

ENHANCING PERSON-CENTERED PLANNING FOR ADULTS LIVING WITH DISABILITIES USING DYNAMIC ORGANIZATION CULTURE

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Abstract

A systematic review was conducted to establish the effectiveness of a dynamic organizational culture in enhancing person-centered planning (PCP) for adults living with disabilities. An in-depth search on PCP showed a major gap in research on the characteristics, and incentives for and barriers to a successful PCP. This is because most studies on PCP focus on practices, benefits and outcomes. An electronic literature search was conducted using search engines such as Rehabilitation Reference Center, ProQuest/Dissertations and Theses, Cochrane Library, PubMed, CINAHL, Eric, PsychInfo and OVID.

The search generated over 350 journal articles that discussed conditions and interventions related to the key words used in the search. One hundred and fifty articles were excluded due to duplication, and a total of 180 articles were dropped after reviewing their abstracts. The full texts of 20 journal articles were appraised to determine their importance to the adoption of dynamic organizational culture and the improvement of PCP for adults with disabilities. During further critical appraisal using Jadad and PEDro quality analysis scales, 11 articles with the poorest scores were excluded. This brought the total number of studies reviewed to nine. The results of the nine studies included in this review showed that a dynamic organizational culture may enhance PCP and improve the quality of care for adults living with disabilities.

Keywords: Person- centered planning, McGill Action Planning System (MAPS), Planning Alternative Tomorrow with Hope (PATH), Personal Futures Planning (PFPS), Essential Lifestyles Planning (ELP), Developmental disabilities, community-based rehabilitation

Introduction

Person-centered planning (PCP) is a systematic process of constant listening, learning and understanding that is centered on what is essential to someone at present, and for the future. The aim is to help an individual meet his or her needs in collaboration with that individual's healthcare providers, family and friends (Sanderson, 2000). It is a process that is designed to increase the power that people have to choose situations and experiences that will help improve their skills (O'Brien, 2000).

PCP originated in North America in the late 1970s. It started as a way of promoting the adoption and implementation of the principle of normalization, and as a response against the traditional planning method in which rehabilitation professionals unilaterally placed individuals living with developmental disabilities in programs (Whitehead, 2001). While the traditional planning method encouraged the growth of local services that focused on accurate diagnosis and therapeutic interventions, PCP involves discovering people's capabilities, talents and identifying the supports they need to express their potentials (O'Brien, 2000).

PCP process mandates that individuals living with disabilities must be at the center of their rehabilitation process with their families, friends and caregivers as partners. Person-centered service plans reflect what is important to the person, his or her capabilities and the supports that he or she needs in order to achieve his or her life goals. PCP is used to design activities that will promote opportunities and skills that will lead to the development of personal relationships, community inclusion, dignity and respect. PCP process involves ongoing listening and review of action plans (Mensell, 2004).

The adoption of PCP has important affects on health care professionals and the organizations that support people living with developmental disabilities (O'Brien, 2000). Even though government funding agencies are mandating service providers to adopt PCP, there is a common concern among people working in community- based rehabilitation facilities that PCP is hard to implement because some healthcare professionals and families of the individuals with disabilities are sometimes uncooperative and do not share in the vision of the rest of the team (Whitehead, 2001).

In addition, some healthcare professionals are reluctant to allow individuals with disabilities to assume a leading role in the planning processes. The greatest challenge of PCP is that it is often being done in community-based rehabilitation facilities that have not fully embraced the need for a profound change (O'Brien, 2000). This makes it difficult for these facilities to develop the needed infrastructure and manpower to realize the full benefits of PCP.

Thus, the aim of this systematic literature review was to verify how the use of dynamic organization culture may enhance PCP in community-based rehabilitation facilities for adults with disabilities. This research is vital as there is a major gap in research of PCP practices and outcomes (Everson, 2000). Most literature on PCP focuses on practices, benefits and outcomes but limited research has been conducted to explore the attributes, barriers, and incentives for a successful PCP (Whitney-Thomas et al., 1998).

