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The Advocates’ Voice

Winter/Spring 2019

2019 Budget Priorities

Governor Cuomo has released his budget for fiscal year 2020. In light of that, we have identified a number of areas that are of concern to us that would impact programs for both children and adults with developmental disabilities. We encourage you to review the information in this issue of *The Advocates’ Voice* and ask you to contact your elected officials in Albany to ask them to support our budget priorities.

We are advocating for a number of issues with regards to the Governor’s proposed budget which are highlighted here:

Funding to cover the next two installments of the **#bFair2DirectCare** payments.

A **2.9%** increase across the board to support cost of living adjustments (COLA) and trends.

Funding increases commensurate to school district increases for both **853** and **4410** non-public schools.

#OurKidsAreYOURKids funding to close the teacher salary gap.

Additional information regarding the **#bFair2DirectCare** and **#OurKidsAreYOURKids** campaigns is provided on page 4 of this issue. For each campaign, we provide some easy steps that you can take to get involved to encourage the Governor and Legislature to support programs for individuals with intellectual and developmental disabilities throughout New York State.

What is the Queens Council on Developmental Disabilities and Why Should You Get Involved?

From the Desk of Lisa Veglia, Chairperson of the QCDD



The QCDD is a membership organization of individuals, parents, family members, self-advocates, and representatives of agencies that serve individuals with developmental disabilities. Most importantly, we are all advocates. We are a voice for positive change and inspiration for all individuals with developmental disabilities, especially for those in our own community here in Queens.

The Council leadership is constantly working to develop new strategies to keep pace with the rapid changes occurring in our service delivery system in order to ensure that the individuals we serve and their families have the information needed to make effective choices for their current and future lives. We continue to sustain partnerships among individuals, families, service provider agencies, schools, other borough councils, and government entities.

The Council serves children and adults with a diagnosis of a wide range of developmental disabilities, which include, but are not limited to, intellectual challenges, cerebral palsy, autism, epilepsy, neurological impairments, and learning disabilities. We are dedicated to assisting and working with their families, caregivers, and loved ones.

Generally, we meet the first Monday of each month from 9:30am to 11:30am from September to June at either Queens Borough Hall on Queens Boulevard or the Queens DDRO/BFDC (see our website for our calendar). I strongly urge you to attend our meetings, and regularly visit our website for updates. You will learn about available programs and meet representatives from provider agencies. You will also find out how legislation may impact you and your loved ones' lives, as well as how you can be an effective advocate.

We frequently have guest speakers who discuss current topics or special services. Representatives from OPWDD, NYC Department of Health and Mental Hygiene, IAC (InterAgency Council), and other government entities regularly attend and provide clarity regarding the evolving changes to services. When you sign-in at meetings, you will be added to our mailing list so that you will be informed about the special events we hold throughout the year.

Our floor is open and your questions are important to us. The Council meetings provide a friendly, supportive environment in which you may ask questions of individuals, providers, and government representatives.

The Council also hosts several events throughout the year that are free for families and may have nominal costs for provider members. Our annual events include our Legislative Breakfast, Family Support Conference, and Celebrating Success.

Parents and family members can join the Council for free. Provider agencies pay low annual dues that help support our events throughout the year. Provider member benefits include:

- List agency name on the QCDD website
- "Membership" discounts for QCDD events (e.g. Family Support Conference)
- Voting rights on QCDD leadership (agency must have participated in at least three general meetings for the year)
- Choice of various subcommittees to attend from multiple service areas
- Involvement and information on policy and advocacy initiatives

Learn more about the QCDD by going to our website at www.QCDDNY.org. Be sure to like QCDD on Facebook and follow us on Twitter. Please see the last page of this newsletter for upcoming Council and Committee dates as well as special events.

We look forward to seeing you!

Governor Cuomo Nominates New Commissioner for OPWDD



The Queens Council on Developmental Disabilities (QCDD) congratulates Dr. Theodore Kastner on being nominated by Governor Cuomo as the new Commissioner for the Office of People with Developmental Disabilities (OPWDD). Dr. Kastner has worked in the field for more than 40 years. He started his career in 1976 as a Direct Support Professional with the Massachusetts Association for the Blind and Visually Impaired.

