

STATE Innovations BRIEFS New & Best Practices in State Government

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Missouri's Autism Projects: Central, Southeast, Southwest and Northwest

by Melanie Donohue

Autism is a lifelong developmental disability and communication disorder that causes difficulty in interpreting language and social behavior. Autism and autistic-like symptoms are the results of a neurological disorder that affects the functioning of the brain. It is often accompanied by severe behavior problems, a lack of affect or show of emotions and a collection of unusual behaviors taken to the extreme. It occurs in about five of every 10,000 births and usually appears during the first few years of life.

Missouri's Autism Projects were initiated to meet the needs of the vastly underserved population of individuals with autism and their families. Before the program began, state mental health officials were not always responding to families' needs. Autism is often misunderstood, inappropriately treated and misdiagnosed. As a result of the projects, parents now determine what services their children need and who provides them.

Embarking on Innovation

Like many families that have been forced to seek out-of-home placement for their children because they could not find help without having to travel large distances, Alan Baumgartner and other parents of children with autism banded together and

rallied state government to change the way money was spent to serve children with autism. With the assistance of Lt. Governor Roger Wilson (then state senator and chairman of the Senate Appropriations Committee), along with the Department of Mental Health's Division of Mental Retardation and Developmental Disabilities, Baumgartner and other families worked tirelessly to plan and implement the Autism Pilot Project in a 20-county area in central Missouri. In turn, they developed a program that is designed to fill the diagnostic and medical needs of children and adults with autism and their families and to work with existing agencies providing services to the best possible outcome for these individuals.



The Council of
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Innovation in Operation

The Autism Project was put into action by creating a parent advisory committee, which selects a provider with expertise in the field of autism. A contract is entered into with that provider to deliver the services families need, which can include:

- assessments and evaluations,
- family support and follow up,
- parent training (including in-home training),
- crisis intervention,
- respite care,
- communication/language therapy,
- occupational therapy,
- training and consultation, and
- professional training.

Due to the notoriety and success of the central project, the program is currently being implemented in 111 Missouri counties. The projects have grown from one initiative serving 41 families scattered across 49 central Missouri counties in 1991 to four projects serving 757 families all across the state in 1995.

The program is administered by the Department of Mental Health's Division of Mental Retardation and Developmental Disabilities with ongoing monitoring by parent advisory committees composed of seven to nine persons who have family members with autism, including family members that are young children, school-age children and adults. As members of the advisory committees, their responsibilities include:

- monitoring contracts,
- determining services to be provided,
- establishing policies,
- formulating the budget,
- prioritizing services,
- reviewing service delivery,
- planning,
- advocating,
- educating the public,

Families Served FY 1995

<i>Project</i>	<i>Families Served</i>	<i>Referrals</i>
Central	260	360
Southeast	162	170
Northwest	185	210
Southwest	150	170
Total	757	910

Autism Project Goals

1. To develop skills of the individual with autism through training and supporting the family in developing their skills in managing the behavior of the family member with autism;
2. To develop the community integration skills of the individual with autism;
3. To provide support to families;
4. To work effectively with other agencies, including the public schools, to coordinate services; and
5. To assist individuals with autism in developing their potential for independence.

- increasing public awareness, and
- selecting service providers.

This approach emphasizes the support system necessary to serve persons with autism and works to ensure that families are satisfied with the program.

An annual survey is conducted to measure the success of the program. A recent survey concluded that the program helps 75 percent of those served to become more independent. In addition, three-fourths of the families surveyed said that they are highly satisfied with the services provided by the autism projects.

The Department of Mental Health's Division of Mental Retardation and Developmental Disabilities picks up the tab for Missouri's autism projects, which totaled \$1.9 million in fiscal year 1996.

Replicating Success

Members of the Missouri General Assembly have said the project is one of the department's best and most cost-effective programs. The Autism Project is able to provide a variety of services for those with autism at a fraction of the cost of other programs. Providing services to individuals in a community-based setting costs the state roughly \$3,600 per year, compared to \$30,000 to \$90,000 for services rendered in an institutional setting.

