

# The Down Syndrome Association of Delaware

## SWOT Analysis

LEAD340-010  
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### Contributions

**Katherine Miller:** Meet the Team Members (Katherine and Her Roles), Interview Key Points, Good to Great, Noah from Baltimore ToolBank: For-Profit vs. Nonprofit, TED Talk: The Way We think About Charity is All Wrong, Dan Pallotta, Short-Term Goals, Long-Term Goals, Board of Directors, Comparable Agencies, Weaknesses and Needs, Threats

**Karli George:** Meet the Team Members (Karli and Her Roles), Meet the Board, Mission Statement, Vision Statement, Brief History, Organization Chart, Financials, Key Concepts from Speakers, Mission Statement Analysis, Volunteers, Location and Logistics, COVID Impact, Strengths and Weaknesses

**Carlson Chang:** Meet the Team (Carlson and His Roles), “Work on Purpose”, Branding and Marketing, Social Entrepreneurial Measures, Opportunities

**Team:** Project Ideas

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# Introduction

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## I. Meet the Team Members

Throughout our time in the Blue Hen Leadership Program, the three members of this team have worked on individual leadership skills and learned how to work together and solve problems efficiently in a team environment. This year we are putting together our shared values, strengths, and passions to grow as community members. We all have shared passion for ending the stigma surrounding the disability community and are very excited to support and work with the Delaware Down Syndrome Association (also known as the DSA) this year. We each have individual values and strengths that will help us work as a team to support this great organization, and we have split up our roles and responsibilities to be the most effective and time efficient team. Following is an introduction to each team member which will include their roles and responsibilities.

### **Katherine Miller**

Katherine is from Wilmington, Delaware, and is a Neuroscience major with a disability studies minor. She has volunteered with the Down Syndrome Association in the past throughout high school, and she had a great time learning more about the disability community and meeting some wonderful people along the way. She wants to support and help the organization in any way possible to help end the stigma surrounding disabilities in our community to help everyone feel loved and accepted. Her core values are compassion, passion, and gratitude, while her top three strengths are developer, empathy, and restorative. Her true color is blue which means she is emotionally driven and seeks harmony in groups. This true color lines up with her values in a great way making her very driven towards the causes that she is passionate about. She loves to help people find their potential while sensing their feelings and helping them deal with problems they are facing. All these values and strengths lineup with her passion and drive to help this wonderful organization. She is highly motivated to support this organization because she feels like they are doing a wonderful job supporting, educating, and advocating for the disability community and I would be thrilled to be a part of it.

Her role during this project is the project manager/organizer. She is here to keep our team schedule organized and make sure we complete our necessary tasks each day to hold all our team members accountable. She takes the notes at meetings among just our team members, and any meetings with DSA to keep us all informed moving from task to task. She also helps with sending emails to the organization members and any third-party members moving forward, if our communication leader, Karli, needs any help with that. She is also going to be our team morale booster to remind us that we are working on this project due to our passion to help the disability community. She wants to make sure we keep having fun while staying focused on our intended outcome throughout our journey this year. Her strengths and values will help me stay organized and keep our group on track to complete a great project for the DSA.

### **Karli George**

Karli is an Accounting and Finance double major from Townsend, Delaware. While a logical thinker and data-driven person, she has always had a passion for respecting and embracing other

people's differences. Being in the public school system, she vividly remembers seeing students with special needs socially ostracized by their peers and ignored by educators. She cannot imagine how difficult it must be for those with Down syndrome to navigate themselves through an ableist society. Instead of wondering what she could do, she decided to jump in and help as much as she can. Her core values from this semester's Strengths Assessment are learner, input, intellection, analytical, and restorative. Learning more about a given problem and the people it affects is the first step to improving the situation. Analyzing and using outside input to see the many facets of the problem can help determine what is needed and what could be fixed to lessen any negative impact. Suffice to say, these values are quite accurate and align with the Delaware Down Syndrome Association's method of operation. They are operated by compassion, but also by the desire to educate and inspire others to learn more about Down syndrome and how to cope with the condition.

Throughout this project, Karli has acted as the liaison between the group and DSA as well as a quality-checker for all our assignments, messages, and interviewing methods. She's taken upon herself to reach out to DSA and secure interviews with board members, volunteers, and the executive director Lauren Camp Gates. Without the information provided in these interviews, it would have been nearly impossible to sufficiently illustrate the strengths and weaknesses of this organization. She then ensures that the rest of the group knows what else needs to be done so we may complete our tasks in a timely manner. Acting as the communicator of our group is extremely important, as it allows her to connect crucial information between both parties and ensure all interactions are transparent.

### **Carlson Cheng**

Carlson is majoring in Computer Science, and is from Wilmington, Delaware. His younger brother has Down syndrome and the DSA has provided a lot of value to him and his family. He wants to help the DSA in any way he can to help other families like his. According to the leadership questionnaire the team took earlier in the semester, his main strengths are Competition, Individualization, Restorative, Empathy, and Achiever.

On the team, he's responsible for leading our research initiatives. This means he researches information on the DSA and other things that could help the project. He helped look for the DSA website and Facebook pages to see how many people were following them and gave the team the idea to look at remodeling these for the project.

## **II. Introduction to Down Syndrome Association of Delaware**

### **Meet the Board**

For the past two months, our team has concentrated on developing a strong connection with the DSA's Board of Directors. We've had the opportunity to interview three out of the five people listed below and have learned much about their reasons for serving on DSA and what they do to keep the organization running. The information about each position comes from the organization's website, which has been summarized and cited under "References", as well as personal interviews with each member.

**Lauren Camp Gates, Executive Director and Liaison**

Laruen Camp Gates currently serves as the Executive Director for DSA, assuming this position in 2017. After volunteering herself in 2010, she started the Days of Summer Camp in 2012 that has become one of DSA's most successful and beloved activities ("Board of Directors", 2021). She then graduated from the University of Delaware with a Master's in Public Administration and became a program coordinator for the DSA in 2014. She also has recognition outside of the organization for her work. She has won awards for her crusade for advocacy in Down syndrome and continues to keep doing so to this day.

Camp Gates has acted as our liaison and primary contact person for any questions, concerns, and interview requests. While she admitted to not having any familial connections with Down syndrome, she is still heavily involved with this cause and shows no signs of stopping.

**Dave Gazzillo, Board President**

Dave Gazzillo is the current Board President for DSA. According to DSA's webpage "Board of Directors", he has been involved with the organization for over 20 years, first serving as the secretary from 1998-2007 before assuming the role of vice president from 2015-2016. When not working at the organization as the board president, he acts as the SVP of Marketing Operations at Bank of America having been educated at the University of Delaware with a degree in economics. Shortly after becoming involved with DSA, his youngest son Jason was born with Down syndrome in 2000. In Gazzillo's interview, this news was a shock especially what occurred just a few years prior.

Before his second child, Jonathan, was born, prenatal testing hinted that there might be a health malformity. Genetic counseling proved to be rather traumatic, with doctors insinuating Jonathan may have Down syndrome. They recommended an abortion right away, implying it to be a better alternative than having a disabled child. Gazzillo's wife Jeanne refused, proclaiming, "My child will always have purpose" before leaving the office with her husband (D. Gazzillo, personal communication, October 2021). Jonathan ended up being born healthy, but this attitude carried on to their afflicted son Jason. The two currently live in Wilmington with their children and are still avid participants of DSA.

**Shelvia Neely, Vice President**

The Vice President of DSA, Virginia-born Shelvia Neely immersed herself in disability advocacy after moving to Delaware in 2003. With her musical background, she uses her expertise to inspire those with special needs to express themselves. She is also involved in event organization. Being a huge supporter of the Buddy Walk, she controls recruiting volunteers to help and participate in the event. This is all according to the DSA webpage "Board of Directors".

