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The Growing Need for Advocacy in the Disabilities Field: An Analysis of Existing Barriers

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The Growing Need for Advocacy in the Disabilities Field: An Analysis of Existing Barriers

As of 2015, approximately 50 million people in the United States experience disability and this number is expected to grow in the next 25 years (Merten et al., 2015). The existence of the Americans with Disabilities Act (ADA) leaves room for the assumption that people with disabilities no longer experience discrimination or everyday barriers in society. However, this is a misconception. People with intellectual, developmental, physical, or other disabilities experience barriers and discrimination in various ways on a daily basis (Hammel et al., 2015; Rimmer et al., 2004; Ward et al., 2010). Therefore, the purpose of this paper is to conduct a literature review on these barriers including economic, environmental, medical, recreational, educational, civic, double discrimination, as well as increased instances of abuse and crime. It is important to understand these barriers and discrimination people with disabilities experience because knowledge of these practices combined with advocacy interventions could alleviate struggles for this vulnerable population. Social workers must take on the responsibility of advocating for people with disabilities as well as equipping them to advocate for themselves.

Historical Background

The history of perceptions and treatment of individuals with disabilities is riddled with discrimination, barriers, and negative societal perceptions. According to Munyi (2012), in the 16th century, it was believed that people with disabilities were possessed by evil spirits. In the 19th century, the perspective of social Darwinism arose with the idea that people with disabilities were unfit (Munyi, 2012). Historically, disability has been used as a justification for discrimination against not only people with disabilities, but minorities and women as well. According to Davis (2016), people who opposed gender equality argued that women had physical, intellectual, and psychological deficits that are categorized as disabilities.

In the United States, this rhetoric regarding the perception of disabilities began to change with the end of World Wars I and II when veterans returned home with disabilities and required government assistance (Greenberg & Carlos, 2015). In 1968, the Architectural Barriers Act brought more accessible buildings. Following close behind were the 1973 Rehabilitation Act prohibiting discrimination of people with disabilities by federal employers, the Developmental Disabilities Assistance and Bill of Rights Act of 1975, and the Education for All Handicapped Children Act of 1975 (Greenberg & Carlos, 2015; Nielson, 2012). These laws and many like them paired with the Civil Rights Movement paved way for the introduction of the ADA.

According to Greenberg and Carlos (2015), the ADA prohibited discrimination on the basis of disability. This hypothetically means that people with disabilities were granted fair treatment, education, housing, healthcare, employment, access, and more. Although the ADA did open doors for the population with disabilities, it was not a fix. The skewed mindsets that existed before the ADA was signed still existed after (Greenberg & Carlos, 2015). In addition, the initial law was criticized for being vague in terms of what the word "disability" included. While laws such as the ADA restricted discrimination on the basis of disability, this population still experiences outdated barriers and requires advocacy and tools for self-advocacy (Greenberg & Carlos, 2015; Nielson, 2012).

Barriers Experienced by People with Disabilities

Economic

Research shows that people with disabilities often experience various forms of barriers that prevent them from getting the resources they need, and one of them is economic barrier (Lindsay, 2010). One way to alleviate the economic struggles of an individual is employment,

which is a critical part of an individual's wellbeing. While the logistical benefits of money may be clear, employment can also benefit physical health, mental health, social needs, and general skills (Hanga et al., 2015). Research also confirms that work is even more beneficial to the population with disabilities to overcome economic barrier (Lindsay, 2010). In addition, it is the legal right of those with disabilities to obtain employment. However, in a study conducted with 85 participants with disabilities ranging in age from 18 to 62, Hanga et al. (2015) discussed primary factors impeding individuals with disabilities from gaining employment: unstable health conditions, inappropriate workloads, inappropriate work tempo, unsuitable work tasks, lack of suitable working skills, low motivation, and physical environment in workplace including transportation. These factors were experienced at varying levels in each individual, but the authors argued that many of these barriers could be eliminated with effective accommodation and trainings. When people with disabilities are able to obtain employment, however, they often experience lower leisure satisfaction and/or quality of life (Wehman, 2011). Nonetheless, a place of employment should be a fulfilling place that improves social functioning for all individuals including those with disabilities.

