



A Day in Our Shoes: Arizonans with Developmental Disabilities Share Their Experiences Living in Small Cities and Towns

Arizona adults with developmental disabilities (DD) face extremely high unemployment rates that have worsened over the past 20 years. They experience greater isolation and higher poverty rates than adults without disabilities. The combination of these elements often lead to social isolation and exclusion from mainstream society. To address these issues, many adults with developmental disabilities rely on state and federally funded programs. However, the types of programs and services that should be offered remain an issue of considerable debate. In an effort to better understand the lives of adults with DD living in small towns and cities, Arizona State University's Morrison Institute for Public Policy conducted four focus groups – one each in Prescott Valley, Flagstaff, Yuma and Sierra Vista - with 35 adults with a wide variety of types of DD.

This project, *A Day in Our Shoes*, sponsored by the Arizona Developmental Disabilities Planning Council, finds that the choices available to individuals with DD are often so limited as to inhibit individual independence and deny these Arizonans the opportunity to realize their potential. Segregated day program and employment options are being utilized more than are community-based options – which clearly provide a more effective path for including adults with DD in the community. The excessive reliance on these formal – but segregating – services is called by some the “disability bubble.” This bubble limits the promise, opportunities, and social networks of Arizonans who desire a fuller, richer life.

A number of additional themes stand out from this research:

Choice or Inclusion? Individual desires for inclusion vary. One person may want to live in his/her own apartment, while another would prefer a group home. Some prefer to keep to themselves while others prefer to socialize. Some prefer group supported or center-based employment over competitive employment. There is no “one size fits all.”

Balancing Safety with Independence: Most individuals desire independence. While their preferred options may, in fact, be available, these choices are not always presented to them due to concerns about stigma or safety.



Settling: Although adults with DD have career aspirations, they have encountered numerous negative experiences when holding or seeking jobs. As a result, many stopped searching. Some will settle for any job they can find. Those who hold jobs in group or center based employment are often satisfied with what they have. In some cases they held jobs in the community in the past, but lost them, and are now participating in group supported and center-based employment programs.

Small Social Networks: Most participants just want to feel normal. Those who have friends typically befriended others with disabilities whom they met through providers. Those who did not receive services through providers either met friends through family or made their own friends in the community. In these smaller cities and towns, their friends often moved away after completing their formal schooling, leaving these individuals with smaller social circles after high school. This poses a problem, as an individual's access to the community is facilitated by his/her support system. Families also fear what will happen in the future to their loved ones with little or no support available.

Location, Location, Location: While a few participants could drive, transportation remains a significant barrier for the majority of participants due to cost, availability, and ease of use. The location of the individual's home determines how much freedom he or she has to see friends, run errands, and get out into the community. Those close to city centers either ride their bikes or walk, while those farther away depend on others, limiting their access.

Lack of Information = Lack of Access: Some participants in all four groups indicated they do not have access to accurate information regarding transportation, available activities or employment. Further, there is an overall lack of knowledge regarding the rules concerning working while receiving Social Security Supplemental Security Income (SSI), how to access job coaches, and other work incentive programs.

Desire for Self-Advocacy: Many of the focus group members indicated that they have become resigned to the barriers they face in their daily lives. However, after hearing from others encountering similar barriers, they unanimously supported coming together as a group to build their own support network to advocate removing some of the barriers, to gather information, and simply to socialize.

Looking ahead, important questions remain concerning how Arizona can overcome these barriers and design programs that recognize individual choice, encourage active participation in the community and "burst" the disability bubble:

- How can individuals be offered more opportunities outside the disability bubble, learn independence, and learn from failure while still remaining safe?
- How can informal systems be expanded to provide mentoring networks, ride sharing, information exchanges, social interaction and support?
- How can individual interests and aspirations be supported by a formal system, given Arizona's current shortage of resources?