Personal Assistant Support for Students with Severe Physical Disabilities in Postsecondary Education

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Abstract

The purpose of this exploratory research is to document the level of personal assistance support provided to students with severe physical disabilities by disability support services in higher education institutions across the United States. A national survey was conducted of members of the Association of Higher Education And Disability (AHEAD) via an online survey. Of the 326 respondents with usable responses, 36 (14.1%) stated they provided some level of personal assistance services to students with severe physical disabilities, ranging from providing emergency services (25 or 69.4%) to providing residential services with in-house personal assistants (4 or 11.1%). Personal assistance support to students with severe physical disabilities were more likely to be provided at master's, comprehensive, and research universities and less likely to be provided at bachelor's, associate's, and trade/technical schools. Those who provided personal assistant support were more likely to be able to identify students with severe physical disabilities who were negatively impacted by the lack of personal assistance support, were more satisfied with their personal assistance support services, had longer tenure in disability support services, and had greater numbers of part-time staff. Implications for service providers and future research are discussed.

Keywords: Personal assistance services, severe physical disabilities, higher education

The ramifications of having a physical disability in America are clear. Individuals with physical disabilities are disadvantaged in terms of higher education, employment, and income (Stumbo, Martin, & Hedrick, 2009; United States [U.S.] Census Bureau, 2006, 2010). This is especially true for individuals with severe physical disabilities. For example, Steinmetz (2006) reported that 10.4% of individuals age 25 to 64 without disabilities did not complete high school, compared to 14.6% for individuals with a non-severe disability, and 26.6% for individuals with a severe disability. Similar trends continued in postsecondary education. Slightly over 43% of individuals without disabilities completed a college degree, compared with 32.5% of individuals with non-severe disabilities, and 21.9% for individuals with severe disabilities. These educational disadvantages may transfer into employment and economic disadvantages that are lifelong and more limiting than the actual disability itself.

These issues will become more significant as the number of individuals with severe physical disabilities continue to grow in the U.S. In 2002, 51.2 million people (18.1%) of the U.S. population of 282.8 million had a disability, with 5.1 million needing assistance with three or more activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) (Steinmetz, 2006). In 2005 there was an estimated 291.1 million people in the U.S., of which 54.4 million (18.7%) claimed a disability (Brault, 2008). Eleven million of those individuals – or 12% - had need for personal assistance ([PAS]; Brault; U.S. Census Bureau, 2010). From 2002 to 2005, the overall number and percent of individuals with disabilities rose (from 18.1% to 18.7%) and the number of individuals needing PAS more than doubled - from 5.1 to 11 million. With the advent of better medical care and pervasive assistive technologies (AT), the number of persons with severe physical disabilities is increasing and may continue to do so in the foreseeable future.

The extent to which these trends may be seen in postsecondary settings is not known, simply because there is extremely limited published data about PAS available to persons with severe physical disabilities provided by disability support offices (DSS) in higher education (Stumbo et al., 2009). After an extensive search of over 30 library databases, no research could be located concerning the numbers of persons with severe physical disabilities in U.S. postsecondary education or their PAS needs. It has been noted that DSS vary widely (Belch, 2004; Stodden & Conway, 2003) and the same may be anticipated for the provision of PAS (Stumbo et al., 2009). The present study provides initial exploratory, although not definitive, data and may prompt future discussion and research to fill the previously mentioned void of information about persons with severe physical disabilities and their PAS needs in postsecondary education.

Use of Personal Assistance and Severe Physical Disability

Verbrugge, Rennert, and Madans (1997) 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" (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 PAS and AT. Those with the most severe physical disabilities may use a variety of AT but rely substantially on personalized, human assistance to perform ADL (e.g., eating, dressing, bathing, transferring, using the toilet, and moving across a small room) and IADL (e.g., taking medication, preparing food, shopping) (Guralnik, 2006; Hoenig, Taylor, & Sloan, 2003; LaPlante, Kaye, Kang, & Harrington, 2004).

Guralnik (2006) specifically defined severe physical disability as when "the individual needs help with three or more of the six ADLs" (p. 162). This definition of severe physical disability, with the emphasis on the need for PAS, is generally supported throughout the disability and health care literature (Desai, Lentzer, & Weeks, 2001; Jans & Stoddard, 1999; Philip, Armstrong, Coyle, Chadwick, & Machado, 1998; Rathouz et al., 1998; U.S. Department of Education [USDOE], 2005).

A number of authors have noted that AT can often augment but not replace human help for these individuals (Agree, Freedman, Cornman, Wolf, & Marcotte, 2005; Hoenig et al., 2003; Kaye, Chapman, Newcomer, & Harrington, 2006; Kennedy, LaPlante, & Kaye, 1997; LaPlante et al., 2004). What is often *not* noted in the literature is that for persons with severe physical disabilities, access to PAS 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, reliable assistance must be available. If the required PAS is not available when needed, the individual will not be able to live successfully in that environment. For tasks common to academic activities, such as turning book pages, getting books from library shelves, opening doors, reaching for items, and turning on/off lights, assistance must be available when it is needed, or again, the individual will not be able to sustain pursuit of a postsecondary degree. To succeed in higher education, individuals with severe physical disabilities need PAS to perform ADL/IADL functions, academically-related tasks, and health-related tasks such as hydration and sun care.

