

Kennedy Willis Center Insights



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A Comparative Survey of Social Roles and Community Engagement of Adults With and Without Disabilities in Rural Upstate New York

Much has been written about the importance of community life and social engagement for persons who live with a developmental disability. It has been suggested that people with disabilities who live in individual, community based group homes experience a higher quality of life and valued social role than do people with disabilities who live in congregate settings. The Centers for Medicare and Medicaid Services (CMS) Home and Community Based Waiver of 2014 signaled a renewed emphasis on assuring community access for persons with disabilities and the importance of maximizing opportunities for persons with disabilities to access the benefits of community life and employment. Language within the CMS Waiver also suggests that some congregate settings isolate and limit the life experiences of persons with disabilities.

Supported by resources of the Upstate Institute of Colgate University, the Kennedy Willis Center (KWC) conducted a survey to compare the social roles and daily life experiences of 32 adults with and without disabilities who live in rural, upstate New York. The survey sought to measure the presence or absence of key elements that have been identified by prior research as contributing to a person's quality of life. The KWC researchers wanted to learn whether people living in Individualized Residential Alternative (IRA) settings located at Pathfinder Village had comparable life experiences, community engagement opportunities and valued social roles to their non-disabled peers of similar age.

Survey Overview

Previous research has shown that an important factor in a person's quality of life is having the opportunity to fill one or more social roles. Social roles "identify the different ways that

people relate to one another, belong to one another, count on each other and are responsible to each other" (O'Brien, 2010). The nine-question interview tool was designed to answer several questions regarding social roles:

How do the day-to-day lives of persons with disabilities compare to those of their non-disabled peers? Is there a difference in the type or frequency of quality of life indicators that are present in the life of a person with a disability than for a person without a disability? How do the types and frequency of social activities compare between the two participant groups?

The study format utilized four age groupings through which to administer the survey and analyze survey results. The groupings enabled the researchers to compare the experiences of survey participants at the same stages of life. The four age groups were: 18-27 yrs.; 28-38 yrs.; 39-46 yrs.; 47+ yrs. All participants were interviewed in person or by telephone in order to enable them to expand upon responses as necessary.

Survey Method

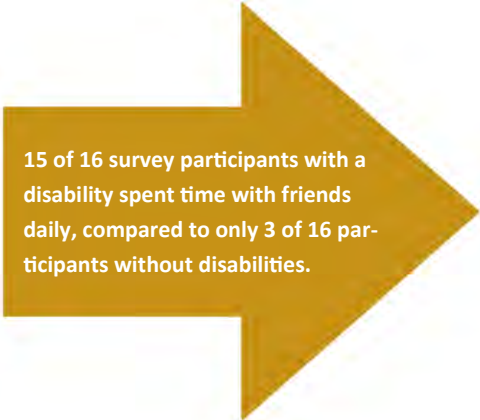
The survey was administered to 32 adults (with and without disabilities) between the ages of 18-62 years, who lived within a 15-mile radius of Edmeston, New York. Survey participants were Caucasian, and included 18 males and 14 females. Each of the 16 participants with disabilities was diagnosed with Down syndrome and lived in an Individual Residential Alternative (IRA) at Pathfinder Village in Edmeston, NY. Participants were recruited through use of community flyers, word of mouth, and a presentation at a local Rotary Club meeting.



Community Activities and Social Roles

The survey found that people with and without disabilities shared many common experiences and social roles, including dining out, using a computer, visiting friends and family, and traveling to new places. In several instances survey participants with disabilities reported a greater number of activities or valued social roles than did their non-disabled peers. Examples of this disparity included number of hobbies, amount of time spent with friends, going to the movies, taking classes in the community and having a network through which to learn about upcoming community events. Survey results noted:

- ◆ 15/16 participants with disabilities spent time with friends daily, compared to only 3/16 participants without disabilities
- ◆ 12/16 participants with disabilities reported attending movies at least monthly, compared to 4/16 of their non-disabled peers
- ◆ 15/16 participants with disabilities had at least one hobby, compared to 13/16 participants without disabilities



15 of 16 survey participants with a disability spent time with friends daily, compared to only 3 of 16 participants without disabilities.

In asking survey participants about various social roles they filled, and the importance of these roles to them, there was minimal to no difference in how people with and without disabilities described the following social roles in their lives: volunteer, friend, family member, student, worker, church member, and club member. However, there were more significant differences in the number of survey participants who filled the social roles of caregiver and voter. 12/16 participants without disabilities described themselves as voters, compared to only 5/16 participants with disabilities. None of the survey participants with disabilities described themselves as caregivers, compared to 5 of 16 of their non-disabled peers.

Obstacles to Community Engagement

Survey participants from both groups faced similar obstacles to engaging with their community, including **financial limitations, lack of time, lack of control over some aspects of their lives, and the rural environment in which they lived.**

Access to transportation was identified by participants of both survey groups as a challenge given the rural setting of Otsego County, but it presented a greater obstacle for participants with disabilities. 9 of the 16 participants with disabilities said that transportation access was a barrier for them, compared to 0 of 16 participants without disabilities.

Despite their greater access to transportation, survey participants without disabilities reported that they had few opportu-

nities to take classes in the community, despite having interest in doing so. They reported having a harder time **learning about available learning opportunities and activities in their community**, especially if they were not connected in some manner to the local school system. 5 of 16 respondents said that learning about activities that were available in their community was a problem.

The survey participants with disabilities reported that they were involved in some type of community based class or learning activity on a monthly basis. No survey participants with disabilities reported having any problem learning about activities available to them.

Community Engagement, Social Roles and Quality of Life

Ultimately, there is no single set of social roles or life activities that defines what constitutes a positive life quality. Indi-

vidual preferences and social identity influence what is most important to each person. However, having the ability to fulfill a meaningful social role and to engage in preferred activities within one's community are important factors that contribute to one's quality of life.

The survey found that people with and without disabilities shared many common experiences and place similar levels of importance on life roles and life activities. While acknowledging the small sample size, the survey found no significant differences in the preferred life activities and meaningful life roles of persons with or without disabilities in this geographic region. Survey results suggest that, in a rural area, having opportunities to engage with others, and to access information and preferred life experiences are equally important to all. It also suggests that congregate living environments alone are not necessarily limiting for a person with a disability.

FOR MORE INFORMATION

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- ◆ O'Brien, J. (2010). *Supporting Social Roles: A Second Bottom Line for Services to People with Developmental Disabilities*. Toronto. Inclusion Press.