Assessment of Transfer to Adult Care & Transition to Adulthood 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 care pillar, 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[2].
- As of June, 2026, there are 39 active CDCCs across the United States (US)[3].

Research Objectives

- To characterize current models of care for patients with Duchenne across CDCCs in the US.
- To understand differences between the approaches of *transfer to adult care* and *transition to adulthood* in order to inform the development of comprehensive adult care models (Figure 1.0).

Figure 1.0 Transfer of Care and Transition to Adulthood

Transfer of Care: "The formal handoff of a patient's medical care from pediatric providers to adult healthcare providers, including the coordination, communication, and continuity needed to ensure ongoing care management."

Transition to Adulthood: "Maximizing independence where feasible and appropriate (physical, intellectual, & financial) to reach adulthood."

Methods

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

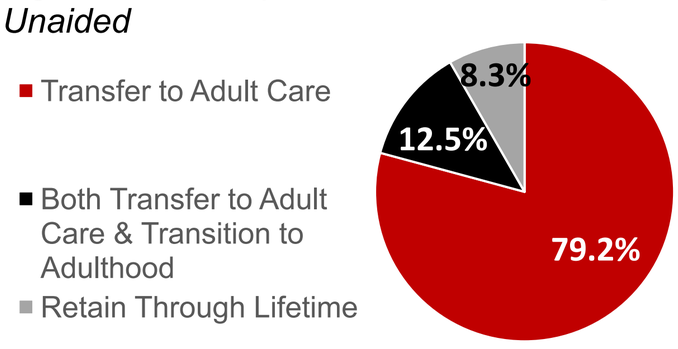
Results: Participation

- 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; 18 centers (46.2%) were represented by more than one individual. In total, 68 participants contributed to the interview portion.
- Centers had been certified between 1.0 and 12.1 years (mean 7.4 years), and included a catchment area that covered the entirety of the US[3].
- The CDCCs managed between 14 and 435 dystrophinopathy patients (mean 139.8), and managed over 5,400 dystrophinopathy patients in total.
- Most CDCCs defined "pediatric" as 0-18 or 0-21 years. Only 5 centers (12.8%) saw more adult than pediatric patients.

Results: Transition Programs

- When asked in an *unaided* manner (without definition) 25 (64.1%) clinics stated that they have a transition program in place.
- Twenty-four (24) CDCCs described their transition program; 79.2% described only aspects related to *transfer to adult care*, 12.5% described aspects related to both *transfer of care and transition to adulthood*, and 8.3% stated that they keep their patients throughout their lifespan (Figure 2.0).

Figure 2.0 Descriptors of Transition Program - Unaided



- Common descriptions of the current programs are noted below (Figure 3.0).

Figure 3.0 Descriptors Related to Current Program

Transfer of Care Descriptors
- Described upcoming changes
- Transfer to another multidisciplinary clinic or MDA center
- Formal policies in place
- Staff meetings to review cases

Transition to Adulthood Descriptors
- Working towards autonomy & independent decision making
- Legal aspects are addressed
- Social/vocational issues are addressed

Results: Topics that *Transition to Adulthood* Should Address

- Among CDCCs with established transition programs, clinic representatives reported that successful preparation for adulthood should include attention to relationships, personal growth, legal matters, community integration, and vocational opportunities for patients with Duchenne (Figure 4.0).

Figure 4.0 Aspects Reported as Important to Address when Discussing Transition to Adulthood in Duchenne

Legal Preparedness (38 mentions)
- Healthcare proxies
- Medical power of attorney & guardianship
- Independent decision-making

Puberty & Relationships (32 mentions)
- Discussion of hormone therapy
- Sexuality and intimacy
- Delayed growth

Education & Vocation (32 mentions)
- Life goals
- Post-secondary plans
- Accessible schooling
- Vocation
- Independent living

Socialization & Community (18 mentions)
- Building friendships
- Pursuing interests and ways to increase social interactions and build community

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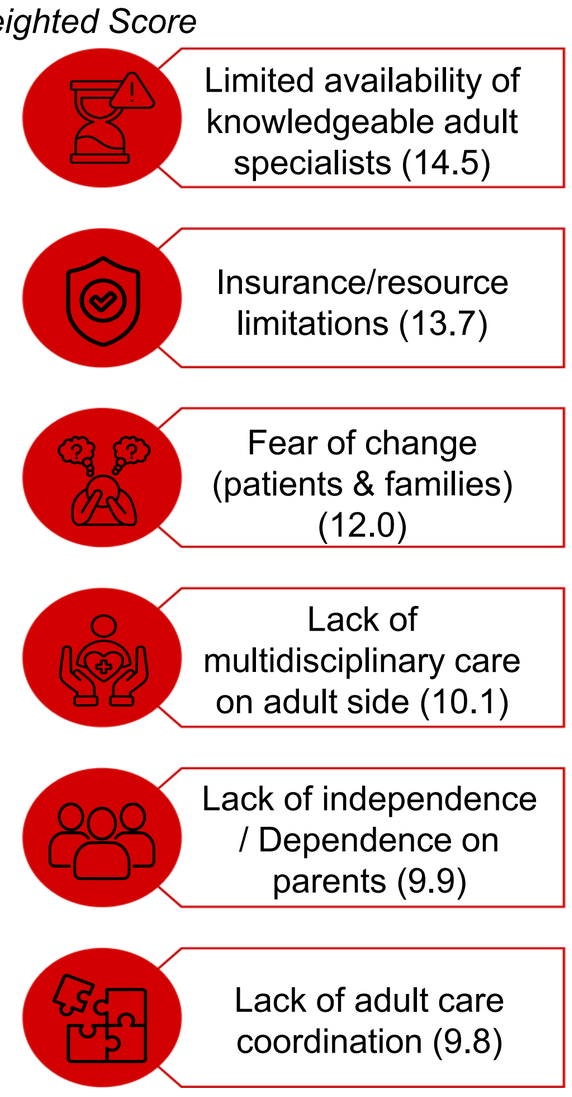
Results: Barriers That Impede *Transition to Adulthood*

- Center representatives identified a range of barriers that may impede a successful transition to adulthood in Duchenne. Scores were weighted according to the relative importance assigned to each domain.
- *"It always feels like there is more we could be doing for these patients, but there is only so much you can provide in the clinic day."*

Figure 6.0 Barriers CDCCs Face in Providing Optimal Care to Duchenne Patients, Weighted Score



Conclusion

The CDCC program has provided a strong foundation for comprehensive care of those living with Duchenne, as evidenced by their coordinated multidisciplinary approach and broad geographic reach across the U.S.[3].

While challenges exist, most CDCCs have a strong program focused on *transferring patients to adult care* as they age, and some described program components related to transition to adulthood.

As individuals with Duchenne live into adulthood, there is an increasing need to establish and refine adult-centered models of care that effectively address the issues associated with both *transfer to adult care* and the broader concept of *transition to adulthood* in Duchenne.

Additional research is needed to define the key components of optimal adult care and to inform the development of sustainable, evidence-based models that support long-term health and quality of life outcomes in patients with Duchenne.

Acknowledgements

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References

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Learn more about PPMD CDCCs here