

Chesapeake Down Syndrome Parent Group, Inc. | P.O. Box 20127 | Baltimore, MD 21286 | www.cdspg.org

# FY 2021 - 2026

#### Vision

To promote a happy, healthy, accepting environment that enables independence for people with Down syndrome so that they may reach their potential at all stages of their lives.

#### Mission

To serve families of and persons with Down syndrome by providing information and support.

# TABLE OF CONTENTS

## Contents

BACKGROUND	1
PURPOSE STATEMENT	5
PROCESS	6
GOALS AND OBJECTIVES	5

# BACKGROUND

### **Organization History**

The Chesapeake Down Syndrome Parent Group (CDSPG) is a 501(c)(3) organization that provides support, education, and advocacy programs to individuals with Down syndrome and their families. CDSPG was founded in October of 1982 by eight families from the greater Baltimore region, including Anne Arundel, Baltimore, Carroll, Harford, and Howard Counties. What started as monthly gatherings in private homes quickly grew and within the first year those monthly meetings moved to a local school in Lutherville, MD with an expanded group of families. In those early years, CDSPG published a newsletter each month and maintained monthly meetings which typically involved guest speakers bringing information and support to families long before the ease and accessibility of social media and electronic communications. As an organization CDSPG has grown significantly since then, but we remain proud and grateful for this spark of community passion that existed in the beginning and continues to sustain our growth. As the joys and challenges we face in the Down syndrome community continue to evolve, our CDSPG community continues to broaden in the region, our network of support continues to increase, and we continue to expand the resources we provide to individuals who have Down syndrome and their families in central Maryland.

The goal was to learn as much as we could to give our children the best opportunity to develop to their full potential; so each meeting we had professional speakers including doctors, therapists (speech, OT, PT), educators, financial advisors, community leaders, etc. to help educate us. We also learned that it was our job to educate our families, friends, neighbors, teachers, school districts and communities about Down syndrome.

In 1986, President Reagan signed a proclamation making October 1986, National Down Syndrome Month, which eventually became law making every October National Down Syndrome Awareness Month. CDPSG worked to advocate in Annapolis to have Governor Hughes sign a similar bill for Maryland, which we are still proud of today.

– Jay Silverman, founding member

CDSPG is now recognized locally, regionally, and nationally as the support and resources organization for families living in the Great Baltimore and Central Maryland region. The organization now provides full time consistent support to our stakeholders led by a full-time executive director who manages a full slate of programming and our volunteer support. The CDSPG community network of families has grown to include over 700 contacts and connections, and with the addition of virtual programs, we provide programming offerings 4 -5 days each week that span topics from education, advocacy, medical updates, behavioral support, and social connection opportunities for individuals with Ds and their families.

In 2015, the board of CDSPG initiated a strategic planning process to:

- Address the ever-evolving needs of the community
- Better position the organization for a strong and sustainable future.

The strategic plan was revisited in 2019 to ensure progress and tracking against goals established in 2015. In early 2021, CDSPG's board reconvened to initiate the planning process for the five years ahead. Having almost a year of experience with the planned shift in governance to paid staff from all volunteer led and the strong leadership of an experienced Executive Director, as well as a lot of lessons learned and clarity gained through the challenges and isolation our community experienced during the pandemic and racial uprising in 2020 - the board approached the 2021 Strategic Planning process looking ahead to a strong 5 year growth plan to expand support for all of our families with particular focus on quality of life of individuals who have Ds as well as racial disparities within our community.

Chesapeake Down Syndrome Parent Group

#### Why a strategic plan?

A strategic plan serves as a roadmap for the future. The goal of the strategic planning process is to provide focus and direction to the organization over the next 5 years, inform prioritization of resources, improve consistency in the delivery of support and programs, and to enhance the organization's ability to expand that support.

This type of planning is particularly critical for a non-profit organization like CDSPG that relies on the support of donations and volunteer hours, to provide transparency and instill confidence for those individuals to know what their valuable time and resources are contributing to and the wonderful growth they are supporting. In addition, the plan is a valuable tool for organization leadership in setting priorities for support services and managing the budget in alignment with the plan. It also provides important continuity during board leadership transitions and serves as a clear definition of purpose and focus for the organization.

