid and continual process of decision making. Importantly, they recognize that developmental factors and aspects of the environment will influence children's participation, as well as the child's interest in participating. Olszewski and Goldkind move the literature forward by describing, in their Table 1, factors to consider when assessing when and how to involve a child in medical decision making.

However, the authors do not go far enough in emphasizing that there are multiple ways for children to be involved in decision making, even if they do not have the final say. The concept of decision making involvement refers to ways that children can be involved in decisions and includes active verbal participation *and* adult attempts to involve the child (Miller & Harris, 2012). For example, children can be asked for their opinions, concerns, or questions related to a decision, they can be told that they have an important role to play and that adults care about what they think, they can be assessed for their understanding of the situation and/or aspects of the decision, or, as the authors note, they can be given choices related to the decision that will be implemented. Even very young children can be asked how they feel about a decision or if they understand certain elements of a decision, even if it is clear that parents will make the final decision. The authors' assertion that the child's wishes

will not be sought in the case of a low-risk, life-saving therapy is a narrow view, because it does not recognize that the child can be involved in different ways and that such involvement may have important benefits. These include increasing the child's sense of control and self-efficacy, enhancing adherence to the implemented decision, and teaching the child how to communicate about and make decisions.

Unfortunately, there is a dearth of prior research for the authors to draw on, because the field has been limited by a lack of measures for assessing children's involvement in decision making. However, in my recent work, I developed a measure of decision making involvement to assess parent-child interactions about decisions having to do with chronic illness management, called the Decision Making Involvement Scale (DMIS)(Miller & Harris, 2012). Research using that measure found that youth's active involvement and joint decision making behaviors during decision making interactions with parents were associated with better adherence in youth with type 1 diabetes (Miller & Jawad, 2014). I adapted the DMIS to measure children's involvement in decisions about research participation. The results of that study indicated that children's perceptions of more researcher facilitation of their involvement in the decision (e.g., asking for their opinion and soliciting questions) were associated with greater perceived decision self-efficacy, after controlling for age (Miller, Feudtner, & Jawad, 2017). Furthermore, children's perceptions of greater autonomy support from the researcher (e.g., indicating that the child was central to the decision) were associated with their perceptions that the decision making process was more fair, after controlling for age. Hopefully, these data as well as future studies using the DMIS or similar measures will provide empirical support for a more expansive notion of children's decision making involvement across different medical settings.

A final concern is that Olszewski and Goldkind refer to children's "ability to participate," which has the, perhaps unintended, consequence of emphasizing the cognitive aspects of decision making. A focus on ability or capacity asks the question, when are children and adolescents capable of making decisions on their own? If deemed incapable, children may be left out of the decision making process entirely. The more relevant question is, how can parents and providers best support children's involvement in decision making and facilitate effective and independent decision making as they mature (Broome & Richards, 2003; Geller, Tambor, Bernhardt, Fraser, & Wissow, 2003)? Again, empirical data to answer this question are lacking, because much of the prior research related to children's medical decision making has taken a cognitive approach, focusing on understanding and decision making skills (Miller, Drotar, & Kodish, 2004). A more expansive view of involvement requires moving beyond the concept of ability and recognizing that parents and health care providers can support and guide decision making involvement in multiple ways.

Perhaps because they focus on the context of life-limiting illness, Olszewski and Goldkind do not adequately recognize that being involved, regardless of capacity, gives children the opportunity to observe and practice aspects of decision making, which is important for becoming good decision-makers themselves (Ruhe, De Clercq, Wangmo, & Elger, 2016). Such practice may provide the foundation for increasingly independent decision making, as children gain experience and maturity (Fuligni & Eccles, 1993; Miller, 2009). For example, children with a chronic illness and their families have to make frequent decisions regarding

daily illness management (e.g., whether and how to respond to symptoms) as well as single-event decisions related to the treatment regimen (e.g., medication changes)(Miller, 2009). Eventually, responsibility for making such decisions shifts from the parents to the child, and children need practice and support before being able to make effective decisions on their own. In these situations, there are potential short- and long-term benefits of attempting to solicit children's involvement, even if they do not respond to such attempts. Facilitating children's involvement in decision making conveys that the child is central to the decision, may give children a sense of control over their situation, and may enhance the likelihood that the child will speak up in the future. Despite these potential benefits, additional research is needed to identify why children's participation in medical decision making remains low (Coyne, 2008) and to develop and evaluate child-, parent-, and provider-directed strategies to enhance the continuum of children's involvement and assess the impact on health-related beliefs and behaviors over time.

In sum, Olszewski and Goldkind make an important argument regarding children's involvement in medical decisions, suggesting that children can almost always be involved. They provide a helpful starting point for thinking about when and how to involve children. However, greater specificity regarding the multiple ways in which children can be involved is needed, regardless of whether or not the child will have the final say, as well as additional research to further develop the evidence base regarding best practices for involving children. Finally, the field needs to move beyond the concept of "ability," which shifts attention away from the important question of how parents and providers can best guide and support children's involvement, with the goals of respecting children's voices and preparing them to be effective decision-makers as they mature.

Acknowledgements:

Some of the research reported in this paper was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD; grant #s 1R21HD067554-01A1, 1R01HD064638-01A1, and K23HD055304). The funding agreements ensured the authors' independence in designing and conducting the study; collecting, managing, analyzing, and interpreting the data; and preparing, reviewing, and approving the manuscript. The content is solely the responsibility of the author and does not necessarily represent the official views of the NICHD or the National Institutes of Health.

References

- Broome ME, & Richards DJ (2003). The influence of relationships on children's and adolescents' participation in research. *Nursing Research*, 52(3), 191–197. [PubMed: 12792260]
- Coyne I (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, 45, 1682–1689. [PubMed: 18706560]
- Fuligni AJ, & Eccles JS (1993). Perceived parent-child relationships and early adolescents' orientation toward peers. *Developmental Psychology*, 29(4), 622–632.
- Geller G, Tambor ES, Bernhardt BA, Fraser G, & Wissow L (2003). Informed consent for enrolling minors in genetic susceptibility research: A qualitative study of at-risk children's and parents' views about children's role in decision-making. *Journal of Adolescent Health*, 32, 260–271. [PubMed: 12667730]
- Miller VA (2009). Parent-child collaborative decision making for the management of chronic illness: A qualitative analysis. *Families, Systems, & Health*, 27(3), 249–266.

- Miller VA, Drotar D, & Kodish E (2004). Children's competence for assent and consent: A review of empirical findings. *Ethics & Behavior*, 14(3), 255–295.
- Miller VA, Feudtner C, & Jawad AF (2017). Children's decision making involvement about research participation: Associations with perceived fairness and self-efficacy. *Journal of Empirical Research on Human Research Ethics*, 12(2), 87–96. [PubMed: 28421884]
- Miller VA, & Harris D (2012). Measuring children's decision making involvement regarding chronic illness management. *Journal of Pediatric Psychology*, 37(3), 292–306. [PubMed: 22138318]
- Miller VA, & Jawad A (2014). Relationship of youth involvement in diabetes-related decisions to treatment adherence. *Journal of Clinical Psychology in Medical Settings*, 21, 183–189. [PubMed: 24659299]
- Ruhe KM, De Clercq E, Wangmo T, & Elger BS (2016). Relational capacity: Broadening the notion of decision-making capacity in paediatric healthcare. *Bioethical Inquiry*, 13(4), 515–524. [PubMed: 27365104]