

2020 Annual Report

Advocate. Collaborate. Educate. njcdd.org

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MISSION >>

To assure that individuals with intellectual/developmental disabilities (I/DD) in New Jersey, and their families, participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination,

independence, productivity, integration and inclusion in all facets of life through culturally competent programs.

The mission according to the federal DD Act is to engage in advocacy, capacity building and systemic change activities.

VISION >>

All individuals with I/DD are participating, equally-included members of their communities who:

- make real choices and have control over their own lives
- have the freedom to strive, excel, and make mistakes
- are in a position to achieve personal goals and affect policy and process decisions that affect their lives
- have the same rights, privileges, responsibilities, and opportunities of citizenship as does any other New Jersey resident

Message from the Council Chairperson & Executive Director

WELCOME TO THE NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES' (NJCDD) ANNUAL REPORT FOR FEDERAL FISCAL YEAR 2020 >>

Fiscal Year 2020 clearly demonstrated the need for adaptability in response to the global pandemic. As a Council, NJCDD shifted to remote operations, while focusing on supporting the immediate pandemic-related needs of individuals with intellectual and developmental disabilities (I/DD) and their families.

The COVID-19 pandemic has had a substantial impact on people from all walks of life. This deadly virus has particularly impacted people with I/DD.

In response to this health emergency, we doubled-down on our efforts to **advocate** for people with I/DD and their families, **collaborate** with our diverse stakeholders and **educate** our many dedicated constituents.

NJCDD EMERGENCY FUNDING >> —

NJCDD authorized \$250,000 in emergency funding for grants up to \$500 to provide needed equipment and supplies to assist individuals during the crisis. Nearly 1,000 applications were submitted, of which approximately 700 individual applications and over 2, 000 individuals supported by agencies were approved for funding. To help deliver the support as quickly as possible, we enlisted the services of The Arc of New Jersey by amending a current contract. The Arc of New Jersey processed the applications and grant awards and, in some instances, expedited the purchases.

Funding was given for such items as hand-held electronic devices, art supplies, music supplies, Internet access and exercise equipment. Funding was provided for individuals of all ages, living in all parts of the state, from rural to urban. Items were then purchased online and shipped to the individuals.

ADVOCATING: HOSPITAL VISITATION POLICY >> _____

When the pandemic first struck, hospitals went into an immediate lockdown to limit exposure to the coronavirus. Patients were not permitted to have visitors, a scary time for people with developmental disabilities who often need around-the-clock care from specific caregivers and/or family members.

The NJCDD and its partners worked with the Governor's Office and the state Department of Health, among other agencies, to obtain approval for a support person to stay in the hospital with patients during treatment. A new visitation policy was quickly negotiated, ensuring people with disabilities would not be traumatized while under locked-down care.

COLLABORATING AND EDUCATING: TOWN HALL FORUMS >> -

Timely and effective communication was critical during this fiscal year. People with disabilities, their loved ones and other advocates, were eager to get answers to many valid questions. In response, DD Act Network Partners- the NJCDD, The Boggs Center on Developmental Disabilities, Disability Rights New Jersey (DRNJ) along with Ombudsman Paul Aronsohn developed an initial four-part webinar series, allowing people in the community to express their concerns, raise important questions and seek answers. Hospital visitation was certainly a top priority, as well as issues pertaining to wearing masks, social distancing and education of students with disabilities.

ENSURING COMPETITIVE WAGES FOR DIRECT SUPPORT PROFESSIONALS (DSPs) >>

Ensuring competitive wages for direct support professionals (DSPs) remains a top priority. NJCDD continued to fund the Coalition for a Direct Support Professional Living Wage. The Coalition for a DSP Living Wage evaluated DSP wage issues in New Jersey and across the country. Materials were developed to promote these issues and to educate individuals with I/DD, their families, providers, DSPs, state administrators and legislators. As a result of NJCDD-led collaborative efforts, the NJ legislature approved increased funding for DSP wages for the fourth consecutive year.

FIVE-YEAR STATE PLAN >> -

The day-to-day work of the NJCDD is based on our Five-Year State Plan. The Five-Year State Plan lays out broad goals and objectives designed to help move the system from where it is today to where we want to be in five years. Based on that plan, an annual work plan details specific activities and projects that will achieve those goals and objectives.

