



Working to ensure that people
with disabilities enjoy the same
quality of life as the rest of society

2019 Annual Report



Who are we

The Delaware Developmental Disabilities Council (DDC) is federally funded through the Administration on Intellectual and Developmental Disabilities (AIDD) and is authorized by Public Law 106-402 to address the unmet needs of people with developmental disabilities through system-wide advocacy, planning, and capacity building efforts that promote self-determination, integration, and inclusion.

More than 60 percent of the Delaware DDC membership consists of individuals with developmental disabilities or their family members. The remainder of Council membership includes advocates and state agency representatives. This diversity enables Delaware DDC to better analyze and improve systems and services within Delaware and ensure that the voices of people with developmental disabilities and their families are heard.

What we believe

The Delaware DDC believes that, given the appropriate supports, all people with disabilities can fully participate in community life. Although people with developmental disabilities have equality under the law; vision and leadership are vital if they are to have equality in their everyday lives. The Delaware DDC strives to create opportunities in the everyday lives of children and adults with developmental disabilities. We are committed to improving the quality of services for this population in Delaware and to serve as an advocate and an instrument of system change. We look to a future where all people will have the opportunity to be included and to exercise control over their own lives.

For more information on the Delaware DDC, please visit:

www.ddc.delaware.gov



January 2020

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"I don't have a dis-ability, I have a different-abilities".

- Robert M. Hensel

Message from the Chairperson

Delaware's Developmental Disabilities Council is lead by members who are passionate about improving the lives of people with disabilities. We strive to make this organization the best it can become by funding projects, improving systems, and communicating issues for the Delaware's disability community. Our goal is inclusion, equality and respect for all individuals which will allow them to live their best life. Meetings are public and we welcome anyone interested in learning about and contributing to our mission.

- Rick Kosmalski

Message from the Vice-Chairperson

With the Disability community representing close to 19% of the population we are considered one of if not the largest minority groups in the United States. It is the one true community that is not separated by race, economics, political line, gender or orientation. In direct coalition with our Chair's vision in reflection to our Mission Statement, I believe Our Goals for inclusion and equality are at the forefront of our decision making practices.

All of our meetings are public and we encourage anyone interested in advocating and working for equality of all persons with disabilities to attend. All opinions are welcome as we work towards full inclusion of persons with disabilities into our communities.

- Michael Harris

February 2020

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“Disability is articulated as a struggle, an unnecessary burden that one must overcome to the soundtrack of a string crescendo. But disabled lives are multi-faceted - brimming with personality, pride, ambition, love, empathy, and wit.”

- Sinead Burke

A Snapshot of Disability in Delaware 2019

According to the most recent American Community Survey (ACS), below are the one year estimates from 2014:

- ◆ The total non-institutionalized population of the State of Delaware is 920,930.
- ◆ Of that number, 109,763 non-institutionalized citizens are individuals with a disability (11.9%).
- ◆ Of the 109,763 individuals with a disability in Delaware, 1.2% are under five years old, 5.4% are between 5 and 17 years old, 9.8% are between 18 and 64 years old, and 30.4% are over the age of 65.
- ◆ DE's total Intellectual/Developmental Disability spending is \$169,412,299 with \$135,169,567 in Medicaid spending (80% of total I/DD spending).

ACS data shows that as of 2016, the following are true:

- ◆ 35.9% of Delaware's workforce is comprised of people with disabilities.
- ◆ Of 398,115 of Delaware citizens who are employed, 20,178 are people with disabilities while 377,937 have no disability. 32,842 individuals with disabilities are not in the work force.
- ◆ The Centers for Medicare & Medicaid Services (CMS) issued a final rule that applies the requirements of the Mental Health Parity and Addiction Equity Act (MHPAEA) to Medicaid managed care organizations (MCOs), the Children's Health Insurance Program (CHIP), and Medicaid alternative benefit plans (ABPs). The rule requires Delaware and its contracted Medicaid/CHIP MCOs to be in compliance with the final parity rule by October 2, 2017. This includes providing documentation of parity compliance to the general public and posting this information to the State's Medicaid website by October 2, 2017.