Prior to his nomination, Dr. Kastner served as the founder and president of the Developmental Disabilities Health Alliance (DDHA) and as the Co-Director of the Rose F. Kennedy Center of the Albert Einstein College of Medicine in the Bronx. In addition to these duties, Dr. Kastner served as Professor of Pediatrics and Professor of Psychiatry and Behavioral Sciences at the Albert Einstein School of Medicine where he also held the Ruth I. Gottesman Chair in Developmental Pediatrics.

Dr. Kastner has served as a consultant to numerous national organizations and agencies, including the U.S. Department of Justice. He has presented at over 200 conferences and training workshops around the country and authored more than 100 publications in the field of intellectual and developmental disabilities.

His research interests are in primary health care, mental health, managed care, and public policy issues. Dr. Kastner has been a member of numerous professional groups in the field of developmental disabilities including a member of the national board of directors of the American Association on Intellectual and Developmental Disabilities (AAIDD). He is the recipient of numerous awards and honors, including the Elizabeth M. Boggs Citizenship Award from United Cerebral Palsy Associations of New Jersey and a Leadership Award from the American Medical Association.

Dr. Kastner earned his medical degree from the University of Connecticut School of Medicine and earned a Master of Science in population health from the University of Wisconsin. Dr. Kastner is board-certified by the American Board of Pediatrics in Pediatrics, Developmental and Behavioral Pediatrics, and Neurodevelopmental Disabilities and by the American Association for Physician Leadership as a Certified Physician Executive.

The leadership and members of QCDD look forward to working with Dr. Kastner as we seek to ensure that all individuals with intellectual and developmental disabilities have access to the supports needed to achieve greater independence and realize their full potential.

Save The Date

QCDD Legislative Breakfast
Friday, March 8, 2019 at 8:30am

Celebrating Success
Tuesday, April 16, 2019 at 6:00pm

your voice MAKES A DIFFERENCE

Budget Priorities

Office of People with Developmental Disabilities (OPWDD)

1. #bFair2DirectCare: Continue to invest in a Living Wage for Direct Support Professionals by adding the next two installments of the six installment plan. Phase three funding for CFR code positions 100, 200 and 300 to be available on 4/1/19 and phase four funding to be available starting 1/1/20.
2. Strong NONPROFITS for a Better New York: Restore the 2.9% COLA for all Human Services.
3. Create a fund to supplement payments for high needs individuals currently receiving services.
4. Double the \$15M in the Governor's budget proposal for the capital cost of affordable housing for people with I/DD to \$30M.
5. Designate \$20M of \$120M (all shares, fully annualized) for certified residential opportunities for people with complex needs currently living at home with families.



#bFair
2DirectCare

State Education Department (SED)

1. Insure that every student in 4410 and 853 schools has a certified special education teacher by increasing the teacher recruitment and retention fund by \$15M to \$23M.
2. Provide a minimum tuition increases for 4410 & 853's comparable to the State Aid general education increase of 3.6%.
3. Permit 4410 and 853 schools to receive rate increases while they are awaiting rate approval from SED (include interim plus rates bill language in the enacted budget).
4. Cap County preschool costs at current levels.
5. In response to the blanket waiver on special education requirements in the Governor's proposal, convene a workgroup to examine special education waivers that would preserve quality educational services for children with disabilities while producing cost savings.
6. Require SED to collect and publish teacher and teacher assistant vacancy and turnover data.
7. Support the Regent's proposal to create a special education and related services data system within SED.

Department of Health (DOH)

1. 5% across the board Early Intervention increase.
2. Include language requiring a covered lives assessment from insurance companies to revitalize the Early Intervention program and eliminate the commercial insurance billing, claiming, denials and appeals currently managed by providers.
3. Promote financial stability of Clinics for people with I/DD:
 - a. Increase the base rate increase for Article 16 clinics
 - b. Increase the APG add on for patient codes 95 and 81 utilizing article 28 clinics from 20% to 30%
 - c. Require MC plans to pay the APG plus add on rate for patient codes 95 & 81
4. Oppose CDPAP changes.
5. Maintain prescriber prevails.
6. Maintain spousal/parental refusal.
7. Eliminate Medicare Part B Cost Sharing Proposal.



