

Using Parent, Provider, and Research Expertise to Design an Early Childhood Autism Waiver: The Kansas Story

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Evolution of the Kansas Autism Waiver


- What is it?
 - Medicaid funding mechanism
 - Gives states flexibility to create alternatives to institutional care
- Why do we have it?
- How did we get here?



Presentation Overview

Part 1: Identifying the Need

Part 2: Designing an Early Childhood Autism Waiver

- Parents
 - Providers
 - State policy-makers
 - Researchers
- 

What is Autism?

- Autism is a complex developmental disability usually appearing in the first three years of life
- Autism is a spectrum disorder that affects each child differently
- It is one of five disorders under the umbrella of Pervasive Developmental Disorders (PDD)



Prevalence of Autism Spectrum Disorders


- 1 in 150 babies born today will be diagnosed with an autism spectrum disorder
- It is more common than childhood cancer, diabetes, and AIDS combined
- It is 4 times more common in boys
- It is found equally among all populations
- It is the fastest growing developmental disability

Symptoms

- Non-responsive to verbal cues
- Often prefers to be alone
- Repeats words or phrases but lacks functional language
- Odd and repetitive play
- Obsessive attachments to objects
- Uneven fine and gross motor skills
- Resists changes in routine
- Little or no fear of danger



Challenges for Families

- Getting screened/identified in a timely fashion
 - *What your well-meaning pediatrician doesn't know or won't tell you!*
 - Getting a proper diagnosis
 - *"The wait"*
 - Getting the appropriate information to develop a treatment plan
 - *Information overload & financial panic*
- 
- The background of the slide is a solid blue color. In the lower right quadrant, there are several decorative elements consisting of concentric circles, resembling ripples in water or a target. These circles are light blue and vary in size and opacity, creating a subtle pattern.

Inadequate Services

- Current “traditional” early intervention services include 30-60 minutes a week of speech therapy, occupational therapy, physical therapy, or other special instruction
- What you know you need: 25 hours a week of intensive evidence-based intervention
- How to bridge that gap...

Research Vignette: Focus Groups

“The past two years I’ve been able to afford the \$2,000 each month that it takes to help my boy get ABA therapy. I think that early intervention would be the most cost effective thing for the state to put the money toward. If I had not been able to afford early intervention then my son would perhaps cost the state a lot more money later... I know parents that have not been able to afford to help their pre-schoolers, and their kids aren’t getting any better. My son is getting a lot better.”



Parent, Baldwin City, KS

AUTISM IS TREATABLE!!

- Early identification and treatment is crucial and has been shown to make an enormous impact
- Must be intensive behavioral intervention for no less than 25 hours a week

Research Vignette: Focus Group



“My daughter was diagnosed in February, and we are managing to afford the core intervention that people have talked about here: ABA. My daughter was nonverbal in February. She can now walk into my kitchen and ask me for an apple. We are seeing *great* things happening...What is really hard to afford is the core, minimum 25 hours a week, one on one, evidence-based therapies that are crucial. If you can catch these kids early enough, you can make great changes.”

