



## Capper Foundation

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Debby O'Neill  
V.P., Programs & Services

Pam Walstrom  
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The mission of  
Easter Seals Capper Foundation  
is to enhance the independence  
of people with disabilities,  
primarily children.

## Testimony to the Kansas House Children and Families Committee

January 26, 2011

Good morning Chair Kiegerl and distinguished members of the House Children and Family Committee. I want to thank Chair Kiegerl for taking time from his busy schedule a couple of weeks ago to meet with us about issues impacting children and families in Kansas and for inviting us here this morning.

A special greeting this morning to Representative Melody McCray Miller. Representative Miller and I served together on the Kansas Autism Task Force several years ago.

Thank you for the opportunity to meet with you this morning and share our concerns with the entire committee about issues impacting children and families in Kansas that need serious attention and action.

I would like to introduce my colleagues joining me from Easter Seals Capper Foundation – Ms. Debby O' Neill, Vice President of Programs & Services and Ms. Linda Burgen, Director of our Kidlink Childcare & Preschool Program & Director of our Autism Services Program. My name is Jim Leiker and I am the President & CEO of Easter Seals Capper Foundation.

Our biographies, testimony and related information are included in file folders for each of you to reference.

HOUSE CHILDREN AND  
FAMILIES  
DATE: JANUARY 25, 2011  
ATTACHMENT NO. 2-1

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## **Sophia's Story:**

Sophia is almost two years old, yet she is not yet talking or making attempts to communicate. Most children say their first word around 1 year of age.

Sophia was referred by her pediatrician to the Shawnee County Infant/Toddler Program (also known as Early Childhood Program).

Because of limited state and federal funding for this program, she was scheduled to receive services from a speech therapist for 30 minutes per quarter – only 4 visits per year – only 2 hours per year

Sophia's pediatrician referred her for more intense speech therapy services at Easter Seals Capper Foundation.

Kansas Medicaid would not reimburse Easter Seals Capper Foundation for speech therapy services and her parents could not afford to pay for them.

In their letter of denial to Easter Seals Capper Foundation, Kansas Medicaid stated: "We made this decision because the child has developmental language concerns. **There is concern that the services offered through the Infant/Toddler Program are not of sufficient intensity.** However, this does not change the nature of the delay – it is developmental."

If Sophia's language problems had been the result of a head injury suffered after birth, or the result of an illness such as encephalitis suffered at one year of age, Kansas Medicaid would have funded rehabilitation services.

## **Solutions Needed:**

Amend the Kansas Medicaid Policy regarding Therapy Services. (see attached)

It is discriminatory for children with motor and language disabilities due to congenital defects and assumes these children can only maintain their skills rather than make functional gains.

It does not allow families to take advantage of more intensive, medically based rehabilitation which is supported by current clinical research. As stated by Dr. Beverly Ulrich: "That rigorous practice...affects recovery of neuromotor function... within areas of the brain in children and adults, is commonly accepted. Without greater opportunities for early treatment, the costs associated with health care needs in subsequent years will be higher, but the real cost is to those affected with early-onset neuromotor disabilities". (**Opportunities for Early Intervention Based on Theory, Basic Neuroscience, and Clinical Science.** *Physical Therapy.* 2010;20: 1868-1878)

**Current Kansas Medicaid Policy regarding Therapy Services:**

“All therapy must be prescribed by a physician.

Habilitative therapy is covered only for participants age 0 to under the age of 21.

Therapy must be medically necessary. Therapy is covered for any birth defects/developmental delays only when approved and provided by an Early Childhood Intervention (ECI), Head Start or Local Education Agency (LEA) program. Therapy treatments performed in the Local Education Agency (LEA) settings may be habilitative or rehabilitative for disabilities due to birth defects of physical trauma/illness. The purpose of this therapy is to maintain maximum possible functioning for children.”

**Revision Needed in Kansas Medicaid Policy regarding Therapy Services:**

All therapy must be prescribed by a physician. Services must be medically necessary. Rehabilitation services are covered only if they are expected to result in functional improvement. Outpatient rehabilitation for children, whether their disability results from a birth defect or postnatal injury, cannot duplicate what is provided in the Local Education Agency (LEA), Headstart and the Early Childhood Intervention (ECI) program.

