

# Personal assistance for students with severe physical disabilities in post-secondary education: Is it the deal breaker?

Norma J. Stumbo<sup>a,\*</sup>, Jay K. Martin<sup>b</sup> and Bradley N. Hedrick<sup>c</sup>

<sup>a</sup>*Midwest Alliance, University of Illinois, Champaign, IL, USA*

<sup>b</sup>*Department of Mechanical Engineering, Midwest Alliance, UW-CREATE (Center for Rehabilitation Engineering and Assistive Technology), University of Wisconsin-Madison, Madison, WI, USA*

<sup>c</sup>*Division of Disability Resources and Educational Services, University of Illinois, Champaign, IL, USA*

Revised /Accepted: September 2008

**Abstract.** Persons with severe physical disabilities are disadvantaged in the postsecondary education and the workforce due to inadequate education and educational supports. One of these educational supports is the availability of reliable and trained 24/7/365 personal assistance. Without adequate access to personal assistance, individuals with severe physical disabilities simply cannot attend and graduate from postsecondary degree programs. It is clear that if individuals with high support needs cannot live within the educational environment, they will not be able to succeed in the educational environment. This article examines the nature of this problem, describes current models of postsecondary disability support structures, and explores the difficulties and challenges inherent in personal assistance service provision. It is hoped that this discussion will prompt broader discourse regarding postsecondary services for students with severe physical disabilities and impact their participation in higher education.

**Keywords:** Students with disabilities, post secondary education, personal assistance

## 1. Introduction

Persons with disabilities, especially those with severe physical disabilities, often experience great difficulty entering and succeeding in the workforce due to inadequate education and educational supports [7]. Individuals with severe physical disabilities need help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) through either technological or human assistance [12,15,22,23,60]. While this is often discussed in relation to older adults being able to remain in their homes (e.g. [1–4,11,16,21,24]) or in workplace personal assistants (e.g. [5,6,10,31,36,42,50,52–54,61,63]), sufficient conversation related to

the need for personal assistance while attending post-secondary institutions seems to be missing.

The intent of this article is to bring this discussion to the forefront by exploring the: (a) characteristics of individuals with severe physical disabilities, (b) current models and descriptions of disability support services in higher education, and (c) difficulties and challenges imbedded in providing postsecondary personal assistance support services for individuals with severe physical limitations. It is anticipated that this discussion will motivate broader discourse about serving students with severe physical disabilities in American higher education institutions.

## 2. Individuals with severe physical disability and the need for personal assistance

Severe physical disability has been defined in a number of ways, from a social construct [2] to difficul-

\* Address for correspondence: N.J. Stumbo, Ph.D., CTRS, Director, Midwest Alliance, University of Illinois, 2432 Sanford Lane Normal, IL 61761-5482, USA. Tel.: +1 309 454 4582; Fax: +1 309 454 4582; E-mails: nstumbo@illinois.edu or stumbo@wisc.edu.

ty with task accomplishment or activities of daily living (ADLs) and instrumental activities of daily living (IADLs) [11,15,22,23,60]. In most of these latter definitions, severe physical disability is characterized by functional limitations to the extent that the individual is unable to perform ADLs and IADLs on his or her own and needs personal/human assistance (PA) to accomplish those tasks [17,21,24]. Kennedy, LaPlante, and Kaye noted that “people with ADL limitations, and in particular those needing assistance, are considered to have fairly severe disabilities” [22, p. 1]. Guralnik more specifically defined severe physical disability as when “the individual needs help with three or more of the six ADLs (eating, dressing, bathing, transferring, using the toilet, and walking across a small room)” [15, p. 162]. This definition of severe physical disability, with the emphasis on the need for personal assistance, is generally supported throughout the disability and health care literature (cf. [12,19,33,35,60]).

However, Verbrugge, Rennert, and Madans noted that individuals “rarely allow disablement to take its course without efforts to retard or stop the process. . . . Personal and equipment assistance reduce task demand. . . . They operate at the immediate periphery of the individual. . . . Both kinds of assistance aim to solve problems” [59, p. 384]. In other words, individuals with severe physical disabilities work diligently to offset their functional limitations, and because of their extensive needs, solve these difficulties through heavy reliance on personal and technological assistance. Those with the most severe physical disabilities may use a variety of assistive technologies but rely substantially on personalized, human assistance to perform everyday tasks.

According to Hoenig et al., personal assistance services (PAS) refers to

human help provided to individuals in specific activities that are generally obligatory for bodily maintenance and for living in the community, comprising the activities of daily living (ADLs; bathing, dressing, transferring from a bed or chair, toileting, and eating) and the instrumental activities of daily living (IADLs; such as taking medications and shopping for groceries). PAS include all help, whether hands-on, standby, or supervisory, whether paid or unpaid [17, p. S99].