### **Ted Griffith, Treasurer**

A Certified Financial Planner, Ted Griffith has been the treasurer for DSA for 4 years after becoming involved as a volunteer in 2014 (“Board of Directors”, 2021). While we were unable to interview Griffith, the organization’s website claims he is married with two sons and is likely a dedicated member of the DSA.

### **Tauheedah Muhammad, Secretary**

Living in Newark, DE, Tauheedah is the secretary of DSA and works in dental hygiene. While we were unable to interview Muhammad at this time, it is clear from the organization’s website why she is involved with the DSA. Her eldest son, Leon II, was diagnosed with Down syndrome shortly after arriving in Delaware. With these experiences, she combines her expertise in dental care and love for children by inspiring those with disabilities to take care of themselves. All of this is according to the DSA’s page “Board of Directors”.

### **Mission Statement**

“The Down Syndrome Association of Delaware’s mission is to be a resource promoting public awareness, education and advocacy supporting individuals with Down syndrome and their families” (“Mission and Vision”, 2021).

### **Vision Statement**

“The Down Syndrome Association of Delaware partners with families and others to create an environment in which individuals with Down syndrome are welcomed and included with fairness, enthusiasm, and encouragement in the community. Together we share knowledge and experiences with other families, and support new parents. We promote the need to continue to educate ourselves, medical and educational professionals, and the public about Down syndrome. We embrace all of the things our children can do and their potential to be an integral part of our local communities. We believe that diversity should be embraced, not merely tolerated, because the entire community benefits when individuals with differences are valued and included in our communities” (“Mission and Vision”, 2021).

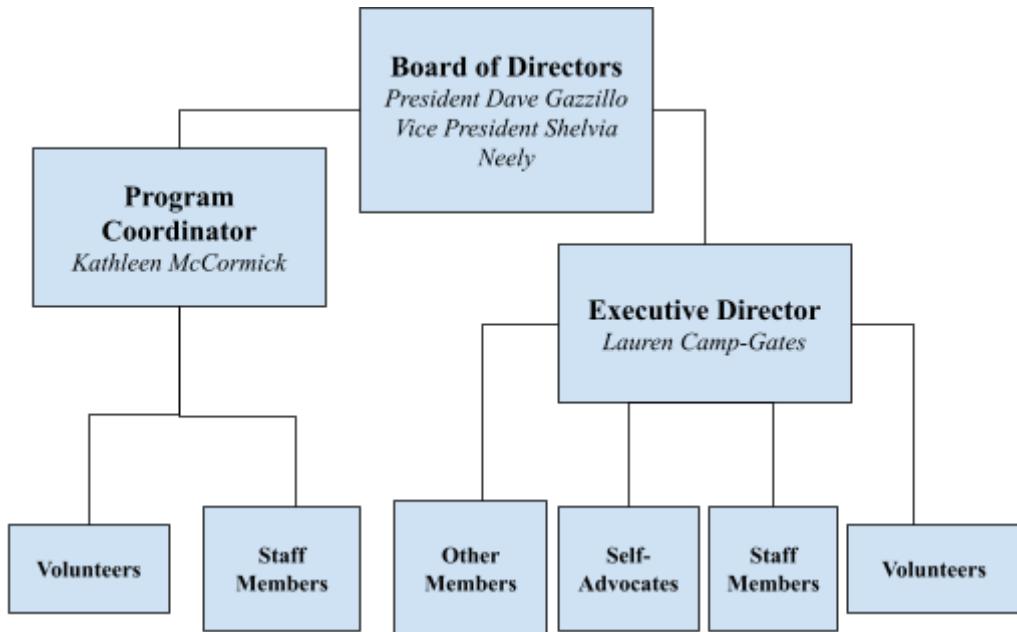
### **Brief History**

Board President Dave Gazzillo was kind enough to give an abridged history of the organization via his interview. According to him, The Down Syndrome Association of Delaware was founded as a grassroots operation in 1972. At this point, the organization consisted of local families affected by Down syndrome in the Delaware community cooperating with one another to raise awareness for the disorder. It also acted as a way for unsure parents to support one another and their afflicted children in a rather ableist period in our nation’s history. With a humble annual budget of \$1,600, the organization did what they could to, as Gazzillo stated, “make things better for people [with Down syndrome]” (D. Gazzillo, personal communication, October 2021). The DSA was officially incorporated and received status as a 501(c)(3) organization in 1979. For a while, the organization had no office space until establishing a singular P.O. box in Middletown, DE around the same time. Gazzillo stated in his

interview that this was to give the DSA a physical representation of itself for the population downstate. Over the years, the DSA began to make a name for itself by creating a variety of programs meant to fundraise and advocate for Down syndrome-related causes. For example, the biggest source for fundraising is the Buddy Walk along with other activities like the Days of Summer Camp developed in 2012. A larger space, albeit a single office room, was established in Middletown, DE but quickly outgrown itself due to an influx of volunteers and not being the appropriate amount of space, the Board needed to successfully execute operations. This led to the Middletown office closing and the Newark, DE office opening. With the cafe opening, along with the addition of a teaching kitchen for the chefs employed at the cafe and a board room, it became apparent that this was a welcomed change. Currently, the plan is to expand the DSA to become a regional organization and become the Down Syndrome Association of Delmarva.

## Organization Chart

According to Lauren Camp Gates, the DSA does not have an official organization chart. So, to counteract this, we made a chart on our own from inferences we made on the duties of the Board of Directors, Executive Director, Program Coordinator, and Volunteers. We also used the organization's website for additional information.



## Financials

Financial information regarding this organization will be discussed in two different viewpoints: DSA's 90 Forms that were filed in the last three years and insight from the interviews with DSA board members. This will give a comprehensive view of the financial health of the organization and understand how much money is going to certain functions, as well as where the DSA receives much of their funding.

## 990 Form Discussion

In the past three years, the financial health of the DSA has fluctuated greatly. For the filing year in 2018, the organization operated in the red. Expenses and revenue were \$165,485 and \$150,983 respectively; this resulted in a \$14,681 loss. Of course, this is not an ideal situation for a small organization. Thankfully, there was an improvement in performance for the 2019 fiscal year. Income rose to \$213,881 while expenses increased slightly to \$167,964, indicating the organization operated in the black with a \$45,917 profit. The COVID-19 pandemic then presented itself the following year, causing the 2020 information to have the worst numbers yet. With an income of \$170,456 and expenses of \$203,133, the organization operated in the red once again with a \$32,676 loss. As cynical as this observation may be, it's no surprise that the 2020 information is so bleak. The COVID-19 pandemic led to the cancellation of several crucial fundraising events like the Buddy Walk and cut sales at the DSA Cafe. A further illustration of these losses, as well as salary expenses between 2018 and 2020, can be found below.

