

## Position and Candidate Specification



National Down Syndrome Congress

### **Executive Director**

**PREPARED BY:**

Katie Tucker  
Charles Jordan  
Shelton Liff

Assignment: 72199-001

# About the Organization

National Down Syndrome Congress

The National Down Syndrome Congress (NDSC) is a not-for-profit organization dedicated to an improved world for individuals with Down syndrome. Founded in 1973, they are the leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome, from the moment of prenatal diagnosis through adulthood.

The purpose of the NDSC is to promote the interests of people with Down syndrome and their families through advocacy, public awareness, and information. The organization has worked tirelessly over the years to foster a network of local and regional groups across the country to reach out and embrace thousands of people with Down syndrome, their families, friends, and the professionals who support them.

The NDSC is comprised of people who believe in individuals with Down syndrome, demand their rights and get them affirmed. The NDSC is a community that supports them in all they do from infancy to adulthood. The NDSC also includes a group people with Down syndrome, working together for a better future.

## NDSC's Vision

*The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.*

## NDSC's Mission

*The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.*

For more information, please visit: <https://www.ndsccenter.org/>

# Position Summary

National Down Syndrome Congress

The Executive Director (ED) of the National Down Syndrome Congress is responsible for executing the organization's strategic vision as defined by the board and advancing programs and activities based on this vision. This person will manage NDSC's financial and organizational growth through the effective oversight and management of operations and resources, including the recruitment, retention, and motivation of a high-performing staff.

The Executive Director will ensure that the NDSC expands a well-served membership base and increases member engagement on priority issues, including but not limited to policy, education, health, and advocacy across individuals' lifespans. This person will lead a wide range of educational, philanthropic, convening, and advocacy initiatives on behalf of the organization and its members.

The position is currently based in Atlanta, GA but the Board is open to other locations.

## KEY RELATIONSHIPS

**Reports to**      Board of Directors

**Direct reports**      Office Administrator  
                            Programs and Partnerships Director  
                            Program Coordinator  
                            Engagement Director  
                            Convention Coordinators  
                            Policy Directors

**Other key relationships**      Board of Trustees  
                            Individuals with Down syndrome and their families  
                            Corporate and program partners  
                            Private donors  
                            General public and volunteers  
                            Health professionals/researchers  
                            Domestic and foreign government representatives  
                            Leaders of other Down syndrome-related organizations

## KEY RESPONSIBILITIES

- Advance the NDSC's mission by providing strategic vision and leadership; this person will establish and execute the organization's objectives and priorities while measuring the impact and results of those activities.
- Expand the influence and effectiveness of the organization and position the NDSC as the leading voice of the Down syndrome community through advocacy at the federal, state, and local level; program development; and innovation.

- Work in partnership with the Board of Directors and the management team to increase and diversify revenue streams for the organization, e.g., by planning and executing an accelerated fundraising program in annual, major, planned, corporate/foundation, and event-based fundraising.
- Plan, execute, and host the NDSC's annual convention, an event that reaches over 2,500 family members, 100-200 presentations and 25-50 sponsors each year; 2022 will be an important return to a live conference after two years of hosting a virtual conference.
- Serve as the primary public policy spokesperson for the NDSC, e.g., speaking at national press conferences and local chapter events, participating in print and television interviews, and testifying before Congress.
- Build, maintain, and energize relationships with key stakeholders, including individuals with Down syndrome and their families, the expansive volunteer network, leaders of other Down syndrome-related organizations, and relevant health, education, employment, and civil rights professionals.
- Continue to develop, manage, diversify, and motivate the NDSC's team, recruiting new talent, as necessary.

## DESIRED OUTCOMES

### Goal 1: LEAD AND MANAGE A SUSTAINABLE, WELL-RUN ORGANIZATION

- 1.1 Ensure financial stability using innovative market practices
- 1.2 Ensure effective & efficient policies and processes
- 1.3 Ensure an effective governance structure
- 1.4 Ensure effective & efficient alignment of staff and resources
- 1.5 Continue proactive fundraising, expand revenue streams and ensure timely program funding

### Goal 2: STRENGTHEN STRATEGIC ENGAGEMENT & COMMUNICATION

- 2.1 Increase engagement efforts to brand and market the NDSC
- 2.2 Incorporate diversity to ensure all interests and perspectives are represented in initiatives, programs, and resources
- 2.3 Form meaningful partnerships to expand the reach and utilization of programs and resources

