Utilizing Generic Community Supports For People With Intellectual Or Developmental Disabilities

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This article explores the development of specialized services for persons with intellectual or developmental disabilities, and the recent shift towards use of more generic resources in community settings. Early developments in supports for persons with disabilities featured the creation of technologies for support. This necessitated the establishment of professions and professional training in rehabilitation. For example, in employment supports, this involved the creation of specialized workplaces and the founding of professional organizations. In special education, this involved specialized schools and classrooms, and founding of training programs for special education teachers. More recent pushes towards community involvement and the use of generic resources, such as regular education, community employment (including One-Stop Centers), and community recreation, established an impetus for the reliance on less specialized supports. This article examines the benefits, costs, and challenges of this reliance, and concludes with recommendations for improving community capacity.

Creation of Specialized Services

The history of support for persons with disabilities has involved services provided in a number of different places and a few different initiatives. Prior to the 20th Century, there were few services for persons with developmental disabilities, but there were few specialized services for any person. As civilizations and cultures began to include specialized professions and areas of learning, resources for persons with a disability began to emerge. Some examples include the Oral School for the Deaf established by Samuel Heinicke in 1755, the Massachusetts Asylum for the Blind opened in 1832 (later renamed the Perkins School for the Blind), which offered the first residential instructional and training program for "idiotic" children in 1848, and the establishment of special

education classes by the State of New Jersey in 1911.

The growth in services and supports for persons with disabilities created an impetus for the creation of a class of professionals working in this burgeoning industry. A science of habilitation and rehabilitation was established. The National Committee for Mental Hygiene was founded in 1909. Additionally, the rehabilitation of injured veterans drove systemic improvements. In 1918, the Smith-Sear Veterans Vocational Rehabilitation Act authorized the Federal Board for Vocational Education for World War I veterans who had acquired disabilities during combat or other military service, putting significant federal funds behind rehabilitation and thus creating rehabilitation professionals and governmental systems.

A theme throughout all of these systemic improvements has been the separation of different types of disabilities, and the creation of different groups of professions, best practices, and skill areas (Benjamin, 1989). Separate technologies were utilized for each type of disability. Braille was invented for use by blind people, and American Sign Language was invented for use by deaf people. Different institutions were established for people with different types of disabilities, and different training programs were created in which professionals could learn the technologies for each. Professional journals were established, such as *Journal of Psycho-Asthenics* (1912) with its lead article, "A revision of the Simon-Binet system for measuring the intelligence of children" (Kuhlmann, 1912); and the book *Mental Defectives: Their history, treatment, and training* published in 1904 (Barr, 1904).

The proliferation in community social services in the United States, beginning in the 1950s created new options for people with intellectual or developmental disabilities to

receive services in the community, beginning of a trend of decreasing numbers of people served in large, state-operated residential facilities (Alba et al., 2007; White, Lakin, Hill, Wright, & Bruininks, 1988). This dynamic was enhanced by legislation in 1971 creating Intermediate Care Facilities for Persons with Mental Retardation (ICF-MR) as a Medicaid eligible service. While intended to improve conditions in institutions, it also spurred the reduction of institutional populations to meet new capacity and treatment requirements (Boggs, 1994). In addition, the establishment of Home and Community Based Waivers made it possible to receive Medicaid reimbursement for services to people in the community as an alternative to ICF-MR care.

The passage of the Education for All Handicapped Children Act (PL 94-142) granted children with disabilities the right to education in public schools, creating the assumption that children with developmental disabilities would be educated in the community. Finally, with regards to Rehabilitation, Section 504 of the Rehabilitation Act of 1973, prohibited discrimination of people with disabilities from any federally-funded program and mandated that vocational rehabilitation programs prioritize people with the most severe disabilities. This act also initiated federal funding for Centers for Independent Living (CILs). CILs are local organizations largely operated by people with disabilities that promote the philosophy of Independent Living, which teaches that all persons with disabilities belong in the community and should control the services they receive and the course of their life (NCIL, 2009). This philosophy is in stark counterpoint to a medical model which sees disability as a condition and problem to be treated and solved by medical experts. Independent Living sees disability as a social construction, not a medical problem, and sees the establishment of proper supports,

determined by the person, to be a civil rights issue (DeJong, 1979). Peer support, a cornerstone of other self-help groups, also plays a prominent role in Independent Living. Centers for Independent Living are mandated by law to provide individual and systems advocacy, information and referral, peer support, and independent living skills training (NCIL, 2009). Independent Living as a philosophy has led to a greater community presence for persons with disabilities, and contributed to the passage of the Americans with Disabilities act.

