Early Intervention, Grassroots Advocacy, Health Care Reform, HIV Testing of Pregnant Women and Newborns

**Early Intervention**
WHEREAS, approximately five percent of all children experience developmental delays during their first 36 months after birth, (27,000 Illinois infants and toddlers); and

WHEREAS, developmental delays result from a wide variety of conditions, including Down Syndrome, Cerebral Palsy, failure to thrive, very low birth weight, and prenatal injury due to substance exposure; and

WHEREAS, untreated developmental delays produce negative individual and societal consequences of lifelong duration; and

WHEREAS, individualized therapeutic intervention on an interdisciplinary basis directed towards family involvement, known as 0-3 Early Intervention, has proved to ameliorate and often eliminate the consequences of developmental delay; and

WHEREAS, the value of 0-3 Early Intervention as a public policy goal was established in 1986 by the United States with the creation of the Part H entitlement program and accepted by Illinois through its participation since 1988 in Part H; and

WHEREAS, the 0-3 entitlement provides for both free services (identification, evaluation, plan development, service coordination, and due process), as well as services billable to families based upon ability to pay (the various therapies); and

WHEREAS, despite Illinois' 1991 passage of PA 87-680, the Early Intervention Services System Act, the federal courts found in 1996 that Illinois was only serving 7,900 children (29% of the eligible 5%)

NOW THEREFORE BE IT RESOLVED: That the Board of Directors approves an institutional policy that 0-3 Early Intervention be established by Illinois legislation as an entitlement for the estimated five percent of children who have measurable delays diagnosed conditions placing them at a high probability of delay.

**Grassroots Advocacy**
WHEREAS, as Medicaid, the nation's health care safety net, is restructured at the state and federal levels and as other changes in health policy related to children take place, it is imperative that the entire children's hospital community be organized to advocate for children and the mission of children's hospitals in the policy making process; and
WHEREAS, the process of organizing local constituencies who are involved with and supportive of Ann & Robert H. Lurie Children’s Hospital of Chicago to take action on behalf of children and the hospital (grassroots organizing) is an appropriate and important role for children’s hospitals; and

WHEREAS, children's hospitals are uniquely positioned to be catalysts for grassroots advocacy on behalf of children because children's hospitals currently enjoy broad community support and have strong ties to constituencies with the potential to wield significant influence; and

WHEREAS, children's hospitals' natural constituents include trustees, physicians, nurses, administrative staff, volunteers, parents, employees, vendors, donors and other supporters from the business and wider community; and

WHEREAS, children's hospitals already are expert in mobilizing many of these groups on behalf of their mission -- expertise that can be brought to bear in organizing these constituents to participate in advocacy efforts to influence the public policy-making process;

NOW THEREFORE BE IT RESOLVED: That Ann & Robert H. Lurie Children's Hospital of Chicago will make grassroots advocacy a top priority and regularly communicate about public policy issues and provide avenues for participation in advocacy to key grassroots constituencies including trustees, physicians, nurses, administrative staff, volunteers, parents, employees, vendors, donors and other supporters from the business and wider community; develop an infrastructure or system to call these key constituencies to action on a timely basis, either selectively or en masse, when critical issues arise at the local, state or national level; and participate in advocacy by sponsoring events with public officials and by encouraging informed voting through nonpartisan voter education, including candidate forums and voter registration.

Date: May 19, 1997

Health Care Reform
WHEREAS, the Board of Directors of Ann & Robert H. Lurie Children’s Hospital of Chicago (the "Medical Center") recognizes its duty, as a leader in the provision of pediatric specialty services and as an institution dedicated to advancing knowledge about the causes and treatment of diseases that affect children, to represent the voices of children in the environs of health care reform; and

WHEREAS, the Board of Directors of the Medical Center has authorized the Public Policy Committee, a committee of the Board of Directors, to take institutional positions, as appropriate, to enhance the health and well-being of children, preserve funding for government funded patients and support the strategic objectives of the Medical Center; and

WHEREAS, the Public Policy Committee has directed its Health Care Reform Task Force to review health care reform proposals for their clinical and financial impact on the Medical Center and assist the Public Policy Committee in its recommendation of an institutional position on health care reform; and