### Summary of 2018 990 Form

<b>Part I Summary</b>		
<b>Activities &amp; Governance</b>	1 Briefly describe the organization's mission or most significant activities DOWN SYNDROME ASSOCIATION OF DELAWARE, INC. IS A STATEWIDE NON-PROFIT SUPPORT GROUP, ORGANIZED TO BE A SUPPORTIVE RESOURCE, ADVOCATING FOR THE ACCEPTANCE AND UNDERSTANDING THAT ALLOWS INDIVIDUALS WITH DOWN SYNDROME TO ACHIEVE THE SAME LEVEL OF ACCESS AND OPPORTUNITY AS THEIR PEERS	
	2 Check this box ► <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets	
	3 Number of voting members of the governing body (Part VI, line 1a) . . . . .	3 18
	4 Number of independent voting members of the governing body (Part VI, line 1b) . . . . .	4 18
	5 Total number of individuals employed in calendar year 2017 (Part V, line 2a) . . . . .	5 2
	6 Total number of volunteers (estimate if necessary) . . . . .	6 300
	7a Total unrelated business revenue from Part VIII, column (C), line 12 . . . . .	7a 0
	b Net unrelated business taxable income from Form 990-T, line 34 . . . . .	7b 0
	8 Contributions and grants (Part VIII, line 1h) . . . . .	Prior Year 59,584 Current Year 72,459
	9 Program service revenue (Part VIII, line 2g) . . . . .	0 4,270
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) . . . . .	1,122 1,124	
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	83,529 72,950	
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	144,235 150,803	
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) . . . . .	4,950 1,415	
14 Benefits paid to or for members (Part IX, column (A), line 4) . . . . .	0 0	
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	36,180 51,807	
16a Professional fundraising fees (Part IX, column (A), line 11e) . . . . .	0 0	
b Total fundraising expenses (Part IX, column (D), line 25) ► 0	0 0	
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) . . . . .	88,580 112,262	
18 Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	129,710 165,484	
19 Revenue less expenses Subtract line 18 from line 12 . . . . .	14,525 -14,681	
<b>Net Assets or Fund Balances</b>	20 Total assets (Part X, line 16) . . . . .	Beginning of Current Year 587,878 End of Year 564,960
	21 Total liabilities (Part X, line 26) . . . . .	15,243 7,006
	22 Net assets or fund balances Subtract line 21 from line 20 . . . . .	572,635 557,954
	<b>Part II Signature Block</b>	
Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge		
<b>Sign Here</b>	***** Signature of officer TED GRIFFITH TREASURER Type or print name and title	2019-05-13 Date

## Summary of 2020 990 Form

Part I <b>Summary</b>	
Activities & Governance	<p><b>1</b> Briefly describe the organization's mission or most significant activities:  <b>DOWN SYNDROME ASSOCIATION OF DELAWARE, INC. IS A STATEWIDE NON-PROFIT SUPPORT GROUP, ORGANIZED TO BE A SUPPORTIVE RESOURCE, ADVOCATING FOR THE ACCEPTANCE AND UNDERSTANDING THAT ALLOWS INDIVIDUALS WITH DOWN SYNDROME TO ACHIEVE THE SAME LEVEL OF ACCESS AND OPPORTUNITY AS THEIR PEERS.</b></p>
	<p><b>2</b> Check this box <input checked="" type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.</p> <p><b>3</b> Number of voting members of the governing body (Part VI, line 1a) . . . . . <b>3</b> <b>17</b></p> <p><b>4</b> Number of independent voting members of the governing body (Part VI, line 1b) . . . . . <b>4</b> <b>17</b></p> <p><b>5</b> Total number of individuals employed in calendar year 2019 (Part V, line 2a) . . . . . <b>5</b> <b>1</b></p> <p><b>6</b> Total number of volunteers (estimate if necessary) . . . . . <b>6</b> <b>400</b></p> <p><b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12 . . . . . <b>7a</b> <b>0</b></p> <p><b>b</b> Net unrelated business taxable income from Form 990-T, line 39 . . . . . <b>7b</b> <b>0</b></p>
Revenue	<p><b>8</b> Contributions and grants (Part VIII, line 1h) . . . . . <b>114,301</b> <b>133,456</b></p> <p><b>9</b> Program service revenue (Part VIII, line 2g) . . . . . <b>4,210</b> <b>16,402</b></p> <p><b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d) . . . . . <b>1,111</b> <b>1,177</b></p> <p><b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) . . . . . <b>94,259</b> <b>19,422</b></p> <p><b>12</b> Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) . . . . . <b>213,881</b> <b>170,457</b></p>
	<b>Prior Year</b> <b>Current Year</b>
Expenses	<p><b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3) . . . . . <b>4,385</b> <b>3,550</b></p> <p><b>14</b> Benefits paid to or for members (Part IX, column (A), line 4) . . . . . <b>0</b> <b>0</b></p> <p><b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) . . . . . <b>55,278</b> <b>58,769</b></p> <p><b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e) . . . . . <b>0</b> <b>0</b></p> <p><b>b</b> Total fundraising expenses (Part IX, column (D), line 25) <b>3,842</b></p> <p><b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) . . . . . <b>108,301</b> <b>140,814</b></p> <p><b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) . . . . . <b>167,964</b> <b>203,133</b></p> <p><b>19</b> Revenue less expenses. Subtract line 18 from line 12 . . . . . <b>45,917</b> <b>-32,676</b></p>
	<b>Beginning of Current Year</b> <b>End of Year</b>
Net Assets or Fund Balances	<p><b>20</b> Total assets (Part X, line 16) . . . . . <b>606,686</b> <b>574,565</b></p> <p><b>21</b> Total liabilities (Part X, line 26) . . . . . <b>2,815</b> <b>3,370</b></p> <p><b>22</b> Net assets or fund balances. Subtract line 21 from line 20 . . . . . <b>603,871</b> <b>571,195</b></p>
	<b>2021-02-06</b> <b>Date</b>
<b>Sign Here</b>	<p>Signature of officer  <b>TED GRIFFITH TREASURER</b>  Type or print name and title</p>

As for financial support, the DSA has seen a rise in government funding over the last three years. Government grants for 2018 started rather modestly at \$28,000 before increasing to \$62,867; that's a \$34,867 increase over three years. The category on the 990 forms marked "Other" (i.e., gifts, donations, etc.) shows the same pattern. Gifts and donations rose from \$44,263 in 2018 to \$69,263 in 2020. Numbers like this show an increased amount of support from third-party donors, even if the organization has mostly operated with debt under its belt.

Likely due to increasing responsibilities and employees, labor costs have increased as well. 2018 annual salaries for DSA employees were \$51,807, \$55,278 in 2019, and \$58,769 in 2020. It is also important to note that the executive director makes most of these salary costs, with the 2020 salary being \$52,857 a year. Granted, the executive director worked 40 hours that year which was significantly more than the rest of the employees and volunteers at the organization. Additionally, this is not a very high salary. According to the 2020 U.S. Census, the median U.S. household income was \$67,521 meaning the executive director and other DSA members are earning below average income (United, 2021). This isn't to be shamed, however. Rather than doing this as a career for monetary gain, the fulfillment of the employees comes from something else.

### **Insight from Interviews**

From the interviews with Executive Director Lauren Camp Gates and Board President Dave Gazzillo, there is more insight on the financial health of the DSA. Gazzillo stated that, during the COVID-19 shutdown, he and the rest of the board deliberated on how to keep the organization afloat. The cafe was closed during this time, there were no IEP meetings for families in need, and all fundraising events were cancelled. One problem that presented itself was that in-person board meetings were out of the question due to government regulations. As a result, the Board had to go against their budget for the year to buy software (i.e., Zoom) to have virtual meetings. This led to a higher total in their expense accounts along with their dropping revenue. While meetings were still able to continue, it was at a higher cost. There was also initiative taken to keep activities going. Volunteer Steven Beard, a regular helper in the Days of Summer Camp, stated the camp was completely shut down due to the pandemic. Gazzillo and Gates had the idea to host an event via Zoom entitled “Camp in a Box” in which participants at home could have all the items necessary for camp-related activities (sans practical items like a tent or sunscreen) and games to keep the event relevant. This almost certainly caused expenses to rise, especially since there isn’t as much money coming in due to these events.

### **Interview Key Points**

Completing interviews was the first step to have a better understanding of the organization as whole. After interviewing the Board Director, Dave Gazzillo, Vice President Shelvia Neely, Executive Director Lauren Camp Gates, Staff Member Kathleen McCormick, Volunteer Steve Beard, and clients, it is evident that this is an outstanding organization within the Down Syndrome community in Delaware. From listening to their stories and answers to the questions asked, they showed they follow the mission and vision statements on their website as closely as possible. All of the members interviewed pointed out how this organization is a safe space for all people with down syndrome throughout Delaware to ask questions, socialize, learn, and grow as people. As Lauren explained in her interview the DSA is a resource and safe space for all of the Down syndrome community, including parents and family members of someone with down syndrome. There was an overwhelming sense of compassion and thoughtfulness that these members put into the organization, which makes it a great resource for so many families throughout the area. Shelvia is the mother of a young boy with Down syndrome, and she started out as a volunteer, and worked her way to the Vice President of the board. Her perspective of being a mother and being on the board, gave us a greater understanding of how important this organization is to so many families and people throughout Delaware.

