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Commentary & Discourse Forum

Putting Advocacy Back Into Rehabilitation: A Discourse on Needs Identified in the Field

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This article seeks to promote discussion about and renew interest in rebuilding the relationship between rehabilitation counseling and the disability advocacy community. Rooted in legislation, rehabilitation counseling was historically grounded in disability rights along with the disability advocacy community. Over the years, however, the nature of this relationship has drifted, with each one concentrating in their own respective domains. In turn, this has created a divide that, in the end, may prove less productive in achieving the mutual goal of full community inclusion of individuals with disabilities. To ignite this discussion, perspective was sought from two leaders of disability advocacy organizations about ways in which rehabilitation counseling and the disability community can reignite and fortify a collaboration in the future.

Historically, legislation has been the primary focus of improving access to all facets of life for people with disabilities—to create an equitable and accessible society. One of the most significant pieces of legislation for rehabilitation counselors was the Smith-Fess Act (1920), wherein vocational rehabilitation (VR) services were made available to *all* civilians with disabilities in the United States and thus creating the institution of VR with which we are now familiar. While legislation inches society towards inclusion, and certainly provides much needed funding to establish and maintain many of the programs vital to the disability community, legislation cannot be the only avenue rehabilitation counselors rely upon to advance our social justice agendas. This paper seeks to stimulate a discourse about the ways the rehabilitation counseling field can reinvigorate our past initiatives in grassroots advocacy work, from the perspectives of leaders within disability organizations. Please note that this paper will interchangeably use person-first (i.e., people/persons with disabilities) and identity-first (i.e., disabled people) language out of respect to the growing movement towards identity-first language from the disability community.

A Brief History

Although vocational support for people with disabilities has been stipulated by law since 1920, there is still significant discrimination, stigma, and rejection of disabled people within society. Even while legislation appeared to be progressive, the American eugenics movement was alive and well at this time (1907-1939), espousing sterilization of 'unfit' Americans: those with disabilities or belonging to socially disadvantaged groups, such as individuals of color or those living in poverty (ultimately inspiring Hitler and leading to Nazism; Remsberg, 2011). Further, many individuals with psychiatric and mental illnesses were still being held in unclean, dangerous asylums, until the deinstitutionalization movement in 1955.

The Rehabilitation Act of 1973 eventually called for the formal establishment of civil rights for people with disabilities, prohibiting discrimination on the basis of disability in any federally-funded program (including schools, employment, and federal contractors), establishing a federal board to ensure accessible architecture and public transportation, and stressing consumer involvement in the rehabilitation process. Since that time, the concept of empowerment in rehabilitation of individuals with disabilities has remained salient in theoretical and hypothetical discussions, but often is missing in practical application. Additionally, the Rehabilitation Act lacked enforceability, which triggered outrage and protests among disability advocates across the country.

The passage of the Americans with Disabilities Act of 1990 (ADA) was intended to address some of these concerns about enforceability of the Rehabilitation Act. The ADA has been considered a massive civil rights vehicle for disability advocates, however it continues to leave much to be desired in terms of enforceability, public acceptance, and actual treatment of people with disabilities by society. The Workforce Investment Act (WIA, 1998) then followed the ADA, and promoted the idea that individuals with disabilities should be "served in an inclusive and integral way" (Elliott

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& Leung, 2005, p. 325). Most recently, the Workforce Innovation and Opportunity Act (WIOA, 2014) was signed into law with additional stipulations seeking to encourage competitive integrated employment for workers with disabilities, another attempt at improving societal representation, equity, and inclusion.

One large caveat to all this intended progress is that clearly many of these policies were developed without input from, or understanding of, people with disabilities and vocational rehabilitation processes. As explained by Keferl et al. (2004), these forms of legislation can be labeled as paternalistic, despite the fact that they attempt to rectify the inequalities encountered by the disability community. Without having a voice at the table, it compromises autonomy by prescribing policy that is believed to be in the best interest of a constituency without input. In no uncertain terms, the National Council on Disability (1996) advocated that "people with disabilities should direct policymaking and decision-making when they are affected by the outcome" (p. 63). Furthermore, their review of policies affecting people with disabilities yielded a conclusion (among several) that most public policies affecting disabled people were not adhering to the anti-discrimination goals of the ADA.