QCDD Annual Family Support Conference was a Huge Success

The annual QCDD Family Support Conference this past October 2018 was a booming success. Dozens of vendors presented their services and available networking opportunities to caregivers and individuals. Participation in available workshops throughout the day was high and enthusiastic. Topics included Front Door in English, Spanish, and Mandarin, Benefits and Entitlements, and Self-Direction from Start to Finish.

This year, we honored Janice Silber with the Beverly Berger Family Advocate Award and Kristi Hickey-Vigilante with the QCDD June Marcus Award. For our keynote presentation, we had leadership from the downstate CCOs including ACANY, Care Design NY, and TriCounty Care.



Keynote Speakers (L to R): James Moran of Care Design, Jackie Spring of Tri-County Care, and Jay Nagy of ACANY.



June Marcus Award



Beverly Berger Family Advocate Award

Medicaid Alert: New Client ID Benefit Card

This is to inform providers, client representatives, hospitals, certified health agencies, and community based organizations that a newly designed Client Identification Benefit Card is available as of August 1, 2016.

Existing cards remain valid. Mailed cards will continue to be produced using current CBIC stock until it is depleted. There will be no mass mailing to replace current cards.



NYC Fair: Family Advocacy and Information Resource



Introducing NYC Fair, NYC Family Advocacy and Information Resource: we are a group of family members from throughout New York City with diverse needs, but with one common problem —New York State is undoing the services we depend on.

We follow the news, what changes are being made, what the budget means for us this year, and all the things that make a difference in our lives. We invite you to participate. Check out our website at www.nycfair.org, Facebook page, and group, and come to our meetings.

Free Psychological and Psychosocial Evaluations

Available in Queens for individuals **without** Medicaid.

All OPWDD services **require** evaluations to determine eligibility for services. This is an excellent opportunity to get FREE and necessary evaluations. Visit www.OPWDD.NY.gov for more information on requirements.

General Human Outreach: (718) 307-6563
New York State Institute on Disability: (718) 494-6457
WellLife Network: (718) 559-0516
QSAC: (718) 728-8476, ext. 1512
YAI: (212) 273-6182

ACCESS NYC



ACCESS NYC is a free service that helps you out if you qualify for over 30 City, State, and Federal benefit programs. You can apply online for certain programs through ACCESS NYC.

To learn more, visit the NYC Mayor's Office for People with Developmental Disabilities online at www.nyc.gov/MOPD.

QCDD Winter/Spring 2019 Calendar of Events

See our website for additional details and updates (www.QCDDNY.org).



March 2019

- March 8, 2019: **Legislative Breakfast at 8:30am at Queens College, 65-30 Kissena Blvd., Flushing, NY 11367**
- March 12, 2019: Children's Committee Meeting at 9:30am at QCP Jamaica, 81-15 164th Street, 2nd Fl, Jamaica NY 11432
- March 13, 2019: Adult Transition Committee at 9:30am at P752Q, 142-10 Linden Blvd, Jamaica, NY 11758

April 2019

- April 1, 2019: QCDD Full Council at 9:30am at Bernard Fineson DDRO, 80-45 Winchester Blvd., Queens Village, NY 11428
- April 16, 2019: **Celebrating Success at 6:00pm at QCP Jamaica, 81-15 164th Street, Jamaica, NY 11432**
- April 17, 2019: Adult Transition Committee at 9:30am at QCP Jamaica, 81-15 164th Street, Jamaica, NY 11432
- April 18, 2019: Residential Committee at 9:30am at YAI Hollis IRA, 82-24 209th St., Hollis, NY 11427

May 2019

- May 6, 2019: QCDD Full Council at 9:30am at Bernard Fineson DDRO, 80-45 Winchester Blvd., Queens Village, NY 11428
- May 9, 2019: Care Management Committee at 930am at QSAC Astoria Office, 25-09 Broadway, Astoria, NY 11106
- May 15, 2019: Adult Transition Committee at 9:30am at QCP Bellerose, 249-16 Grand Central Parkway, Bellerose, NY 11426
- May 22, 2019: Family and Community Support Committee at 9:30am at Bernard Fineson DDRO, 80-45 Winchester Blvd., Queens Village, NY 11428

