

**A COMPARATIVE SURVEY OF SOCIAL ROLES AND COMMUNITY ENGAGEMENT
OF ADULTS WITH AND WITHOUT DISABILITIES
IN RURAL UPSTATE NEW YORK**

August 10, 2016

Executive Summary

The Kennedy Willis Center (KWC) at Pathfinder Village, supported by resources of the Upstate Institute at Colgate University, conducted a survey to compare the social roles and daily life activities of 32 adults with and without disabilities who lived in rural upstate New York. The survey sought to measure the presence or absence of key elements that have been identified by previous research as contributing to a person's quality of life. These elements included social activities, hobbies, friendships, levels of employment, travel opportunities, engagement in church or spiritual linkages, etc. The KWC wanted to learn whether people living in the Individual Residential Alternatives (IRAs) located at Pathfinder Village had comparable life experiences, community engagement and overall quality of life to people without disabilities living in Edmeston, NY and the surrounding area.

Findings indicated that there were many common quality of life factors and barriers for participants from both groups (people with and without disabilities). The survey also discovered some differences in experiences between the two participant groups, in such areas as voting, interest in hobbies, opportunity to take enrichment classes, knowledge of events taking place in the region, and access to transportation. These similarities and differences are identified and discussed within the report. The survey results may help to further inform current and future community living support models for people with disabilities.

Survey Overview

Much has been written about the importance of community life and social engagement for persons who have a developmental disability. It has been suggested that people with disabilities who live in group homes located in local communities experience a higher quality of life and valued social role than do persons with disabilities who live in congregate settings. The Centers for Medicare and Medicaid Services (CMS) Home and Community Based Waiver of 2014 has also signaled a movement away from congregate living settings based on the assumption that congregate support settings isolate and limit a person's life experiences. The goal of the waiver is to maximize opportunities for people with disabilities to have access to the benefits of community living. Because Pathfinder Village is a congregate living community, it was important to look into the similarities and differences between the quality of life and community engagement of people with disabilities living in the IRAs at Pathfinder Village and people without disabilities that live in the surrounding area.

Previous research has shown that an important factor in quality of life is filling social roles, which “identify the different ways that people relate to one another, belong to one another, count on each other, and are responsible to each other.”ⁱ A nine-question survey tool was designed to answer the following questions based on previous research related to social roles:

How do the day-to-day lives of individuals with intellectual and/or developmental disabilities compare to those of their non-disabled peers? When considering those elements that contribute to the quality of life for a person, is there a difference in the type or frequency of quality of life indicators for a person living with a disability? Do persons with disabilities have more or fewer social activities, hobbies, friendships, levels of employment, travel opportunities, engagement in church or spiritual linkages, etc. than do their non-disabled peers? Do people with and without disabilities in rural Upstate New York face similar barriers to filling social roles and engaging in activities that may be indicators of their life quality?

Four age groupings framed the comparison of the experiences of people with and without disabilities during various stages of life: 1) 18-27 years old, 2) 28-38 years old, 3) 39-46 years old, 4) 47+ years old. Because people with developmental disabilities age differently than people without disabilities, there was also an added a 5th age grouping of people over the age of 63 without disabilities. This group near the retirement age or at the retirement age provided a better comparison to the 4th age group of people with disabilities.

Methods

Participants:

The survey was administered to 32 adults (with and without disabilities) between the ages of 18 and 62 years of age who live within a 15 mile radius of Edmeston, New York, where Pathfinder Village is located. There was no racial or ethnic diversity in this survey, which was unsurprising given that the Edmeston population is 97% whiteⁱⁱ. All 16 of the participants with disabilities were diagnosed with Down syndrome and live in an NYS certified Individual Residential Alternative (IRA) in Pathfinder Village.

| | Without a disability | With a disability | Total |
|--------|----------------------|-------------------|-------|
| Male | 11 | 7 | 18 |
| Female | 5 | 9 | 14 |

Recruitment:

To recruit survey participants, Pathfinder Village distributed flyers at their weekly produce market and in the village bakery. The purposes and goals of the survey were also presented to the local Rotary Club. Most of the participants without disabilities were recruited through word of mouth or connections with Pathfinder Village employees and local business partners.

Survey Tool and Process:

A nine-question survey tool was designed to examine the demographics, activities, roles, and barriers experienced by participants. The online Survey Monkey platform was used to aggregate and analyze data, but responses were handwritten by the interviewer and later entered online.

Participants with disabilities were interviewed in person, either in their homes or in an office at Pathfinder Village. A Pathfinder Village staff member was present for these interviews, both to make the participant more comfortable and to assist the interviewer with rephrasing or understanding responses as needed. One participant who is nonverbal used an iPad to assist him during the interview. Participants without disabilities were interviewed in person in a Pathfinder Village office or over the phone. All of the interviews were conducted by a single interviewer to ensure consistency.

Findings and Discussion

Activities:

Participants were asked how they spent their time and how often they engaged in certain activities. The survey found that there was minimal or no difference in the frequency that people with and without disabilities participate in the following activities: going to a restaurant, physical activities, going to the doctor, using a computer, going out with friends or family, and traveling to a new place.