The Consumer-Directed Theory of Empowerment

The Consumer-Directed Theory of Empowerment (CDTE; Kosciulek, 1999) was borne of the same belief: that people with disabilities need to be, at a minimum, partners in the development of policies and implementation of services designed to help them. Legislation has come a long way, but Kosciulek bridges the underlying philosophical beliefs with a theoretical model to guide research, clinical practice, education, and program evaluation. Essentially, CDTE recognizes that legislation represents attempts at distributive justice, but does not allow for social or institutional reframing of the treatment of people with disabilities. Distributive justice can be understood such that: "A focus on the distribution of material goods and resources inappropriately restricts the scope of justice, because it fails to bring social structures and institutional contexts under evaluation" (Young, 1990, p. 20). One does not need to look far to identify a public space, media representation, or social conversation that is exclusionary of people with disabilities, which exemplifies the limitations of the legislation and their attempts at distributive justice, or limitations of distributive justice in general.

CDTE comprises four overarching constructs: Consumer Direction, Community Integration, Empowerment, and Quality of Life. The theory postulates that Consumer Direction impacts Community Integration, and that both constructs impact Empowerment, which ultimately influences Quality of Life (QOL). The development of CDTE is one of the earliest representations of the concept of Consumer Direction in rehabilitation literature. Up to that point, "choices made by persons with disabilities are often based on the avoidance of undesirable alternatives or on the acceptance of the available rather than on true preferences" (Kosciulek, 1999, p. 197). It is hard to find evidence that this is no longer the case two decades later.

Representational Justice

At the outset, it is necessary to recognize that CDTE was developed to advocate for distributive justice within neoliberalist politics. While current and past legislation demonstrated a historical need to include the voice of people with disabilities in the programs developed for them, "...such a focus [on distributive justice] ignores and tends to obscure the institutional context within which those distributions take place" (Young, 1990, p. 22). The overarching goal of CDTE was to provide a model to propose the inclusion of disabled people in disability policy and programming, and also to provide an outcome tied to positive improvements in quality of life for disabled people as a result of such inclusion. With respect to many discussions of social justice, Young (1990) argued that providing such an outcome tends to assume specific institutional structures, taking for granted the fact that inclusion is a multifaceted and complex concept that many policymakers are apt to disregard. Linking outcomes such as empowerment and quality of life to inclusion of people with disabilities (e.g., Consumer Direction and Community Integration) might be indicative of an attempt to overcome historically oppressive political institutions via a linear path to achieving QOL, but without any actual change to existing structures. However, there needs to be institutional and structural change that underpins and supports this linear relationship for any real meaning to occur.

Where Do Rehabilitation Counselors Fit?

All of the above legislation discussed is the fruit of advocacy efforts that, at one time, were collaborative efforts between rehabilitation counselors, the disability community, and disability organizations. CDTE is an excellent example of a scholar utilizing their platform and skills for advocacy work, within the academic space that ultimately prepares students as rehabilitation counselors. However, these efforts are restrained by the structural nature of vocational rehabilitation, which has paternalistic tendencies because of the power dynamic that inherently exists between the counselor and client (Keferl et al., 2004). Moreover, rehabilitation counselors increasingly indicate they are overworked, and are experiencing such levels of occupational stress that they consider leaving their positions (Tabaj et al., 2015). This in turn leaves little energy to engage in initiatives that can move the profession beyond paternalism. The combination of structural paternalism and ableism, unsustainable work demands, and increasing uncertainty (e.g., current and post-COVID environments) has contributed to a great decline in the grassroots efforts put forth by rehabilitation counselors and educators.

Voices from the Field

To explore the revitalization of grassroot advocacy within rehabilitation counseling, two leaders from disability organizations were invited to respond to the following question: *How can disability organizations and vocational rehabilitation agencies collaborate better in the future towards forming one unified voice that advocates for individuals with disabilities?* In a time when the world is craving inclusivity and accessibility, it oftentimes can feel as though we in rehabilitation counseling are only able to react in the aftermath, rather than proactively impact our societal ails. Following are the full responses from both leaders, which are positioned from a proactive vantage point, and edited only for clarity.

