

THE DIRECT SUPPORT WORKFORCE CRISIS: CAN UNIONS HELP RESOLVE THIS?

A Policy Paper from the Center on Human Policy

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THE DIRECT SUPPORT WORKFORCE CRISIS

A 2006 report to Congress, The Supply of Direct Support Professionals Serving Individuals with Intellectual and Other Developmental Disabilities, by the Office of Disability, Aging, and Long-Term Care Policy (Assistant Secretary for Planning and Evaluation, U. S. Department of Health and Human Services, January 2006) confirms concerns expressed by researchers, advocates, and policy makers about the quality and stability of the direct support workforce for people with intellectual and developmental disabilities and their families:

- Turnover rates of direct support workers in residential, in-home, and day and vocational services are an estimated 50% per year.
- The current total of 874,000 full-time workers (or full-time equivalents, FTEs) assisting people with intellectual and developmental disabilities is expected to grow to 1.2 million by 2020 due to population increases, increases in life expectancy, aging caregivers, and an expansion of home and community-based services. This represents an increase in demand of approximately 37%. At the same time, the number of workers who typically perform direct support roles, adults aged 18-39 years, is only expected to grow by about 7%.
- At current turnover rates, by 2015, an estimated 741,000 new direct support workers will be needed simply to replace

workers leaving their jobs. The need to replace workers while meeting the expanded demand for supports will tax an already over-burdened service system.

- The national vacancy rate for direct support workers is an estimated 10-11%.
- High turnover rates result in increased costs for staff recruitment, overtime pay, and training.
- High vacancy and turnover rates have negative effects on the quality of supports offered to people with disabilities and their families. High vacancy and turnover rates can cause gaps in service coverage, create discontinuities in care, and interfere with the development of positive relationships between support workers and those they support.

The problems faced by the developmental disability service system in recruiting and retaining direct support staff will be exacerbated by demands from competing service industries, including long term supports for the increasing aging population in the United States.

National averages for turnover and vacancy rates for direct support workers obscure the dramatic differences in rates between public institutions and state-operated services, on the one hand, and community services operated by the private sector, on the other. According to the Report to Congress, in 2002, public institutions had an average turnover rate of 28%, while

community services averaged 50%. Larson, Hewitt, and Lakin (2004) similarly reported that staff turnover rates averaged between 40-70% in community settings and 28% in public institutions. The 10-11% vacancy rate noted in the Report to Congress compares to a vacancy rate of 5.8% in large state facilities in 2004 (Larson, Byun, Coucouvanis, & Prouty, 2005). If there is a direct support workforce crisis in the developmental disability system, it is a crisis that affects community services and not public institutions.

Many factors account for high turnover and vacancy rates in the community service system: conditions of employment (e.g., hours of training provided), service model characteristics (e.g., staff ratios), employment context (e.g., urban location, area unemployment rates), and others (Report to Congress, 2006). However, studies have consistently attributed high turnover and vacancy rates, and especially the discrepancy between rates in community settings as opposed to institutions, to low wages and benefits. The Report to Congress indicates that between 1998 and 2002, the average wages were \$11.67 an hour in public institutions and \$8.68 in community services (2006, p. 19). In 2004, the starting hourly wage in large public institutions was \$10.12 and the mean wage was \$12.53 (Larson et al., 2005). Braddock, Hemp, and Rizzolo (2003) reported hourly wages of \$11.67 in state-operated facilities and \$8.68 in community settings; the poverty level was \$8.19.

The discrepancy between pay and benefits in state-operated institutions and private community services does not necessarily represent an "institutional bias." Rather, the discrepancy reflects the fact that state workers are likely to be represented by public employee unions, while private sector workers have not been unionized by and large. For example, New York State, which operates a dual community service system comprised of both state-operated and privately operated services, offered the same wages in 2004 (\$11.61 starting; \$14.59 mean; Larson, et al. 2005) to state workers in community services as in institutions.

Various efforts have been made to address the inadequate wages and benefits of direct support workers. As indicated in the Report to Congress, the Centers for Medicare and Medicaid Services (CMS) has awarded 10 demonstration grants to help states improve recruitment and retention, including offering health benefits, and the State of Wyoming gave a wage and fringe benefit increase to direct support workers, which has reportedly resulted in a decrease in staff turnover by 15% in one year. Organizations such as the American Network of Community Options and Resources (ANCOR) and the New York State Association of Community and Residential Agencies (NYSACRA) have promoted the Direct Support Professional Fairness and Security Act that would achieve parity between the wages paid in Medicaid-funded private (predominately community) and public (predominately institutional) programs. A California federal court

case, *Sanchez v. Grantland Johnson, et al.*, filed by disability groups was unsuccessful in making the claim that increased wages and benefits to community service workers would protect the rights of people with developmental disabilities to the “most integrated setting appropriate” standard established by the *Olmstead* Supreme Court case under the Americans with Disabilities Act.

There is one other major national initiative to improve the wages and benefits of direct support workers in the community: the unionization of workers in the private sector. It is extremely controversial among private service providers, advocacy groups, and policy makers. This policy paper examines this controversy. It explores the historical roots of efforts to address direct support workforce issues, reviews the role of unions in the field in the past, considers the fit between disability rights and worker rights, examines emerging support models, and comments on current union efforts.

THE WORKFORCE CRISIS AND REFORMS IN THE 1940s

The direct support workforce crisis is not new. Nor are efforts to address the crisis by improving the training and elevating the status of direct support workers.

During World War II, state mental hospitals and training schools faced a workforce crisis that makes today’s problems in recruiting and retaining staff pale in comparison. Due to military enlistments and the lure of higher pay in defense industries, the workforce at state institutions was utterly depleted. At Philadelphia

State Hospital in 1943, for example, there was one paid attendant on duty for each shift for every 144 patients on the male side of the institution.

To address their staffing needs, state mental hospitals and training schools, including such well-known state schools as Pennhurst in Pennsylvania, Mansfield in Connecticut, and Rosewood in Maryland, turned to an unlikely source: Conscientious Objectors (COs).

During the war, approximately 12,000 men “conscientiously opposed to participation in war” based on “religious training and belief” (primarily Mennonites, the Brethren, Quakers or the Friends, and Methodists, although over 120 religions were represented) served in the Civilian Public Service or CPS. Initially, COs were involved in fighting forest fires, planting trees, park preservation, fire prevention, and similar activities. By 1942, the CPS had expanded to include forms of alternative service beyond environmental projects. COs were assigned to farms, to build sanitation facilities in rural communities, to serve as “guinea pigs” in medical experiments, and to address the labor shortages at state institutions. Between 1942 and the end of the war, approximately 3,000 COs worked at 40 state mental hospitals and 16 state training schools in 22 states.

What the COs found at the institutions shocked them: overcrowding, understaffing, neglect, abuse, and brutality. Most COs worked as attendants at the institutions. In return, they

received room and board and a small monthly allowance to cover expenses, but were not paid for their work.

Before long, COs at many of the institutions started to bring the conditions at the institutions to the attention of the media and public officials. The COs' efforts resulted in exposes of institutional conditions and abuse reported in the Richmond Times-Dispatch, the Cleveland Press, the Poughkeepsie New Yorker, and other newspapers. In 1946, a CO who had been at Rosewood Training School in Maryland published a scathing three-part series of articles in The Catholic Worker: "State School Unnatural, Maltreats Children," "Slaves or Patients?," and "Abandon Hope."

Like their counterparts at other institutions, COs at Philadelphia State Hospital, also referred to as Byberry, were concerned about the treatment of patients and the conditions under which they lived. With the support of the superintendent and the American Friends Service Committee, the Byberry COs established a clearinghouse for sharing information among CPS units and concerned persons at institutions nationally in 1944. They began publishing a national newsletter, The Attendant (later named The Psychiatric Aide). The Attendant featured articles by professional experts, COs, and others on such topics as "Patient Restraint and Attendant Protection," "Socializing Institutionalized Mental Defectives," and "Obstacles to Care and Treatment."

The Byberry COs next set their sights on documenting conditions at state mental hospitals and training schools. They sent

letters to COs at mental hospitals and training schools asking them for information, and within a short period of time they had received over a thousand reports documenting abuse and neglect.

Through the American Friends Service Committee, the COs were put into contact with national figures. One of the COs met with a senior editor of Reader's Digest and showed him photos of Byberry. The editor was immediately interested and arranged for Life Magazine, which was published by the same company, to do a story on state mental hospitals based on the COs' reports.

On May 6, 1946, Life published an article titled, "Bedlam 1946: Most U.S. Mental Hospitals are a Shame and Disgrace." Accompanied by photos captioned with terms such as "Neglect," "Restraint," "Nakedness," and "Overcrowding," the article reported widespread abuse, brutality, and substandard conditions at institutions. A condensed version of the article was published in Reader's Digest in July 1946.

Although they cultivated relationships with professional groups and influential psychiatrists, the COs sought to create a national movement led by "laymen," rather than professionals. The same day the "Bedlam 1946" Life article was published the formation of the National Mental Health Foundation (NMHF) was announced in Philadelphia. The NMHF was conceived by the Byberry COs, who had worked hard to recruit prominent physicians and civic leaders to support their cause. In April 1947, the NMHF released a report, Out of Sight, Out of Mind, based on

COs' accounts. The book contained one report after another of neglect, professional negligence, brutality, and abuse.

From its founding until 1950, the NMHF conducted aggressive public relations campaigns to change public attitudes and established a legal division to draft state legislation to reform institutional commitment laws. The NMHF continued to publish handbooks and manuals on caring for people with psychiatric and intellectual disabilities. The NMHF also established a highly publicized "Psychiatric Aide of the Year" award to recognize outstanding efforts by institutional attendants.

Beset by financial problems and tensions between the "lay" COs and some of its professional advisors, the NMHF had a short lifetime. In 1950, the NMHF merged with other organizations to create the National Association for Mental Health (now Mental Health America). The new national association adopted other priorities than those that had motivated the COs.

The history of COs at state institutions during World War II has been largely forgotten in the fields of psychiatric and intellectual and developmental disabilities. This history is important because it can teach us lessons relevant to services and workforce issues today:

- The COs brought unprecedented media attention to conditions at institutions and enlisted the support of prominent public figures in reform efforts. Yet, decades later in the 1960s and 70s institutions faced yet another

wave of public exposés (Blatt & Kaplan, 1966; Taylor, 2006). The COs did not question institutionalization itself. So the reforms they advocated did not result in significant change.

- The COs led the first organized efforts to improve the training, attitudes, and status of direct support workers. Their primary motivation was to try to ensure humane care of people supported by the workers. In 1944, the COs at Byberry organized a union to address their concerns. Their first objective was "to improve patient care by improving the working conditions of hospital employees." The COs demonstrated that the interests of direct support workers and people with disabilities are not incompatible.
- Throughout their brief history, the COs had an uneasy relationship with professional leaders. Although some psychiatrists gave their support to the COs, many disparaged their efforts and the foundation they created for refusing to accept medical leadership and direction. The COs captured the public spotlight for a brief period of time, but before long, professionals re-established their control of the public and political discussions regarding psychiatric and intellectual and developmental disabilities.
- The COs confronted a "crisis," but the crisis they confronted was never resolved, as evidenced by events in the 1960s and 70s. It faded from public and professional

view. Today's recognized crisis in the direct support workforce could suffer the same fate.

UNIONS: A CHECKERED HISTORY

By the 1970s, employees at public institutions in many states had become unionized. In response to initial stage of deinstitutionalization, some public employee unions became vociferous opponents of the movement of people from state institutions to privately operated community programs (Taylor & Searl, 2001). Unions representing nursing home workers in the private sector also have opposed deinstitutionalization at times.

In 1975, the American Federation of State, County, and Municipal Employees (AFSCME), a public employee union representing 250,000 mental health workers nationally, released a scathing report that blasted the policy of deinstitutionalization. The report, titled Out of Their Beds and into the Streets, presented deinstitutionalization as a plot to relieve state governments of the responsibility for caring for people with mental disabilities, the elderly, and other groups and to put money into the pockets of private profiteers (Santiestevan, 1979). Jerry Wurf, the president of AFSCME, wrote the introduction of the report: "It seems to us that 'deinstitutionalization,' a lofty idea, has become something very ugly—a cold methodology by which government washes its hands of direct responsibility for the well-being of its most dependent citizens."