# PURPOSE STATEMENT

#### **Purpose Statement**

As the current stewards of the organization, the board of CDSPG set out the following priority commitments to guide the planning process:

- Establish a strategic plan that builds on the strengths of the organization's history, effectively meets the needs of our community, and creates a sustainable framework for the future.
- Engage in the planning process while following these principles:
  - Uphold and stay true to the organization's existing Mission and Vision
  - Ensure that support and information will always be available for families during the critically sensitive time of initial diagnosis.
  - Maintain focus on our primary stakeholders, individuals who have Down syndrome.
  - Maintain a strong sense of community while recognizing and respecting the diverse backgrounds, beliefs, and choices of the families and individuals whom we serve.

# PROCESS

### **The Planning Process**

The initial 2015 strategic plan was developed by assimilating information from the following sources:

- A benchmarking exercise for similarly situated organizations
- Input from organization members through a survey
- In-depth input from organization members through a focus group discussion
- Input from organization members who had volunteered ideas and concerns via one on one discussion
- A Strategic planning meeting discussion attended by all board members.

Both the focus group and the strategic planning meeting were facilitated by outside professionals who volunteered their time to CDSPG to add their professional experience to the process. In addition, the process was aided by consultation with Down Syndrome Affiliates in Action (DSAIA) and a collaborative strategic planning workshop team made up of leaders of other Down syndrome organizations in the country.

It is important to note that strategic planning is a process and while the product of this effort is a longrange planning document, it is critical to recognize that the core value of the process is to actively engage members of the community and give a voice to their ideas and concerns, better define members' needs and expectations, create an actionable plan that reflects those needs, and to develop a sense of collective community ownership of the plan and its successful implementation. For the long-term health of the organization and to ensure that the plan continues to reflect the needs of the community, it is critical that the strategic planning process be revisited periodically and that assumptions are confirmed or updated over time.

To continue to facilitate this ongoing input, in the last five years CDSPG has added feedback surveys to post programming messages, solicited feedback through post walk surveys, an education survey and a branding focused survey, in addition to in person interviews of program participants to better understand the needs of the community.

In 2019 and in 2021, the full board participated in planning sessions facilitated by an outside professional experienced in strategic planning. These meetings utilized the community feedback described above as well as participant data, programming, and budget metrics as foundational components of the planning process.

# GOALS AND OBJECTIVES: 2021-2026

### Goals

To provide context and transparency for evolution of organization goals and objectives, below is a summary of accomplishments, continuation/expansion of objectives and additional goals added in 2021. The CDSPG strategic plan identified the following goals, organized into three categories: member support and programs, organizational operations, and future growth.

Member support and programs goals:

- Increase diversity; age, race, and socioeconomic status with additional focus on more substantial outreach and support for all geographic areas served.
- Sustainable programs that focus on individuals who have Ds of all ages and their families, including the addition of more robust programs created by and for self-advocates, young adults and adults.
- Sustainable educational programs for families and caretakers of individuals who have Ds.
- Development of a cohesive and active advocacy strategy to support, organize, facilitate and/or lead advocacy efforts that improve the lives of individuals with Ds (Added goal in the 2021 process as an extension of the focus on in individuals with Ds in our community)

Organizational operations and future growth goals:

- Establish an organized and consistent development program (fund raising).
- Improve organizational diligence, transparency, and communications, as well as strive to implement operational best practices.
- Continue growth of the organization to add full-time staff equivalent for education and medical advocacy programs and hire part time equivalent paid staff for individuals with Ds for advocacy and outreach support. (*Prior goal: Support the growth of the organization by including paid staff and ultimately an Executive Director, recognizing that this will be a key element of volunteer support and long-term sustainability. In 2020, CDSPG successfully shifted governance to an ED led model from an all-volunteer model. Next steps include continued expansion of paid staff to support the community)*
- Establish physical and accessible space; community center and/or office.
- Change the organization name and implement rebranding to better reflect inclusion of individuals with Ds, all of their family members, and other stakeholders.