A number of authors have noted that assistive technology (AT) can often augment but not replace human help for these individuals [3,17,21,22,24]. What is often not noted in the literature is that for individuals

with severe physical disabilities, access to personal assistance is necessary 24 hours a day, 7 days a week, 365 days a year. While the person will not require assistance every minute of every day, proximal standby help must be continuously available. Consider personal care, for example: In addition to the normal daytime activities, during sleeping hours assistance for essential needs such as turning while in bed or arranging pillows and bedding are required. In the event of illness or emergency, assistance must be available and reliable. If the required PA is not available when it is needed, the student will not be able to live successfully in that environment. For tasks common to academic activities, such as turning book pages, opening doors, reaching for items, and turning on/off lights, assistance must be available when it is needed, or again the student will not be able to sustain pursuit of a postsecondary education.

LaPlante et al. [24] noted that PA services occur across a continuum or hierarchy of expanding needs; the need for PA services, of course, being more acute as the number of ADL and IADL deficits likewise increases. As noted by Newcomer, Kang, LaPlante, and Kaye [30, p. S205], “rates of unmet need increased as the number of ADL limitations increased.” When there is not enough personal or technical assistance, the needs of a person with a severe physical disability go unmet, and may cause a cascade of secondary health complications, such as discomfort, weight loss, dehydration, falls, and burns [24], as well as the inability to function in school, work, and community settings.

There is an extensive and burgeoning literature on personal assistance for older individuals with severe physical disabilities and limitations (e.g. [1–4,11,17,21,24]) as well as the use of personal assistants in employment settings (e.g. [5,6,10,31,36,42,50,52–54,61,63]). Yet only one study could be located that dealt specifically with the need for personal assistants for individuals with severe physical disabilities in postsecondary education and that study describes services in England (cf. [32]).

This total exclusion of research and discussion about this issue likely reflects the dilemma surrounding the relatively small number of individuals affected compared to those with other disabilities enrolling in higher education (such as individuals with learning disabilities or less-severe physical disabilities). This is further exacerbated with their comparatively higher resource-intensive needs and the lack of legal mandates for the provision of personal assistance services in postsecondary education as opposed to those found in secondary education [58,59]. However, it is clear that

post-secondary education degrees are essential for all individuals to obtain and retain competitive employment [13,46,47,49] and this may be especially true for individuals with severe physical disabilities.

It is also clear that this dilemma is not easily resolved and has many layers of intricacies. For example, the transition from secondary education to postsecondary education, and being away from home for the first time, is overwhelming to many first-year students. Normally, secondary schools are responsible for hiring, training, and supervising personal assistants for high school students with assessed needs and the student and his/her parents are not usually involved in that process. State and local elementary and secondary education agencies that accept federal education funding are required under the Individuals with Disabilities Education Act (IDEA) to provide personal services and aides, including PAS personnel, as warranted to ensure that students with disabilities are afforded a free appropriate public education.

On the other hand, postsecondary institutions are not legally required to provide similar services with regard to personal assistants [58,59]. Thus, incoming students with severe disabilities must face the more typical academic and social demands of a first-year experience while also negotiating the inherent difficulties of finding, hiring, and managing human assistants for help with school work and for the most private and personal of bodily tasks. From the perspective of the institution, meeting the very resource-intensive needs of a small minority of students is difficult to justify given the increasing numbers of students with disabilities entering higher education and whose needs can be met more simply through computer technology or physical and environmental accessibility [49,51].

The US Department of Education [58,59] has made it clear that postsecondary institutions cannot discriminate against individuals with disabilities due to Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act. These acts indicate that postsecondary institutions must provide appropriate auxiliary aids (such as videotext displays and assistive listening systems) and academic adjustments (such as priority registration and reduced course load) to students with disabilities who show need. However, personal assistants are not included in these mandates.

An issue that is often misunderstood by postsecondary officials and students is the provision of personal aids and services. Personal aids and services, including help in bathing, dressing, or other personal care, are not required to be provided by post-

secondary institutions. The Section 504 regulation states: Recipients [postsecondary institutions that receive federal funding] need not provide attendants, individually prescribed devices, readers for personal use or study, or other devices or services of a personal nature. Title II of the ADA similarly states that personal services are not required [58].

However, from the perspective of the individual with a severe physical disability, the lack of personal assistance services in higher education may become the deal breaker for entering and being successful in the post-secondary environment and in future career endeavors.

### **3. Demographics of individuals with severe physical disabilities**

The US Census Bureau [55] and Jans and Stoddard [19] noted that the definitions of disability used by the federal government in programs, policies, and population surveys have changed over the years and are often not in agreement. In many cases, individuals with severe physical disabilities are not separated from individuals with less-severe physical disabilities, let alone from individuals with other disabilities (e.g., cognitive, psychological, and learning impairments). When possible we have been selective about our use of terms; we use “disability” when all disabilities are included, “physical disability” when the disability impairs motor functions or mobility, and “severe physical disability” when a majority of ADLs and IADLs are affected, as suggested by Guralnik [15] and others.