Success is due primarily to the fact that the program is family focused and consumer driven as can be documented by the increasing number of families on the waiting list for the programs. The Autism Project now brings specialized services and

training to families in their home communities and greatly reduces out-of-home placements.

The biggest challenges encountered in implementing the program include: 1) finding staff that have the proper experience and knowledge in the field of autism and are willing to travel to the homes and communities of those with autism; 2) trying to meet the needs of every family, regardless of how different those needs are; and 3) obtaining enough funding to provide all families with the intense services the program aims to provide.

For more information on Missouri's Autism Project, contact:

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State Innovations Briefs highlight award-winning programs in state government selected by state leaders and managers. Through publications like this, The Council of State Governments' Innovations Transfer and Awards Program fosters the sharing of information on the best new and creative approaches to significant problems across the states. *State Innovations Briefs* are published eight times a year. Individual copies (\$10) and annual subscriptions (\$56). *State Innovations Briefs* can be ordered through CSG's publication sales department, 1-800-800-1910.

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Innovations Awards and Transfer Program

Since 1975, the Innovations Transfer Program of The Council of State Governments has identified and disseminated information on innovative policies or programs that have been successfully implemented by individual states and have the potential for use in other states. CSG's Innovations program takes its cue from former U.S. Supreme Court Justice Louis D. Brandeis:

"It is one of the happy incidents of the Federal System that a single courageous state may, if its citizens choose, serve as a laboratory and try novel social and economic experimentation without risk to the rest of the country."

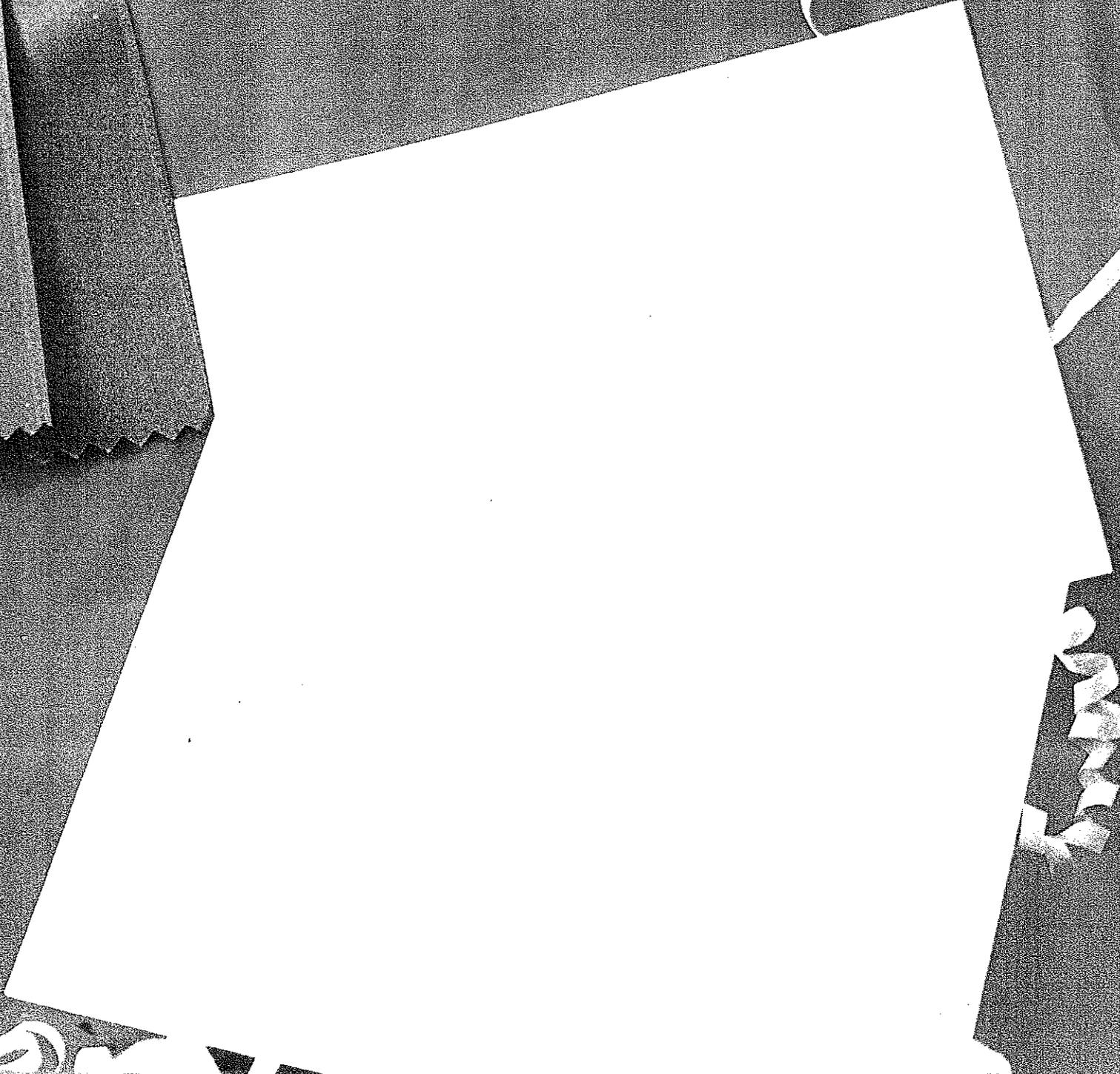
The Innovations Awards Program, initiated in 1986, was designed to afford greater visibility to the innovative and exemplary state programs selected each year and to facilitate the transfer of those successful experiences to other states. State agencies with award-winning programs are recognized at CSG's Annual Meeting, typically held in December.

