

core need

FOR AUTISM SERVICES & INFORMATION

Eric and Deb Hench partner with DC and other non-profit agencies to form an autism studies program

by Kathy Punches '96, Director of Public Relations

As parents of an autistic child, Eric and Deb Hench often felt frustration and isolation as they searched for suitable educational, health, and support services. Sometimes, after much searching, they found what their son needed. Oftentimes, they didn't.

Seeing what he calls a core need in northwest Ohio, Eric Hench says there are few services "and a huge lack of information" involving autism. "We really struggled with that when our son was diagnosed when he was about five years old. There were few services, if any, and little knowledge."

The Defiance couple worked hard to help school officials find the right classroom setting. They looked endlessly for physicians, dentists, therapists, psychiatrists, babysitters, and summer camps that were appropriate for autistic youth.

So it was with 19 years of first-hand experience that the Henches sat down earlier this year with Defiance College administrators to design a one-of-a-kind program to address the multi-faceted needs of a growing population of individuals with autism.

According to the Centers for Disease Control and Prevention, about one in 150 eight-year-old children have some form of autism. "So obviously there is a need, it's growing, and we wanted to do something about it," says Eric.

The Henches' initial thoughts were for basic programming in the areas of teacher training and family respite. What has evolved through their significant financial gift to Defiance College is a partnership with the College, local school officials, and representatives of area non-profit agencies for the creation of the Hench Autism Studies Program (HASP).

CREATING A PARTNERSHIP

How could Defiance College address what has come to be recognized as a tremendous void in delivery of services to autistic youth and their families?

Because Defiance College has extensive experience with creating partnerships locally, nationally, and internationally through its "culture of engagement," DC administrators and faculty were able to pull together existing expertise on campus and beyond to develop a model with tremendous potential to make a difference.

The vision of the Henches provided the catalyst for collaboration between the College and regional school districts, especially the Northwest Ohio Educational Service Center. Dr. Jo Ann Burkhardt, head of teacher education, notes that DC did not want to duplicate the work of school districts, but combine efforts for maximum effectiveness. "The area school districts are highly skilled in developing programs, hiring highly qualified



President Wood announced the Hench Autism Studies Program at a recent press conference in Toledo. A similar announcement and reception followed on the Defiance College campus.

teachers, and working with parents to meet the needs of students with disabilities,” she says.

John Wilhelm, superintendent of the four-county NwOESC, appreciates partnership in addressing something as complex as the autism spectrum. He calls it “one of the top rungs of our challenge ladder” as more children are identified as autistic.

What Defiance brought to the table was a highly qualified faculty skilled at working cross-disciplinarily. “This is something that we can really do, because we know how,” says Burkhardt. “When I make presentations across the United States, the number one question is, ‘How do you convince your president and administration that working in social justice is important?’ I don’t have to,” she says, explaining that Defiance is already committed to a mission of civic engagement and social responsibility. “Those are the roots of higher education. How do you make the world a better place? This is something that could really, really change the world, meaning Defiance city, Defiance County.”

Discussions revealed several needs, particularly better and more integrated services for late-adolescents with autism and for their families. While schools are required to provide services for all children between the ages of 3 and 22, officials struggle with finding the best and most appropriate services for autistic students, particularly when they reach high school and are challenged by sensory issues, communication problems, and interpersonal interactions.

“When they are younger, parents have a lot of hope that their child is going to progress through school and have a wonderful experience and lots of friends ... that they will be happy and healthy and socially integrated,” said Burkhardt. “But once they get to middle and junior high, they often have no peer interaction that’s appropriate.”

Adds Eric Hench: “What we see happening is a lot of awareness now on early childhood diagnosis and early childhood intervention, and that’s really important in the core development of an autistic person. But what is not being addressed is what happens to this population when they reach age 22 and no longer does the school system provide a safety umbrella.”

Once the needs were spelled out, administrators were excited to take the



At Bumble Bean Coffee: Deb and Eric Hench get acquainted with the first two students in the country accepted into the program.

challenge. “It was uncanny how it all fell into place,” says Dr. Catharine O’Connell, academic dean and vice president for academic affairs. “We had faculty expertise in appropriate areas within the social sciences and education. We had experience as a faculty working in close partnership through the McMaster School projects. We are a community focused on the needs of late adolescents and had a ready pool of peer-age mentors and companions. As we worked on program development, it almost felt as if this were meant to be. To my knowledge, no one else is doing what we’re doing.”