In 1998, Stoddard et al. [43] reported that 32.1 million individuals or 18.7 percent of individuals ages 15 to 64 reported a severe disability. Similarly, Steinmetz [40] reported that in 2002, some 51.2 million Americans (18.1 percent of the total population) had some level of disability, and 32.5 million (11.5 percent of the total population) had a severe disability, although this included individuals with developmental disabilities [40]. In the same survey, about 10.6 million (4.8 percent) of individuals aged 15 or older had difficulty with one or more ADLs or IADLs and needed assistance. About 5.1 million (2.3 percent) required personal assistance with three or more ADLs or IADLs [40], thus fitting the most stringent definition of severe physical disability by Guralnik [15]. It is clear that individuals with severe physical disabilities constitute a significant segment – nearly 10 percent of all individuals with disabilities – of the U.S. population.

### 3.1. *Enrollment and persistence in secondary and postsecondary education*

Individuals with disabilities have marginally participated, succeeded, and enjoyed the benefits of a postsecondary education, although the situation is improving [7]. Belch [7, p. 5] noted that mere “attendance on campus does not equate to earning a degree” for many individuals with disabilities. She noted that attendance did not automatically translate to persistence and graduation.

Steinmetz [40] reported that about 10.4 percent of individuals age 25 to 64 without disabilities did not complete high school, compared to 14.6 for individuals with a nonsevere disability, and 26.6 percent for individuals with a severe disability. Similar trends continued to postsecondary education. Slightly over 43 percent of individuals without disabilities completed a college degree, compared with 32.5 percent of individuals with nonsevere disabilities, and 21.9 percent for individuals with severe disabilities [40].

College enrollment for individuals with disabilities is 50 percent lower for people with than people without disabilities [13,49]. Stodden et al. determined that the “proportion of first-time, full-time students with disabilities tripled between 1978 and 1994 from 2.6% to 9.2% . . . By 1998, the full range of students with disabilities (i.e. part-time students and students enrolled in graduate programs) had risen to 10.5% of the postsecondary student population” [49, p. 189].

While Belch [7] noted that only 12% of all individuals with disabilities entering college actually graduate, Stodden [44] reported that more than half of all students with disabilities who enrolled in postsecondary education persist to graduation. These attrition rates are higher than for other student groups. Stodden quoted the National Center for Educational Statistics’ (NCES) 1999 report that found that, five years after launching their postsecondary program 41% of students with disabilities reported they had earned the intended degree or credential, with an additional 12 percent remaining enrolled in their course of study. It is clear, as the National Center for the Study of Postsecondary Education Supports declared, “persons with disabilities enroll and maintain their participation in postsecondary education at a much lower rate than the general population” [28, p. 1] which undoubtedly corresponds to lower rates of full-time, well-paid employment.

### 3.2. *Employment of individuals with severe physical disability*

In 2000, physical disabilities affected 6.2 percent of the working-age population [55]. Although over 75 percent of Americans 16 to 64 years of age without disabilities are employed, only 31.7 percent of the comparative cohort of individuals with physical disabilities are employed – a gap of over 43 percent [56]. This gap likely widens for individuals with severe physical disabilities – for example, Stoddard et al. [43] reported that only 26.1 percent of individuals with severe disabilities ages 21 to 64 were employed at a job or in a business. Kaye [20] and the National Council on Disability [29] reported that this gap has been relatively consistent since the mid-1990s.

While less than 10 percent of working-age adults lived at or below the poverty rate, their peers with disabilities were almost twice as likely (18.8 percent) to do so [55]. Steinmetz [40] reported that median earnings for individuals with no disability were \$25,000, for individuals with nonsevere disability were \$22,000, and for those with severe disability, \$12,800. The National Council on Disability [29] recently concurred with both of these data points. Perhaps lower salaries, and thus increased poverty levels are due to fewer individuals with disabilities attaining college degrees, as Shaw and Scott [37] and Horn and Berkold [18] reported that individuals with disabilities who graduate from college have very similar employment rates and salaries as their non-disabled counterparts.

Kaye [20] revealed that individuals with severe physical disabilities, such as quadriplegia, often reported being unable to work, not due to health reasons but due to the severity of their functional limitation – likely indicating the lack of workplace assistive technology and/or personal assistance. Conversely he reported “it is clear that people with disabilities who are able to work have seen significant improvements in employment opportunities” [21, p. 39]. Again, it is likely that many employment opportunities are predicated on postsecondary degrees.

The National Council on Disability [29, p. 126] emphasized: “The time may be closer than any of us care to acknowledge when public resources or attitudes no longer will be able or willing to sustain high levels of dependency [for individuals with disabilities]. Viable strategies for replacing dependency with opportunities for productive employment are urgently needed.”