Methods

Study Design

This study was a systematic review of journal articles that discussed the use of dynamic organizational culture or multiple organization strategies in designing and implementing PCP. This review included studies that used qualitative, quantitative, randomized and mixed research methods.

Sources of Information and Search Strategies

A detailed literature review was conducted of peer-reviewed journal articles that focus on adults with disabilities that are living in community-based rehabilitation centers. In addition, peer-reviewed journal articles that included discussion on the impact of organizational culture on PCP and quality of care were selected for appraisal. All selected articles were published between 2000 and 2010, and contained relevant information on:

- person-centered planning on adults with developmental disabilities living in a community based rehabilitation center,
- effectiveness or ineffectiveness of dynamic organization culture or multiple organizational strategies on person-centered planning or adult health promotion,
- various models of person-centered planning for effective comparisons,
- successful person-centered planning for adults living with developmental disabilities with or without the use of a dynamic organizational culture,
- government social policies or societal norms that support or discourage person-centered planning for adults living with developmental disabilities,

- information on the perceptions of adults living with developmental disabilities on the role of caregivers in enhancing person-centered planning and the effectiveness of the adoption of a dynamic organizational culture or multiple organizational strategies on PCP,
- how family members and friends of individuals living with developmental disabilities perceive the effectiveness or the ineffectiveness of dynamic organization culture or multiple organization strategies on person-centered planning, and
- caregivers' perceptions of the effectiveness and the ineffectiveness of the use of dynamic organization culture or multiple organization strategies in providing a community-based rehabilitation for adults living with developmental disabilities.

The following search engines were utilized: Rehabilitation Reference Center, ProQuest/Dissertations and Theses, Cochrane Library, PubMed, CINAHL, Eric, PsychINFO and OVID. The following the key words were used to locate journal articles:

- person- centered planning
- Individualized service plan
- McGill Action Planning System (MAPS)
- Planning Alternative Tomorrow with Hope (PATH)
- Personal Futures Planning (PFPS)
- Essential Lifestyles Planning (ELP)
- Developmental disabilities
- Adults and developmental disabilities
- Community-based rehabilitation
- U.S. social policies on person-centered planning
- Evidence of person-centered planning in Canada
- Person-centered planning in United Kingdom
- Organization changes
- Organizational culture and developmental disabilities
- Quality of care
- Health care -models
- Socioeconomic empowerment
- Community inclusion
- Community exclusion
- Role modeling

- Family centered practice
- Group homes
- Community care facilities

Quality Assessment

The Jadad scale was used to measure the possibility of bias (Portney & Watkins, 2009). A thorough analysis was done on randomization, blinding and attrition as they helped to determine the quality of the studies being appraised (Portney & Watkins, 2009). A point was assigned to randomized articles while non-randomized articles received zero points.

The same was applicable to double- blinded articles. The similarity (homogeneity) and the dissimilarity (heterogeneity) of the various facets of the studies in the reviewed articles were considered to facilitate the accurate interpretations of the results of this review (Portney and Watkins, 2009). In addition, the PEDro Scale was used to help establish the validity of the reviewed journal articles. This method ensured that specific eligibility criteria were met (Portney & Watkins, 2009). All studies meeting each criterion received one point while a zero point was assigned to each criterion that was not met.

This research was based on the concept that a dynamic organizational culture may promote PCP and facilitate quality patient care. PCP is different from the traditional forms of planning and caring for the disadvantaged population in that it is the collective approach to organizing and guiding community change with the cooperation of individuals living with disabilities and their families and friends (O'Brien et al., 1993). Thus, it is important for healthcare workers to understand the various organizational dynamics that will either encourage or discourage the adoption of PCP in a community based rehabilitation facility.

Results

The electronic search generated over 350 journal articles. All of the articles included some discussion related to the conditions and interventions targeted by the key words used in the search. After application of the inclusion and exclusion criteria, the number of eligible article was reduced to 20. During further critical appraisal using Jadad and PEDro quality analysis scales (Portney & Watkins, 2009), 11 articles with the poorest scores were excluded. This brought the total number of studies to nine.

