Perspectives

Community Inclusion of Individuals With Behavioral Challenges: Who Supports the Careproviders?

Russell J. Kormann and Michael R. Petronko

Deinstitutionalization, normalization, inclusion: These terms have defined the field of developmental disabilities for over 3 decades and continue to pose serious ideological and practical dilemmas for policymakers, advocates, families, administrators, and clinicians alike. The Olmstead decision reached by the United States Supreme Court (Olmstead et al. v. L.C. et al., 1999) was a landmark judgment in that it furthered the service delivery crisis experienced by many providers across the country. Individuals with developmental disabilities who present with medical, psychiatric, and/or behavioral challenges have been entering community-based programs at an ever-increasing rate for years. The federal government has made its message clear: “Provide services for individuals with developmental disabilities that are community based, and do it quickly.” The service community has heard the message and has opened residential, vocational, and therapeutic programs at a record pace to accommodate these new consumers. A critical question, however, remains unanswered: Has the practical reality of inclusion developed as smoothly as the philosophical underpinnings? Has the community-based infrastructure developed sufficiently to ensure that a full range of appropriate services is available to this extremely challenged population? Finally, and maybe most important, How is the workforce that must bear the increasingly difficult professional load supported so that they can provide these crucial support services without “burning out” and leaving the field?

Individuals who present with a combination of a developmental disability and severe behavioral and/or psychiatric disorder are labeled as dually diagnosed (Reiss, 1982) and make up a significant portion of the developmental disabilities population (Reiss, 1985). When considered with medically frail patients who have developmental disabilities, this population has historically represented a group of individuals who have received more intensive, and sometimes segregated, care in developmental centers, hospitals, or specialized residential programs. Treatment protocols are often complex, behaviors may be severe, and the physical and emotional toll exacted on staff and families may be extraordinary. Maintaining the treatment environment as separate from the community may have been misguided but was nonetheless multifunctional, resulting in centralization of expertise and “protection” of the community.

Times have changed and so has the philosophy regarding the support of individuals with dual diagnosis or medical fragility. What has not changed, however, is the dilemma of implementation, a dilemma that must be addressed in this time of growing concern for our most fragile consumers and at a time when shrinking budgets plague every service delivery system.

The Dilemma That Is Inclusion

Holburn (2001) provided a useful lineage of a “revolution” in the field of developmental disabilities that has been labeled in many ways but, ultimately, rests with the dilemma of how to promote a sense of inclusion for individuals with complex clinical profiles. Braddock, Hemp, Parish, and Westrich (1998) and Bruinsinks, Meyers, Sigford, and Lakin (1981) presented a historical look at issues that are related to successful integration of individuals with developmental disabilities into community residential programs. They list variables such as quality of supervision; supportive family, friends, and neighbors; acceptance of individuals’ behaviors by staff and community; and the level of competence demonstrated by staff charged with their care as critical in the development of the integration process. Adults with developmental disabilities face challenges when attempting to develop social rela-
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Challenges to Community Support Models

Persons with a dual diagnosis present the community residential system with a daunting challenge. Although the symptoms of these individuals may not easily fit into categories for the Diagnostic and Statistical Manual for Mental Disorders, fourth edition (American Psychiatric Association, 2000) or be considered to constitute behavioral disorders alone, they clearly present family or staff members with significant challenges when providing daily support. Behavioral manifestations such as aggression and self-injury often place the referred individual and others entrusted with his or her care in considerable personal jeopardy. Some of these individuals have spent a lifetime in institutions, in proximity, mutually reinforcing events, reciprocity, and choice as some of the issues that impact on both the number and quality of social relationships that individuals with developmental disabilities can expect to develop. Programs designed to serve individuals with dual diagnoses and provide the kinds of socially relevant experiences described above face a variety of barriers. Community misconceptions, biased attitudes, and fear of property value reduction are but a few of the enduring hurdles that community-based programs must overcome on a daily basis (Hiemenan & Dunlap, 2000; Koegel & Koegel, 1996; Petronko, Harris, & Kormann, 1994; Yucker, 1986).

