# Education and Employment Among Individuals With Duchenne Muscular Dystrophy: Results From a Caregiver Survey

Bryan Innis,[1] John Jarvis,[2] Taylor Renteria,[2] Shivangi Patel,[1] Ivana Audhya[1]

[1]Sarepta Therapeutics, Inc., Cambridge, MA, USA; [2]Medicus Economics, LLC, Milton, MA, USA

## Introduction

- Duchenne muscular dystrophy (DMD) is an X-linked degenerative neuromuscular disease characterized by progressive muscle weakness[1–3]
- Progressive muscle weakness develops in early childhood, and loss of ambulation typically occurs by teenage years, reducing functional independence[1–3]
- While the physical and medical impacts of DMD are well documented,[1–3] the effects of DMD on education and employment opportunities have not been thoroughly explored in the United States (US)

## Objectives

This study assessed education and employment participation among individuals with DMD in the US

## Methods

- A noninterventional, retrospective online survey was completed by caregivers of individuals with DMD, who provided information on financial, social, and other aspects of life influenced by DMD
- The survey collected de-identified background information for both the caregiver and the individual with DMD and included questions regarding care recipients' education and employment participation

### Study Inclusion Criteria

- Aged ≥18 years and read, understood, and spoke English
- Resided in the US for ≥12 months
- Provided care or support to individual(s) with DMD (aged ≥2 years) in their household for ≥12 months
- Could provide estimates of the household's costs to support the individual(s) with DMD
- Home modification– or transportation-related expenses within the past 5 years (at least 1 expense was required)
  - Moved to or built new home
  - Modified home entrance (eg, ramp)
  - Modified bathroom, bedroom, or kitchen
  - Modified interior home doorway(s)
  - Installed elevator or lift
  - Purchased and/or modified a handicap-accessible vehicle
- The survey provided data for 2 other separate analyses

## Results

### Caregivers

- A total of 90 caregivers representing 106 individuals with DMD completed the survey
- 98.1% self-identified as the primary or co-primary caregiver
- 74 caregivers cared for 1 individual and 16 caregivers cared for 2 individuals with DMD
- Caregivers were mostly female (94.4%), predominantly White (90.0%), with a mean age of 45.6 years (SD: 8.4)
- Caregivers lived in the South (36.7%), Midwest (31.1%), Northeast (16.7%), or West (15.6%), in a town or suburban area outside of a city (57.8%), rural or countryside area (30.0%), or urban city (12.2%)

### Individuals With DMD

- 74 individuals with DMD were currently receiving formal education (**Table 1**)
- Of these individuals, 77.0% were enrolled in a mainstream school/university, 6.8% in a school/university especially equipped to serve students with disabilities, and 16.2% were homeschooled
- Enrolled students missed on average 3.3 school days (range: 0–16 days; SD: 3.3) per month due to their health
- 56.9% of non-homeschooled individuals relied on a school aide (**Table 2**)
- Reliance on a school aide was highest among students who always used a wheelchair or scooter (nonambulatory, n=20/25; 80.0%) compared with individuals who used a wheelchair or scooter some of the day (transitional, n=8/15; 53.3%) or walked all day (ambulatory, n=5/18; 27.8%)
- 94.8% of non-homeschooled individuals attended a public school
- Among the 26 individuals aged ≥18 years, 3 (11.5%) were employed in any capacity (**Table 3**)

***Table 1*** *Education Participation Among Individuals With DMD*

| **Individuals with DMD** | **N=106** |
|---|---|
| Age in years, mean (SD) | 14.5 (5.3) |
| Aged ≥18 years, n (%) | 26 (24.5) |
| **Current education status, n (%)** | **N=106** |
| Currently enrolled in school/college/university | 74 (69.8) |
| **Type of school, n (%)** | **N=74** |
| Enrolled in a mainstream school/college/university | 57 (77.0) |
| Enrolled in a school/college/university especially equipped to serve students with disabilities | 5 (6.8) |
| Homeschooled | 12 (16.2) |
| **Current school grade, n (%)** | **N=74** |
| Kindergarten–5th grade | 21 (28.4) |
| 6th grade–8th grade | 27 (36.5) |
| 9th grade–12th grade | 22 (29.7) |
| College/university | 3 (4.1) |
| Other | 1 (1.4) |

DMD=Duchenne muscular dystrophy.