#### 4. Current models of disability support services in American higher education

Postsecondary disability support services are at the crosshairs of two strong but opposing trends. While students with disabilities are enrolling in higher education institutions at unprecedented rates (from a low of less than three percent in 1978 to over 17 percent in 2000), budget support for higher education in general and support services specifically are shrinking [8,16]. This has resulted in variable, sometimes minimal or patchwork models of disability support services, especially for individuals with high support needs resulting from a physical disability. Belch [7] noted that disability support services range from a single individual in charge of all accommodations, services, and programs for all students with disabilities, to departments with a full range of services and staff who specialize in specific areas of disability, and every configuration in between these two extremes. She also noted a clear and distinct difference between services that focus on inclusion versus accommodation. According to Belch, inclusion means that all aspects of the instructional, educational, and living environments are accessible and welcoming to all individuals, while accommodations means that accessibility and integration are often afterthoughts subsequent to someone with a disability appearing at the doorstep. When services, supports, and programs reflect the latter approach, “there may be a significant disconnect between the knowledge and expectations of secondary school providers and student with that of the higher education community” [7, p. 6]. Similarly, Stodden and Conway [45, p. 27] remarked

Postsecondary educational services, supports, and programs available to students with disabilities: (a) vary extensively across states as well as from campus to campus; (b) are generally not well developed or linked programmatically to instruction; and (c) tend to lean toward advocacy, informational services, or remediation of content rather than support in the compensation areas necessary for independent learning and self-reliance.

Stodden and Conway continued that the quality and breadth of such services was variable – a fact clearly recognized by the consumers of these services.

##### 4.1. *Students’ evaluations of disability support services*

The National Center for Education Statistics [27] reported that among students with disabilities, 26 percent

reported receiving disability-related services or accommodations, although 22 percent reported not receiving the ones they needed. This rate was lower at private, for-profit schools (10.6 percent), than for public 4-year (21.2 percent), public 2-year (23.2 percent), or private, not-for-profit 4-year schools (24.0 percent).

These findings are verified in research asking students with disabilities as consumers of these programs, about their experiences and satisfaction with current levels and types of programs, supports, and services. In a study of 10 postsecondary institutions across the nation, students with disabilities felt disability service offices were understaffed and aimed solely at students with the most urgent needs [13]. “They also indicated that postsecondary support service providers should focus on each individual’s needs rather than a formula according to the individual’s disability. Because of these types of difficulties, students discussed the need for individual internal motivation to succeed in postsecondary education” [p. 44][13]. One conclusion from this study was that “students would be better served at postsecondary institutions if there were a more comprehensive network of support services, working cooperatively to support students with disabilities and educating peers and faculty” [13, p. 45].

This also was a conclusion of a study by Lehmann, Davies, and Laurin [25] of 35 college students with a variety of disabilities. Their findings included four dominant themes of students with disabilities experiences in postsecondary education. These included:

1. The lack of understanding and acceptance concerning disabilities in general and their disabilities in particular, on the part of people in general, fellow students, staff, and even faculty.
2. The lack of adequate services to assist in tackling academic and nonacademic responsibilities.
3. The lack of sufficient financial resources and the knowledge of how to acquire them, to live a more self-sufficient life.
4. The lack of self-advocacy skills and training needed to live independently. (p. 2)

Comparable results were found in a 1993 study by West, Kregel, Getzel, Ming, Ipsen, and Martin [62]. Amid complaints of inadequate or spotty services, students reported feeling like advocating for services and accommodations was a constant struggle. Findings also included that many students with disabilities remarked the office or coordinator of services for students with disabilities had made valiant but largely ineffective attempts to alleviate their distress or provide

needed services and accommodations. While most students were largely satisfied and had seen improvements in services, many felt that including students in developing disability-related policies and services would be beneficial.

#### 4.2. *Empirical studies of postsecondary disability support services*

Few empirical studies have been conducted to determine the “full range” of types and extent of postsecondary services, supports, and programs for students with disabilities. One of the earliest studies was conducted by Stilwell and Schulker [41], and reviewed services and programs at 39 public and private colleges and journal colleges. A second effort was documented by Marion and Iovacchini [26]. These researchers surveyed 155 colleges to determine program efforts resulting from the Rehabilitation Act of 1973. Five more recent studies, all produced since 2001, will be highlighted.

Two studies used overlapping data sets obtained by the National Center for the Study of Postsecondary Education Supports (NCSSPES): Stodden et al. [49] and Tagayuna et al. [51]. In the 2001 report, AHEAD and non-AHEAD members were surveyed in 1999 concerning, among other research questions, the supports or accommodations provided to students with disabilities on their respective campuses. Disability support center staff was asked to indicate how often during a calendar year they offered each of the 34 supports listed on the survey. Of interest to this article, is that, while the range of services mentioned is broad – from job placement services to document conversion to adaptive furniture, personal assistance aside from note takers as a support for individuals with severe disabilities is not listed among the items.

The second study by Tagayuna et al. [51] repeated the prior study to compare the change over a two-year time period. Again, although this study divided the 34 supports into six categories (common generic supports, educational and personal strategies instruction, career assessment and work experiences, assistive technology supports, administrative support, and financial assistance), no mention was made of personal assistance for individuals with substantial physical limitations, beyond note takers. Christ and Stodden [8] conducted a factor analytic study of the same data and determined that the majority of the 34 services fit under four categories of: (a) strategies, (b) assistive technology, (c) accommodations, and (d) vocation work support.

