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Impact of disability rights advocacy on service delivery

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Abstract

This research explores the impact of disability rights advocacy on service delivery across various sectors, including healthcare, education, and employment. Disability rights advocacy has played a crucial role in raising awareness and influencing policies that promote accessibility and inclusivity for individuals with disabilities. Using a mixed-methods approach, the study combines quantitative data on service utilization and quality with qualitative interviews from advocates, service providers, and individuals with disabilities. Findings indicate that effective advocacy leads to significant improvements in service delivery, including enhanced access to resources, increased responsiveness of service providers, and the implementation of inclusive practices. The research also highlights the challenges faced by advocates, such as systemic barriers, lack of funding, and resistance from institutions. Furthermore, the study underscores the importance of collaboration between advocacy groups and service providers to create sustainable change. By showcasing successful advocacy initiatives and their tangible effects on service delivery, this research aims to inform policymakers and practitioners about the critical role of disability rights advocacy in fostering equitable and effective services for individuals with disabilities.

Keywords: disability rights, advocacy, service delivery, accessibility, inclusivity, healthcare, education, systemic barriers.

1. Introduction

Throughout much of history, Western societies and those aligned with them have marginalized and consequently neglected individuals with disabilities. Debates about what to do about people with disabilities began to change in the 1960s, and with it came the emergence of many new advocacy movements. Today, there are numerous characteristics of successful advocacy; this essay will focus almost exclusively on what happens after this work has been done and highlight how advocacy influences policies and subsequent service delivery. But suffice it to say that if our goal is for individuals to have services that are good, the ingredients for successful advocacy and the outcomes that transpire are something that we should all be concerned with. This essay is divided into four sections. The first describes and defines what advocacy is and what can be learned from successes in working for policy change conceptually. The second section looks at what we currently know based on research about how successful advocacy impacts service delivery outcomes. The third section looks at the contemporary interaction between local service delivery and legislative requirements that have been shaped by advocacy, public values, or community input. The final section argues the core of this essay: if advocacy is successful, ultimately service outcomes change for the better; this is the true potential of disability advocacy. (Harris et al.2022)

2. Historical overview of disability rights advocacy

In the 1960s, concern over the 'severely retarded' started to emerge. By 1975, there was a nationwide 'moratorium' on the development of new residential facilities for people with severe mental retardation. This growth in awareness fostered a grassroots advocacy movement, and, in 1975, disability advocates sought to establish a national organization and had a series of meetings with a gerontologist and an advocate, resulting in the formation of a national advocacy group called 'CITIZENS UNHOMED' (sic). This was six years before American Advocacy began, and consequently, very little is known publicly about this early advocacy. (Mitchell et al.2022)

Since then, there are numerous examples of activism and advocacy. Historically, what is often cited as the beginning of advocacy in the United States started in the 1960s with two parent-led activist groups, the Association of Retarded Citizens ('ARC') established in 1968 (now known as The Arc) and the National Association of Parents and Friends of Mentally Retarded Persons (now known as The Arc); and by people labeled with disabilities throughout the 1970s and 1980s, such as Judith Heumann and Max Starkloff. The modern disability rights movement was supported by other civil rights movements, anti-institutionalists, and other allies. Dissatisfaction with service quality emerged, for example, in the early 1970s in Oregon. The state was making the transition from a workshop agency to a normal setting, and many looked for guidance on best practices from a dozen other countries in the world. Over time, several factors shaped the movement; these included witnessing the resources dedicated to civil rights activism, collaboration with older advocacy organizations, and individual empowerment/outcome data. In 1987, a federal law passed that established the Wellness and Prevention Fund that assisted state protection and advocacy programs with lawsuits against institutions. Prior to 1987, these programs focused on violations of the Individuals with Disabilities Education Act. The International Classification of Functioning, Disability and Health was also utilized as an organizing principle. These individuals who have been labeled as having a disability primarily engaged in protest politics, which is a form of social movement that is oriented towards the specific goal of redressing a concrete grievance or harm that itself is not... (Murphy et al., 2022)