By the early 1980s, serving people with intellectual or developmental disabilities in the community was an expectation. The paradigm for community services, however, was placing people in community "programs" such as group homes and sheltered workshops. People were served congregated with other people with disabilities and staff provided services accordance with the program's model.

In the mid 1980's, the broad realization emerged that with appropriate supports even people with significant disabilities can live and be fully included in the activities of their community. This concept was reinforced by the enactment in 1990 of the landmark Americans with Disabilities Act which mandated that accommodations be made by community entities such as schools, businesses, and public transportation to ensure people with disabilities enjoy their full rights as citizens. Since then, the primary paradigm in service delivery for people with developmental disabilities has been the provision of person centered supports to assist people to live in their own homes and participate in activities of their choice in the community (Prouty, Lakin, & Robert Bruininks , 2007). An important element of this paradigm is that people have the opportunity for employment if they so chose.

Positive Aspects to Generic Supports

Supporting people to be included in their community involves linking people to both paid and generic supports. The term generic supports refers here to supports provided by family, friends, neighbors, co-workers, or by services generally available for purchase to members of the community. There are many positive aspects to utilizing generic supports. First, the use of generic supports is a fundamental element in the community inclusion paradigm. As a member of a community, people with disabilities should be using the same doctors, dentists, gyms, classes, or labor resources as other people in the community. Being a member of the community and present in the community is valuable in terms of networking and developing social capital in the community.

Second, utilizing generic community supports promotes social role valorization (Wolfensberger, 2000). Once again, being a part of the community and present in the community denotes filling a valued social role in the community. By seeing people with disabilities using the same resources, the community may grow more likely to accept people with disabilities, an argument often made in support of inclusive education (Kliewer & Biklen, 1996; TASH, 2000).

Third, people with disabilities experience social growth by adapting to typical community environments (Baker, 2003). Universal access opens numerous opportunities to people, and leads to an enriched quality of life and social relationships (Lee, Odom, & Lofton, 2007). This may result in improved self-esteem.

Fourth, there generally is no wait list. While community health care, and in specific mental health care, may have long wait lists, most services to people in the

general community do not have long waiting lists to receive services. If the list is too long, one can simply use the power of the customer and go elsewhere. The invisible hand of capitalism generally creates a capacity to support demand. In places where there is a long wait list, it is due to the fact that profit incentive does not exist to create or fund extra capacity (for example, in publicly-funded substance abuse programs).

Fifth, generic supports often utilize non-specialized funding. For example, a cost-benefit study of community living noted that the transfer of people with developmental disabilities into broader public health care may not have saved taxpayer money overall, but did not utilize funding for developmental disabilities services (Knobbe, Carey, Rhodes, & Horner, 1995). At that point, economies of scale may come into play. In a similar note, students with developmental disabilities can participate in vocational education programs that are open to all students, rather than participating in transition services run entirely by special education programs, with New Jersey's Structured Learning Experience initiative as an example (New Jersey Department of Education, 2007). This once again does not utilize special education funding.

Sixth, utilizing generic supports takes advantage of programs and services that already exist in the community. There is no need to either create programs or duplicate existing efforts. For example, in considering the establishment of a child care program for youth with disabilities, can an existing program run by a generic childcare provider such as a YMCA be adapted to include students with disabilities? Here again, there would be advantages of scale and advantages associated with having no start-up costs and the use of existing facilities that may be under-utilized.

Are There Problems?