There were differences, however, in how often people with and without disabilities participated in the following:

- *Spending time with friends:* 15/16 people with disabilities spent time with their friends daily, compared to 3/16 people without disabilities.
- *Going to the movies:* 12/16 people with disabilities went to the movies at least monthly, compared to 4/16 people without disabilities.
- *Going to the grocery store:* 4/16 people with disabilities went to the grocery store weekly, compared to 11/16 people without disabilities who went weekly.
- *Going to the bank:* 1/16 people with disabilities went to the bank weekly, compared to 7/16 people without disabilities.
- *Using a cell phone:* 4/16 people with disabilities use a cell phone daily, compared to 14/16 people without disabilities.

Social Roles:

Participants were asked about which social roles they filled and whether or not these roles were important to them. There was minimal to no difference in how many people with and without disabilities filled the following social roles: volunteer, friend, family member, student, worker, church member, and club member. There were more significant differences in the number of people with and without disabilities who filled the following social roles:

- Caregiver: 0/16 people with disabilities were caregivers, compared to 5/16 people without disabilities.
- Have a hobby: 15/16 people with disabilities had hobbies, compared to 13/16 people without disabilities. Having a hobby was significantly more important to people with disabilities.
- Voter: 5/16 people with disabilities were voters, compared to 12/16 people without disabilities.
- Athlete: 13/16 people with disabilities considered themselves athletes, compared to 11/16 people without disabilities. Being an athlete was significantly more important to people with disabilities.

Because of the small sample size (32 participants), many key findings emerged from participant comments. These comments revealed themes relating to obstacles and restrictions and individual quality of life factors. Within both categories of obstacles and quality of life, there were comparable life experiences for people with and without disabilities, but also areas of difference. Both are highlighted in this report.

Obstacles and Restrictions:

Participants with and without disabilities faced the similar obstacles of *financial limitations, lack of time, lack of control or choice, health limitations*, and a *rural location* far away from many activities and conveniences. However, there were some barriers that participants with and without disabilities did not experience to an equal degree. The participants with disabilities that were interviewed had a harder time getting *access to transportation*. 9 out of the 6 participants with disabilities said that transportation was a barrier for them, compared to 0 out of 16 participants without disabilities. Participants without disabilities in the Edmeston area said they had fewer *opportunities to take classes* in the community, as they almost never took classes despite expressing interest. Participants with disabilities at Pathfinder Village take classes (such as art, computer, CPR, Tae Kwon Do, or horseback riding, etc.) almost monthly. Participants without disabilities also had a harder time *learning about available activities* in their community, especially if they were not connected to the school system. 5 out of 16 people without disabilities said that this was a challenge for them, compared to 0 out of 16 people without disabilities who were interviewed.

Individual Quality of Life Factors:

Quality of life is complicated to track because it means different things to different people. In general, participants with and without disabilities had many common factors that contributed to their individual quality of life. Based on participant comments, the following themes were shared by people with and without disabilities: *fulfillment* (self-worth/ work, goals, passion for hobbies), *relationships* (communication and information channels, reciprocity, and friends as family you

choose), *community participation* (voting, service, volunteering), *choice/ self-determination* (self-advocacy, clubs), and *social roles* (identity).

However, there were also some differences in the lives of people with and without disabilities. One major gap that this survey found was there were significantly fewer voters in the group of people with disabilities that were interviewed [*note: a Pathfinder Village administrator verified that a community forum for voting is scheduled in early October to provide education to understanding the voting process as well as assistance with the registration process*]. Out of 16 people with disabilities, only 5 were voters, compared to the 12 out of 16 people without disabilities. Another interesting finding was that people with disabilities living in the IRAs were more likely than people without disabilities to have hobbies and their hobbies were significantly more important to them.

Survey Limitations

When looking at the results of this study, the following limitations should be noted:

- A limited sample size of 32 participants
- Recruitment strategies: most survey participants were referred by people with connections to Pathfinder Village, and did not represent a random sample of the community in and near Edmeston.
- A lack of sample diversity: members of the 63+ age group were involved in the same club and may not be truly representative of their age group.

Conclusion

Ultimately, there is no one set of social roles or daily activities that defines what constitutes a positive quality of life, because an individual's preferences and social identity play a key role in determining what is most important to him/her. However, fulfilling meaningful social roles and having opportunities to engage in preferred activities are important factors to assuring one's life quality.

The survey found that people with and without disabilities share many common experiences and social roles, such as going out to eat, using a computer, going out with friends or family, traveling to a new place, volunteering, being a family member, being a friend, belonging to a church or religious group, or belonging to a club. In some cases, people with disabilities living in the IRAs at Pathfinder Village had more experiences or roles that may suggest a better quality of life, such as having hobbies, spending more time with friends, going to the movies, taking classes in the community, and having a network to learn about events in the community. The survey also revealed areas where there were evident differences in the responses of people with and without disabilities, notably access to transportation and the percentage of people with disabilities who saw themselves as voters. Fewer survey participants with disabilities identified themselves as a voter. Transportation access was also a greater obstacle for this group.

Despite the small sample size, the survey found that there was no significant difference in the overall number or variety of day-to-day activities or meaningful life roles between participant groups of people with and without disabilities. The survey results suggested that in a rural area, the relationships and individual experiences of people with disabilities in a congregate living setting, are not necessarily limiting, and in fact, overall are comparable to the life experiences of their non-disabled peers.

Survey conducted by
Emily Rooney, KWC Upstate Institute Fellow, Colgate University Summer 2016

ⁱ O'Brien, J. (2010). *Supporting Social Roles: A second bottom line for services to people with developmental disabilities*. Toronto: Inclusion Press.

ⁱⁱ <http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF>