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Experiences of Young Adults with Deafblindness after High School

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Literature and research on deafblind youths and young adults has historically been limited. Despite a recent increase in the number of journal articles regarding deafblind youths (see, for example, Bruce, Nelson, Perez, Stutzman, & Barnhill, 2016; Correa-Torres & Bowen, 2016; Hartshorne & Schmittel, 2016; Kyzar, Brady, Summers, Haines, & Turnbull, 2016; Kyzar & Summers, 2014), most existing publications focus on school-related issues, family issues, or communication for children and youths. The literature related to post–high school outcomes is much more limited, with only three publications specific to this population identified (Peracchio & Stetler, 2009/2010; Petroff, 2001, 2010).

These publications include results from surveys of parents of young adults with deafblindness that were conducted in 1998 (Petroff, 2001), 2007 (Peracchio & Stetler, 2009/2010), and 2008/2009 (Petroff, 2010). Petroff's seminal 1998 study provided important information about the status of young adults who were 18 months post–high school, including demographic and disability information, services, and employment; however, the information is dated and was derived from a convenience sample. More recent survey results indicated that few young adults were working (30% and 37%), and that many were not receiving adequate post-school services (Peracchio & Stetler, 2009, 2010; Petroff, 2010). Although these later two reports are valuable, they provide limited descriptive statistics and are based on convenience samples. The purpose of the present study is to describe the experiences and outcomes of a nationally representative sample of young adults with deafblindness after completion of high school, taking into consideration their cognitive abilities. Evaluation of post-school experiences and outcomes can help us better understand the needs of young adults with deafblindness, especially in light of the Workforce Innovation and Opportunity Act's (WIOA, 2014) emphasis on transition and competitive integrated employment.

METHODS

Data source

Data were obtained from the National Longitudinal Transition Study-2 (NLTS2) dataset. SRI International conducted NLTS2 under contract with the U.S. Department of Education to document the experiences of students with disabilities during and after secondary school. Data were collected approximately every two years at five time points (called waves) from 2001 to 2009. NLTS2 used a two-stage stratified, clustered, random sampling process to identify a nationally representative sample of youths receiving special education services in 2001. Additional information about the NLTS2 data and sampling procedure is available online: https://nlts2.sri.com/studymeth/index.html.

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Sample

The NLTS2 deafblind sample included youths whose primary disability was deafblindness as identified by their school district, and youths with visual impairment (that is, blindness or low vision), as well as those with hearing impairments or deafness according to school district or parent report (Wagner, Newman, Cameto, Levine, & Marder, 2007). This approach was necessary to identify a sufficient sample of youths who are deafblind for participation in the NLTS2. We restricted our analysis sample to youths with deafblindness who were out of secondary school during the Wave 5 data collection (2009) and had data available for the Wave 5 Parent/Youth Survey, resulting in an unweighted sample size of approximately 90 (weighted $N = 2{,}830$). We divided participants into two groups based on whether they had a cognitive disability in addition to deafblindness. Young adults were identified as having a cognitive disability if they had autism, intellectual disability, traumatic brain injury, or multiple disabilities based on school district or parental reporting; approximately 30 (weighted $N = 969$) young adults had a cognitive disability. As NLTS2 is a restricted-use dataset managed by the Institute of Education Sciences (IES), all sample sizes in this article were rounded to the nearest 10 per IES reporting guidelines.

Variables

The NLTS2 Parent/Youth Survey covered many topics regarding young adults' characteristics, experiences, and outcomes. Participants completed the survey by telephone or mail, depending on their preferences. For the present study, we extracted variables from the Wave 5 Parent/Youth Survey in the following categories: demographics, personal characteristics, services received or needed, postsecondary education, and employment. All variables were measured after high school, except for the communication methods variables, which were only available in prior waves.

Data analyses

Descriptive statistics were used to provide information about post–high school outcomes of young adults with deafblindness. The tables include descriptive statistics for the whole sample and for two groups, based on presence or absence of a cognitive disability. The IES prohibits publishing data from fewer than three respondents; therefore, table cells with one or two respondents are represented by a dash. We used SAS (version 9.4) survey procedures with a sampling weight (np5wt) to adjust for NLTS2's complex sampling design. Accordingly, percentages are weighted estimates with design-adjusted standard errors to allow for generalizability to the population of young adults with deafblindness in 2009. Estimates are based on the maximum available sample size for each variable.