Personal Assistance Services in Postsecondary Education

A number of factors surrounding PAS in postsecondary education have led to its almost total exclusion in the American research literature. First, a relatively small number of individuals are affected compared to those with higher incidence disabilities in higher education. In addition, this group has comparatively higher resource-intensive needs per person than other groups of people with disabilities. From the perspective of the institution, reconstructing the environment to meet 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 (Stodden, Roberts, Picklesimer, Jackson, & Chang, 2006; Strobel & McDonough, 2003). Finally, there is no legal mandate to provide PAS in higher education as there is for secondary education (USDOE, 2005, 2007). However, postsecondary degrees are increasingly essential for all individuals to obtain and retain competitive employment (Diab & Johnston, 2004; Dowrick, Anderson, Heyer, & Acosta, 2005; Stodden & Conway, 2003; Stodden & Dowrick, 1999/2000; Stodden et al., 2006). This may be especially true for persons with severe physical disabilities (Brault, 2008; Steinmetz, 2006).

Related Research on PAS in Higher Education

The only published study that focused solely on the provision of PAS in higher and further education was authored by Parker (1999), who conducted a qualitative investigation at the University of East London in the U.K. Six students with significant disabilities and seven personal assistants were interviewed. The investigator noted similar issues to the U.S: (a) difficulties with organizational structure, (b) lack of consistent funding and fair wages, (c) newness of roles for the individual as a first-time student and new employer, (d) difficulties in maintaining employer/employee relationships, (e) quality/quantity of the PAS providers, (f) training for the student (e.g., assertiveness, communication, etc.) and the personal assistant, and (g) lack of clear mandates to provide PAS.

Two studies used overlapping data sets obtained by the National Center for the Study of Postsecondary Education Supports (NCSSPES): Stodden, Whelley, Change, and Harding (2001) and Tagayuna, Stodden, Chang, Zelenik, & Whelley (2005). In the 2001 report, AHEAD and non-AHEAD members were surveyed about, among other issues, the supports or accommodations provided to students with disabilities on their respective campuses. DSS staff were asked to indicate how often during a calendar year they offered each of the 34 supports listed on the survey. While the range of services surveyed is broad – from job placement to document conversion to adaptive furniture, the only form of PAS as a support for persons with severe physical disabilities was notetakers.

Singh (2003) studied 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 (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 2% of the institutions provided 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, recognition is given for the PAS needs of students with orthopedic disabilities.

Fuller (2003) surveyed 81 large, public institutions about 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" (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.

The second study using the NCSSPES data, by Tagayuna et al. (2005), replicated 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 PAS for students with severe physical disabilities beyond note takers. Christ and Stodden (2005) 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 (2007) 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% of students with physical disabilities (defined as including deafness and hearing loss; low vision and blindness; and mobility, systemic, or disease-related disabilities) used classroom assistants.

Collins, Hedrick, and Stumbo (2007) reported on program evaluation data of the residential transition service provided by the University of Illinois to students with severe physical disabilities necessitating PAS. Between 1981 and 2003, 151 individuals with severe physical disabilities utilized these services while attending the university. Of these individuals, 109 (87%) had earned degrees. Data on the 65 graduates from 1994 to 2010 (when better records were kept), show that 26 (40.0%) have earned professional employment within one year of graduation and 28 (43.1%) had enrolled in graduate or professional school within one year of graduation. Thus, less than 16.9% (n=11) were unemployed and not enrolled in graduate or professional school within one year of graduation (P. B. Malik, personal communication, September 29, 2011). Such outcomes offer compelling, albeit preliminary, support for the value of providing PAS services.

Although Stodden et al. (2001, 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. Even under ordinary circumstances, the transition from secondary to postsecondary settings, and being away from home for the first time, is overwhelming for many first-year students. For incoming students with severe physical disabilities who 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, the road is difficult at best. And for many college staff, the provision of personal assistants for students with severe physical disabilities is not even "on the table." As noted by Parker (1999, p. 500): "Full equity of access to higher education for students with disabilities is unlikely to be achieved until the law establishes this [PAS] as a right."

Purpose of the Study

According to Behrens (1997) and Yeager, Parkhurst, and Henshel (2007), there are two types of approaches to targeting and analyzing data. The first is confirmatory data analysis that is used when the research topic is mature enough to allow "statistical investigation of the hypotheses that motivated the study" (Yeager et al., p. 673). The second type is exploratory data collection and analysis, a coalition of procedures used to "learn from the data at all stages of research" (Behrens, 1997, p. 132). In exploratory data analysis the researchers are interested in the broad question, *What is going on here?*, often focusing on graphic representations of data and tentative model building, emerging and unexpected outcomes, and data as starting points rather than conclusions (Behrens, 1997). Tukey, in 1977, was among the first to strongly advocate exploratory data analysis alongside confirmatory data analysis (Behrens, 1997). According to Behrens, Tukey (1980) is quoted as saying: "(a) *both* exploration and confirmation are important, (b) exploration usually come *first*, and (c) a given study can, and usually should, combine *both*" (p. 133).

The current study focused on the degree to which PAS were provided by disability service personnel to students with severe physical disabilities in higher education institutions and differences between those who do provide such services and those who do not. Researchers collected descriptive information such as the numbers of institutions that provided PAS, their enrollments of students with disabilities, what types of

PAS they provided, and the characteristics of the disability service providers themselves. In addition, because there is such a lack of literature on the topic of PAS for students with severe physical disabilities in postsecondary education, the research team adopted an exploratory strategy to search for graphical representations and potential models that may further illuminate the topic at hand.