### **Ryan's Story:**

- Diagnosed with Autism by age 2.5
- Received Infant Toddler Part C intervention services
- Received Special Education from Public School
- Therapeutic Child Care – Out of pocket expense
- Purchased Therapy that family insurance covered of which parents still paid deductible and copay.
- His name was not selected for the Autism Waiver lottery selection so he did not receive autism services. He will age out soon.
- Autism services were denied through commercial insurance
- Paid out of pocket for 33 days for 30 minutes of Autism Services
- Made documented progress in 4 areas one of which an Occupational Therapist had been trying to make progress on for months. Additional skills were also increased that were not specific to the plan.
- Parents could no longer afford this type of service so it stopped after 33 days.

### **Solutions Needed:**

- Autism Waiver needs to be expanded to more families
- Autism waiver services need to go beyond age 5.
- Autism services are not a duplicated service to school's special education or other therapies such as Occupational Therapy, Physical Therapy, and Speech and Language Therapy.
- Parent or caregiver component is important. We need to develop plans and technologies that can be done by parents in multiple repetitions within the daily routines with professional guidance. We need to increase the involvement in families to help develop functional skills.
- An early aggressive approach is needed which will optimize development and be financially feasible with family involvement. Early intervention is most cost effective as well as proactive in eliminating more severe issues in the future by teaching skills to both the family and child.



# Capper Foundation



**“Ryan and Kidlink preschool teacher work on fine motor skills with a single-piece insert-puzzle. “**

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## **Issues Adversely Impacting Children & Families in Kansas That Need Serious Attention & Action**

### **Kansas Medicaid Policy**

The current Kansas Medicaid Policy is discriminatory to children with disabilities due to congenital defects. This policy has a detrimental impact on children with developmental disabilities who are unable to access appropriate services based solely on the fact that their injuries occurred at the time of birth.

**By limiting access to therapy services for children with birth defects to only those provided by an Early Childhood Intervention (ECI) service provider or Local Education agency (LEA), the Kansas Medicaid Policy denies a child the right to Medicaid services defined by federal law and needed to correct or ameliorate a health concern.** Children with disabilities, whether those impairments are from a birth injury/defect or from an illness or accident occurring after birth, should have the same options in selecting an approved provider for medical rehabilitation therapy services. **This policy is unfair and action should be taken to change it immediately.**

### **State of KS Autism Insurance Coverage Implementation**

Autism insurance coverage for children of state employees under age 19 on the state health insurance plan was signed into law in mid-2010, requiring coverage effective January 1, 2011. Despite phone calls, emails from parents and service providers and meetings with the Kansas Health Policy Authority (KHPA) who oversees the state health insurance plan, and health insurance carriers, this autism health insurance coverage has not been implemented and it is uncertain as to when it will be. There has been more than ample time to prepare and implement this Kansas Law requiring autism insurance coverage on January 1, 2011.

This law has autism insurance coverage for children on the state health insurance plan on a one year test track, followed by an analysis of the implementation data and report to the Kansas Legislature. The implementation of this law has been unduly delayed along with cumbersome requirements for eligibility, treatment coverage definitions, benefit provisions and exclusions. This means it will take even more time for children with autism to actually receive covered services. Since the implementation has been delayed, there will be less data to report to the legislature and potential expansion of autism insurance coverage for Kansans with autism spectrum disorders will also be unfairly delayed and adversely impacted. **Action should be taken to implement this state law immediately.**

**Kansas Medicaid Autism Waiver & Critically Important Early Identification & Intervention Services**

Kansas has a Medicaid Autism Waiver for children with autism up to age 5. In December 2007, the Report of the Kansas Autism Task Force to the Legislative Planning Committee said, "Current available funding for the Autism Waiver limits its services to 25 children." That is 25 children in the entire state of Kansas! This was an unbelievably minimal number of children covered, which is very embarrassing and dismal at best for our state.

Now, let's fast forward to 2011, 5 years later. My understanding is that currently the Kansas Autism Waiver covers 45 children and 270 children are on a waiting list. Again, this is 45 children in the entire state of Kansas! Again, this is a very minimal number of children covered. This continues to be embarrassing and dismal coverage of young children with autism in Kansas since as many as 1 in every 110 children is diagnosed with some form of autism – for boys it's 1 in every 70 – that's a new diagnosis every 20 minutes.

**We recommend that the Kansas Legislature get serious and take action to Make the First Five Count!** When kids get the right treatment and therapy they need before the age of 5, they are ready to learn alongside their peers, succeed and achieve their goals and dreams. Early diagnosis and early intervention are critical. Getting the right support at the earliest stage of life can help a child gain the skills he or she needs to be successful.