Every five years, NJCDD engages in a robust strategic planning process, inviting the public to help make decisions about priorities, goals, and objectives. The current Five-Year State Plan ends on September 30, 2021, so a new Five-Year State Plan must be in place. The new plan will cover the 2022, 2023, 2024, 2025, and 2026 federal fiscal years, which begin on October 1 and end on September 30. Despite the pandemic, NJCDD focused on gathering stakeholder input to the planning process by conducting a series of virtual events, surveys and feedback opportunities to gather input for its next five-year plan.

FY2020 was a very productive and challenging year. You can read more in this annual report about how NJCDD continued to **advocate** for people with I/DD and their families, **collaborate** with our diverse stakeholders and **educate** our many dedicated constituents.

With advocacy,



Paul A. Blaustein Chairperson



Mercedes Witowsky
Executive Director

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In accordance with the Developmental Disabilities Assistance and Bill of Rights Act 2000, the New Jersey Council on Developmental Disabilities (NJCDD) develops and implements the NJCDD Five-Year State Plan.

The NJCDD Five-Year State Plan for FY2017–2021 focused on the following areas of significance to the I/DD community:

- SELF-ADVOCATE AND FAMILY TRAINING & INFORMATION
- DIRECT SUPPORT STAFFING ISSUES
- SPECIAL EDUCATION ADVOCACY
- EMPLOYMENT
- TRANSPORTATION
 HEALTH & WELLNESS
- HOUSING

NJCDD addressed these areas through in-house projects, programs and collaborations, and innovative grant-funded activities.



New Jersey Developmental Disabilities Advocacy Network

People with I/DD face some of the greatest challenges seen in a generation. These challenges range from the availability of affordable and accessible housing options, systems funding, direct support professional salaries, potential cuts to Medicaid and other social services, and more.

In response, more than 57 advocates representing 29 organizations formed the New Jersey Developmental Disabilities Advocacy Network (DDAN). It is comprised of self-advocates, family members, providers and other key stakeholders.

DDAN's goal is to bring advocates together to work toward advancing the rights, opportunities, and service systems for people with I/DD in New Jersey by addressing following key issues:

- Medicaid
- Adequacy of System Funding
- Housing
- Transportation

The COVID-19 outbreak transformed advocacy efforts nationwide. As the impact of the pandemic spread, the DDAN housing. Committees evolved to virtual meetings, and continued to meet and develop The Pers strategies and goals.

The Medicaid Workgroup recognized the importance of federal funding programs and convened several meetings that concentrated on maintaining and expanding information and policy changes, many focused on the impact of COVID-19.

Responding to the experiences of its members, the Employment Workgroup conducted essential research concerning WorkAbility and the legislation needed to provide flexibility and fairness, as well as increasing employment opportunities.

The Housing Workgroup, in collaboration with the New Jersey Supportive Housing Association, worked to develop substantive recommendations for the

- Employment
- Health, Safety and Quality Assurance
- Person-Centered/Self-Direct Services
- Communication

state and legislature to increase the amount of affordable and accessible housing.

The Person-Centered/Self-Directed Service Workgroup created an online survey for individuals and families on the New Jersey Comprehensive Assessment Tool, a needs assessment used by Division of Developmental Disabilities to determine level of needs and funding.

The Adequacy of System Funding Workgroup prepared issue papers recommending more funding and flexibility to ensure the wellbeing and quality of life outside of residential settings, in particular, during hospitalization and vacations.



Direct Support Professional Wages

New Jersey experiences a 44 percent turnover rate and 25 percent vacancy rate in the direct support professional (DSP) workforce. NJCDD has taken an active leadership role in working toward solutions to address New Jersey's DSP workforce crisis.

NJCDD subcontracted with the NJ Association of Community Providers to create a strategic work plan to address the information and advocacy needed to maintain adequate funding to pay workers a wage consistent with DSP's responsibilities. The Coalition for a DSP Living Wage was established to advocate effectively for DSP worker recognition and long-term funding to secure competitive DSP wages at 25 percent above minimum wage.

Individual advocates, families, DSPs, providers and other stakeholders have been actively engaged in education and advocacy efforts to raise awareness regarding the recruitment and retention issues facing the DSP workforce. As a result of collective advocacy efforts, the NJ legislature approved increased funding for the fourth consecutive year.







