

"The Other Side of Inclusion" draws 200+ to create more welcoming community for individuals with Intellectual and Developmental Disabilities

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A key role for families and human service professionals who support families is to create opportunities for community participation and success for their loved ones. Yet, many vulnerable people with disabilities remain removed from the community and struggle with the social ramifications of poverty, unemployment, difficulty with housing and transportation. It is clear that traditional methods have not brought many successes to include people with disabilities.

"The Other Side of Inclusion: Creating a More Welcoming Community for Individuals with Intellectual and Developmental Disabilities (IDD)" brought together more than 200 providers, family members, and others who support people with IDD on Feb. 19 at Rodef Shalom Congregation, Oakland, for a broad discussion of this challenge. This Merakey AVS Initiative was made possible by a grant from the Polk Foundation.

Presenters Al Condeluci, Ph.D., Special Advisor/ Retired CEO at CLASS, and Guy Caruso, Ph.D., Western Coordinator for the Institute on Disabilities at Temple University, Philadelphia, set the stage for the session.

"For so long we looked at an individual with IDD on a "micro" level – all about the individual," Dr. Condeluci said. Micro change seeks to clinically, or therapeutically change the person or their circumstances, having the individual learn something, acquire something, or utilize something that will make them more viable.

"When the focus is on the individual, we build institutions to support them – separate schools, homes, apartments, transportation," Dr. Condeluci explained. "Individuals with disabilities become trapped in a 'medicalized' viewpoint. People get 'therapies.' I get gardening, you get garden therapy. I have a pet, you get pet therapy. People with disabilities don't have a choice to be with others who have similar interests but are often grouped with those with similar disabilities because current systems are not set up to offer these opportunities," Dr. Caruso stated.

"Having the choice to be fully involved in our community is one of the things we all want and take for granted," commented Jamie Walker, MA, Staff Development Facilitator, Merakey.

"During the session we learned ways that we can make being of the community, rather than simply in the community, more of a reality for the individuals that we support."

Macro change is about the environment around the individual. This type of change revolves around the perceptions, attitudes and assumptions about the issue and attempts to change these attitudes in either formal ways (through laws) or informally through relationships.

The community is the other side of inclusion – a place where we all can champion the effort to help the wider society to think differently, behave differently, and change attitudes and perceptions of those with disabilities. But how?

According to Condeluci and Caruso, listening and having genuine relationships are central to creating this shift. What is it that people with disabilities and their families want? Listening to the individual and their interests is essential. "Put yourself in the shoes of individuals with disabilities and their family members," Dr. Caruso advised. Dr. Condeluci said "Find common passions and similarities. Then look for places and communities where these common passions are celebrated and create true linages for individuals in these communities."

Attendee Liz Humphrey said, "My favorite part was when they talked about getting to know a person. It's not talking about their diagnosis. It's about talking about their likes and dislikes and favorite activities."

Attitudinal change also comes from relationships. The presenters emphasized that attitudinal change comes from friendships and relationships (social capital). The goal is to help a person build social capital. Social capital heals people. It is the key to longer life. "Reports show that social isolation is more lethal than obesity and heart disease," noted Dr. Condeluci. He said that "Research at Chatham University has revealed that the average person has 150 friends, but someone with a disability has an average of just 24."

To assist people in having a typical and valued life, we must include individuals with disabilities in natural ways and we must challenge the negative or stereotypic ways they are portrayed in the community, Dr. Caruso said. Both speakers challenged attendees to identify valued roles in the community and assign gatekeepers for an individual that will connect them to organizations and groups. Ms. Humphrey added, "We don't just come out into the community. We are members of society just like anyone else."

"The whole macro view versus micro view was really informative, helping me to even further shift my view towards the community rather than 'trying to fix' the individual," said attendee Emily Vogt, Friends On the Town Coordinator, Friendship Circle, Squirrel Hill. Condeluci and Caruso noted that these concepts are simple in principle but complex to apply. They concluded with this challenge, "Returning to work tomorrow, it's going to be the same paradigm. Given that laws do not always promote these new assumptions, macro change suggests a simultaneous effort at informal change." They explained, "This is best done when people have conversations and build solidarity. Their sameness begins to promote attitudinal change. Figure out how you can build community. We need to provide opportunity. Who knows where it will lead."

The Other Side of Inclusion was the first of four community-wide programs being offered through Merakey Allegheny Valley School's program transformation initiative. "Merakey AVS is enthusiastic about the changes ahead for our programs and services," states Staff Development Executive and Transformation Project Lead Carol Erzen. "For so many of the individuals we support, shifting services from site-based to community based is the right thing to do. But change is challenging, and we are so grateful for the grant from Polk Foundation which is making it possible for us to carefully and thoughtfully make critical changes throughout our organization. We are delighted that through the grant we are able to provide access to internationally known thought-leaders to help us all move the needle."

Additional programs in the series include:

Thursday, April 18 – Supported Decision Making with Desiree Loucks Baer – Rodef Shalom Congregation, 9:30am-3:30pm

Thursday, June 6 – Graphic Facilitation to Support Person Centered Planning with Carol Blessing and Mary Jo Caruso – Beth El Congregation of the South Hills, 9:30am-3:30pm

Tuesday, September 3 - The Importance of Belonging with David Pitonyak – Rodef Shalom Congregation, 9:30am-3:30pm

All sessions are open to families and human service professionals who support families of individuals with IDD to create opportunities for community participation.

For more information, email Merakey_AVS@merakey.org