Down Syndrome Association of Delaware focuses on advocacy, education, and awareness for the Down syndrome Community throughout Delaware. Based on all the interviews the organization does complete these goals in their mission statement by implementing programs for families, providing information to the public to educate and advocate for the community. They provide weekly programs like cooking classes, or boxing classes to bring the community together to socialize. They have multiple fundraisers throughout the year like the annual buddy walk and sporting events to raise money for the organization and bring awareness to the community. According to the interviews they want to have more events and large fundraisers throughout the year, instead of just the buddy walk to bring

more awareness and educate more of the community. After speaking with Shelvia, a current board member and mother of a young boy with Down syndrome mentioned that this organization has brought so much joy and socialization into their lives, which inspired her to want to work more with the organization. Lauren, along with many of the other interviewers also mentioned the organization's new focus on their new cafe that is employing young adults with down syndrome to prepare them for long-term jobs. This new endeavor of theirs provides financial income for the organization, along with advocating for and educating young adults with Down syndrome in the community.

From most of the interviews we learned about how they want to expand their programs, office, camp, and help throughout the rest of the state, especially into the southern part of Delaware. One of their biggest goals that we discovered throughout several of the interviews is that they want to diversify their fundraising events, which they have already started to do. After speaking with Kathleen, Lauren, and Shelvia, we noticed that the organization has started to diversify their fundraising efforts to more than just the annual buddy walk that used to bring in all their donations. They have already started implementing new fundraisers such as a softball tournament, and golf tournament, which has already shown to be very successful. As Lauren mentioned in her interview one of her main goals within the next eighteen months is to open another office just like the one they have now in Newark in Sussex County for DSA to help more families and make it easier for the families down state. She explained to us that DSA answers questions and helps families throughout every step of the individual's lifetime; from diagnosis of Down syndrome during pregnancy all the way until death, so by opening another office they can eventually start to help even more families throughout their journey.

The Pandemic, after the last two years, has affected many people and nonprofit organizations throughout the world, so one of the most important questions during the interview process was to see how COVID-19 affected DSA. Overall, from all the interviews, we learned that the organization was not severely affected by the Pandemic, they were still able to run their operations. Mostly it made the organization be innovative and think outside of the box to provide programs, camp, and education to their community still. They were able to deliver camp in a box and did not have a difficult time financially to provide programming. Of course, they did not bring in as much as previous years because they did not have the Buddy Walk in person, but they were able to do a drive-by Buddy Walk, which still allowed them to bring in a decent amount of money. DSA has many strengths and great qualities which allow them to work as a great team to provide education, advocacy and awareness to the community within Delaware.

## Application of Class Knowledge

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### III. “Good to Great”

Jim Collins wrote *Good to Great* and the Social Sectors to apply typical business ideology to the nonprofit social sector. He framed this piece by addressing the many questions pop up for the social sector leaders into five different sections. Applying these sections to our organization can help DSA understand their greatness and their potential.

#### First Who

The “First Who” concept from *Good to Great* includes making a team full of committed individuals and putting them in positions that they are prepared for as the priority to create a successful organization. DSA has put the best individuals on their “bus” or on their team to create a great organization that fully helps their community in the best way they can. They all, from the board members to the volunteers are immensely passionate to help their community and have done great things while they have worked for DSA. Lauren, the Executive Director, took over after being a volunteer eight years ago and she has brought a great new perspective to the organization. She has made the decision when she started to not only do the buddy walk anymore for their sole fundraising event. She did not want to put all their eggs in one basket anymore and wanted to bring in fundraising dollars in other ways, so they have started a softball and golf tournament to raise money also. They are more successful financially and have brought in more awareness to the community by having more than one event a year.

Lauren Camp Gates has a long list of accomplishments and qualifications. First, she received her Master’s in Public Policy concentrating on the nonprofit sector, which gives her insight and knowledge on how a quality nonprofit should run. Her prior experience with certain educational policies (i.e., Individualized Education Programs) allows her to have productive meetings with the organization’s parents asking about how to obtain IEPs. The Board of Directors also have their own set of qualifications that improves the quality of the organization. For example, Dave Gazzillo mentioned in his interview that he graduated with an Economics degree from the University of Delaware and holds a high position at the Bank of America. These allow Gazzillo to have financial insights on the organization and make sound decisions about the DSA’s budget and allocation of resources.

#### Hedgehog Concept

The hedgehog concept is a three-tiered Venn diagram that focuses on; What drives the economic engine? What can you be the best in the world at? and What are you deeply passionate about? With these three pillars being used in an organization it can make the organization run smoothly and the best they possibly can be. This concept can be applied to how the DSA runs their organization. The overall meaning of this concept is to stick to what you are good at to do the best for the community, and this is just what DSA does. They follow this by choosing to focus on only one disability in the community, rather than advocating for all the disability community. They do their best to focus on and help the Down syndrome community only. Laruen said in her interview that they are successful and great at what they do because they do not spread themselves thin and only focus on

Down syndrome in their community. By doing this they really make a great impact educating and advocating for the community.

### Level 5 Leadership

The Level 5 Leadership concept is a pyramid idea going from lowest to highest level of leadership. This concept includes how the team benefits from operations and how they can further the mission within their community. From lowest to highest the level five leadership concept is as follows. This graphic is from the *Harvard Business Review* and explains this concept very well and concisely.

## THE LEVEL 5 HIERARCHY

The Level 5 leader sits on top of a hierarchy of capabilities and is, according to our research, a necessary requirement for transforming an organization from good to great. But what lies beneath? Four other layers, each one appropriate in its own right but none with the power of Level 5. Individuals do not need to proceed sequentially through each level of the hierarchy to reach the top, but to be a full-fledged Level 5 requires the capabilities of all the lower levels, plus the special characteristics of Level 5.



There are plenty of examples of these levels throughout DSA, starting with the volunteers being highly capable individuals and contributing team members. A great example of this is the volunteer we interviewed Steve Beard, who has been volunteering with the organization for multiple years. He has a lot of different skills and knowledge to give to the organization which makes him a great team member and helps them with many different projects; from setting up at an event to helping fix something at the office. An example of a competent manager would be the vice president of the board Shelia. She runs the Easter Egg Hunt, and Valentine's Day party and is a very competent manager because she can organize where everyone is working the day of the event and is able to delegate their resources to make the best events possible for the community. A great example of an effective leader is Kathleen, their staff member that has been focusing on creating new events, and social media for DSA. She works directly alongside Lauren and has a great vision and detailed plan for the events she wants to plan in the future for fundraising, and for awareness of the organization. Lauren, their executive director, is a wonderful example of a level five executive because in the few years she has taken over she has sacrificed a lot to make lasting greatness for the organization. They focus on multiple different fundraisers throughout the year instead of just the buddy walk, and she spends so much extra time helping families read through legal documents even though that is technically a service they provide the community.

One of the facets of Level 5 Leadership is to make difficult decisions, especially ones that

directly affect the reputation of the organization. This is something that Dave Gazzillo emphasizes in his interview several times: without a good reputation, it's all over. There was once a moment in which Lauren had to handle two difficult situations: the previous head cook for the Cafe's performance and a controversial interview with a newspaper about abortion. Both times, she consulted other members of the Board to discuss ways of going about dealing with these issues head on. It would've been easier to tell the newspaper her own personal views and act out of emotion since abortion is a heavily divisive topic. However, she instead crafted a message that was both compassionate and professional. The DSA is an organization that helps individuals and families dealing with Down syndrome and that the doors are open for anyone seeking advice or assistance; it is not a political organization. While the journalist was infuriated at the lack of a stronger opinion, it was the best decision for the DSA to keep an agreeable stance.

