Empowering People with Disabilities

written by Ravi Malhotra | January 26, 2010

WHEN MOST ON THE LEFT THINK about the politics of caregiving, they think about finding a caregiver for their elderly parent or daycare for their preschool child. Or they think about the (frequently romanticized and flawed) feminist debates that interrogate whether there is a feminist ethic of caring and the implications of this for feminist politics. One issue that has largely been ignored is the provision of what has come to be known as attendant care or personal assistance services for primarily, but not exclusively, working age people with physical disabilities. This is rather unfortunate because attendant care services actually raise many complex and unique issues that require a close analysis of the politics of attendant care apart from broader issues in caregiving.

Attendant care or personal assistance services refer to assistance with activities of daily living such as bathing, dressing, and toileting. While the exact model of service delivery varies, attendants are trained and directed by the disabled person, generally referred to as a consumer of attendant care services, to allow the disabled person to live independently in the community. No special medical skills are required. And they are fundamental for many people with disabilities, a historically oppressed group that tends to be on the margins of society with respect to employment status, educational levels and income levels,[1] to achieve full citizenship. This encompasses participation in the labor market or the ability to pursue post-secondary studies, the freedom and opportunity to enjoy recreational opportunities and generally flourish as respected equals.

Moreover, adequate attendant care is crucial in maintaining health and a high quality of life for many people with disabilities. A failure to provide attendant care services would be particularly disastrous for parents with disabilities and may even result in a judicial determination that parents with disabilities ought not to have custody of the child.[2] Unfortunately, funding for such programs is often very limited and the work force, one that is disproportionately made up of women of color and recent immigrants, is often transient and poorly paid. An alliance between union activists who organize personal assistance services and consumers would dramatically transform the politics and legal regulation of the sector from below and potentially enrich two distinct social movements in a mutually beneficial way. Nevertheless, while highly desirable, such an agenda can only proceed to fruition if both constituencies truly respect the other and overcome a number of barriers that impede greater solidarity.

A Brief History of the Disability Rights Movement

HISTORICALLY, PEOPLE WITH DISABILITIES who required assistance with activities of daily living either (a) lived with family members or other relatives until their death and received informal assistance, or (b) were placed in some kind of institutional setting such as a nursing home. The horrors of institutional care for people with disabilities have been well documented, particularly in the case of people with intellectual and mental health disabilities. For example, sexual abuse, neglect, and even deaths have been common problems in many institutional settings including the very recent past.[3] Lack of freedom and significant dangers to the institutionalized disabled person's safety have been all too commonplace features of institutional settings. At the notorious Partlow School in Alabama that has been at the heart of lengthy litigation, a litany of extreme abuses in the 1970s, including a resident who was scalded to death during a bath, have been documented.[4] This is one reason why one must be very careful not to conflate the experiences of people with disabilities with other relatively non-stigmatized populations who might require caregiving, such as elderly people or children. While abuse may occur in all segments of the population, the widespread stigmatization of

disability as something that is not normal and is deviant makes people with disabilities particularly vulnerable to abuse. Many people with disabilities have expressed a desire to commit suicide rather than live in the highly restrictive environment of a nursing home.

In the case of those people with disabilities who have avoided institutionalization, family members or friends perform the attendant care on an unpaid basis, and most disabled people live in extreme poverty.[5] This of course leads, in many cases, to considerable friction, unhappiness and abuse within families. The autonomy of many adults with disabilities is compromised as they are forced to adjust their schedules to meet the needs of their unpaid and increasingly elderly caregivers.[6] In the most tragic cases, children with disabilities have been murdered by their parents, at least in part because of a lack of appropriate support services.[7] Unfortunately, this pattern largely continues even today because of the lack of adequate funding for personal assistance care services. The lack of alternatives means that working age people with disabilities either end up in nursing homes or often become regarded as burdens as family members give up employment or leisure opportunities to assist relatives with disabilities. In some cases, caregivers may even endanger their own health.[8]

The emergence of the independent living movement in the early 1970s in California, and soon thereafter nationally and internationally, marked a dramatic shift in attitudes on personal assistance services specifically and disability rights generally. The independent living movement is based on the idea that people with disabilities ought to have the same civil rights, choices and control over their lives as those without disabilities. It entails allowing disabled people to be empowered so that they may undertake the same risks as others and resist a paternalism that fosters oppression.[9] The politics of the independent living movement are complex and even somewhat contradictory. While its origins are rooted in multiple social movements including largely untheorized campaigns such as the self-help social movements associated with Alcoholics Anonymous and other such support groups as well as conceptualizing disabled people as consumers with rights associated with their status as customers,[10] it is apparent that the African American quest for civil rights that emerged in the 1960s has had a major impact in the development of the independent living movement.[11] It is therefore closely associated with the social model of disablement which posits that it is structural barriers in society, from a lack of wheelchair ramps to a lack of attendant services and stereotypical attitudes, which are the fundamental problems faced by people with disabilities.[12] At the same time, it has a very market-oriented and conservative individualist strain to resolving social issues which has implications for all issues that it seeks to analyze including the politics of attendant care.