The Civil Service Employees Association (CSEA), a New York State union representing institutional employees, took up the cause. In 1978, CSEA sponsored a major public relations campaign to convince politicians and the public that deinstitutionalization meant "dumping." "The State Calls It Deinstitutionalization," read one advertisement, "We Call It Cruel." As part of its campaign, CSEA prepared a series of 60 second radio advertisements that painted deinstitutionalization as a cruel rip-off. In response to CSEA's campaign, New York State's Governor Hugh Carey authorized the establishment of state-operated group homes staffed by public employees as part of deinstitutionalization at Willowbrook in New York City (Rothman & Rothman, 1984). New York State's dual state and privately operated community service system reflects a political compromise to avoid union opposition to deinstitutionalization.

Public employee unions in some states continue to be opponents of deinstitutionalization and institutional closure. In the late 1990s, the California Association of Psychiatric Technicians (CAPT), the union representing state institutional employees, joined with institutional parent groups in advocating for a moratorium on community placements (Taylor, 2001).

The opposition to deinstitutionalization by public employee unions representing institutional workers has left a bitter legacy. Many disability advocates are distrustful of union efforts to organize direct support workers and believe that unions will

always sacrifice the interests of people with disabilities in favor of the interests of workers and the unions themselves.

EMERGING SUPPORT APPROACHES AND THE DIRECT SUPPORT WORKFORCE

Since the late 1960s, the residential service system has undergone several transitions. The first major change involved a shift from an exclusive institutional model to a system comprised of institutions and community facilities of various sizes known as group homes, community residences, supervised apartments, and, in the latter part of the 1970s, “small” (15 or fewer people) Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Although these community facilities were more likely to be physically integrated into the community, they still provided people little control over their supports. Like institutions, community agencies hired and supervised staff. Staff worked for and were accountable to agencies, not to individuals supported by the agencies.

The 1980s, in particular, witnessed the emergence of alternatives to agency-operated facilities. Under supported living and related approaches, people with disabilities could be supported in their own homes and, hence, could exercise greater control over their personal space and routines of life. Yet, agencies typically continued to be responsible for hiring and supervising direct support staff. An individual might be matched with the most compatible

direct support worker, but still did not control his or her own supports.

Later in the 1980s and continuing until today, approaches were developed that gave people with disabilities direct control over support staff. From the independent living movement, self-directed personal assistance emerged. An individual needing personal support, or in some cases a “self-directing other” (e.g., a family member), could recruit, select, supervise, schedule, and terminate direct support workers. An independent living center or other agency typically served as the employer of record and handled payroll and benefits, but the individual with a disability had the final say over who will provide assistance or support.

Another more recent approach is referred to as cash and counseling, individual budgeting or funding, or self-determination. Although there are variations in this approach, they all provide funding directly to people with disabilities or their families. People can decide what services and supports to purchase and have the flexibility to recruit direct support workers. A “support broker” or consultant may be available to help an individual or family member to manage funds or to decide upon needed services. Typically, a “fiscal intermediary” serves as a conduit for public funds to be allocated to individuals.

Self-directed personal assistance and individual funding schemes are popular among people with disabilities and family members participating in these programs. These approaches

afford greater choice and provide increased control over services and supports.

These approaches alter the relationship between consumers and providers of direct supports. Direct support workers are directly accountable to people with disabilities or family members, rather than agencies. Their role is not to supervise people in accord with standard agency policies, but rather, to support people in ways in which they wish to be supported. Any solution to the direct workforce crisis must leave room for self-directed approaches and this new form of relationship between consumers and support workers.

ARE THE INTERESTS OF PEOPLE WITH DISABILITIES AND DIRECT SUPPORT WORKERS COMPATIBLE?

The interests of people with disabilities and direct support workers are often viewed as being at odds or at least unrelated to each other. Current approaches for supporting people with disabilities emphasize personal control, empowerment, and self-determination. Representatives of direct support workers stress worker rights, job security, and improved pay and benefits. Yet, the interests of these two groups are not incompatible.