WHEREAS, the Public Policy Committee recommends the Position on Health Care Reform. A Recommendation by Ann & Robert H. Lurie Children’s Hospital of Chicago Board Committee on Public Policy to the Board of Directors ("Lurie Children’s Position on Health Care Reform") as the institutional position on health care reform; and
WHEREAS, Ann & Robert H. Lurie Children’s Hospital of Chicago Position on Health Care Reform recommends; health care reform should include a federal guarantee of universal and comprehensive health care coverage for all children; health care reform should include a uniform benefits package that includes comprehensive coverage for the treatment of children with mental illness, as well as, comprehensive coverage for congenital, chronic and acute conditions requiring long-term treatment; health care reform should include that children's hospitals be recognized as Essential Community Providers and Pediatric Centers of Excellence due to their unparalleled role in the provision of, and access to, pediatric specialty care services in the community they serve; health care reform should adequately reimburse pediatric physicians and other health care providers specializing in the care of children based on the provider's level of experience and amount of time and resources required to care for their patients; health care reform should adequately finance, apart from reimbursement for patient care, the costs of graduate medical education and research; health care reform should promote the establishment of integrated child health care networks which contract with managed care plans for the provision of pediatric care; and health care reform should facilitate and enable families to choose such integrated health care networks for the provision of care to their children,

LET IT BE RESOLVED: that Ann & Robert H. Lurie Children’s Hospital of Chicago Position on Health Care Reform as presented to the Board of Directors of the Medical Center and as described above is hereby adopted this 27th day of June, 1994.

HIV Testing of Pregnant Women and Newborns

Each year, more than 40,000 persons in the United States contract HIV infection. Women are at increasing risk for acquiring HIV infection and developing AIDS. While women accounted for less than 1% of persons with AIDS in 1984, in 2000 they accounted for almost 25% of the reported cases. Even more alarming is the fact that almost a third of the people testing HIV-positive in 2000 were women.

African-American women are at particularly high risk for acquiring HIV/AIDS. Although only 39% of the total population of women in Chicago are African-American, they represent 73% of the HIV-infected women in Chicago. In addition, the number of HIV-infected pregnant African-American women is also increasing. The rate of HIV infection in African-American women of childbearing age doubled from 0.46% to 0.96% in 3 years (from 1994 to 1996). This rate is 15 times higher than in Caucasian women.

Perinatal transmission from mother to child accounts for 95% of pediatric AIDS cases in Chicago and 90% in Illinois. Although pediatric HIV infection is now managed as a chronic illness with life expectancy that can extend into adolescence and beyond, it is a fatal disease fraught with significant human suffering and financial costs (more than $10,000/year). Most importantly, transmission of HIV infection from mother to child can be prevented.

A major breakthrough in the prevention of HIV transmission occurred in 1994 when a standard of care for routine prenatal HIV testing of all pregnant women was established as an outcome of a National Institutes of Health (NIH) study. The study found that if pregnant women are identified as HIV-positive prior to giving birth and administered antiretroviral therapy during pregnancy, delivery, and to the newborn in the first 6 weeks of life, the transmission of the virus to the newborn is reduced by two thirds. Although great progress has been made in advancing routine prenatal HIV testing in Illinois, up to 25% of pregnant women do not undergo HIV testing. Accordingly, only a 45% reduction in transmission has been documented in Chicago to date. Thus, children continue to be born infected with HIV.
Routine prenatal HIV testing offers the most effective method of reducing HIV transmission from mother to newborn (perinatal transmission). However, recent scientific studies showed that if antiretroviral therapy is given ONLY to the newborn in the first 48 hours of life, more than a third of the children born to unidentified HIV-infected mothers will be prevented from acquiring HIV disease. To achieve this outcome, they must be identified and administered prophylactic treatment within the first 24 to 48 hours of birth. Furthermore, newborn HIV testing offers the opportunity to provide HIV-infected newborns, in whom treatment did not prevent the transmission of the virus, with early medical care that will prevent significant suffering and premature death.

The mission of Ann & Robert H. Lurie Children’s Hospital affirms its commitment to advocacy on behalf of children. We believe that it is the responsibility of Ann & Robert H. Lurie Children’s Hospital of Chicago to speak for the otherwise unarticulated right of children to be born without HIV; and the right of HIV-infected children to receive early medical care that will prevent premature death. In 1995, the hospital adopted a public policy position in support of routine prenatal HIV testing with right of refusal. In light of current medical advances, Ann & Robert H. Lurie Children’s Hospital of Chicago reaffirms its support for routine prenatal HIV testing of pregnant women, and for mandatory HIV testing of all newborns whose mothers’ HIV status is unknown; and further supports legislative efforts to advance this standard of care.