Early Intensive Intervention Services Using Applied Behavior Analysis for Young Children with Autism Spectrum Disorders: Provider and Family Perspectives

Nan Perrin
Lisa Smith
Shelly Gaudreau
Louise Heinz

Our plan for the next hour

- Early Intensive Behavioral Intervention
- Family
- Team Building
- Statewide Advocacy

Early Childhood Autism Program (ECAP®)

- Established in 1990 by a group of parents
- Behaviorally based program
- Providing in home and center-based support
- A program within Community Living Opportunities, Inc.

What are Autism Spectrum Disorders?

- Pervasive developmental disability
- Problems with social and communication skills
- Behavior concerns, such as repetitive movement, rituals
- Lifelong disability
- Incidence estimated at 1/500 or 1/166 children (CDC, 2006)
  - New incidence reports in February 2007, 1/150 eight year olds with Autism Spectrum Disorders (CDC, 2007)
  - Latest Incidence reports in October 2009, 1/91 (Pediatrics, 2009)

What is Early Intensive Behavioral Intervention?

- Based on Applied Behavior Analysis
  - Prompting
  - Shaping
  - Reinforcement
- Used with children with Autism and related disorders
- Purpose is to decrease aberrant behavior and increase socially appropriate behavior
- Attempts to remove behavioral characteristics of autism

Key Factors of Early Intensive Behavioral Intervention

- Begin early in child’s life
- Significant number of hours per week (25-40)
- Typically 2 to 4 years
- Teaching takes place in the child’s home
- One-on-one instruction from a behaviorally trained therapist, teacher, and/or parent
General Description of Early Intensive Behavioral Intervention

- Intervention takes place in a secluded or private setting and involves time at the table and play
- Targeted skills are determined by team
- Focus on skills the child does not do or at least not consistently
- Follows a developmental progression
- Therapists are trained in behavioral techniques
- Specific strategies are used to address problem behavior
- Intervention is overseen by a behavior analyst
- Periodic team meetings are often held

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 (see Rogers, 1998).”

- Mental Health a Report from the Surgeon General, Chapter 3 Autism
  retrieved April 24, 2006 from http://www.surgeongeneral.gov

Some additional references

- Kansas Best Practices Report
- National Autism Standards Project

What the research about Early Intensive Behavioral Intervention tells us…

- Intervention is most successful if begun at a young age, between 2.5 and 4 years old
- Intensive Intervention appears to be much more effective than less intensive intervention (most success is with children who have 25-40 hours per week, 5-8 hours per day)
- Long term intervention appears to be needed (probably 2 to 4 years at a minimum)
- Behavioral programs have demonstrated a high degree of effectiveness in increasing functional skills and replacing challenging behavior.
- Both the Surgeon General and the Center for Disease Control have identified Behavioral Intervention as an effective intervention for children with autism.

Results from the 1987 UCLA Young Autism Project

<table>
<thead>
<tr>
<th>Intensive Group</th>
<th>40 hours per week of ABA</th>
<th>47% (9) successfully completed regular 1st grade</th>
<th>42% (8) successfully completed 1st grade in Learning Disabled (LD) or Language Delay class</th>
<th>11% (2) attended school in class for children with autism or mental retardation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control Groups</td>
<td>10 hours per week or less of ABA</td>
<td>2% (1) child successfully completed regular 1st grade</td>
<td>45% (18) children are in Learning Disabled or Language Delay class.</td>
<td>53% (21) attend school in class for children with autism or mental retardation</td>
</tr>
</tbody>
</table>
An example of our one-on-one settings and a few teaching interactions

Cost Savings

- 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.

How does Kansas compare?

Cost of Community Services: Includes residential and day support, wellness monitoring, and Targeted Case Management

- High Needs (HCBS Tier 1 Funding): per year = $72,398.99
  per 52 years = 3.76 million
- Tier 2 funding: per year = $58,714.53
  per 52 years = 3 million
- Tier 3 funding: per year = $44,529.23
  per 52 years = 2.3 million
- Tier 4 funding: per year = $30,997.11
  per 52 years = 1.6 million
- Low Needs (Tier 5 funding): per year = $24,572.94
  per 52 years = 1.27 million

Cost of Kansas Institutionalization

- Kansas Neurological Institute: per year = $112,785.00
  per 52 years = 5.8 million*
- Parsons State Hospital: per year = $134,685.00
  per 52 years = 7 million*

Cost of Early Intensive Intervention for Children with Autism - $204,780.00
- 4 years, 35 hours per week of systematic, behavioral 1:1 teaching in the areas of language, social communication, behavior support, self-care, and pre-academic skills. Includes parent training and program development/oversight by a behavioral consultant. $38,000 per year for 4 years.
- 4 years, 15 hours per week of continued teaching and specialized 1:1 support with behavioral consultant oversight. $13,000 per year for 4 years

Lisa Smith

A mother of seven children, ages five to twenty-one. Two of Lisa's children have special needs. Lisa's son, Tate, is eight years old and was diagnosed on the autism spectrum at age two and a half. For the past five and a half years Lisa has spent much of her time learning about autism spectrum disorders and advocating for her son.
What autism looked like in my toddler:

- Toys and play were not typical.
- There were strange attachments to objects.
- Interaction with other children was nonexistent with the exception of siblings.