Pingry [34] studied the records of 1,289 students with a variety of disabilities from three postsecondary institutions in Missouri. Her list of 15 disability supports included classroom assistants, for example note takers or laboratory assistants, but did not include personal assistants for personal ADLs or IADLs. She concluded that nearly 20 percent of students with physical disabilities (which she defined as including deafness and hearing loss, low vision and blindness, and mobility, systemic, or disease-related disabilities) used classroom assistants.

Singh [39] performed a study focusing solely on postsecondary students with orthopedic disabilities in terms of service provision in four categories: (a) structural accessibility, (b) academic accessibility, (c) dorm living, and (d) recreational opportunities. Interestingly, Singh defined accessibility of dorm living as “availability of wheelchair accessible dorm rooms throughout residence halls, accessible laundry facilities, accessible bathrooms, accessible dining rooms, accessible fire exits, availability of 24 hour nurse on call in the residence halls, on-campus repair of mobility equipment such as wheelchairs and crutches, and help in the recruitment and training of personal care assistants” [39, p. 368]. Respondents were asked to rate each of these areas on a 1 to 5 scale, with a rating of 4 or 5 indicating accessibility. The investigator reported that only two percent of the institutions provide accessible dorm facilities/services (as defined above). Unfortunately, no further break down of item scores is provided, leaving unclear how many institutions provided “24 hour nursing care” or recruitment and training of personal care assistants. However, of interest to the current study, recognition is given for the personal assistance needs of students with orthopedic disabilities.

Fuller [14] surveyed 81 large, public institutions on 20 supports that ranged from alternate test formats to course substitutions, to transportation. Of the 43 respondents, two reported providing personal assistants. The only item with fewer responses (one) was “waiver of admissions proficiency requirements” [14, p. 67]. While the number of institutions providing any accommodation of personal assistants is miniscule, of importance to the present examination is that personal assistants were mentioned at all.

As can be seen from the above studies, services and accommodations for students with disabilities are inconsistent across college campuses, and sometimes miss the mark in providing students with the supports they need to succeed within the postsecondary environment and beyond. Indeed, it is highly likely that

the accommodations needed by individuals with severe physical disabilities are minimized or negated in a majority of the disability service support programs that exist throughout the country.

Although Stodden et al. [49, p. 190] advocated that “the nature of an individual’s disability and the level of severity of that disability will likely influence not only specific educational supports that are needed, but also the entire support strategy,” it is also clear that if individuals with high support needs cannot live within the educational environment, they will not be able to succeed in the educational environment.

Variation and conflicting emphasis among postsecondary institutions of which support services should be offered leaves students with disabilities with the task of finding institutions that best suit their needs in order for them to survive and succeed in their postsecondary life. The lack of consensus among postsecondary institutions of what should be considered a ‘standard base service,’ as well as their inability to offer individualized accommodation plans, impacts the decision making process of this population and oftentimes forces students with disabilities to make the time-consuming effort of mapping and negotiating their postsecondary lifestyle [51, p. 20].

## 5. What comes next?

As mentioned earlier, the intent of this article is to ignite and broaden the discussion of the necessary support services in order for individuals with severe physical disabilities to be included and hopefully welcomed on postsecondary campuses nationwide. Of course, this begs the question – Which comes first, the development and provision of personal assistance services in postsecondary institutions or enrollment (in larger numbers) of students with severe physical disabilities who need these services? Clearly, there is not an easy “option A” or “option B” answer to this dilemma.

As noted throughout this paper, numerous barriers serve to diminish postsecondary education options for students needing personal assistance services. Secondary schools are required to provide personal services and aides, while postsecondary institutions are under no obligation to provide aids, devices, or services of a personal nature that are not otherwise provided to their students without disabilities. As a result, the PAS support model with which the student and family are most familiar is rendered irrelevant in the milieu of higher education, and frequently, students have not

acquired the knowledge, skills and self-confidence necessary to effectively manage such services independent of familial and/or school assistance.

As a result of the aforementioned incongruity between secondary and postsecondary practices related to personal assistance services, and the widespread absence of transitional programming to prepare students with disabilities to effectively manage their personal assistance needs in the postsecondary context, their postsecondary options are frequently restricted to institutions that are close to home so that they may continue to utilize familial personal assistance support. Conversely, if they do enroll at an institution away from home they frequently must devote an inordinate amount of time to learning to manage these needs while simultaneously adjusting to college curricula. As a result of having to manage these competing priorities, their academic performance and ultimately their achievement of their academic goals can be undermined.