Method

Sampling Technique

This study used all 2,229 professional members of AHEAD as of May 2008 as a purposeful sample (Babbie, 2010). In addition to the AHEAD membership, due to the funding source, all DSS coordinators in Illinois, Iowa, and Wisconsin (approximately 150 individuals) were sent email requests for participation. This sample was selected as they are individuals who provide support services to students with disabilities enrolled in higher education institutions across the U.S. and Canada. Each institution was limited to one response via the survey software.

Instrument

No instrument was located that queried the status of PAS in higher education institutions. Therefore, the research team developed the project-specific, web-based survey used for this preliminary study. The survey consisted of three areas of interest: (a) staff description, (b) university description/student enrollments, and (c) PAS offered. These categories were determined to be important to the description of the current state-of-the-art in PAS in higher education. An expert panel was used to review the survey, as this method is less expensive and may be more productive than other types of survey pretesting such as pilot tests (Presser & Blair, 1994; Yan, Kreuter, & Tourangeau, 2010). In a study examining whether expert reviews are sufficient to determine survey item inadequacy, Olson (2010) noted that "average expert ratings successfully identify questions that are more likely to have high levels of item non-response or inaccurate reporting," (p. 312), although this may vary across surveys and experts. Olson concluded, "Not only do expert reviews identify question problems, but that these problems are related to meaningful data quality issues. Survey practitioners are advised…to use multiple experts to review questionnaires" (p. 313). The expert panel of seven individuals (three DSS staff, three professionals with extensive experience with disability, one individual with a severe disability who attended postsecondary institutions) reviewed the survey and suggested revisions to ten items prior to its use. The final version of the survey contained 36 items.

The web survey consisted of 35 questions: (a) seven items concerning the number, characteristics, and qualifications of the respondents; (b) nine concerning the institution or enrollments; and (c) 18 on the types of PAS offered. Item formats included fill in the blank (i.e., "How many of the other staff work full-time?"), forced choice (i.e., "Is personal assistance support provided to your school's students with severe physical disabilities?" Yes or No), and Likert scales ("About how satisfied are you with the range of personal assistance services that is currently available to the students with severe physical disabilities at your school?" 1 = Very Dissatisfied to 5 = Very Satisfied). Prior to items about students with severe physical disabilities, the following definition was provided: "If an individual needs help with three or more of the six activities of daily living--eating, dressing, bathing, transferring, using the toilet, and walking across a small room--the individual has a severe physical disability." The final question on the survey was open-ended and asked for further comments or questions regarding PAS in postsecondary education.

The survey was designed so that respondents were only asked questions pertinent to their prior answers. For example, if respondents replied they did not provide PAS, the remaining questions on types of PAS were automatically skipped. The study was exempted from full review by the two universities' IRB review boards prior to its initiation, due to the unlikelihood of harm to its subjects.

Data Collection Procedure

The AHEAD office staff sent to all 2,229 professional AHEAD members a cover letter (email) from the researchers as well as a link to the survey. All DSS coordinators in Illinois, Iowa, and Wisconsin were sent similar email cover letters from the investigators with a direct link to the web survey. The cover letter/email explained the purpose of the study as well as conditions of anonymity and established a deadline for response. The link directed participants to the web survey, where they first clicked through an informed consent prior to viewing and answering the items. A thank you followed their reply to the last statement.

After two weeks, a follow-up email was sent by the AHEAD administrative staff to AHEAD members and by research staff to the additional Illinois, Iowa, and Wisconsin DSS coordinators to remind persons who had not filled out the survey to do so in order to increase the response rate. The survey was open to respondents for 39 days, from May 5 to June 12, 2008. Out of 367 (15.4% of 2,379) returned responses, 326 were usable. Unusable surveys included those filled out by staff other than the coordinator. The final return rate was 13.7%. A number of reasons may have produced the relatively low return rate, including timing of the survey (May and June) and the lack of salience of the topic to the audience (Fan & Yan, 2010). Overall, web surveys are expected to produce lower return rates (about 11% lower than mailed surveys) but are often preferred due to low cost, geographic penetration, and easy transfer to analytic software (Fan & Yan, 2009; Kaplowitz, Hadlock, & Levine, 2004; Manfreda, Bosnjak, Berzelak, Haas, & Vehovar, 2008).

The survey allowed for users to stop at any time or skip items; consequently, several questions have a different number of responses compared to respondents. The total number of respondents per item is noted when that number deviates from the total sample of 326. In addition, the survey parameters only allowed one person per school to respond to the survey.

Data Analysis Procedures

WebSurvey@UW software automatically creates a database of respondents' answers that can be exported to data analysis software programs. Soon after the survey URL was closed, quantitative data were exported to SPSS 18.0. Data analysis, including descriptive statistics, correlations, and mean comparisons, were employed depending on the variables and research question. Content analysis was used to code open-ended, qualitative data. Additionally, a statistician was hired specifically to aid with exploratory data analysis, including model building and graphical display of results.

Results

The intent of this study was to explore the status of PAS for students with severe physical disabilities in higher education and provide foundational data concerning the institutions, the PAS provided, and the DSS coordinators themselves. Furthermore, graphic representations, preliminary models, and insights were sought via exploratory data analysis. Results are presented in two parts. The first provides demographic characteristics of the sample respondents, their institutions, and the students for whom they provide services. The second section provides results of additional exploratory analyses.