New Jersey Regional Family Support Planning Councils



The New Jersey Regional Family Support Planning Councils (RFSPCs) provide a venue to exchange knowledge and provide input to state and community leaders. Ten regional councils represent all 21 counties in New Jersey. All members have a family member with I/DD.

RFSPCs monitor and evaluate NJ's service delivery system for children and adults with developmental disabilities. They disseminate critical information to other families, and gather their feedback for public policymakers. They also closely collaborate with the Department of Human Services, Division of Developmental Disabilities (DDD) and the Department of Children and Families, Division of Children's System of Care (CSOC).

In FY2020, RFSPCs conducted 5 public forums/provider fairs, 3 statewide meetings and 1 Education Day. They also participated in various outreach events. Due to the COVID-19, in-person meetings were cancelled starting March 2020, but RFSPCs continued to host virtual meetings.

During the public health emergency, RFSPCs worked harder to deliver the voice of people with I/DD and their families. When a strict "no accompany" policy was enforced by hospitals, they collected testimonies in collaboration with NJCDD and the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families to advocate for people with I/DD to be allowed to bring a caregiver with them, should they need to be hospitalized. These efforts led to the NJ Department of Health's revision of its Hospital Visitation guidance which requires hospitals to allow certain individuals with disabilities to have a designated support person remain with them if hospitalized.

RFSPC members also actively participated in multiple DD Network Town Hall meetings conducted by NJCDD, The Boggs Center (New Jersey's Center for Excellence) and Disability Rights New Jersey (New Jersey's Protection and Advocacy agency). The RFSPC Chair and NJCDD Executive Director served as Day Program Re-Opening Taskforce members to ensure that the DD community to be included in rapidly changing guidelines and policies.

NJCDD launched an online survey on 5/21/19 for individuals and families focusing on how the fee-for-service (FFS) transition impacted their services. More than 816 respondents participated. The key findings included the following:

- 548 respondents (67.7%) reported they (or their loved ones with disabilities) transitioned to the FFS system. Seventy-seven respondents (9.5%) were not sure.
- 234 respondents (34.1%) experienced reductions or loss of services in the last two years. Goods and services (63 respondents), transportation (28 respondents), and day programs (20 respondents) were the top three reported services impacted.
- 150 respondents (23.3%) reported that their services increased during the last two years.
- Asked if there is a service wanted but not yet obtained, 93 respondents reported goods and services followed by transportation (53 respondents) and direct service professionals (44 respondents).

People First NJ

People First is an international advocacy movement for people with disabilities. NJCDD launched it in New Jersey during 2014. People First is grounded in the philosophy that all people with disabilities are capable and entitled to pursue advocacy on their own terms. People First chapters strive to be as independent as possible, setting their own agendas and maintaining their own network of volunteers and partners.

In New Jersey, People First chapters have been established in seven counties with about 100 self-advocacy members. Chapters are led by advocates with support from Council staff.

NJCDD's People First Coordinator and advocates gave People First New Jersey presentations at schools and community organizations, throughout the pandemic speaking virtually to more than 500 students and community members. People First New Jersey information and resources were disseminated virtually at statewide resource fairs, conferences, and other community events.



Youth Leadership

The NJCDD's Youth Leadership
Project works with schools and
community organizations to
provide leadership and advocacy
training to young adults with
developmental disabilities aged
15 to 25. While attending fun
and engaging training sessions,
these young people develop
valuable skills to become the next
generation of disability advocates.

During eight two-hour sessions, participants hone their advocacy and public speaking skills,

participate in team-building exercises, and develop a better understanding of how government and public policy works.

This year presented additional challenges while moving from face-to-face interaction to a virtual learning environment. Participants used technology during a challenging year to maintain collaborative programs like Road to Independence Success and Employment (RISE).





Grants

NJCDD offers grants each fiscal year to organizations that provide innovative services for people with I/DD. The following grants were active during FY2020:

THE ARC OF NJ TRAINING AND RESOURCES DATABANK

The Arc of NJ developed a bibliography and database of current training and materials for advocates and families. The DD Training Resources (DDRT) provides a centralized location for statewide cognitively accessible training materials.