Finally, individuals with disabilities who require personal assistance have a number of potential options available to them for the underwriting of such services. Individuals may, depending upon their state of residence, receive financial underwriting via Medicaid or vocational rehabilitation. However, personal assistance services funding constitutes a necessary but insufficient condition for successful matriculation. Students must know the communities into which they are moving. They must understand the local personal assistance labor force and know how to most effectively communicate with them. In some college/university communities local independent living centers provide invaluable assistance in helping students learn how to most effectively and efficiently access prospective personal assistants in those communities. However, in the end, students who require personal assistance are unlikely to enroll at a postsecondary institution away from home if they perceive themselves as lacking the knowledge and skills necessary to effectively recruit, screen, interview, hire, train, schedule, manage, and fire personal assistance personnel.

These service and funding gaps point to a number of areas in which further investigation is warranted. First, research needs to be conducted on the specific services offered on various campuses across the country for individuals with high support needs as well which models work best for which students under which conditions. Investigations into the barriers and facilitators experienced by individuals with severe physical disabilities as they attempt to progress through postsecondary degree programs need to be undertaken. Pilot programs based

on this research should to be developed and evaluated by both the service consumers and providers. Results of successful programs need to be disseminated so that pilot-program, evidence-based practices can be implemented and their wider adoption ensured.

Second, since funding of personal assistance services remains a critical issue for many people with severe physical disabilities [20,21,24], additional research is needed about the extreme inconsistencies that exist in state and federal waiver-based funding policies, programs, and outcomes. For example, Medicaid consumer direction of personal assistance services (CD-PAS) is a growing and promising trend that affords Medicaid beneficiaries control over hiring, scheduling, training and paying of personal care attendants. However, according to a recent study by the Kaiser Commission on Medicaid and the Uninsured [9] the overall enrollment in these programs is small, and such services are not well suited for all persons with disabilities who necessitate PAS. The study notes that consumers often lack the requisite abilities to hire, schedule, and pay direct service employees and training for service providers and consumers with disabilities is not universally available. In the final analysis, the study noted that the current CD-PAS programs do not afford consumers an adequate sense of security that should part of their support system fail them on a particular day, they have resources to turn to for assistance. The extent to which these variations and gaps affect the ability of persons with severe physical disabilities to attend postsecondary education and enjoy fruitful and meaningful careers is a prime topic of the needed research.

These areas are but two of the many lines of research that need to be conducted so that individuals with high support needs can enjoy the lifetime advantages of higher education. Programmatic and policy barriers that continue to be detrimental to the long-term career success of individuals with severe physical disabilities need to be studied and remedied. If higher education is serious about access and opportunity for all, including individuals with severe physical disabilities, we can do no less.

## 6. Summary

Persons with severe physical disabilities are not on a level playing field with their lesser-disabled or non-disabled counterparts when it comes to postsecondary education and competitive employment. Individuals who need personal assistance with basic living activi-

ties are clearly disadvantaged in education and employment, often by the lack of recognition of their needs as well as the high degree of assistance needed. Virtually no discourse has been undertaken about the fundamental need for personal assistance for individuals who wish to pursue a postsecondary degree and a high-quality career. The intent of this article is to kindle these discussions and bring this issue to the forefront.

## Acknowledgements

The information contained in this publication is based upon work supported by the National Science Foundation under Grant No. 0533197. Any opinions, findings, and conclusions or recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of the National Science Foundation.

## References

- [1] E.M. Agree, The influence of personal care and assistive devices on the measurement of disability, *Social Science and Medicine* **48** (1999), 427–443.
- [2] E.M. Agree and V.A. Freedman, A comparison of assistive technology and personal care in alleviating disability and unmet need, *The Gerontologist* **43**(3) (2003), 335–344.
- [3] E.M. Agree, V.A. Freedman, J.C. Cormman, D.A. Wolf and J.E. Marcotte, Reconsidering substitution in long-term care: When does assistive technology take the place of personal care? *Journal of Gerontology: Social Sciences* **60B**(5) (2005), S272–S280.
- [4] S. Allen, L. Resnik and J. Roy, Promoting independence for wheelchair users: The role of home accommodations, *The Gerontologist* **6**(1) (2006), 115–123.
- [5] J.M. Barcus and P. Targett, Maximizing employee effectiveness through use of personal assistance services in the workplace, *Journal of Vocational Rehabilitation* **18** (2003), 99–106.
- [6] J.C. Barrett, Being an effective workplace personal assistant, *Journal of Vocational Rehabilitation* **18** (2003), 93–97.
- [7] H.A. Belch, Retention of students with disabilities, *Journal of College Student Retention* **6**(1) (2004), 3–22.
- [8] T.W. Christ and R. Stodden, Advantages of developing survey constructs when comparing educational supports offered to students with disabilities in postsecondary education, *Journal of Vocational Rehabilitation* **22** (2005), 23–31.
- [9] H. Claypool and M. O'Malley, Consumer direction of personal assistance services in Medicaid: A review of four state programs, 2008, Accessed September 19, 2008, at <http://www.kff.org/medicaid/7757.cfm>.
- [10] A. Coble-Temple, L.R. Mona and T. Bleecker, Accessing personal assistance services in the workplace: Struggles and successes, *Journal of Vocational Rehabilitation* **18** (2003), 113–123.