One of its earliest manifestations was the incorporation of the first Independent Living Center (ILC) in Berkeley in 1972, growing out of the activism of the Rolling Quads, an activist organization at the University of California. There seems little doubt that the Rolling Quads were to a large degree influenced by the vibrant social movements that were so dominant in Berkeley at the time. Indeed, many who provided attendant care services to this generation of disabled student activists were conscientious objectors to the Vietnam War performing alternative services instead of being drafted. Within a few years, hundreds of ILCs flourished across the United States and eventually internationally. Embodying the principles behind the slogan "Nothing About Us Without Us," ILCs sought to empower people with disabilities through advocacy and peer support. Some of these ILCs have offered personal assistance services.[13] Nevertheless, the majority of personal assistance services for even people living in the community is delivered through home health agencies.[14]

The Independent Living Movement and MiCASSA

IN ORDER TO UNDERSTAND contemporary debates around attendant care, it is crucial that advocates of social justice appreciate how both the social model of disablement and the independent living movement have each fundamentally shaped the demands for attendant care services. At the very

core, the social model is reflected by the demand that people with disabilities who receive the service control the nature of the services provided by the attendant. It consequently severs what one might call executional autonomy from decisional autonomy.[15] To provide an illustration, a disabled woman might choose to wear a green blouse and a red skirt on Monday. The fact that her attendant actually puts the clothes on her body because she is unable to execute the task of dressing herself does not detract from the fact that she has elected to make the choice of what clothes to wear. In many institutional settings, such choices have been frequently made by others. While it is true that not every single disabled person may be able to direct his or her own attendant, it is also clear that the vast majority of disabled people, if empowered, are perfectly capable of doing so.

Consequently, the independent living movement has generally advocated placing the disabled person in charge of the funding to pay for attendant care so that he or she may hire, fire, and manage the attendants as needed. For instance, the National Council on Independent Living has played a key role in lobbying, to date unsuccessfully, for the enactment of the important Medicaid Community-Based Attendant Services and Supports Act (MiCASSA).[16] This proposed bill, which has been introduced several times in Congress over the last several years with no success despite support from such unlikely sources as former House Speaker Newt Gingrich, would mandate that states provide the option of community-based attendant services for Medicaid-eligible people with disabilities, rather than solely in nursing homes which have continued to receive the lion's share of Medicaid dollars. The choice would then rest with the person with the disability to select the option that best suits her or his needs.[17] It should be stressed, however, that this refers only to people with disabilities who are eligible for Medicaid. Activists who are committed to social justice from below must not forget to maintain the broader horizons of ultimately facilitating, as with the very attainable dream of single payer health care, a universal attendant services program for middle-class Americans with disabilities who should not have to sacrifice precious income to pay for badly needed services. A universal and portable attendant services program would also enable users to have the freedom to move from state to state without having to worry that suitable services will not be available in another state.[18]

This issue has also been adopted by perhaps the most radical disability rights organization in the United States, American Disabled for Attendant Programs Today or ADAPT.[19] Originally founded to campaign for wheelchair accessible intercity buses, it shifted priorities (and correspondingly changed the meaning of its acronym) once it successfully won that goal to focus on attendant services. Although it manifests no explicit ideological line, it has demonstrated a flair for innovative forms of direct action and protest including pickets, guerrilla theater, and civil disobedience that, to a degree, represent the best of committed activist struggles from below.[20] This can be illustrated in the Free Our People March that ADAPT organized in September 2003 that attracted hundreds of people with disabilities in a march from the Liberty Bell in Philadelphia to Capitol Hill in Washington. Such marches also help to foster a more cohesive consciousness around disability politics and disability identity that facilitates further struggles and avoids the dysfunctional fragmentation whereby disabled people organize on the basis of a single medical condition and irrationally compete against each other for resources.[21]

While the powerfully influential American Health Care Association has, not surprisingly, strongly opposed MiCASSA,[22] there have also been significant tensions between unions and disability rights activists on the issue, given the facts that many nursing homes are unionized and that the argument of disability rights activists has sometimes taken on a neoliberal tone of highlighting the advantage of cost reductions, at least partly due to lower non-union salaries. When one recalls the individualist strain of the independent living movement, this is hardly surprising. ADAPT has not hesitated to criticize unions that it feels have threatened its interests. For instance, in 2002, it blocked the headquarters of the AFL-CIO, as well as two unions representing nursing home workers,