The sample (see table 1) comprised five (56 %) qualitative studies, one (11%) quantitative study, two (22%) randomized clinical trials, and one (11%) descriptive study. In addition, seven (78%) of the selected studies targeted adults living with various disabilities as their study participants while the two remaining studies targeted parents of individuals with disabilities and family members as well as friends and staff in the lives of adults with

disabilities as the study participants. Five (56%) of the studies were conducted in the United States while Finland, England, Canada and Australia shared the remaining 44% equally. All the studies that make up this sample used behavior and lifestyle as the method of interventions or treatments.

There were no pharmacological treatments because all of the studies used at least nine different behavioral or lifestyle modification interventions techniques. Similarly, five (56%) out of the nine selected studies incorporated dynamic or flexible organizational culture into their treatment techniques. The remaining four of studies reviewed used the community inclusion care method without the adoption of flexible or dynamic organizational culture. All of the nine studies reported some level of positive treatment outcomes. Seven (78%) of the study sample indicated high Jadad and PEDro quality scores while two (22%) of the studies had average scores, which speaks to the validity and credibility of these studies (Portney & Watkins, 2009).

Table 1
Description of Sample

Description of Studies (Sample)	Number of Studies (%)
Selected Study Methods	
Qualitative Study	5 (56)
Quantitative Study	1 (11)
Randomized Clinical Trials	2 (22)
Descriptive Study	1 (11)
Targeted Study Participants	
Adults living with various disabilities	7 (78)
Parents of individuals living with various disabilities	1 (11)
Family members, friends and staff in the lives of adults living with various disabilities	1 (11)
Selected Study Settings	
United States of America	5 (56)
Finland	1 (11)
England	1 (11)
Canada	1 (11)
Australia	1 (11)
Treatments Used in selected Studies	
Pharmacologic	0 (0)
Behavior/ Lifestyle	9 (100)
Total treatment found in the studies	9 (100)
Treatment organizations	
Cultural dynamism or flexibility	5 (56)
Community inclusion without the adoption of flexible Or dynamic organizational culture	4 (44)

Outcomes of selected studies	
Positive outcomes	9 (100)
Negative outcomes	Not reported
Study validity	
Studies with high Jadad and PEDro quality score	7 (78)
Studies with low Jadad and PEDro quality score	2 (22)

Outcome Measures

The effectiveness of dynamic organizational culture in enhancing PCP for adults with developmental disabilities is presented in Table 2. All of the nine studies underscored the importance of dynamic organizational culture in implementing PCP. This approach to PCP helped to improve the lives of adults living with developmental disabilities. This supports the assertion that PCP must be flexible in order for it to improve the lives of those living with developmental disabilities.

For instance, One-Stop Career Centers, enacted under the Workforce Investment Act, provide “training referrals, career counseling, job listings, and similar employment-related services” to assist unemployed Americans to acquire skills and opportunities that will enhance their chances of securing employment (United States Department of Labor, n.d.). Gervy, Dickel, Gao, Kneubuehl, and Tillman (2009) studied the effectiveness of this employment and training program by recruiting 25 of One-Stop’s clients who were recommended for Person-Centered Employment Teams (PCEPT). This was a demonstration project to enhance employment and training outcomes for adults living with disabilities that were using the One-Stop Career Center System. Out of the 25 clients, 17 participated in the PCEPT project. At the end of the project, eight people (48%) were gainfully employed while three individuals (18%) enrolled in either post-secondary or a vocational technical training program.

Eleven of the 17 people (68%) who participated in the employment planning team process were successful in participating in an activity of their choice. Out of the six participants that did not achieve their goals, two were completely lost in the project. The remaining four did not indicate any interest in participating in the activities to which they had been referred (Gervy et al., 2009). One of the major reasons for these positive outcomes was the ability of the staff members to adjust to each of the client’s recurring interruptions to job development, and constant symptom exacerbations and crises such as continuous job losses until the individual was able to find a suitable employment (Gervy et al., 2009).

