

Title: "Determining the Attitudes of Program Managers toward the Deinstitutionalization of Individuals with Intellectual Disabilities"

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Abstract:

We have moved from a period of institutional and facility-based thinking in which people were seen as patients, through an intermediary phase in which these individuals were seen as citizen with disabilities, but who share with all other citizens the potential for, and the right to, full community participation and integration. The movement of deinstitutionalization was (and is still in process) designed to gradually shift perception of mental defects and how professionals and the general public treat and label person with disabilities.

Deinstitutionalization is when adult individuals with disabilities that have been housed for the majority of their lives in institutions are put back into the community. These adults with disabilities are usually adults with moderate to severe intellectual disabilities. These adults, many who require twenty-four hour care, are now being forced out of their familiar surrounding into the hands of unfamiliar caregivers (Herge, 2002).

These individuals are fated to leave these institutions that have been their homes for most of their lives. These adult individuals with intellectual disabilities are being mainstreamed into an environment that is totally unfamiliar from what they have been used to. Program managers fear this deinstitutionalization movement will lead to functional regression and an increase in maladaptive behaviors.

Introduction

As stated by Carling (1995), "We have moved from a period of institutional and facility-based thinking in which people were seen as patients, through an intermediary phase in which these individuals were seen as citizen with disabilities, but who share with all other citizens the potential for, and the right to, full community participation and integration." Herge (2002) states that the deinstitutionalization movement has been around for a very long time and according to research, this movement began in the early 60's. The movement of deinstitutionalization was (and is still in process) designed to gradually shift perception of mental defects and how

professionals and the general public treat and label person with disabilities.

Deinstitutionalization is when adult individuals with disabilities that have been housed for the majority of their lives in institutions are put back into the community. These adults with disabilities are usually adults with moderate to severe intellectual disabilities. These adults, many who require twenty-four hour care, are now being forced out of their familiar surrounding into the hands of unfamiliar caregivers (Herge, 2002). Although community advocates believe that all people, even those with severe and profound disabilities, must be permitted opportunities to live in their home community, close to family and friends, and with their non-disabled peers; community support for such a movement has not been widely accepted. However, in spite of the resistance from the community, it has been mandated that individual with mental disabilities be best served in the least restrictive environment (Kaplan & Sadock, 2004).

Statement of the Problem

The purpose of this study was to determine the attitudes of program managers toward the deinstitutionalization of adult individuals with intellectual disabilities. For over the past forty years, adult individuals with moderate to severe intellectual disabilities have been removed from training institutions and placed in group homes within the community. This movement has caused program managers who work with these individuals to question the feasibility of this movement.

Significant of the Study

This study was significant because it dealt with the attitudes of program managers who worked directly with adult individuals with intellectual disabilities in state institutions. These individuals are fated to leave these institutions that have been their homes for most of their lives. These adult individuals with intellectual disabilities are being mainstreamed into an environment that is totally unfamiliar from what they have been used to. Program managers fear this deinstitutionalization movement will lead to functional regression and an increase in maladaptive behaviors. Hopefully, the results from this study will cause local and state politicians and lawmakers to reconsider their positions of the deinstitutionalization of adult individuals with intellectual disabilities.

Limitations

There were several limitations to this research study.

The first limitation was the survey used to determine the attitudes of the program managers toward the deinstitutionalized movement was developed by the researcher and was not pilot-tested for standardization. The second limitation of the study was the participants in the study may not have answered the survey items truthfully. The third limitation was that the sample size was small and was not randomly selected and the sample included a selected group of participants who worked directly with the adult individuals with intellectual disabilities. The

fourth limitation was the decay of the study; sending out several reminders to the participants may have caused feelings that may be misrepresented in the answers given to the responses to the survey items. The final limitation was that the study used two to three institutions; therefore the result cannot be generalized to other national institutional settings that housed adult individuals with intellectual disabilities.

Research Question

The research question that guided this study was:

What were the attitudes of program managers toward deinstitutionalization of adult individuals with intellectual disabilities from Training Centers X and Y?

The Deinstitutionalization Movement

The deinstitutionalization movement began in the early 60's as individuals with disabilities moved from large institutions to smaller group home in the community.

By the mid- 1970s state institutions had reached a population of almost 200,000 residents. During the late 1970's efforts were begun sharply to reduce new admissions to institutions and to transfer individuals with intellectual disabilities already residing in large facilities to community-based programs, such as group home, foster homes, and supervised apartment. Over the years those efforts have been largely successful.

Because of the deinstitutionalization movement substantial numbers of state institutions have been closed and most residential care for individuals with intellectual disabilities has shifted from large public institutions to community programs. Many public facilities are faced now with geriatric care of severely and profoundly adult individuals with intellectual disabilities and with severe developmental disabilities (Kaplan & Sadock 2004).