What autism looked like at age two and a half:

- Language had regressed.
- He became withdrawn from most of the family.
- There was anxiousness in unfamiliar surroundings.
- Stereotypic behaviors began.
  - Echolalia
  - Hand Flapping
  - Running without a purpose
  - Tossing cloth and watching it fall
  - Fanning pages of books
  - Watching reflection in doors, mirrors, screens

The Diagnosis:

- Initially, I found autism on the internet.
- The Pediatrician
- The Developmental Pediatrician

Early Intervention:

- Infants and Toddlers
- Research Based Therapy
  - Behavior Consulting
  - In Home ABA: discrete trial and incidental teaching
- Preschool
  - Public (free)
  - Private (costly)

Hard Work and Growth:

- Language recovery
- Play Skills
- Academics
- Social Skills

Challenges:

- Finding appropriate activities that interest children with autism is challenging.
- Public schools have been a real challenge
  - Educating the educators is a must.
  - Educating the other students about autism is a must.
- Prompt dependence
- Outings
- Behaviors
  - Stereotypic Behaviors
  - Anxieties
Positives from our life with autism:

– Our family is educated, compassionate and involved with people with special needs.
– People we have met along the way are a huge part of our life now.
– Educating others about autism has helped our community.
– Book explaining autism to children
  • That book is also included as a handout.

Shelly Gaudreau

The mother of two boys, one affected with ASD. Her eldest was diagnosed with PDD NOS at seventeen months, and is now nine years old with an autism diagnosis. Her youngest son is five. Her family has been involved with ECAP and practicing ABA for over seven years. She is a member of the Lawrence Autism Society and a supporter of Autism Speaks.

How to build an effective team!

Team Collaboration

Who should be involved?

- Individual
- Family
- Individuals
  - Circle of Support
- Related Service Personnel
- Teachers
- Paraprofessionals

Importance of developing relationships

Maintaining open communication
Louise Heinz

Louise is a mother of 3 children. Her youngest daughter was diagnosed with autism at age 2 ½. For the past 3 ½ years Louise has been running an intensive behavioral intervention program for her daughter supported by the Early Childhood Autism Program (ECAP). Louise is the Vice-President of the Lawrence Autism Society and was a parent appointee to the Kansas Autism Task Force. Louise spends much of her spare time advocating for evidence-based intervention for children with autism.

Statewide Parent Advocacy

- Need for Evidence-based Intervention
- Financial Burden on Families
- Growing Number of Children Diagnosed
- Cost to the State of Kansas

Kansas Coalition for Autism Legislation

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

Services Provided

- Parent friendly entry process
  - Evaluation by an outside agency, once identified
- Services for children with autism spectrum disorder, entry through age 5
- Consultative and clinical services: Autism consultation
- 1:1 supports: Intensive In-home supports, respite care
- Parent Support and Training
- Family adjustment counseling

Kansas Early Autism-application for families
Where Are We Now.

• Began January 2008
• 45 children currently served
• 275 children waiting
• A number of children have aged out

Kate’s Law (House Bill 2367)

Private health insurance companies…

• Do not consistently cover diagnosis of autism
• Do not cover the appropriate treatment of autism
• Policies specifically list autism as a diagnostic exclusion

Kate’s Law – Premium Increases?

• 0.62% increase in premiums to cover both small and large group policies combined
• An increase of $22.60 per year or $1.88 per month*

* Lambright, February 2009.

Kate’s Law – Other States

• 15 states have enacted autism health insurance bills
• 30 states, including Kansas, introduced bills in 2009
• Indiana and Minnesota have required unlimited coverage for autism treatment, including ABA, for over 8 years.

• Autism Votes

Other States continued..

There is no data that demonstrates any negative impact …

• on premiums
• The viability of small businesses
• Or, the number of uninsured

Video
How to get on important lists!

- Contact your local CDDO (Community Developmental Disability Organization)
- Kansas Autism Waiver
  - www.kansasearlyautism.org
- Kansas Coalition for Autism Legislation
  - http://web.mac.com/wasmer_ms/KCAL/Home.html
- Autism Votes - Kansas

Some recommended readings

Louise
- “Let Me Hear Your Voice” Catherine Maurice
- The Autism Sourcebook by Karen Siff Ekorn
- Ten Things Every Child with Autism Wishes You Knew, by Ellen Notbohm
- Unwritten Rules of Social Relationships, by Dr. Temple Grandin and Sean Barron
- Teach Me Language, by Sabrina Freeman Ph.D. and Lorelei Dake B.A.
- Shelly
  - Overcoming Autism, Lynn Kern Koegel, Ph.D., and Claire LaZebnik
  - Just Take A Bite: Easy, Effective Answers to Food Aversions and Eating Challenges! Lori Ernsperger, Ph.D., Tania Stegen-Hanson, OTR/L

Thank You!!