

# Assessment of the Needs of Children and Adolescents with Duchenne Muscular Dystrophy Based on Patient and Family Experiences

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## Authors

Sabanur avdar

Özlem Özaydın

Özlem Köksal

Gonca Akbaş

Aylin Yetim Şahin

Vefik Arıca

Hüseyin Dağ

Şirin Güven

## Introduction

Duchenne Muscular Dystrophy (DMD) is a progressive neuromuscular disorder that begins in childhood, with physical, psychosocial, and social impacts becoming more pronounced during adolescence. Beyond the clinical progression of the disease, adolescence is a critical life stage where specific requirements for psychological well-being, education, social integration, and independence emerge. This study aims to identify the thematic needs of children and adolescents with DMD based on patient and family experiences and to develop relevant policy recommendations.

## Aim and Method

This study evaluates the outcomes of the "Duchenne Muscular Dystrophy Awareness Meeting," organized in a hybrid format on September 17, 2025, by the Health Institutes of Türkiye (TÜSEB) and the Türkiye Maternity, Child, and Adolescent Health Institute

(TAÇESE). A total of 70 participants including patients and their families, representatives from patient advocacy groups, academics, clinicians, and public institution officials attended the meeting. The data, consisting of meeting recordings, written participant feedback, and organizational notes submitted post-meeting, were analyzed using qualitative content analysis.

## **Findings**

The needs of DMD patients and their families were categorized under seven primary themes: (1) establishing multidisciplinary neuromuscular disease centers and enhancing the functionality of existing ones; (2) strengthening home care and rehabilitation services; (3) streamlining the processes for medical and disability reports; (4) expanding psychosocial support mechanisms; (5) supporting educational rights and social participation; (6) accelerating domestic research and development for pharmaceuticals and medical devices; and (7) strengthening protective regulations against non-scientific practices. Within these themes, the increasing need for psychological support during adolescence, accessibility issues in educational environments, and the risk of social isolation were particularly prominent.

## **Conclusion**

The findings indicate that the requirements of adolescents with DMD must be addressed through a holistic framework that encompasses psychosocial and educational dimensions beyond conventional medical care and monitoring. The workshop results highlight an urgent need for the development of adolescent-centered approaches in the management of DMD.

## **Keywords**

Duchenne Muscular Dystrophy, Rare Diseases, Needs Analysis

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## **Image Content**

# Living with DMD: Essential Needs and Solutions

A holistic framework for Duchenne Muscular Dystrophy (DMD) patient care, addressing systemic and psychosocial barriers beyond clinical treatment, intensified during adolescence.

## Health and Institutional Needs



### Multidisciplinary Muscle Disease Centers

Establish specialized centers and increase the functionality of existing healthcare facilities.

### Streamlined Reporting Processes

Reduce the bureaucratic burden required to obtain health and disability status reports.



### Home Care and Local Development

Strengthen home rehabilitation services and accelerate domestic medical device and drug research.

## Psychosocial and Educational Support

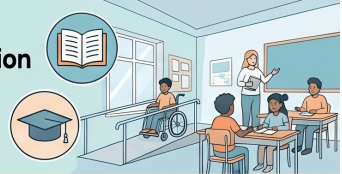


### Adolescent-Focused Psychological Support

Address increased mental health needs and social isolation risks during the transition to puberty.

### Accessibility and Participation in Education

Ensure physical accessibility in schools while promoting full social inclusion for students.



### Protection of Science-Based Practices

Implement legal regulations to protect patients from non-scientific or unproven medical treatments.