Len Statham, Chief Operating Officer of the New York Association of Psychiatric Rehabilitation Services, Inc.

The former Premier of South Australia, Jay Weatherill, once remarked, "*You don't get unity by ignoring the questions that have to be faced*." Our efforts to form a more unified voice on issues of employment will be strengthened if we involve peers (people with lived experience), create a sense of urgency, and sell employment as essential to a person's recovery.

Involving Peers

We need to be mindful of the questions we ask ourselves. The question above leaves out the voice of the person central to the advocacy efforts: the person seeking services. In other words, our advocacy efforts should be with individuals with disabilities and not for them.

From the 1943 Barden–Lafollette Act that introduced Vocational Rehabilitation for individuals with developmental and behavioral disabilities to the 2014 Workforce Innovation and Opportunity Act (WIOA), our history has been laden with efforts "for them" and not "with" them. The peer voice must be at the center of our efforts. I would go as far to say they are the glue that can keep disability organizations and vocational rehabilitation agencies working together in unity with their eyes on the prize.

Since 1981, the New York Association of Psychiatric Rehabilitation Services (NYAPRS) has proven that supporting peers to be at the center of public policy discussions is not only the right thing to do, but ultimately the most effective way of advancing our efforts. In 2003, NYAPRS staff members joined our colleagues in the disability rights movement in getting arrested to win state adoption of the Medicaid Buy-In, a program that supported people with disabilities to return to work while keeping their Medicaid healthcare benefits in place. NYAPRS subsequently helped to design and distribute a Tool Kit to explain the workings of the program and sponsored a statewide series of forums to educate and encourage people to enroll into the program.

In 2009, NYAPRS launched "WE Can Work", a peer-led, grassroots public awareness campaign that was designed to build hope and capacity among people with psychiatric disabilities in New York State to achieve meaningful employment and economic integration. Following a series of statewide community presentations and forums, enrollment in the Medicaid Buy grew by over 50%.

Creating a Sense of Urgency

In addition to keeping the peer voice front and center in our advocacy efforts, we've needed to create a sense of urgency. Let's face it, fighting for employment for people with disabilities is not an attention-grabbing headliner. It doesn't sell seats. We not only need to sell the seats, but we need to fill them.

Despite a recommendation in New York State's 2014 Employment First Commission Report to create an online application system to simplify and speed enrollment into the Medicaid Buy-In program, action has not been taken to put the plan into practice. Yet, the COVID-19 crisis resulted in the overnight creation and launching of a "COVID Rental Relief" portal in 2020. A sense of urgency was needed to make this happen. In 2021, we need that same sense of urgency to move our agenda forward. Ironically, in order to bring this about we need to talk about unemployment. We focus so much on employment that we forget that unemployment is the enemy. We have not been good at telling what unemployment does to people. It creates poverty, isolation, conflict, and trauma. It tears families and communities apart. It robs people of their dignity and their worth. These are the stories we should be telling. These are the seat sellers. These are the stories that grab people's attention to create that sense of urgency. And these are the stories that peers tell. This sense of urgency can help us create a mandate to all state agencies to prioritize employment.

Selling Employment as Essential to Recovery

In addition to creating a sense of urgency, vocational rehabilitation agencies, disability organizations and their peer partners must work together to promote employment as essential to a person's recovery. We have come to believe that recovery should be the expectation for everyone. We should now view employment in the same light. When we say 'WE Can Work,' we mean everyone! The second phase of NYAPRS' WE Can Work campaign was centered around educating providers and peers that employment is an essential component of one's recovery and not an endeavor one begins after one attains recovery. This message must be embedded in the culture of every human service provider, governmental agency, and in the heart of everyone that desires to recover.