BEST BUDDIES SUMMER INTERNS

Best Buddies was awarded a contract to deliver a paid summer intern program for students in positions within a wide variety of businesses.

COALITION FOR A DIRECT SUPPORT PROFESSIONAL LIVING WAGE

This project develops a strategic coalition to educate state leaders on the critical role of the direct support professional and create urgency around wages for direct support professionals (DSPs). The project's goal is to achieve a more competitive

COMMUNITY OPTIONS (AUTOBILITY)

Community Options, Inc. received a grant to study the feasibility of using provider agencies vehicles as rideshare services for people with I/DD. The study focused on Northern New Jersey while collaborating primarily with Uber. The study determined that it was cost prohibitive for traditional provider organizations to expand into ridesharing platforms like Uber to effectively serve people with I/DD due to low anticipated ridership and the costs.

SHA HOUSING NAVIGATOR

The Supportive Housing Association of NJ (SHA) received a grant to deliver training for people who support individuals with I/DD seeking supportive housing. Participants received thirty-five hours of housing navigation training over nine weeks.

SPAN-SEVA SPECIAL EDUCATION VOLUNTEER ADVOCATES

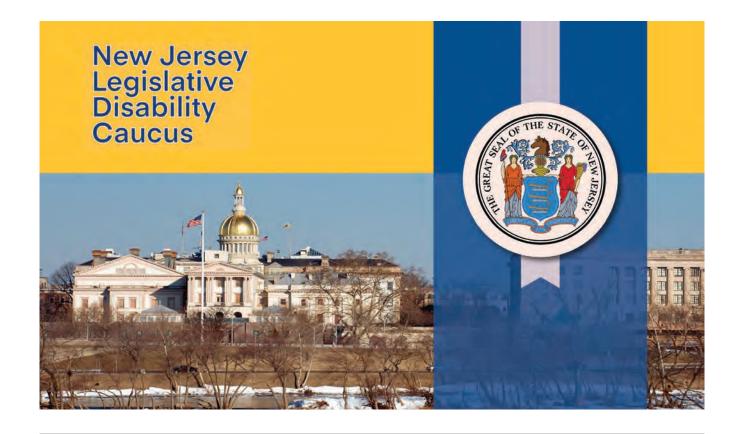
The SPAN Parent Advocacy Network received grant funding to develop Special Education Volunteer Advocates (SEVAs). The program provides trained volunteers to support families during IEP and related meetings, advocacy coaching, and resources for families.

NEW JERSEY LEGISLATIVE DISABILITY CAUCUS

NJCDD retained the services of the Association for Business Solutions (ABS) to expand advocacy on behalf of individuals with I/DD and their families by developing a bipartisan New Jersey Developmental Disability Caucus within the New Jersey Legislature to advance the mission and vision of the NJCDD.

ABS met with Council staff to lay the ground work for the Caucus. Senate President Stephen M. Sweeney (D) agreed to serve as Caucus chair. Bipartisan legislators with documented histories of advocacy for the I/DD community were contacted. Approximately 40 legislators agreed to participate.

The purpose of the caucus is to create a forum for state lawmakers and their staff to become more educated about the complexities of the NJ developmental disabilities system while building a greater understanding of the issues affecting individuals with I/DD and their families in NJ.



Community Innovation Projects

NJCDD awards up to \$10,000 in funding for Community Innovation Projects (CIPs) to encourage innovative activities designed to bring meaningful change. The following organizations were awarded CIPs during FY2020:



THE Arc MERCER TRANSPORTATION

The long-term goal is to replicate the transportation best practices The Arc Mercer has developed across more than 200 agencies funded by the New Jersey Division of Developmental Disabilities. The intent of this project is to leverage The Arc Mercer's five-year effort to transform its transportation capabilities to a more efficient and reliable system.

FINDING YOUR INDIVIDUALITY

The primary goal of this project is to deliver sexuality education with trauma sensitivity for youth and adults with intellectual and developmental disabilities. Programming included content geared towards increasing bodily awareness, building self-esteem, practicing healthy boundary setting, recognizing abuse, exercising rights, and seeking personal safety.

