CREATING COMMUNITY
AMONG ADULTS WITH DEVELOPMENTAL DISABILITIES IN APPALACHIA OHIO

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ABSTRACT

Although, attitudes towards people with disabilities have been changing over the past 30 years, many remain separated from their community in social and employment situations. Attempts toward inclusion have still left many people with disabilities behind and many barriers still remain in Appalachia Ohio. In this report interviews will be conducted and case studies reported of adults with developmental disabilities participating in a small pilot program in Appalachia Ohio. The purpose of these studies is to explore the value of the program and to understand the perceptions of community from the individual in an effort to help remove barriers and increase quality of life.
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Chapter 1

INTRODUCTION

When speaking about the obstacles people with disabilities must overcome in the community, Ted Kennedy, Jr. claims “it is not so much a person’s physical or mental condition that creates a lot of the barriers... it’s really the perceptions of society” (as cited in Bevins, 2004). In essence it is these perceptions that deter individuals with disabilities from truly becoming part of the community. By exploring the perceptions of community through the eyes of people with disabilities, one can better understand these obstacles and begin effective methods to remove them.

In the past twenty years many barriers have started to fall. Treatment and living conditions for adults with developmental disabilities throughout the country have changed from the multi-residential institutional setting to more individualized, single-family homes within the community. However, opportunities for employment and socialization among people with developmental disabilities still remain largely segregated from the majority of the community. When choosing to work or interact within the community, this population is faced with limited options. Across the nation “about two-thirds of people with disabilities who are willing and able to work are unemployed” (Bevins, 2004). While work environments within Appalachian Ohio have, throughout the past thirty years, greatly remained within the sheltered workshops (Bash, 2004). Even social activities tend to remain segregated as various support groups offer dances and activities to their clients. To truly participate with the community around them, individuals need the opportunities to not only live within the community, but also to choose ways to contribute to it through social, educational and employment means. Adults with developmental
disabilities simply do not have the same opportunities as the majority population.

There is evidence that attitudes within the field of mental retardation and developmental disabilities (MRDD) are shifting to including a “high quality life, not merely a ‘normal’ life” (Cinamon, 2004) and attempts to break down barriers and embrace such concepts as making choices, independence and empowerment are occurring. Current federal funding allows individuals with disabilities more empowerment in determining their own destiny. Opportunities to learn new skills outside the realm of workshops and institutionalized buildings are opening. And in the last two years, the effects are beginning to be felt in Ohio. The Ohio Department of MRDD has begun addressing the issue of self determination. This initiative challenges individuals with disabilities to accept “a role within the community through competitive employment, organizational affiliations and general caring for others within the community.” (Ohio Department of Mental Retardation and Developmental Disabilities). As a result, there are more services available in Ohio and more freedom of choice for adults with developmental disabilities. With these changes come greater opportunities to interact independently within the community and to form closer, personal relationships with a wider range of individuals.

Program Summary

This researcher is currently the Community and Support Director for a non-profit agency in Appalachia Ohio. The organization has been providing residential services to adults with developmental disabilities in several counties in southeast Ohio for over 25 years. As a direct result of the initiatives occurring across Ohio, the decision was made to develop a new day program of social interaction and community involvement to serve the individuals in their area.

The program, itself, is open to any adult with a developmental disability and creates
individualized plans to help the client reach a variety of specified goals including independent living skills and community access. It provides individual and group activities, volunteer opportunities and support with community employment. The goal of the program is to create more independence for the individuals by assisting them in gaining skills and finding natural supports within the community.