Currently, NYAPRS is employing two strategies to advance our 'employment for all' agenda: We have successfully advocated for the creation of an Employment subcommittee of the state's Most Integrated Setting Coordinating Council that is empaneled to assure that New Yorkers with disabilities both reside and work in the most integrated settings of choice. We also continue to press our Medicaid agency to identify employment as a key measure of provider and health plan success, one that will be tied to financial incentives that ultimately drive provider priorities.

In closing, community providers who serve people with disabilities and vocational rehabilitation agencies share a common mission: to assist individuals with disabilities to obtain employment. Our success in helping people to get to or back to work will rely on identifying champions in the community and within government to make this goal a top priority. As we've demonstrated here, strong and persistent self-advocacy efforts by people with disabilities are essential to creating a sense of urgency that mass unemployment among people with disabilities is no longer acceptable. When we can do that, we will have taken a giant step in assuring that employment becomes an expectation for us all.

Kathy Sheppard Jones, Executive Director of the Human Development Institute at the University of Kentucky

I am the Executive Director of our state's University Center for Excellence in Disabilities (UCED). I began my career as a rehabilitation counselor and have always held the field of rehabilitation in high regard. I feel very fortunate in that our organization works in concert with our state rehabilitation agency. I believe that our interactions, approach, and shared efforts do represent a unified voice of advocacy for people with disabilities.

Understanding of Mission

Our UCED's mission is to promote the inclusion, independence, and contributions of people with disabilities and the families throughout the lifespan. We do this through education, research and evaluation, information sharing, leadership, and advocacy across the state and the nation. Our state VR agency is focused on employment and independence. This is a narrower area of focus that means that there are times when UCED advocacy is beyond the scope of the state VR agency. That's not a barrier, but it's important to recognize. Taking the time to develop a clear understanding of mission across organizations also pays tribute to the value of each entity's work and role in the state. It also is a valuable tool when making interagency connections for the community.

Making Time to Connect

Leadership across both organizations carve out time to communicate on an ongoing basis. This means sharing relevant updates, identifying grants of interest, and otherwise checking in on any collaborative activities to ensure that if issues exist, they are identified and addressed quickly. Connections happen with many staff across our organizations. We know that leaders change, and we want to ensure that knowledge of the other organization is not lost if one leader moves on.

Recognizing Strengths

Our UCED strives to be a resource for the state rehabilitation agency. We can help carry out research to answer questions posed by agency staff, and this gives our interdisciplinary student trainees experience. While the state VR agency's primary function is in service to individuals with disabilities, our organization does not always have direct service opportunities. An understanding of strengths has also led to partnering on grant proposals for decades with a solid track record of success. As one example, we partnered with VR on the Retaining Employment and Talent After Injury/Illness (RETAIN) program. This grant is funded by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), with the Employment and Training Administration and Social Security Administration. We were one of eight states funded to help workers stay at or return to work after an injury or illness. VR brings vast workforce expertise. Our UCED brings universal design and peer supports. It makes for a powerful combination.

Understanding Limitations

This isn't a negative statement, but it's intended to convey that we all operate under certain systemic constraints. There are limits to the type of advocacy that is set forth in administrative regulations for all of us. There are also protocols and processes required that may mean that one organization or the other may be better suited to take the lead in a certain advocacy area. There are also times when it is far more impactful to bolster the voices of people with disabilities to share their own stories and tell their truths. Finding platforms and developing leadership skills for people who have been marginalized for far too long can lead not only to individual change, but also to systemic change.

Leveraging Shared Experience

There are many occasions where our organizations are on the same advisory groups, task forces, and advisory boards related to employment and workforce. Before COVID, this meant time for conversation before or after meetings to touch base. Technology brings different mechanisms to accomplish this—a text or email substitutes for the face-to-face time. Navigating the world of work in times of COVID-19 has provided real-time analysis of approaches to remote work as taken by a state agency and a major university. Both of our organizations shifted to remote work at approximately the same time. We shared guidance and protocols that were created for respective staff when they might serve as a starting point and guide for the other.

Sharing Opportunities

Our UCED includes a strong training arm that utilizes both face-to-face, virtual, and hybrid formats. Whenever appropriate, we include continuing education for certified rehabilitation counselors (CRCs). Continuing education is a marketing tool for all training, and benefits both organizations. We also make efforts to co-present at state and national events whenever those opportunities arise.