John O'Brien and Connie Lyle O'Brien (O'Brien and Lyle O'Brien, 2005) provide a useful way of thinking about the relationship between people with developmental disabilities and direct support workers in Figure 1. O'Brien and Lyle O'Brien's figure addresses two considerations, represented by sectors. One

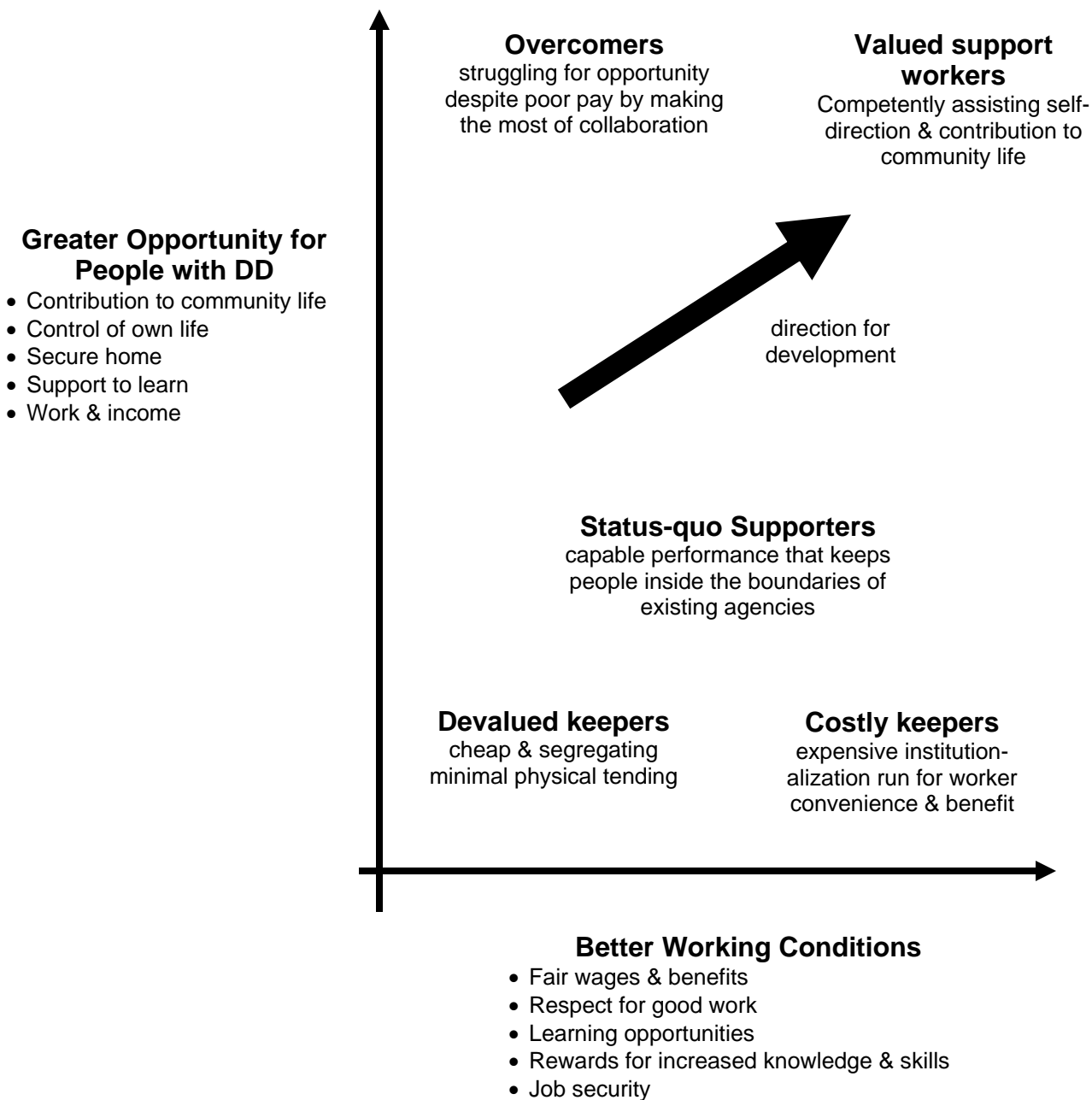
consideration relates to better working conditions (fair wages and benefits; respect for good work; learning opportunities; rewards for increased knowledge and skills; job security), conditions that have been associated with the interests of direct support workers. The other consideration has to do with opportunities for people with developmental disabilities (contribution to community life; control of own life; secure home; support to learn; work and income). Within the figure, possible roles of direct support workers are presented:

- Devalued keepers: poor working conditions and few opportunities for people with developmental disabilities.
- Costly keepers: good working conditions and few opportunities for people with developmental disabilities.
- Status-quo supporters: fair working conditions and some opportunities for people with developmental disabilities.
- Overcomers: poor working conditions and many opportunities for people with developmental disabilities.
- Valued support workers: good working conditions and many opportunities for people with developmental disabilities.

