CONNECTED KIDS

Training Parents To Use Developmental and Behavioral Strategies with Their Child with Autism Spectrum Disorder

A report by:

Oklahoma Autism Network

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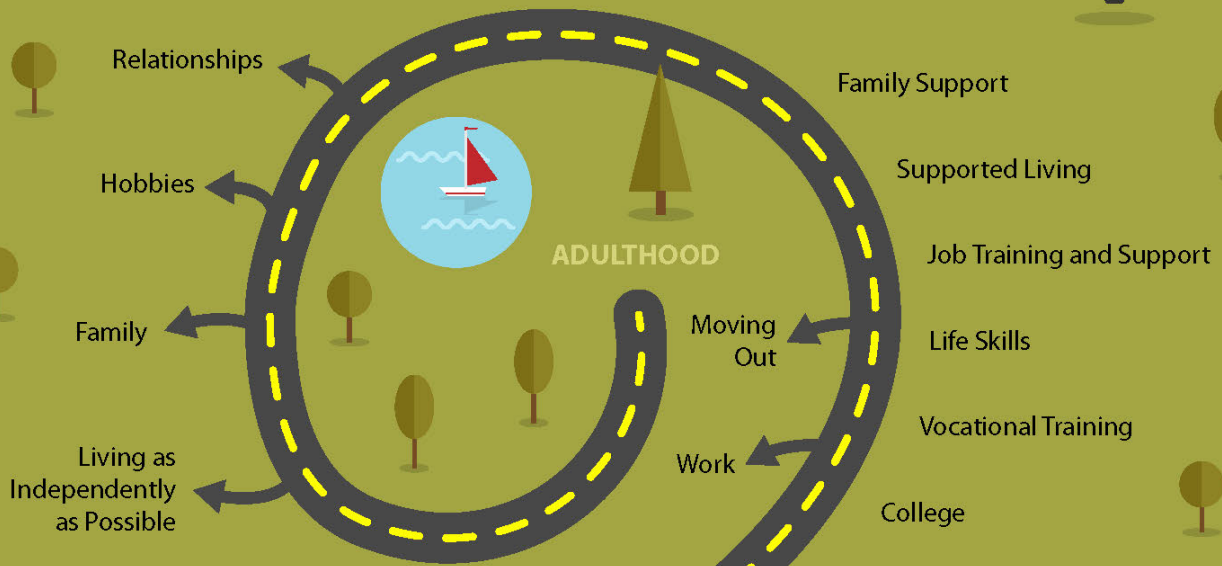Fax: 405.271.2630
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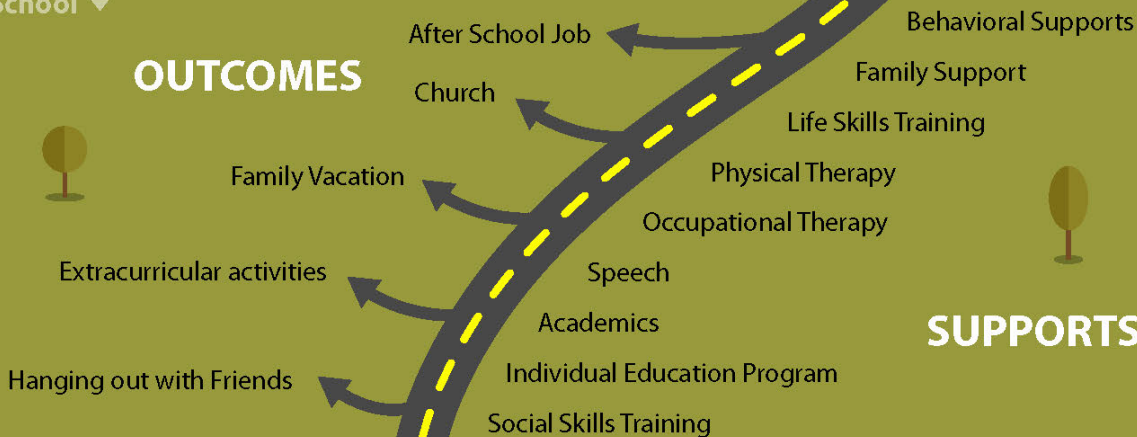Web: www.okautism.org

LIFE CONNECTIONS

Developmental Disabilities Services and Department of Rehabilitation Services ▾

ADULTHOOD

Relationships

Hobbies

Family

Living as
Independently
as Possible

Family Support

Supported Living

Job Training and Support

Moving
Out

Life Skills

Vocational Training

Work

College

School ▾

OUTCOMES

After School Job

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Hanging out with Friends

Behavioral Supports

Family Support

Life Skills Training

Physical Therapy

Occupational Therapy

Speech

Academics

Individual Education Program

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SUPPORTS

Early Intervention ▾

**CHILD DIAGNOSED
WITH AUTISM**

Family Support

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Occupational Therapy

CONNECTED KIDS

Mother's Day Out

Feeding Therapy

SoonerStart

Speech

Playdates

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Birthday Parties

Family Outings

Executive Summary

Helping Oklahomans with Autism: Senate Bill 135

The Oklahoma legislature conducted an interim study in 2008 that identified the need for expanded services and supports for Oklahomans diagnosed with an autism spectrum disorder (ASD). The legislature responded by passing Senate Bill 135 (SB 135) to expand programs and expertise of professionals in the diagnosis and treatment of ASD. The ConnectedKids program was designed and implemented in response to SB 135, which called for research to evaluate behavior analytic strategies within a consultative model that included parent training.

ConnectedKids

ConnectedKids trains parents to use developmental and behavioral strategies with their young child with ASD. The program focuses on the use of evidence-based techniques to increase the child's social-communication skills with the parent during play and daily routines. Trainers work with families in their homes and other community settings over a four month period of time with periodic follow-up for an additional six months.

> **"We wouldn't be anywhere right now. Within a month or so with ConnectedKids it's like a different kid already. It was amazing to see such a difference in such a short amount of time." (dyad 13)**

Impact

Parents reported that day-to-day life was much better because of the strategies they learned through the ConnectedKids program. Parents learned strategies to interact with their children, and reported that the strategies became a natural part of daily life with their child. In turn, their children demonstrated improvements in language, imitation, play, and engagement.

Recommendations

1. Develop a plan for statewide implementation of ConnectedKids within SoonerStart, Oklahoma's early intervention program (SoonerStart providers to provide training for parents).
2. Develop a plan for feasibility testing of ConnectedKids within early childhood programs (Early childhood providers to provide training for parents).
3. Develop a plan for feasibility testing of the model for older children and youth with ASD (teachers and specialists of school-age students provide parent training).
4. Develop sustainable funding streams to recruit and retain Board Certified Behavior Analysts and other professionals competent in the provision of the ConnectedKids program.