AFSCME and SEIU, to demand a meeting with union leaders on the issue.[23] There has also been tension between disability rights activists and unions over the closure of institutions such as the Laguna Honda nursing home in San Francisco. Nevertheless, dialogue between the two constituencies has led to some progress as the SEIU has endorsed MiCASSA and is increasingly focused on organizing community based attendants.[24]

The Contradictory Politics of Coalition Building

IN PRACTICE, HOWEVER, there are many difficulties that highlight the possibilities for both coalition building between disability rights activists and advocates for the rights of attendants, as well as potential perils and pitfalls that have to be creatively mediated. First, the low wage and low benefits nature of the attendant services labor market means that it is not always easy for even disabled people with direct funding or personal wealth to find attendants to hire.[25] The transient nature of the market is extremely frustrating for many people with disabilities who have invested significant time in training attendants, only to find that they very soon move on to other opportunities. Regrettably, people with disabilities are often victims of thefts or even physical, sexual, or mental abuse by some attendants. One study found that nearly forty percent of people with disabilities in a random sample had been robbed at least once by an attendant.[26]

Moreover, the low wages and lack of essential benefits surely plays a role in both the high turnover rate and many of the complaints that people with disabilities often express about some attendants who are insensitive or rude. Indeed, a study of San Francisco County found that higher wages and benefits among home care workers reduced turnover.[27] This suggests some common ground between disability rights advocates and union activists. To its credit, one of the main twelve planks of the proposed MiCASSA initiative is a living wage and quality benefits for attendant workers.[28] This is a promising first step and a crucial gesture of solidarity on the part of disability rights activists.

However, the libertarian strain within the independent living movement often leads some disability rights activists to be unduly suspicious and dismissive of trade union activists who are trying to improve their lives and earn a living wage. At the same time, unions need to be sure to appreciate the systemic discrimination faced by people with disabilities, educate themselves about the social model of disablement and acknowledge why control by the disabled consumer is so important. It would be a serious mistake if union activists were to use the tools of collective bargaining to try to impose unreasonable restrictions on the kind of work they will perform that infringe on the rights of the disabled consumers to live their lives as equal citizens. Particular sensitivity has to be accorded to respecting the disabled consumer's right to select an attendant of his or her choice of gender for what is, after all, in many cases very intimate care.[29] I would also suggest that unions align with disabled people in rejecting the unwarranted restriction of certain simple procedures to performance by medically trained specialists only and simply focus on unionizing workers regardless of skill or training. This sort of craft protectionism arbitrarily and negatively limits the rights of people with disabilities and simultaneously divides the union movement into weak, discordant units.

Enabling collective bargaining while honoring the principle of consumer control is a tricky matter but creative solutions ought to permit both the labor rights of workers and the rights of people with disabilities to be respected. As organizing attendant care workers already entails surmounting restrictions under the National Labor Relations Act because of the legal ambiguity over the identity of the employer and management efforts to define workers as independent contractors, it should not be impossible to integrate the needs of disabled consumers within a union-friendly paradigm. Advocating for the adoption of the legal doctrine of "dependent contractors" that is operative in many Canadian provinces and allows such workers to collectively bargain despite some

affinities with independent contractors may provide one avenue of admittedly uphill resistance.[30] Smart, politically savvy unions will forge grassroots alliances with progressive disability rights activists to secure both creative legal reforms that re-regulate the market to empower the marginalized as well as better funding that benefits both parties. In a labor market where many employees in all sectors work at home or in non-traditional post-Fordist employment arrangements, this kind of flexibility should simply be seen as part of a larger project that grapples with the legacy of globalization. Reformulating current highly bureaucratic labor law structures from below to allow the organization of dispersed workers while respecting the rights of disabled clients are entirely attainable objectives. Only rank-and-file movements of disability rights activists and union activists working in tandem can bring about effective attendant services that are empowering for disabled people, while providing quality jobs for workers.

Footnotes

1. See Ravi Malhotra, "The Politics of the Disability Rights Movements," in *New Politics* no. 31 (Summer 2001): 65-75.

2. See Michael A. Stein, review of *A Mother's Touch: The Tiffany Callo Story,* by Jay Mathews, *Brooklyn Law Review* 60 (1994): 1082-83. Tiffany Callo was a mother with cerebral palsy whose custody of her child was threatened by child welfare authorities. While some might want to frame this as an issue of child care, Ms. Callo clearly required what may be accurately described as attendant care to assist with parenting the child, not rearing of her child while she was absent from the home.

