

TESTIMONY BEFORE HOUSE HEALTH & HUMAN SERVICES COMMITTEE - 2/17/04

Thank you, Mr. Chairman and members of the Committee. My name is Dr. Chet Johnson. I am Professor of Pediatrics at the University of Kansas School of Medicine and Director of the Developmental Disabilities Center, a diagnostic center for children with a wide variety of developmental problems. I am a member of the Kansas Coordinating Council on Early Childhood Developmental Services and the American Academy of Pediatrics. I currently serve as the Chair of the AAP National Committee on Early Childhood. My specialty is child development and children with special needs. I have been committed to this population of children and their families for the last 20 years.

Young children with developmental delays often go on to have permanent developmental disabilities, including mental retardation, cerebral palsy, speech disorders, autism, and learning disabilities. There is evidence that early identification and treatment of children with developmental problems can help prevent behavioral problems and improve their abilities in later years.

In addition to teaching and administration, I care for children with disabilities on a daily basis. As part of my work, I regularly see young children with very significant delays who are not receiving any services, and whose parents have no knowledge of the services available to their child and themselves.

Kansas hospitals and physicians generally do a satisfactory job of referring very premature babies to early intervention programs. This, however, depends to a large degree on the relationship of the hospital to local programs. There is no system that makes sure that all babies who should be referred are connected to available services. Babies who live in rural areas or sites some distance from the hospital are also less likely to be reliably referred.

HB 2350 was introduced by Representative Ethel Peterson, at the request of the Kansas Coordinating Council on Early Childhood Developmental Services. This bill will enable the Secretary of Health and Environment to review the data base created from birth certificates on a routine basis. Parents (or guardians) of newborns whose birthweight was below 1200 grams or who had low APGAR scores or have certain genetic or neurologic conditions will receive a single letter. The letter will simply inform them that their child's condition has been shown to sometimes correspond with later developmental delays. If they choose to investigate further, free evaluations are available in their own community. There will be no subsequent phone calls or contacts of any kind, unless the family requests it.

The intent of HB 2350 is to inform parents of free services for which they might qualify. These intervention services are voluntary, and quite user-friendly. More importantly, these services have been proven to prevent or ameliorate later complications (health, educational, and behavioral) in the lives of young children.

Thank you for your consideration of this bill. I will gladly stand for questions.