Hearing Children's Voices

by William G. Bartholome

The Guidelines *Document published in this issue of* Bioethics Forum *is both unique in its approach and ahead of its time. It moves all parties involved in the direction of viewing children as persons whose wishes in matters of health care should be heard and taken seriously.*

The set of guidelines that form the "centerpiece" of this special edition of *Bioethics Forum* is the result of the work of a highly dedicated group of professionals, parents, and children. The document is an attempt to provide guidance to health care professionals, parents and children on the difficult question of how decisions regarding the health care of children *ought* to be made. In addition to providing background information, definitions, and assumptions, the task force addressed this central ethical question at three different levels: 1) by proposing a conceptual framework; 2) by recommending information to serve as the basis for written materials to be provided to children and their parents; and 3) by providing a detailed analysis of the ethical obligations, rights, and responsibilities of child, parent, provider, and health care organization in three overlapping models for ethical decision making involving the entire population of minors.

The conceptual framework proposed by the task force is based on a proposal originally developed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the late 1970s (National Commission 1977). The commission began its work by addressing the difficult set of ethical questions involved in the participation of children in research. The commissioners proposed that the concept of "proxy" or "parental consent" to the participation of children in research was not an adequate ethical basis for research involving children. They recommended that only persons with decisional capacity be allowed to "volunteer" to be part of research and to provide "informed consent" to becoming research subjects. The idea that parents or guardians could "volunteer" their children as research subjects was explicitly rejected and replaced with the concept of "informed parental permission." The commissioners also felt strongly that children should be involved in making decisions about their participation in research to the extent that they were able to do so. In addition to the informed permission of parents or guardians, investigators were obligated to obtain the "assent" of the child when the child was old enough to participate in the decision-making process. The commission also proposed that under most circumstances the "dissent" of a child to become a research subject should be respected. By linking the question of consent to participation in research to the concept of decisional capacity, the commission also challenged society to look beyond structures like the legal "age of majority" to the obvious fact that many minors have developed the capacity to make informed choices about their participation in research. They proposed that minors who have the capacity to provide informed consent to participate in research should be allowed to do so regardless of age.They further proposed that, for some studies, the informed consent of the minor would serve as an adequate ethical basis for involvement of the minor in research even without parental permission. These recommendations were incorporated into

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the federal regulations that have governed the conduct of research involving children in the United States since the early 1980s.

Before and during the course of the work of the task force, the Bioethics Committee of the American Academy of Pediatrics also proposed that this conceptual framework be adopted by the Academy as part of what might be called the ethical basis of pediatric practice; that its use should no longer be limited to the context of the involvement of children in research. We are extremely pleased that now this recommendation has been approved by the Academy's Council on Child and Adolescent Health and recently published in the journal *Pediatrics*. (American Academy of Pediatrics 1995). This new conceptual framework was also adopted by the American Society of Human Genetics and the American College of Medical Genetics in its recently published report on genetic testing in children and adolescents (ASHG/ACMG 1995).

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Although I consider the shift in this new framework from "parental consent" to "parental permission" to be an important clarification regarding the range of discretion open to parents in making health care decisions regarding their children, I am most excited about the potential changes in the decision-making process precipitated by incorporation of the concept of the assent of the child. Ever since the explosion of information about child development began to unfold in the second half of this century, there has been increasing recognition of the need for a conceptual framework that recognized the developing capacity of children for autonomy, for rationality, and for participation in decisions about their lives. Respect for children as moral agents requires a respect for the developing capacity of the child for making choices, for the exercise of autonomy. Autonomy can be thought of as the process by which the "self" of the child is continuously asserted, constructed, de-constructed, and re-constructed. From the exuberant "I did it!" of the toddler to the profound "I do" of the bridegroom, the evolving "self" must work at the business of autonomy. To become a self-governing person, one must relentlessly practice the governing of one's self. We are also becoming increasingly aware that the use of force, coercion, and manipulation in dealings with a child are destructive of the child's sense of predictability and control; they undermine the child's sense of trust in parents and other adults and threaten the child's evolving sense of self-control, of mastery of one's life.

Yet, assent is a fragile and vulnerable concept. The task force feels strongly that providers are obligated to solicit assent, that is, to assist children to develop an appropriate awareness of the nature of their conditions; to disclose to them the nature of the proposed treatments and what they are likely to experience in undergoing them; and, finally, to solicit children's expression of willingness to accept and to undergo the proposed treatments. Providers are also being asked to hear and respect the "dissent" of the child and to respond to the fears, concerns, and informational needs that may have prompted the child to withhold assent. The implications of this framework are quite revolutionary. Providers are being asked to develop and maintain functional interpersonal relationships with child patients based on mutual respect. They are being asked to take the time to listen to children and to involve them in the decision-making process in ways that would have been unimaginable only decades ago. They are being asked to minimize the use of force or coercion in dealing with children. They are being asked to take seriously conflicts between the desires of parents and those of "mere" children. This is a very far cry from the adage: "children should be seen but not heard."