Statement of Problem

The problem is that while developing the above noted program, this researcher noticed a profound hesitancy among adults with developmental disabilities when becoming involved in non-segregated community activities, especially employment, volunteering and individual activities. Yet, when attempting to find solutions, very little research was available to understand the phenomena, and, more importantly, there was almost nothing that gives voice to the individuals involved.
Chapter 2

REVIEW OF LITERATURE

Research in the area of community involvement has become available relatively recently. The studies are wide ranging and generally are comparisons of existing programs or on the statistical effects on individuals who are already in the workforce in some capacity. For example, there is evidence which indicates that adults with developmental disabilities who are active within the community, i.e., who work, attend school or volunteer, generally have an increase in life satisfaction (Salkever, 2000). Other studies state that employment program objectives in integrated programs are of higher quality than segregated programs (Pendergast, 1999). Yet, even with these encouraging reports many studies indicate that the majority of adults with developmental disabilities still remain withdrawn from the community. One study indicates that “despite efforts to provide job placement for persons with disabilities, up to half of (special education) graduates remain unemployed” (Cinnamon, 2004). Furthermore, there is little research available that investigates the concept of community involvement from the perspective of the adults with disabilities. And, there is almost nothing at all investigating this relationship within the Appalachian region of Ohio.

Purpose of Research

The purpose of this study is to give voice to individuals with developmental disabilities and to give insight into their lives through the telling of their stories. The study examines the pilot program and its effect on the concept of community from the viewpoint of the individuals. It, likewise, investigates the effects of the program on the individuals’ willingness to embrace the community and on the individuals’ own perceptions of their quality of life. Through this
exploration, barriers to individuals’ emergence within their communities are investigated and attempts are being made to understand the view of community from the perspective of the individuals. The questions remained open-ended to allow for the individuals to share stories and personal experiences.
Chapter 3

METHODS

This study will be a grounded theory investigation into the lives and experiences of adults with developmental disabilities as it pertains to the program. It consisted of interviewing several individuals living in Appalachian Ohio who have participated in the program for at least six months. It began with an open discussion with each participant about the program itself and then the participants directed the progress and investigation from there.

Participants

The participants in the study consisted of individuals with developmental disabilities living in Washington County, Ohio. Each of the participants was diagnosed with some form of mental retardation or other disability before the age of 22. Most already received at least 15 hours a week of residential living support prior to joining the program. All participants receive these services through the common service provider and are currently participating in the pilot program at least once a week and have done so for several months. The variables of present community involvement and age were random and not pre-selected.

Procedures

Interviews were conducted in a place familiar to the individual. Each participant was informed of the purpose of the paper and asked to speak about the program at the beginning of the first interview. From there, participants were encouraged to relate stories and ideas throughout the sessions. Each session was tape recorded for transcription and new questions were written for the next sessions. The transcriptions were used to search for commonalities and themes from the perspective of one participant or the group. Each participant was given a fictitious name for the
sake of the paper.

**Limitations of the Study**

The limitations of the study are mainly a matter of access to the information for the participant pool. Due to current confidentiality issues, this researcher is limited in the sampling population. Individuals who are currently not receiving services were not part of the investigation and may have significantly different views.

A further limitation to the study is the communication barrier. Many adults with developmental disabilities have speech impairments that make communication difficult for someone who does not interact with them on a regular basis. As a result, the researcher relied on staff members to tell some of these individual’s stories.

**Case Studies**

**ABBY**

Abby is a 36 year old female who lives in the community with two roommates and full-time staff. She joined the program at its initial start up. She entered the program because she didn’t feel challenged at the sheltered workshop and wanted to learn to answer phones and how to work in an office. Initials interviews with Abby, her case manager and residential staff gave evidence of her strong will, defined goals and history of aggressive behavior. Files documented her tendency to strike out physically and verbally when frustrated or bored. The decision was made to work on developing office skills while also working on appropriate office and community behavior.

One of the events that most highlights Abby’s progress, (and for that matter, the direction of the program) came as a result of her desire to eat out with the group. She requested this as a
community access event early in the design stage of the program. Everyone, staff and participants alike, was involved in the planning process for the activity-selecting a restaurant which was accessible to everyone, deciding on fair price limits so no one was excluded due to financial restraints, and choosing a day when everyone who wanted to go could go. The first trip to eat out took about two weeks to plan, and she was there helping with it all. A day was finally selected and the day before was spent scheduling the van route to make certain everyone knew when to be ready, what to expect and when they would return home. Two weeks of planning and everything was finally set. Then, as she was leaving that afternoon, the staff said, “See you tomorrow!” and her reply was, “Oh. I’m not going.”

