

# ***SBANT Education Day – March 2023***

## **A Glimpse at the Research: Education and Employment in Young Adults with Spina Bifida**

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ORIGINAL ARTICLE

# Education and employment as young adults living with spina bifida transition to adulthood in the USA: A study of the National Spina Bifida Patient Registry

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# Aims of the Study

1. To describe the educational and employment profiles among individuals with spina bifida aged **18-26 years**
2. To better describe how SDOH are associated with employment status
  - Sociodemographic factors
  - Factors related to the condition (Spina Bifida) itself
  - Specific health outcomes



# Methods of the Study

## Statistical Analyses

From 2009 to 2019:

- **1,909** NSBPR participants between 18 and 26 years contributed 4,279 annual clinic visits
- *Median* age was 21 years
- Female 55.5%
- Non-Hispanic White 66.8%
- Non-private insurance 52.6%

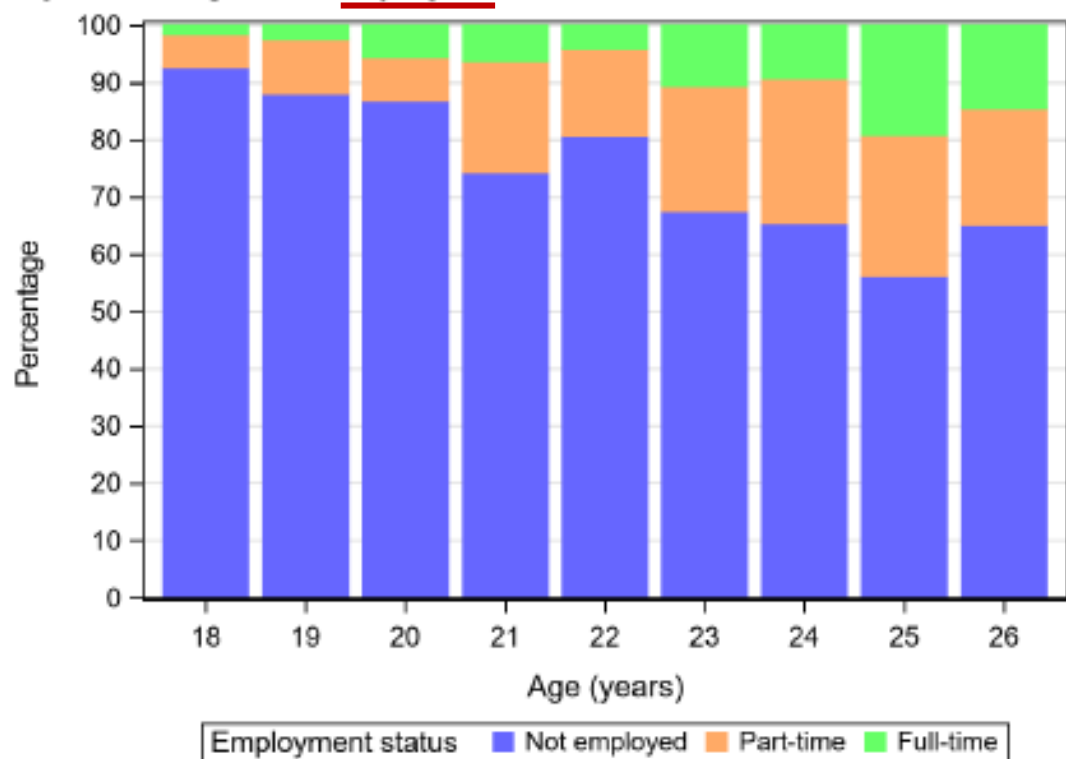
### Statistical analysis

We examined the association of employment outcomes with covariates using all visits excluding those reported as being a current student with 'Not employed – child or student' status. Time-independent variables included sex, race/ethnicity, and spina bifida type. Time-dependent variables included age, lower extremity functional level, health insurance, educational level, ambulatory status, continence status, history of shunt, non-shunt surgeries since last visit, and episodes of skin breakdown since the last visit. Associations between spina bifida type and all other variables shown in [Table 1](#) were examined using a  $\chi^2$  test or Fisher's exact test.