March 2020

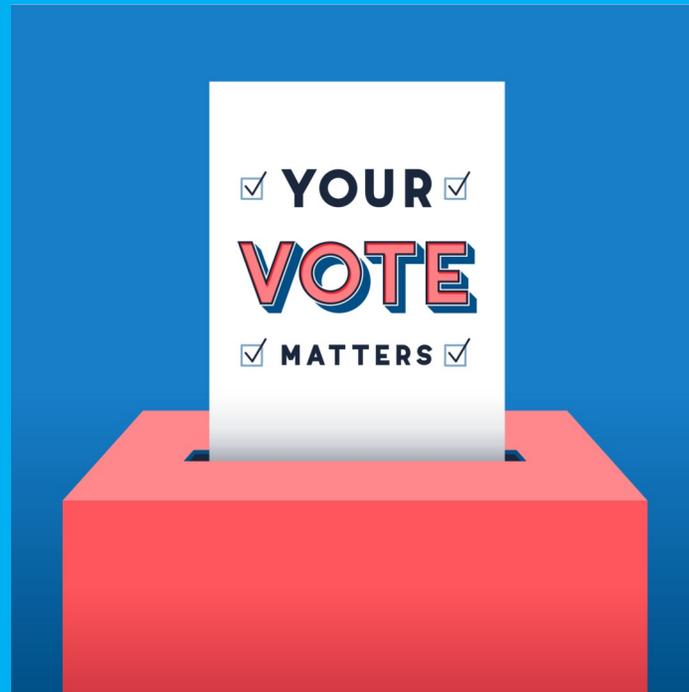
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“When you hear the word 'disabled,' people immediately think about people who can't walk or talk or do everything that people take for granted. Now, I take nothing for granted. But I find the real disability is people who can't find joy in life and are bitter.”

- Teri Garr

Are you ready?

Are you registered to vote? Do you know where your voting place is? If not, that's okay. Schedule an appointment today to meet with one of our dedicated staff who will help you get ready for election day so that your voice can be heard on November 3, 2020. During this appointment, our staff can help you become registered to vote, locate your polling place, explain the voting process and show you how to use the accessible voting booth. Call to schedule your appointment today by calling our main office at 302-739-3333. We are here to answer any voting question you may have.



"Being disabled does not mean Un-abled, just Different Abled.

- Mr. Noel Helm

April 2020

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Delaware Fun Facts



- ◆ The United States battleship Delaware was commissioned in 1910.
- ◆ Delaware is the only state without any National Park System units such as national parks, seashores, historic sites, battlefields, memorials, and monuments.
- ◆ Delmar is popularized as the little town too big for one state. The community has the distinction of being located partly in Delaware and partly in Maryland.
- ◆ The most historic site in Frederica is Barratt's Chapel east of town. The chapel is where the Methodist Church of America was organized in 1784.
- ◆ Today about 500 descendants of the original Nanticoke Indians reside in Delaware. They celebrate their heritage each September with the Nanticoke Indian Pow Wow.
- ◆ The log cabin originated in Finland. Finnish settlers arrived in Delaware in the mid-1600s and brought with them plans for the log cabin, one of the enduring symbols of the American pioneer. One of the cabins has been preserved and is on display at the Delaware Agricultural Museum in Dover.
- ◆ John Dickinson was called the Penman of the Revolution for his writings on independence. His boyhood home is preserved in Dover.
- ◆ Tradition holds the first time Betsy Ross's famous flag was flown was at the Battle of Cooch's Bridge. This historic site is located on Route 4 in Newark.
- ◆ The Blue Hen chicken is the official state bird. The hens were noted for their fighting ability. Delaware is sometimes referred to as the Blue Hen State.
- ◆ The Lady Bug is Delaware's official state bug.

May 2020

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“I have had this desire my whole life to prove people wrong, to show them I could do things they didn’t think I could do.”