Sullivan (1992) found that the deinstitutionalization movement was driven, in some part, by a desire to preserve community-based services for individuals with intellectual disabilities. The deinstitutionalization movement from institution to community based care was consistent with the Human Rights' concerns which included reducing the harmful effects of institutionalization, and fostering dependence and passivity on individual with intellectual disabilities. He further stated that the deinstitutionalization movement included reducing stigma and discrimination while allowing individuals with intellectual disabilities to be cared for in the community and continue to participate in the life of the community.

The deinstitutionalization movement has brought important benefits. These benefits include newly established rights for individuals with disabilities, for example, the right to publicly financed health care coverage. Support living and other types of programs were also created to help individuals living in their communities. Staff-to-resident ratios in-group homes typically

improved compared with ratios in the other institutional care sites (Braden, 2001).

The Olmstead Decision

On February 1, 2001, President George W. Bush announced the New Freedom Initiative (NFI), promising to promote “full access to community life” through swift implementation of the “Olmstead Decision”.

In the Olmstead decision (1999), the supreme Court ruled that Title II of the American with Disabilities Act (ADA) required states to provide the services, programs, and activities developed for persons with disabilities in the “most integrated setting appropriate” because “unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by Title II of the American with Disabilities Act of 1990” (Lakin, Braddock & Smith, 2004).

In the Executive Order 13217, President Bush committed that Executive Branch of the United States government to the principal finding of Olmstead Decision and stipulated that “the United States is committed to community-based alternatives for individuals with disabilities and recognized that such services advance the best interests of Americans”. President Bush called on federal department to work with States to help them assess their compliance with the Olmstead Decision and the American with Disabilities Act (ADA) and to assist them in removing barriers the impede opportunities of community placement (Lakin, Braddock & Smith, 2004).

The implementation of the Olmstead Decision has deflected advocates’ attention from the more important issues to how managed care plans treat Medicaid beneficiaries with disabilities. States Supreme Court decided in an Opinion issued on June 22, 1999 that a State is required under Title II of the American with Disabilities Act to provide community-based treatment for persons with mental disabilities when:

- the State’s treatment professionals determine that such placement is appropriate,
- the affected persons do not oppose such placement, and
- The placement can be reasonably accommodated, taking into account the resources available to the State and the need of those with disabilities (Lakin, Braddock & Smith, 2004).

The Court further stated that nothing in the American with Disabilities Act (ADA) or its implementing regulations requires community placements for persons unable to handle or benefit from community setting. Virginia has taken many steps to implement the Olmstead Decision, including developing mental health and intellectual disabilities facility discharge protocols;

setting up a discharge assistance program; and establishing several community-based programs of Assertive Community Treatment across the state. Virginia is also formulating a Task Force to address concerns raised by the Olmstead Decision by August 31, 2003. This Task Force and its activities will be inclusive of all consumers and services providers who have an interest in Olmstead issues (<http://supct.law.cornell.edu/suspect/html/98-536.ZS.html>).

Attitudes of Workers in State Institutions

The attitudes of program managers who work with adult individuals with intellectual disabilities in institutions are diverse in their response regarding deinstitutionalization movement.

Some are optimistic about the quality of care the individuals with intellectual disabilities will receive under community-based services. Others think the quality care will be better for these individuals in the community setting as opposed to institutional care.

Many workers feel that the individual with intellectual disabilities will regress functionally and maladaptive behaviors will increase substantially because of being deinstitutionalized. In addition a great number of these individuals they believe may be misplaced in the community.

Workers feel that some of the clients who are there did not belong in the institution from the start, but because of the no family intervention and financial resources, they ended up in the institution.

Overall many workers feel that the institutions are better prepared to handle the adult individuals with intellectual disabilities versus a community setting because of the deinstitutionalization movement (Vladeck, 2003).

On the hand, reality causes worker's attitude to be apathetic and negative towards change that may result in jobs being lost because of this movement. Many of these workers have spent five to thirty years of their lives working in institution, and because of this movement, these institutions may close.

Methodology

Population and Sample

This study used 30 program managers from Training Centers X and Y.

The training centers were located in the central and eastern parts of the Commonwealth of Virginia.

These training centers have a combined resident population of over 550 clients.

They housed an education department for the education of adult individuals with intellectual

disabilities until May of 2002. After this time, the centers' educational wing was closed because it no longer had school-age residents with disabilities in attendance. Because of this move this institution has gone from education to rehabilitation of its residents.

There are approximately 50 program managers employed at this training center. All of these program managers have experience working with individuals with intellectual disabilities. The program managers' experience range from five to thirty years of services. Many of the program managers' caseload has been drastically changed due to the closing of the educational wing and deinstitutionalization movement.