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Introduction

Autism Spectrum Disorders (ASDs)

Autism spectrum disorders (ASD) are complex conditions that usually become apparent in early childhood. Children with ASD have varying degrees of difficulty in social interaction, receptive and expressive communication, and frequently display restricted repetitive behaviors. The Center for Disease Control and Prevention (CDC) reports ASD is the fastest growing developmental disability, with a 78% increase in prevalence between 2002 and 2008 (CDC, 2012). Current estimates indicate 1 in 88 children in the United States have an ASD (CDC, 2012). In 2012, 4,121 children in Oklahoma received special education services under the autism category (Data Accountability Center, 2013). This is an 807% increase compared to 1998-1999 data. The number does not include children with ASDs who were not receiving special education services, or those under age 3 or over age 21. Currently Oklahoma has no mechanism for tracking individuals with ASD outside the public education system.

ASD is a lifelong disability with a profound impact on the life of the person and the family. ASD has no cure, but with appropriate intervention individuals can make significant improvements that lead to markedly improved function in daily life.

Impact on families and communities

Parents of children with ASD experience a greater caretaking burden and greater stress than parents of children with other developmental disabilities (Dabrowska & Pisula, 2010). Families are less likely to participate in the community, including church and extracurricular activities (Lee & Harrington, 2008). ASD is also associated with a significant financial burden. Parents are more likely to leave a job or decrease work hours to care for their child, resulting in family earnings that are approximately 21% less than those of children with other health limitations (Cidav, Marcus, & Mandell, 2012; Lee & Harrington, 2008). The additional cost of caring for a child with ASD is approximately $17,081 per year, including cost for health care, education, and therapy related to the ASD. The lifetime cost to care for a child with ASD is estimated at $3.2 million with societal costs estimated at $11.5 billion in 2011 for children age 3 to 17 years living in the United States (Lavelle et al., 2014).

Services for Oklahomans with Autism

In 2012, the Oklahoma Autism Network (OAN), in collaboration with the Oklahoma Family and Interagency Autism Council, conducted the first needs survey in our state specifically focused on individuals with ASD. The Oklahoma Autism Needs Assessment Survey (OANAS) gathered information from parents who have a child with ASD and from adults with ASD about diagnosis, services, crisis intervention, employment, and impact of ASD on the family.

Receiving a diagnosis early is a critical first step in accessing intervention specifically focused on addressing the core deficits of ASD. Parents in Oklahoma reported an average age of receiving an ASD diagnosis ranging from 3.5 years of age (autism) to 6.7 years of age (Asperger syndrome). After a child is diagnosed, parents report

barriers to accessing effective interventions for their child. The majority of families with children under 21 years of age access services through SoonerStart, Oklahoma's early intervention program (birth to 3 years of age) or through their local public school (3 – 21 years of age). These programs have limited resources to support children with ASD and their families. Programs in rural areas are challenged to find and retain professional staff, and have particular difficulty finding staff with expertise in ASD. Metro area systems typically have more resources, but face challenges in meeting the need of a greater number of children with ASD who live in these areas.

Due to the limited resources and assistance available through the public system, families often seek additional private services to support their child and family. However, relatively few private providers are available in Oklahoma, and resources to cover costs are limited. Caregivers report a lack of insurance or the high cost of services as a barrier to accessing additional services for their child. According to the OANAS, almost 60% of caregivers paid out of pocket for services in the past three years, with the average monthly cost of $825 per child. The monthly out of pocket expense is even greater for parents of children under the age of 9, with an average monthly cost of $1,339.

The need for support continues into adulthood, with the focus shifting to supports that enable the individual to seek additional education and vocational training and to work, and live as independently as possible. Of the survey respondents with an adult child or adults themselves, 83% report being unemployed (OANAS, 2012). The supports individuals report needing to be successful include job coaching, social skills training, and vocational training. Currently, the Oklahoma Department of Human Services, Developmental Disabilities Services and the Oklahoma Department of Rehabilitation Services are the only agencies providing support to individuals for employment as they transition out of high school or reach adulthood. Many individuals with ASD, however, do not qualify for these services or may not find adequate services in their area. Beyond assistance with employment, adults with ASD are pressed to find support for independent living skills or other areas of adult life. Adults with ASD are often unemployed, have limited social relationships outside immediate family, live with parents or in other supported environments, and are at greater risk for depression and other mental health conditions, thereby incurring greater human and financial cost to the person with autism, the family, and society (Howlin, Goode, Hutton, & Rutter, 2004; Volkmar & Wolf, 2013).

The Oklahoma legislature's response
In 2008, advocates sought coverage for applied behavior analysis services for people with ASD through an insurance mandate. The requested mandate included coverage of services based on applied behavior analysis evidence for children under 21 years of age with a $75,000 per year cap. In response to this request, the legislature conducted an interim study to better understand the needs of individuals with autism in Oklahoma. As a result of the interim study, the legislature passed Senate Bill 135 in 2009 to address difficulties faced by families

raising a child with ASD. The Bill included multiple components for expanding the workforce and expertise of professionals in Oklahoma who support individuals with ASD and their families. These components included 1) licensure for Board Certified Behavior Analysts as the first step toward Medicaid coverage for behavior analysis services, 2) funding for the SoonerStart early intervention program to provide training to staff specific to ASD, 3) funding to train primary care providers to evaluate children with ASD, 4) funding for a program modeled after Early Foundations, and 5) establishment of an applied behavior analysis treatment pilot project. The pilot project was to use the best scientific evidence to create an applied behavior analysis intervention using a consultative model that included a parental training component. The project was to study the effects of the training on parents and measure the functional outcomes of their children with autism.

Developing a model for Oklahoma

The Oklahoma Autism Network at the University of Oklahoma Health Sciences Center developed and implemented the ConnectedKids Program to meet the requirements of the applied behavior analysis treatment pilot project outlined in SB 135. SB 135's mandate to develop a consultative model that includes parent training, while considering Oklahoma's limited resources, led to the development of a program that focuses on empowering parents to use strategies to support their child with ASD. Although individuals with ASD often require some level of support throughout their lifetimes, the early years following a diagnosis are a critical time when effective interventions can significantly affect long term outcomes for the child and the family.

The Life Connections graph (see inside front cover) illustrates how programs such as ConnectedKids are a critical part of effective interventions for all children with ASD. In Oklahoma, four agencies are primarily responsible for services and supports to individuals with ASD across the course of their lifetimes. The evidence suggests that effective early intervention for families and children results in fewer support needs across the lifespan. The more effective the supports, the more likely the long term beneficial output and the less supports required by agencies and programs later in the person's life.