People with disabilities primarily receive funding for their care with federal revenues through Medicaid which involves waiver programs (Parish & Lutwick, 2005). However, Medicaid is often a complex and difficult route to utilize when obtaining resources. A case example below is presented to help understand the economic challenges experienced by people with disabilities.

Andrew is a client referred through the Department of Developmental Disabilities. He had a specific need of a toileting chair on wheels that comes with straps and a tray. This chair was also used for Andrew in the shower because he struggled with balance. Andrew required a

new chair because over time, the chair he used had worn down from usage and being rolled from the toilet to the shower. To get a new chair, the process began with getting two separate cost estimates. The cost of the chair had a high chance of being rejected by Medicaid and needing to be funded by waiver services. However, Andrew still needed proof of the cost being rejected by Medicaid twice before submitting the request to waiver services. In addition to the required rejections, it was decided that two separate chairs for toileting and showering would benefit Andrew and increase the longevity of the chairs. However, it was not possible for him to receive two chairs, and he was only able to access one. Therefore, his old chair is still utilized for toileting, and his new one for the shower. The process to get a new chair took almost a year. While Andrew did benefit from the insurance he receives and did at least get some of the devices he needs, it was extremely long, complex, and complicated to receive something to complete a basic need such as toileting. This case example shows that the complicated process people with disabilities have to go through to have the resources they need creates unnecessary limitations.

Environmental

Environmental barriers involve conditions around an individual that may affect his or her growth, health, and progress (Iezzoni, 2011). People with disabilities experience environmental barriers in physical, sociocultural, political, and economic environments. According to Hammel et al. (2015), these barriers may disable participation more than an individual's impairment. A qualitative study with a sample of 201 participants was conducted to analyze the major categories of environmental factors that affect social functioning of individuals with disabilities (Hammel et al., 2015). The eight factors that influenced participation included built, natural, transportation, assistive technology, information and technology access, social support and societal attitudes, systems and policies, and economic environment. For example, transportation

is a major obstacle for wheelchair users. They often experience difficulty shopping due to narrow aisles in grocery stores or attempting to get around in the snow (Bezyak et al., 2017). These environmental barriers keep individuals with disabilities from being fully integrated in their communities.

Lack of Long-Term Care

According to Parish and Lutwick (2005), there has been a large shift in the beliefs people have about individuals with disabilities in the past four decades. This shift was long fought for and legally began with the ratification of the ADA. This shift in beliefs has also seen a shift in care. Instead of being segregated or sent away, there are now group homes and other long-term residential care options. Many individuals with disabilities are also assisted by a family member or guardian who resides with them (Iezzoni, 2011). However, the demand for these care options outweighs the supply. According to Parish and Lutwick (2005), in 2000, 36 states had almost 60,000 people on wait lists for long-term care. While wait lists grew longer, the incarceration of people with disabilities and prevalence of psychiatric hospitalization increased. In fact, research confirms the high rates of incarceration and psychiatric hospitalization in this population (Davis, 2016). It is suggested that social work professionals respond to these needs through political advocacy, organizational development, and inclusive family-centered practice (Parish & Lutwick). If there is not a change in advocacy and services, individuals with disabilities and their families are likely to experience exacerbated financial and emotional strain.

Medical

As the population with disabilities increase, it is likely that they will be unsatisfied with medical care, struggle with unmet care needs, and face barriers to preventative health care and

services (Merten et al., 2015). Their care also may be compromised by appointment times that are too short for their needs, physically inaccessible care sites, inadequate staff, and insufficient equipment. One critical form of preventative health care is cancer screening. This is because the best chance of survival of cancer is early detection and treatment (Hanna et al. 2010). However, Merten et al. found that while people with disabilities may have been at a greater risk for different cancers, they were not screened as often as those without disabilities. Many different demographics affect screening rates, but the authors found that barriers to screening of breast, cervical, and colorectal cancers included intellectual ability, mental health issues, provider communication barrier, lack of spousal support, and physical barriers.