Generic Community Supports

In the previous section, we outlined the numerous benefits of persons with developmental disabilities utilizing generic services. In this section, we will detail some of the problems. First, generic systems may not always welcome persons with disabilities. Consider the failure of the "Regular Education Initiative" (Will, 1986; Bryan & Bryan, 1988). The argument was made that special education was created to educate students with disabilities, as regular education, at the time, was seen as being ill-equipped for these students. Efforts to include students in regular education, to this day, may encounter a lack of welcome from the "generic" educational system with related challenges regarding access to general curricula (Dymond, Renzaglia, Gilson, & Slagor, 2007; Putnam, 1993). A similar scenario can be found in community recreation as well. If a person with obvious disabilities registers for a community recreation class, that person may be told or encouraged to participate in the specialized recreational programs, as "those were created for you." If that person perseveres, he or she may still be denied access to the general recreation opportunities (Schleien & Werder, 1985).

Generic supports may not offer the necessary level of assistance, or may perceive that they do not. Part of the reason for the perception of the need for specialized services may have come from the fact this field strove to create specialized supports for so long (Voeltz, Wuerch, & Wilcox, 1982). These authors argue that as long as there are requests for specialized supports, generic support people will argue that they do not have the skills or expertise to work with individuals who have developmental disabilities, a discussion that continues (Rusch & Braddock, 2004).

However, the reality is that there is an importance for expertise in some areas of disability supports. To say that there is not would ignore the fact that some disabilities do

present some challenges, and technical knowledge and/or skills may be needed to support some people with disabilities, whether in school settings, employment setting, residential setting, recreational settings, or health care (Reichard & Turnbull, 2004). If this was not the case, we would not be calling for increased training for direct support staff, particularly in areas of behavior support (Kormann & Petronko, 2004).

Among the areas of expertise that are necessary in supporting people with disabilities are strategies for accommodations. Accommodation is a significant factor in supporting persons with disabilities in all types of settings, and appropriate accommodations are proven to lead to success, from employment (Unger, 1999) to higher education (Wilson, Getzel, & Brown, 2000). As noted previously, accommodation also is seen as a key to inclusive education. While resources to assist in designing accommodations are now readily available (e.g., the Job Accommodation Network; (http://www.jan.wvu.edu/), knowledge about the creation of accommodations is not resident within community settings unfamiliar with disabilities supports, and may provide a barrier to access. Similar arguments are made in regards to the continuation of segregated education for students with disabilities, as noted previously. Education regarding accommodation has long been recognized as a primary activity of many support providers who work to create more inclusive community settings, such as job developers (Nisbet & Hagner, 1988). Without this education of the community, generic community settings may not offer people with developmental disabilities the opportunity for success.

Many generic settings might not have the capacity to support people with developmental disabilities. Elements of capacity include the ability to provide

accommodations, staffing, assistive technology, and knowledge of specific support strategies. Despite years of advocacy for increases in the capacity of regular education settings in the creation of inclusive education, time and resources in classrooms remains a major barrier to inclusion in schools. Creating such capacity in settings such as One-Stop Centers is a major effort at the time in which the manuscript was prepared (Fesko, Hoff, Jordan, Fichera, & Thomas, 2000). Accessible settings are a primary consideration. Settings designed for or dedicated to people with disabilities are more likely than generic community settings to be accessible and ADA-complaint (though not necessarily so).

Consider natural supports in employment settings. Relying on existing supports is a recommended practice (Griffin, Hammis, & Geary, 2007; Hoff, Gandolfo, Gold, & Jordan, 2000; Nisbet & Hagner, 1988). However, some individuals present support needs beyond what might be provided. If an individual requires numerous trials to learn a job skill, a manager in a retail setting might not have time or interest in the additional training required. Participation in community life offers a multitude of similar situations. All shoppers can expect some level of assistance from clerks in stores. That is a generic support than many people use frequently, particularly when patronizing a new store. In most cases, clerk or sales floor representative will offer extra support to a person with disabilities in order to make a sale. However, in a busy store around peak periods, such as holidays, the extra assistance may not be forthcoming. From the clerk's point of view, a single sale may be lost, but better service will be offered to a larger number of people.

What is Needed?

Increasing accessibility to generic community supports will require a coordinated, two-pronged approach: (a) educating generic service providers and employers about the

benefits of supporting people with developmental disabilities to be consumers and employees, and (b) changing the service delivery strategies of agencies that serve people with developmental disabilities.