KINDERSMILE ORAL HEALTH PROGRAM

The KinderSmile Oral Health Program "Special Smiles" provides access to dental care and developmentally-appropriate oral health education to individuals with disabilities. This project funded bi-annual program coordinator visits to schools where dental professionals provide age-appropriate oral health education, dental exams, prophylactic cleaning and fluoride varnish. Tooth brushing stations including individually-marked toothbrushes were established at every partnering Special Smiles school. School staff were also trained in daily hygiene protocols.

In House Projects

NJCDD EMERGENCY TECHNOLOGY FUNDING

When the COVID-19 pandemic hit in mid-March of 2020, the impact was immediate among people with disabilities and their families.

In an effort to help get people what they needed during the crisis, the NJCDD authorized \$250,000 in emergency spending for grants up to \$500. Nearly 1,000 applications were submitted, of which approximately 700 applications were approved for funding. To help spread the support as quickly as possible, NJCDD enlisted the support of The Arc of New Jersey by amending a current contract. The Arc of NJ processed the applications and grant awards and, in some instances, expedited the purchases.

Some individuals lacked Internet access, computers or tablets. Family members couldn't keep their loved ones actively engaged without new equipment or recreational/educational supplies. In response, funding was provided for hand-held electronic devices, art supplies, music supplies, Internet access and exercise equipment. Funding was provided for individuals of all ages, living in all parts of the state, from rural to urban. Items were then purchased online and shipped to the families.



Partners in Policymaking

New Jersey Partners in Policymaking is an 8-month leadership development and advocacy education program for adults with developmental disabilities (over age 21) and family members. It is available through a collaboration between NJCDD, The Boggs Center on Developmental Disabilities, and Disability Rights New Jersey.

The goal of this program is to prepare the

next generation of disability advocates to work toward meaningful change in. Participants (Partners) gain knowledge and skills that improve their ability to influence public policy.

Fourteen family members and 11 self-advocates graduated on April 17, 2020. They joined other graduates who continue to advocate for themselves, their families, and people with I/DD.





Education Day: Passing the Torch to Successive Caregivers

NJCDD sponsored an education day in response to the common, but often unaddressed concern of parents: "What should I do to prepare for the day when I become unable to take care of my child with disabilities?" In October 2019, the New Jersey Family Support Planning Council hosted the meeting, Caregiver Succession Planning: How to Pass the Torch Effectively. Parents were encouraged to

attend with their prospective successors. Professionals, individuals, parents and siblings shared their experiences with succession planning.

More than 100 families and their successors attended. The evaluation survey shows overall positive feedback. Ninety-four percent of respondents expressed their desire to attend another Education Day event.



Conferences

NJCDD staff hosted information tables during conferences and events in order to increase awareness about NJCDD programs and resources. The following is a list of some of the conferences attended during FY2020:



Autism NJ Conference



Black Issues Conference







NJ Education Association Conference



NJ Association of Community Providers



NJ League of Municipalities



NJ Self Advocacy Conference

Publications

PEOPLE & FAMILIES MAGAZINE

NJCDD's nationally-recognized quarterly magazine, focusing on issues of importance to New Jersey's developmental disabilities community. Issues highlight public policy, individuals, programs and organizations who make positive contributions to the I/DD community.

A wide range of relevant topics were featured during FY 2020 including Fee-For-Service Self-Directed Models and Assistive Technology. Two issues highlighted the impact of COVID-19 on families and individuals with I/DD, and how they adjusted to the new normal.





COMMON GROUND

Published three times a year, Common Ground features articles about special education, legal and legislative developments that shape the education system. During FY 2020 this online publication continued to provide indepth articles for families, educators and professionals. Topics included culturallycompetent approaches to mental health services, compassion fatigue for teachers, and graduation in the time of COVID. An article highlighting how advocates successfully pushed for legislation (S3434) to extend the age of eligibility for special education services beyond age 21 was also featured. For more information, visit NJCommonGround.org.



ADVOCACY IN ACTION NEWSLETTER

This monthly e-newsletter provides important announcements about NJCDD's programs, grants and initiatives. It also includes key information about public policy, and other news about the developmental disability community.

Issues highlighted a broad range of timely and relevant information during FY 2020 including the work of the Coalition for a DSP Living Wage, national news, NJCDD Community Innovation Projects, NJCDD position statements and a variety of events.