Likewise, Hasnain, Ghiloni, and Sotnik (2003) conducted a qualitative (focus group) study on the use of culturally sensitive PCP as a method of improving the vocational rehabilitation for people with disabilities. The program participants included individuals with physical, cognitive, and sensory disabilities as well as those with psychological and emotional disabilities. The project used several outreach strategies like working with trusted community leaders such as the clergy, church elders, and teachers who had close ties to the majority of the people. In addition, project staff participated in special cultural activities where they related with individuals with disabilities and their families and friends. Individuals who participated in this project became aware of new employment options and opportunities available to them. One of the notable outcomes of this study is that it established the fact that individuals with disabilities are experiencing positive gains in employment options because of the innovative and culturally responsive PCP (Hasnain et al., 2003).

The Turku project and the Finnish National Schizophrenia project used Open Dialogue to enhance PCP (Borg et al., 2009). This is an example of innovative patient care that focuses on person-centered care and social context. The focus of Open Dialogue was to establish helpful relationships among individuals living with disabilities, their families, the network involved and providing support in the people's homes rather than in institutions or rehabilitation facilities (Borg et al., 2009). According to this study, flexibility and ability of the staff to quickly accommodate unforeseen changes in the participants' lives significantly affected the outcomes of the project. A follow up survey conducted by the Finnish Western Lapland facility over a five year period showed that 82% of the participants did not have any residual psychotic symptoms and 86% returned to their studies or full time employment while only 14 % of the participants received disability benefits (Borg et al., 2009).

Cloutier, Cotton, Hagner and Malloy (2006) conducted a descriptive study on the New Hampshire's' Individual Career Account Demonstration Projects. The goal of this project was to develop a mechanism for greater individual choice and control over vocational service planning and services. The individual Career Account process involved interconnected intensive and continuous personal futures planning, individualized service budgeting, and benefits counseling designed to help individuals with psychiatric disabilities to gain more control over their life goals and provide the support needed to achieve them (Cloutier et al., 2006). At the individual level, participants were allowed to identify their individual funding options and to choose their service providers.

At the systems level, flexible funding options were increased to enable participants to learn about specific dollar amounts that were available for use in their individual budgets (Cloutier, Cotton, Hagner and Malloy, 2006). People who used person-centered plans and individualized budgets stated that they were better able to self-advocate and receive support from social service and vocational agencies. The overall outcome of this project showed that the Individual Career Account Demonstration Projects enabled the participants to play more active and self-directed role than that experienced by the recipients of traditional services (Cloutier et al., 2006).

Downs and Carlton (2009) investigated the benefits of the “School-to -Work Transition Programs” within third-party government. These programs involved changing public sector agencies from service providers to service managers. The authors studied major practices within school-to-work transition programs for students with developmental disabilities. The study involved parents of people with developmental disabilities (such as Down syndrome, spinal bifida and autism), secondary and post secondary teachers, and administrators in educational and rehabilitation institutions. This intervention used multiple clusters. The admission processes were bureaucratic while the training and developmental processes were non-bureaucratic (Downs & Carlton, 2009). The outcomes of these programs showed that variation and flexibility in government’s funding policies encourage school-to-work “transition” for individuals living with disabilities.

Hacking and Bates (2008) used inclusion web as a tool for enhancing PCP and service evaluation. To test this tool, the researchers recruited 149 clients at the Mainstream Project in Liverpool, United Kingdom. These clients were enrolled in several community activities such as the sport and exercise, volunteering, education, family, and neighborhood social engagements of their choice. Staff organized the groups, advised and supported participants in locating places, and people outside the mental health system where they could form a personal relationship. Some of the participants received improved service due to the use of a multidisciplinary team that comprises the psychiatrist, social worker, and community psychiatrist nurse (Hacking & Bates, 2006). The overall outcome of this project showed more holistic interactions between the participants and the community members. This shows that even though some clients did well in a more structured environment, there was a stronger correlation between innovative rehabilitation services and community inclusion of individuals living with disabilities.

Lafortune, Beland, Bergman and Ankri (2009) used a randomized clinical trial to demonstrate the importance of service variability in affecting positive change in an aging population. The researchers used data collected for the System of Integrated Care for Older Persons (SIPA) to perform latent analysis. This study was conducted in Montreal, Canada and it involved 1164 participants. The participants were divided into homogenous groups of health profiles based on observed indicators of health common issues. Latent Transition Analysis captured the multidimensional and dynamic nature of health, and validated the importance of a flexible or dynamic approach to PCP in addressing these health issues.

