Children, Society, and Health Care Decision Making

by James M. Caccamo

Viewed realistically in the context of modern family and social conditions, the Guidelines Document may be difficult to implement. Education will be the key.

If we could have but one generation of properly born, trained, educated and healthy children, a thousand other problems of government would vanish.
— Herbert Hoover

A Frame of Reference

This paper will explore the issue of decision-making rights for minors as expressed in the Midwest Bioethics Center's document *Health Care Treatment Decision-Making Guidelines for Minors* in the context of modern society. What is the societal frame of reference in which the guidelines are being placed and used? And how can such guidelines be implemented, considering the current status of our nation's children and their relationship with parents and other adults?

Status of Our Children

The National Task Force on School Readiness (1991) reported that 500,000 children each year are exposed to health risks such as low birth weight, prenatal alcohol abuse, drugs, lead poisoning, malnutrition, or child abuse and neglect. The report further indicated that one in four children younger than six are growing up in families that cannot afford safe housing, adequate nutrition, health care, or quality child care.

One third of all children are born out of wedlock (*The State of America's Children Yearbook* 1994). Thirty-eight percent of our nation's children live in poverty (Damon 1995). One in five children live in a family with an income below the federal poverty level (National Center for Children in Poverty 1993). Over eight million of our children below the age of six have no health insurance (Children's Defense Fund 1994).

Serious crime committed by children under the age of eighteen has increased significantly in the past five years and death by gunshot is the leading cause of death among our youth (*Report on the Use of Handguns in Crime* 1994).

Reports of child abuse, too, have increased 259% from 1976 to 1989 (*Beyond Rhetoric* 1992). It is estimated that one in four girls and one in six boys has been sexually abused. Psychological disorders among children have increased with teen suicide, eating disorders, and substance abuse continuing to grow (*Marriage in America* 1995).

In addition, families are suffering. Twenty-six percent of all children below the age of eighteen live with a divorced parent (Behrman 1994). Forty percent of women are likely to divorce (Behrman 1994). Our nation is the world leader in fatherless families (Blankenhorn 1995). Most children born out of wedlock will live in a single-parent household and that household has a significant probability of being in poverty.

Damon (1995) postulates that because of societal changes, the American family has become more child-indulgent. He demonstrates that our adult society has fading expectations for children, making a case that parents and schools are doing children a disservice by not providing them more rigorous guidance, discipline, challenging learning situations, core values, and spiritual direction.

National political issues also affect the development and implementation of guidelines concerning health care treatment decision making for

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minors. We live in a country that did not sign or ratify the United Nations Convention on the Rights of Children (Carnegie 1994). This national behavior begs the question: "Do we, as a nation, support the concept of children's rights?"

Considering the current status of children and families and our national mood toward parental rights and the re-establishment of the family, the importance of the *Guidelines* becomes obscure. They might be like Nero, fiddling as Rome burns. If the lives of our children are on a decline, what true impact will the *Guidelines* have?

Education, Education, Education

It could be argued that the *Guidelines* might be workable and could be a catalyst in bringing about improvement in the ways parents deal with their children. If the *Guidelines* are to be successful, however, parents must respect their children's ability to understand, discuss, and make decisions regarding their health care treatment.

To make the *Guidelines* a reality, education of parents, children, and health care professionals must take place. Education for each group must include general information about children's capabilities and how raised expectations will bring about more responsible behavior. Children can, and will, rise to our expectations.

The Education of Parents

Parents need to understand that they have a legal right to make health care treatment decisions for their children. This was a central issue for parents with whom I spoke in preparing this manuscript. Once assured of their parental role, a more constructive discussion could ensue about giving children a voice in health care treatment decisions.

The *Guidelines* do a remarkable job in placing the minor's decision-making capacity along a continuum. They speak to:

1. minors without the capacity to participate in decision making in any meaningful way;
2. minors with a developing capacity to participate in decision making; and
3. minors who have achieved the capacity to make most health care decisions.

This process of development must be explained to parents so they understand that different levels of decision making are expected from a preschool-aged child compared with a fifteen year old.

In preparing this essay, I discussed the *Guidelines* with many parents. Their main concern centered around a minor's capacity to make decisions without benefit of experience, breadth of knowledge, and wisdom that comes with age. Once the concept of a continuum of decision making was explained, parents seemed more relaxed and open to discussing the guidelines.

From a parent's point of view, concepts of "child assent" and "informed parental/guardian permission" are not easy issues with which to deal. The level of a child's knowledge and understanding regarding subtle implications of health care were stumbling blocks. While the idea of a continuum of developmental readiness to make decisions seemed clear to parents, their inability to judge their child's position on that continuum clouded their acceptance of the concept of assent. What if my child is not ready to make that level of decision? How do I know when my child has reached a level of assent? What if I'm wrong and he or she is not really ready?

Education of parents will be critical for the implementation of the MBC *Guidelines*. Organizations such as the Parent Teacher Association would be excellent partners in the development and implementation of instructional programs for parents. Other civic organizations such as the Junior League also could be partners in helping educate parents about the *Guidelines*, as would churches and Sunday schools.

Education: Children

The minors with whom I spoke about decision making had not yet had to make any significant health care decisions. Nevertheless they liked the idea of having input into treatment decisions, and many said their parents would listen to their opinions. They believed they were more capable of making decisions that affect their lives than most adults expect.

Education: Health Care

Responsibility for successful implementation of the *Guidelines* will fall heavily on those in the health care profession. Physicians, nurses, medical social workers, and other health care providers are prime players in ensuring that informed consent and informed permission can be given by the minor and his?her parents. The role of the health care provider is clearly delineated in the *Guidelines*.

Educational efforts for health care providers should avoid focusing on professional areas of expertise and instead focus on communicating with children. Children's ability to understand, their breadth of knowledge and experience, and their processing of information differ from those of adults. Child development specialists and professionals in education would be significant resources in developing curriculum materials for the health care profession.

Conclusion

Assuming the *Guidelines* are workable and that an in-depth educational effort is underway to implement them, there still is concern about the importance of the *Guidelines* juxtaposed with the world in which our children live.

It is imperative that all people, regardless of age, be treated fairly and have an opportunity to make decisions that affect their lives. Young people are capable of working with parents, health care providers, and clergy to make serious medical decisions. But what about other, more pressing ethical issues in our health care industry? What about children who never get to see a physician? How do we care for more than eight million children who have no health insurance and who do not receive adequate health care, regardless of their assent? How do we ensure that health care reform includes meeting children's health care needs? How do we engage society to see that we provide children with a safe, healthy environment in which to grow?

While the *Guidelines* document is a helpful vehicle for raising the issue of minors' health care treatment rights, implementing the guidelines may be difficult in a society burdened with family and societal problems. The *Guidelines'* effectiveness will rest on the effort put into the development and implementation of educational components for parents, children, and health care providers. Education will be the key to successfully implementing the *Guidelines*.

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