Assessment of Underserved Populations in Duchenne and Becker Muscular Dystrophy: The CDCC Landscape

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Background

- Parent Project Muscular Dystrophy (PPMD) was founded with the goal of fighting to end Duchenne and Becker muscular dystrophies (Duchenne and Becker respectively) through investments, connecting the muscular dystrophy community, and leadership[1].
- PPMD accomplishes its mission through four central pillars: research, care, advocacy, and engagement[1].
- As part of the pillar of care, PPMD established the Certified Duchenne Care Center (CDCC) program using standards established by the MD-CARE ACT (2001) and in partnership with the Center for Disease Control, creating the Duchenne Care Considerations used by the clinics today[3].
- As of June, 2026, there are 39 active Certified Duchenne Care Centers across the United States (U.S.)[2].

Research Objectives

- As individuals with Duchenne live longer, barriers to accessing comprehensive Duchenne care are becoming more apparent.
- Recognizing underserved populations within the Duchenne community is essential to identifying existing services, care gaps, and where CDCCs can adapt to better support patients and families.
- Understanding differences between the approaches of transfer to adult care and the broader concept of transition to adulthood, especially in underserved populations, can inform the development of equitable care models.

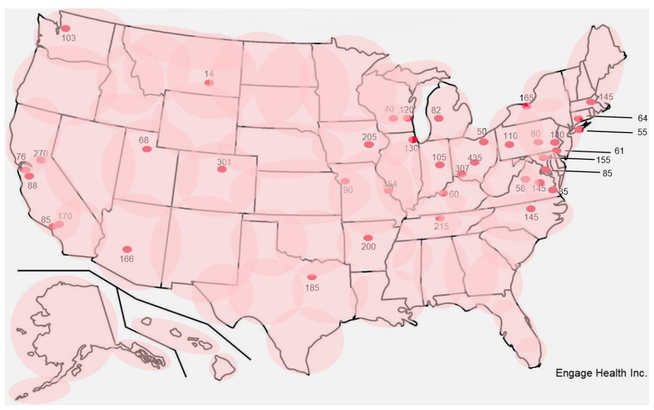
Methods

- A qualitative mixed methods study was conducted with representatives of 39 CDCCs across the U.S. between April-June 2026 to assess the landscape of care in Duchenne.

Results: Participation

- There was excellent participation across the CDCCs, with 100% center ascertainment. This included:
  - Quantitative survey: one representative from each of the 39 CDCCs completed the questionnaire.
  - Qualitative interviews: all 39 CDCCs participated, with 18 centers (46.2%) represented by more than one individual. In total, 68 participants contributed to the interview phase.
- The CDCCs managed between 14 and 435 dystrophinopathy patients (mean 139.8) and managed over 5,400 dystrophinopathy patients in total.
- Centers had been certified between 1.0 and 12.1 years (mean 7.4 years).
- The 39 CDCCs displayed a catchment area that covers the entirety of the U.S. (Figure 1.0)[2].

Figure 1.0 Catchment Areas of PPMD CDCCs Across the U.S.[2]



Results: Ethnically Diverse Populations

- Ethnic diversity among patients varied widely across the 39 CDCCs, with some centers serving populations that are up to 98.7% ethnically diverse and four reporting zero.
- Of the 108 mentions of ethnic groups served, Hispanic/Latino individuals were the most prevalent (29.6%), followed by Asian Indian (9.3%) and African American (7.4%).
- There were 114 programs/services mentioned. These were most often availability of live and/or video interpreter (52.6%), translated written materials (38.6%) or special program (8.8%).
- Expanding consistent language and culturally tailored services across all centers is key to equitable care.

Figure 2.0 Programs, Barriers, and Gaps in treating ethnically diverse Duchenne patients

<u>Programs</u>
- Translation-related resources included after-visit summaries, materials from PPMD, comic books, disease education, and appointment reminders.

<u>Barriers</u>
- 29 barriers were mentioned in serving ethnically diverse populations, most commonly:
  - Amplification of existing challenges
  - Difficulty in adult transfer
  - Cultural differences

<u>Gaps</u>
- Gaps in expectations vs. offerings
- Interpreter shortages
- Limited legal support
- Increased care complexity in Duchenne

Results: Economically Underserved Populations

- Access to specialized care is important for all patients with Duchenne.
- Of the 39 CDCCs interviewed, 36 reported serving economically underserved populations with an estimated population percent ranging from 10% to 100%.

Figure 3.0 Programs, Barriers, and Gaps in treating economically underserved Duchenne patients

<u>Programs</u>
- 69.2% reported having internal programs including:
  - Transportation services (24.5%), housing services (20.9%), and supplies programs (17.3%)
- 100% reported referring to external programs

<u>Barriers</u>
- 50 barriers were mentioned, most commonly including:
  - Transportation (12.0%)
  - Competing priorities (Duchenne secondary) (10.0%)
  - Economic burden amplifies Duchenne (8.0%)
- There was a lack of visibility into programs offered across centers

<u>Gaps</u>
- No universal therapy access (despite economic status)
- Minimal DME funding
- Need for home modification support
- Challenges for emergency transport (e.g., for those in wheelchair)

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Results: Geographically Diverse Populations

- Although CDCC catchment areas collectively covered the entire U.S., there were 47 mentions of geographically diverse populations seen by the CDCCs, with 42.6% of the mentions being rural patients, 27.7% out-of-state patients, and 6.3% international patients.
- There were 132 mentions of programs/services implemented by the CDCCs as a means of addressing the inequities in care faced by geographically diverse Duchenne patients.

Figure 4.0 Programs, Barriers, and Gaps in treating geographically diverse Duchenne patients

Programs
- 87.2% of CDCCs reported having programs to aid geographically diverse populations including:
  - 40.9% access to local care coordination
  - 23.5% transportation arrangements
  - 22.0% appointment management
  - 13.6% food/lodging

Barriers
- 36 barriers were reported in serving geographically diverse populations:
  - 7.8% inability to find knowledgeable providers
  - 13.9% heightened importance of care coordination
  - 13.9% transportation

Gaps
- Gaps that exist for geographically diverse Duchenne patients included:
  - Medicaid should cover the closest provider
  - Telemedicine should be more widely available
  - Parking passes and transportation assistance should be more widely available

Conclusion

Overall, CDCCs provide a strong foundation for comprehensive Duchenne care, as evidenced by their multidisciplinary approach and broad geographic reach, with catchment areas collectively serving patients across the U.S..[2]

However, as longevity improves for individuals with Duchenne, there is an increasing need to establish adult-centered models of comprehensive care that address the complex needs of Duchenne patients, including the unique issues experienced by underserved populations.

Further research that is focused on characterizing and addressing inequities in care among underserved Duchenne populations, particularly those affected by economic disadvantage, geographic isolation, and ethnic disparities, is needed to improve access and outcomes for these populations.

Acknowledgements

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References

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Learn more about the PPMD CDCCs here!