- [11] M.M. Desai, H.R. Lentzner and J.D. Weeks, Unmet need for personal assistance with activities of daily living among older adults, *The Gerontologist* **41**(1) (2001), 82–88.
- [12] M.E. Diab and M.V. Johnston, Relationships between level of disability and receipt of preventive health services, *Archives of Physical Medicine and Rehabilitation* **85** (2004), 749–757.
- [13] P.W. Dowrick, J. Anderson, K. Heyer and J. Acosta, Postsecondary education across the USA: Experiences of adults with disabilities, *Journal of Vocational Rehabilitation* **22** (2005), 41–47.
- [14] S.S. Fuller, An investigation of service delivery models for the provision of academic accommodations to students with disabilities at public universities, PhD. Dissertation, Rutgers, The State University of New Jersey, 2003.
- [15] J.M. Guralnik, Aspects of disability across the life span: Risk factors for disability in late life, in: *Workshop in America: A New Look: Summary and Background Papers*, M.J. Field, A.M. Jette and L. Martin, eds, The National Academies Press, Washington, DC, 2006, pp. 157–165.
- [16] L.M. Hall and H.A. Belch, Setting the context: Reconsidering the principles of full participation and meaningful access for students with disabilities, *New Directions for Student Services* **91** (2000), 5–17.
- [17] H. Hoenig, D.H. Taylor and F.A. Sloan, Does assistive technology substitute for personal assistance among the disabled elderly? *American Journal of Public Health* **93**(2) (2003), 330–337.
- [18] L. Horn and J. Berkhold, Students with disabilities in postsecondary education: A profile of preparation, participation, and outcomes, Washington, DC: US Department of Education, National Center for Educational Statistics, 1999.
- [19] L. Jans and S. Stoddard, Chartbook on women and disability in the United States, An InfoUse Report, Washington, DC: US National Institute of Disability and Rehabilitation Research, 1999.
- [20] H.S. Kaye, Improved employment opportunities for people with disabilities, Washington, DC: National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, US Department of Education, 2003.
- [21] H.S. Kaye, S. Chapman, R.J. Newcomer and C. Harrington, The personal assistance workforce: Trends in supply and demand, *Health Affairs* **25**(4) (2006), 1113–1120.
- [22] J. Kennedy, M.P. LaPlante and H.S. Kaye, Need for assistance in the activities of daily living, *Disability Statistics Abstract* **18** (1997), 4.
- [23] M. Kohler, C.F. Clarenbach, L. Boni, T. Brack, E.W. Russi and K.E. Bloch, Quality of life, physical disability, and respiratory impairment in Duchenne muscular dystrophy, *American Journal of Respiratory Critical Care and Medicine* **172** (2005), 1032–1036.
- [24] M.P. LaPlante, H.S. Kaye, T. Kang and C. Harrington, Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences, *Journals of Gerontology* **59B**(2) (2004), S98–S108.
- [25] J. Lehmann, T. Davies and Laurin, Listening to student voices about postsecondary education, *Teaching Exceptional Children* **32**(5) (2000), 60–65.
- [26] P.B. Marion and E.V. Iovacchini, Services for handicapped students in higher education: An analysis of national trends, *Journal of College Student Personnel* **24**(2) (1983), 131–138.
- [27] National Center for Educational Statistics, The condition of education 2003, (NCES 2003-068), Washington, DC: US Department of Education, 2003.
- [28] National Center for the Study of Postsecondary Education Supports, Research findings brief: Topic Review: Postsecondary education and employment, 4 2000, 2 pp.
- [29] National Council on Disability, *National Disability Policy: A Progress Report*, Washington, DC: Author, 2008.
- [30] R. Newcomer, T. Kang, M. Laplante and H.S. Kaye, Living quarters and unmet need for personal care assistance among adults with disabilities, *Journals of Gerontology* **60B**(4) (2005), 205–213.
- [31] M. Nosek, Personal assistance: Key to employability of persons with physical disabilities, *Journal of Applied Rehabilitation Counseling* **21** (1990), 308.
- [32] V. Parker, V. Personal assistance for students with disabilities in HE: The experience of the University of East London, *Disability & Society* **14**(4) (1999), 483–504.
- [33] I. Philip, G.K. Armstrong, G.G. Coyle, I. Chadwick and A.B.C. Machado, A better way to measure disability in older people, *Age and Ageing* **27** (1998), 519–522.
- [34] L.N. Pingry, Factors that predict graduation among college students with disabilities. Ph.D. Dissertation, University of Missouri-Columbia, 2007.
- [35] P.J. Rathouz, J.D. Kasper, S.L. Zeger, L. Ferrucci, K. Bandeen-Roche, D.L. Miglioretti and L.P. Fried, Short-term consistency in self-reported physical functioning among elderly women, *American Journal of Epidemiology* **147**(8) (1998), 764–773.
- [36] H.A. Schartz, D.J. Hendricks and P. Blanck, Workplace accommodations: Evidence-based outcomes, *Work* **27** (2006), 345–354.
- [37] S.F. Shaw and S.S. Scott, New directions in faculty development, *Journal of Postsecondary Education and Disability* **17**(1) (2003), 3–9.
- [38] R. Silverstein, The applicability of the ADA to personal assistance services in the workplace, Policy brief 10, Retrieved August 18, 2008, from: [www.communityinclusion.org/article.php?article\\_id=21](http://www.communityinclusion.org/article.php?article_id=21).
- [39] D.K. Singh, Students with disabilities and higher education, *College Student Journal* **37**(3) (2003), 367–375.
- [40] E. Steinmetz, Americans with disabilities 2002, Current population Reports, US Census Bureau, Washington DC, 2006.
- [41] W.E. Stilwell and S. Schulker, Facilities available to disabled higher education students, *Journal of College Student Personnel* **14**(5) (1973), 419–424.
- [42] S. Stoddard, Personal assistance services as a workplace accommodation, *Work* **27** (2006), 363–369.
- [43] S. Stoddard, L. Jans, J.M. Ripple and L. Kraus, Chartbook on work and disability in the United State, Washington, DC: National Institute on Disability and Rehabilitation Research, 1998.
- [44] R.A. Stodden, Supporting persons with disabilities in postsecondary education and life long learning, *Journal of Vocational Rehabilitation* **22** (2005), 1–2.
- [45] R.A. Stodden and M.A. Conway, Supporting individuals with disabilities in postsecondary education, *American Rehabilitation* **27**(1) (2003), 24–33.
- [46] R.A. Stodden and P.W. Dowrick, Postsecondary education and employment of adults with disabilities, *American Rehabilitation* **25**(4) (1999/2000), 19–24.
- [47] R.A. Stodden, P.W. Dowrick, J. Anderson, K. Heyer and J. Acosta, Postsecondary education across the USA: Experiences of adults with disabilities, *Journal of Vocational Rehabilitation* **22**(1) (2005), 49–64.
- [48] R.A. Stodden, K.D. Roberts, T. Picklesimer, D. Jackson and C. Chang, An analysis of assistive technology supports and ser-

