Summary and Synthesis of Papers and Discussion at Ethics in Oral Health Policy Seminar January 21, 2000

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This report summarizes and synthesizes the papers prepared for and discussed at a seminar: "Allocation of Resources for Children: First Bioethics in Maternal and Child Health Policy Seminar" along with some of the discussion that occurred on January 21, 2000.

Language and Structure of the Moral Arguments for Children's Access to Health Care

Responsibilities, Obligations, and Rights. The papers prepared for the seminar presented several moral arguments for children's access to health care, including dental and oral care. Several of these arguments appeared in different papers; several of them overlap, while others are distinctive. Whatever their differences, and whatever the differences among all the participants, there was a strong consensus -- no votes were taken -- that children should have access to health care including dental care. This consensus could be stated in at least two ways: (1) The society has an obligation or responsibility to provide such care, or (2) children have a right to such care. Some participants expressed reservations about the language of rights. Nevertheless, virtually everyone stressed that society has a responsibility, sometimes stated as an obligation, to provide such care and, by implication, that we should translate this responsibility into a political legal right so that children or those speaking on behalf of children can make justified claims within the political legal system. The idea of societal responsibility leaves open numerous questions about who should exercise that responsibility -- i.e., which institutions, organizations, professions, or individuals should discharge the societal responsibility. Most concur that state and federal governments, at least as a last resort, should ensure that this societal responsibility is met.

Justifying and Motivating Reasons. Some reasons offered in moral discourse attempt to justify an act, practice, or policy, while others attempt to motivate agents to act in certain ways. It would oversimplify moral discourse to try to separate justifying reasons from motivating reasons, particularly because justifying reasons often also function as motivating reasons. For instance, an appeal to children's vulnerability can both justify a social policy of providing health care to children and also motivate people to realize that policy. Nevertheless, it is sometimes useful to distinguish justifying and motivating reasons, and some moral discourse in the papers and the discussion mainly concerned how to motivate the society to implement what it ought to implement, specifically, a policy that ensures adequate health care for all children. Some moral discourse also appeals to our imagination by confronting us with particular and powerful stories, for instance, of the impact of poor dental health, sometimes as a result of lack of access to dental care, on children's self-esteem.

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Strategies of Moral Argument for Children's Access to Health Care. In the U.S., approximately 45 million citizens and residentsⁱ lack health insurance and millions more are underinsured, in contrast to other industrialized, Western countries. As a result in the U.S. it is necessary to mount moral arguments for children's access to health care that would not be needed in other countries. One question in mounting these moral arguments is whether to defend (1) a societal obligation to provide health care to all citizens and residents and, thereby, for all children, (2) a societal obligation to provide health care for children and then build up to all citizens and residents, or (3) a societal obligation to provide health care for children, without regard for the implications of such an obligation for others in the society. The first strategy would recognize a general moral obligation to all citizens and residents, including children; the second would start with the specific group of citizens and residents who are children and then generalize to others in the society because of their relevant similarities; the last would target children in a strategy that resembles "spot-zoning," which because of special characteristics of children may not extend to others. The first strategy is indirect; the latter two are direct. The first is broadly inclusionist, while the second one builds up, or out, to all from a societal obligation to care for children, and the third one stops with children. Even the broadly inclusionist approach may still recognize the special claims of children to access to health care. In general, the following summary treats the arguments in the seminar as arguments focused on children, even though some of them also started with or moved to health care for all citizens and residents.

Principles, Values, and Moral Arguments for Health Care for Children

The principles or values that support moral arguments to provide health care to children appear in different forms in various ethical theories. Those theories often take one or more principles or values to be central, while viewing others as derivative or, in some cases, irrelevant. However, several of these principles or values have wide appeal outside the context of any particular ethical theory. We invoke them in our day-to-day moral discourse without explicit appeals to those theories. While the papers prepared for the seminar sometimes invoked different theories, they often presented their underlying principles and values as independent of those theories. This summary selects several arguments that participants explicitly made for children's access to health care, and probes the values and principles, particularly those of justice, to which the arguments appealed. The arguments specifically focus on (1)individual well-being, (2) responsiveness to children's vulnerability, (3) social empathy, care, and solidarity, (4) equality of opportunity, (5) formal justice, (6) social utility, and (7) self-interest.

1. <u>Individual Well-being.</u> Health care, including dental care, can contribute to the children's well-being, both now and in the future. As Dan Brock notes, "On any account of human well being, the prevention or relief of pain, suffering and disability, together with the avoidance of the loss of life . . . , are fundamental benefits to persons and fundamental in promoting their well being." Basic health care is thus fundamental to people's well-being, just as nutrition, shelter, and personal security, because they all are important "in making possible a decent and worthwhile life." Hence, Brock contends, justice requires that all persons have these instrumental goods available to them.