Gates also mentioned in her interview that the previous chef for the Cafe was not performing up to par. There were several problems with his conduct and task performance that resulted in his termination. This was not to burn any bridges, but to keep the Cafe running smoothly. Any weakness could damage the organization and come back around to tarnishing the reputation of the DSA.

### **The Flywheel**

This concept includes the idea that the success of an organization continues to build upon older successes, and it keeps on going and going. DSA has fundraised for years at their annual buddy walk. The first year it was a small walk and it showed to be significantly successful, and year after year they have put more and more effort into it, and it has become more successful every year. Now in the past few years they have realized how successful it has been and decided to use some of the same strategies for other fundraisers which have become very successful as well. By continuing to use the same strategies they continue to make the organization more and more successful year after year.

## **IV. “Work on Purpose”**

### **Head, Heart, and Hustle**

“Work on Purpose” emphasizes that the most successful people bring together their talents and their passions. Formally called “Head + Heart = Hustle”. The book came with five stories of people who at first were without a strong direction in their lives, but then were able to connect their talents with problems they felt strongly about to eventually thrive. All the individuals in the book had a passion. In our interview with Kathleen, we learned that she really likes helping kids and running inclusive events. This is compatible with her position as program coordinator at the DSA.

From the equation, the sum is described as “hustle”. This refers to the bridge of what someone is good at and what they enjoy doing more than anything else. It's that sweet spot where skills and passion perfectly mesh together. In Lauren Camp Gates case, she has always been a supporter of the DSA and helping children and families dealing with Down Syndrome. At the same time, she is also educated in how to run a nonprofit as well as having prior knowledge of the inner workings of the organization. These come together to form the hustle that “Work on Purpose” is advocating for. Operating on Head alone would be unwise, as the task might not be fulfilling.

## SWOT Information for Analysis

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### V. Mission Statement Analysis

The mission statement for the DSA is located under their “Mission and Vision” page on their website. It states the following: “The Down Syndrome Association of Delaware’s mission is to be a resource promoting public awareness, education and advocacy supporting individuals with Down syndrome and their families” (“Mission and Vision”, 2021). From this statement alone, there are clearly many strong points and details of a proper mission statement. Here, the wording is clear and concise, so it is easy for potential donors and volunteers to understand. It also succeeds in displaying the element of purpose in the statement. From what we’ve learned throughout our BHL experience, a quality mission statement should include the value, business, and purpose of the organization. DSA’s purpose for existence is to educate the Delaware community everything about Down syndrome, from advocating for those with Down syndrome to educating affected families about the condition and how to live with it. While the statement does not state *how* the organization educates, advocates, and raises awareness, there is enough information in the statement to pique one’s interest about the organization.

However, there are some aspects of the statement that are a bit unclear. There is a clear sense of purpose stated in the mission, but it doesn’t reinforce the value of the DSA. According to our research and many members of the Board, the DSA is the only organization in Delaware that specializes in raising awareness specifically for Down syndrome. Keeping this information out of the statement may cause this organization to seem like a generic Down syndrome-centered organization. There’s nothing wrong with this, but it is difficult for the DSA to distinguish itself from other state and national organizations without this detail. In addition to this, the business of the mission statement is a bit unclear. For example, the most recent project the DSA created was the DSA Cafe located at its Newark headquarters. One form of advocacy is empowering those affected by Down syndrome to have the lifestyle skills necessary to succeed, such as cooking and managing finances. The Cafe is a fun way to teach these skills! Let it be clear that the mission statement is by no means poor; it’s an excellent starting point.

### VI. Short-Term Goals

After assessing the organization, we noticed the many goals that the DSA wants to complete. For short term goals the organization, especially Lauren the executive director, wants to establish the cafe more permanently and set it up so the profit they make can run the cafe excessively. She wants to establish the Cafe, and have it become a well-oiled machine because she can see a lot of grants coming from the cafe and that would be helpful because it is expensive to run. To bring in grantees and more money, the organization needs to be well established. The cafe can bring a lot of visibility which could expand the budget to help with other aspects of the organization.

Another short-term goal that the organization has is to diversify their fundraising efforts more than they already have started to. When Lauren became the executive director, she decided it would be better for the organization to have more than one large fundraising event each year. For the past several years they have focused all their attention on making the most money possible at their annual buddy walk, which is now named the Down syndrome Association of Delaware walk. They focused most of their time

and efforts in the past on this fundraising event and Lauren decided that they need to implement more fundraising events throughout the year to take pressure off the walk being successful and to also bring more money in and more awareness to the Down syndrome community throughout Delaware. Within the past few months, they have started a charity softball tournament and a charity golf tournament which brought a lot of money and awareness to the organization. Their goal is to continue designing and implementing more events like this soon and for years to come.

These events are crucial to the DSA's sustainability. It's reputation is important for its lifetime and needs to be looked after to ensure donors keep coming back. One goal that will accomplish this is to develop an event or promotional initiative that will convey the message of the DSA, bring the community together, and successfully establish the DSA as the organization to go to for Down syndrome advocacy in the tristate area. This can be accomplished, but the challenge is determining what event is cost effective and impactful enough that can be continually updated by DSA staff. A marketing initiative could work, but that would require skills in digital marketing and may need to be self-taught.

## **VII. Long Term Goals**

The overarching goal of this organization is to educate, advocate, and bring awareness to the down syndrome community throughout Delaware. Recently DSA has made strides doing this by opening a permanent office along with opening a brand-new Cafe that employs young adults who have down syndrome with an internship before they go off to find a long-term job. By doing this they are bringing more awareness to the community and advocating and teaching the young adults that work there. Their long-term goals for this cafe and permanent office are to replicate it throughout the rest of Delaware, especially Sussex County. Laruen wants to open another office first in Sussex County to allow easier access to their information and amenities for the families who live down state. Their second goal following the first would be to open another, or multiple cafes throughout the state eventually to bring in more profit and give more opportunities to young adults with Down Syndrome. Overall, after interviewing multiple perspectives from the organization, most if not all of them brought up this long-term goal of opening another office and more cafes, which means that it is a long-term team goal that everyone has a focused vision on.

## **VIII. Finances**

At first glance, the DSA seems to have a decent foundation for financial management. The treasurer Ted Griffith is a Certified Financial Planner, so his education and expertise match perfectly with the demands of his job and the rest of the organization. Gazzillo stated in his interview that, at one point, the organization had a personal Certified Public Accountant who helped manage their finances. However, to be more cost effective, they decided to hire an accounting firm to help with their services. Gazzillo uses his experience in the banking industry to assist in overseeing finances and ensuring those needs are met.

After analyzing the 990 Forms from the last three years and interviews from the Board of Directors, the DSA has seen a fair share of financial struggle. As established under the 990 Form section of this analysis, the organization operated in the red for 2018 and 2020. The latter is easily explainable (i.e., the COVID-19 pandemic), but 2018's information has an unclear explanation. There seems to be a slightly larger dependence on gifts and donations from donors rather than government

grants. However, after the interview with Lauren Camp Gates, the goal is to advocate for more government funding and make both sections of the 990 have equal weight so there is no greater dependence on one or the other. In short, while there have been financial struggles, there is no sign of DSA closing its doors permanently, which is certainly a relief after how many nonprofits COVID-19 has shuttered.

## **IX. Branding and Marketing**

From the interviews with Kathleen McCormick and Lauren Camp Gates, there seems to be a lack of direction with DSA's branding and marketing. Camp Gates stated in her interview that one of the organization's most ambitious projects, the Cafe, could have a lot more customers. This seems to be a weakness of the DSA because it was also brought up in a community member interview that diversity could be improved within the community. The organization's core community seems to consist of mostly middle-class Caucasian families. Whether this is a matter of genetics (i.e., what communities does Down syndrome appear most prevalent in) or the social stratification in our nation making it more difficult for certain communities to ask for assistance. More outreaches could be done to include other socioeconomic groups and ethnicities. Most of the branding and marketing seems to be done through their Facebook page (622 members from a quick Google search), website, as well as through flyers, posters, and banners at in-person events.