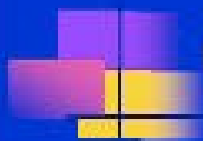


Parent, Lawrence, KS

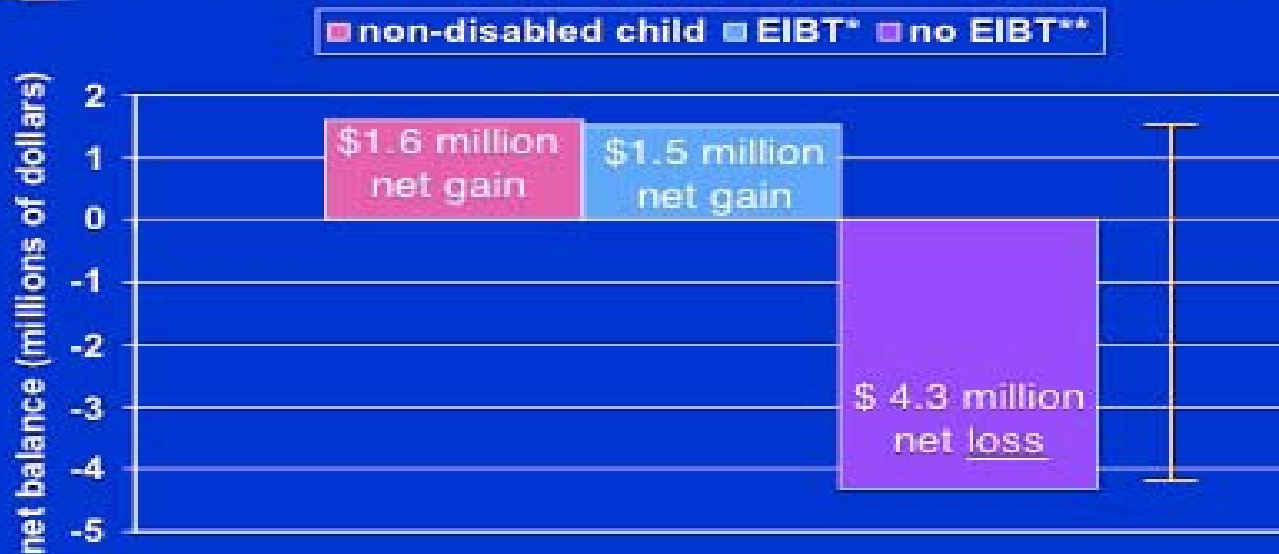
Cost Savings

- Jacobson, Mulick & Green (1998) completed a cost-benefit analysis of EIBI utilizing Pennsylvania.
- They estimate cost savings from \$187,000-\$203,000 per child for ages 3-22 and \$656,000-\$1,082,000 per child for ages 3-55.
- This only takes into consideration the saved expenditures, not the improvement in quality of life and the corresponding benefit of economic self-sufficiency.

Estimated Cost Benefit of Early Intensive Behavioral Intervention



Cost-benefit of EIBT for autism



* normal range effects

** inferred from minimal effect of EIBT

Jacobsen, et al (1998)

Provider Challenges in Serving Children with ASDs

- Families request support
 - Diagnostic challenges
 - Waiting list, referral, responsiveness of doctor
- The child gets the diagnosis
 - Problem identified = solution
 - Oops – forgot to mention this is not paid for
 - Helping parents navigate the maze of services

Gaps in Services

Which direction to send families?



Recommended Practices

➤ Surgeon General

- National Research Council, Educating Children with Autism

➤ Professionals disagree on recommendations

- Intensity
- Across environments, across funding streams

➤ What is evidence-based?

Surgeon General Report

- Thirty years of research demonstrated the efficacy of *applied behavioral methods*
- Lovaas and colleagues
(Lovaas, 1987; McEachin et al., 1993)
- A number of other research groups have provided at least a partial replication of the Lovaas model

Provider Survey Findings

Lack of Coordination Between Systems

Community Mental Health

“My understanding is that if the child has ASD, the MR/DD system is to take lead. This does not happen because of a lack of slots for HCBS waiver. We only serve these children when they have a co-occurring disorder but the families often need the services of the CDDO as primary.”

CDDO

“Mental health are not responsive to their needs; they keep saying it is a DD issue.”

Provider Survey Findings

Lack of Expertise/Training

Community Mental Health

“Some staff are not as well versed as others in diagnosing and treating these disorders. The functional limitations a child with ASD experiences makes the treatment of co-occurring mental health disorders much more difficult.”

CDDO

“After the referral process is completed, and recommendations are given by specialists, the difficulty is finding local or reasonable distance agencies to provide such supports or being specialized in providing supports to children with ASDs.”