- David A. Paterson

Council Membership Requirements

According to Federal Law, the state council representing individuals with developmental disabilities must be composed of no less than sixty percent of people who are:

Individuals with developmental disabilities;

Parents or guardians of children with developmental disabilities;

or immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves.

Individuals must not be employees of a state agency that receives funds or provides services under this subtitle, and who are not managing employees (as defined in section 1126(b) of the Social Security Act (42 U.S.C.132a-5(b)) of any other entity that receives funds or provides services under this subtitle.

“If I fail, I try again, and again, and again. If YOU fail, are you going to try again? The human spirit can handle much worse than we realize. It matters HOW you are going to FINISH. Are you going to finish strong?”

- Nick Vujicic

June 2020

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Our Council Members

Teesie Bonk— Family Member

Maitri Campbell— Self-Advocate

Monica Edgar—

Alvin Emory, Jr.— Self-Advocate

Karen Gallagher—Individual now/ever living in an institution

Derrick George— Self-Advocate

Laura Greene— Self-Advocate

Terri Hancharick— Family Member

Michael Harris— Family Member

Katie Howe— Member in Accordance with Title XIX of the Social Security Act

Rick Kosmalski— Family Member

Nancy Lemus— Family Member

HarrietAnn Litwin— Member in Accordance with the Rehabilitation Act of 1973

Debra McCann— Family Member

Karen McGloughlin— Member in Accordance with Title V of the Social Security Act (1st half of the year)

Daniese McMullin-Powell— Self-Advocate

Katie Macklin— Member in Accordance with Private Non-Profit Agency

Dale Matusевич— Member in Accordance w/ Individuals with Disabilities Education Act (IDEA)

Carrie Melchisky— Family Member

Joseph Merritt, Jr.— Self-Advocate

Beth Mineo— Member in Accordance with DD University-Affiliated Program

Angela Mitchell— Family Member

Christine Oakes—Older Americans Act of 1965

Sue Ellen Powell— Self-Advocate

Isabel Rivera-Green—Member in Accordance with Title V of the Social Security Act (2nd half of the year)