Supporting the “Caretaker”

The stress associated with providing services to individuals with developmental disabilities and behavioral challenges in both community residences and classroom environments is well documented. The literature is replete with discussions of the burden of ongoing crisis management, burnout, and turnover (Bersani & Heifitz, 1985; Blumenthal,

ports to residential environments has remained a difficult one (Turnbull, Wilcox, Stowe, & Turnbull, 2001). As these individuals age and their behaviors have increased, parents actively seek residential and vocational programs that are inclusive in nature (Ruef, 2000). Transitioning these individuals, however, into community-based inclusive environments that will demand program participation and were not designed for people who have significant behavioral deviance poses the service delivery system with complex societal, ideological, and clinical challenges (Kormann, 1997). Until fairly recently, community residential and vocational providers have not been required to provide services for individuals with the kinds of medical, psychiatric, and behavior challenges that many of these aforementioned individuals possess. Preparing for their arrival involves much more than securing a bed and a day program. Inadequate training and planning can have devastating effects, as many individuals who could be very successful in their new homes instead experience significant behavioral struggles and untold emotional trauma as they attempt to “fit into” a system clearly not ready for them. Instances in which staff members in new residences are not prepared for the kinds of behaviors that some new residents present are common. Without adequate support, staff members are unable to effectively assist these individuals in the social accommodation process necessary when moving into a new neighborhood. Helping people develop social adaptation skills is difficult if staff members are not competent in the training process and/or are mired in a constant state of anxiety regarding their ability to manage residents’ behavior. If staff must be overly concerned about the safety of their residents and other community members (i.e., neighbors), direct training and habilitative support to consumers will suffer. The resulting behavioral instability may lead to some residents being unsuccessful in their new environment, not because they are inappropriate for the setting but because they are inadequately supported.

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Lavender, & Hewson, 1998; Hagopian et al., 2002; Hastings & Brown, 2002; Mitchell & Hastings, 2001). Low pay, long hours, inadequate training in behavior management, and the potential for personal injury are all variables that have been reported to be associated with an increased sense of stress and burnout among residential and educational staff alike. Burnout has also been linked to the presence of chronic challenging behaviors, ineffective behavior management skills, and negative emotional reactions generated in staff members because of the targeted behavior (Hastings & Brown, 2002; Mitchell & Hastings 2001). Moreover, burnout has been linked to a reduction in a caretaker’s sense of self-efficacy, the perception of one’s skills and ability to have a positive impact on life’s outcomes (Bandura, 1977, 1986; Campo, Sharpton, Thompson, & Sexton, 1997). Individuals who present with chronic behavioral challenges will surely increase the likelihood of staff members feeling ineffective if they do not have adequate behavioral/psychiatric support and are forced to deal with stressful and perhaps even dangerous individuals on a daily basis.

Considering all of the above, how does the developmental disability community broaden its support network to assist those staff members and parents who are clearly the Lynch pin to any inclusive setting? “Care for the caretakers,” is a slogan that has been used in several arenas (Tomasulo, 2002) to address methods of acknowledging the stress involved in the field of direct service and to communicate a message of hope. Typically, feedback to staff members regarding their work performance is hierarchical in nature, meaning that supervisors evaluate it on a periodic basis and strengths are noted while deficiencies are addressed through additional training or other administrative avenues. It seems clear that many staff members believe that the only way to address their sense of stress and burnout is through the receipt of more support (i.e., additional staff persons and training, salary increases, programmatic resources). It is also clear that these resources are beneficial, when available, and have a positive impact on self-efficacy and burnout (Coleman & Karraker, 1998; Dyson, 1997; Taylor, 1983). Many of these avenues, however, are controlled by larger system variables (i.e., state funding, agency budgets, static employee pool) that have made the system’s ability to attend to many staff members’ needs exceedingly difficult. An area that may provide promise in the “fight against burnout,” however, may reside with the staff members themselves. The transfer of ownership for interpersonal and professional support to members of existing residential staffs or even family-based support teams shifts the focus away from a “top down” support network and asks the question. “What can we do for each other that will help us cope with these consumers better?” Resources such as environmentally relevant behavioral support programs, improved staff communication, and a focus on staff reinforcement are areas that have received relatively little attention but may provide large benefits for staff and family members struggling with challenging consumers and their loved ones.