Applications for CSG's Innovations Award are solicited yearly from February through April. Each application must meet a set of seven criteria:

1. It must be a state program or policy.
2. The program must represent a new and creative approach to a significant problem.
3. The program or policy must have been operational for at least one year.
4. The program or policy must be relatively unknown across the states.
5. The program or policy must have been effective in achieving its stated goals.
6. The program or policy must address an issue or problem area that is regional or national in scope.
7. The program must be transferrable to other states.

Eight programs are selected each year for CSG's Innovations Awards. For further information, please contact Cathy Wiley at (606) 244-8247.

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provided since 1990. Sexton said, "Seeing teachers redesign their own schools is going to take time. Some want to do it, but they don't appear to be a majority."

But James Rath, chairman of the department of educational studies at the University of Delaware, said some teachers are making the transition. He reported to the Prichard Committee that teachers have put the reforms into practice and are seeing results. He said, "We're astounded at the progress we've seen; there are first-rate programs with high potential out there."

In Pillow's primary class in northern Kentucky, the new hands-on approach to teaching means textbooks no longer dictate class activity. The mixed-age classes make chapter-by-chapter teaching impossible. Pillow said, "You can't teach just out of a first-grade book if you have students at the second- and third-grade level."

Instead, Pillow's students learn how machines make work easier by reading a book about machines, searching through a science text for pictures of them and drawing their favorites. The lesson is brought to life when the students take a field trip to ride on an old-fashioned steam train.

Pillow said the biggest complaint teachers have is the heavy workload. Designing creative lessons takes longer than textbook teaching, and keeping anecdotal records on

student progress takes longer than handing out grades. With a school day that begins before 8 a.m., Pillow often comes home at 7 or 8 in the evening — relying on her husband to take care of their daughter after school. She said, "Our biggest worry is how long teachers can keep going, especially if they have families."

Teacher burnout was a problem with the move to ungraded primaries in Wisconsin, Colorado and other states 20 years ago, said Chris Pipho, director of state relations for the Education Commission of the States, who directed Colorado's effort. The school-by-school effort was launched with Kettering Foundation support, but few schools continued it beyond the first several years. He said, "We failed because we were running on nervous energy, and it took a lot of energy to run that type of school."

While it's too early to tell whether Kentucky's effort will succeed, Pipho said Kentucky's breadth of change makes it the national model for school reform. He said, "There's hardly a reform being discussed in other states that doesn't have a mirror image in Kentucky."