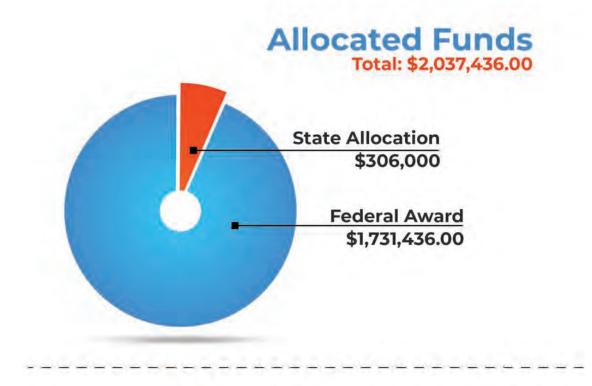


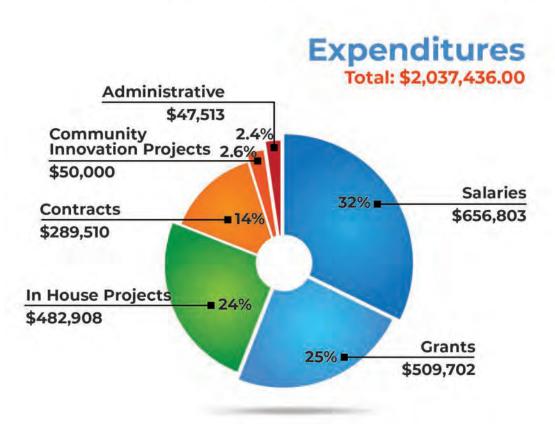
DISABILITY IN FOCUS BLOG

This blog provides valuable first-hand insight on key issues impacting people with development disabilities and their families. Blog writer Jeremy Einbinder examined in depth topics ranging from how societal barriers impact people with disabilities to how COVID-19 disproportionally impacts people with disabilities.

In addition to the above publications, NJCDD produces a number of brochures, fact sheets, and pamphlets highlighting key programs, initiatives and available resources. NJCDD also uses broadcast emails and social media tools to share information and gather valuable feedback. Visit www.njcdd.org to find more information, and to subscribe to our publications.

Fiscal Report





NJCDD Members

Council Members

Paul A. Blaustein, Chairperson Kevin Nunez, Vice Chair

Self-Advocates Members

Todd Emmons Andrew McGeady Myrta Rosa Gary Rubin

Parent, Family Member and Guardian Members

Sarah Aziz Ellie Byra Elizabeth C. Dalzell Walter Fernandez Margaret Kinsell Kara Kushnir Tara Montague Safiyyah Muhammad Helen Steinberg

Council Staff

Mercedes Witowsky, Executive Director
Maria Ali, Graphic Designer/Web
Administrator
Gary Brown, Communication Officer
Kyoko Coco, Regional Family Support
Planning Council Coordinator
Jodi Fox, Chief Fiscal Officer
Gail Hodges, Receptionist
Frank Latham, Youth Leadership Coordinator
Rebekah Novemsky, Family Support Liaison
Robert Titus, Public Policy Coordinator
Jacinta Williams, Administrative Assistant

Public Member

William Testa, Executive Director **The Arc of Morris County**

Federally-Mandated Members

Gwen Orlowski, Executive Director **Disability Rights New Jersey**

Joyce Jelley, Training & Consultation Specialist The Boggs Center on Developmental

Lisa Asare, Assistant Commissioner

Disabilities at Rutgers University

NJ Department of Health, Division of Family Health Services

Dawn Mergen (Designee)

Peri L. Nearon, MPA, Executive Director Department of Human Services, Division of Disability Services

Jacqueline Moskowitz (Designee)

Susan Martz, Assistant Commissioner

NJ Department of Education, Office of Special Education Policy and Dispute Resolution

Kimberly Murray (Designee)

Karen Carroll, Director

NJ Department of Labor, Division of Vocational Rehabilitation Services

David Free (Designee)

Meghan Davey, Director

NJ Department of Human Services, Division of Medical Assistance and Health Services

Phyllis Napier Melendez (Designee)

Jonathan Seifried, Assistant Commissioner

NJ Department of Human Services, Division of Developmental Disabilities

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Advocate Collaborate **Educate**

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