Supporting parents is a critical component of an effective intervention program for children with ASD (NRC, 2001). Unfortunately, many intervention programs focus primarily on the child and the child's development of new skills. The family is the constant in a child's life and without the stable, solid base of support that a family provides, the child is less likely to succeed.

The ConnectedKids program is designed to enhance families' capacities to support the developmental needs of their children and to access, evaluate, and advocate for supports and services for their children's meaningful participation in everyday activities. The ConnectedKids program works directly with the parent to improve the child's skills and abilities. Research indicates intervention that includes behaviorally based parent training has

multiple benefits. It results in better generalization and maintenance of skills compared to therapist-directed models, increases parent optimism about their child's future, decreases parent stress, and is cost effective (Koegel, Bimbela, & Schreibman, 1996; McConachie & Diggle, 2007). Intervention that includes parent training is also an effective way to increase the number of hours of intervention the child receives (Ingersoll & Dvortcsak, 2010). Increased intervention intensity and duration are associated with more favorable outcomes (Matson & Smith, 2008).

ConnectedKids

The ConnectedKids program includes two primary components 1) service coordination and 2) training parents in the use of developmental and behavior analytic strategies within the context of family life. Service coordination involves partnering with parents in ways that support their roles as primary decision makers for their families. It is an individualized process that includes, but is not limited to: 1) providing a care notebook; 2) conducting a needs assessment by identifying needs and building on current resources and supports; 3) assisting families in completing applications for services and programs such as the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), Supplemental Security Income (SSI), and Oklahoma Department of Human Services, Developmental Disabilities Services; 4) assisting families in preparing for Individualized Family Service Plan (IFSP) / Individualized Education Program (IEP) meetings; 5) attending IFSP / IEP meetings with families per family request; and 6) connecting families with other community resources, including parent support groups and professionals to address specific needs the family identifies.

To train parents in the use of developmental and behavior analytic strategies, we combined several evidence-based, manualized, and operationally defined practices including the Routines-Based Interview (RBI) (McWilliam, 1992, 2010; McWilliam, Casey, & Sims, 2009), the Project ImPACT (Improving Parents as Communication Teachers) curriculum (Ingersoll & Dvortcsak, 2010), and coaching (Rush & Shelden, 2005). The Routines-Based Interview is a structured process for gathering information about family daily routines and activities. The interview is intended to set the tone for a positive relationship between the trainer and the family, offer an opportunity to gather in-depth information about child and family functioning, and result in the identification of functional outcomes chosen and prioritized by the parent (McWilliam et al., 2009).

Project ImPACT (Ingersoll & Dvortcsak, 2010) is a parent training curriculum for young children with ASD. Based on developmental and behavior analytic strategies, parents learn how to expand their child's communication, social engagement, play, and imitation skills during play and family and child routines. Research indicates that everyday activities offer rich sources of learning opportunities for children (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). Bruder and Dunst (2000) found "parents prefer interventions that are easy to do, fit into their daily lives and emphasize children doing and learning things that help them be part of family and community life" (p. 35). During the ConnectedKids program, all intervention sessions take place in the home and other community settings

identified by the family and occur within the context of play and routines. Visits occur with the parent and child two times per week for approximately 90 to 120 minutes each for 12 weeks following the schedule of topics outlined in the curriculum (Ingersoll & Dvortcsak, 2010). Three follow-up sessions occur with the parent post intervention at one month, three month and six month intervals. The order of activities during each intervention session include (a) review of the prior plan for specific practice between sessions; (b) videotape and review of a 10-minute play or mealtime routine video; (c) review of homework from the prior session and problem solving concerns or challenges before discussing new topic; (d) discussion and instruction in developmental and behavioral strategies using the Project ImPACT curriculum; (e) trainer modeling and parent practice of the strategies with the child; (f) development of a specific plan for practice between sessions; and (g) discussion and assignment of questions to answer and reading in the parent manual for the next session. During the sessions, trainers use coaching (Rush & Shelden, 2005) as the interaction style between the parent and trainer.

Increasingly, coaching is (a) being applied in research (Foster, Dunn, & Lawon, 2013; Friedman, Woods, & Salisbury, 2012; Graham, Rodger, & Ziviani, 2009); (b) identified as a key element for implementing effective early intervention services under Part C of the Individuals with Disabilities Education Act and the medical home (Adams, Tapia, & the Council on Children with Disabilities, 2013; Ideishi, Chiarello, & Nixon-Cave, 2010); (c) used in the provision of professional development and technical assistance regarding evidence-based practices for learners with ASD (Kuzcharcyzk, et al., 2012); and (d) the focus of a program logic model developed for Head Start (McGroder, Howard, Fishman, Rankin, & Helsel, 2014). Rush and Shelden (2005) describe coaching as a reflective capacity building conversation between families and professionals to enhance, gain, and use knowledge and skills in the context of natural learning environments. Coaching is defined as:

> an adult learning strategy in which the coach promotes the learner's ability to reflect on his or her actions as a means to determine the effectiveness of an action or practice and develop a plan for refinement and use of the action in immediate and future situations (p. 3).

An example of coaching occurs during the review of 10-minute parent-child interaction videos. The trainer and parent watch the video taken during each session. Rather than telling the parent how they should have interacted with the child, the trainer engages the parent in a reflective conversation about the parent's understanding and intentions. The trainer, rather than directing, partners with the parent to reflect on the interactions with the child, to generate alternative strategies, and to develop plans for implementation and evaluation. The trainer uses coaching throughout each session to enhance the parent's capacity to use the strategies outlined in the curriculum.

ConnectedKids: Pilot

The purpose of the pilot study was to test the feasibility of a program that combined three evidence-based components: Project ImPACT curriculum (Ingersoll & Dvortcsak, 2010), Routines-Based Interview (McWilliam, 2010), and coaching (Shelden & Rush, 2005). During the pilot, we tested video codes that measured changes in parent-child interaction following intervention, and trained and measured trainer fidelity in implementing the program's various components.

Methods

Participants

Six parent-child dyads were recruited from local diagnosticians, therapy programs, and Oklahoma's early intervention program, SoonerStart. Inclusion criteria included (a) age of child between 2 to 5 ½ years; (b) meeting criteria for autism, Asperger syndrome, or pervasive developmental disorder not otherwise (PDD-NOS) specified on the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; DSM-IV; American Psychiatric Association, 1994) or the *Autism Diagnostic Observation Schedule* (ADOS; Lord, Rutter, DiLavore, & Risi, 1999); (c) at least one parent (or primary caregiver) agreed to participate in all training sessions 2 times per week for 90-120 minutes in the home; (d) residing within 45 miles from the OUHSC-OKC campus; and (e) parent speaking fluent English and reading English. Exclusion criteria included (a) the child having a dual diagnosis aside from ASD, (b) having a neurological or genetic disorder of known etiology, (c) receiving applied behavior analysis (ABA) services exceeding 10 hours per week not including attendance of school or childcare, (d) beginning an ABA program exceeding 10 hours per week, (e) demonstrating behavior resulting in harm to self or others, and (f) the parent had attended a University level course in the basic principles of ABA. The University of Oklahoma Health Sciences Center (OUHSC) Institutional Review Board approved the study. Parents provided informed consent prior to participation.