Educating Generic Service Providers and Employers

Information should be provided to generic service providers and employers that present people with disabilities living in the community and participating as full citizens. Acceptance from the broader community has been seen as a key element to the success of educational inclusion, and the same must be seen as the case for community acceptance and the successful utilization of community resources. Recent media awareness of issues of disability, such as consideration in popular movies, books, and commercials, will assist with this over time. However, grass roots efforts again will be necessary. Inclusion as members of community will assure that generic services become available, but cultures across the world struggle with issues of diversity and community, and diversity of ability will present the same challenges. One factor that might ameliorate this, however, is the fact that disability exists in all cultures. Awareness of disability may become a variable that builds cross-community cooperation and tolerance. Information should also include the implications of serving or employing people with developmental disabilities. What services do they need? What accommodations are necessary? What supports are available to assist?

Finally, information should include the financial benefits of serving or employing people with intellectual or developmental disabilities. For generic service providers, information should include the potential for new customers and increasing sales. Information for employers should emphasize that people with developmental disabilities

represent an underutilized labor pool, and are dependable employees who can positively impact the company's bottom line.

Changing Service Delivery Strategies

Provider organizations supporting people with intellectual or developmental disabilities need to convert from providing direct services to supporting inclusion in the community. This changes the role of direct support professions. The job becomes connecting people with intellectual or developmental disabilities to community resources and supporting the generic resources to meet the person's needs, as opposed to individually providing all of the supports.

As noted earlier, generic community services providers and employers may not perceive that they have the capability of serving or supporting a person with a developmental disability. Provider organization staff need to assist in the development of support strategies that include the staff assuming some responsibilities if necessary. For example, if a person with a developmental disability is hired by an employer, an employment specialist should initially organize supervisors and co-workers to provide natural supports and subsequently be available support them on an on-going basis. Additionally, support workers can provide assistance to generic resources to provide accommodations for people with disabilities. Support from provider organizations can facilitate access to generic community supports for the people they serve. The lessons learned in this process will create opportunities for all people with disabilities whether or not they have support services.

In conclusion, this article considers the way in which generic community services are becoming more of an issue in the lives of persons with disabilities living in the

community. Use of generic services can be lauded for its beneficial effects on community inclusion, but a caution also exists, in that generic services are less likely to have knowledge about how to accommodate persons with disabilities. Successful utilization of generic services is incumbent on preparing and supporting the community in providing welcoming services in a manner that will assist the person with disabilities.

References

Kathryn Alba, K., Prouty, R., Bruininks, R., & Lakin, K.C. (2007). Current Populations and Longitudinal Trends of State Residential Settings (1950-2006). In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Baker, J. (2003). *Social Skills Training*. AAPC: Shawnee Mission, KS.

Barr, M.W. (1904). *Mental Defectives: Their history, treatment, and training*. P. Blakiston's Son & Co: Philadelphia, PA.

Benjamin, S. (1989). An ideascape for education: What futurists recommend. *Educational Leadership*, *47*, 8-14.

Boggs, E.M. (1994). Benchmarks of Change in the Field of Developmental Disabilities. In V. Bradley, J. Ashbaugh, & B. Blaney (Eds.), *Creating Individual Supports for People with Developmental Disabilities.* Brookes: Baltimore, MD.

Bryan, J.H., & Bryan, T.H. (1988). Where's the beef? A review of published research on the Adaptive Learning Environment Model., *Learning Disabilities Focus, 4*,

9-14.

DeJong, G. (1979). Independent Living: From Social Movement to Analytic Paradigm. *Archives of Physical Medicine and Rehabilitation*, 60.

Dymond, S., Renzaglia, A., Gilsomn, C., & Slagor, M. (2007) Defining access to the general curriculum for high school students with significant cognitive disabilities. *Research and Practice for Persons with Severe Disabilities, 32*, 1-15.

Fesko, S., Hoff, D., Jordan, M., Fichera, K., & Thomas, C. (2000). One-Stop Centers: a guide for job seekers with disabilities. *Tools for Inclusion, 8*(1).

Griffin, C., Hammis, D., & Geary, T. (2007). *The Job Developer's Handbook*. Baltimore, MD: Brookes.