3. See Marta Russell, "Abuse: Sanctioning Societal Violence" (June 10, 2001), for a truly chilling account of abuses. The record of the for-profit institution, Leben Home for Adults, where incidents include a missing resident, sexual violence and even deaths, is particularly shocking.

4. Mark C. Weber, "Home and Community-Based Services, Olmstead and Positive Rights: A Preliminary Discussion," *Wake Forest Law Review* 39 (2004): 276.

5. Andrew I. Batavia, "A Right to Personal Assistance Services: 'Most Integrated Setting Appropriate' Requirements and the Independent Living Model of Long-Term Care," *American Journal of Law & Medicine* 27 (2001): 18.

6. *Ibid*. at 19, 21.

7. This of course in no way excuses criminal acts committed by parents against their disabled children. Providing context should not be conflated with exculpation. For a discussion of a notorious Canadian case in which a father murdered his twelve year old daughter with cerebral palsy, see my article, "Tracy Latimer, Disability Rights and the Left," *Canadian Dimension* (May/June 2001): 23-25.

8. Batavia, 18.

9. Samuel R. Bagenstos, "The Americans with Disabilities Act as Welfare Reform," *William and Mary Law Review* 44 (2003): 989.

10. Gina McDonald and Mike Oxford, "History of Independent Living," (accessed January 25, 2006). Ralph Nader was of course a major figure in promoting consumer rights more broadly prior to his political career.

11. Richard K. Scotch and Kay Shriner, "Disability as Human Variation: Implications for Policy,"

Annals of the American Academy of Political and Social Science 549 (1997): 150-51.

12. See Michael Oliver, *The Politics of Disablement* (London: Macmillan Press, 1990) for an overview.

13. Bagenstos, "Americans," 987-91.

14. Bob Kafka, "Empowering Service Delivery," *Ragged Edge* (1998) (accessed January 31, 2006).

15. Bagenstos, "Americans", supra note 9 at 992-93.

16. *Ibid.* at 994, fn. 316.

17. Samuel R. Bagenstos, "The Future of Disability Law," *Yale Law Journal* 114 (2004): 68.

18. See Kari Krogh and Jon Johnson, "A Life without Living: Challenging Medical and Economic Reductionism in Home Support Policy for People with Disabilities," in *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law*, eds. Dianne Pothier and Richard Devlin (Vancouver: University of British Columbia Press, 2006), 154.

19. This is not to suggest ADAPT's politics are flawless. They in fact do not consistently adopt an activism from below perspective. For a discussion of this, see Malhotra, footnote 1.

20. See here (accessed January 31, 2006).

21. For a perceptive analysis by a left disability rights activist who participated in this action, see Sunny Taylor, "Notes on ADAPT's Free Our People March,"(accessed January 31, 2006).

22. See here (accessed January 31, 2006).

23. "Disability Rights Activists Get Unions' Attention," *Labor Notes* (July 2002) (accessed January 31, 2006).

24. Bob Kafka, "Disability Rights Vs. Workers Rights: A Different Perspective", ZNet (accessed January 31, 2006).

25. See "The Personal Assistance Services and Direct-Support Workforce: A Literature Review," (2003) (accessed January 31, 2006). For an insightful discussion of this point in the Canadian context, see The Roeher Institute, *Direct Dollars: A Study of Individualized Funding in Canada* (North York: The Roeher Institute, 1993), 56.

26. See Gary R. Ulicny and Michael L. Jones, "Consumer Management of Attendant Services: Benefits and Obstacles," (accessed January 31, 2006).

27. Candace Howes, "Upgrading California's Home Care Workforce: The Impact of Political Action and Unionization", (2004), University of California Institute for Labor and Employment. *The State of California Labor, 2004*. Paper 03, 86 (accessed January 31, 2006).

28. See here (accessed January 31, 2006).

29. The Canadian wing of SEIU has in the past litigated for the right of union members to provide attendant care to nursing home residents of the opposite sex. See "Attendant Care and Gender Issues," (accessed January 31, 2006).

30. Cynthia J. Cranford, "From Precarious Workers to Unionized Employees and Back Again? The Challenges of Organizing Personal-Care Workers in Ontario," in *Self-Employed Workers Organize: Law, Policy and Unions*, eds. Cynthia J. Cranford *et al.* (Montreal: McGill-Queen's University Press, 2005), 105-06. See also Elizabeth Kennedy, Comment, "Freedom from Independence: Collective Bargaining Rights for 'Dependent Contractors'", *Berkeley Journal of Employment and Labor Law* 26 (2005): 144-49.