

# Developing a Down Syndrome Clinic Center of Excellence Designation:

## A Network of Clinics Dedicated to Enhancing Care and Outcomes

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### BACKGROUND

Individuals with Down syndrome (DS) face significant health disparities, including challenges accessing comprehensive, coordinated care. Despite the existence of DS-specific clinical guidelines, there is currently no standardized designation to ensure quality and consistency across clinics caring for individuals with DS. This initiative aims to develop a Down Syndrome Clinic Center of Excellence designation that defines high-quality care through evidence-based standards to improve patient outcomes

### OBJECTIVES/AIMS

- Establish Evidence-Based Standards:** Create a set of standards for DS Centers of Excellence to guide clinics in delivering high-quality care.
- Promote Consistency and Excellence:** Ensure that clinics adhere to best practices in medical care, care coordination, research, and patient/family engagement.
- Foster National Collaboration:** Connect clinics with DSMIG, and other partners to improve care outcomes and share resources.
- Expand Access to Underserved Populations:** Develop strategies to identify and provide care to underserved populations with DS.

### PROCESS

The Clinic Support Committee tasked us with forming a subcommittee to explore and draft initial standards for a Down Syndrome Clinic of Excellence. We consulted the Spina Bifida Association's Clinic Care Partner standards and surveyed DSMIG members on key components of high-quality Down syndrome clinics. Using SBA's framework and survey insights, we adapted the standards to better serve individuals with Down syndrome, creating a foundational template for a potential certification program.

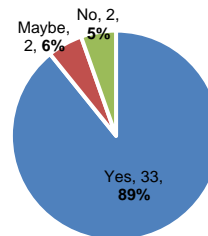
### DESIGN/STANDARDS



**Survey Participation:** A survey was conducted among 37 DSMIG members to assess the need for a CoE designation and gather feedback on proposed standards.

### RESULTS/FEEDBACK (Survey Data)

Is a DS Center of Excellence Designation Needed?



What are things you consider to be important in high quality care?



### CONCLUSIONS

A Down Syndrome Clinic Center of Excellence designation is essential for standardizing and improving care for individuals with DS.

The proposed 12-point framework ensures a comprehensive, patient-centered approach that promotes quality, research, and family engagement.

#### Future Goals:

- Refinement and Validation:** Continue to refine the standards based on provider feedback and emerging evidence.
- Pilot Implementation:** Test the standards through pilot programs at selected DS clinics.
- National Rollout:** Implement the designation nationwide with additional support.
- Monitoring and Evaluation:** Develop long-term mechanisms for performance assessment and continuous improvement.

### FEEDBACK