Characteristics of the Sample

Service providers. Each respondent was asked if he or she was the person responsible for coordinating DSS at his or her university. A total of 326 (88.8%) responded in the affirmative. The 41 (11.2%) who either said no or did not answer were not permitted to continue with the survey. The number of additional full-time staff (n = 218) ranged from 0 to 35, with an average of 3.7 staff members (SD = 4.4). The number of additional part-time staff (n = 193) ranged from 0 to 100, with 4.8 being the average (SD = 12.1).

The vast majority of coordinators (234 of 242 or 96.7%) were members of AHEAD at the time of the survey. Their work experience in DSS ranged from one year to 34 years, with a mean of 10.0 years (SD = 7.4). Almost two-thirds (155 of 240 or 64.6%) had worked in DSS for 10 years or less. The majority (182 of 242 or 75.2%) held masters degrees, while 24 (9.9%) had doctoral degrees, and five (2.1%) held medical degrees. In summary, most coordinators employed almost four additional full- and almost five part-time staff in the DSS, were members of AHEAD, had worked 10 or less years in the field, and held masters degrees.

Institution, enrollment, and student experience characteristics. Respondents were asked nine questions about their institution's characteristics. The majority of institutions (237 of 243 or 97.5%) were located in the U.S. The states with the highest responses were Illinois (23 or 9.8%), California (18 or 7.7%), Texas (17 or 7.2%), and New York (11 or 4.9%). Most were public or government-sponsored (154 of 241 or 63.9%) instead of private (87 or 36.1%). Most respondents (n = 241) worked at two-year colleges offering associates degrees (63 or 26.1%), comprehensive universities (47 or 19.5%), colleges offering master's degrees (43 or 17.8%), and research universities (40 or 16.6%).

Table 1 provides the overall enrollment patterns at the respondents' institutions. Overall, the average enrollment of respondent's institutions was 11,442, with an average of 416 students with disabilities enrolled per institution and 362 registered with DSS. Respondents

Table 1

Average Student Enrollments at the Respondents' Postsecondary Institution

	Range	Mean	Standard Deviation
Total number of students enrolled at institution (n=235)	1,000 - 70,000	11,442.2	11,832.4
Students with disabilities enrolled at institution (n=125)	100 - 4,000	416.1	604.5
Students with disabilities registered with DSS at institution (n=248)	100 - 2,000	361.6	352.9
SWSPD* enrolled at institution (n=201)	1 - 50	5.2	15.4
SWSPD registered with DSS at institution (n=130)	1 - 197	7.5	18.5

*Note: *Students with Severe Physical Disabilities*

reported an average of about five students with severe physical disabilities enrolled per institution and eight registered with DSS.

Table 2 provides an overview of student enrollments by type of institution. Overall, research universities reported the highest average numbers of total student enrollments, students with disabilities enrollments, and students with disabilities being registered. Colleges offering master's degrees drew highest averages of students with severe physical disabilities enrolled and registered. Colleges offering primarily bachelor's degrees held the lowest averages for all categories of students with and without disabilities.

Experiences of Students with Severe Physical Disabilities

Respondents were asked six questions about students with severe physical disabilities whose academic experience was negatively affected by the lack of PAS within the last 12 months ("Are you aware of any prospective students with severe physical disabilities who did not enroll in your school because they were concerned about difficulties in securing personal assistance services?"). Of the 255 respondents to this question, 30 (11.8%) replied that they knew of prospective students who did not enroll at the institution due to concerns about difficulties securing PAS. Respondents were asked to report the number of students in this category. Twenty-six respondents reported a total of 47 students, with an average of one or two students per school. A similar question was asked about students with severe physical disabilities who left the institution due to difficulties with PAS. A total of 15 respondents reporting knowing of such students, with an estimated total of 21 students dropping out. The final item in this grouping asked if any students' success at school was negatively affected by the lack of PAS. Thirty-three respondents recalled this situation, with an average of two students per response institution.

Respondents' Overall Satisfaction with PAS Provision

The final question in this section of the survey asked respondents their degree of satisfaction with their provision of PAS ("About how satisfied are you with the level or amount of PAS provided to students with severe physical disabilities at your institution?"). The intent was to measure the DSS coordinators' appraisal of their service offerings for students with severe physical disabilities. The item was framed so

Table 2

Average Student Enrollments by Type of Postsecondary Institution

	Two-year College Offering Associates Degree (n=63)	Comprehensive University (n=47)	College Offering Master's Degree (n=43)	Research University (n=38)	College Offering Bachelors Defrees (n=25)
Total Number of Students Enrolled	*M*=10,582.2	*M*=11,871.2	*M*=5,252.8	*M*=20,963.7	*M*=4.210.7
	SD=12,972.5	*SD*=8,433.5	*SD*=4,195.1	*SD*=12,395.5	*SD*=6,258.2
Students with Disabilities Enrolled	*M*=364.3	*M=4*55.5	*M*=207.8	*M*=703.3	*M*=121.8
	SD=424.6	*SD*=353.9	*SD*=218.2	*SD*=993.9	*SD*=198.8
Students with Disabilities Registered with DSS	*M*=376.4	*M*=365.8	*M*=189.9	*M*=597.0	*M*=146.6
	SD=356.0	*SD*=268.4	*SD*=212.3	*SD*=449.5	*SD*=141.9
SWSPD Enrolled	*M*=4.1	*M*=4.8	*M*=8.4	*M*=7.8	*M*=1.0
	SD=5.4	*SD*=11.5	*SD*=32.2	*SD*=9.5	*SD*=1.5
SWSPD Registered with DSS	*M*=5.8	*M*=8.0	*M*=12.2	*M*=8.6	*M*=2.0
	SD=5.3	*SD*=14.2	*SD*=39.6	*SD*=9.6	*SD*=1.3