O'Brien's figure provides a direction for the future: increasing opportunities for people with developmental disabilities, while improving the working conditions of direct support workers. People with intellectual or developmental disabilities benefit when their support workers receive fair wages and benefits and are

FIGURE 1

Workforce Sectors
defined by balance of potentially compelling values of better working conditions
and greater opportunity for people with DD



O'Brien and Lyle O'Brien, 2005

well-trained and respected. Poorly paid and trained support staff and high turnover rates interfere with the quality of life of people with developmental disabilities. Workers benefit not only when they have decent working conditions, but also when their work is meaningful and enables them to support people with developmental disabilities to lead quality lives.

UNION PROS AND CONS

One proposal to address the direct support workforce crisis is the unionization of direct support workers in the private sector. Unions have already established a foothold in the nursing home and home health care industries and have achieved gains in organizing workers in the community service system in developmental disabilities. Unions as diverse as the Service Employees International Union, United Domestic Workers, and the International Brotherhood of Teamster's have successfully organized non-public direct support workers. Even New York's Civil Service Employees Association, which represents state workers, has made in-roads in organizing community workers in the private sector.

The unionization of direct support workers in the private sector is deeply controversial among people in the field of developmental disabilities. Many advocates and service providers distrust unions and resist any efforts at collective bargaining. Among the arguments made by opponents of unionization are the following:

- As evidenced by the opposition of public employee unions to deinstitutionalization, unions have a history of letting the interests of workers trample the interests of people with disabilities. Unions would obstruct the right of people with disabilities to community living and participation in order to protect union jobs.
- Private community agencies, and especially non-profits, operate on extremely tight budgets and simply cannot afford to offer workers significant increases in wages and benefits. Unionization would force agencies to cut-back services or to go out of business entirely.
- Unions would interfere with the employer-employee relationship based on a common commitment to supporting people with disabilities.
- Unionization would make it extremely difficult to discipline or terminate sub-standard or even neglectful workers.
- Unions' most powerful weapon, the work stoppage or strike, would leave people with disabilities in the community extremely vulnerable.
- Unionization would force workers to become union members regardless of their personal desires.
- Union dues would off-set any increases in wages or benefits obtained through unionization.

- Unionization would interfere with the ability of people with disabilities or family members to select their own support workers.
- As long as unions continue to represent workers at institutions and nursing homes, they will continue to advocate for these industries to receive a large slice of the public fiscal pie.

Other advocates are open to or supportive of the unionization of direct support workers in the community. Union supporters can make the following arguments:

- Unionization would increase wages and benefits significantly and would reduce staff vacancies and turnover.
- Unions have a proven track record of improving worker wages and benefits and job security.
- The vast majority of direct support workers in the community are women and members of racial or ethnic minority groups who must have tools to protect themselves against the ongoing pattern of discrimination.
- Workers have inherent rights to living wages, health care, and other benefits.
- People with disabilities and their families have the right to be supported by a stable workforce.
- Community agencies, and especially large providers and for-profit organizations, have their own vested interests

and cannot be counted upon to protect the rights of people with disabilities.

- Unionization of direct support workers would lead governments to increase the amount of funds allocated for services.
- Unions are well-organized and can use their political clout to improve the situations of people with disabilities.
- Not all unions are the same. At least some unions would be willing to make concessions to safeguard the interests of people with disabilities and family members.

How can we weigh the potential pros and cons of unionization?

PROMISING UNION INITIATIVES

With over 1.9 million members as of July 19, 2007, Service Employees International Union (SEIU) is one of the fastest-growing and largest unions in the country. SEIU has been successful in organizing nursing home and home care workers. Today, it is expanding efforts to organize personal care attendants supporting people with disabilities and direct support workers in the intellectual and developmental disability system.