Inadequate dental and oral care can cause not only pain, suffering, and major dental and oral problems, but can also create other health and social problems. Thus, as Loretta Kopelman

notes, prevention of dental caries and common dental problems is "extremely important" for the individual's well-being. Furthermore, some forms of dental and oral care can be provided at relatively modest costs, especially in preventive programs. As Rosemarie Tong stresses, one argument for "providing all U.S. children with health care is that relatively inexpensive interventions can aid in the treatment of many problems common in children, including vision impairments, hearing loss, dental pathology, allergies, and asthma, as well as a variety of chronic disorders that cause considerable, functional impairments."

2. Responsiveness to Children's Special Vulnerabilities. A closely related argument focuses on children's special vulnerability to risks and threats to their well-being. According to Daniel Callahan, "If we take at all seriously the idea that life in any community is to some extent a life of interdependence, and if we believe that those unable to care for themselves have the strongest claim on our health, then the case for giving a priority to children is strengthened." And, in Larry Churchill's view, "The moral quality of any health care system is measured by how the most vulnerable are treated." Society's special duties toward children stem, to a great extent, from children's special vulnerability and thus their dependence on others. These duties, as Loretta Kopelman notes, are partially reflected in society's appeal to the best-interests standard for intervention with and treatment of children (and other incompetent individuals), even against familial decisions. Nevertheless, difficult questions remain about how to draw boundaries or spheres of responsibility, for example, between the family and the state. Furthermore, this best-interests standard points to an ideal or goal in relation to children, not an absolute requirement in all circumstances.

As Dan Brock emphasizes, the vulnerability of children, relative to most other members of the society, appears in several characteristics: Children have limited knowledge and experience and thus do not know and cannot determine their health needs; they usually cannot pursue and secure their own care; families have substantial (though not unlimited) autonomy to care for their members without outside accountability often even when their care falls short of a best-interests standard. According to Brock, these aspects of children's vulnerability help us understand why children are among the society's worse off: Many are, to be sure, are worse off in terms of health, along with overall well-being and opportunity, if they are poor. But another sense of vulnerability is also important: "they are vulnerable to their health or well being worsening from causes beyond their control in ways and to extents that adults typically are not."

For these reasons, it may be morally important not only to remove financial and other barriers to children's access to health care. As Brock contends: "For children, access is not enough; we have a moral responsibility to ensure that children actually receive needed health care services in ways that reflect their special vulnerabilities."

3. <u>Social Empathy, Care, and Solidarity</u>. A third argument focuses on social empathy, care, and solidarity. In its 1983 report, <u>Securing Access to Health Care</u>, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research noted that the societal provision of health care expresses social bonds of empathy and compassion in relation to birth, illness, and death, all of which are interpersonally significant.

Rosemarie Tong draws on what philosopher Sara Ruddick calls "maternal thinking" -- the kind of thinking exemplified by mothers caring for their children but not limited to them. Tong highlights three features of maternal thinking and practice-- preserving children's lives because, particularly as infants, they are so vulnerable; fostering their growth as emotional, cognitive,

sexual and social beings; and training them to be socially acceptable. Children's vulnerabilities, discussed above, obviously evoke maternal thinking and practice. And children's vulnerabilities to threats to their health put at risk their well-being, including their growth and social acceptability. Tong notes that "maternal practitioners" should be concerned about all these risks. For instance, "it is difficult to help a child with poor oral health grow and to achieve social acceptability. Children with bad teeth and gums suffer through meals, can neither concentrate on learning nor enjoy playing, and continuously live 'with the embarrassment and diminished self-esteem [which results] from an unattractive appearance."

Thus, according to Tong, "if we really value children, society has to start thinking maternally. . . . The new millennium requires a new kind of moral thinking. I suggest that we Americans start to think maternally about each other; for only when we start caring about each other's survivability, growth, and social acceptability, will we be able to adequately meet our children's many needs." As Kopelman observes, "for empathy to generate a genuine, enduring and just social change with regard to children, we need to be aware of the number of children lacking good health and access to good health care."