Defiance College president Dr. Gerald Wood credits “the support and leadership of Eric and Deb Hench, a wonderful group of community and regional partners, and a knowledgeable and dedicated group of faculty led by the academic dean” with bringing the program to fruition. “It fits beautifully into the vision and mission of

Defiance College to educate our students for responsible citizenship and service for the greater good.”

There are five primary components to HASP at Defiance College:

- p◆ A new licensure within the Master of Arts in Education Program for Intervention Specialist, Mild and Moderate (K-12), with an emphasis in autism
- ◆ An on-campus NwOESC classroom for late adolescents with autism;
- ◆ Specialized training for undergraduate students to have peer interaction with autistic students;
- ◆ Focused coursework for undergraduate Social Work majors and additional training for licensed social workers;
- ◆ A resource and referral center for families of children and adults with autism



Deb and Eric Hench at their home in Defiance.

The NwOESC classroom is up and running this fall, providing services to students with autism, and an invaluable educational opportunity to DC students.

Wilhelm says the program at DC “gives us the opportunity to bring other resources to the table when trying to find appropriate learning objectives for our high school aged students with some form of autism.” No two autistic students are alike in their needs, and it takes a variety of trained professionals to meet the unique needs. “I am as excited about the long-term implications of developing a program for future educators as I am about helping us with our immediate needs,” says Wilhelm. “Families will also begin to see some long-term benefits as the College incorporates this program into other learning paths.”

LIVING WITH AUTISM

The challenges faced by families with autistic children are complex, hard to comprehend, and harder still to deal with on a daily basis.

“Jon went to the infant stimulation program at Good Samaritan when he was a couple years old,” recalls Deb Hench. “He was in their preschool program and did not qualify for their kindergarten program. We took him to Toledo for a psychiatric evaluation, and she diagnosed him with attention deficit, and so he was treated for that for a little while.”

When the medicine for attention deficit

didn’t affect their son’s other behaviors, they went to a different psychiatrist. “She finally nailed it,” says Deb. “She called it pervasive development disorder, which means he has a little bit of a lot of things. It was at the time when they were just starting to diagnose people with autism.”

For the next several years, the Henches spent uncountable hours focusing on Jon’s needs. They made frequent trips, sometimes as often as four or five days a week, to Toledo for various appointments. There were few if any services available in Defiance for autistic individuals. “We went to Toledo for his psychiatrist and speech therapy so that he could talk and be understood and learn some behaviors that he could control. He was in small group therapy for kids his age,” says Deb. “It takes special people to deal with people with special needs. He needs the right doctor, he needs the right dentist, he needs the right babysitter.”

During Jon’s middle school years, the school system was inclusive, that is, all students participated in all classes. “And that just doesn’t work for an autistic person because there are too many sensory things that disturb them,” says Deb. In junior high, the school set up a special needs classroom. “They found 10 students that would succeed in a classroom without all the commotion of junior high,” she says. A similar classroom was established in high school.

Beyond meeting their child’s educational and health needs, the Henches learned to

cope with the challenges of everyday life, whether it was going to church, to the grocery store, or to McDonald’s. “There are behavior nuances that occur frequently,” says Eric. “We just didn’t know what might happen. It was an opportunity for oddities in behavior to happen and be observed by others and think ‘What is going on there?’ And so, I think at first we were embarrassed as you naturally would be as parents when your child is behaving oddly, but somehow we got numb to it, and you learn it is what it is. And that’s a philosophy of life that you almost have to follow to survive.”

Now an adult, Jon lives in a residential setting with other autistic individuals. He has a job and lives a full life. “I think Jon became who he is because we untiringly got him the services he needed,” says Deb. “And when we look at where he is now, and how far he’s come, it’s phenomenal. I think there are a lot of autistic people who given the right services can just be happy and they can be productive. It’s there. The possibilities are there if they’re understood better.”

ADDRESSING THE NEEDS

The HASP team moved quickly to implement the first several elements of the program. It was a team effort on DC’s part to completely remodel space for the classroom and make the college community aware of some of the challenges of autism so the campus would be a welcoming environment.

The on-campus classroom currently has two students with capacity for four additional students. The College provided physical space for the classroom, and NwOESC staffed the unit with two teachers.