RESULTS

Sample characteristics and demographic information

Demographic information, disability information, and other characteristics of the sample are provided in Table 1. Participants were all in their early to mid-20s. Length of time since leaving high school varied from within the last two years to eight years before, with the majority leaving between two and six years before. Most participants had one or more additional disabilities; the most commonly reported were health impairment (31.0%, $SE = 3.94$), physical or orthopedic impairment (28.8%, $SE = 4.49$), speech disorder (22.6%, $SE = 3.63$), and learning disability (19.1%, $SE = 3.13$).

Post–high school services

Percentages of young adults who received specific post–high school services and percentages that needed those services are provided in Table 2. Almost all young adults (92.8%, $SE = 1.75$) received one or more

Table 1
Characteristics of young adults who are deafblind.

		Cognitive disability	
Variable	Overall % (*SE*)	No % (*SE*)	Yes % (*SE*)
Age			
21	9.4 (2.14)	8.6 (2.55)	11.0 (3.02)
22	27.0 (4.10)	31.0 (5.76)	19.3 (4.16)
23	20.7 (3.51)	12.9 (3.49)	35.8 (7.71)
24	22.6 (3.74)	23.8 (4.49)	20.2 (5.89)
25	20.3 (4.31)	23.8 (5.33)	13.7 (6.75)
Gender			
Male	61.1 (4.64)	54.8 (6.85)	73.4 (5.81)
Female	38.9 (4.64)	45.2 (6.85)	26.6 (5.81)
Race or ethnicity			
White	63.9 (6.62)	59.0 (8.27)	73.4 (7.09)
African American	11.0 (3.35)	12.4 (4.26)	8.3 (4.06)
Hispanic	23.2 (5.22)	28.6 (6.21)	12.8 (5.05)
Asian or Pacific Islander	-	-	-
Annual household income			
$25,000 or less	29.6 (3.90)	40.0 (5.13)	10.1 (4.89)
$25,001–$50,000	18.2 (3.64)	16.1 (4.21)	22.0 (5.74)
$50,001 or more	52.2 (5.11)	43.9 (5.61)	67.9 (7.02)
Vision loss			
Sees normally	21.0 (3.83)	21.0 (5.19)	21.1 (6.14)
A little trouble seeing	26.6 (3.72)	26.7 (4.71)	26.6 (6.54)
A lot of trouble seeing	32.3 (4.97)	29.1 (5.19)	38.5 (9.62)
Does not see at all	12.8 (3.96)	16.7 (5.49)	-
Data unavailable	7.2 (2.26)	6.7 (2.94)	8.3 (3.74)
Hearing loss			
Mild	21.6 (3.63)	20.5 (4.13)	23.9 (6.36)
Moderate	24.4 (4.09)	18.6 (4.55)	35.8 (6.29)
Severe to profound	40.4 (4.79)	47.6 (5.34)	26.6 (7.08)
Data unavailable	13.5 (2.85)	13.3 (3.61)	13.8 (4.73)
Communication method			
Oral speech	78.3 (3.66)	84.6 (4.40)	65.1 (5.33)
Sign language	44.7 (5.54)	47.7 (6.85)	38.5 (9.66)
Lip reading	30.5 (4.67)	36.8 (6.43)	16.8 (4.13)
Cued speech	15.2 (2.89)	15.2 (3.90)	15.2 (3.59)
Communication board	15.6 (3.64)	11.6 (3.78)	23.9 (7.67)
Something else	16.8 (3.41)	15.6 (4.26)	19.3 (5.80)
Number of additional disabilities			
0	36.4 (4.89)	52.4 (6.22)	-
1	17.6 (3.36)	18.6 (4.31)	15.6 (5.37)
2	20.7 (4.68)	20.0 (5.31)	22.0 (7.39)
3 or more	25.4 (4.81)	9.0 (2.66)	56.9 (9.01)
Years since high school			
Within 2	14.3 (2.39)	7.3 (2.67)	27.5 (5.09)
2 to 4	31.7 (4.39)	34.3 (5.03)	26.6 (6.54)
4 to 6	36.4 (5.23)	36.2 (6.71)	36.7 (6.80)
6 to 8	17.7 (4.32)	22.2 (5.55)	-

(cont.)