- vices offered in postsecondary educational institutions, *Journal of Vocational Rehabilitation* **24** (2006), 111–120.
- [49] R. Stodden, T. Whelley, C. Chang and T. Harding, Current status of educational support provision to students with disabilities in postsecondary education, *Journal of Vocational Rehabilitation* **16** (2001), 189–198.
- [50] W. Strobel and J.T. McDonough, Workplace personal assistance service and assistive technology, *Journal of Vocational Rehabilitation* **18** (2003), 107–112.
- [51] A. Tagayuna, R.A. Stodden, C. Chang, M.E. Zelenik and T.A. Whelley, A two-year comparison of support provision for persons with disabilities in postsecondary education, *Journal of Vocational Rehabilitation* **22** (2005), 13–21.
- [52] E. Turner, Finding the right personal assistant, *Journal of Vocational Rehabilitation* **18** (2003), 87–91.
- [53] E. Turner, Personal assistance services in the workplace, *Journal of Vocational Rehabilitation* **18** (2003), 69–70.
- [54] E. Turner, Using a personal assistant in the workplace, *Journal of Vocational Rehabilitation* **18** (2003), 81–85.
- [55] US Census Bureau, Disability Status: 2000, Washington, DC: Author, 2000.
- [56] US Census Bureau, American Community Survey, Washington, D.C: Author, 2006.
- [57] US Department of Education. Auxiliary Aids and Services for Postsecondary Students with Disabilities, 2005, Retrieved August 18, 2008, from: [www.ed.gov/about/offices/list/ocr/docs/auxaids.html](http://www.ed.gov/about/offices/list/ocr/docs/auxaids.html).
- [58] US Department of Education, Students with Disabilities: Preparing for Postsecondary Education: Know Your Rights and Responsibilities, 2007, Retrieved August 18, 2008, from: [www.ed.gov/about/offices/list/ocr/transition.html](http://www.ed.gov/about/offices/list/ocr/transition.html).
- [59] L.M. Verbrugge, C. Rennert and J.H. Madans, The great efficacy of personal equipment assistance in reducing disability, *American Journal of Public Health* **87**(3) (1997), 384–392.
- [60] L.M. Verbrugge, L. Yang and L. Juarez, Severity, timing, and structure of disability, *Social and Preventive Medicine* **49**(2) (2004), 110–121.
- [61] A.C. Ward and P.M.A. Baker, Disabilities and impairments: Strategies for workplace integration, *Behavioral Sciences and the Law* **23** (2005), 143–160.
- [62] M. West, J. Kregel, E. Getzel, Z. Ming, S.M. Ipsen and E.D. Martin, Beyond section 504: Satisfaction and empowerment of students with disabilities in higher education, *Exceptional Children* **59** (1993), 456–467.
- [63] A.J. Young, The evolution of personal assistance services as a workplace support, *Journal of Vocational Rehabilitation* **18** (2003), 73–80.