- 4. Equality of Opportunity. Several papers invoked the principle of fair equality of opportunity, especially as articulated by John Rawls and as extended by Norman Daniels. The basic idea is that the ability to function in a "species typical manner" is indispensable for equal opportunity in our society, and that each person needs the goods, such as education, that can provide equal opportunity. Health care is necessary to meet persons' special health needs and thus to promote equality of opportunity, which is such an important value in American political culture. According to Dan Brock's interpretation, "While health care's impact on people's well being is fundamental to why justice requires that it be available to all, it is possible to capture most of this impact of health care under the concept of opportunity. . . . It is health care's role in promoting equality of opportunity that makes ensuring access to health care for all a fundamental requirement of justice." In Loretta Kopelman's analysis, "Health care for children is especially important in relation to other social goods, because diseases and disabilities inhibit children's capacities to use and develop their talents, thereby curtailing their opportunities.... [C]hildren cannot compete as equals among their peers if they are sick or cannot see or hear the teacher, and so a society committed to a fair equality of opportunity for children should provide adequate health care." The points already made under children's well-being, vulnerabilities, and social empathy, care, and solidarity establish that dental and oral health plays a major role in children's opportunities to flourish in various contexts.
- 3. <u>Formal justice</u>. Many of the arguments the seminar considered depend in part on the requirement of formal justice that we should treat similar cases similarly. Because this requirement is purely formal, it cannot guide actions, unless we have ways to identify relevant similarities and differences and to determine how we should treat those within the different categories.

Various material criteria of justice identify relevant similarities and differences for purposes of distributing benefits and burdens, costs, etc. Material criteria for just distributions in different contexts include such characteristics as ability to pay, effort, and desert. Much of the debate about access to health care hinges on arguments about which material criteria are relevant.

Formal justice plays a significant role in arguments that oral or dental care should be covered along with medical care. Despite the widespread misconception that dental problems are trivial, mainly cosmetic, and rarely serious, these forms of health care are relevantly similar in that dental problems cause pain, suffering, and otherwise affect well-being. For instance, according to Jonathan Kozol, as quoted by Rosmarie Tong:

Although dental problems don't command the instant fears associated with low birth weight, fetal death, or cholera, they do have the consequence of wearing down the stamina of children and defeating their ambitions. Bleeding gums, impacted teeth, and rotting teeth are routine matters for children I have interviewed. . . . Children get used to feeling constant pain. They go to sleep with it, they go to school with it. . . . To me, most shocking is to see a child with an abscess that has been inflamed for weeks, and that he has simply lived with and accepts as a routine part of life.

In addition, dental or oral problems may also cause other non-dental or non-oral health problems. For instance, oral problems often have an impact on children's growth, because of problems in eating, and on their social acceptance because of embarrassment and low self-esteem as a result of their appearance. These problems are especially prevalent among poor children.

In a different kind of appeal to formal justice, Loretta Kopelman argues that "it is unfair that children are denied access to potentially beneficial, state-supported health-care programs available to many adults." Justice requires that "any state-funded, health-care goods, services or benefits for adults should also, as a matter of justice, be available to children." This is a conditional argument: If adults have access to state-funded health care, children should have similar access. But other participants noted that much depends on the basis of the societal responsibility to particular adult groups -- for instance, if our society recognizes an obligation to provide health care to veterans, on the basis of their particular past societal contribution, that recognition would not imply, on grounds of formal justice, an obligation to provide health care for children. In discussion, Kopelman noted that the other arguments she (and others) accepted could stand alone, but she saw the conditional argument, based on formal justice, as a way to shame the society into providing health care for children. Hence, for her, it offers a motivating reason more than a justifying one.

6. Social utility. The societal provision of health care to children, many argue, would contribute to societal welfare. After all, Daniel Callahan notes, "it is children who make up the future adult citizens of our society. In the short run, children need our care, but it is no less important to realize that in the long run we will need their adult good health for our common care and welfare." Indeed, children "represent the principal social capital of the country." According to Loretta Kopelman, even though a utilitarian moral perspective might not always justify priority for children's health care, "it would certain regard as unjust an age bias against children as we seem to have in this country." In some countries "children receive dental care unavailable to adults because the treatments have lifelong benefits and avoid later costly problems."

The social utility argument may take different forms depending on the calculus used. On the one hand, health care for children might have priority over health care for adults because it will, in general, produce more benefits over time. However, as Dan Brock notes, if those benefits are discounted because they occur in the future, or because those who receive them are not in the work-force, cost-effectiveness analysis may actually discriminate against children. Thus, as we will note below, it is important to attend to the impact on children of different

approaches to allocation of resources within health care and to constrain those approaches by standards of justice, fairness, and equity.

7. <u>Self-interest</u>. While accepting various other arguments for providing all citizens and residents, including children, access to health care, Larry Churchill notes that these arguments, individually or collectively, have not proved to be politically compelling, in part because they appear to require acting against self-interest. Hence, he seeks to find a motivating reason for societal action in health policy, and, drawing on philosopher David Hume, he finds this motivating reason in a broad conception of self-interest. Hume's conception of justice includes self-interest along with sympathy, and such a combination provides "the best chance" for reforming the health care system. In evaluating health policies, too many Americans pit fairness against self-interest, rather than recognizing that a fair and equitable system would be advantageous to all of us personally. In particular, our own children will not lose if uninsured children gain.