3. Key principles of disability rights advocacy

Disability rights advocacy operates on several key principles. Foremost among these is the principle of equality. This means that advocacy work for accessibility does not promote or justify segregated service with a separate space, program, or service designated only for people with disabilities. Alongside other equality-based movements, the push for disability rights advocates for the adoption of universal design principles to ensure all people can access all services, regardless of the particular or adjustable needs of an individual. Further, programming and services should celebrate diversity and be welcoming to participation from everyone. Self-determinism is another guiding principle of disability rights. Policies and practices must mutually respect the informed choices, autonomy, preferences, and inclinations of individuals with disabilities. This means that disability rights advocacy will advocate for change to remove systemic or other barriers experienced by individuals and groups when seeking the activities, services, and communities of their choice. Lastly, individual disability rights advocacy can be intersectional, recognizing and respecting that people with disabilities also carry with them other forms of identity and the ways this can present differently. Community involvement and capacity building are keys to effective disability rights advocacy. In order to work towards change, a strong, person-directed perspective and being as inclusive of individuals and their personal networks as possible when pursuing an advocacy initiative in systems-level or organization-level advocacy. Empowerment is a key principle of disability rights advocacy. Empowerment is the ability to define one’s own needs, communicate them, and take action based on this understanding. It is key to both self-advocacy and systemic advocacy and, when successful, seeks to facilitate positive individual outcomes for persons with disabilities. In the context of systemic advocacy, empowerment advocates for the development of communities, where organizations and systems are empowered to adapt or develop new programs based on the needs of their community members, including persons with disabilities. It means that individual, person-centered approaches are more likely to also be inclusive and community-based. (Green et al., 2022)

4. Challenges and barriers in disability rights advocacy

Many challenges and barriers can impede the effectiveness of efforts to advocate for the rights and inclusion of people with disabilities. Prejudice, fear, ignorance, and stigmatization can greatly diminish the quality of life for people with disabilities. Advocates, activists, and allies of people with disabilities often need to successfully address these societal attitudes and challenges to be very effective in their advocacy. Lack of representation within the service systems creates barriers in access and equity for people with disabilities. Many systems are designed without individuals with disabilities in mind, resulting in mass segregation, isolation, or neglect. When designing advocacy efforts or seeking systemic changes, consideration of the institutional barriers is vital. Similarly, systemic barriers often limit the success of advocacy. Components of these systemic barriers may include bureaucratic complexities, legal impediments, economic constraints, and social prejudices. In many instances, governmental units or bureaucratic regulations create environmental and economic barriers that are troublesome, if not impossible, for individuals with disabilities to overcome. Many advocacy areas require varying levels of bureaucratic advocacy to press for additional resources or supports for individuals with disabilities. Discrimination in employment and policy makers can create a double barrier. Advocacy efforts on the level of systemic and policy change often lead to legal and regulatory complexities that are hard to change or influence. Focusing on the barriers faced by members of historically unrepresented communities is essential. It is believed that members of these communities face the same challenges as other advocates, plus additional issues. (Pearson and Meadan2022)

5. Case studies of successful disability rights advocacy initiatives

Case studies of successful disability rights advocacy initiatives reveal how advocacy has improved service delivery. The foundational role of community organizing and building a broad-based multi-sectoral coalition has been highlighted throughout the case studies. The case studies illustrate the core advocacy activities that comprise efforts to transform the system of service delivery. In Boston, Memphis, and Durham, policy changes were the direct result of an advocacy initiative. In Kansas City and New York, effective bilingual services and good faith efforts were made where the system reform took place, but they were not undertaken in response to an immediate advocate request; rather, they were integrated into a proactive advocacy effort to improve services. A fully integrated continuum of services was developed in Green Bay as part of a proactive advocacy strategy. The establishment of crisis intervention services in Alameda County, the creation of a transitional program in San Francisco, and the employer education and technical assistance functions provided in Seattle were direct outcomes of advocacy efforts. In selecting a case study location, the project staff suggested that a case study be conducted in Connecticut, where significant policy advancements have been made. In this report, we highlight some of the things you should look for as the project team develops the case studies and focuses on the common elements of the successful strategies in each of these communities. (Fisher & Miller, 2022)

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