Shawn Rohe— Family Member

Laura Waterland— Member in Accordance with Protection and Advocacy

Steve Yeatman— Family Member

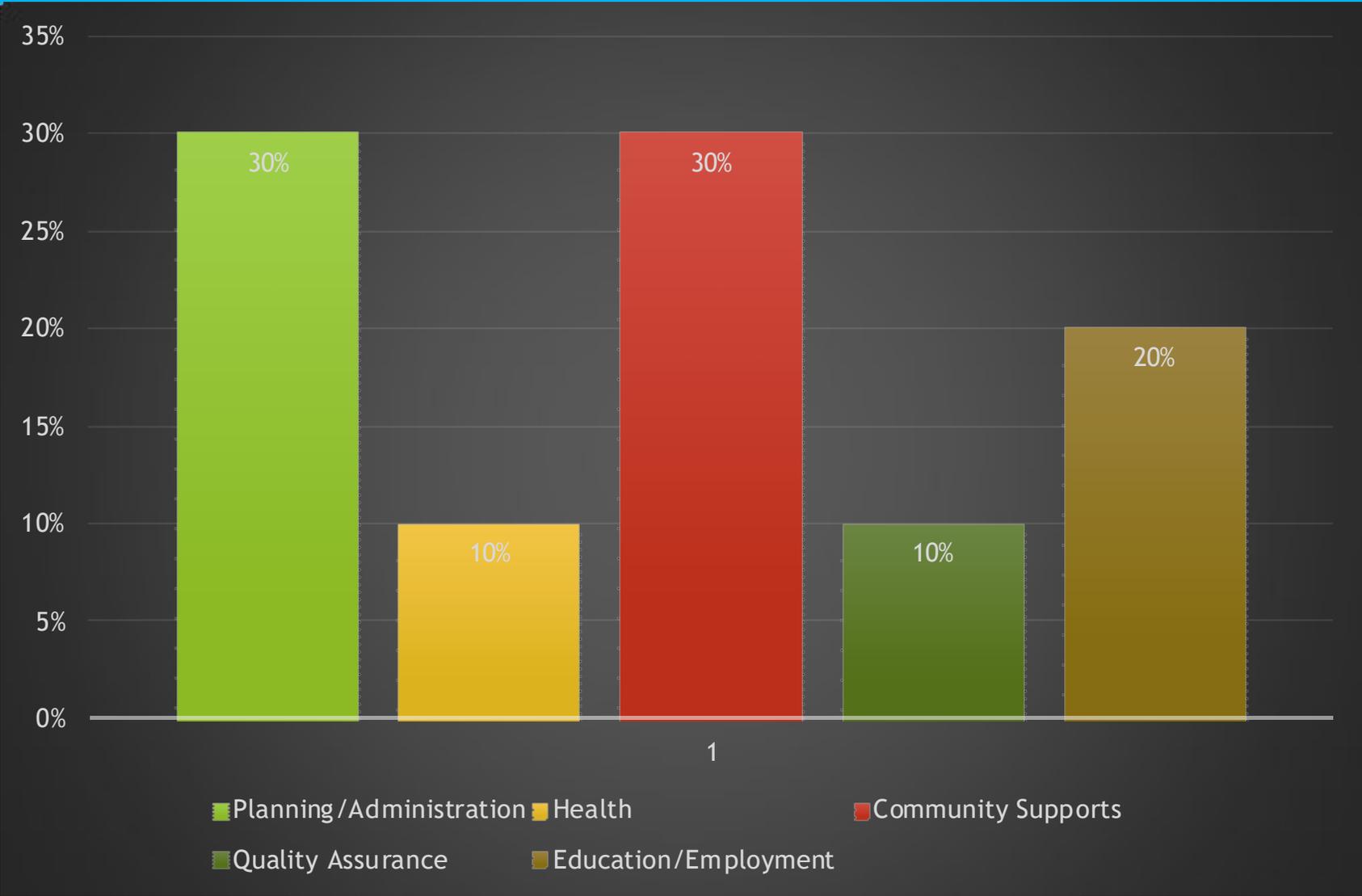
July 2020

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“Your success and happiness lies in you. Resolve to keep happy, and your joy and you shall form an invincible host against difficulties.”

- Helen Keller

Investments in Delaware's Disability Community



August 2020

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“Disability is a matter of perception. If you can do just one thing well, you’re needed by someone.”

- Martina Navratilova

Down syndrome and Alzheimer's Disease Public Awareness Campaign

Council continues to distribute materials and resources developed in 2018 concerning the staggering correlation between individuals with Down syndrome and the development of early-onset Alzheimer's disease. Sobering statistics that show people with Down syndrome are almost 100% likely to develop early-onset Alzheimer's disease. Partnering with the Alzheimer's Association of Delaware, Christiana Care Health Systems, the Swank Memory Care Center, the Down syndrome Clinic at Wilmington Hospital, doctors, geneticists, and numerous parent advocates of children with Down syndrome, the Council began developing a public awareness campaign in 2017, with implementation and distribution taking place in 2018 and continuing into 2019. Campaign materials seek to educate parents of people with Down syndrome on the risks of developing early-onset Alzheimer's, to familiarize them with signs and symptoms of early cognitive decline, and to urge them to start planning service coordination and future financial planning now. The materials intended for legislators and policymakers are similar, but also include information about the potential impact on the state's service system and Medicaid budget. Parents, as well as doctors, were interviewed and shared their insights. The parent and doctor video interviews are available on the DDC's YouTube channel. Council is currently planning Phase II of this project, which will build on the materials and feedback from Phase I in 2018. The goal of Phase II in 2019 is to present materials that show more real-life experiences shared by caregivers and people with Down syndrome who have experienced or who are currently experiencing the effects of Alzheimer's disease.



