



REACHING OUT

Making an Impact in Ohio's Underserved Communities



The Ohio Developmental Disabilities Council is one of a national network of state councils, committed to self-determination and community inclusion for people with developmental disabilities.

The Council consists of at least 30 members appointed by the governor. Members are people with developmental disabilities, parents and guardians of people with developmental disabilities, representatives from state agencies, and nonprofit organizations and agencies that provide services to people with developmental disabilities.

One of the Council's goals is to educate and inform how state and local government services and policies can be improved, expanded or strengthened on behalf of people with disabilities.

What is Community Outreach?

- Outreach is an activity of providing services to populations that might not otherwise have access to those services.
- A key component of outreach is mobility. The group providing outreach cannot be stationary.
- Outreach also has an educational role, raising awareness of existing services.
- Outreach is often meant to fill a gap in services provided by the mainstream.

Ohio Developmental Disabilities Council

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MAKING SURE NO ONE FALLS THROUGH THE CRACKS OF SOCIETY

Ohio Developmental Disabilities Council's Outreach Efforts Extend from Amish Communities to Inner City

In such Amish communities as Baltic, Killbuck and Millersburg, the Ohio Developmental Disabilities Council's outreach programs are having a big impact. A five-year, \$100,000 grant from the Council to the DDC Clinic in Middlefield has helped open a medical clinic in Wayne County that not only provides needed healthcare, but supports research into the diseases unique to geographically and genetically isolated societies.

The grant is proving valuable to unlocking the secrets to some of these unique diseases and providing medical treatment that has dramatically changed the lives of individuals - children, in particular - suffering from these ailments.

For example, glucose-galactose malabsorption is a rare, recessive genetic disorder that was once a death sentence in the Amish community. This disease prevents the body from absorbing nutrients broken down in the small intestine. Now, when children are diagnosed with the disorder they are put on a carbohydrate-free diet and do quite well.

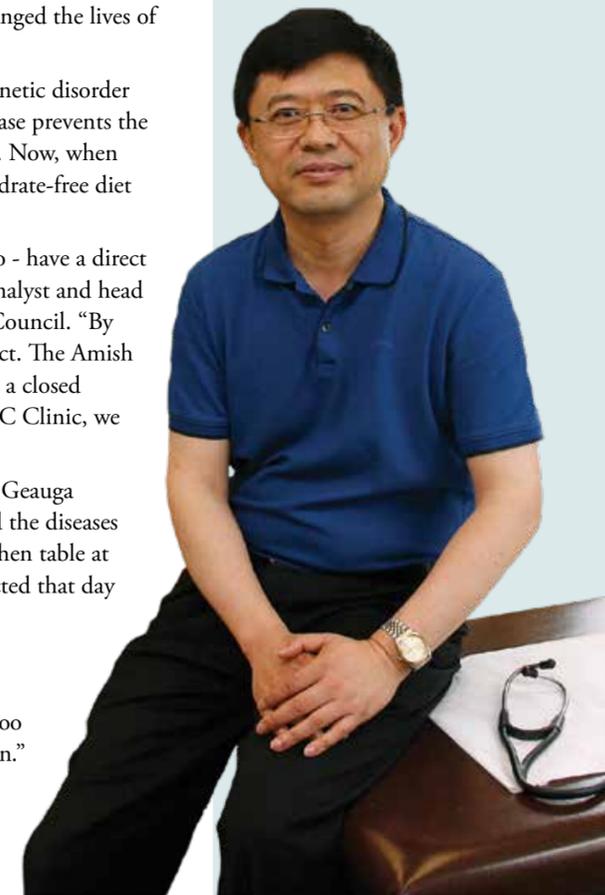
"At our core, this is what our outreach programs are intended to do - have a direct impact on the lives of individuals," said Kenneth Latham, policy analyst and head of community outreach for the Ohio Developmental Disabilities Council. "By issuing this grant to the DDC Clinic, we are seeing that vital impact. The Amish community is not an easy one to reach because they are very much a closed society. However, by utilizing the inroads already made by the DDC Clinic, we are able to assist in gaining the trust of the Amish."