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— Elaine Stuart Knapp

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Putting parents in charge

There was a time when the Baumgartners had to live 100 miles apart so Alan Baumgartner could continue working and daughter Abby could get help for her autism, which made her

a program with the state's Department of Mental Health that now brings services for the autistic into homes. Think of it as house calls for mental health.



Photo courtesy of Columbia Missourian

Tim Wheeler, left, gives a 'high five' to Jeff Boyes, a specialist working with autistic children at the Juedine Center in Columbia, Mo.

scream and cry for as long as 10 hours a day.

"My wife had an apartment in St. Louis; I stayed up here with the other kids," said Alan Baumgartner, who lives in Auxvasse, a small town in central Missouri. "We had to make a decision: Either we continued on like that or we put Abby in an institution."

But the Baumgartners didn't have to do either. After phone calls and conversations with Missouri lawmakers, the Baumgartners and others helped develop

The program, called the Autism Project, is unusual because it puts power into the hands of parents.

Parents of autistic children make up the program's advisory committees, which are the foundation of the Autism Project. Before the program began, state mental health officials weren't always responding to families' needs. Now parents determine what services their areas need and who will provide them.

"That's the beauty of it," said Donna Evert, the state's coordinator for

WATERSHED IDEA

1862 - Settlers are given 160 acres of land if they promise to farm it for five years by the Homestead Act.



Photo courtesy of Missouri Dept. of Mental Health

Sam Denker, a child with autism, poses with Roger Wilson, the lieutenant governor of Missouri, at the dedication of the Juviedine Autism Program building at Columbia, Mo., in 1992.

autism services. "It's so simple it's amazing things like this don't happen more often."

The Autism Pilot Project began in January 1991 with an annual budget of about \$110,000 and a mission to serve a few dozen families in central Missouri. Today, the program has expanded to other parts of Missouri, has an annual budget of about \$1 million and should cover the entire state during 1994, Evert said.

The program serves about 250 families in the state, Evert said. Officials estimate that 2,500 to 5,000 autistic people live in Missouri.

The Autism Project provides a variety of services. Parents can have a child evaluated through the program to see if the child is autistic. If so, the program can help intervene during a crisis and can train parents and others to deal with the child. The parents usually help share the cost of the services, Evert said, and their share is based on their ability to pay.

Autism occurs in about five of every 10,000 births and usually appears during the first few years of life, according to the Autism

Society of America. Autistic people have limited social and communication skills. Some process sound, smell and sight differently. Some engage in repetitive acts, such as rocking back and forth. And many autistic people are resistant to changes in their environment.

This last symptom can be particularly troublesome for parents who live in rural areas but need to go to the city for treatment.



"Traveling with a child with autism is not the easiest thing in the world," Evert said. "Some of these parents were losing it."

Baumgartner said he can relate to that. Before his wife got an apartment in St. Louis, the family would stay in a hotel when they went to the city for Abby's treatment. Because of Abby's screaming, the family would wonder the entire time if they were going to be kicked out of the hotel.

But those days have

passed. Abby is treated at home, and her behavior has improved, Baumgartner said.

Things also have improved for the rest of the family. Baumgartner said he knew the program was a success when Abby threw a fit at home one day, and Baumgartner's son asked if that meant

Mom would have to go back to St. Louis.

"I said, 'No, son. We can deal with this here,'" Baumgartner said.

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— Christopher Schwarz

INNOVATIONS

Sunday-sized classifieds — every day

New York labor officials call their program the Gateway Information Exchange, but it's easier to think of it as one of the biggest classified ad sections you've ever seen.

Since the beginning of 1990, the New York

State officials estimate about 50,000 job seekers use the continually updated list each month.

About half the listings are for jobs in New York, and the rest are for jobs in other states, officials said. The network also has information about civil service examinations and job training courses.

The idea for the system came from George T. McDonough, the director of data processing information services for the Department of Labor.

It began when state educators asked if they could get the department's job listings on computer diskettes.

"I said: Whoa. If I wanted to be successful with that program that would mean tens of thousands of diskettes," McDonough said. "So I said we should hook our computers together."

They did. And it was relatively cheap, too. McDonough said building the system was mostly a