As far as digital marketing goes, DSA doesn't seem to have a very seasoned marketing mix. The organization has a website and a Facebook page, but no other online mediums. Having other interactive platforms, especially to get younger people involved, could attract more potential donors, volunteers, and self-advocates. For instance, many youths use Instagram which allows them to post videos and photos with memes or humorous trends for their friends to share. If DSA has at least two other platforms, it could be possible to advertise many of DSA's services and activities to a brand-new audience.

## **X. Board of Directors**

The board of directors are a vital part of overseeing and providing structure to a non-profit. Typically, the members of the board of directors are individuals of the community that make the overarching decision and provide resources for the organization, but not typically the ones that do the work of the nonprofit. They are more the group of people who oversee big decisions on behalf of the nonprofit and are separate from the organization. The board of directors must monitor and watch over the nonprofit's financials, and how the organization is operating day to day. One of the major responsibilities of the board is to think of the best interest of the nonprofit and not in the interest of an individual member on the board. It is important for an organization to have members on the board that will think of the best interest of the whole organization and not to further themselves individually. They can do this by hiring a third party to oversee both the board and how they operate regarding the organization. Another crucial role of the board is to bring in donors, and complete financial data to let the donors know where their money is going within the organization. A lot of times the board is the face of the organization at fundraising events, they give speeches, and win people over to bring in more financials for the nonprofit. Shelvia, one of the members of the board, explained that she runs the egg

hunt and is the face of that event for DSA. With the board the financials are transparent to the organization and to the donors and other members of the community, due to their fiduciary responsibility.

After interviewing the Board of Directors, they value all the members of the organization, especially Lauren the executive director. Both the president of the board and the vice president talked very highly of Lauren and the organization as a whole and were happy to explain that they give most of the decision making to Lauren and do not need to step in for many big decisions, because of the trust they have in their members. It is very important for the members of the board and the employees and volunteers of the organization to have a lot of trust, as that is the basis of a good working team relationship. Dave the president of the board mentioned that it is crucial to have a team of hard-working individuals to have a successful organization. He said that when things get tough make sure you have a great group of people to work with to get the job done, which he has seen through the difficulties with COVID-19 and how prosperous Lauren and the other staff has been for the organization.

Through the interview with Shelvia, we gained insight on how decisions are made and the overall structure of the board working together with the staff members. She explained that DSA has a group called the members at large who helps make big decisions for the organization. They are a group of parents or family members of someone with Down syndrome in the Delaware area and they meet every month to talk about the direction of DSA and how things are running. When a decision needs to be made the board of directors takes it to the members at large where they vote on whether to approve or disapprove the decision. Then the board of directors takes that vote back to a confidential meeting with just the board and uses the member at large's decisions in their final choice on the topic. This is a great way to hold the board members accountable in that they are making decisions based on the interest of the overall organization, by including the community members' voices in the decision making.

Recently the board of directors for DSA have been working very well with Lauren the executive director in bringing in new finances and starting up the cafe in Newark. The sense from the board is that operations are running very smoothly recently, and they are excited for what is to come with expansion and solidifying the cafe to bring in more of a profit. It is seen that the board has the best interest of DSA at heart, because most of the board does have a family member or friend with down syndrome so they really want to impact their community in the best way they can. Overall, the board of directors at DSA have a lot of heart in the organization and have a lot of trust within their group and within the staff members, like Lauren and Kathleen.

## **XI. Volunteers**

The DSA has a very strong network of families, regular members, and volunteers. Lauren Camp Gates herself stated in her interview that many, if not all, of the volunteers and board members have family members, friends, or even children with Down syndrome. Volunteer Steven Beard, who is typically involved with assisting activities during the Days of Summer Camp each year, many volunteers are involved due to having personal connections with people who have Down syndrome. In Beard's case, it's his surrogate grandson Jackson. In Beard's interview, who is educated in Kindergarten Education and volunteers for the University of Delaware's College of Engineering,

initially became involved with the camp to accompany Jackson as an opportunity for him to make friends. Beard ended up loving it, volunteering for the camp for 7 years. He personally had glowing opinions about the organization and the volunteers DSA attracts.

Beard claims that the volunteers for DSA and Lauren Camp Gates' efforts as the Executive Director are among the strongest points of the organization. He mentioned that, at the camp, nurses from AI Dupont Hospital for Children come to give children with special physical needs care during and in between activities. "They see the sickest kids and love coming to see them," Beard stated, proving that the volunteers have a genuine desire to help children with disabilities (S. Beard, personal communication, October 2021).

Volunteers have also proven to be efficient problem solvers. During the camping event one year, it is typical for the last day of camp to have a "Water Day"; water slides and bounce houses are installed to close off the event. A storm began to form, causing immediate evacuation and one of the bounce houses to blow over. Seemingly without a second thought, volunteers ran after the bounce house and began to drag it back to the campgrounds while also binding the tears with duct tape. Within an hour, the storm was over, and the bounce house was reinstalled. This not only shows dedication in the volunteers, but also the mutual goal to keep the event running smoothly for the kids looking forward to this event every year.

## **XII. Location and Logistics**

The location of the DSA had a rocky beginning as far as where to find a home base. Initially, the goal was to attract afflicted families living downstate (i.e., Middletown, DE area). This resulted in the organization having a single P.O box, and later an office space, in Middletown before being shuttered a few years ago. With the headquarters moved to Newark, DE about 10 minutes from the University of Delaware, there is some potential for the organization to expand to other areas. Gazzillo stated that one of the organization's goals is to go from being the Down Syndrome Association of Delaware to the Down Syndrome Association of Delmarva to serve the tri-state area. According to Gazzillo, this is to accommodate other nonprofits who have the same area of functionality (i.e., The Blood Bank of Delmarva, Delmarva Power, etc.).

Logistically, this is an achievable goal. Maryland and Virginia are roughly within an hour and half of headquarters so it's not difficult to make a connection. However, Maryland and Virginia already have organizations dedicated to Down syndrome Awareness. Located in Baltimore, MD, the Chesapeake Down Syndrome is a parent group serving the Baltimore area for those affected with Down syndrome; they provide the same services DSA does from educational sessions to getting families connected to genetic counseling ("What", 2021). Virginia has not one, but three organizations related to Down syndrome awareness. These include groups serving Greater Richmond, Northern Virginia, and Roanoke (Global, 2018). With all these preexisting organizations, the DSA will likely have to reach out to them personally and make plans of merging with one another or work together to make more creative initiatives.

## **XIII. Social Entrepreneurial Measures**

The DSA runs a wide array of social entrepreneurial measures. They run a cafe that employs adults with Downs syndrome to provide them job training, a summer camp built to support the needs of

kids with Downs syndrome, an annual walk to fundraise while also bringing the community together, art events where kids paint boards, a 5k or 10k run, and a softball tournament to name a few. All these events serve to bring families and their children with Downs syndrome together, while also fundraising, educating, and/or providing other forms of value to the community.

One crucial facet of entrepreneurship is the willingness to take risks, perhaps even costly ones. The Cafe was one example of these risks. It was a venture used to both promote and fundraise for the organization and teach people with Down syndrome basic life skills such as cooking and financial management. However, there was no guarantee that it would be a successful venture. Opening a business like this comes with several risks, such as inventory problems, low patronage, and, sadly due to the nature of the organization, discriminatory thoughts and behaviors from less-than-decent customers. However, these were risks the DSA was willing to take and now the Cafe is in the first stages of becoming an established venture.