The outreach into Holmes and Wayne counties has its roots in the Geauga County Amish settlement. In 1998, community leaders recognized the diseases unique to their community. Six Amish families sat around the kitchen table at the home of Bill Fisher and passed a straw hat. The \$50 they collected that day was used as seed money to start a clinic for special-needs children.

"The leaders of their community recognized that they needed to do something for the unique diseases afflicting their children," said DDC Clinic Executive Director Blake Andres. "They knew it was probably too late for some of their kids, but they wanted to help tomorrow's children."

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Dr. Heng Wang, who made house calls in a horse and buggy when he started, is now medical director of the DDC Clinic



DDC Clinic Director Blake Andres holds the hat that six Amish families passed to get the clinic started.

As a symbol of their humble origins, the hat remains on display today at the clinic.

From that modest start, only a year later they established the Das Deutsch Center for Special Needs Children, which later became the DDC Clinic. In 2002, Dr. Heng Wang began providing medical treatment to children in the area. Because the physical clinic had yet to be constructed, he made 400 house calls that year, some of them by horse and buggy.

In the years since, the DDC Clinic has grown at light speed. Dr. Baozhong Xin was hired in 2005 to head research into the genetic disorders plaguing Amish children. Since then, the clinic has identified more than 70 rare genetic disorders for which it can test and treat. Of those, Andres said, two-thirds are "highly treatable."

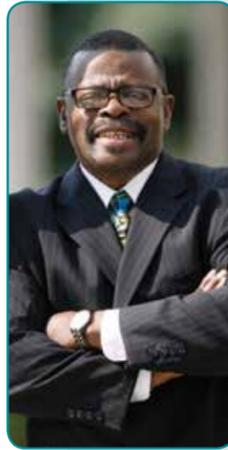
"The success we've had at the DDC Clinic has been nothing short of astonishing," Andres said. "Eleven years ago, 80 percent of those coming to the clinic had no diagnosis. Now, thanks to the tremendous research that has been conducted here, nearly everyone who walks through the door can be diagnosed on the same day."

This success did not go unnoticed by the Amish community in Holmes and Wayne counties. This is the largest Amish community in Ohio and one of the largest in the United States. They saw the success that the DDC Clinic was having and wanted to incorporate those services in their community.

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A Decade After Commitment by Ohio DD Council, Progress Being Made with State's Underserved

BY KEN LATHAM, POLICY ANALYST-COMMUNITY OUTREACH



For more than a decade, the Ohio Developmental Disabilities Council has been committed to increasing its presence with the state's underserved populations through a dedicated outreach program.

The Council recognized that far too often, certain segments of our society continue to fall through the cracks of our provider services system. In 2002, the Council assigned me as the point person to pursue outreach programming projects. The Council and the state of Ohio remain committed to the philosophy

of full inclusion, serving all individuals within the developmental disabilities community.

Through grant funding opportunities with the Council, the state's unserved/underserved communities have been the recipient of a host of successful programs. The Council's collaborations include:

- *ReachOut* – An electronic newsletter designed to bring awareness of inclusion to the developmentally disabled community. Subjects covered are designed to ensure maximum participation in the workforce and in the community for individuals with developmental disabilities.
- *SomoliCAN* – A dual-language, electronic newsletter for the large Somali population in Central Ohio.
- Eligibility brochures created in six different languages, including Chinese, Vietnamese and Japanese.
- A safety tip booklet printed in English and Spanish for parents of children with developmental disabilities.
- Partnering with the Supreme Court of Ohio, the Council created the DVD, *The Cultural*

Misconceptions About Deaf People and the Challenge for the Courts.

To understand the value of the Council's programs, we must first be able to identify our audience - the unserved/underserved. This term includes such populations as:

- Individuals from racial and ethnic minority groups.
- Disadvantaged individuals, including those from low-income groups.
- Individuals with limited English proficiency.
- Individuals from underserved geographic areas - rural and urban.
- Specific groups of individuals with developmental disabilities, including individuals who require assistive technology in order to participate and contribute to community life.
- Ethnic, cultural and disability groups that typically do not receive services and supports because of language or cultural barriers.

I have the support of a strong team, including Fatica Ayers, who contributes technical support to programming, Gary Groom, manager of fiscal support, and Robin Shipp, who is part of the fiscal support team.