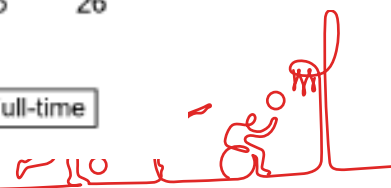
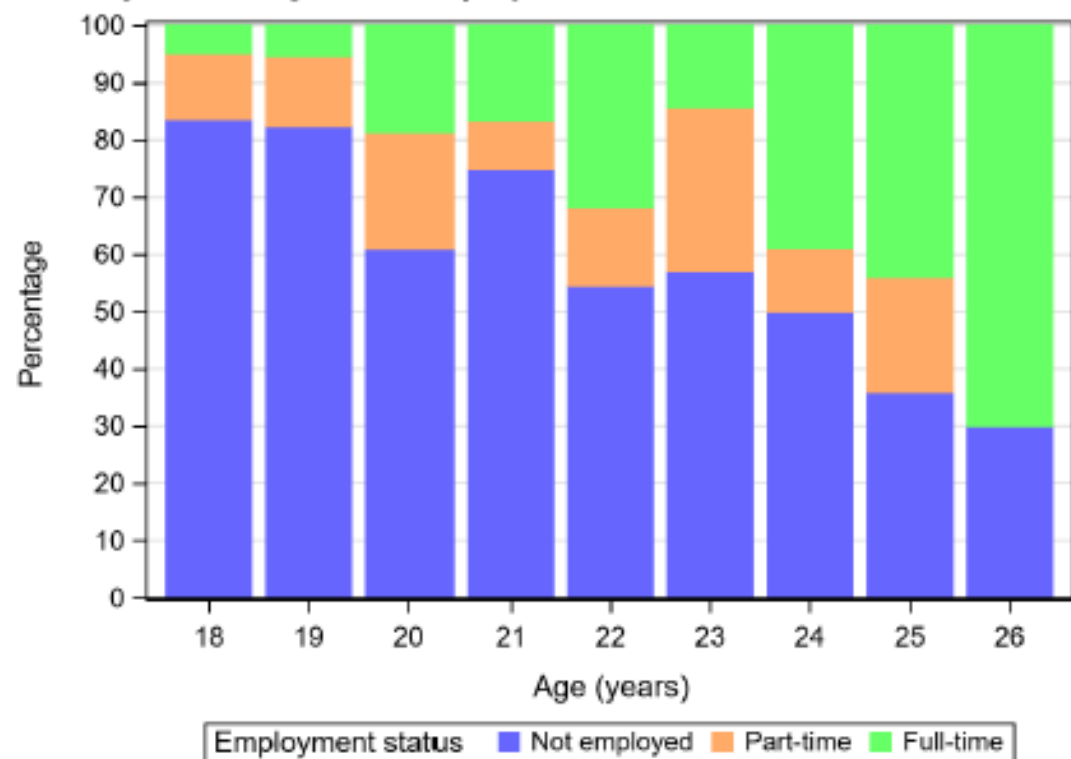
To account for the effect of repeated observations of employment status and other time-dependent variables from the same person, we used generalized estimating equations (GEE) models with logit link function.<sup>21</sup> The outcome of the main analysis was any employment. An outcome of sub-analysis was full-time employment among all visits at which participants reported being employed. GEE regression models estimated the odds ratios of these outcomes. The GEE regression models also accounted for correlated data from participants clustered by clinic. Multiple GEE regression models were conducted to test the independent association between outcome and covariates; an independent correlation structure was specified. Multiple collinearity was checked for both multiple regression models by examining the estimated correlation matrix. Any *p*-values less than 0.05 were considered significant; 95% confidence intervals (CIs) were calculated for odds ratio point estimates. Association between medical characteristics and health outcomes was also tested and is presented in [Table S2](#). Statistical analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA). All analyses were replicated by a second analyst.

Variables	Overall ( <i>n</i> = 1909)	Spina bifida type		<i>p</i>
		Myelomeningocele ( <i>n</i> = 1597)	Non-myelomeningocele ( <i>n</i> = 312)	
<u>Employment status</u>				
Not employed	1452 (76.1)	1247 (78.1)	205 (65.7)	<0.001
Part-time	276 (14.5)	233 (14.6)	43 (13.8)	
Full-time	181 (9.5)	117 (7.3)	64 (20.5)	

**Myelomeningocele, Employment**



**Non-myelomeningocele, Employment**



# Summary of Numbers



At the time of the participants' last visits:

- 41.9% were non-ambulatory
- 50.1% were continent of *bladder*
- 62.4% were continent of *bowel*
- 41.8% had at least 1 year of post-high school education/training
  - 23.9 were employed.