June 2019

- June 3, 2019: QCDD Full Council at 9:30am at Bernard Fineson DDRO, 80-45 Winchester Blvd., Queens Village, NY 11428
- June 11, 2019: Care Management Committee at 930am at QCP Jamaica, 81-15 164th Street, 2nd Fl, Jamaica NY 11432

Important Phone Numbers

Developmental Disabilities Regional Offices (DDROs)

Region 4 NYC and Metropolitan Area

Bronx	(718) 430-0885
Brooklyn	(718) 642-6000
Manhattan	(646) 766-3222
Queens	(718) 217-5890
Staten Island	(718) 983-5233

Area Developmental Disabilities Councils

Bronx Developmental Disabilities Council	(718) 231-7711
Brooklyn Developmental Disabilities Council	(718) 642-6000
Manhattan Developmental Disabilities Council	(212) 799-2042
Staten Island Developmental Disabilities Council	(718) 983-5276

Government Numbers

Medicaid Office	(800) 505-5678
NYC Medicaid Card Replacement	(718) 557-1399
NYC Medicaid Training	(929) 221-0868
NYS OPWDD Revenue Support	(646) 766-3472
SNAP F61/S61 Unit	(718) 722-4817
Social Security Administration	(800) 772-1213

Queens Front Door

(718) 217-6485

QCDD Subcommittees

Queens Council on Developmental Disabilities Subcommittee Chairs

Care Management Subcommittee

Dorothy Wohl, Advance Care Alliance, (Phone) (646) 868-0175 (Email) dorothy.wohl@myacany.org

Children's Subcommittee

Cathy Warkala, ECDC, (Phone) (718) 215-1299 (Email) cwarkala@queenscp.org
 Dana Decolator, (Phone) (718) 441-5333 (Email) dana.decolator@heartshare.org
 Nina Roberto, Parent, (Phone) (718) 846-6606 (Email) nroberto@praderwilli.org

Adult Transition Services Subcommittee

Josephine Davide, QCP, (Phone) (718) 380-3000 x363 (Email) jdavide@queenscp.org
 Wendy Schoenfeld, Lifespire, (Phone) (212) 741-0100 x4575 (Email) wschoenfeld@lifespire.org
 Sheila Mastrangelo, Parent, (Phone) (718) 357-3851 (Email) sheila169@verizon.net

Family and Community Support Subcommittee

Karlene Dambreville, Able Health Care, (Phone) (718) 779-7000
 Pat Liu, GHO, (Phone) (718) 307-6563 (Email) pat@ghoinc.org

Legislative and Public Information Subcommittee

Jim Karpe, Parent, (Phone) (516) 655-2713 (Email) karpe.jim@gmail.com
 Eric Fenton, Nassau CP, (Phone) (516) 378-2000 x272 (Email) efenton@cpnassau.org
 Pat Barrientos, QSAC, (Phone) (212) 244-5560 x2015 (Email) pbarrientos@qsac.com
 Gnanendra Sinha, AABR, (Phone) (718) 321-3800 x245 (Email) gsinha@aabr.org

Residential Subcommittee

Brien Cummings, YAI/NIPD, (Phone) (212) 273-6100 x2528 (Email) brien.cummings@yai.org
 Linda Renyi, Life's WORC, (Phone) (516) 741-9000 x8120, (Email) lrenyi@lifesworc.org
 Joanne Buccellato, Parent, (Phone) (718) 347-0185 (Email) trajanj@verizon.net

FSS Conference Planning

Jay Kleinman, Lifespire, (Phone) (718) 454-6940 (Email) jkleinman@lifespire.org
 Toni Martinez, YAI, (Phone) (212) 273-6100 x2376 (Email) toni.martinez@yai.org