What?! She was so excited. How did this happen? She was taken aside by one of the staff and asked why she had suddenly changed her mind. Her reply was short and concrete. She said she wasn’t going because people stared at her. This was a teachable moment. In her thirty-some years, she had not learned how to interact with the community and apparently some members of the community had not learned how to interact with her. The fact that the person who was staring was the one who was wrong, had never entered her mind. Furthermore, she did not realized that there were socially acceptable ways she can make her opinions known through self-advocacy and speaking out.

Abby now, 7 months later, joins the group in almost all the community events, including eating out once a week. She has adapted various ways of dealing with impolite people, such as smiling back at them, writing letters to the owners of businesses if the employees are the cause, or even choosing not to continue frequenting business who have repeatedly been impolite. A couple weeks ago she even felt comfortable enough in one business to inquire what skills would be
necessary to work there. She has had no aggressive behaviors while attending the program or participating in community events and few, if any, behaviors at home since starting the program.

**BEN**

Ben is a 21 year old male who works part-time at the agencies local office. He lives with family, has residential support part-time, uses a wheelchair and volunteers frequently with the local high school sports teams. He has graduated from high school, taken several classes at a community college and drives his own car. He has never attended the sheltered workshop and has no desire to do so. He was, however, interested in increasing his employment skills and participating in some of the organized social activities sponsored by the program.

He joined that program after a flood forced the closing of his office for repairs. His hours were temporarily reduced and he began filling the extra time by participating in the program. He became a regular at a weekly bowling league and began working on new skills on the computer. His love of computers and self-advocacy has lead to the program adding a weekly adaptive-technology computer classes at the community college. Several of the other clients join him at these classes and are venturing into new worlds on the internet and computer software.

**CHARLES**

Charles is a 56 year old male who has grown up in the old system. He, currently, lives in the community with two roommates and 24-hour residential staff, but spent most of his life living with his family. As a result, documentation of his history is slim. There are, however, some written stories of his youth as told by family and community members. These stories indicate that his life was very sheltered and his family had little support. He had a strong history of violent behaviors which resulted in either police involvement or family imposed punishments involving
the withholding of food.

His behavior at the onset of the program indicated none of this history. He presented as extremely withdrawn and quiet and he continually stared at the floor. He shuffled as he walked, mumbled, initiated no interaction and when asked a direct question, replied only with a question about when he would be eating. His guardian requested he attend our program in an effort to provide variety and more social interaction to his day. It was decided the program would create opportunities through everyday events for him to make decisions and practice social skills.

One of these opportunities created was a weekly visit to Wal-mart. His social skills while there have increased from greatly. Initially, he behaved as described above, looking down and initiated no interaction. Lately, however, his behavior has changed. “He walks down the isles, facing straight forward; he waves and smiles at children. His comfort level has changed and he is able to interact more with others on his own terms” (Lawrence, 2005). He has taken charge of knowing where his lunch is and happily tells the staff that lunchtime is at 11:30. He has begun telling short stories about people from his past and even played a guitar he saw in a store. On Valentine’s Day he joined the group for karaoke, singing a solo of Anchor’s Away.

DAVID

David is 27 years old with limited sight. During his childhood and early adult years he had no disabilities. He played sports, graduated from high school and was studying engineering at a local university when he began experiencing difficulties. Family members report the loss of his sight as a virtual overnight experience. He lives independently in the community and enjoys a strong family support group around him. He was referred to the program by a family member who was concerned he might feel isolated during the week. It was decided to work with him on
gaining more independence in the community and exploring employment opportunities.

David has made remarkable strides in community independence. Often, it is hard to meet with him now, because he is always off doing something. But, pursuing employment has presented David with a number of barriers, the largest, of course, being the community’s view of his disability and the limits they believe it supplies. On one occasion, a staff member found a possibility with a large local employer who notified his human resource department. Upon calling, the human resource manager was very positive until she heard that David had limited sight. At that time she informed him that she didn’t have anything suitable for him at this time. The staff explained that he would have assistance learning the layout of the job, building, etc., if needed, until he could function independently. Yet, it was suggested he call the volunteer coordinator.