Note: SWSPD = Students with Severe Physical Disabilities; DSS = Disability Support Services; M = Mean; SD = Standard Deviation

that both providers and non-providers of PAS could respond - those who provided PAS services may be satisfied/dissatisfied with the services they offered and those who did not may also be satisfied/dissatisfied that they did not provide PAS. The answers were recorded on a five-point Likert scale, with 1 being 'very dissatisfied' and 5 being 'very satisfied.' Two hundred and forty persons responded, with an average rating of 3.2, indicating mostly 'neither dissatisfied nor satisfied.' When those who provided PAS (n = 32 respondents) were compared with those who did not (n = 209 respondents), the former group had an average satisfaction rating of 3.19 and the latter group of 3.17. There were no statistically significant differences between these groups in terms of satisfaction ratings with PAS provisions at their institutions.

Provision of PAS

Of all 367 respondents, 36 (10.2%) provided PAS, 219 (59.7%) did not provide PAS, and 112 (30.5%) did not respond to the question. Figure 1 illustrates that MA-granting institutions were much more likely to provide PAS, with 2-year schools the least likely. Research universities and comprehensive universities were almost equally likely to provide or not provide PAS services.

Table 3 contains the list of PAS to which the sample responded. The most frequently offered PAS was dealing with emergencies and the least frequently offered service was providing residential housing that included PAs and PA training. As PAS got more complex and resource-intensive, fewer institutions were involved.

Following the examination of descriptive data, exploratory analyses were conducted. The first area explored was the key demographic differences between DSS coordinators who did and did not provide services to students with severe physical disabilities. Although institution type as a predictor was certainly the strongest differentiator (as shown on Figure 1), two other elements differentiated PAS providers from those who did not provide PAS: (a) percent of respondents who cited their satisfaction with their PAS generally, and (b) number of part-time staff. These data are displayed in Table 4. Percentagewise, individuals who provided PAS were more satisfied with their overall level of PAS compared to non-providers, although their average ratings of satisfaction were not statistically different. Additionally, PAS providers had significantly more part-time staff members than non-providers of PAS.

It was initially surprising that tenure within disability services did not emerge as a significant differentiator between PAS providers and those who do not provide PAS. Therefore, further analysis examined the relationship between tenure in disability services and satisfaction with services provided. This relationship is depicted in Figure 2. In particular, individuals with less than six years of experience in disability services are the least satisfied with the PAS they provided.

Given the interesting relationship between tenure and satisfaction with PA services offered, it seemed worthwhile to explore differences in tenure by type of PAS offered. It is important to note that this examination is only on a subset of 36 respondents who indicated providing PAS, and the results are presented as a direction for future consideration rather than as definitive proof. Of interest is the fact that more tenured individuals in disability services are also more likely to provide PAS that include having a person on-call 24-7, provide training to PAs, and offer residential services (see Figure 3).

Finally, these data provide an opportunity to explore how offering different PAS relate to each other. Not all services are created equally; some services require more effort or expense. The investigators wanted to see if persons indicating they provided one service made them more likely to offer a different service. It is again important to note that these results are a first exploratory step and represent only 36 participants from the entire sample. A "heat map" was created as a way to display hierarchical data in a matrix that showcases the patterns of data (Wilkinson & Friendly, 2009). The heat map (Figure 4) displays services offered, from least comprehensive (top) to most comprehensive (bottom). Also, darker shading on the map represents lower percentages of individuals who provide that service. This figure shows that, given the high concentration of black in the upper right corner of the figure, few people who offer less comprehensive services indicated also offering more comprehensive services. As depicted in the lower left of the heat map, individuals who offer comprehensive services are more likely to offer less comprehensive services, too. In other words, institutions that provide 24-hour residential housing with PA services also are likely to offer the less comprehensive services such as PA training, needs assessments, home health contacts, and handling emergency situations. Conversely, those who handle emergency situations are not likely to offer