Disability Information Websites

A.D.D. Warehouse

www.addwarehouse.com

American Association on ID/DD

www.aamr.org

American Foundation for the Blind

www.afb.org

American Speech Language Hearing Association

www.asha.org

The Arc

www.thearc.org

Attention Deficit Disorder Association

www.add.org

Augmentative Communication Centers

www.aac.unl.edu

Autism Resources

www.autism-resources.com

Autism Society of America

www.autism-society.com

Autism Speaks

www.autismspeaks.org

Best Buddies

www.bestbuddies.org

Developmental Disabilities Resources

www.ddhealthinfo.org

Down Syndrome: Health Issues

www.ds-heath.com

Brain Injury Association of America

www.biausa.org

Cerebral Palsy Guidance

www.cerebralpalsyguidance.com

Cerebral Palsy Guide

www.cerebralpalsyguide.com

Epilepsy Foundation of America

www.epilepsyfoundation.org

Helen Keller Center for Deaf-Blind

www.hknc.org

International Dyslexia Association

www.interdys.org

LD Online

www.ldonline.org

Lighthouse International

www.lighthouse.org

National Association of the Deaf

www.nad.org

National Center on Birth Defects & DD

www.cdc.gov/ncbddd/autism/actearly

National Down Syndrome Society

www.ndss.org

NIH—Rare Diseases

www.rarediseases.info.nih.gov

National Resource Center on AD/HD

www.help4adhd.org

Prader-Willi California Foundation

www.pwcf.org

Presidents Committee for People with ID

www.acf.hhs.gov/programs/pcpid

Special Olympics

www.specialolympics.org

Spina Bifida Association of America

www.spinabifida.org

Tourette Syndrome Association

www.tsa-usa.org

Useful Websites

- NYS Department of Health— www.health.ny.gov
- Medicare Questions—www.medicare.gov or call 1-800-MEDICARE
- Medicaid or MBI (Medicaid Buy-In) Questions—health.ny.gov/health_care/medicaid or health.ny.gov/health_care/medicaid/program/buy_in
- Social Security Questions—www.socialsecurity.gov
- Estimate your future social security retirement benefits—www.socialsecurity.gov/estimator
- My Social Security Account to view social security statement online — www.socialsecurity.gov/myaccount
- OPWDD Questions—www.opwdd.ny.gov
- NYC, NYS Benefit Program, or Access NYC Questions—nyc.gov or mybenefits.ny.gov
- Affordable Care Act (ACA) Questions—nystateofhealth.ny.gov

Care Coordination Organizations Serving New York City

- ACANY—www.advancecarealliance.org
- Care Design—www.caredesignny.org
- Tri-County Care—www.tricountycare.org

Important Family/Caregiver Resources

Are you the parent/caregiver of a person with an intellectual/developmental disability (I/DD)? Do you know where you can get information about educational, medical, recreational, behavioral services and others? Below you will find the names and contact information for organizations that can offer information and/or referrals to guide your through the various service systems.

Office of Persons with Developmental Disabilities (OPWDD): The State agency that provides services and supports for persons with I/DD. Contact information for your local Developmental Disabilities Regional Office (DDRO) can be found at: https://opwdd.ny.gov/opwdd_contacts/ddsoo or call 1-(866)-946-9733. To keep up-to-date on services and changes and offer your input, it is important to sign up for their email list by going to: <https://opwdd.ny.gov/opwdd-email-distribution-list>.

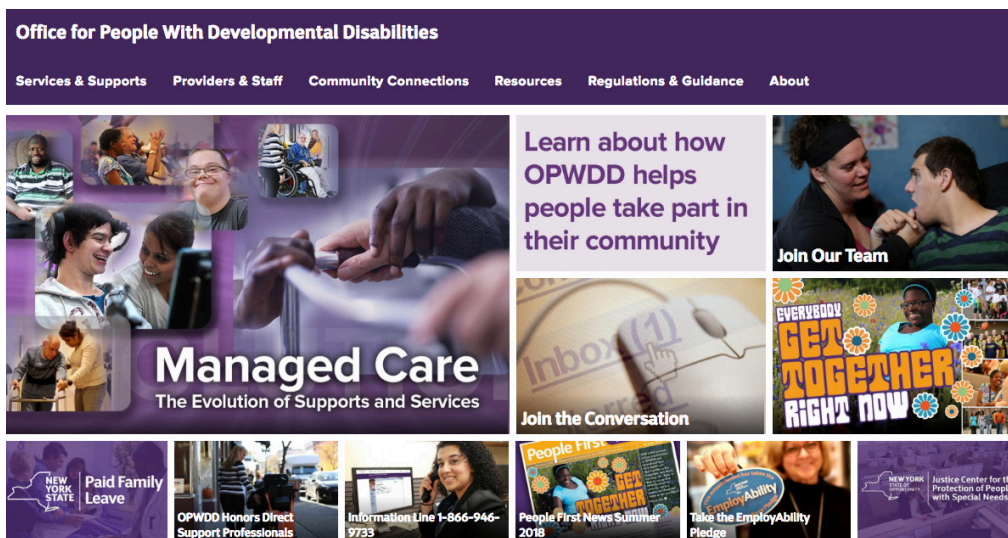
NYC Family Advocacy and Information Resource (NYCFair), This organization provides information in a parent friendly manner. They work with other agencies to follow service changes and make our voices heard at City and State levels. Contact information is: <http://www.nycfamilyadvocacyinformationresource.org/> or email: info@nycfair.org or NYCFAIR@gmail.com or call Elly Rufer 917-833-4738 or “LIKE” them on FACEBOOK: www.facebook.com/nycfair.