Provider Survey Findings

Lack of Funding

Community Mental Health

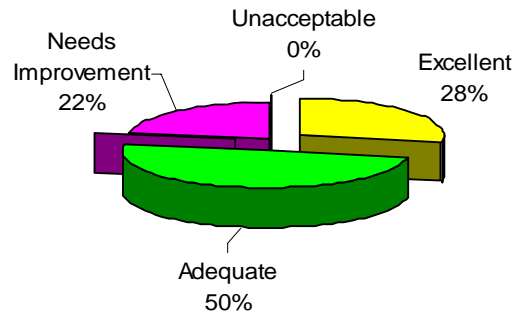
“Lengthy, lengthy waiting list for kids who qualify for MR/DD services and complete lack of direct services available to the family.”

CDDO

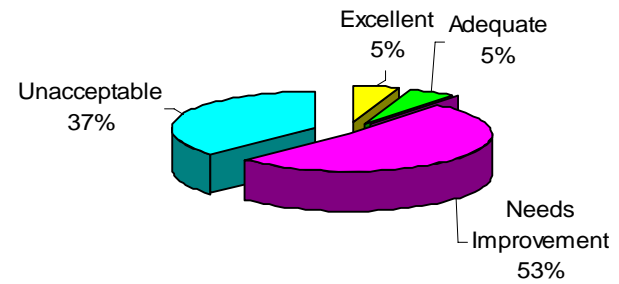
“The biggest challenge would be funding. In MR/DD services, funding is not available to provide in-home supports or respite services to new referrals. Unless there is a crisis, individuals must be placed on the statewide waiting list for funding.”