SEIU has broken ranks with public employee unions that oppose deinstitutionalization and has expressed public support for community living. In 2005, SEIU joined over 180 disability and family organizations in endorsing The Community Imperative declaration (Center on Human Policy, 1979, 2001) at its annual

meeting: "All people, regardless of severity of disability, are entitled to community living." Endorsement by the international union followed endorsements by six SEIU local affiliates, one in Massachusetts and five in California. SEIU also has supported the Living Assistance Services and Supports Act of 2007, which would shift Medicaid funds from institutions to community living and expand self-directed personal assistance. The union has supported or provided funding to disability rights and self-advocacy groups as well.

Unionization of direct support workers conjures the image of an agency by agency organizing effort. Although SEIU locals have used this approach with nursing homes and some community providers, SEIU adopted a different strategy in an effort to organize personal care attendants or home care workers in California, Massachusetts, Michigan, Oregon, and Washington. In these states, SEIU worked with other groups, including disability rights and advocacy groups, to have legislation passed to establish workforce councils and to increase funding for personal assistants. The concept behind the workforce councils is to have a central directory of personal assistants or support workers, who would have the right to unionize. The workforce councils can set wages, benefits, and working conditions for workers, but individuals with disabilities have the right to hire or fire their own assistants or support workers.

In 2002 and 2003, SEIU and a relatively small group of supporters promoted California Assembly Bill 649. A.B. 649 would

have established public workforce service centers that would employ and set wages and benefits for all direct support workers in California's private community service system. Community providers and individuals with intellectual and developmental disabilities would select direct support workers from the workforce service centers' registries. Drafts of A.B. 649 supported the principle of consumer direction. A.B. 649 encountered stiff opposition from the provider community and a number of statewide advocacy organizations. The bill died amid California's fiscal crisis that resulted in the recall of Governor Gray Davis and the election of Arnold Schwarzenegger.

The 300 locals affiliated with SEIU vary widely. Many represent workers in nursing homes, which house both elderly people and people with disabilities, and consistently advocate for increased funding for these facilities. As long as SEIU locals advocate for segregated facilities and remain silent on the right of people with disabilities to community living, many people will remain skeptical of the union. At the same time, some SEIU locals have supported forward-looking initiatives on behalf of people with disabilities and their families. In Connecticut, SEIU worked with advocacy groups to have the legislature fund a program to provide services to adults with autism who do not have intellectual disabilities. In southwestern Pennsylvania, SEIU joined with Tri-County Patriots for Independent Living to endorse a statement supporting both the right of people with disabilities

to live in the community and the right of personal assistants to a living wage, access to benefits, and affordable family health insurance (Johnson, 2007).

OPINION: CAN UNIONS HELP?

Many years ago, a colleague, Bob Bogdan (1983), made the following analogy. “Is mainstreaming a good idea?” is a bit like asking, “Is Tuesday a good idea?” Both are the wrong questions. It is not so much whether mainstreaming and Tuesdays are good ideas as what we make of them (also see Biklen, 1985).

Is unionization of direct support workers in the community a good idea from the vantage point of people with disabilities, family members, and advocates? This too is the wrong question.

The direct support workforce crisis is real, and it is likely to get worse unless something is done. Unionization of workers is one potential way of addressing this crisis. It would be counter-productive to reject unions out-of-hand. At the same time, unionization could do more harm than good if it is not done in a thoughtful way or if unions are willing to sacrifice the interests and rights of people with disabilities.

- Although unions necessarily put the interests of workers first, they must also support the values surrounding full inclusion and community participation for people with disabilities. Improved benefits for workers must not come at the expense of people with disabilities or their families.

- Efforts to unionize workers must be tied to policy initiatives to increase the funding available for worker wages and benefits.
- Consistent with self-directed and individual funding approaches, individuals with disabilities or their families must have the ability and sole authority to select, supervise, and terminate the relationship with unionized direct support workers.
- Community providers must have the ability to set reasonable performance standards and training expectations for workers.
- For individuals who are supported in their own homes, unions must agree to forego strikes or other actions that would place people at risk.

If the direct support workforce crisis is not resolved—if direct support workers in the community continue to receive low wages and poor benefits, people with disabilities, family members, and advocates may not have a say in the matter of whether direct support workers become unionized. It is far better to engage in constructive dialogue with forward-looking unions or even a single union than to let events unfold on their own.

