



Children and Youth with Special Health Care Needs

WHEREAS: Approximately 13 – 18 percent of all children (9 – 12.5 million) have special health care needs; and

WHEREAS: Many such children who are medically fragile, technology dependent, and/or disabled may now be safely cared for at home instead of institutional care settings; and

WHEREAS: Many children with special health care needs who once died in childhood are now living into adolescence and adulthood; and

WHEREAS: Medical and psychosocial support for children with special health care needs through adolescence is a critical bridge for them to access adult care and to developing independence in community-based settings; and

WHEREAS: Care of children with special health care needs requires an increased amount of physician and other practitioner time and intensity; and

WHEREAS: Care coordination of children with special health care needs also requires an increased amount of time, intensity and communication among primary and specialty care providers; and

WHEREAS: The American Academy of Pediatrics recommends a “Medical Home” for children with special health care needs as accessible, family centered, continuous, comprehensive, coordinated, compassionate and culturally effective; and

WHEREAS: Many children with special health care needs need support from federal and state programs and resources, but face barriers to access and achieving independence.

WHEREAS: is Ann & Robert H. Lurie Children's Hospital of Chicago participating in the Consortium for Children with Complex Medical Needs comprised of a community-based coalition of medical professionals, government agencies, community activists and parents, dedicated to improving the quality of life for children with special health care needs.

THEREFORE BE IT RESOLVED THAT:

Ann & Robert H. Lurie Children's Hospital of Chicago engage in program and policy initiatives for children with special health care needs that support comprehensive care, including medical homes; enhanced access to medical care, therapies, care coordination, and state and federal programs; enhanced access to home and community based services that allow children to be cared for at home whenever possible; provider reimbursement that is proportionate to the time and intensity spent; and provider education regarding resources that are needed and available to care for these children and support for transition into independent or supervised community living as they mature into adulthood.