Table 1
(cont.)

Variable	Overall % (*SE*)	Cognitive disability No % (*SE*)	Cognitive disability Yes % (*SE*)
Living situation			
Parent(s) or foster parent(s)	63.6 (4.78)	63.3 (5.42)	64.2 (9.89)
Alone or with spouse or roommate	20.0 (4.38)	21.4 (6.02)	17.4 (5.83)
College dorm or military housing	5.3 (1.76)	8.1 (2.63)	0.00
Group home or assisted living	7.2 (3.09)	4.3 (2.99)	12.8 (6.73)
Other	3.8 (1.22)	-	-

Note: Based on parent- or self-report or both. Overall percentages are weighted population estimates based on a sample of approximately 90. Cells with fewer than three respondents were not reported.

services after high school. The most commonly received service was case management, followed by vocational services or job training. Young adults with and without cognitive impairments received most services at an approximately similar rate. A smaller percentage of those with cognitive impairments, however, received vocational services, assistive technology, and readers or interpreters; and a larger percentage of those with cognitive impairments received medical diagnosis or evaluation, speech therapy, and adult day or recreation programs. There were particularly large discrepancies in the receipt of vocational services and assistive technology, and 30% fewer young adults with cognitive impairments received these services. Of all young adults who received vocational services, only 42.5% (*SE* = 6.68) received them from a vocational rehabilitation agency.

Although the majority of young adults received multiple services, over half (54.0%, *SE* = 5.30) needed additional services they were not receiving. The two areas of greatest reported need were vocational services and occupational therapy or life skills training; all other general services were needed by a much smaller proportion (see Table 2). The amount of effort required for families to obtain services for these young adults varied, with a large portion reporting that it took "a great deal of effort" (45.1%, *SE* = .33) or "some effort" (23.0%, *SE* = 4.56), and smaller percentages reporting "a little effort" (14.4%, *SE* = 3.30) or "almost no effort" (17.5%, *SE* = 3.62).

Engagement after high school

Most young adults with deafblindness were engaged in scholarly or vocational activities in the two years before their Wave 5 interviews (or since high school, if they left less than two years before). The most common forms of engagement were employment and postsecondary school (28.2%, *SE* = 4.47), followed by employment (26.0%, *SE* = 4.47), and postsecondary school (16.3%, *SE* = 3.00). Although most deafblind young adults were engaged recently, 27.6% (*SE* = 3.92) were not engaged in any way during the preceding two years. Lack of engagement was more common among young adults with cognitive impairments: 43.1% (*SE* = 8.28) compared to 19.5% (*SE* = 3.97).

Postsecondary education. A small majority of young adults attended postsecondary school following high school, and those with cognitive impairments were less likely to attend (see Table 3). More than one-fifth were currently attending a postsecondary institution, and 16.0% received a postsecondary diploma, certificate, or license in the past. Almost all young adults (95.4%, *SE* = 4.55) who were currently attending postsecondary school were working toward a degree, certificate, or license. Community or two-year colleges were the most commonly

Table 2
Post–high school services: received versus needed but not received.