***Table 2*** *Education and School Aide Use Among Non-Homeschooled Individuals With DMD*

| **Ambulatory status in non-homeschooled individuals in kindergarten through 12th grade** | **N=58** |
|---|---|
| Ambulatory, n (%) | 18 (31.0) |
| Transitional, n (%) | 15 (25.9) |
| Nonambulatory, n (%) | 25 (43.1) |
| **Use of school aide in non-homeschooled individuals in kindergarten through 12th grade** | **N=58** |
| Aide utilized, n (%) | 33 (56.9) |
| **Use of school aide in non-homeschooled individuals in kindergarten through 12th grade, by ambulatory status** | **N=33** |
| Ambulatory, n (%) | 5 (27.8) |
| Transitional, n (%) | 8 (53.3) |
| Nonambulatory, n (%) | 20 (80.0) |
| **Type of school attended in non-homeschooled individuals in kindergarten through 12th grade** | **N=58** |
| Public school | 55 (94.8) |

DMD=Duchenne muscular dystrophy.

***Table 3*** *Employment Participation Among Individuals With DMD*

| **Current employment situation** | **N=106** |
|---|---|
| Not employed, n (%) | 101 (95.3) |
| Employed full time, n (%) | 1 (0.9) |
| Employed part time or as a contract worker, n (%) | 3 (2.8) |
| Other, n (%) | 1 (0.9) |
| **Current employment situation for adults (age ≥ 18 years)** | **N=26** |
| Employed in any capacity, n (%) | 3 (11.5) |

DMD = Duchenne muscular dystrophy.

## Key Findings

**Most individuals with DMD were enrolled in a mainstream school, and required additional support in the classroom**

## Conclusions

This survey provides insights into how the progressive muscle weakness and decreasing mobility of DMD reduced time spent in class

Two-thirds of individuals with DMD were enrolled in education, principally in a mainstream school

Need for a school aide was higher among individuals who were nonambulatory

This survey was also used in an analysis of household costs (PCR62) and sources of financial support to households (podium presentation May 7; 1:45 PM), also presented at ISPOR 2024

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**Disclosures: BI**, **SP**, and **IA** are employees of Sarepta Therapeutics, Inc., and may own stock/options in the company. **JJ** and **TR** are employees of Medicus Economics, LLC, which received consulting fees from Sarepta Therapeutics, Inc.

## References

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**International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Annual Meeting; May 5–8, 2024; Atlanta, GA**

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## Methods (cont)

### Recruitment and Screening

- Survey participants were recruited in collaboration with Rare Patient Voice, an organization with a panel of caregivers for individuals with DMD
- Rare Patient Voice encouraged and invited referrals to join the Rare Patient Voice panel and complete the survey
- Rare Patient Voice contacted panelists and caregiver members living in the US via email with an online link, which directed respondents to an online screening questionnaire
- A Rare Patient Voice screener reviewed the consent and screening sections of the questionnaire. Respondents who passed the screening questions were directed to complete the survey
- Medical records or other personal documents were not accessed or assessed to inform screening or recruitment

### Ambulatory Status

- Ambulatory, transitional, or nonambulatory status were determined based upon caregiver-reported scooter or wheelchair usage by individuals with DMD

### Statistical Analysis

- Primary analyses summarized education- and employment-related descriptive characteristics for individuals with DMD based on caregiver responses

### Limitations

- Due to the retrospective nature of this study and reliance on self-reported data, there is a potential for recall bias to influence the results
- Findings may not be demographically representative of all US households caring for individuals with DMD
- The outcomes should be viewed as indicating correlation rather than suggesting a causal relationship