All of these elements give us the ability to be strong and unified partners that give voice to the needs of people with disabilities. Building and maintaining good organizational relationships take time and care. When we start from a place that finds common ground, we know that we can amplify our efforts and voice.

How Do We Take This Advice Forward?

Some common themes surfaced from the perspectives shared by the stakeholders about a partnership between vocational rehabilitation and disability organizations (please note that this is not an empirical analysis of the responses). A core theme foremost to both was the importance of employment for individuals with disabilities and the necessity for more advocacy to push an agenda that leads to better employment outcomes (e.g., competitive integrated employment). To that end, the value of a collaborative relationship between vocational rehabilitation and disability organizations was fully validated—the founding principles of vocational rehabilitation closely aligned with improved employment outcomes and advocacy work. Both stakeholders made the important and central point that none of the VR work can or should be done without the additional partner of the disabled individual, who is seen as paramount to the relationship. Both stakeholders stressed the need to ensure that the stories of disabled folks are heard when policy decisions are being made and that they are also informed decision-makers on the team. Although vocational rehabilitation and disability organizations operate with some differences in their agendas, both stakeholders saw a mutual collaboration functioning at a more systemic level to effectively impact policy change around the employment issues encountered by individuals with disabilities.

The Importance of Collaboration

Within these commonalities were some unique, but complementary perspectives about the ingredients needed for a successful collaboration between vocational rehabilitation, disability organizations, and individuals with disabilities. One of the stakeholders focused more conceptually on important agenda items to address together, including the need to create a sense of urgency on all matters related to unemployment within the disability community and the necessity to reconstruct the definition of recovery to include employment. While this stakeholder shared important initiatives already underway, there was recognition that combining forces would galvanize these efforts more effectively on a systemic level.

Separate from agenda building, insight was offered by the other stakeholder about the mechanics of building a successful collaboration. The main takeaway here is for each partner (i.e., disability organizations, State VR, and individuals with disabilities) to fully engage in understanding who they are in relation to their partners through a discussion about one another's fundamental purpose, along with their strengths and limitations. Common ground upon which to advocate can be found through this kind of dialogue, while appreciating the individual contributions each partner can make to the joint venture. In order for this to happen, however, the partners need to invest in time with one another and have a willingness to openly share their own experiences as a way to strengthen the collaboration.

With the stakeholders' perspectives in hand, the question now becomes how to reenergize solidarity among disability organizations, State VR, and individuals with disabilities in working together towards grassroots advocacy. It is clear this will require a commitment from all parties involved along with an element of trust, given the need for each partner to share information about themselves that will contribute to the strength of the partnership. Such partnerships also require a mindset that all partners have equal status in the collaboration to ensure no one partner over another carries more power, regardless of their position in the community. This is especially important since certain organizations like State Vocational Rehabilitation may be larger as an institution in contrast to disabled individuals represented in the relationship. Below is a discussion about ways in which to logistically reconstruct this alliance, first focusing on the role graduate rehabilitation counselor education (RCE) programs can play in this process, second exploring the use of existing structures at the state level, and finally proposing new initiatives between national organizations that could revitalize the partnership.

The Role of Training Programs

To move ahead with this initiative, it seems appropriate to adopt the philosophy embraced by grassroots organizations by building from the ground up. One way in which to do this is to utilize graduate RCE programs at the local level in two ways. First is to capitalize on the Professional Advisory Boards (PAB) that typically exist within most programs. In many cases, the PAB already has membership, including vocational rehabilitation agencies. Inviting disability organizations and representation from the disabled community to join would provide a reliable mechanism for ideas to percolate into active collaborations that prioritize advocacy and inclusion within and outside the employment realm. Second, RCE programs have the capability to create community-based learning experiences in conjunction with local rehabilitation agencies. Extending these experiences to include disability organizations (e.g., Centers for Independent Living) could foster a stronger and more sustainable professional identity involving activism. As rehabilitation counseling students graduate, it is hoped they would carry this identity into their lifelong careers.