Instrumentation, Scoring and Design

The instrument used in this study was a research-designed survey. This was a descriptive research study. The survey consisted of a 10 questions with a Liker-scale response style. This survey was designed to determine the attitudes of program managers on the deinstitutionalization of adult individuals with intellectual disabilities from training centers X and Y located in central and eastern Virginia.

Threats to Validity

There were several threats to the validity of this study.

- The participants were not randomly selected.
- The research results cannot be generalized to other state institution or population of individuals with intellectual disabilities.
- The participants were not demographically screened to ensure that they were representative a larger population of program managers.
- The survey questions were not pretested to improve the scoring or eliminate response items that did not contain the language necessary to elicit certain responses.
- The instrument used in this study was research-designed and not field tested; therefore, the validity could not be determined beforehand.

Answer to Research Question

The research question that guided this study was answered using the percentage tabulations of each survey item. According to the statistical analysis, the attitudes of program managers towards the deinstitutionalization of adult individuals with intellectual disabilities at

Training Centers X and Y were those of concern. These program managers felt that the deinstitutionalization movement was good for some clients; but they also felt negative toward the movement because it will eventually mean the loss of their jobs.

Research Findings

Survey item #1 asked if program managers believed that deinstitutionalization is the best for all institutionalized individuals with intellectual disabilities?

For survey item #1 – 44% of the respondents agreed that deinstitutionalization is for most institutionalized clients, 53% did not agree, and 3% expressed no opinion at all.

Survey item #2 asked if program managers believed that deinstitutionalization will allow individuals with intellectual disabilities the freedom to make their own choices?

Survey item #2 – 67% of the respondents agreed that deinstitutionalization will allow individuals with intellectual disabilities the freedom to make their own choices, 30% did not agree, and 3% expressed no opinion at all.

Survey item #3 asked if program managers believed that deinstitutionalization was enforced at training centers because of the Olmstead Decision?

Survey item #3 – 67% of the respondents agreed that deinstitutionalization was enforced at the training center because of the Olmstead Decision, 30% did not agree, and 3% expressed no opinion at all.

Survey item #4 asked if program managers believed that deinstitutionalization is the clients that need related services?

Survey item #4 – 83% of the respondents agreed that deinstitutionalization is about the clients that need the services, 14% did not agree, and 3% expressed no opinion at all.

Survey item #5 asked if program managers believed that deinstitutionalization is about the individuals who need the services?

Survey item #5 - 73% of the respondents agreed that deinstitutionalization is about the clients that need the services, 17% did not agree, and 10% expressed no opinion at all.

Survey item #6 asked if many workers would lose their jobs because of the deinstitutionalization movement occurred?.

For survey item #6 – 83% of the respondents agreed that worker will lose their jobs because of the deinstitutionalization movement, 17% did not agree.

Survey item #7 asked if program managers believed that individuals with intellectual disabilities are prepared to be deinstitutionalized?

For survey item #7 – 57% of the respondents agreed that majority of clients are prepared to be deinstitutionalized, 37% did not agree, and 7% expressed no opinion at all.

Survey item #8 asked if program managers believed that deinstitutionalization process is efficiently done?

For survey item #8 – 41% of the respondents agreed that the deinstitutionalization process is efficiently done, 56% did not agree, and 3% expressed no opinion at all.

Survey item #9 asked if program managers believed that the clients who have been deinstitutionalized have benefited from the movement?

For survey item #9 – 27% of the respondents agreed that clients who have been deinstitutionalized have benefited from the movement, 56% did not agree, and 17% expressed no opinion at all.

Survey item #10 asked if program managers believed that deinstitutionalization movement is a success?

For survey item #10 - 26% of the respondents agreed that deinstitutionalization movement is a success, 61% did not agree, and 13% expressed no opinion at all.

SUMMARY AND CONCLUSIONS

This study would need to be replicated with a larger population of program managers before the results could be inferred on a larger population of workers involved in the deinstitutionalization movement. The attitudes and the perceptions of the sample group felt toward the deinstitutionalization movement ranged from total acceptance for those clients with mental retardation to indifferent because it meant job insecurity. The data collected from the survey indicated that overall the program managers displayed negative perceptions of deinstitutionalization and the clients it affected.

RECOMMENDATION

It is recommended to future researchers who might like to replicate this study, that a

larger sample of program managers be used for valid result. It is also recommended that researcher-designed survey be piloted to validate the survey items. With a researcher-designed instrument, certain biases of the research come through, but if the instrument is piloted; those item which do not seek the desired results would be eliminated.

It is also recommended for further study to include those state institutions who have gone through deinstitutionalization and the results of the movement on both the clients and the workers and compare those results to the results gathered from this study. The demographics of the study could include state institutions from other areas in the state or in the United States

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