Six parent-child dyads met eligibility criteria to participate in the pilot study. Six children (28 to 63 months old, *M* = 50.3 months) with ASD and their parents completed the study. One "parent" was a grandparent. Table 1 summarizes child and parent characteristics.

Table 1

Demographic Characteristics of Participants

Children (n=6)	
Age (mean age in months)	50.3
Gender	
Male	4
Female	2
Ethnicity	
Caucasian	4
Minority	2
Language level	
Non-verbal	3
Single words	2
Phrase speech	1
Complex language	0
Parents (n-6)	
Age (mean age in years)	38.7
Gender	
Male	1
Female	5
Caregiver role	
Parent	5
Grandparent	1
Highest education level	
Some high school	1
High school diploma/GED	0
Some college	2
College degree	2
Advanced degree	1
Marital status	
Married	4
Divorced/Separated	1
Single	1
Employment status	
Not employed	2
Employed part or full-time	4

Settings and Materials

Baseline and treatment sessions occurred in the child's or grandparent's home. During the sessions, we used toys, materials, and food available in the home. We video recorded a 10-minute parent-child interaction during all sessions. Trainers rated parent fidelity using a revised fidelity scale provided by the first author of the Project ImPACT (Ingersoll & Dvortcsak, 2010) while coding pre and post-intervention videos. For each child, the parent and trainer completed independently the Social Communication Checklist (SCC; Ingersoll & Dvortcsak, 2010) pre and post-intervention. The SCC is a checklist of skills for social engagement, language, imitation, and play. Within two weeks following intervention, parents participated in semi-structured interviews conducted by a person not directly involved in other aspects of the study.

Research Design

We used a mixed-methods research design to strengthen the study's quantitative methods by gathering qualitative data to better understand the experiences of parents participating in the study. The quantitative method was a quasi-experimental group pre-test,-post-test design that combines repeated measurement and design phases (baseline, intervention, and post follow-up) (Portney & Watkins, 2009). The qualitative method was a phenomenological approach (Patton, 1990).

Research Team Training

The research team included two graduate-level therapists (principal investigators) with master's degrees in rehabilitation science and two board certified behavior analysts (trainers), one with a doctorate in special education and one with a master's degree in behavior analysis. Team members received training in the use of Project ImPACT (Ingersoll & Dvortcsak, 2010), the Routines-Based Interview (McWilliam, 1992, 2010; McWilliam et al., 2009), and coaching (Rush & Shelden, 2005).

Results

These results address the following research questions.

Did the trainers implement the program as designed?

The principal investigators assessed trainers' procedural fidelity for the components of ConnectedKids, including the RBI, Project ImPACT, and coaching. The data indicated that the trainers implemented the Project ImPACT curriculum and the Routines-Based Interview as outlined in the protocol. One trainer implemented coaching with procedural fidelity. The other trainer worked towards completing reliability in coaching during the pilot study.
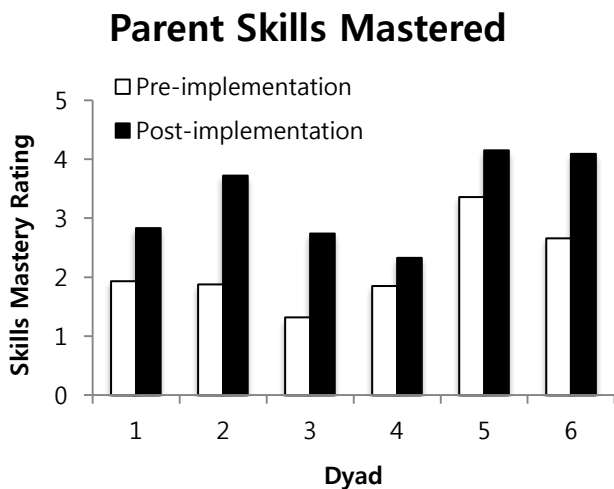
Parent Skills Mastered

Figure 1

How did the parents change after ConnectedKids?

As a group, parents increased their mastery of new skills by 66.9% (p = 0.0026), including skills such as using simplified language, waiting for their child to initiate, modeling and expanding play skills, and providing reinforcement for their child's responses. Figure 1 depicts the parents' use of the strategies before and after the program. Dyad 4, which showed the smallest gain in skill, included an adult who was not the primary caregiver and did not have custody of the child, resulting in limited practice time during portions of the program.

How did ConnectedKids help parents to help children?

Four of the six children showed improvements in social communication skills, as measured by the Social Communication Checklist (SCC). The checklist revealed improvements in social engagement, expressive and receptive language, and play and imitation skills. As a group, the mean change from pre to post-intervention was 13.7% (p = .1297). Two parents, both of whose children were nonverbal, rated their child lower in one or two areas after the program. Parents reported a better understanding of the questions on the rating scales following intervention, which contributed to their lower scores. Figure 2 depicts the.parent ratings of change in their child's social communication skills as measured by the SCC. Trainers also completed the SCC and reported that the children used all social communication skills more frequently following intervention.
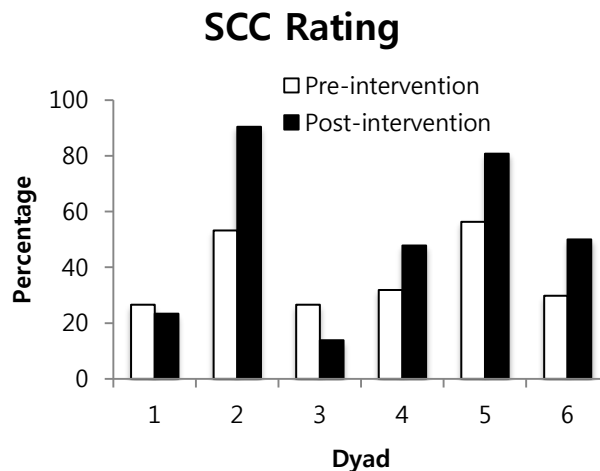
SCC Rating

Figure 2

At the beginning of training, trainers set goals in collaboration with the parents. They updated goals as they tracked progress in social engagement, language, imitation, and play skills throughout the training. Across the six dyads, 51 goals were set. *By the end of the treatment phase, 38 (75%) goals were met.* An additional 12 (24%) goals were partially accomplished.

What did the parents say about ConnectedKids?