In addition to a lack of preventative screening and increased rates of cancer, people with disabilities experience higher rates of chronic conditions such as heart disease and secondary conditions such a bowel obstruction than those without disabilities (Hanna et al. 2010). Ward et al. (2010) used focus groups and interviews with adults with disabilities, their parents/guardians, community support professionals, and health providers to understand the experience individuals with disabilities had with obtaining health care. Results showed that individuals with disabilities struggled to find health care providers and often remained with their pediatricians because it was the only available care. They also reported delays in obtaining appointment dates, lack of sufficient training in health care professionals, lack of direct communication with health professionals due to language barriers or assumptions from the professional, and negative effects quality of care took on the behavior of the individual. The findings of this study recalled not only barriers to obtaining health care for individuals with disabilities, but restrictions placed on the individual even when they were able to go to a doctor or other medical professional.

Recreational

Fitness and recreation benefit an individual's health and mind. However, research shows that 47.1% of adults with disabilities do not participate in any physical activities in their leisure time as opposed to 26.1% of those without disabilities (Carroll et al., 2014). Although the ADA established public and commercial facility standards in order to increase accessibility, Rimmer et al. (2004) found that accessibility in these spaces was still a barrier for people with disabilities and the natural environment was inherently inaccessible to them. Other barriers included individuals' budgets, lack of information regarding accessible facilities, unfriendly environments, concerns about needing assistance, lack of support, insufficient time, and lack of transportation. The authors conducted focus groups with different types of professionals including city planners, park district managers, fitness and recreation professionals, and architects. Many of these professionals found the ADA guidelines difficult to interpret, cost of adaptive equipment too high, a lack of information about adaptive equipment, a lack of knowledge in employees about disabilities and the services accessible to them, and a fear of liability issues (Rimmer et al., 2004). A deficiency in knowledge of guidelines and accessible measures creates a barrier for people with disabilities when it comes to being emerged in their hobbies.

Educational

One of the most important topics in the midst of the COVID-19 pandemic is the new wave of online learning. The ability to learn online has increased the opportunities for individuals with disabilities to obtain academic degrees and higher education. However, the growth of technology in academia is not without barriers for the 19% of higher education students identifying as having at least one disability (Snyder et al., 2019). For example, a student with a learning disability may struggle with technical barriers when utilizing a computer. There

may be a lack of user-friendliness of websites. Online learning for students with disabilities also comes with difficulties of reading, time management, auditory or visual deficits in processing information, and a cluttered online course layout (Roberts et al., 2011). According to Tandy and Meacham (2009), advanced technology such as multimedia content is also difficult for students who are deaf to utilize. Tandy and Meacham propose different ways to make online learning more accessible, such as larger font, high contrast between text and background in presentations, alternative text, and utilizing PDF documents. They assert that a lack of accessibility in this area creates needless class divisions.

Different barriers come when people with disabilities attend college in person. People with disabilities are 27% less likely to possess a college degree than their counterparts without disabilities for reasons such as academic dismissal, personal reasons, family responsibilities, and a lack of assistance on campus (Marshack et al., 2010). The ADA requires postsecondary institutions to provide accessible accommodations to students with disabilities, including academic adjustments to avoid discrimination (Nielson, 2016). However, when services are available, few students seek out and make use of them because of a desire to redefine personal identity, fear of social stigma and negative peer and faculty reactions, difficulty explaining their needs, and failure of accommodations to meet their needs (Marshak et al., 2010). People with disabilities experience lack of accessibility in academia. In addition, the fear of and experienced discrimination creates a barrier to attending university.

Sex Education.

According to previous research (as cited in Adams-Rueda et al., 2014), people with disabilities are at least 36% more likely to have sexually transmitted infections, experience forced sex, and face-increased frustration with social cues relating to sexuality Bernert and

Ogletree (2012) state that people with disabilities have unique sexual health needs that may require additional education. While sex education in schools is lacking in the United States, this gap of information is even more prevalent for adolescents with disabilities. Adams-Rueda et al. interviewed school social workers and found that one of the concerns most commonly reported by adolescents with disabilities was issues about dating and sexuality, and many of these adolescents were less likely to advocate for themselves. The authors recommended that all schools include comprehensive sex education and school social workers working with this population should advocate on behalf of the reformation of policies. These changes would assist in ensuring the health, safety, and communication in dating and sexual relationships involving individuals with disabilities, especially adolescents.