Parent Training Information Centers (PTICs): Advocacy agencies in the down state area providing information, referral & assistance to families for persons birth to 26 years on educational, recreational and other services. There are 4 PTIC’s and one Community Parent Resource Center (CPRC). Their web sites and phone numbers can be found at <http://www.nysparentnetwork.org/about-the-network.html>.

Residential Information and Opportunities: The types of residences that are available and what is needed to get into a residence can be found at: https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/housing_options and https://opwdd.ny.gov/opwdd_services_supports/residential_opportunities/Residential_Support_Categories. You need to be sure your family member is on OPWDD’s Certified Residential Opportunities registry list and know in what category they are on the registry.

Sign up for email updates from OPWDD online at: <https://opwdd.ny.gov/jointheconversation>

Be sure to visit OPWDD’s website for regular updates and news related to Managed Care and other issues. OPWDD’s website is www.opwdd.ny.gov and here’s a screenshot of the website’s main page:



About SWAN (Statewide Advocacy Network of New York)

The State-Wide Family Advocacy Network of New York State (SWAN of NYS) is dedicated to advocating for individuals with Intellectual and Developmental Disabilities. We are an independent coalition of families and guardians of people with Intellectual and Developmental Disabilities. Caring for our loved ones is our life-long commitment.



We have come together from across New York State. We are the parents and families of children with developmental disabilities. We were there at the start, and we are not going away.

We are independent of any government or private agency. We are committed to a constructive, cooperative effort with all parties wishing to improve the lives of our loved ones, the citizens with disabilities of New York State. We welcome you to join our coalition!

You can learn more about SWAN of New York and sign-up to receive updates from them online at:

<http://swannys.org/join-in/>.

About Family Support Services Coordinators and FSS Advisory Councils

Family Support Services Coordinators are available at each of OPWDD's Developmental Disabilities Regional Offices (DDROs) to help families access Family Support Services. DDROs work with local community agencies to ensure that family support services for people with developmental disabilities and their loved ones are available when and where they are needed. These services may include: information and referral, family and individual counseling, family-member training, after-school programs, transportation, sibling services, support groups and service coordination.

Nineteen local FSS Advisory Councils made up of individuals with developmental disabilities and family members plan, coordinate and monitor the delivery of FSS across the state. In addition, a Statewide FSS Committee made up of one representative from each of the nineteen local FSS Advisory Councils advises OPWDD regarding families' support needs and the design, implementation and monitoring of FSS. The Statewide FSS Committee is a committee of the Developmental Disabilities Advisory Council (DDAC), a standing advisory body, established by New York State law, that has the ongoing responsibility to advise OPWDD in its development of its comprehensive state plan and on the ongoing improvement, policies, goals, budgets and operations of the developmental disabilities services system. To get in touch with your local advisory council or to learn more about the Statewide FSS Committee, contact your Family Support Services Coordinator or the Statewide FSS Committee Coordinator.

Family Support Coordinators for Queens County:

Bernard M. Fineson DDRO (Queens County)

Robyn Mooney

robyn.mooney@opwdd.ny.gov

Telephone 718-217-6027

Fax 718-217-2176

Vilma Gilling

vilma.gilling@opwdd.ny.gov

Telephone 718-217-6802

Fax 718-217-4009