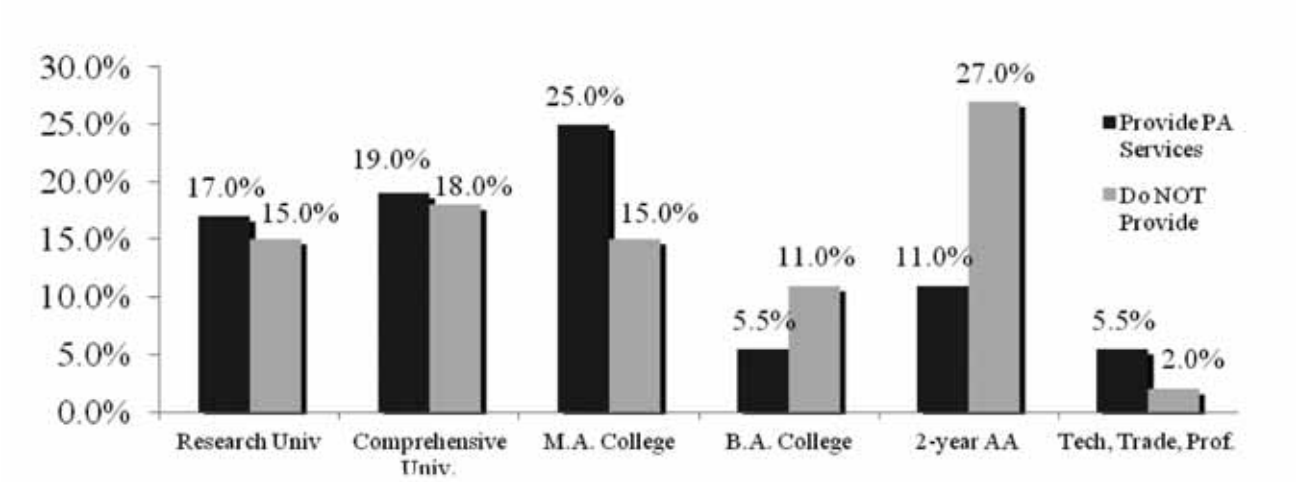


Figure 1. Respondents Who Did and Did Not Provide PAS by Institution

Table 3

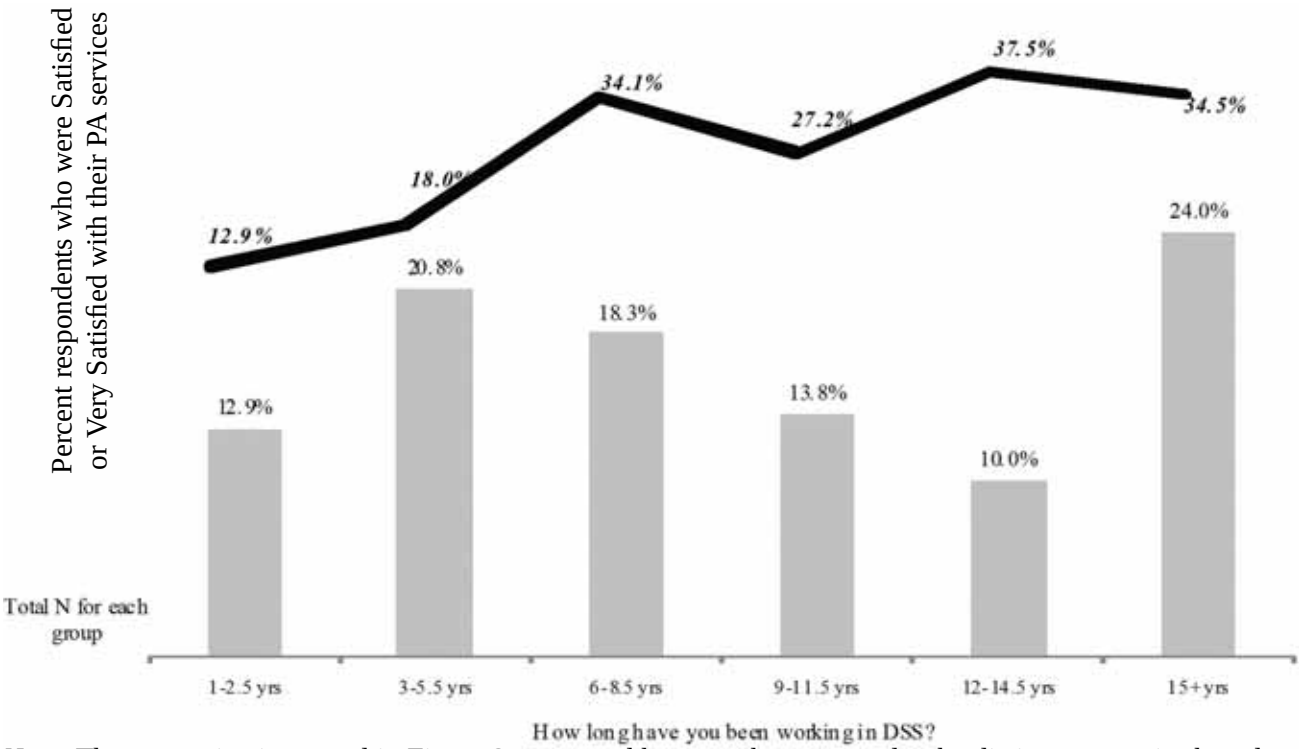
Types of Services Provided by Those Who Provide PA Services

Type of PAS Provided (n=36)	n	%
Deal with emergency situation	25	69.4
Maintain contact with home health care agencies	16	44.4
Help student create announcements to recruit PAs	15	41.7
Help students secure and train qualified PAs (n=35)	11	31.4
Maintain current list of individuals available as PAs	11	30.6
Assess individual student needs related to PAS	9	25.0
Provide PA management training to students	7	19.4
Have on-call person 24/7/365	6	16.7
Provide general training to PAs (e.g., lifting, transferring, etc.)	4	11.1
Provide residential services that include PAs and PA training	4	11.1

Table 4

Satisfaction and Number of Part-time Staff of Those Who Did and Did Not Provide PAS

	% of Respondents "Satisfied / Very Satisfied" with PAS	*M* and *SD* of # of Part-time Staff
Provided PAS (n=36)	36.2	*M*=8.0 *SD*=19.7
Did Not Provide PAS (n=145)	24.2	*M*=4.9 *SD*=12.1



Note: The categorizations used in Figure 2 were used because these seemed to be distinct categories based on trending of other metrics and face validity of these categories. In general, the longer someone has been working with DSS, the more satisfied they are with PAS.