Abuse and Other Crime

Rand and Harrell (as cited in Child et al., 2011) has shown that people with disabilities encounter higher rates of interpersonal violence than those without disabilities. According to previous research (as cited in Child et al., 2011), people with disabilities experience unique forms of violence such as perpetrators denying care, destroying medical equipment, and manipulating medications. Another difference that makes their experience unique is that perpetrators may be intimate partners, personal care assistants, or other service providers. Although people with disabilities experience more violence than those without, law enforcement sees low rates of reporting, prosecution, and conviction. Research (as cited in Child et al., 2011) has identified fear as the main reason why people with disabilities do not report interpersonal violence: fear of having their social or disability-related services interrupted, losing the opportunity to live independently, and losing support if a caregiving perpetrator is arrested. Law enforcement may also lack the communication skills and training to support victims with

disabilities (Stern et al., 2020). These barriers keep people with disabilities who experience interpersonal violence in direct danger. Child et al. suggests collaboration between agencies and advocates, survivors of interpersonal violence, social service providers, and others to review police policies and procedures regarding accommodation to mend these issues. Training in law enforcement to address the needs of people with disabilities who are crime victims is also recommended for successful implementation.

In addition to a lack of reporting from people with disabilities, there is also a gap in protection for children with disabilities through county child protections services (CPS) agencies. Children with disabilities are at increased risk of maltreatment compared to those without disabilities (Center for Disease Control and Prevention, 2019). While professionals often collaborate to gain information on serving people with disabilities, there is little standardization in training and collaboration that impedes effectiveness in assisting children with disabilities in abusive situations (Lightfoot & LaLiberte, 2006). This may be in part due to a lack of requirement of states to collect data on a child's disability status. Improvement in CPS agencies to protect children with disabilities could bring down the staggering difference in incidence of maltreatment experienced (Sinanan, 2011).

Civic

Citizens of the United States have the political right to vote, influencing decisions that impact an individual's life. However, voting rights for people with disabilities vary on a state-by-state basis (Friedman & Rizzolo, 2017). States use the following four methods to evaluate voter competence: barring one's guardianship status, court determination of general incapacity, a court baring vote for specific individuals, and barring based on outdated groups. Lacking in the evaluated competencies may bar an individual from exercising their right to vote (Friedman &

Rizzolo, 2017). This is critical as people with disabilities make up a large enough percentage of the county that macro-change could be initiated with a higher voter turnout.

In many states, people with disabilities do have the right to vote. For example, in Ohio, people with disabilities have the right to vote regardless of guardianship, literacy, and ability to be present at a voting site (American Civil Liberties Union of Ohio, 2018). However, a judge in probate court can deem a person with a disability as without the capacity to vote. According to Friedman and Rizzolo (2017), approximately 30% of people with disabilities who would be otherwise eligible were not registered to vote. The authors found several variables that affected the likelihood an individual with disabilities may vote. These variables included primary communication method (devices, American Sign Language, etc), guardianship status, daily hours of support, residence, organization preference, importance of rights to the individual, proper support needed to vote, fair treatment, security, direct support professionals, and community participation.

There are several ways to combat these barriers. One way to do this is additional attention to individualized supports, as Friedman and Rizzolo (2017) found that people with on-call supports were more likely to vote than those who receive six to twelve hours of daily support. Furthermore, it was found that people with disabilities were more likely to vote when they were equipped to identify rights that are important and exercise them. These rights include the right to participate in the political process, to participate in decisions that affect one's life, and to be treated equally as citizens under the law (United Disability Services, 2019). There are also several larger systemic barriers such as living in a care facility. When individuals are well equipped to identify and exercise their rights, they are more likely to participate in voting.

Double Discrimination

Double discrimination happens when an individual is a member of multiple marginalized groups and therefore experiences twice the barriers, or the same number of barriers in additional ways (Lindsay, 2010). This creates more difficulty for individuals with disabilities to improve their social functioning due to a reinforcing of societal restrictions to accessibility.

Ageism.