On the other hand, the evidence is rapidly accumulating that incorporating this challenging and fragile concept into our relationships with child patients has measurable and powerful effects on how well they adjust to illness, on the course of chronic diseases of childhood like diabetes, cystic fibrosis and juvenile rheumatoid arthritis. The more these children can be given a sense of control over the impact of the disease on their lives, the better they respond to treatment, and the more successful they are with the often daunting task of adjusting to the demands of the illness and of growing up with a chronic illness. Providers and parents are increasingly being challenged to allow children to "own" their diseases; to trust in the willingness and capacities of children to monitor their own signs and symptoms; and to assist them in playing an increasingly active role in their own care. Over the course of the child's development, the child gradually displaces the parent as the primary guardian of the child's health and as the "partner" of the health care provider in decision making.

In terms of the second "level" of its work, the task force attempts to provide health care professionals and their organizations with specific guidance regarding how to meet the informational needs of two overlapping populations of children: those with a developing capacity to participate in health care decision making and those who have developed the capacity to make most of their own health care decisions; and the informational needs of the parents of both populations of children{See Sections 6.0-6.4}. Although the specific listing of the proposed ethical rights of minors who have developed the capacity to make decisions and the recommendations regarding information to be given to parents will prove helpful, the "new ground" broken by the task force is the development of a "Bill of Rights" for the child with a developing capacity to participate in decision making. These are intended for the child mature enough to "assent" to health care interventions. Although a written text is clearly an inadequate vehicle for providing these children with information regarding their decisional rights, this text will hopefully serve as the basis for a wide variety of informational programming which attempts to educate them and to empower them to play an active role in the decision-making process. To my knowledge, this represents the first attempt to develop a comprehensive listing of the ethical rights of patients in this age range that is intended to be provided directly to them when they enter the clinical setting. The children who participated in the process of developing this listing of rights were not only excited about this concept, but very helpful to the task force in developing appropriate language for expression of these rights.

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I am proud of the fact that The University of Kansas Children's Center is one of the first centers in the country to develop a set of information booklets based on the task force's recommendations which are now being given to children and their parents on admission. Although the program is less than a year old, it has won the enthusiastic support of our staff. Our hospital-based teachers and Child Life staff are also in the process of developing supplemental curricular materials and play therapy projects for educating our child patients about their rights.

And, finally a few comments about the third "level" of the work of the task force. The basic assumption involved in this proposal for decision-making "models" is that health care of minors requires not one, but at least three separate but overlapping models: one for infants and small children too young to play any meaningful role in the decision-making process; one for children with the developing capacity to participate (above the "age of assent"); and, one for young people who have developed the capacity to make most health care decisions (capable of providing an informed consent to most treatments) but are still considered "minors" by the laws of most states {See Sections 7.0- 7.3}. The reader will note that the task force has attempted to provide a detailed ethical analysis of each of these models in which the ethical roles, obligations, rights, and responsibilities of all the parties are described: those of the child patient; of the parent; of the health care professional; and, of the health care-providing organization. Again, I am not aware of any other attempts to describe these three models with this degree of specificity. In this lengthy section of the report, the task force has attempted to provide practical guidance about the application of its proposed conceptual framework to these three populations of minors in a manner that anticipates at least some of the pragmatic hurdles that patients, parents and health care providers are likely to encounter. Specific recommendations are made about dealing with the inevitability of ethical conflict between parents and children, between care providers and parents, and between providers and their child patients. The task force has also pointed out areas in which the operation of these three models for decision making interface with and present challenges to the legal system. In addition, the task force provides specific recommendations regarding the clinical determination of decisional capacity; appropriate surrogates for minors with decisional capacity; and, implementation of the Patient Self-Determination Act of 1991 in a pediatric population {See Sections 7.4 - 7.7}.

It is the hope of the members of this task force that this document will be read as an attempt to open up dialogue, to stimulate a systematic and critical re-examination of our society's assumptions and practices as they relate to children,parents, and health care providers. In an important sense, I see this text as significantly "ahead of its time." The conceptual framework, informational recommendations, and decision-making models it proposes are clearly not those that shape the health care of America's children today. Our goal was to describe what we felt "ought to be," to paint a picture of an "ideal clinical world."

We anticipate that these guidelines will continue to evolve and change as we attempt the task of bringing these ideals into the "real world" in which we attempt to serve these special patients and their families. Will we be able to change the clinical context to one in which the voices of children can be heard and respected? Are we willing to assist children to participate to the extent of their capacity in making decisions about their health? For me, to do anything less is to fail to respect them for the persons they are in the process of becoming and to fail to live up to the ethical demands of being parents of and professionals for children. As the reader will note in the commentary provided by my own daughter, Claire Bartholome, our kids are expecting nothing less than this degree of respect for the persons they are working so hard to be.

References

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