Service	Received			Needed but not received		
		Cognitive disability			Cognitive disability	
	Overall % (*SE*)	No % (*SE*)	Yes % (*SE*)	Overall % (*SE*)	No % (*SE*)	Yes % (*SE*)
Case manager	65.8 (4.32)	62.3 (5.48)	72.5 (6.19)	4.7 (2.21)	-	-
Vocational services or job training	58.9 (4.28)	69.0 (5.66)	39.4 (6.39)	29.2 (4.38)	29.2 (5.81)	29.1 (7.15)
Transportation	47.6 (5.59)	50.0 (7.14)	43.1 (9.82)	5.0 (2.24)	-	8.7 (5.16)
Medical diagnosis or evaluation	42.0 (3.92)	33.8 (5.18)	57.8 (6.74)	-	-	0
Audiology	37.6 (4.09)	38.6 (5.08)	35.8 (6.94)	3.0 (1.35)	-	5.8 (2.99)
Occupational therapy or life skills training	37.0 (5.83)	34.8 (7.74)	41.3 (10.18)	33.8 (5.22)	30.2 (5.79)	40.8 (9.26)
Personal assistant or aide	36.7 (4.81)	35.7 (5.45)	38.5 (9.08)	-	-	-
Assistive technology	35.1 (5.45)	45.2 (7.58)	15.6 (4.69)	5.7 (2.19)	7.1 (3.02)	-
Tutoring or educational assistance	31.7 (4.50)	34.8 (5.52)	25.7 (6.01)	4.0 (1.94)	4.6 (2.43)	-
Orientation and mobility training	27.9 (5.27)	36.2 (6.76)	11.9 (6.10)	5.7 (2.29)	7.1 (3.05)	-
Reader or interpreter	24.8 (4.23)	34.8 (5.31)	-	-	-	0
Social work	21.6 (3.11)	13.8 (3.68)	36.7 (6.94)	-	-	0
Psychological or mental health	20.7 (3.48)	21.9 (4.64)	18.3 (4.91)	3.0 (1.59)	-	-
Speech-language therapy	20.6 (3.92)	13.5 (4.22)	33.9 (6.21)	5.7 (2.79)	-	13.6 (6.72)
Physical therapy	16.0 (3.50)	11.9 (3.74)	23.9 (6.36)	4.0 (1.57)	-	8.7 (3.37)
Adult day or recreation program	10.7 (2.96)	-	23.9 (5.95)	-	-	-
Housing assistance	9.4 (3.86)	9.5 (4.14)	-	4.7 (1.34)	5.6 (2.06)	-

Note: Overall percentages are weighted population estimates based on a sample of approximately 90. Cells with fewer than three respondents were not reported.

Table 3
Postsecondary attendance and degree status of young adults who are deafblind.

		Cognitive disability	
Variable	Overall % (*SE*)	No % (*SE*)	Yes % (*SE*)
Any postsecondary school			
Ever attended	53.6 (4.69)	65.7 (4.99)	30.3 (7.86)
Currently attends	22.0 (3.28)	30.7 (4.63)	-
Received degree	16.0 (4.07)	20.5 (5.67)	-
Two-year or community college			
Ever attended	35.7 (4.33)	44.7 (5.69)	18.3 (5.56)
Currently attends	15.0 (2.66)	21.4 (3.76)	-
Received degree	10.3 (3.49)	14.3 (5.26)	-
Vocational or technical school			
Ever attended	24.1 (4.33)	29.0 (5.21)	14.7 (6.36)
Currently attends	2.8 (1.38)	-	-
Received degree	-	-	-
Four-year college or university			
Ever attended	21.3 (3.59)	28.6 (5.05)	-
Currently attends	8.2 (2.15)	12.4 (3.24)	0.00
Received degree	5.0 (2.42)	7.6 (3.56)	0.00

Note: Overall percentages are weighted population estimates based on a sample of approximately 90. Cells with fewer than three respondents were not reported.

attended type of postsecondary institution, followed by vocational or technical schools, and four-year colleges or universities.

Employment. A small majority of young adults (55.3%, *SE* = 4.32) worked for pay since leaving high school, although those with cognitive disabilities were less likely to have worked (44.0%, *SE* = 7.10), compared to those without cognitive disabilities (61.3%, *SE* = 5.19). Fewer young adults were currently working at the time of the interview (30.5%, *SE* = 3.70). Characteristics of young adults' current or most recent job (if not currently employed) are presented in Table 4. Of particular interest is that more than 40% of young adults worked full-time, but approximately 30% earned below minimum wage. Respondents with cognitive impairments were less likely to find their jobs independently. Of young adults who had worked, 30.0% (*SE* = 4.69) had been fired from a job since leaving high school.

Table 4
Characteristics of jobs held by young adults who are deafblind.

		Cognitive disability	
Variable	Overall % (*SE*)	No % (*SE*)	Yes % (*SE*)
Worked full-time	43.3 (6.83)	45.8 (7.79)	34.3 (12.47)
Earned below minimum wage	29.6 (6.21)	26.3 (6.12)	41.2 (14.16)
Found job independently	28.9 (7.50)	37.2 (9.85)	-
Received paid vacation or sick leave	44.4 (7.36)	48.9 (7.55)	35.4 (12.53)
Received health insurance	27.3 (7.11)	31.9 (8.41)	-
Received retirement benefits	29.5 (7.52)	28.7 (9.29)	31.1 (12.63)

Note: Overall percentages are weighted population estimates based on a sample of approximately 40. Cells with fewer than three respondents were not reported.