We systematically evaluated parental perspectives through follow-up interviews. *Parents reported feelings of empowerment through a better understanding of how to support their child's unique needs. Parents reported improvements in family relationships. Parents also reported increased confidence in their ability to go out in the community and participate in activities that are meaningful to their family.* Some families commented about the challenges with a program that required them to read and do homework between sessions. Below is a sample of the parent's responses.

> **"Before when he sat on my lap I was a chair, now when he sits on my lap, I am his Mom."** (dyad 2)

"...a lot of people don't have the luxury of having high dollar therapy and this teaches parents to be able to help their children adapt." (dyad 1)

"...just having her [service coordinator] say what other resources can we help you with. And having her come to an IEP just to sit. That was awesome. I thought honestly that she would do a lot of talking and they wanted her to lead the meeting, the school did. And she just said, "No. She's going to do this." And just for me to have the confidence to lead it, not cry not one time, which is very unusual through an IEP meeting. It was just a new me. A completely new me." (dyad 1)

"...I see him happy. I see him with self-esteem is higher than ever, and I see him less anxious, less frustrated...But without the project, I think we'd never be able to be in church for an hour. My next step is theater. We never could enjoy a movie with him because something was bothering him, and now we're going to try that." (dyad 2)

"She's a happier child after the program. She's not miserable all the time. We haven't given up on her and she hasn't given up on us either." (dyad 3)

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"I'm not saying there weren't days that I was like, I forgot to do my homework and I'm so stressed out, and I don't know if I can get it done and you kind of feel like you're in college all over again. But, I think all in all it was an extremely good experience and…if we had to go back and do it all over again, I would go back and do it all over again." (dyad 6)

What we learned

At least three groups of people experienced change. The trainers learned the protocol and effectively taught parents, and as a result the children showed positive changes in their social-communication skills. The results of the ConnectedKids pilot were promising, and we learned ways to strengthen implementation and evaluation for the main study. Specifically, we refined our outcome measures for the main study and adjusted procedures for research evaluation.

ConnectedKids: Full Study

The purpose of the full study was to evaluate the effects of the ConnectedKids program on parent and child skills. The findings from the pilot study informed intervention and research refinement for the full study.

Methods

Participants

Parent-child dyads were recruited from local diagnosticians, therapy programs, and Oklahoma's early intervention program, SoonerStart. Inclusion criteria included (a) age of child between 2 to 6 ½ years and no older than 5 years and 0 days at the time of consent; (b) meeting criteria for autism or pervasive developmental disorder not otherwise (PDD-NOS) specified on the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; DSM-IV; American Psychiatric Association, 1994) and on the *Autism Diagnostic Observation Schedule* (ADOS; Lord, Rutter, DiLavore, & Risi, 1999); (c) at least one parent (or primary caregiver) with whom the child resided who committed to participate in all training sessions 2 times per week for 90-120 minutes in the home and to practice a minimum of 5 additional hours per week; (d) residing within 30 miles from the OUHSC-OKC campus; and (e) parent speaking fluent English and reading English. Exclusion criteria included the child (a) having a dual diagnosis aside from ASD, (b) having a neurological or genetic disorder of know etiology, (c) receiving applied behavior analysis (ABA) services exceeding 10 hours per week not including attendance of school or childcare, (d) beginning an ABA program exceeding 10 hours per week, (e) demonstrating behavior resulting in harm to self or others and (f) the parent had attended a University level course in the basic principles of ABA. The University of Oklahoma Health Sciences Center (OUHSC) Institutional Review Board approved the study. Parents provided informed consent prior to participation. Following consent, an independent licensed psychologist with expertise in autism confirmed the diagnosis of autism using the ADOS for any child who had not been assessed with the ADOS within six months of entering the study. All children met the cutoff for autism or ASD on the ADOS.

A total of 16 parent-child dyads met eligibility criteria to participate in the study. One parent withdrew before completion of the program because a change of employment did not allow time for practice. Fifteen children (26 to 58 months old, M = 41.8 months) with ASD and their parents completed the study. Two "parents" were grandparents. Table 2 summarizes child and parent characteristics.

Settings and Materials

Standardized pre and post-assessments and baseline, treatment, and follow-up sessions occurred in either the child's or grandparent's home. During the sessions, we used toys, materials, and food available in the home. We video recorded a 10-minute parent-child interaction during all sessions. Trainers rated parent fidelity using a revised fidelity scale provided by the first author of the Project ImPACT (Ingersoll & Dvortcsak, 2010) while coding videos from pre-intervention, post-intervention and follow-up sessions. For each child, the parent and trainer completed independently the Social Communication Checklist (SCC; Ingersoll & Dvortcsak, 2010) pre and post-

intervention. The SCC is a checklist of skills for social engagement, language, imitation and play. Following intervention, parents participated in semi-structured interviews conducted by a person not directly involved in the study. Standardized child assessments were administered pre-intervention, post-intervention, and six months post-intervention. Child developmental assessments included the Social Responsiveness Scale, second edition (SRS-2; Constantino & Gruber, 2012), the Preschool Language Scales, 5th edition (PLS-5; Zimmerman, Steiner & Evatt Pond, 2011), and the Merrill-Palmer-Revised Scales of Development (M-P-R; Roid & Sampers, 2004).

Table 2

Demographic Characteristics of Participants

Parents (n=15)		Children (n=15)	
Age (mean age in months)	37.9	Age (mean age in months)	41.8
Gender		Gender	
Male	1	Male	13
Female	14	Female	2
Caregiver role		Ethnicity	
Parent	13	Caucasian	12
Grandparent	2	Minority	3
Highest education level		Language level	
Some high school	0	Non-verbal	4
High school diploma/GED	1	Single words	6
Some college	4	Phrase speech	4
College degree	8	Complex language	1
Advanced degree	2		
Marital status			
Married	13		
Divorced/Separated	2		
Single	0		
Employment status			
Not employed	7		
Employed part or full-time	8		

Research Design

We used a mixed-methods research design to strengthen the study's quantitative methods by gathering qualitative data to better understand the experiences of parents participating in the study. The quantitative method was a quasi-experimental group pre-test,-post-test design that combines repeated measurement and design phases (baseline, intervention, and post follow-up) (Portney & Watkins, 2009). The qualitative method was a phenomenological approach (Moustakas, 1994, 1996).

Results

These results address the following research questions.

Did the trainers implement the program as designed?

The principal investigators assessed trainers' procedural fidelity for the components of ConnectedKids, including RBI, Project ImPACT, and coaching. *The data indicated that the trainers implemented all components of the program as outlined in the protocol.*

How did the parents change after ConnectedKids?