#### **XIV. Comparable Agencies**

According to our interview with DSA's Executive Director (Lauren Camp Gates), DSA is the only organization catered specifically to those with Down Syndrome in the state of Delaware. Further research on GuideStar confirms this. Therefore, there is little competition between other organizations. However, there are some national nonprofits that happen to have locations in Delaware and serve those with intellectual, developmental, and genetic disabilities. The first organization to discuss is the Delaware Special Olympics. They empower people with intellectual disabilities to find new abilities and skills to give them more self-esteem through sports. This is a nationwide organization that is broader than our organization, since ours focuses on Down syndrome specifically. Sports and activities play a large and important role in this organization, so maybe our organization could use some of their ideas to make the down syndrome community in Delaware feel more included in sporting events. They could provide more events for team sports specifically for people with down syndrome instead of just individual group classes, like boxing.

The second organization that DSA could learn from is National Down Syndrome Congress which focuses on promoting disability advocacy by advocating and fighting for better rights based on disability targeted discrimination throughout the community. Providing health advice and services to families affected by Down syndrome. What is particularly interesting about the NDSC is that it has an advocacy training program, which prepares parents and self-advocates of Down syndrome to learn more about the social issues facing those with the condition and how to combat discriminatory attitudes/legislation. One of the biggest problems Laruen mentions is giving IEP services and meetings to families in the area. IEP documents are incredibly difficult for many parents to understand, leading to miscommunications and difficulty for everyone involved. We could use these resources and ideas from the NDSC to help our organization learn more about the IEP process, and potentially set up a program to help families with the IEP process.

The third organization that could give insight to the DSA is the Easter Seals organization. This is a national organization that gives services, education, and outreach to people with disabilities. This group does not have a focus on a certain disability, but rather supports the whole disability community throughout the country and in some communities throughout the world. They work to enrich education, enhance health, expand employment, and elevate community throughout programs,

education, and fundraising. The programs that they provide to the disability community focus on four key areas: enhancing health, expanding employment, elevating the community, and enriching education. After looking at the easter seals website and learning about their organization, there is a potential to reorganize the way our organization provides their information on their website. Lauren the executive director and the rest of the organization do so much to help the down syndrome community and try to find answers for them in any way they can, so maybe it would be useful to have a spot on their website with links to resources based on different aspects of the persons lives, like community, employment, or education. Right now, they have the website mostly based on the age of the person with down syndrome, but there could be a potential to reorganize if they think they need it.

The last organization that was identified that could give us ideas for our organization was The Arc. This is another organization that's goal is to protect and promote the lives of the disability community by focusing on inclusion and participation. This organization works for the disability community throughout the nation, but they focus more on advocacy and policy for the community compared to our organization. They have less programming and activities for the disability community compared to other organizations, including ours, but they do focus on advocacy and policy change more than our organization does. They do have a whole section of their website dedicated to changing the education policy and system throughout the country which we noticed from talking with Lauren is a very big issue throughout the down syndrome community. After looking at the arc website and comparing it to our organizations, we noticed that, even though advocacy is one of the main parts of our mission statement, on their website it is kind of hidden to find the resources, and there are not a lot of resources listed. Our website does list an email address with any questions about the advocacy section, but we feel that they could provide more information about current policy change and advocacy information regarding the down syndrome community.

## **XV. COVID Impact**

COVID-19 had a lasting impact on both the nonprofit and for-profit sectors throughout the world the past two years. In fact, according to a PBS News article, roughly 33% of nonprofit organizations are in danger of closing their doors due to the financial strife COVID-19 thrust upon them (Gamboa, 2021). This became a very real threat for DSA, especially being a small organization in an equally small state. Gazzillo, as he stated in his interview, had to make sacrifices by spending more money on virtual appliances to ensure the organization kept running during the shutdown. Going over budget to get Zoom for all the Board members was not only a sign of wanting to keep this organization afloat, but a testament to how adaptable these members are. Many of the fundraising events, notably the Days of Summer Camp and the Buddy Walk, were cancelled due to government shutdown regulations. This led to Camp Gates and Gazzillo meeting up with one another to develop the “Camp in a Box” event so that camp goers could get the Days of Summer Camp experience from the comfort of their own homes. While a virtual event doesn't have the same experience as a live one, it once again shows the dedication of this staff. In short, after assessing DSA, COVID-19 was rather detrimental to the organization's finances, but not the spirit of the board members and volunteers.

## SWOT Analysis

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### XVI. Strengths

From the information presented in this analysis, DSA's Top 3 Strengths are as follows: the organization and strength of the Board, passion in volunteerism, and the ambition of its fundraising projects. According to Camp Gates, several members of the Board have children or family members with Down syndrome, thus giving them a personal reason to become involved in the organization. This shows a clear dedication to the mission, something the Board takes pride in. Gazzillo has a son with Down syndrome, as does the secretary of the organization. Everyone has a personal reason to be there and give it their all. There is also a lot of open collaboration between Board members. From the conversation with the news journal to how to accommodate the budget for Zoom, the Board members openly talk to one another on what the best course of action is. From what we've seen, it seems to be paying off.

Beard has also shown how strong the volunteer network is for the DSA. Not only are volunteers willing to help put a bounce house back together in the middle of a storm and have AI Dupont nurses take time out of their summers to care for special cases, but they have a genuine love for what the organization stands for. This indicates a high level of morale within the organization; volunteers who feel supported by the organization are likely more willing to put their best foot forward.

Gazzillo is very proud of the efforts being done to improve the image of the DSA, especially the Cafe. One problem he had is that people from the outside looking in and even some volunteers questioned the importance of the Cafe. According to Gazzillo, the Cafe employs those with Down syndrome and teaches them various self-care and lifestyle skills such as financial management, cooking, and maintaining clean quarters. At the same time, it is a fun and creative way to raise money and awareness for the DSA via food and merchandise sales.

### XVII. Weaknesses

While a well-run and well-intentioned organization on the surface, there are some aspects of the DSA that need some revision. The biggest issue seems to be the DSA's lack of diversity in its social media presence, as well as marketing initiatives to the Delaware community. The only online presence the DSA appears to have been their website and a Facebook page for members to keep themselves updated on upcoming events and meetings. This is a great start to reaching a larger audience within the community, but it isn't keeping up with the ever-changing field of technology. Many young people are spending more time on Instagram or TikTok rather than Facebook, an app typically used by older adults. That is a missed opportunity to get potential younger donors and volunteers interested in DSA. Expanding an audience could very well help the organization reach new heights.

Another issue the DSA has is how they plan to distribute their volunteers among different activities. Gazzillo stated in his interview that those who decided to volunteer for the DSA may have their hearts in the right place, but they don't have the skills required to succeed

in the activity they want to accomplish. For example, the organization has a need for volunteers with experience in technology and computer work for digital marketing and other purposes. It would be difficult for a volunteer to deliver the quality of work needed if they are not qualified to work with computers, even if they have the right spirit for volunteering to advocate those with Down syndrome. This seems to have occurred in the past and leads to a misplacement of the "Head, Heart, and Hustle" concept in "Work on Purpose". Without the skills necessary, the heart and hustle for completing a job well done just can't work alone.

One other weakness is the fact that COVID has not completely dissipated, as evidenced in the 990 Forms for 2020. The organization was still operating at a loss, which has the potential to bleed into this year's fiscal year. In short, the organization needs more money than it ever did before.

### **XVIII. Opportunities**

As the only association dedicated towards Downs syndrome in Delaware, the DSA has a massive window to expand and serve all families in Delaware with children with Down's syndrome. Now the DSA doesn't serve as many low-income families as it could. In addition to that, most of its events happen in northern Delaware, leaving middle and southern Delaware families with less resources and opportunities to engage with each other and receive value from the DSA. Fortunately, these holes in the DSA's service are wide open for the DSA to capitalize on since there aren't other organizations in Delaware that are dedicated to its Down's syndrome community.

Since there isn't as high a population density in middle and southern Delaware, there's a huge opportunity to create a small but committed community there.