University of Chicago Distinguished Professor James J. Heckman, a Nobel laureate and expert in the economics of human development makes the case that investing in the first five years of children's lives is a sound and critical investment on our nation's future on the world stage. Professor Heckman reports that "early interventions" have much higher economic returns than later interventions for disadvantaged children. As an economist, James Heckman is an advocate for early education and care and strongly recommends that we "Make greater investments in young children to see greater returns in education, health and productivity."

We agree completely and hopefully a word to the wise in the Kansas Legislature is sufficient to get serious about the critical importance of early identification and intervention services. **It is critically important that your House Children and Families Committee and the entire Kansas Legislature take appropriate action in the 2011 legislative session to increase the number of children on the Kansas Autism Waiver to a reasonable number for a state our size.**

## **Current Kansas Medicaid Policies Regarding Therapy Services for Children**

The Kansas Medical Assistance Professional Services Provider Manual states:

*"Habilitative – Therapy is covered for any birth defects/developmental delays only when approved and provided by an Early Childhood Intervention (ECI), Head Start or Local Education Agency (LEA) program. Therapy treatments performed in the LEA settings may be habilitative or rehabilitative for disabilities due to birth defects or physical trauma/illness. Therapy of this type is covered only for participants age 0 to under age 21. Therapy must be medically necessary. The purpose of this therapy is to maintain maximum possible functioning for children.*

*Rehabilitative – All therapies must be physically rehabilitative. Therapies are covered only when rehabilitative in nature and provided following physical debilitation due to an acute physical trauma or illness."*

Kansas Medicaid has established an arbitrary, capricious and unfair policy which prevents access to appropriate therapy by children with disabilities resulting from birth defects or birth injuries. Under the current policy children with congenital/developmental disabilities are unable to receive the medical rehabilitation therapy services they need to correct or ameliorate a health concern. Families of children with disabilities resulting from a birth injury cannot choose a clinic-based therapy provider with specialized training nor can they take advantage of specialized equipment that would only be available in a clinical setting.

The definitions of habilitative and rehabilitative therapy in the Kansas Medicaid Policy are discriminatory and presume that children with impairments resulting from a birth injury or genetic/neurological/orthopedic differences present at birth have a more limited potential than children who suffer a physical trauma or illness after birth. The implied outcome of therapy for children with birth defects/developmental delays is described as "maintaining maximum function" rather than progressing and achieving independence. The Kansas Medical Assistance Program limits therapy options for these children to an ECI, Headstart Program or LEA. These educational agencies are not designed, equipped or staffed to provide the medical rehabilitation services often necessary to help these children achieve independence. These agencies focus on learning opportunities for a child, not on increasing independence through the reduction of disability based on the science of medical rehabilitation.

Kansas Medicaid views therapy services in ECI programs, LEA programs or medical rehabilitation clinics as essentially the same. There are, however, major differences between medically rehabilitation therapy services, educationally based therapy services provided by the local education agency (LEA), and early childhood intervention (ECI) therapy services. These differences include the physical environment, the persons determining the need for service, the goals of the service, the frequency and duration of the service and the techniques and equipment utilized.



Medical rehabilitation services are individualized, hands-on, and derived from the science of medical rehabilitation. They are generally more intense in frequency and shorter in duration than LEA or ECI services and may be provided in periodic "episodes of care" to address specific impairments. Treatment goals are established by the therapist with input from the referring physician's prescription and the parent. Medical rehabilitation services often incorporate technology and modalities such as augmentative communication equipment during speech therapy or electrical stimulation during occupational and physical therapy sessions.

Local Education Agencies (LEA) which provide therapy services are considered a related service. A related service is defined as a supportive service provided to assist a child with a disability to benefit from special education. Physical, occupational and speech therapists working in local education agencies (public schools) do not develop separate goals for physical, occupational and speech therapy. All goals are considered discipline-free and address educational success.

Early Childhood Intervention (ECI) service providers are responsible for consulting with parents and other service providers, participating in multidisciplinary team assessments, and training parents and others to provide those services. Early Childhood Intervention therapists are discouraged from utilizing any "clinic" equipment or materials in the home. ECI programs in Kansas have adopted the coaching model which requires providers to limit hands-on treatment and to serve as consultants in coaching the family in learning opportunities for their child.

