

# STRATEGIC PLAN



cdspg |

CHESAPEAKE  
DOWN SYNDROME  
PARENT GROUP

Chesapeake Down Syndrome Parent Group, Inc. | P.O. Box 20127 | Baltimore, MD 21284-0127 | [www.cdspg.org](http://www.cdspg.org)

## FY 2015 - 2020

### 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.*

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## 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. Each month, CDSPG published a newsletter and maintained the monthly meetings which typically involved guest speakers. As the joys and challenges we face in the Down syndrome community continue to evolve, our CDSPG community has broadened tremendously in the region, our network of support has increased, and we continue to expand the resources we provide to our families.

CDSPG is recognized locally, regionally, and nationally as the support group for Greater Baltimore Area families with children with Down syndrome. 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 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,*

### Why a strategic plan?

A strategic plan serves as a roadmap for our future. The goal of the strategic planning process is to provide focus and direction to the organization over the next 5 years, 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 in all-volunteer organizations like CDSPG that experience frequent changes in leadership and fluctuations in the availability of volunteer resources. The plan can provide continuity during leadership transitions and 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 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

This 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 long-range 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.

# DISCOVERY

## Information Gathering

This planning would not be possible without a wealth of information gathering. While this information gathering exercise involved in-depth analysis that was thoroughly reviewed, this section provides a summary of the key findings.

The services and events that members most appreciate and value include:

- Networking and connecting with other families for a variety of reasons, whether it be a specialist recommendation, guidance on a particular challenge, or to share a joyful experience, milestone or accomplishment. Reminding each other and ourselves that we are not alone, as individuals with Ds, parents, siblings or caretakers.
- Social gatherings that provide a space that is both immediately welcoming and provides a great social experience in a safe environment, together, for individuals with Ds and their families.
- Collaborative support, information, and training to help address educational issues and therapy approaches and to help navigate the IEP process for school age individuals as well as available services for individuals of all ages.

New Services and Initiatives suggested:

- More significant and/or more structured advocacy efforts, for either facilitating a stronger collective voice or providing information and education regarding relevant legislative policy issues and regarding 'trends' in education that are impacting individuals with Ds.
- Increase diversity (e.g., accommodate bi-lingual presence, hold events in different areas to better meet the needs of the broad geography, and engage in more active outreach in the City).
- Greater focus on programs created by and for adults with Ds; both social and educational (e.g., education/information regarding housing, transportation, job training, available services, financial planning, elder care, and opportunities to enhance independence/autonomy and quality of life).
- Programming for siblings to support the invaluable and unique sibling relationship. As average lifespans of individuals with Ds wonderfully increase, sibling relationships become ever more critical as lifelong advocates.
- The addition of paid staff to support programs, and provide consistent communications and support for our volunteers.

Items frequently mentioned as challenging and/or needing improvement:

- Inconsistent programming with unpredictable frequency.
- Inconsistent communications, both web-based and paper based; lack of continuity in how programs, activities, and organization operations are communicated.
- The organization serves a large geographic area that is perceived to be ill-defined and events seem to be held frequently in the same or similar locations that are not necessarily convenient to the larger membership.
- Finding resources to support volunteers in sustaining programs as opposed to overwhelming a small group of volunteers or a single person.
- Clearly communicating how funds that are being raised are utilized on needed or desired programs.
- Clear communication and transparency regarding how the organization operates, how membership works, what the organization does or does not do, and how to get more involved.

# SETTING THE STAGE

## Short-Term Priorities

It was quickly determined that to better enable the organization to meet our members' needs and to appropriately position the organization for the future, several critical short-term priorities for 2015 needed to be addressed.

They were identified as:

- Examine and update organizational systems:
  - Review and update the Bylaws to meet current legal framework
  - Update and document the organizational structure
  - Update the definition of “membership” and define the geographic area served
  - Examine and better organize the current program offerings
  - Examine current financial processes and document the financial management protocols
  - Define the organizational development (fund raising) framework.

Much work was completed to address these items in 2015. While working on the above tasks, volunteers engaged with DSAIA to learn from shared experiences of other Down syndrome organizations around the country and, in addition, CDSPG also engaged with Maryland Association of Non-Profit Organizations allowing for access to the knowledge and experience of other local non-profits as well as gain access to legal, financial, programming, and fund raising information and guidance. CDSPG is now an active member of DSAIA and MANO, both of which provide a tremendous depth of resources for best practices in nonprofit organization operations and administration.