Ageism is the systematic stereotyping of and/or discrimination against people because they are elderly (Kane et al., 2007). In a study with a group of 152 individuals age 60 and older, Reynolds (2010) found that the most common types of ageism were jokes that made fun of older people and being ignored, patronized, treated without dignity, and/or stereotyped. Reynolds reports that ageism may be more common in individuals with disabilities due to recent advances in medical care that have extended the life span of this population.

It has been found that older adults with disabilities experience ageism on a macro-level (Bugental & Hehman, 2007). An example of this is the encouragement for younger people with cognitive impairment to live independently while older adults losing cognitive function are often institutionalized, even if the individual expresses an aversion to it (Kane et al., 2007). In addition, an increasing reluctance on state and federal levels to invest in social programs causes struggle between younger and older individuals with disabilities for a limited pool of resources (Kane et al., 2007). Ageism and discrimination on the grounds of disability further mistreatment of older adults with disabilities.

Sexism.

Women with disabilities are one of the most impoverished subgroups of the population due to their disproportionate representation among those living in poverty (Parish et al., 2009).

They are also more likely to live in conditions of hardship, deprivation, and unemployment than women without disabilities (Schur et al., 2016). It has been suggested that this is due to the double discrimination or gender and disability (Parish et al., 2009). This specifically is a failure of social policy needing to be targeted on a macro-level.

In a study of 11 men with violently-acquired spinal injuries, Ostrander (2008) found that the participants' most vocal struggle was the effects of their injury on their masculinity. The participants reported feeling like a burden to intimate partners because of their newfound dependence, shame in their body image, and a fear of requiring self-defense. Similarly, Shuttleworth et al. (2012) also stated that masculinity and disability conflict due to a societal expectation of men to be powerful and autonomous whereas disability is associated with being dependent and helpless. Due to societal expectations of men being in power and being strong, sudden disability affects men in different ways than it may affect women for the reasons listed above.

Advocacy

Social Work Professionals

Advocacy has often been identified as the primary way to overcome barriers for people with disabilities (Krahn & Campbell, 2011). Social work advocacy is meant to improve the social functioning of marginalized individuals to enhance their standing in the systems which they participate in. This may include a focus on policy, reform, class, or individual cases (Bliss, 2015). Advocacy also requires partnership with the individual, not authority or paternalism (O'Brien, 2011). Bliss argues that the advocacy of individuals must not rely on emotional appeal, but on pertinent data, characteristics, and structured argument. In addition, Bliss asserts that

feasible outcomes are critical in advocacy, as short-term outcomes build to long-term ones. Advocacy requires sustained application with needed modifications, as opposed to utilizing only petitions, protests, and the like. Following this, evaluation is critical to see success (Bliss, 2015).

Advocacy in the social work field is a way to promote social justice, one of the core values of the profession (National Association of Social Workers [NASW], 2017). Actions toward advocacy can vary depending on micro-, mezzo-, and macro-level social work. Micro-level social workers tend to emphasize individual advocacy through therapy. Social workers participating in mezzo- or macro-level work tend to lean toward political action such as lobbying as a form of advocacy. Mattocks (2018) suggests the need for a wider focus on macro social work to increase social action, especially with the increase of political attack on marginalized groups in recent years. Mattocks also recommends specific training in how to engage in social action as well as increased continuing education opportunities that promote advocacy through social action. Social workers have the ethical responsibility to engage in evidence-based advocacy to promote social justice on behalf of people with disabilities.

Children

Children are often excluded from decisions about their lives due to their lack of life experience. This tends to happen even more often with children with disabilities who struggle to communicate. Children with disabilities are more vulnerable to abuse and neglect at home or through care systems (Knight & Oliver, 2007). Children with communication impairments or other disabilities should be viewed as active participants in society, rather than passive objects, in order for the individual to feel empowered and valued. Advocates are crucial in the process of empowering children with disabilities as they have been shown to help individuals feel nurtured, taken seriously, and confident in having someone to confide in (Knight & Oliver, 2007). From a

legal standpoint, advocates of children with disabilities play a crucial role in protecting children from discrimination by helping them realize their rights under the ADA. Combatting prejudicial acts assists clients and their families in utilizing services and supports they are entitled to (Parish & Cloud, 2006).