Waiting Lists

CMHC-Waiting Lists/Immediacy of Services

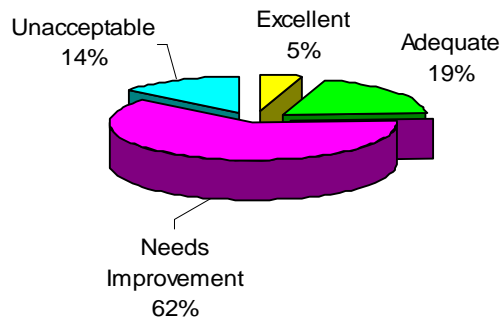


CDDO-Waiting Lists/Immediacy of Services

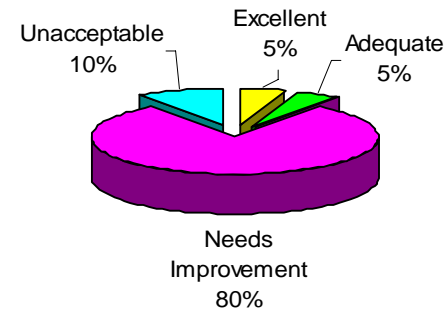


Adequacy of Regional Services

CMHC-Adequacy of Regional Services

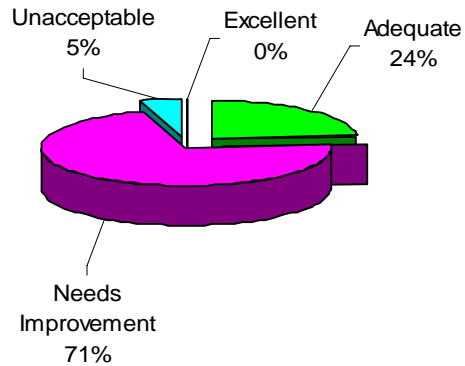


CDDO-Adequacy of Regional Services

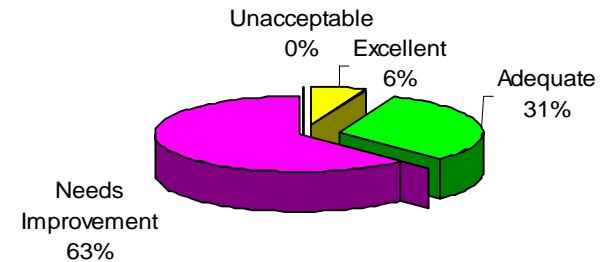


Implementation of Best Practices

CMHC-Implementation of Best Practices



CDDO-Implementation of Best Practices

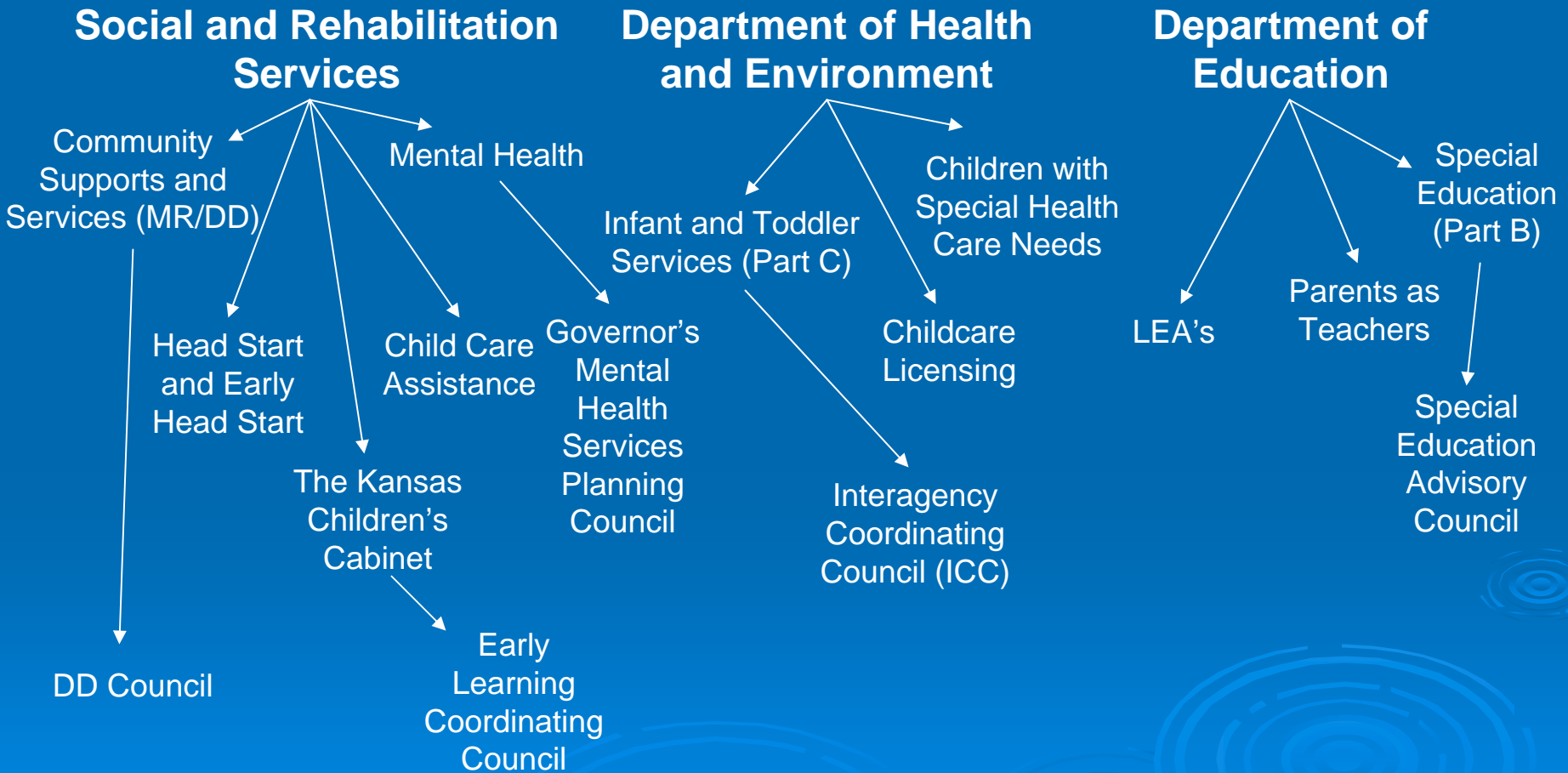


The State Perspective

➤ Needs:

- Increasing number of children with autism
- Existing service systems were not meeting the needs
 - Coordination between existing systems
 - Responsibility under competing laws, regulations, etc.
- Gaps in coverage for young children and families with income above the poverty threshold.