In their home school districts, autistic students are often placed in a multi-handicap classroom where teachers must address a wide range of physical and mental challenges. In the HASP unit, programming is specific to the autistic student and includes emphasis on peer interaction, one of the greatest challenges in a typical high school. To provide peer interaction, the College created a curriculum for DC students. Incoming first-year Bonner and Citizen Leaders were given the opportunity to volunteer for the program, and planners hoped to get 10 or 12 students. They had to draw the line at 23 volunteers. Many signed up because they have friends or relatives whose families have been affected by autism. The students are in a special class in which they study and discuss autism, and they have volunteered at Bittersweet Farms, a Northwest Ohio residential facility.

The college students provide socialization by having lunch in the cafeteria with students from the autism classroom or sharing activities such as knitting and reading.

Now at the mid-point of the semester, “we’re so much further than I thought we’d be,” says Burkhardt. “I didn’t expect that at week four or five that a freshman would ask a student with autism to come and eat lunch with them.”

DC freshmen and HASP students meet in a book club every week and talk about their readings. Others meet weekly in a knitting club. The interaction provides opportunities for communication and modeling of social behavior, or “teachable moments.” The program also allows other DC students to design field experiences within their areas of study. A wellness major is currently designing a health and wellness plan for special populations, learning how individuals with autism approach physical activity and healthy lifestyles. The end result will be a guidebook of accessible venues and activities to be used as an instructional resource.

Teachers and students in the HASP classroom have created a business, Bumble Bean Coffee, to sell coffee, tea, juice, and baked goods on campus three mornings a week. The business offers more teachable moments for students with autism to develop business and communication skills. “The efforts that faculty and staff have made to communicate with the students have just been amazing,” says Burkhardt. It was hoped that the faculty and staff could help create a learning environment within the framework of the coffee business. They have supported the learning initiatives of the classroom and provided opportunities for social interaction for the students in the program.

A crucial goal of the on-campus program is to help students begin to develop job skills and refine social interaction. “We want to help them transition to successful and productive adulthood,” says O’Connell. “Focused interventions in late adolescence can really make the difference in terms of providing these individuals with a hopeful future.”

In development as part of HASP is a new special education licensure that will fill an unmet need voiced by area school administrators. Defiance College will offer courses focused on autism within its Master of Arts in Education degree program. The social work program is also developing courses toward certification in case management for individuals with disabilities.

Area teachers will have a rare opportunity in April to participate in three days of training on the Defiance College campus conducted by the TEACCH Autism Program from the University of North Carolina. TEACCH is a highly regarded service, training and research program that, until now, has been inaccessible to northwest Ohio teachers due to cost and distance.

The fifth component of HASP, a resource and referral service for families, is something that the Henches view as equally important as the educational services. “We want to help the parents of the people that will follow us, to give them some hope,” says Eric. “We want to give them better knowledge of what lies ahead and what they can do about it. And we want those services laid out almost menu-like for them. In the past, many times we had to, by luck and discovery, just find the services we needed.”

The special needs of an autistic child place a tremendous strain on families, so the Henches are hoping that the HASP initiative will be able to not only provide a resource center but respite care as well. Defiance College faculty member Dr. Fred Coulter has an extensive background in family studies and is planning to conduct research on support of families dealing with autism. He is also working to develop appropriate services for area families.

HOPE FOR THE FUTURE

O’Connell sees great potential in HASP. She says, “If this program grows like the McMaster School has grown, in four years we could have a clearinghouse for families providing information and support

services; a thriving graduate program where people come who are interested in autism; undergraduate students committed to service seeking out Defiance because of their interest in autism; and an ongoing presence of young adults with autism on the DC campus with the entire campus community attuned to the kind of diversity these students represent.”

O’Connell envisions HASP as eventually emerging as a national model for college-community partnerships dealing with adolescents with autism, supporting families, and providing best-practice education to both undergraduate and graduate students around the intellectual problem of autism.

And for the Henches, “We just hope that there is growing awareness that goes beyond autism, that people accept others that are different than them,” says Eric.

NwOESC’s Wilhelm sees great potential for a long-term partnership between Defiance College, area schools, and the autism community. Risks and setbacks will be outweighed as understanding and awareness grow among teachers and students. He says, “These groups will benefit because others dared to take a chance on a new way of doing things.”

He says that additional research will be needed to fully understand the complexity of autism spectrum disorders. But with appropriate levels of support at home, school and community settings, “only positive things can happen for children and their families. All children can learn, and some will need more creative and well informed teachers, schools and families to make it happen. That is what makes this partnership exciting and hopeful.” ♦



Teacher Jane Barber and assistant Matt Schultze in the HASP on-campus classroom.