Hoff, D., Gandolfo, C., Gold, M., & Jordan, M. (2000). *Demsytifying Job Development*. St. Augustine, FL: TRN.

Kliewer, C., & Biklen, D. (1996). Labeling: Who wants to be called retarded? In W. Stainback & S. Stainback (Eds.), *Controversial issues confronting special education: Divergant perspectives* (2nd ed., pp. 83-95). Boston: Allyn & Bacon.

Knobbe, C. A., Carey, S. P., Rhodes, L., & Horner, R. H. (1995). Benefit-cost analysis of community residential versus institutional services for adults with severe mental retardation and challenging behaviors. *American Journal on Mental Retardation, 99*, 533-541.

Kuhlmann, F. (1912). A revision of the Simon-Binet system for measuring the intelligence of children, *Journal of Psycho-asthenics, 1*(1), 3-41.

Lakin, K.C., Prouty, R., Polister, B., & Coucouvanis, K. (2004). States' initial response to the president's New Freedom Initiative: slowest rates of deinstitutionalization

in 30 years, *Mental Retardation, 42*, 241-244.

Kormann, R.J., & Petronko, M.R. (2004). Community inclusion of individuals with behavioral challenges: Who supports the careproviders? *Mental Retardation, 42*, 223-228.

Lee, S., Odom, S., & Loftin, R. (2007). Social engagement with peers and stereotypic behavior of children with autism. *Journal of Positive Behavior Interventions, 9*, 67-79.

National Center for Independent Living. (2009). *The Disability Rights and Independent Living Movements*. Retrieved June, 2009 from www.ncil.org.

New Jersey Department of Education. (2007). Structured Learning Experiences. http://www.nj.gov/education/voc/sle/ retrieved November, 2007.

Nisbet, J., & Hagner, D. (1988). Natural supports in the workplace: a reexamination of supported employment. *Journal of the Association for Persons with Severe Handicaps, 13*, 260-267.

Prouty, R., Lakin, K.C., & Bruininks, R. (2007). Changing Patterns in Residential Service Systems: 1977-2006. In R.W. Prouty, Gary Smith & K.C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2006*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Putnam, J. (1993). *Cooperative learning and strategies for inclusion*. Baltimore: Brooks/Cole.

Reichard, A., & Turnbull, H.R. (2004). Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental

disabilities, *Mental Retardation, 42*, 181-194.

Rusch, F., & Braddock, D. (2004). Adult day programs versus supported employment. *Research and Practice for Persons with Severe Disabilities, 29*, 237-242.

Schleien, S., & Werder, J. (1985). Perceived responsibilities of special recreation services in Minnesota. *Therapeutic Recreation Journal, 19*, 51-62.

TASH. (2000). *TASH resolution on inclusive quality education*. Baltimore, MD: TASH.

Unger, D. (1999). Workplace supports: a view from employers who have hired supported employees. *Focus on Autism and Other Developmental Disabilities, 14*, 167-169.

Voeltz, L.M., Wuerch, B.B., & Wilcox, B. (1982). A social validation of leisure activities training with severely handicapped youth. *Journal of the Association for Persons with Severe Handicaps, 7*, 3-13.

White, C.C., Lakin, K.C., Hill, B.K., Wright, E.A., & Bruininks, R.H. (1988). *Persons with mental retardation in state-operated residential facilities: Year ending June 30, 1987 with longitudinal trends from 1950 to 1987* (Report No. 26). Minneapolis, MN: University of MN, Department of Educational Psychology.

White, C.C., Lakin, K.C., Wright, E.A., Hill, B.K., & Menke, J.M. (1989). *Populations of residential facilities for persons with mental retardation: Trends by size, operation, and state, 1977 to 1987 (Brief Report No. 32).* Minneapolis, MN: University of MN, Center for Residential and Community Services.

Will, M. (1986) Educating student with learning problems: A shared responsibility. *Exceptional Children, 52*, 411-415.

Wilson, K., Getzel, E., & Brown, T. (2000). Enhancing the post-secondary campus climate for students with disabilities. *Journal of Vocational Rehabilitation, 14*, 37-50.

Wolfensberger, W. (2000). A brief overview of Social Role Valorization. *Mental Retardation, 38*,105-23.

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