Even though Churchill argues from general access to health care to the case for children, he notes that it is easier to argue for children's access than for adults' access: Children's voluntary actions have not caused or contributed to their illnesses, and they are not free riders who could afford to purchase health insurance but refuse to do so. Not only can self-interested reasons remove impediments to including children in health care, they can even provide additional reasons for providing health care to children. First, focusing on the family, Churchill contends that all parents have a stake in avoiding "intrafamilial struggles" about whose health care needs will be met; "familial unfairness" arises when some members of a household can be covered through a policy while others cannot be. Second, Churchill argues that a broader conception of self-interest should also motivate adults who no longer have children, or who have never had children and never plan to do so. This self-interested reason is that the common resources on which adults hope to draw in their retirement depend on future workers who are both able to work and who are willing to continue a tradition of providing medical and social care for the elderly. Hence, providing health care to children both helps to keep them healthy and encourages a sense of community among different age groups.

Several participants raised questions about self-interest as a motivating reason. In particular, some noted that, as a matter of fact, it is not possible to avoid competition between age groups, thus pitting children against others.

Social and Cultural Obstacles

Several participants addressed social, cultural, and other obstacles that stand in the way of providing universal access to health care, including dental and oral care. We can remove some of these but perhaps not others, and the hard question is whether we can remove enough in order to implement children's access to health care. Some participants noted the obstacles that professional divisions, an inadequate number of dental and oral health care professionals, and their uneven geographical distribution create.

For Daniel Callahan, important obstacles include the complacency that has resulted from the reduction of infant and child mortality rates; the bias toward cure over care; the "rescue principle," which concentrates great care on those most in danger of death or severe disability; and our cultural individualism. Although each value back of these obstacles is important, now, Callahan contends, we must balance them against other communal values in order to meet the

needs of children. We need to consider how to set appropriate communal priorities for our time and place among the various goals of medicine -- (1) the prevention of disease and injury and the promotion and maintenance of health; (2) the relief of pain and suffering caused by maladies; (3) the care and cure of those with a malady and the care of those who cannot be sure; and (4) the avoidance of premature death and the pursuit of a peaceful death. We need to attend less to the avoidance of premature death and concentrate on the reduction of illness and disability, including chronic conditions among children; we need to use preventive programs, such as good, early dental care, to avoid later problems; we need to consider the health needs of families; and we need to seek ways to reduce the negative impact of low socioeconomic status on children on children. Furthermore, in making the political case for health care for children, it will be important to envision a sustainable health care system, which may require scaling back some aspirations in the pursuit of new technologies and in the level of benefits sought.

Scope and Limits of a Right to Health Care

No society has ever instituted a social-political-legal right to health care for its members without at the same time setting some limits on that right. Every society rations health care by not providing some health care that would potentially benefit some of its members. To take a few examples, this rationing may occur through a distinction between access to a basic level of health care and access to other levels of health care, through setting priorities within health care, through distributing some health care according to potential recipients' ability to pay or age, or through queuing for certain procedures.

Nevertheless, some ways to set limits and to arrange priorities may unfairly discriminate against children and thus require special moral scrutiny. Dan Brock stresses that securing the greatest health benefits or ensuring cost-effectiveness, as indispensable and important as these efforts are, should not be the sole bases for setting priorities in health care because they neglect moral concerns about justice and equity in the distribution of benefits. As noted previously, cost-effectiveness and cost-benefit analyses can support much health care for children because it produces benefits that last longer; however, if analysts discount future benefits or concentrate only on benefits to those in the work force, then their cost-effectiveness analyses may actually discriminate against children. For these reasons, as noted earlier, such tools for allocation decisions require constant scrutiny in light of standards of justice, fairness, and equity.

Another way to approach allocation decisions is to explore conceptions of medical necessity and related categories. In a background paper for the seminar, Wendy Mouradian noted the need and possibility for child-specific definitions of medical necessity that should be guaranteed for all children. Her list includes: "timely and appropriate preventive care and treatment for medical and dental problems; primary care medical and dental providers who are knowledgeable in child health and development; access to tertiary care when special medical or dental problems are beyond the expertise of primary care providers; coordinated, comprehensive interdisciplinary care for children with special health care needs (CSHCN) that integrates oral health into overall medical planning." Judgments of what is medically necessary, just as judgments of what is medically indicated, appropriate or reasonable, depend on setting out appropriate ends of health and the means that can help realize those ends.

Society cannot, of course, make allocation decisions for any particular group, such as children, in total isolation from the needs of other groups. However, if the arguments pursued at the seminar are sound, then the case for ensuring access to health care, including dental and oral

care, for children, is partially independent of the arguments for other groups, and may establish a strong case for priority for children.

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¹ This short-hand express "citizens and residents" is not intended to prejudge the question whether illegal immigrants should have access to health care. Many of the arguments presented in the seminar would support their children's access to health care.