As a group, parents increased their mastery of new skills by 20.2% (p = <.0001) including use of simplified language, waiting for their child to initiate, modeling and expanding play skills, and providing reinforcement for their child's responses. This change was sustained throughout the six month follow-up with a 30.9% improvement (*p* = .0019) from pre-intervention to the six month follow-up. Figure 3 depicts parents' use of the strategies before and after the program. Two parents showed a decrease during the six month follow-up compared to previous sessions based on coding of a 10-minute video of a parent-child interaction. Dyad 10 engaged in an activity that limited the opportunities for use of the strategies to increase complexity of language and play. Change in data for Dyad 11 can be attributed to competing factors of the environment that drew the parent's attention away from the child during the parent-child interaction video.
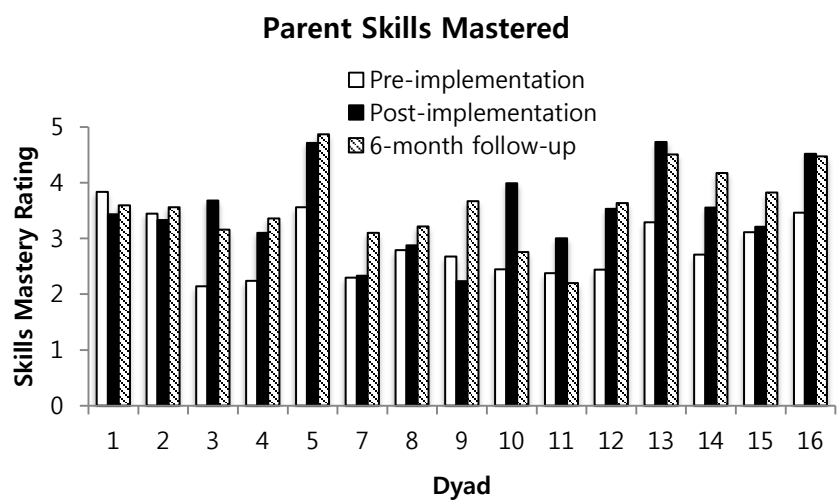
Parent Skills Mastered

Figure 3

How did ConnectedKids help parents to help children?

Twelve of the 15 children showed improvements in social communication skills as measured by the Social Communication Checklist (SCC). This includes improvements in social engagement, expressive and receptive language, and play and imitation skills. Three parents rated their child lower on the SCC following intervention. Two of the three reported a better understanding of the questions on the rating scale following intervention, which contributed to the lower score. The third parent rated her child one point below the maximum score possible at entry and rated the child slightly lower following intervention. As a group, children significantly improved on the SCC from pre-intervention to post-intervention by a mean change of 17.0% ($p = .0002$). Figure 4 depicts parent ratings of change in their child's social communication skills as measured by the Social Communication Checklist.
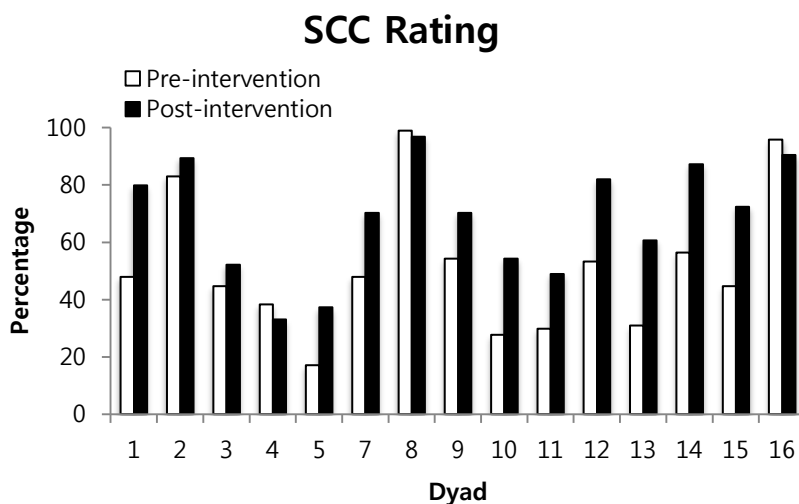
SCC Rating

Figure 4

We used standardized assessments to measure change in child skills before and after the ConnectedKids program. *Children showed significant improvement in communication, cognition, fine and gross motor, and self-help skills as measured by the PLS-5 and the M-P-R following intervention and to the six month follow-up* (growth scores in all domains $p < .05$). Children's social emotional development, including being more cooperative and organized during testing also improved following intervention ($p = .009$) and to the six month follow-up ($p = .002$). Parents also rated their children's temperament as less difficult following the intervention.

In addition to standardized measures, video recordings of play interactions between the parent and child were coded to assess change in social engagement (supported joint attention) and problem behavior. *As a group, the amount of time the children were engaged with their parents improved significantly following intervention with a mean increase of 15% (p = .0130) between pre-intervention and post-intervention. This change was sustained through the six month follow-up.* Overall, the baseline levels of problem behavior were relatively low. However, several children had more frequent occurrences of problem behavior before intervention. *The mean percentage of time that children engaged in problem behavior decreased significantly following intervention by a mean of 8.6% (p = .0078) and was sustained to the six month follow-up.*

At the beginning of training, trainers set goals in collaboration with the parents. They updated goals as they tracked progress in social engagement, language, imitation, and play skills throughout the training. Across the dyads a total of 215 goals were set. *By the end of the six month follow up, 173 (80%) of the goals were met.* An additional 26 (12%) goals were partially accomplished. The remaining goals (8%) were either not accomplished or determined by the parent to be no longer relevant.

"It's so much easier. It's very hard when you don't- when you have a child that cannot talk or will not talk and they just scream. You are totally consumed by it. You're constantly looking for an answer…I just wanted to know, his mother and I both needed to know how to deal with him, and they showed us how to deal with him. And now he is talking, and so it made our lives easier."
(dyad 9)

What did the parents say about ConnectedKids?

Parents participated in a follow-up interview after the completion of the intervention. *Generally, parents reported tremendous improvements in family relationships and feeling empowered with skills to help their child.* Parents reported transformation of child skills and family life from challenging to easier. Two themes represented the essence of the parents' experience: (a) it's so much better day by day; and (b) having the tools now to know how to help. Although not consistent across interviews, parents also referred to feeling more hopeful about their child and families' future. Below is a sample of the parents' responses.