REFERENCES AND FURTHER READING

Biklen, D. (1985). *Achieving the complete school: Strategies for effective mainstreaming*. New York: Teachers College Press.

- Blatt, B., & Kaplan, F. (1966). *Christmas in purgatory: A photographic essay on mental retardation*. Boston: Allyn & Bacon.
- Bogdan, R. (1983, February) "Does mainstreaming work?" is a silly question. *Phi Delta Kappan*, 64(6), 427-428.
- Braddock, D., Hemp, R., & Rizzolo, M. K. (2003). *State of the states in developmental disabilities project (preliminary data)*. Boulder, CO: University of Colorado Department of Psychiatry.
- Center on Human Policy, Syracuse University. (1979, 2001). *The Community Imperative: A refutation of all arguments in support of institutionalizing anybody because of mental retardation*. Syracuse, NY: Author. Retrieved January 8, 2007: http://thechp.syr.edu/community_imperative.html
- Johnson, T. T. (2007, July-August). Personal assistants join union. *Mouth Magazine*, 18(1&2), 4-5.
- Larson, S. A., Byun, S., Coucouvanis, K., & Prouty, R. W. (2005, July). Staffing patterns, characteristics and outcomes in larger state residential facilities in 2004. In R. W. Prouty, G. Smith, & K. C. Lakin (Eds.), *Residential services for persons with developmental disabilities: Status and trends through 2004* (pp. 47-59). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved January 8, 2007 from <http://rtc.umn.edu/docs/risp2004.pdf>.
- Larson, S. A., Hewitt, A. S., & Lakin, K.C. (2004). A multi-perspective analysis of the effects of recruitment and retention challenges on outcomes for persons with intellectual and developmental disabilities and their families. *American Journal on Mental Retardation*, 109, 481-500.
- Maisel, A. Q. (1946, May 6). Bedlam 1946: Most U.S. mental hospitals are a shame and a disgrace. *Life Magazine*, 102-118.
- O'Brien, J., & Lyle O'Brien, C. (2004). *Competent and committed direct support relationships: Development modules for organizations seeking better quality* [Book & CD]. Lithonia, GA: Responsive Systems Associates.
- O'Brien, J., & Lyle O'Brien, C. (2005). *Finding meaning in the work: Ten exercises to encourage reflection on direct support*. Toronto: Inclusion Press.
- Prouty, R. W., Smith, G. & Lakin, K. C. (Eds.). (2007). *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. Retrieved December 15, 2007 from <http://rtc.umn.edu/docs/risp2006.pdf>.
- Rothman, D. J., & Rothman, S. M. (1984). *The Willowbrook wars*. New York: Harper & Row.

- Santiestevan, H. (1979). *Out of their beds and into the streets*. Washington, DC: American Federation of State, County and Municipal Employees.
- Sareyan, A. (1994). *The turning point: How persons of conscience brought about major change in the care of America's mentally ill*. Scottsdale, PA: Herald Press.
- Taylor, S. J. (2001). The continuum and current controversies in the USA. *Journal of Intellectual & Developmental Disability*, 26(1), 15-33.
- Taylor, S. J., & Searl, S. J. (2001). Disability in America: A history of policies and trends. In E. D. Martin, Jr. (Ed.), *Significant disability: Issues affecting people with significant disabilities from a historical, policy, leadership, and systems perspective* (16-63). Springfield, IL: Charles C. Thomas.
- U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. (2006, January). *The supply of direct support professionals serving individuals with intellectual disabilities and other developmental disabilities: A report to Congress*. Washington, DC: Author. Retrieved January 4, 2007 from <http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.pdf>.
- Zahn, G. C. (1946a). "Abandon hope." *The Catholic Worker*, 13(8), 1,4,6. Retrieved January 4, 2007 from <http://www.disabilitymuseum.org/lib/docs/1732.htm>.
- Zahn, G. C. (1946b). Slaves or patients? *The Catholic Worker*, 13(7), 1,6. Retrieved January 4, 2007 from <http://www.disabilitymuseum.org/lib/docs/1720.htm>.
- Zahn, G. C. (1946c). State school unnatural, maltreats children. *The Catholic Worker*, 13(6), 5-7. Retrieved January 4, 2007 from <http://www.disabilitymuseum.org/lib/docs/1733.htm>.

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