Social Work Education

As of 2001, the Educational Policy and Accreditation Standards of the Council on Social Work Education (CSWE) mandates content on disabilities in social work curriculum (Bean & Krcek, 2012). Most of the top social work programs in the United States utilize an infused model when teaching about disabilities, such as integrating the topic into an ethics or policy class. This indicates a need for knowledge about disabilities in varying fields of social work, not only for social workers who work exclusively with people with disabilities (Bean & Krcek, 2012). O'Brien (2011) emphasizes the need to discuss the history of social work frameworks when teaching the different models of disability. He argues that any message portrayed in educational settings about people with disabilities should be consistently focused on self-determination and empowerment, not necessarily on diagnostic perspectives and "fixing" people with disabilities.

Although many schools take an integrated approach to disabilities in the social work field, it has been found that few accredited schools offer evidence-based courses focused specifically on the diverse issues experienced by individuals with developmental disabilities (Laws et al., 2010). To equip students with advocacy skills, a learning environment uniquely focused on service and supports for this population must be ensured. This is a disservice to future clients as it leads to ill-trained social workers, especially because social workers outside of the field of disability often still encounter this population. It is recommended that schools work directly with community-based providers to identify training needs and employ further training

for professionals to work with people with developmental disabilities. It is also critical that these skills build on the structure of cultural competence so that social workers are prepared to work with various ethnicities of people with disabilities (Laws et al., 2010). It is necessary for social work curricula to integrate information on disabilities in existing classes as well as develop exclusive curriculum to work with the population in an isolated manner (Bean & Krcek, 2012).

Self-Advocacy

As previously discussed, advocacy and education in the social work profession are crucial in overcoming barriers for individuals with disabilities. Equally as crucial is equipping clients with disabilities to advocate for themselves because self-advocacy encourages empowerment, which would lead to increased self-esteem and independence in individuals. Self-advocacy and self-determination are deeply connected, as self-advocacy involves an individual deciding what is best for themselves and speaking up for it (Ryan & Griffiths, 2015). Self-advocacy can motivate change in communities, political environments, and in the individual themselves through a growth in capabilities and change of self-concept. It impacts family members and other supports (Caldwell, 2010).

It is the social worker's job to equip the clients with the skills they need to advocate for themselves and see change in themselves and the systems around them. A study of school-based social work interventions indicated that treatment with the school social worker resulted in increased self-advocacy knowledge and skills for children with learning disabilities (Mishna et al., 2012). People with intellectual disabilities who participated in a self-advocacy group reported that the training resulted in improved livelihood and a more fulfilling lifestyle (Gilmartin & Slevin, 2010).

Self-advocacy has many benefits to individuals with disabilities outside of the changes it implements. Research has shown many positive effects of advocacy, including a better understanding of oneself, increased ability to ask for help, and increased confidence (Mishna et al., 2012). In a study conducted on advocacy activities by people with physical disabilities, 173 individuals identified as fulfilling leadership roles in organizations advocating for people with physical disabilities (Jurkowski et al., 2002). Respondents were given a survey exploring factors that contribute to participation amongst people with physical disabilities. The findings showed that involvement in self advocacy led to an outcome of increased access of resources. Self-advocacy and equipping individuals to advocate for themselves align directly with the values of social work (NASW, 2017). These acts must take place in order to witness barriers broken down for people with disabilities.

Conclusion

Even with the existence of the ADA, people with disabilities experience a multitude of barriers on a daily basis. These barriers encompass but are not limited to economic, environmental, medical, recreational, social, educational, civic, double discrimination, and increased instances of abuse and crime. The overarching strategies to overcome these issues can be summed up in three categories: education, training, and advocacy. Professionals need specific education on the ADA to ensure compliance and accessibility. Because any profession, particularly helping professions such as social workers, will encounter individuals with disabilities, there needs to be extensive training on the ADA and information on disabilities. Finally, barriers will see no change without advocacy. It is important that social workers are well equipped and prepared to advocate for individuals with disabilities on micro-, mezzo-, and

macro-levels. In addition, social workers need to be prepared to equip clients with disabilities

with the self-advocacy skills needed to see personal and institutional change.

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