We will continue to identify diverse communities throughout the state. We will contact community leaders, explain who we are and seek ways to facilitate partnerships between their communities and service providers for individuals with developmental disabilities and their families.

We will target these populations to increase their awareness of the services available for individuals with developmental disabilities.

It is our wish - our mission - to reach out to the underserved. And we will continue those efforts with great vigor.

However, this did not automatically create an atmosphere of trust.

To get started, Dr. Wang began making visits to Holmes and Wayne counties in 2006, visiting the community once a month, setting up shop in the Holmes County Training Center, which is operated by the Board of Developmental Disabilities in Holmesville. At first, he only had a couple of patients, but it wasn't long before he was heading to the area twice a month and the list of patients grew.

The Amish and Mennonite communities in Holmes and Wayne counties responded by opening a clinic of their own. In January 2013, the New Leaf Clinic for Special Children opened under the guidance of medical director Dr. Olivia Wenger, who had been visiting the Holmes and Wayne county areas as part of an Akron-based practice.

Dr. Wenger, who was raised Mennonite, said the New Leaf Clinic has been an opportunity to serve the community and utilize her background. "My skills are being put to good use here," Dr. Wenger said. "I could see a large gap in the culture of the Amish and the way medicine is being practiced today. I believe I can help bridge that gap."

The Ohio Developmental Disabilities Council's grant has assisted in this effort and contributed to furthering the research being conducted at the DDC Clinic.

"We see needs in many minority and underserved communities," said Latham. "The apprehension of the outside world is not unique to the Amish community. You have to develop a level of trust. This grant has helped the DDC Clinic make more inroads into the Amish community and we are proud to be associated with the great work it's doing."

Columbus Couple Launches Minority Autism Awareness Program

Reginald and Angela Fields knew there was a problem.

They didn't have a name for it, but they could tell something wasn't right with their youngest son, Grant. He was about 2 years old and wasn't developing at the same pace as his older brother. There were speech issues, and at times he seemed to be regressing.

There were many trips to doctors and specialists. However, it wasn't until Grant was 4 that Reginald and Angela received the diagnosis: autism.

Reginald, then a reporter in the Cleveland Plain Dealer's Columbus bureau, and Angela, who is in sales, began researching autism to learn all about the disability afflicting their son. During this process, they discovered that children with autism in minority and underserved communities were diagnosed, on average, 18-24 months later than white children.

"We believe it's a case of a lack of information available in those communities," Reginald said. "There is no cure for autism, but early diagnosis and treatment is the key to making the greatest strides with a child. The earlier treatment begins, the better chance the child has of living a more independent life."

To help meet the challenge, Reginald and Angela formed the nonprofit organization, Living Beyond Autism, in 2011. Its mission is to educate and inform the minority and underserved communities around Ohio of the importance of early diagnosis of autism.

To help Living Beyond Autism meet its goals, the Ohio Developmental Disabilities Council awarded the organization a \$20,000 grant.



"We believe it's a case of a lack of information."

– Reginald Fields

Living Beyond Autism has used the funds to:

- Host focus groups of 21 minority parents of children with autism. The sessions focused on their knowledge of the disability and chronicled their efforts to seek a diagnosis.



Reginald and Angela Fields started Living Beyond Autism to spread autism awareness in the minority community. They are shown here with their son, Grant.

- Create a video documentary, created from focus group participants, to show at schools and churches in hopes of making people aware of autism and encouraging them to seek early diagnosis.
- Create public-service announcements to run on television stations throughout the state.
- Host a one-day program on autism awareness at the King Arts Complex in Columbus.
- Organize a walk to increase autism awareness in minority and underserved communities.

Most of their efforts have been focused on Central Ohio, but the couple hopes to expand the effort across the state.

"It's all about raising awareness," Reginald said. "The gap between when a white child is diagnosed and when an African-American child is diagnosed was more significant than I had anticipated. I think that gap can be tightened simply by making people more aware of autism."

Grant is now 12-years old, attending a charter school and doing well.

Reginald and Angela are taking their video documentary to local churches and

civic organizations to spread the word of autism. If you would like to have them speak to your organization, contact Living Beyond Autism at 614.975.5582 or via email at info@livingbeyondautism.org.