### Objectives

To move the organization toward meeting those goals, this prioritized list of objectives was developed as well as a timeline for completion. On an annual basis, the CDSPG board, in collaboration with the Executive director and staff, and with input from CDSPG's many volunteers, will evaluate progress against these objectives, realign or readjust and communicate progress to our stakeholders.

Objectives	Maintain Existing	Short Term (1-2yrs)	Long Term (3-5yrs)	Beyond 5 Years
MEMBER SUPPORT AND PROGRAMS				
Increase diversity; age, race, and socioeconomic status with additional focus on more substantial outreach and support for all geographic areas served. Establish annual implicit bias training for the board and volunteers representing CDSPG Provide implicit bias education for educators, medical professionals, offered annually Hire part-time staff/contractor to lead / prioritize outreach for BIPOC community members Expand community connections - be the first organization mentioned by providers serving individuals with I/DD in each county we serve		<ul> <li>•</li> <li>•</li> <li>•</li> </ul>	•	
Translate materials into Spanish and provide Spanish translation option at education events,				
Sustainable programs for individuals who have Ds of all ages and their families,			•	
including more robust programs created by/for self-advocates.				
Medical outreach and first call	•			
New parent welcome baskets and expanded welcome packet for new families	•			
Sibling program	•			
Age Specific Programs – In person and Virtual	•			
Develop corporate and family-sponsored programming to increase sustainability and broaden scope/frequency of offerings		•		
Build culture/structure of giving and power in small "chip-in" donation amounts when registering for events to increase sustainability		•		
Implement annual corporate-sponsored programs		3	6	
Develop self-advocate communication / connection forum			•	
Identify opportunities, competitors, locations, pros/cons, ability to offer CEs/CEUs via our offerings, and funding opportunities for outreach activities			•	
Sustainable educational programs for families and caretakers				
of individuals who have Ds. Serve as a consistent education and resource connection in community				
Average of 7 educational/therapeutic offerings monthly	•			
Provide annual offerings, to include: Parent mentor training, Board Training Dynamic educational "plan" for each age group		•		
Identify opportunities, competitors, locations, pros/cons, ability to offer CEs/CEUs via our offerings, and funding opportunities for educational conference, medical conference			•	
Support vision and path forward for the sustainability and growth of TFS in collaboration with MD DSA's		•		
Development of a cohesive advocacy strategy to support, organize, facilitate and/or lead advocacy efforts that improve the lives of individuals with Ds				
Participate and support evolution of MDAC CDSPG representatives gain a seat at the table/support statewide advocacy coalitions (ie. Ethan Saylor Alliance, SESAC, etc.)	•	•		

# **Objectives (cont.)**

Objectives	Maintain Existing	Short Term (1-2yrs)	Long Term (3-5yrs)	Beyond 5 Years
ORGANIZATIONAL OPERATIONS AND FUTURE GROWTH				
Establish an organized and consistent development program, increase financial security				
Increase annual income by 35%		•		
Diversify donation/revenue sources			•	
(1/3 walk, 1/3 grant funding, 1/3 individual giving)				
Improve organizational diligence, transparency, and communications, as well as strive to implement operational best practices				
Annual audit		•		
Annual Report-style reporting to full community, made publicly available. Include DEI work in report by end of 2021		•		
Create board development plan and network of consistent resources for board development		•		
Create an advisory board of self-advocates and sustainable process to maintain			•	
Continue growth of the organization to add full-time staff equivalent for education and medical advocacy programs and hire part time equivalent paid staff for individuals with Ds for advocacy and outreach support				
Support continuity of full time Executive Director	•			
Hire second, full-time staff equivalent for education and medical advocacy programs.		•		
Hire self-advocates part-time to complete advocacy presentations and outreach.		•		
Establish physical and accessible space; community center and/or office				
Review opportunities, partnerships, locations pros/cons for community space		•		
Determine if one space or multiple co-working space would be best to serve the community		•		
Establish space – whether one or multiple – by 2022		•		
Change the organization name and implement rebranding - to better reflect inclusion of individuals with Ds, family members, and other stakeholders				
Prioritize rebranding/naming effort for roll out by fall 2021	•			