In conclusion, the current Kansas Medicaid policy is discriminatory to children with disabilities/developmental delays due to congenital defects. By limiting access to therapy services for children with birth defects to only those provided by an ECI or LEA, the Kansas Medical Assistance Program is denying a child the right to Medicaid services defined by federal law and needed to correct or ameliorate a health concern. Children with disabilities, whether those impairments are from a birth injury/defect or from an illness or accident occurring after birth should have the same options in selecting an approved provider for medical rehabilitation therapy services.

## Biographies of Presenters

### Jim Leiker

Jim is the President and CEO of Easter Seals Capper Foundation. He earned three Bachelor's degrees from Washburn University of Topeka in 1976 and a Master's Degree in from Wichita State University in 1980.

Jim has proactively led Easter Seals Capper Foundation through significant organizational changes for the past 18 years, expanding services and number of people served. He is actively involved in civic, religious and professional organizations in the Topeka community. In 1989 Jim was named to the Leadership Topeka Class of the Greater Topeka Chamber of Commerce. Jim served as a member of the Kansas Autism Task Force and is currently a member of the Easter Seals National Autism Spokesperson Network.

Jim is the Easter Seals Leadership Association (ESLA) Midwest Regional leader, serves on the ESLA Board and Easter Seals National Planned Giving Team. He serves as a Regional Advocacy Leader for the Kansas Coalition for Autism Legislation (KCAL) and is a member of the Downtown Topeka Rotary Club and Greater Topeka Chamber of Commerce.

### Debby O'Neill

Debby is Vice President, Programs and Services at Easter Seals Capper Foundation. She holds a Bachelors Degree in Physical Therapy from the University of Kansas and a Master of Education Degree in Special Education from the University of Washington.

Debby has over 35 years of experience as a pediatric physical therapist working in private practice clinics, hospitals, public schools and university settings. She has held a management position at Capper for over 12 years.

### Linda Burgen

Linda is Director of the Kidlink Childcare and Preschool program and Director of Autism Services at Easter Seals Capper Foundation. Linda earned a Bachelors Degree in Human Development and Family Life from the University of Kansas and completed her MS in Early Childhood Special Education from Emporia State University in 1996. Linda is an Autism Specialist and approved provider by Kansas Department of SRS.

Prior to joining the Easter Seals Capper Foundation Team in 2001, Linda taught in the public schools, directed a private community childcare center and served as an educator and coordinator with Parents As Teachers in Wabaunsee county. Linda has been a Field Based Consultant with the Inclusive Network of Kansas Since 1996. She is one of a small group of professionals selected to provide expert consultation to educational teams throughout the state of Kansas. As the Director of the Kidlink program, Linda has led the childcare staff in achieving accreditation through the National Association for the Education of Young Children and has increased enrollment in the program. Linda is one of 53 Early Childhood Specialists selected by Easter Seals to help develop the National Inclusive Child Care Training Modules.



# Easter Seals Fact Sheet

[www.easterseals.com](http://www.easterseals.com)

- Easter Seals is the leading non-profit provider of services for individuals living with autism, developmental disabilities, physical and intellectual disabilities and other special needs. For more than 90 years, Easter Seals has been offering help, hope and answers to children and adults with disabilities and their families who love them. Through therapy, training, education and support services, Easter Seals creates life-changing solutions so that people with disabilities can live, learn, work and play in their communities.
  
- Founded 91 years ago in 1919
- First National Society for Crippled Children
- Largest Health Charity in United States
- 1.6 Million People Served
- Top Global Brand
- Over \$1 Billion Entity
- 75 Affiliates in U.S.
- Global Partners: Ability First Australia, Easter Seals Canada, CONFE – Mexico
- Primary Services include:
  - Medical Rehabilitation
    - Early Intervention
    - Physical Therapy
    - Occupational Therapy
    - Speech & Hearing Therapy
  - Job Training & Employment
  - Child Care
  - Adult Day Services
  - Camping & Recreation

## Professional & Family Training

The Capper Professional and Family Training program offers continuing education courses designed to enhance clinical decision-making skills, therapy and educational intervention for direct services providers such as therapists, special educators, healthcare professionals, parents, childcare providers and social workers. By enhancing their knowledge and skill, providers ultimately improve and increase the independence of people with disabilities.

Programs feature a variety of topics and are presented by speakers recognized locally, nationally and internationally. Our on-site conference center provides a professional and comfortable academic atmosphere.