The Service System Maze:



The Perfect Storm

➤ Federal Interest:

- CDC's newest prevalence reports
- Legislative interest in Addressing the problems
- National Media Attention

➤ State Interest:

- State Mental Health and Community Supports and Services identified gaps in treatment services
- Department of Education was studying effective treatment of autism
- Early Childhood Partners were coordinating care for all young children
- Legislative Interest

➤ Other Tipping Points:

- Active consumer and family advocacy



Federal

- **CDC:** CDC's Autism and Developmental Disabilities Monitoring ([ADDM](#)) Network released data in 2007 that found about 1 in 150 8-year-old children in multiple areas of the United States had an ASD.
- **Other Legislative Interest:**
 - Children's Health Act of 2000
 - Coalition for Autism Research and Education (C.A.R.E.) 2001
 - Combating Autism Act of 2006
- **National Media Attention**

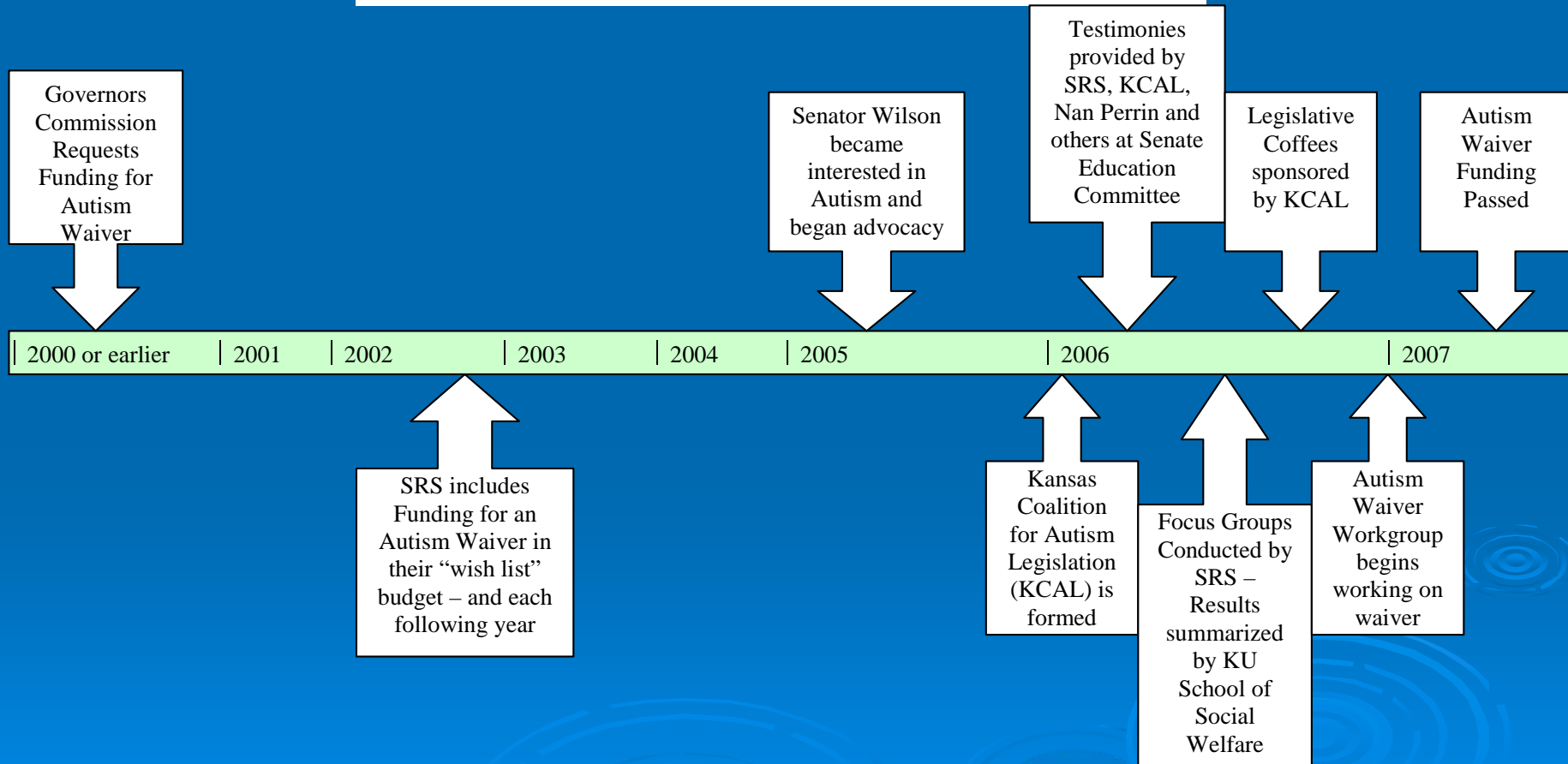
The State, Part I

- The Division of Mental Health and the Division of Community Supports and Services Identified Autism Spectrum Disorder as a gap area.
 - The Division of Mental Health commissioned a study by the University of Kansas School of Social Welfare to examine this gap.
- The Kansas Department of Education identified a growing number of children with autism being served in the education setting.
 - The Special Education Advisory Council commissioned a study on the Education of Children with Autistic Spectrum Disorder.

The State, Part II

- Advocates in the State of Kansas have pursued a Autism Waiver for several years. However, FY 06 was the first year that an Autism Waiver made it to the floor for debate.
- The Governor of Kansas had as priority areas, children's health insurance and early childhood.
- Parent and family meetings were held throughout the state by SRS to examine the service gaps in coverage.
 - KU – School of Social Welfare compiled the feedback for SRS

Some of the Advocacy in Kansas



The Result:

As a result of the Legislative Interest and the Governor's priority areas, and under the direction of a new Secretary, Kansas Social and Rehabilitation Services began to explore the need for enhanced autism services to be provided through a 1915 (c) **HCBS Autism Waiver.**

What is an HCBS Waiver?

- Waives against institutional care
- Waives some federal rules
- Waives parental income
