CARE Down Syndrome: Responding to an Unmet Need

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CARE DOWN SYNDROME

national down syndrome society

Background

- Since the 1950s, the number of individuals with Down syndrome has increased fourfold—and the number of adults with Down syndrome has grown eightfold. Over the past 40 years, life expectancy for individuals with Down syndrome has also doubled to 60 years. Medical education has not kept pace, especially considering the pattern of health conditions in adults with Down syndrome differs significantly from that of individuals without Down syndrome.
- Data from a 2023 National Down Syndrome Society (NDSS) survey identified a gap in access to healthcare professionals with expertise in Down syndrome, with individuals with Down syndrome and caregivers reporting significant challenges due to a shortage of knowledgeable clinicians.
- Key concerns include delays in transitioning from pediatric to adult care and difficulty locating clinicians equipped to meet the needs of adults with Down syndrome, including age-related conditions, such as Alzheimer's disease.
- **Only 5% of adults with Down syndrome in the U.S. have access to specialty clinics.**[1] Many continue to receive care from pediatric healthcare professionals, resulting in more adverse outcomes than those transitioning to adult clinicians.[2] Distance and state lines further limit access.[3]
- In response, NDSS created CARE Down Syndrome, a free online clinical education and resource hub, which was launched in October 2025 to equip primary care professionals (PCPs) with evidence-based knowledge on caring for adults with Down syndrome.

Methods

Conducted two community listening sessions to identify priority topics and unmet needs among adults with Down syndrome and their families.

Engaged 40+ healthcare professionals to develop and review content across key clinical areas, including Alzheimer's disease, Down Syndrome Regression Disorder, weight management, and more.

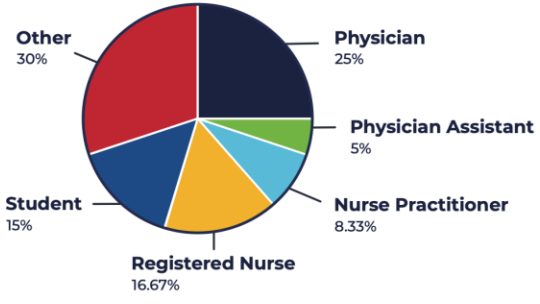
Developed a free suite of educational materials, including a foundational 2-hour CME-accredited eLearning course, 17 accredited reference article courses, and a resource library.

Recruited medical school students and residents to pilot test the foundational eLearning course and evaluate content effectiveness and learner experience.

Incorporated lived experience by co-creating video content with adults with Down syndrome and their families to ensure relevance and authenticity.

Results

- In the first 6 months (October 2025 – April 2026), there have been more than 256 total completions across the 18 available accredited eLearning options.
- The three most popular courses were: the foundational 2-hour eLearning course, Alzheimer's Disease article, and Avoiding Diagnostic Overshadowing article.
- While healthcare professionals (physicians, PAs, NPs, and RNs) accounted for most of the foundational course completions, 30% of participants were other professionals, including waiver support coordinators, caseworkers, and social service staff.



Discussion & Future Directions

- 100% of evaluation respondents reported they were likely to share it with a colleague, and 91.5% said they agreed that the content and format were effective in meeting the educational objectives.
- High participation from "other" professionals highlights demand beyond PCPs.
- Additional topics will continue to be added annually.
- American Nurses Credentialing Center accreditation (coming soon).
- Exploring integration of content into medical school and residency curricula.

References

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