“When a tree has been transplanted, though fierce winds may blow, it will not topple if it has a firm stake to hold it up. But even a tree that has grown up in place may fall over if its roots are weak. Even a feeble person will not stumble if those supporting him are strong, but a person of considerable strength, when alone, may fall down on an uneven path.” - Nichiren

September 2020

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2019 LIFE Conference

The Delaware Developmental Disabilities Council was pleased to once again join with their community partners to plan and present the 2019 LIFE Conference. Community partners included representatives from the 321 Foundation, ADAPT Delaware, the Center for Disabilities Studies & Delaware Assistive Technology Initiative, University of Delaware; Community Legal Aid Society; Delaware Department of Education; Delaware Developmental Disabilities Council; Delaware Division of Services for Aging and Adults with Physical Disabilities; Delaware Health and Social Services – Birth to Three Early Intervention; Delaware Transit Corporation (DART), Division of Developmental Disabilities Services; Division of Medicaid & Medical Assistance; Division of Public Health – Child Development Watch; Governor’s Advisory Council for Exceptional Citizens; State Council for Persons with Disabilities; and St. John’s Community Services. The conference was held on January 31, 2019 at Dover Downs Hotel and Conference Center.

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For 2019, 18.26% of the 564 LIFE Conference attendees identified as being either a person with a disability or the parent/caregiver of a person with a disability. It is important to note that this data was collected from registration entries, and that the question regarding whether a registrant is a person with a disability or parent/caregiver is voluntary, so the number of attendees may actually be higher. The conference planners have observed a steady uptick in the number of individuals with disabilities and parents/caregivers to attend the conference, with 2017 registration data showing just 14.6% of attendees registered as a person with a disability or a parent/caregiver. Attracting more people with disabilities and parents/caregivers to attend the conference by presenting meaningful content as described by attendees in their feedback surveys remains a priority for the LIFE Conference Planning Committee as they begin work on each year’s conference.

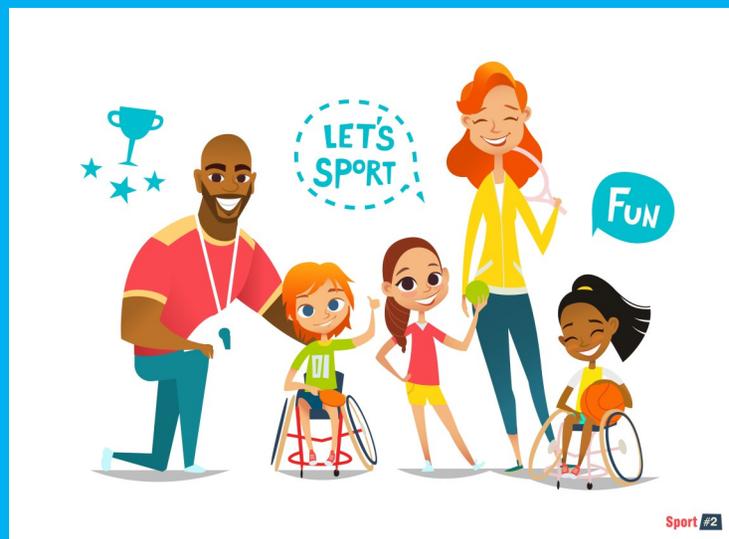
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“Education is the most powerful weapon which you can use to change the world.”
- Nelson Mandela

Healthy Kids with Disabilities Public Awareness Campaign

Inclusive, accessible health and wellness activities are not always readily available to children with disabilities in Delaware. With this in mind, the DDC began working with Sage Strategy & Communication in late 2018 to create a public awareness campaign to shed more light on this topic. Council first set out to identify barriers experienced by families as they sought inclusive health and wellness opportunities by speaking with sample groups of parents. For families, resources and advocacy tools will be provided, as will information regarding the health/wellness/recreation opportunities that are currently available and fully accessible in Delaware. For legislators, information will be provided regarding why expanding access to health/wellness options for children with disabilities is a solid investment in the state's future. Currently, an interactive website is in the production phase and should be launched by the close of 2019.