- Provide non-traditional services and supports not covered under Medicaid

Designing an Early Childhood Autism Waiver

- The development process
- Contentious issues
- Current status



Making a Waiver: The Process

- Get all the players to the table:
 - SRS facilitated stakeholder meetings with families of children with autism and providers
- Decide what to do:
 - Who will we serve? (i.e. eligibility guidelines)
 - What services will be provided?
 - Who will be the gatekeeper, service providers?
 - What are required limitations, exclusions?
- Find the money to pay for it...

Contentious Issues

- Current capacity to provide services versus capacity building
 - Since the waiver will be statewide, it is hard not to just recommend what is already possible
 - What gap will that fill?
- Who decides best practice?
- Geographic limitations in Kansas
- The language of a waiver
 - Requires state experts to translate services to understandable language for bureaucrats

Current Status

- The Kansas Legislature approved funding for waiver services to begin in January of 2008, pending waiver approval by Center for Medicaid Services
- In June, the draft of the waiver will be presented to the large stakeholder group
- This summer the waiver will be submitted to CMS for approval



Congratulations

Services Proposed in the Draft

- Parent friendly entry process
- Services for children with autism spectrum disorder, through age 5
- Consultative and clinical services: Autism consultation
- 1:1 supports: Intensive In-home supports, attendant care, respite care
- Day habilitation
- Family adjustment counseling

Keys to Success

- When stakeholders, the state, and providers come together at the same time
 - Identify legislative champions
 - Use common language
 - Bring personal experience to the table
 - Provide data to support requests



What can families do?

- Seek commonalities with other families and providers; figure out how to deliver one, coherent message.
- Join or form a local autism society or support group. You will be key in helping researchers and policy makers. If there is no “centralized” place for parents to voice concerns, it slows down the process.
- Find out what initiative are already going on in your state (Kansas example: KCAL) and offer to help or synergize efforts

Activities provided along with advocacy



Video of Robbie playing drums

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