### **XIX. Threats**

Though the threat of a COVID case showing up at the cafe is subsiding, the DSA should remain vigilant and take proper precautions. Another possible threat are bigger, large umbrella organizations that might take up funding through wider spread brand recognition such as the Special Olympics, Easter Seals, and the National Down's Syndrome Association. If potential donors from Delaware were passionate about helping people with Down syndrome, they might not know about the DSA. They would probably donate to these larger organizations who do not provide frequent and specialized value to the Downs syndrome community in Delaware.

Also, the necessary expansion of the DSA into wider demographics and locations presents a threat to the organizations well-being. Expansion when done carelessly and too rapidly can cause the DSA to incur expenses far greater than its revenue can keep up with. For example, spending more money with the prediction that it will come with the appropriate additional revenue can be problematic when that predicted additional revenue doesn't come in to offset the costs. Care should be taken during the DSA's expansion.

## Summary

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### **XX. Greatest Needs for the Organization**

The DSA organization has many great aspects and people that keep the nonprofit running and prosperous for the community that they intend to help. As their mission states they want to be a resource, promote awareness, and advocacy to the Down syndrome community throughout Delaware. After analysis of the organization, we have noticed that they are completing their mission statement to the best of their abilities. They have a wonderful website that provides a lot of information and resources for the families with Down syndrome. They also provide ample programing and fundraising to advocate and educate the community. One of the greatest needs of this organization, which came to light during the interview process is regarding the new Cafe that they just implemented in the past few months. This cafe is located at their office and provides an internship to young adults within the Down syndrome community to learn how to handle a job and learn the skills needed to maintain an independent life. Their main goal for the future of DSA is to have a solid foundation for the Cafe to make it more of a profit to cover its expenses and to bring in more grantees and grants to the organization overall. To do this, they need to bring in more customers and attention to the cafe. DSA needs to bring more attention to the community of Newark and Delaware that are not related to the Down syndrome community to bring more awareness and business to the Cafe. The cafe can become more profitable if more business is brought to it

Another need of the organization is to make a solid plan to open another office like the one they have in Newark to Sussex County, Delaware. One of the main goals for their future, which was brought up by many of the members of the organization, is to spread their office to the rest of the state to provide better and more services to the families in the lower part of Delaware. In order to do this, they need to come up with a concrete plan of when exactly they want to open it up in order to work backwards and make a strong plan that they can follow through from start to finish. The organization needs to decide exactly where they want the new office, who is going to be working there, how big, what time they want to start, and what kind of resources such as financials they are willing to give to the second office. This would be a long-term plan, as the first step would be to make the original office show to be very successful. Opening a second office does not necessarily need to include another cafe along with it but there still are plenty of details to discuss and decide on to even start the concrete planning of a second office.

Another need for the organization is to bring in more ideas for fundraising and more events throughout the year as one of their main goals is to bring in more fundraising efforts and not only put all their resources into the annual Down Syndrome Walk. The organization needs to come up with more ideas to diversify their fundraising efforts. They did a great job recently by coming up with the softball and golf tournament, but to bring more donors in they could have fundraisers that do not revolve around sports. This could bring in different types of donors who have different interests and could also give another socializing event for the families with Down syndrome to interact in a new way.

Another need for the organization is to update and include more resources regarding advocacy

and policy change for the Down syndrome community. After looking through the website and basing their goals off their mission and vision statements they need to include more about advocacy. They do a great job providing awareness and education regarding the Down syndrome community, but by navigating through their website it is difficult to find how they are advocating and trying to change policies for the community. They do provide ample information and resources for the families during every age of life, but it is hard to find anything on advocating in the government for the Down syndrome community.

## **XXI. Possible Projects**

### **Project 1: Social Media Campaign via Instagram or TikTok**

- Our goal for this project would be to attract more people, especially donors to the organization who do not have a direct connection to someone with down syndrome. The goal would also be to bring more traffic to the cafe.
- Research which social media platforms have the highest amount of usage among youths (those above the age of 10).
  - Some possible choices would be Instagram, Snapchat, and/or TikTok.
  - These allow the sharing of videos, photos, and other forms of media in a fun and concise way.
- Meet up with the Board and determine what aspects of the DSA should be promoted via social media (i.e., the Cafe, Buddy Walk, Meet the Self-Advocates, etc.)
- Start up to two new social media accounts on different platforms and designate which team member(s) will be responsible for running the pages
- Once people are attracted to the website though, we feel that there needs to be more about how they can be involved and why this mission is important to their lives. Right now, when people open the website, it does not really draw you in to learn more about the organization and it does not prove as to why the organization is important for the community as whole
- Our goal is to revamp the information on the main page of the website, include better and more interesting graphics and try to immediately draw the new people into wanting to commit time and effort to learn more about the organization and the Down syndrome community.
- At the end of the project, conduct a data analysis on the traffic towards both social media pages and determine whether there has been an increase in donations or volunteering activity.
- This project could also focus on branding and marketing for the new cafe, to bring more business in and make it a more substantial income for the organization as a whole
  - We could set up social media for the cafe; focusing on the interns perspective and showing what a great environment it is
  - We can promote the cafe with flyers, videos, pictures of the cafe and the people working there around UD's campus, and the Newark area, specifically on kirkwood highway. It is kind of hidden in the shopping center so maybe if we market it at other locations around Newark it could bring in more business.
  - We can set up a reporting system to see what is drawing the traffic into the cafe: is it from social media, flyers, word of mouth, videos online etc.
    - This can help keep the marketing sustainable and allow DSA to know what is

working for them and what is not.

### **Project 2: Plan for Expansion into Southern Delaware**

- Here, the goal is to assist the DSA to find a potential area to find a place to hold a second office.
- We aren't real estate agents, but perhaps finding possible trends in nonprofit activity in the area could give the organization insight on what areas and costs to consider.
  - It would be helpful to understand the demographic in the rest of the state to understand where the greatest need is to have a second office. If there is not a large enough population of Down Syndrome families in one area, there is not necessarily a need to open an office there.
- Start off by assessing which cities in Sussex County have the highest rates of Down syndrome to find the appropriate target community.
  - This could be done using a county-wide survey or public medical information to find any trends in which residents have connections to Down syndrome.
- Next, we could identify which specific areas in these communities have available real estate.
- Another important step would be to identify how much money DSA is willing to put into this endeavor, and how much they can afford.
  - We need to think about who is going to work at this second office, and how they are going to afford to hire a new employee if they think they need a permanent employee there.
- Overall, the DSA can't just open a second office overnight, so our plan for this project would be to make a detailed plan with many thought out steps for the organization to follow to complete their end goal.

### **Project 3: Diversifying Events and Fundraisers**

- One of the main needs that was identified throughout this process is to bring in new programming and fundraising events to the community.
- Recently Kathleen and Lauren have decided to step away from only having the annual walk to raise money for the organization, so they have started the softball and gold tournament fundraiser this past year.
  - These new events have brought in a lot of money, but there is a potential to start more events that can bring in different types of donors. We want to implement new fundraising ideas along with more programming for the families to socialize.
- Parents of families expressed the desire to have more social events for the parents where the children could be taken care of, and they could talk freely. Frequency: once every 1-2 weeks.
  - We would take a survey of the families to gather information on what type of events the parents would like to attend and what they would like to see their kids involved in.
  - Plan a weekly event for kids and parents to attend based on the interest of the families.
- The buddy walk is a large event once a year and we feel that it could be split up into multiple smaller events throughout the year to offer more opportunities and programs of the families throughout the entire year

- We could implement a larger art and basket auction event that includes activities for the kids where volunteers would take them one on one to allow the parents to socialize amongst themselves. This could also be a way to bring in new donors that are interested in art, because most of the other fundraising events are sports related.

## References

\*NOTE: Under APA 7, there is no official full citation for personal interviews. Just in case, the in-text citations will be included here to account for all speakers. The class books will also be cited even though there are no quotes used and are referenced in the text\*

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