"I would have never had the time to learn all of this if it I wasn't in the study, and I would tell another parent "look at what goes behind everything and why, why therapist do things a certain way and once you kinda understand the why behind it and then it starts working, it just helps you see any situation not as a potential pitfall, where oh my gosh we could have a huge meltdown, we're not even gonna go and try it. Now I don't see it that way. Now I see ok this could be a learning, this could be a potential learning experience and maybe there maybe some struggles, but I'm not scared anymore to go into something. I would tell any parent to be able to not be scared to go somewhere is just a blessing. I would tell them this program helped give me that." (dyad 1)

"It was a lot of work, and it was a lot of information. And I think it has definitely been a benefit for him and for us as well. It's kinda motivated us to do more. We were already motivated, but it even gave us a different direction to go. It just gave us more ideas, more techniques, more to work with." (dyad 4)

"...he never said Mom or anything like that. Which was frustrating not knowing how to communicate when he's thirsty or hungry. And then after learning several of the techniques it wasn't long actually that he started wanting me to join in. It was smaller segments of time. It may just be a little bit, but he would draw me in. Now after 15 minutes of playtime together, sometimes more. Now he says Mom all the time which is great. I love it. It's my favorite." (dyad 13)

Several parents also shared thoughts about the service coordination provided. A few of their statements included:

"...knowing that I had...people behind me-with all the support tools too...the notebook thing they gave you at the beginning of the course. I had never been given something like that; is the most amazing thing I have in my life right now. I was like we haven't even started this thing and even if you just gave me this and nothing else I would have been so happy because you gave me all the- everything I needed and all the tools. I was surprised by that because I knew that we would be getting some of this therapy, and this parent training, but to also get like "Hey are the schools working with you?" "Hey do you need this, do you need that? Have you heard about this program?" and that was totally unexpected, and I'm really thankful for it, cause there were several programs I had never heard of and nobody had ever told me about...it was great knowing that I had that kind of support even on that level; where I really feel like I could send an e-mail right now to anyone on the team and say, "Hey I have a question about this" and I know I am going to get an answer back. That was totally unexpected. I thought I'd get the training and you know probably be just let loose and that would be the end. It's very obvious that's not the case." (dyad 1)

"She's been very helpful. Very helpful. I know in the beginning when [my child] had the opportunity to go into the school system, which I was very nervous about, to receive services. [She] was able to go with me. I have support from friends and family, but not really anyone who wants to be directly involved with the process, and she was able to help me out and give me a lot of good advice." (dyad 11)

"[She] has been wonderful. I mean she knows my situation and so she has been very good about helping me find information about programs that can help not only [my child], but our entire family as a whole. She's always said if you need anything let me know. I know that I have a lifeline there." (dyad 14)

Parents also completed a 23 question satisfaction survey after they finished the intervention phase of the study. They rated their satisfaction with the ConnectedKids program as strongly agree, agree, disagree, and not sure (Table 3). The survey resulted from modifications to surveys by Ingersoll & Dvortcsak (2006, 2010) and Schertz and Odom (2007). *The majority of parents rated their satisfaction as agree and strongly agree.*

Table 3

Parent Satisfaction Survey

Question	Strongly agree	Agree	Disagree	Not sure
The purpose of the research study was to train you on the use of developmental and applied behavior analysis (ABA) techniques. This goal was important to me	15	0	0	0
I understand how to use the different techniques to address social-communication and engagement goals I have for my child	11	4	0	0
I am satisfied with my child's goals	10	4	0	0
I think that providing parent-child interaction activities throughout the day is important	14	1	0	0
I understand how to use the techniques at home during everyday activities	10	5	0	0
I like making my own decisions about which materials or toys to use in daily activities	9	1	2	3
The assignments were clear and manageable	9	6	0	0
The amount of intentional practice was reasonable (at least five hours per week)	9	6	0	0
The amount of time spent with the trainers was about right (about four hours per week)	11	4	0	0
The trainer was concerned that I learn the information	13	2	0	0
Session discussions with the trainer were helpful	12	3	0	0
The trainer was available to answer my questions	14	1	0	0
Reviewing and discussing videotapes of me interacting with my child was helpful	8	6	0	1
I am satisfied with my child's progress in social engagement	7	6	1	0
I am satisfied with my child's progress in language skills	8	5	1	1
I am satisfied with my child's progress in imitation skills	9	6	0	0
I am satisfied with my child's progress in play skills	11	3	1	0
I feel that my child enjoyed the program	8	6	0	1
I believe the approach used with this study was no more intrusive than necessary	9	6	0	0
I believe the approach used with this study fits well with my family's needs	10	5	0	0
I feel I am more competent in helping my child to interact as a result of the intervention	10	5	0	0
I believe that my child will have better long-term social and communication skills because of this intervention	10	5	0	0
I would recommend this program to others	14	1	0	0
Total	241	91	5	6

Five parents provided additional comments.

"This program was LIFE CHANGING! I have no idea where we would be if we hadn't participated. So thankful to be a part of this."

"We continue to work on social engagement. He had a long way to go."

"So thankful to have been given the opportunity to participate. My child has grown so much and it has been so exciting to see!"

"Learning how to interact with my son was the best thing for him and our family. He is like a whole new child. He makes eye contact, has imitation skills, talking more and starting to understand emotions, what we learned in this program helped me connect with my son. Everyone should have access to learning ABA techniques. I can't say enough good things about the program & every person we interacted with."

"[Trainer] Rocks!"

What we learned

The results of the ConnectedKids full study indicate that parents can learn strategies to improve their child's social communication skills. Parents learned to implement these strategies within the context of daily routines and play with their child, reporting that the strategies became a natural way to interact with their child. As a result, the children improved in multiple areas of development, including social-communication skills that are critical to success for individuals with ASD.

Research involving children with ASD often occurs in clinical settings to enable control the environment. Intervention in clinical settings, however, can limit generalization of what is learned into family homes and other natural environments. We chose to conduct this research project with families in their homes and other community settings that the parent identified. This reflects an implementation science approach, in that training and measures take place in natural environments under conditions of use. We supported the parents to learn and apply the strategies within the context of their daily lives, using their child's toys and including younger siblings and other factors within the home environment. It is important to note these methods are consistent with those of the SoonerStart early intervention program.

Both the pilot and main study included a diverse population, with parents from a wide range of socio-economic and educational backgrounds. The children in both studies were diverse as well. Some of the children were nonverbal and had significant problem behavior at the beginning of the study. Other children in the study were highly verbal with strong academic skills. The diversity of our study participants further strengthened the program and allowed us to identify supplemental components that will be beneficial to include for future participants such as augmentative communication and specific strategies to address challenging behavior.

Discussion

ConnectedKids is a 12-week parent training program that includes one, three and six month follow-up visits and teaches parents strategies to positively influence their child's development. Parents reported that the program had a positive effect on family relationships and increased their hope and optimism about their child's future. The program focuses on building family capacity and establishing a strong foundation for the family and child as they begin a lifelong journey.