Behavioral support plans that are (a) specifically sensitive to a consumer’s individual profile (i.e., medical, psychiatric, and behavioral), his or her environment, and personal routine and that (b) factor in the training, competence, and emotional readiness of staff or parents is the hallmark of community-based applied behavior analysis (Carr et al., 1999; Feldman, Condillac, Tough, Hunt, & Griffiths, 2002; Kormann & Petronko, 2002a, 2002b). A critical component of any well-constructed behavioral support system is its ability to provide a mechanism for staff to communicate more accurately regarding the myriad of concerns that affect the consumer. Everything from developing methods to target and define behavior so that everyone working with the consumer is clear as to what is being addressed and when to improve communication systems between programs (i.e., residential/home and work/school) is critical to effective programming and to a reduction in burden. The development of a therapeutic playbook that outlines in writing the behaviors, procedures, and daily programmatic outcomes is one such method for assuring that all staff members are consistently trained and informed. Finally, significant attention should be paid to the development of adaptive behaviors and the effective and consistent reinforcement of those alternatives for all consumers. It is an endeavor on which many have based a career and one that clearly needs ongoing attention. The principle of reinforcement and other behavioral techniques are exceedingly difficult for staff members and parents to perform effectively with challenging consumers in the community. Training, practice, and supervision is often required over long periods of time to ensure that a staff or family member not only understands the behavioral concepts but, more importantly, can carry them out in their daily life.

Then what about the caretakers? Who rein-
forces them for the incredibly difficult job that they perform each day? It seems clear that staff members can function as very powerful reinforcers to their professional partners if they so choose; but how often do staff members or parents actually think to capitalize on their unique and important position within the programmatic framework? The following techniques and suggestions are a way to utilize the training, knowledge, and energy that direct service workers bring to their consumers to support one another. It is well-documented that behavioral support works and has helped many consumers live more effective and satisfying lives. Can this technology be used to support direct service and family members?

**Staff–Parent Reinforcement**

1. **Warm Fuzzies**: staff noticing and providing specific and knowledgeable praise to their co-workers. Who knows what it is really like to work with a challenging individual better than the staff or family member who just worked with him or her an hour earlier? Feedback from a knowledgeable peer may carry more weight than an administrator who makes observations periodically.

2. **Give a Break, Take a Break**: giving each other time off after managing a stressful situation. Offering to “take over” for a few minutes while a struggling staff member takes a minute to disengage, get a breath of fresh air, pick up the mail, etc., is often extremely helpful and sensitive to the needs of a coworker or family member.

3. **Staff Member of the Week**: staff electing their own staff member of the week and providing him or her with reinforcers agreed upon and procured by the staff community. These can be as simple as a ribbon or as elaborate as a cash award. The actual reward may pale in comparison to being recognized by your peers for a job well done.

4. **Social Outings**: staff members spending time together socially, despite the stress of the job, the necessity for secondary employment, etc. These are the people who truly understand and require the least explanation about a bad day. Periodic social gatherings at which staff members can lean on each other can be effective in managing stress and realizing that you are not in this alone.

5. **No Complaint Rule**: It is important that these outings not become complaint sessions in which all of the problems inherent in the program or the consumers are perseverated upon. It is acceptable to talk and laugh about work, but no complaints!

5. **Stress Management/Group Support**: acknowledging that this is a difficult business that includes behaviors that may be unpleasant and, on occasion, potentially dangerous. If the behaviors and/or other components of the consumers overwhelm a staff person, it will be impossible to manage and ultimately improve them. Formal techniques for managing stress include diaphragmatic breathing, guided imagery, group support in restructuring distorted perceptions of the job, and problem-solving.

**Conclusion**

A staff or family member’s ability to address issues of burnout and support each other seems to be a relatively untapped, yet powerful resource. As the movement toward full community inclusion progresses, it behooves us to utilize each and every precious resource available. In this way, consumers with behavioral challenges and co-workers and family partners can be effectively served.

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