Off-site training opportunities are also available and can be customized to best meet the needs of the audience requesting the training.

## Numbers of People Served\*

Easter Seals Capper Foundation provided 46,382 hours of services to 2,180 individuals in fiscal year 2010. Individuals from 17 counties and 48 cities in Kansas were served.

*\*Some individuals were served by more than one program.*



Easter Seals Capper Foundation provides help and hope to families living with disabilities. Your caring support is needed and truly appreciated.

## Who & Where

### Senior Management

**Jim Leiker**  
*President & CEO*  
**Debby O'Neill**  
*Vice President, Programs & Services*  
**Pam Waisfrom**  
*Vice President, Development*  
**Sandy Warren**  
*Vice President, Operations*

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**Marlou Wegener**  
**Terry A. Young, Ex-Officio**  
**Jim Leiker, Ex-Officio**



**Capper  
Foundation**

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# AT A GLANCE



**Capper  
Foundation**

2011

## Mission

Founded in 1920 by Sen. Arthur Capper, the mission of Easter Seals Capper Foundation is to enhance the independence of people with disabilities, primarily children and their families.

## Who We Serve

Easter Seals Capper Foundation provides services to infants, children and young adults with developmental and intellectual disabilities. Some of these disabilities include autism, cerebral palsy, sensory processing disorder and other orthopedic and neurological conditions.

## Outcomes

We enhance the independence of people with disabilities, primarily children, so they can speak, learn, write, play, be mobile, work, and function as independently as possible.

## Strategy

Our staff of pediatric specialists work in collaboration with families, healthcare providers and educational professionals, to creatively adapt and apply therapies, education and equipment. We also provide training for those who live and work with individuals with disabilities. Services are provided at Easter Seals Capper Foundation and in the community.

## Funding

Our \$2.5 million budget is primarily supported by voluntary contributions. We also receive funding from fees for services and grants.

## Staff & Volunteers

There are 34 staff members including pediatric physical, occupational and speech therapists. Last year, 276 volunteers contributed 6,133 hours of volunteer services in a wide variety of direct and indirect service roles.

# Programs & Services

## Kidlink Childcare and Preschool

Kidlink is a year-round inclusive childcare and preschool program serving children aged two-and-one-half to six years with and without physical disabilities. The curriculum is designed to address all areas of development: cognitive, communication, social/emotional, physical and self-help skills.

Computer assisted learning and swimming in our warm-water therapy pool are favorite activities for both the children and volunteers.

Our staff includes certified special education teachers, teacher assistants, physical, occupational, and speech therapists.

All team members work collaboratively to meet the individual needs of each child. Developmental evaluations and Individual Program Plans are provided for each child.



## Physical Therapy

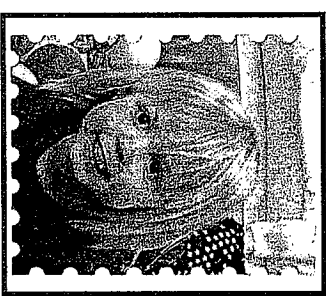
Physical Therapists provide services to increase strength, improve range of motion, coordination and balance with the ultimate goal of empowering the children we serve to be as independent as possible in their functional gross motor abilities.



Our physical therapists also assist in the acquisition and modification of adapted mobility equipment, splints/braces and wheelchairs.

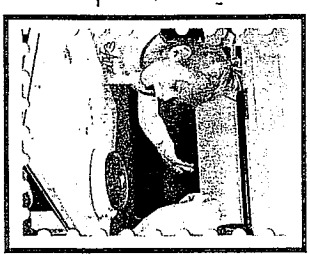
## Occupational Therapy

Occupational Therapy is the art and science of facilitating the development of skills necessary for daily functions such as fine motor skills, self-care and play/leisure activities. Our occupational therapists treat children with neurological and/or developmental disabilities as well as children with sensory processing disorders.



## Speech-Language Therapy

Speech-Language Therapists provide treatment for children with impairments in respiratory function, articulation, voice, fluency and receptive-expressive language skills. Our staff have experience in augmentative and alternative communication (AAC) for individuals with severe physical impairment and communication disorders. AAC includes picture boards, communication devices and communication software for developing written and spoken output.



## Ability Awareness Program

Led by our Director of Volunteers, this program is designed to increase understanding, awareness and acceptance of people with disabilities. The program includes interactive activities to educate adult and youth participants and focus on people's abilities, not limitations.