Figure 2. Percent of Respondents Satisfied or Very Satisfied with Their PAS by Length of Service

		Emergency Situations	Announce to Recruit	Home Health Contact	List of PAs	Train PAs	Need Assessment	PA Management	24/7 Success	PA Training	Resident
Emergency Situations	*N=25*		52%	56%	32%	32%	36%	24%	24%	16%	16%
Announce to Recruit	*N=21*	62%		43%	48%	38%	19%	19%	14%	10%	10%
Home Health Contact	*N=16*	88%	56%		50%	19%	50%	25%	25%	19%	19%
List of PAs	*N=11*	73%	91%	73%		46%	46%	36%	27%	27%	18%
Train PAs	*N=11*	73%	73%	27%	46%		27%	27%	9%	18%	18%
Needs Assessment	*N=9*	100%	44%	89%	56%	44%		44%	33%	33%	22%
PA Management	*N=7*	86%	57%	57%	57%	57%	57%		57%	43%	29%
24/7 Access	*N=6*	100%	50%	67%	50%	50%	50%	67%		17%	67%
PA Training	*N=4*	100%	50%	75%	75%	50%	100%	100%	75%		50%
Resident	*N=4*	100%	50%	75%	50%	50%	50%	50%	50%	50%	

Figure 4. “Heat Map” Showing the Likelihood of Offering Service

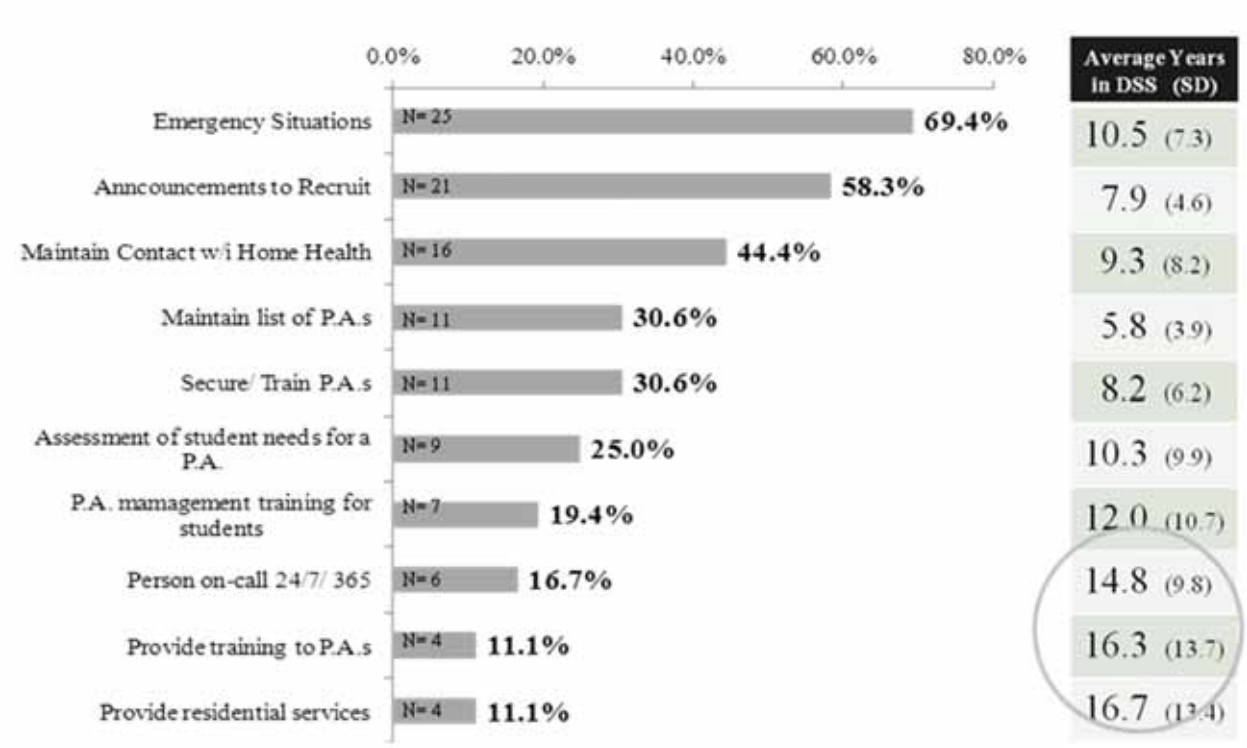


Figure 3. Influence of Tenure in DSS on Type of Services Provided

additional services beyond helping students develop announcements to recruit PAs and maintaining contact with home health agencies. Again, these are small samples but this provides a formative look at how the PAS offerings interrelate.