# GOALS AND OBJECTIVES: 2016-2019

## Goals

The CDSPG strategic planning committee and board propose the following specific 5-year 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 for 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.

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.
- 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.
- Establish physical and accessible space; community center and/or office.
- Evaluate the group name (brand) to assess an alternative that may better reflect inclusion of individuals with Ds, all of their family members, and other stakeholders.

*In 2015, in conjunction with working on the established 2015 priorities, the board also set about initiating work on the following;*

- *More fully develop and prioritize long-term organization goals and objectives (identified herein)*
- *Take steps to prepare for future paid staff that would best support volunteers and program consistency*
- *In parallel, maintain operations/planned programs and be supportive of and encourage volunteers to launch programming that is consistent with member feedback. As a result, in 2015 the following new or newly revitalized programs were initiated:*

- *Education Series*
- *Young Buddies*
- *Big Buddies*
- *Tweens Club*
- *Siblings Program*
- *Education for genetic counselors*
- *Increased number of welcome socials*
- *Gift bags to new families*

## 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, and with input from all of CDSPG’s many volunteers, will evaluate progress against these objectives, realign or readjust objectives based on experiences gained, and communicate progress via our website and other forms of communications.

Objectives	Maintain Existing	(1 Year) 2016	(3 Year) 2018	(5 year) 2020	Beyond 5 Years
<b>MEMBER SUPPORT AND PROGRAMS</b>					
<b>Membership Expansion and Increased Geographic Accessibility</b>					
Increase membership outreach by 50%			◆		
Increase membership outreach by 100% (double)				◆	
Increase participation from varied geographies			◆		
Increase number of events in each geographic area			◆		
<b>Membership Expansion and Outreach in Baltimore City</b>					
Increase membership and events in the City by 50%			◆		
Establish plan for outreach with specific program goals		◆			
Consistent dedicated outreach programs in Baltimore City			◆		
<b>Establish Programs that Occur Consistently and Sustainably</b>					
Medical outreach and first call	◆				
New parent welcome baskets	◆				
Sibling program		◆			
Welcome committee - increase gatherings to every 4 months	◆				
Welcome committee - vary geographic location of gatherings		◆			
Education committee - consistent monthly two-hour seminars			◆		
Education committee - One consistent annual conference			◆		
Family Networking - Annual Holiday Party	◆				
Family Networking - Annual Summer Picnic	◆				
Family Networking - Annual Adult Social (re-introduce)			◆		
Age Specific Programs - Spring and Fall Fling	◆				
Age Specific Programs - Little Buddies (0-5) consistent events*	◆				
Age Specific Programs - Big Buddies (5-9) consistent events*		◆			
Age Specific Programs - Tweens Club (9-13) consistent events*			◆		
Age Specific Programs – High School (14-21) consistent events*			◆		
Age Specific Programs - Book club, maintain/expand/replicate		◆			
Age Specific Programs - Adults (Age 22+) consistent events*			◆		

## Objectives (cont.)

Objectives	Maintain Existing	(1 Year) 2016	(3 Year) 2018	(5 year) 2020	Beyond 5 Years
<b>ORGANIZATIONAL OPERATIONS AND FUTURE GROWTH</b>					
<b>Establish a more robust and consistent development program</b>					
Consistent annual Buddy Walk	◆				
Consistent annual Golf Tournament		◆			
Consistent annual Bull Roast		◆			
Consistent annual fund drive			◆		
Organized major gifts program			◆		
Identify and apply for grant funding			◆		
Establish development plan with clear fund raising goals		◆			
<b>Establish consistent and clear communications for:</b>					
a) Better reach to members for programs and information sharing,					
b) Volunteer support and recognition,					
c) Development and fund raising					
d) Organization planning and financial transparency					
Update website		◆			
Consistent electronic newsletters	◆				
Initiate annual report and produce consistently		◆			
Consistent social media messaging		◆			
Update and establish functional member database			◆		
Creation and use of a communications plan			◆		
Re-evaluate branding/name to be more inclusive			◆		
<b>Organizational Diligence and Best Practices</b>					
Finalize bylaws update		◆			
Finalize organization chart		◆			
Create organization guidance / protocols for operations		◆			
<b>Paid Staff and Volunteer Support</b>					
Establish volunteer recognition program		◆			
Bring on paid admin staff to support increased activities		◆			
Hire Executive Director				◆	
Evaluate acquisition of physical space; office/community center			◆		

(\*) At least 6 per year