Tondora et al., (2010) randomly recruited 360 African Americans and Latinos who were 18 years and older and living with psychosis. The participants came from two large state- operated Community Health Centers located in urban areas of Connecticut. After completing the baseline evaluation, participants in each facility were randomly assigned through a computer-generated random number protocol which the research assistants used to assign the participants to one of the three groups. The first group was the control group and other two groups served as the treatment groups. The first group consisted of 120 patients. This group was given standard care. The second group also comprised of 120 patients. This group received standard care and peer facilitated PCP. The third group had 120 patients who received standard care, PCP and community inclusion activities. Patients in the third group recorded better recovery results with regard to improved quality of life. This emphasized the need for cultural modifications around both the design of peer-based interventions and staff training (Tondora et al., 2010).

Similarly, Cohen-Mansfield and Bester (2006) conducted a qualitative (descriptive) study on the management strategies, principles, and environmental characteristics used by the Adards nursing home in Australia. The study concluded that the Adards' flexibility in daily routine and staff scheduling enhanced both resident and staff independence which in turn encouraged staff retention, and improved residents' quality of life. According to these researchers, flexibility is an important component of PCP.

Table 2
Summary of Outcome Measures

Journal Article Citation	Summary of Outcomes
Gervey et al., 2009	Person-Centered Planning Teams enabled people who are at risk to regain some of their functioning freedom. Out of 17 people that participated in the PCEPT project eight people (48%) were gainfully employed while three individuals (18%) enrolled in either post secondary or a vocational technical training program.
Hasnain et al., 2003	The State-wide Employment Vocational Program enabled large number of people with disabilities to experience positive gains in employment options because of the dynamic and culturally responsive PCP.
Borg et al., 2009	It is possible to embody the values of PCP care and recovery in everyday clinical and rehabilitation practice by changing how professionals see their roles and those of their clients, families and peers through open dialogue.
Cloutier, et al., 2006	PCP when used in conjunction with Individualized Budgeting and Benefit Counseling was shown to enable individuals with disabilities to have control so long as their sources of funding are flexible.
Downs, et al., 2009	Transition Programs using PCP was shown to enhance the lives of individuals with disabilities with flexible funding and appropriate government care regulations.
Hacking, et al., 2008	Inclusion Web is a useful PCP tool that has shown the potential to enable people with disabilities to develop meaningful relationships within the community.
Lafortune, et al., 2009	Latent Class Approach is a PCP tool that captures the different health issues that affect the frail elderly and enables care facilities to designs a multidisciplinary care plan geared towards providing holistic care to this population.
Tondora, et al. 2010	Cultural modification was shown to facilitate PCP when there is a continuous relationship between the clients and the caregivers.
Cohen-Mansfield, et al., 2006	Adards nursing home in Australia has shown that flexibility in daily routine, staffing and patient care is an important component of a successful PCP. Residents of this nursing home were reported to have a higher quality of life than most long-term facilities in the United States most likely due to the dynamic PCP approach.

Discussion

The objective of this systematic review of literature was to establish how the use of a dynamic organizational culture enhances PCP and the quality of care that adults with disabilities receive. It was hypothesized that a dynamic organizational culture will promote PCP and facilitate quality patient care. The nine articles included in this review showed that the use of a dynamic organizational culture may enhance PCP and improve the quality of care for adults living with disabilities. It is necessary for community-based rehabilitation facilities to cultivate organizational flexibility in order to successfully adopt and implement PCP for adults with disabilities. While it is generally believed that flexibility is an important part of PCP, the outcomes of this review expanded on the assumption that flexibility is not only important in the care process of adults living with disabilities, but it is also essential in the management of staff members and other resources within a care facility (Cohen-Mansfield & Baster, 2006).