### Goal 3: BE THE LEADER IN EDUCATION, HEALTH & ACROSS THE LIFESPAN ADVOCACY

- 3.1 Increase member engagement on the three priority issues: Education, Health & Across The Lifespan Advocacy
- 3.2 Review and analyze pending legislation, regulations and policies for community impact with timely dissemination to promote unified response
- 3.3 Influence coalition partnerships and relationships with key decision-makers on education, health and policy related issues
- 3.4 Provide education, training and support for members to effectively influence policy at state and local level
- 3.5 Increase access and utilization of online-resources and trainings

### GOAL 4: BE THE BEACON FOR CONNECTING AND EMPOWERING SELF-ADVOCATES

- 4.1 Provide annual trainings to empower Self-Advocates
- 4.2 Provide a platform for self-advocates to share their stories and lead
- 4.3 Connect self-advocates with the best resources in post-secondary education, independent living and employment
- 4.4 Develop mentoring program at convention for ages 10-14

The National Down Syndrome Congress' (NDSC) Board of Directors are seeking a forward-facing, compelling, driven, energetic, donor-centric leader for their Executive Director role. The successful candidate is one who is looking to grow and find exceptional meaning in their professional life by making a real difference as leader of the NDSC. The Executive Director will be strong, visionary leader who has non-profit experience and a record of strengthening organizations, delivering breakthrough results, and setting the direction for sustainable growth and impact. The new Executive Director will be an inspirational and compelling voice for the NDSC's mission.

## IDEAL EXPERIENCE

### Leadership

Successful professional experience in a leadership role with demonstrated success and achievement. Preferred candidates will have experience managing an equal or larger organization or possess a professional background in successfully leading large teams.

### Non-Profit Management

Management experience in the not-for-profit sector with particular interest in those coming from human services, the disability community, or the Down syndrome community is preferred.

### Disability Community

Experience, understanding of and connection to the disability community is preferred but not required.

### Education

Bachelor's degree required; advanced degrees, certifications, and professional designations are additive.

## CRITICAL LEADERSHIP CAPABILITIES

### Strategic Thinking

The new Executive Director will provide visionary leadership that enhanced financial performance and strategic agility by:

- Working with the Board of Directors boards to revise the organization's strategies and adapt to the evolving environment in the short term, and identifying and prioritizing future, longer-term areas of opportunity for the organization to increase and enhance its impact.
- Challenging assumptions, the status quo, and identifying innovations to the traditional business model that ensure the organization is financially sustainable in the long term.
- Envisioning the organization's longer-term direction (e.g., the next five years).

### Collaborating and Influencing

In this highly visible outward and inward facing leadership role, the Executive Director will advance the NDSC's mission and enhance the organization's impact by:

- Engaging and developing trust and credibility with the Board, staff, donors, research community, policymakers, and other external constituencies.
- Articulating the NDSC's mission, value proposition, and impact effectively and with passion, and serving as an eloquent and compelling spokesperson.
- Cultivating and building relationships and partnerships with current and potential donors, in part to grow the NDSC's revenues and enable greater impact.

### **Leading People**

The next Executive Director will successfully harness the passion and commitment of the staff by serving as a team builder, mentor, and motivator. This includes:

- Engaging, inspiring, and empowering a diverse, motivated, and high-performing team, bringing out each team member's best while modeling passion for the organization's mission.
- Communicating the NDSC's long-term direction and collaborating with the management team/staff on how to reach it.
- Holding the organization accountable for its commitments, providing clarity, fairness, and constructive feedback, and motivating team members to achieve their goals.
- Creating an inclusive workplace environment and addressing recruiting practices, policies, procedures, and unspoken rules that disadvantage underrepresented employees because of their ethnicity, disability, gender, race, religion, sex, sexual orientation, or socioeconomic status.

### **INDICATIONS OF INTEREST AND NOMINATIONS**

If you wish to indicate personal interest in the role or nominate someone to serve as the next Executive Director of the National Down Syndrome Congress, please email [NDSCED@SpencerStuart.com](mailto:NDSCED@SpencerStuart.com). Compensation of the next executive director will be nationally competitive and reflect candidate experience and potential.