Discussion

The purpose of this study was to examine the degree to which PAS were provided to students with severe physical disabilities in postsecondary education and to explore potential graphic displays and models that may help explain current service provision. Results must be considered within the context of the study's limitations. The researchers used a web survey, which can result in lower return rates than mailed surveys (Kaplowitz et al., 2004), although this is not always the case (Presser & Blair, 1994). However, the use of a web survey with a specific group such as AHEAD members who are most likely proficient in computer technology may, in fact, produce higher response rates since respondents may view it as more efficient and less time consuming (Wright, 2005). The present study's return rate of less than 14% may suggest that individuals who did not provide PAS were not interested or invested in the topic. Another limitation of web surveys is that they may be viewed as 'spam' by the respondents, although this would have been a much less concern for this study due to the 'cover email' sent by the AHEAD administrative office. While the use of a web survey allowed the research team to focus very narrowly on a specific group of respondents (Schmidt, 1997), web surveys do not allow respondents to clarify questions by asking the researchers directly, much like mailed surveys. Therefore, respondents may have misinterpreted the questions about types of PAS and been unable to ask clarifying questions. Also, it is difficult to know whether this sample represents all DSS coordinators as other published studies have asked only about AHEAD membership (Dukes, 1997) or only about familial veteran status and gender, but no other demographic information (Vance & Miller, 2009). Research developing a demographic profile of DSS coordinators and members of AHEAD may be helpful in the future. Additionally, the present study surveyed DSS providers and not students with severe physical disabilities themselves. Thus the results may or may not be similar to how students with severe physical disabilities would describe or evaluate PAS services or their impact on the students' ability to participate in postsecondary education.

The results of this study, however, illuminate a number of interesting trends concerning the provision of PAS to students with severe physical disabilities enrolled in higher education. To our knowledge it provides a number of data points not found in past literature. First, a very small number of disability service providers include PAS in their program array. In the present study, 10.2% provided PAS compared to 5% in Fuller (2003), the only other study that reported on PAS as a DSS service. Again, it should be noted that there is no legal mandate in the United States that institutions of higher education provide services of a "personal" nature, such as PAS. Those who do provide PAS often provide less complex, less resource-intensive services such as helping students develop PA recruitment materials and maintaining contact with home health agencies instead of more resource-intensive PAS such as 24-hour/7 days per week residential services. Given the dearth of institutions that offer extensive PAS support, it is unlikely that postsecondary students who need extensive assistance in obtaining and managing their PAS needs are receiving adequate services, and less likely that they are attending their institution of first choice since so few institutions provide a full array of services. No other studies reporting parallel data could be located for data comparison.

Second, it is also interesting to note that PAS are more likely to be provided at master's level, comprehensive, and research institutions which, as one might surmise, also have higher average numbers of students with severe physical disabilities. PAS are least likely to be provided at associate's, bachelor's, and trade/technical institutions, which have the lowest average enrollments of students with severe physical disabilities. This is an unexpected finding. One might assume that the latter three kinds of institutions, in fact, would be more likely to have higher enrollments of students with severe physical disabilities as their reach is more localized and students would be more able to remain in parental or familial homes and use family members as PAs while attending school; however, this was not the case. Further research is needed to investigate this unexpected finding. Again, no similar studies could be located for comparison.

Third, DS providers' level of satisfaction/dissatisfaction with their provision of PAS provided interesting data. A higher percentage of those who provided PAS were more satisfied with their PAS services, indicating that perhaps coordinators who did not provide services felt a greater need to do so. This point needs clarification through future research. However, both groups were similar in the ratings of services satisfaction. In addition, those who had served in disability services for fifteen years or more were more likely to be satisfied with the PAS services they provided while individuals serving less than three years were the least satisfied. This may be due to individuals with longer tenure either being more likely to provide more extensive PAS or being more aware of how their PAS compared with services provided at other institutions. Other research data concerning the satisfaction of DSS coordinators with their services could not be located.

Fourth, the heat map data may help those individuals dissatisfied with the PAS offered at their institutions, by serving as a road map of sorts for future program development. As one goes from less to more comprehensive services, the probability 'clusters' of services are illuminated. While this finding is extremely tentative, the data suggest that there may be three levels of PAS provision. Category I/Minimal Assistance includes handling emergency situations, helping students develop PA recruitment materials, and maintaining contact with home health agencies. Category II/Intermediate Assistance includes Category I plus keeping a current list of PAs, generically training PAs, and conducting needs assessments of students' PA needs. Category III/Extensive Assistive includes Categories I and II plus PA management training to students, 24/7 access, specific PA training, and residential housing support with PA services. While these are not inflexible categories with impermeable boundaries, they may help program developers advance to the next level of services.

Implications for Future Research

The results of this study point to the need for additional investigations. First, it would be valuable to obtain students' perceptions of PAS in postsecondary education. Are students with severe physical disabilities limited in their selection of appropriate institutions by the lack of PAS available or the inadequacy of the services that are available? The present study suggests that access to PAS supports is extremely limited. The enrollment, retention, and graduation rates of students with severe physical disabilities may be severely compromised although these outcomes were not the focus of the present study. In addition, enrolled students who

require PAS should be queried about their satisfaction with the current array of services at their schools, with a focus on availability, adequacy, and relationship to success in school, and potentially, in their careers.

It would also be beneficial to explore more fully the barriers to offering more comprehensive PAS from the institutional perspective. Is the lack of a legal mandate a primary barrier? Although there is an unspoken assumption that resources, both financial and personnel, constitute significant barriers to PAS provision, the validity of this assumption warrants exploration given that the institutions that provide significant PAS support do so on a cost recovery basis.

Third, it would also be interesting to further delve into the histories of DSS coordinators who are employed by institutions that provide PAS. What circumstances prompted the institution to take this very unique action? What were the key motivators? Do the providers have personal experience with PAS that predisposes them to advocate for the enactment of such services? Are institutions that provide PAS more or less likely to provide more extensive support services for other subgroups of students with disabilities? Data provided by this study may bring a sharper, yet preliminary, focus to the availability and variability of PAS in higher education and encourage future discussions surrounding the viability of providing these services.

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