Similarly, we found that for PCP to be successful, the systems within the community must work together. Past research demonstrates that adults with severe disabilities can be gainfully employed when care providers, the government and members of the community work together (Gervey et al., 2009). PCP is remarkably different from the traditional forms of planning and caring for the disadvantaged population. It is the collective approach to organizing and guiding community change with the cooperation of individuals living with disabilities and their families and friends (O'Brien, 2000).

The global applicability of dynamic organizational culture in facilitating PCP and quality patient care is the most important finding of this review. New Hampshire's Individual Career Account Demonstration Project is a promising method of care that offers individuals with disabilities increased choice and control of vocational service planning and services (Cloutier et al., 2006). In Australia, the Adards nursing home used flexibility in daily work and task scheduling to enhance both resident and staff autonomy which resulted in higher staffing levels, reduced staff turnover and better quality of life for the residents than in several nursing homes in the United States (Cohen-Mansfield & Baster, 2006).

In addition, Hackling et al. (2008) demonstrated that Inclusion Web in England can be a useful PCP tool that will enable people with disabilities to develop meaningful relationships within their communities when tailored to individual's care needs. Likewise, studies in Finland and the United States demonstrated that it is possible to use the values of PCP care and recovery in everyday clinical and rehabilitation practice by changing how professionals

see their roles and those of their clients, families and peers through Open Dialogue (Borg et al., 2009).

Implications

Policy and Practice

It is evident that there is a link between policy and practice issues. Adopting a dynamic organizational culture in implementing PCP for adults with disabilities requires a change in government's policy that will encourage PCP and provide incentives to community-based rehabilitation facilities to use more flexible approaches while implementing PCP. However, the current economic recession makes it difficult for some care facilities to educate their staff about cultural changes. Federal and state government legislations and projects such as the 1998 Workforce Investment Act (Gervey et al., 2009) and New Hampshire's Individual Career Account Demonstration Projects (Cloutier et al., 2006) would support care facilities to practice PCP using different care, and administrative methods even in the worst economic situations.

In England, the Department of Health endorsed the first British policy on PCP in its White Paper, *Valuing People* (Department of Health, 2001). This paper mapped out a strategy for the planning and delivery of health and social services for individuals living with learning disabilities (Department of Health, 2002). The creation of this policy further supports the assertion that effective government support is required to bring about social changes that will promote PCP.

Similarly, the adoption of a dynamic organizational culture in facilitating PCP for adults with disabilities involves collaborative efforts between local agencies, members of the community, care providers, and facility managers in building an inclusive community. Government policy alone will not transform the type of care that is offered to people living with disabilities. However, educating the public, empowering caregivers, and supporting the families of individuals living with disabilities will create a care environment that is sensitive to the needs of adults with disabilities.

Advocacy

The outcomes of this review indicate the need for health and social service professionals to change their method of advocacy. Instead of focusing mainly on working with the government to change its policies, the whole community should be involved in order to enhance the quality of life for an adult with disability. Community-based rehabilitation advocates should devote more time in educating the public on the importance of inclusive society. Civil engineers should be encouraged to construct more accessible houses.

Additionally, social services should be encouraged to design financial and social programs that can be easily tailored to people's care needs and not allow bureaucracy to dictate what type of funding or which programs will be provided. School administrators should be encouraged to develop curricula that will enable individuals with disabilities to transit from childhood to adulthood without significant challenges while the private and public business sector leaders should be trained on how to create a working environment that will accommodate people with disabilities.

Limitations

Although measures were taken to reduce journal articles selection bias through the use of Jadad and PeDro Scales (Portney & Watkins, 2009), it should be noted that the articles were appraised and scored by the principal researcher. Thus, there is a slight chance for selection bias.

Conclusion

This review was motivated by the need to discover a better way to facilitate PCP, with the hope of improving the quality of life of adults living with disabilities. At the moment, evidence seems to support the assertion that PCP will improve the lives of adults living with disabilities with the use of dynamic organizational culture. Similarly, there is enough evidence to support the claim that the benefits of PCP cannot be fully realized in a static health or social care system. Just as the human body will not function when the various human systems are not well coordinated, PCP will be ineffective when people with disabilities cannot access health and social services whenever and wherever they want.

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