Similarly, RCE programs can and should be leading their regions as resources for information and research about disability rights legislation, advances in accessible pedagogies (e.g., Universal Design for Learning), and workplace accommodations, and in preparing people with disabilities to join the rehabilitation workforce. Leveraging a strong, community-based PAB with targeted recruitment and networking campaigns would allow for training programs to lead inclusion initiatives by example.

State-Level Needs

Another avenue for potential partnership is through the formation of a disability task force at the state level with representation from key stakeholders. Currently, each State VR system has an advisory council known as the State Rehabilitation Council (SRC). Typically convening on a quarterly basis, the composition of this council includes stakeholders similar to what is being proposed in this discussion. Often SRCs have subcommittees of which some are devoted to advocacy. In some instances, they consult with other bodies, such as the Statewide Council for Independent Living Centers. With an already existing platform in place, it may be useful to reevaluate the way in which the SRCs collaborate with other stakeholders to determine if there is room to support the existence of a taskforce in their current structure with a primary purpose to extend and strengthen beyond their current advisory role into more activism through collaborative grassroots advocacy.

Nationwide Opportunities

Alongside efforts originating from a bottom-up approach to partnership, a top-down approach may also be advantageous to consider. Ideas here may include joint ventures between professional associations such as the National Rehabilitation Association (NRA) and national disability organizations like the National Organization on Disability (NOD). NRA might consider creating a division solely dedicated to community advocacy with mutual oversight of the division shared with NOD (with a contractual agreement in place). This relationship could extend into hosting joint conferences that feature topics on advocacy and lobbying, inviting peer organizations such as the Association for People Supporting Employment First (APSE) to partner with them, and involving academics (e.g., the Rehabilitation Counselors and Educators Association [RCEA] and the National Council on Rehabilitation Education [NCRE]) to bolster the advocacy movements with research so often requested by lawmakers.

As a final consideration, the Council of State Administrators of Vocational Rehabilitation (CSAVR) could also be instrumental in building collaborations on a larger scale with national disability organizations and other advocacy groups. Together, they could form an advisory council that sets the stage for shared priorities for lobbying in Washington D.C. As an advisory group, they could also establish guidelines for best practices in forming and sustaining effective grassroot partnerships that then serve as a model for communities to utilize at the state and local levels. Given CSAVR's national standing and composition of top administrators, they have the capacity to influence buy-in from State VR across the country to reengage in this type of partnership, as they did many years ago.

Conclusions

Historically, the profession of rehabilitation counseling has sought to advance opportunities for independence and vocational success for people with disabilities. At the origins of the profession and the disability rights movements, rehabilitation counselors advocated alongside disability rights organizations, agencies, and leaders. Over time, VR grew and developed alongside changes in legislation, and state and federal administrations. As such, rehabilitation counseling shifted its priorities to examine the competencies necessary for qualified providers of rehabilitation services (e.g., Leahy, 2012; Leahy et al., 2019; Leahy & Syzmanski, 1995) and to establish evidence-based practices for the field (Chan et al., 2010; Kosciulek, 2010; Leahy et al., 2014). A byproduct of this shift is that disability organizations and VR operate in parallel spaces with less opportunity to merge their agendas on issues of advocacy and disability policy. In the late 1990s, Kosciulek identified and theorized a method for creating a shared agenda among all constituents of the disability community: the Consumer-Directed Theory of Empowerment. CDTE harkens to the slogan of disability rights organizations: “Nothing about us without us”.

The leaders of two large-scale disability organizations discussed in this paper, NYAPRS and HDI, demonstrated that with advances in programming and collaborative relationships, they are able to embody CDTE. With initiatives that involve peer leaders, state-level training and advocacy programs, and an eye on competitive integrated employment, both organizations provide a blueprint for larger, multi-state advancements and opportunities for rehabilitation professionals at all levels to engage with “Nothing about us without us”. Ranging from opportunities for collaboration between community organizations and university training programs to multi-state initiatives stemming from professional associations, it is apparent that the time is right for a change to be made whereby closer relationships are forged between VR and the disability community.

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