# Applying the Research: Bowel Continence

This study's findings are consistent with other research indicating a strong association between bowel continence and employment

- 58% of adults with spina bifida are bowel continent
- Bowel continence is a *modifiable* factor
  - Physical, Medical and Rehabilitation (PMR) doctor can assist with bowel management



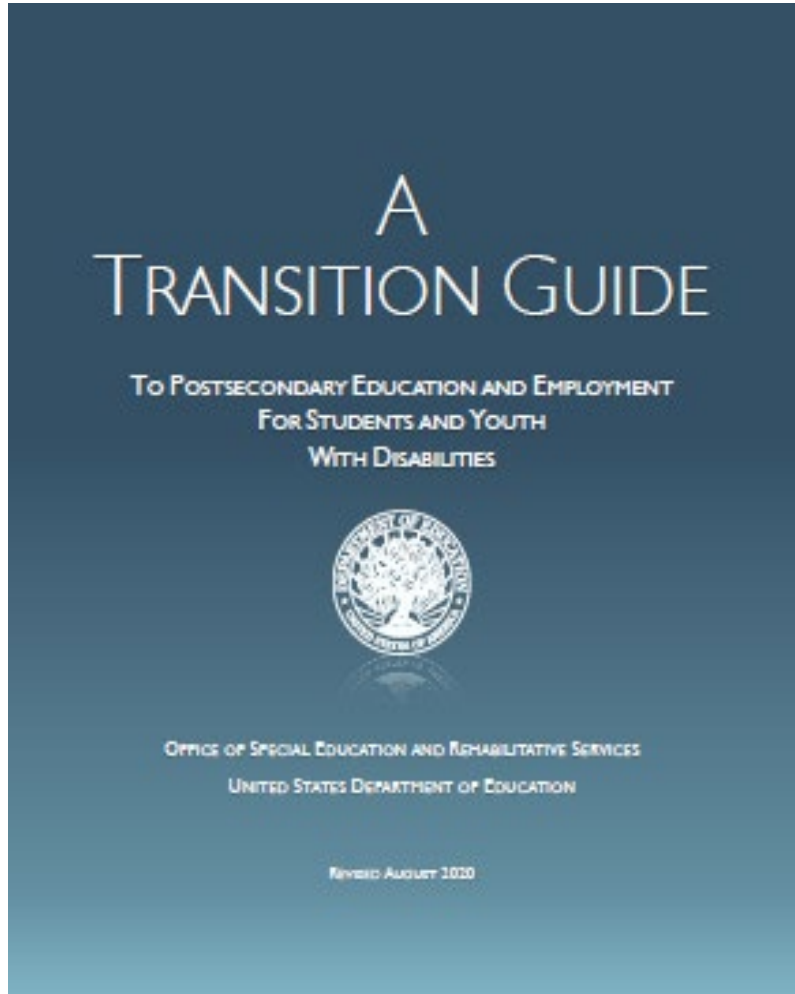
# Applying the Research: Post-high school education/training

Vocational Rehab Agencies, like the Texas Workforce Commission offer:

- Vocational counseling
- Vocational training
- Supported employment services
- Post secondary education
- Career Development
- Job placement







# **A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities**

**Office of Special Education and Rehabilitative Services**

**<https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-august-2020.pdf>**



# Integrating Transition Planning - Developing Creative Solutions

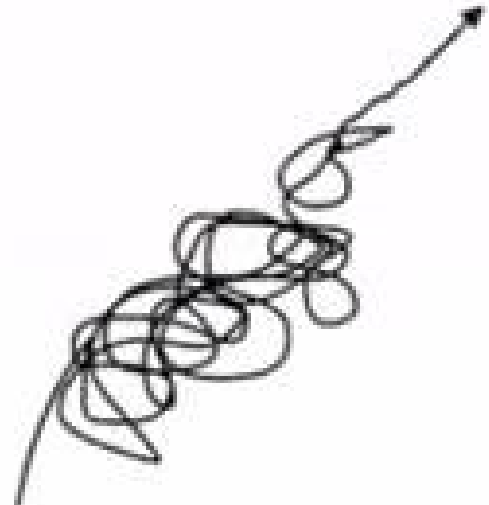
The Journey of Transition to Adult Community Services / Education / Employment

**SUCCESS**



What people think it looks like

**SUCCESS**



What it really looks like



[Armando's Story - Spina Bifida - YouTube](#)

