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Isolation or Inclusion?

Panel discusses how to 'be friends' with people with developmental disabilities

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Reporter

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An invitation to residents in the Quad-cities to talk about the everyday barriers people with developmental disabilities face in work and life drew about 30 audience members at an Isolation or Inclusion? Forum on Oct. 10 at the Prescott Resort. Most of the audience either work or volunteer in the disability field.

Larry Clausen, executive director for the Governor's Developmental Disabilities Planning Council, said every state has a council, and part of its role is to bring about change for people with disabilities. The forum's panel talked about residential and transportation choices, social and leisure time, employment, and how to balance safety with independence.

Panel member Dr. Allison Cohen Hall, senior research associate at the Institute for Community Inclusion at the University of Massachusetts in Boston, said for her the word "inclusion" equals "contribution."

"They want to be productive, valued, and to have meaningful relationships," she said of residents with developmental disabilities.

One way of improving inclusion is to make use of resources that aren't disability-centered, she said. Social networks shrink after high school graduation, leading to less interaction with people without disabilities. For instance, group home residents hang out with other residents and the staff - sometimes exclusively.

If the group home is on the outskirts of town, that leads to greater isolation because of lack of transportation options.

Having higher expectations and finding interests at the middle and high school grades could lead to better skill development for potential employment outside of center-based or shelter jobs, Hall added.

Prescott Valley resident Corey Marshall, founder of Core Support, Inc., agreed that individual planning needs to begin at a younger age. It also needs to be a collaborative and educational effort with parents.



Christopher Mountain, Prescott, right, jokes with the other members of the panel at the Isolation or Inclusion? forum on people with developmental disabilities in the workforce and community that took place Oct. 10 at the Prescott Resort.

Trib photo/Sue Tone

"All parents deal with fear. It takes courage to let go," he said about encouraging independence.

Ray Morris, a Scottsdale paramedic who founded the non-profit Dads 4 Special Kids, is a parent of a 25-year-old son with autism and severe cognitive delay. He connects fathers of special kids with dads who've been "down this road" and who are struggling to figure out what to do next.

"You have to have realistic aspirations," he said. His son's school focused on teaching job skills, but his son didn't have those abilities.

"Inclusion for my son means that he is happy. He can't hold a job or ride a bus," Morris said.

"You have to believe you are the perfect parent for your child. It's about getting the right people around you to go on the journey, with support, validation and love," he added. "You've got to support the parents who have this child they didn't ask for."

Morris said he does not call Dads 4 Special Kids a "support group." That doesn't work for fathers. He calls it an advocacy group and "there's no estrogen allowed," he said with a laugh.

Morris also relates on another level to society's view of those who are different. His father became a quadriplegic when Morris was 9 years old, and he watched how the community excluded his father because they didn't know how to interact with a quadriplegic.

"The (wheel)chair didn't identify who he was, and he didn't want pity," he said. The more exposure one has with "different" people, the more comfortable one becomes, he added.

The fourth member of the panel, Christopher Mountain, 46, has worked at the Prescott Good Samaritan Society for two years. He has Down's syndrome. Mountain reached his career goal when recently promoted to prep cook; his new dream is to become a cook. He also wants to get a driver's license.

Mountain said he was bullied and picked on when he was in school, and acknowledged that he knew the school had ways to help.

"But they didn't care," he said about the adults.

Later in life, he would get together with a group of friends to socialize and participate in fundraisers, but that group has since folded. His answer to what would help communities include people with disabilities was, "Be a friend."

Erica McFadden, policy analyst at Morrison Institute for Public Policy and faculty member at Arizona State University, presented a PowerPoint on recent research and a study of 35 adults with DD from Flagstaff, Prescott Valley, Sierra Vista and Yuma.

She compared her results with National Core Indicators, and found transportation and access are lacking. For example, some restaurant bathrooms are too small, sidewalks are lacking, many dirt roads and no streetlights.

"Location means everything. If they can walk to get somewhere, they are included," she said. But the wait list for affordable, accessible housing is more than a year.

About 75 percent are not employed and not looking for work for a variety of reasons: employers' bias, job market changes (decline), fear of losing SSI benefits, negative past work experience, and didn't think they could work.

Through its study, the Morrison Institute found that many said that exclusion - and a resulting

sense of alienation - has become the norm. Others have found creative ways to achieve the kind of inclusion they want.

The forum sessions across Arizona reaffirmed that including more voices from people with developmental disabilities will help find innovative solutions to difficult policy issues.

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