November 2020

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“A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.” - Christopher Reeve

Healthy Sexuality and People with Disabilities Education and Resource Program

Building on the success of Phase I of this project, Council began planning Phase II in 2019. Council was pleased to begin working with Planned Parenthood of Delaware. The Director of Planned Parenthood met with Council staff and the committee charged with overseeing this project to develop an informed approach utilizing the feedback captured from participants in Phase I.

The program is designed for young adults ages 14-22. There is also a separate, companion program designed for parents. While Education and Resource meetings take place at the same time and in the same building, young adults and parents do not participate in the same session, nor are they in the same room. This facilitates free discussion without either parent or young adult fearing being overheard. The information shared with each audience complements the other. Workshops will be held in each county in Delaware during 2019 and 2020. Council will continue to evaluate feedback data to inform “course adjustments” throughout the program.



"Not everything that is faced can be changed, but nothing can be changed until it is faced." - James Baldwin

December 2020

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Junior Partners in Policymaking 2019

Council welcomed Donna-Marie King of Sage Marketing and Communication to facilitate our 2019 Junior Partners in Policymaking program. Donna-Marie used her marketing experience to conduct extensive outreach efforts to recruit participants for the 2019 class. English and Spanish versions of fliers were created & distributed to transition coordinators & special education teachers throughout Delaware, as well as to several organizations that serve teens & young people with developmental disabilities. On-site recruitment was conducted at the 2019 LIFE Conference & the 2019 Transition Fair in New Castle County.

On Sunday, June 16, 2019, The Council welcomed the twelve newest members of the Junior Partners in Policymaking family to the Delaware State University campus in Dover, Delaware. Most of the participants would live in campus housing for the following six days and five nights spending their days learning about advocacy, setting goals and transitioning into adult life, and their evenings building a community. Staff was on-call for the participants around-the-clock, with staffers working 12-hour shifts. Staffers were comprised of parents of children with Autism, job coaches, and special education teachers. The participants bonded extremely well with the staff members, with many forming friendships that will continue long after the program's completion.

The Class of 2019 class was unique in that almost all of the participants were male. All of the 2019 participants had already graduated from high school. Historically, the program has not seen the same level of participation from young adults in Sussex County; however the DDC was pleased that all three of Delaware's counties were represented in this class. Disabilities represented in the Class of 2019 included Autism, ADHD, Hydrocephalus, speech difficulty, anxiety, hearing loss, learning disability, Epilepsy, cognitive disability, and Cerebral Palsy.

The participants received a visit from two distinguished guests- House Majority Leader Representative Valerie Longhurst and Senate Majority Leader Senator Nicole Poore. Rep. Longhurst and Sen. Poore facilitated an engaging discussion with the students regarding advocacy and outreach. The participants jumped in with both feet, with one participant drafting a petition on the spot seeking to overhaul DART and asking for the Representative and Senator's signatures, and another requesting legislation to make the Delaware State Fairgrounds more wheelchair accessible. Yet another young participant asked about coordination of services. The Representative and Senator were incredibly gracious, taking all of the participants' contact information and following up with them. The young participant's petition regarding DART now has over 500 signatures on change.org (his goal was 100), and the young man who advocated for improved access at the Delaware State Fair noticed some positive changes at the fairgrounds this year, thanks to the efforts of Rep. Longhurst and Sen. Poore.

As is tradition, the week culminated in the participants giving mock testimony at Legislative Hall. While the exact topics presented varied widely from participant to participant, the common theme was one of empowerment, positivity, and a strong desire to advocate for change not only for themselves, but for all people with disabilities.

Photo Gallery



* To view more photos, visit our website at DDC.Delaware.gov

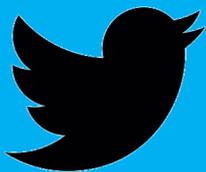
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