Senate Bill 135 outlined implementation of this research project by behavior analysts. Behavior analysts are an important member of a multidisciplinary team for children with ASD. A strength of the ConnectedKids Program is that it can be implemented by a variety of professionals, as long as they achieve the implementation competencies. Each of the individual components of ConnectedKids has been implemented by a variety of professionals. Early interventionists from a variety of disciplines use the RBI and coaching. A clinical psychologist, who also is a behavior analyst, and a speech-language pathologist developed the Project ImPACT curriculum. The Project ImPACT curriculum is implemented by master's level psychology students and has been effectively implemented by early childhood educators as well. Currently, an occupational therapist is implementing the ConnectedKids program in the SoonerStart early intervention program with promising results. The ability of multiple disciplines to implement the ConnectedKids program makes it applicable within a variety of settings and service systems. This includes, but is not limited to, the SoonerStart early intervention program and early childhood education programs in local public schools or private settings. As we move forward, the prerequisite behavior analytic competencies must be operationally defined and included in any training that is to be effective.

In this study, we tested the ConnectedKids program following a specific protocol with limited follow-up after completion of the 12-week primary intervention phase. Children with ASD need some level of ongoing support as they grow and develop. As we move forward, the duration of the primary intervention phase and the frequency of the follow-up visits should be evaluated to determine the best approach to continue to support the family.

Children with autism vary considerably in their skills and abilities. Approximately 33-50% of children with ASD will not develop functional speech (NRC, 2001). Behavior often becomes a form of communication for many with ASD, and the only way an individual can express needs or wants. These behaviors can be challenging for families and providers (Autism Speaks, 2012). Identifying effective interventions to support children in developing a functional means of communication is important.

Seven of the 21 children who participated in the ConnectedKids pilot and main study were nonverbal upon entering the program. Three of the seven children developed verbal communication during the program. Four of the seven demonstrated smaller gains in communication, despite provision of additional support for communication through the use of pictures and signs. Immediately following the program we referred one of the four children to obtain an augmentative communication device. This child is now using the device effectively to communicate.

Through our research and the experience of the Project ImPACT authors (Ingersoll & Wainer, 2013) additional research is needed to identify effective methods for incorporating augmentative and alternative communication into the ConnectedKids program for children who have limited verbal communication skills. We plan to develop additional modules such as challenging behavior and resources to support service coordination.

Although we didn't directly compare ConnectedKids with other more intensive models, we achieved positive results with the protocol as implemented. ConnectedKids, which included 4 hours/week of professional time and an average of 6 visits for service coordination based on family need, costs less and allows more children to receive intervention than more intensive models that require at least 20 hours a week of professional time.

Recommendations

1. Develop a plan[*] for statewide implementation of ConnectedKids within SoonerStart, Oklahoma's early intervention program (SoonerStart providers to provide training to parents).

   SoonerStart leaders at both the Oklahoma State Department of Education and the Oklahoma State Department of Health are interested in training SoonerStart staff in the ConnectedKids program. They have requested a proposal outlining the cost and time commitment for staff to become reliable in implementation of ConnectedKids.

   The ConnectedKids program is a natural fit within SoonerStart because the philosophies and conditions of the programs are consistent. ConnectedKids is cost effective and can be implemented with families in SoonerStart in both urban and rural areas of the state. Limited funding has affected recruitment and retention of SoonerStart staff, as well as training and professional development for the staff. Currently, the program has approximately 100 full time positions unfilled statewide. Funding to hire and train staff is critical for the implementation of evidence-based intervention such as the ConnectedKids program.

   Because children in SoonerStart have diverse communication needs, the statewide implementation would include a plan to test and refine the ConnectedKids program to incorporate augmentative communication for children who are nonverbal.

2. Develop a plan[*] for feasibility testing of ConnectedKids within early childhood programs (Early childhood providers to provide training for parents).

   The curriculum used within the ConnectedKids program has been studied and used in other states to train teachers in early childhood settings (Ingersoll & Dvortcsak, 2006; Ingersoll & Wainer, 2011). Public school programs are often challenged to meet the needs of young children with ASD due to limited resources and lack of staff training in ASD. When implemented in an educational setting, teachers learn to incorporate the strategies within the classroom setting. Teachers also partner with the parents to teach the parent the strategies to incorporate with their child at home. Achieving the best possible outcomes for children with ASD requires consistency across the child's environments to attain generalization and maintenance of skills. The ConnectedKids program provides a structured way to accomplish this goal for children in early childhood education settings.

3. Develop a plan[*] for feasibility testing of the model for older children and youth with ASD (teachers of school-age students and specialists incorporate the program into the educational setting and also provide parent training).

   Parents of children with ASD need varying levels of support throughout the child's lifetime. Parents need support during the early years, as outlined in the ConnectedKids program, but also as the child grows. Times of transition are particularly critical, when the child is moving between service systems or experiencing change

that occurs during puberty and the transition to adult life. Some research indicates that parents of children with ASD experience greater stress when the child is an older adolescent or adult (Donovan, 1988). As a next step we recommend development of a program that supports parents of older children with ASD, adjusting the strategies and curriculum to be relevant for older children.

4. Develop sustainable funding streams to recruit and retain Board Certified Behavior Analysts and other professionals competent in provision of the ConnectedKids program.

Other professionals, such as occupational therapists, physical therapists, psychologists, and speech-language pathologists, have mechanisms for reimbursement through public and private insurance companies. Conversely, BCBAs are not recognized as reimbursable providers through the Oklahoma Health Care Authority (OHCA) or most private insurance companies in Oklahoma, with the exception of Tricare. Senate Bill 135 included licensure in Oklahoma for Board Certified Behavior Analysts (BCBAs) who are nationally certified. The intention was to recognize BCBAs as licensed providers in Oklahoma as a first step in creating a mechanism for reimbursement through the OHCA.

The six states that border Oklahoma (New Mexico, Colorado, Kansas, Missouri, Arkansas, and Texas) have passed autism insurance reform legislation. Nationally, 34 states have passed legislation that provides reimbursement for BCBA's either through State Medicaid and/or private insurance mandates. States that pass insurance reform typically see a greater rate of growth in the number of BCBAs as a result of developing a mechanism of reimbursement for their services. Oklahoma currently has 37 BCBAs statewide, an increase from 20 BCBAs in 2010. Although the number of BCBAs has increased, it has not kept up with the growing need, and several BCBAs who moved to Oklahoma from out of state left due to the lack of funding to pay for their services.

Oklahoma currently has two programs to train Board Certified Behavior Analysts. Eligibility to take the national certification requires completion of approved coursework and completion of supervised fieldwork. The University of Central Oklahoma provides the coursework and some fieldwork supervision. The University of Oklahoma - Norman, in collaboration with the University of Oklahoma Health Sciences Center, offers the coursework and supervised field work. Development of sustainable funding streams to retain these programs and professionals in our state is crucial.

* all plans would include cost analysis for implementation.

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