That was not the only time this type of thing has happened to David. He has seen it repeatedly over the years. As a result, he has become very vocal on his beliefs and begun advocating for himself. At the end of March, staff helped him secure an appointment with the U. S. Representative from his area and he spoke to him about the need to support people with disabilities and to educate the community.

FRANK

Frank is a 44 year old male who lives in the community with one roommate and full-time staff. He had once attended the sheltered workshop, but found it did not engage him intellectually. He was, at that time, choosing to stay home and only going out on weekends. And, he often used a wheelchair instead of walking, because he got tired easily. At the beginning of the program, Frank wanted only to answer phones and investigate the possibility of becoming a
disc jockey. Meetings with him and his residential staff indicated his need for encouragement in exercising, a tendency toward verbal outbursts when angered and a pattern of mild depression when isolated at home. Frank decided that while attending the program, he would work on phone skills, investigate the needs of starting a disc jockey business, find appropriate, socially accepted ways of expressing anger and be involved in various forms of social interaction.

As Frank became more comfortable with the group he began to express his desire to stop using his wheelchair. The staff checked into local agencies and discovered an indoor track that was open to anyone in the community. The participants of the program all voted and decided the best way to support Frank in his goal was to walk with him. So, now everyone goes to the track once a week and monitors the number of laps each person does each week. Frank started by taking his wheelchair and walking half the lap, then riding the second half. Now, Frank can walk 5 laps in an hour using only his walker. He only brings his wheelchair now as a place to sit and rest at the track or when going on a longer community based activity.

Furthermore, Frank has had no outburst while involved with program activities and his periods of depression have been shorter and fewer. He has begun attending everyday, answers the phone at the office and joins the program staff in working a part-time at a job in the community about one weekend a month.
Chapter 4

RESULTS

The results of the study indicate that the participants do in fact like the program, choosing to participate more and more. One participant claimed “It’s the best program ever”. Across the board, participants stated that they were happy as a result of the program and pointed to specific improvements in each participant. Both situations support the findings that people involved in the community rate their life satisfaction higher and that programs with objectives in integration tend to be higher quality.

Another pattern that came to light was client appreciation for variety. The fact that the program allowed for interaction in the community in a variety of different ways was definitely a plus. All the participants listed this as one reason they liked the program. One participant stated, “It breaks up the monotony” of being at home.

The participants unanimously stated that the staff is a key reason for their and the program’s success. One participant commented that she liked how everyone treats her like an adult. Another client remarked, “I like them a lot. I like hanging out with them and doing everything”. However, when asked to elaborate, most could not find a way to express it. All they said was they just do.

Community involvement and barriers were other areas where the participants had trouble finding the words to express their feelings. All state they like being out in the community and being part of the community but only one person could find the words to express these interactions. In reference to dealing with barriers, he states, “I learned that you can pretty much teach yourself how to do anything. You just have to design your own way to do it”. When
speaking about what the community needs to know to help remove some of the barriers, he replied, “getting to know me as a person, as a disabled consumer, as a disabled neighbor, a disabled part of the community”. He suggests that the good relationship he feels with his community is a result of people in the community getting to know him as an individual and him getting to know the community as a collection of individuals.

Furthermore, the progression of the research led to informal interviews with staff and members of the community at large. Each was asked impromptu questions about their interactions with people with disabilities, their comfort levels, knowledge and frequencies of interaction. The bulk of the community members expressed limited knowledge and little frequency of interaction. Most said they would appreciate the opportunity to find out more and to learn new ways to make accommodations and help people with disabilities feel more comfortable. Everyone expressed good comfort levels, just limited opportunities to interact.
CONCLUSIONS

The results of both the formal interviews and the informal interactions with community members point directly to the need for more *individual* interaction between adults with developmental disabilities and other community members. The need exists for people to get to know each other and learn about each other on an individual basis. Programs of segregation that provide only segregated activities in the community are not as effective as programs of individual or small group integration. If it is true that people who are accepted within their community are happier, then it is also true that people with disabilities who are accepted within their community are happier. It is this researcher’s opinion that by creating opportunities for members of the community to interact with and get to know people with disabilities, the quality of life for all members of the community, disabled and non-disabled alike, increases.
References