Among young adults who were not working, over a third (36.6%, *SE* = 4.49) reported that they were currently looking for a job. The most common reasons given for not looking were: disability too severe (40.4%, *SE* = 5.66); in school or training program (30.3%, *SE* = 6.39); and other, not specified (25.2%, *SE* = 5.77).

DISCUSSION

More than half of young adults with deafblindness in our sample were not receiving all of the post-high school services they needed, and the greatest needs were in occupational therapy or life skills training and vocational services. Parents identified a large need for vocational services in general and a greater need for more specific vocational services compared to other services. Young adults with cognitive impairments were much less likely to receive vocational services, yet they are equally, if not more, likely to need assistance in this area. Many families reported substantial challenges to obtaining services, as has previously been reported for this population (Peracchio & Stetler, 2009/2010).

Since high school, more than half of young adults had attended postsecondary school and had been employed, although only 30% were currently employed. Most young adults had also been engaged in some way recently; however, more than a quarter were not engaged at all. Those with cognitive disabilities were substantially less likely to be engaged: they were less likely to attend postsecondary school and less likely to work for pay since high school, and more than 40% of those who worked earned less than minimum wage.

These findings support the need for additional vocational services for young adults with deafblindness, particularly for those with cognitive disabilities. Parents, or the young adults themselves, may believe that their impairments are too severe for employment, yet exposure to vocational rehabilitation may offer a different perspective. WIOA promotes competitive integrated employment for youths with the most significant disabilities, and designates targeted vocational rehabilitation funding for this purpose. It is a concern that less than half of these young adults received vocational services from a vocational rehabilitation agency, as all youths with deafblindness should be referred to their state vocational rehabilitation agency while in high school. Timely referral allows for vocational rehabilitation involvement in youths' transition planning, thus facilitating more coordination between the youths and adult service systems. If youths or young adults have a vocational goal, vocational rehabilitation can help them obtain services in the two most important need areas identified in this study, and can improve their post–high school engagement.

This study provides additional information about the status of a nationally representative sample of young adults with deafblindness by supporting and supplementing the existing literature. A limitation of the study is the age of the data; additional research with more recent data is needed to determine the current status of this population. Another important direction for future research is identifying factors and practices associated with positive post-school outcomes.

REFERENCES

Bruce, S. M., Nelson, C., Perez, A., Stutzman, B., & Barnhill, B. A. (2016). The state of research on communication and literacy in deafblindness. *American Annals of the Deaf, 161*(4), 424–443.

Correa-Torres, S. M., & Bowen, S. K. (2016). Recognizing the needs of families of children and youth who are deafblind. *American Annals of the Deaf, 161*(4), 454–461.

Hartshorne, T. S., & Schmittel, M. C. (2016). Social-emotional development in children and youth who are deafblind. *American Annals of the Deaf, 161*(4), 444–453.

Kyzar, K. B., Brady, S. E., Summers, J. A., Haines, S. J., & Turnbull, A. P. (2016).

Services and supports, partnership, and family quality of life: Focus on deaf-blindness. *Exceptional Children, 83*(1), 1–15.

Kyzar, K. B., & Summers, J. A. (2014). Students with deaf-blindness and their families: Service utilization and satisfaction. *Inclusion, 2*(3), 195–211.

Peracchio, J., & Stetler, B. (2009/2010). NFADB survey and position paper on transition. *News from Advocates for Deaf-Blind, 14*(1), 5–7.

Petroff, J. G. (2001). *National transition follow-up study of youth identified as deaf-blind: Parent perspectives.* Monmouth, OR: The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind.

Petroff, J. G. (2010). A national transition follow-up study of youth with deaf-blindness: Revisited. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3*, 132–138.

Wagner, M., Newman, L., Cameto, R., Levine, P., & Marder, C. (2007). *Perceptions and expectations of youth with disabilities. A special topic report of findings from the National Longitudinal Transition Study-2* (NLTS2). Menlo Park, CA: SRI International.

Workforce Innovation and Opportunity Act, 29 U.S.C. § 3101 et seq. (2014).

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