



Lisa Veglia
Chairperson - Provider
QSAC
253 West 35th Street, 16th Floor
New York, NY 10001
(212) 244-5560 ext. 2017
Lveglia@qsac.com

Aliya Hussein
Chairperson - Parent
P.O. Box 660043
Fresh Meadows, NY 11366
(718) 591-0978
helloaliya@hotmail.com

Mary Knox
Vice-Chairperson - Provider
HHCS
882 3rd Ave., Suite 10-2
Brooklyn, NY 11232
(718) 788-5252 ext. 130
mknowx@hhsny.org

Jim Karpe
Vice Chairperson - Parent
P.O. Box 15-0006
Kew Gardens, NY 11415
Karpe.jim@gmail.com

THE ADVOCATES' VOICE

Calling for Justice, Respect, and Quality of Life

Spring 2017

QCDD NYS Budget Position 2017-2018 #bFair2DirectCare

OPWDD

- Include \$45 million to allow non-profit providers to begin to increase salaries for direct support professionals and other lower paid staff over a six year period to a living wage
- Support the Governor's proposal adding funds for the development of new services and supports but add \$25 million in additional funding for the development of residential supports for 2000 people with high priority needs who reside at home and need 24 hour residential support
- Include funds for a COLA/Trend for OPWDD services based on the Rate of Medical Inflation rather than the Consumer Price Index

SPECIAL EDUCATION

- Include \$18 million to allow 853 schools and 4410 preschool providers to increase salaries for certified teachers so that they can attract and retain enough qualified teachers to provide federally mandated FAPE to children with the most significant disabilities
- Include a 4% tuition increase for the 2017/18 school year for classroom based 4410 pre-schools and 853 school age special education approved programs
- Additional UPK seats

DEPARTMENT OF HEALTH: EARLY INTERVENTION PROGRAM &

ARTICLE 16 CLINICS

- Include a 4% increase in the Early Intervention Program reimbursement rates
- Support the Governor's proposal to increase insurance company participation in the Early Intervention program except the requirement that providers appeal rejected insurance claims

Check WWW.QCDDNY.ORG
for updated information on QCDD activities

Your Child is Entitled to SSI

Charlie Hope, Revenue/Entitlement Manager at QCP

Caregivers and service providers must carefully research entitlement program choices to ensure their child receives maximum medical, dental, and ancillary benefits. While schools are often a great resource, they may not always be able to provide for specific needs (diapers, camps, respite, sensory items, etc.). Medicaid and Supplemental Income (collectively known as SSI) provided by the Social Security Administration is one way caregivers can attain additional financial support.

Before applying, caregivers are encouraged to either read about Supplemental Security Income on www.ssa.gov or to seek the assistance of a trained Benefit Specialist, to ensure the costs/benefits/requirements all meet their individual circumstances and needs. Once the benefit program is understood, caregivers can apply for SSI at a Social Security Office, over the phone, or through a requested field visit (provided the child applying for SSI has a medical/physical/psychological condition preventing them from attending the office).

Eligibility for SSI is based on the child's caregivers' monthly income, resources (excluding expenditures such as ancillary services and items purchased not covered by Medicaid). Once all documentation is prepared, caregivers can phone their local SSA office at 1-800-772-1213 to arrange an appointment. The SSA requires the following documentation to apply for SSI:

- The child must be under 18 years of age
- The child must have a disability: a medically determinable or physical/mental impairment, which results in marked and severe functional limitations expected to last at least 12 months
- Psychological, psychosocial, and medical evaluations dated within 1 year of SSA application
 - It is recommended that all doctors/clinicians who have evaluated child sign release forms
 - If no psychological evaluation exists, Article 16 Clinics in the Queens area will provide free evaluations. Bernard Fineson DDSO (718-217-6485) will also help caregivers locate a local program.
 - It is **not** advised to only use Department of Education evaluations or to wait for the SSA Disability Review Department to assign an appointment. In order to assure the best services are provided, it is recommended to use as many physicians and clinicians who are already familiar with the child's history
- The following ID/income verification:
 - The child's birth certificate
 - The child's social security card
 - Income verification (pay stubs, W2, and/or bank statements)
 - Insurance policies for all members of the household

The resource limit for a couple is \$3000 and for a single caregiver, \$2000. Income is calculated comparing the number of individuals in the household against household expenditures and medical expenses. For the most accurate calculation, it is recommended that caregivers obtain therapy plans from each clinician/doctor the child's sees, in order to ensure a precise calculation of expenditures (cost of services, prescriptions, additional therapy needs, etc.). All services the child receives should be included, even those that are not an out-of-pocket expense (i.e. therapy paid for by the DOE or the caregivers' insurance). It's important to note that private/commercial insurance can coexist with Medicaid coverage—caregivers need not drop one to obtain the other.

The entire review process usually takes approximately six months. However, a new SSA initiative—called the Presumptive Eligibility Disability Process—allows the applying child to receive benefits 30-60 days after the initial interview, if all medical/psychological/income verification documents are presented during the initial interview. After the initial interview, the Human Resource Administration will send the caregiver a notice asking if they want to enroll in a Medicaid Managed Care program. It is vital the caregiver determine if their child currently participates in an OPWDD program, because certain Medicaid Managed Care programs do not cover OPWDD services. An alternative option is a new Medicaid Managed Care insurance plan (still currently a pilot program), which offers select programs; however, it may not provide the specific services the applying child needs. If SSI is denied after the six month review process, any early funds received through the Presumptive Eligibility Disability Process do not need to be repaid. Caregivers can challenge the denial by applying for a Reconsideration or Fair Hearing. It is also important to note that a caregiver cannot be told their child is ineligible through a phone interview. Everyone has a right to the full application (and reconsideration) process.

**Check WWW.QCDDDNY.ORG
for updated information on QCDD activities**

QCDD ANNUAL FAMILY SUPPORT CONFERENCE

The annual QCDD Family Support Conference this past October 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 ranging from Navigating Across Systems to Bullying Prevention to Benefits and Entitlements were highly attended. Ann Hardiman, Executive Director at NYSACRA, gave a keynote speech before the presentation of the June Marcus Award. Dr. Julian Bower was presented with the award, for his tremendous contribution to the I/DD Community.



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 8/1/16. Existing cards remain valid. Mailed cards will continue to be produced using current CBIC's stock until it is depleted. There will be no mass mailing to replace current cards.



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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 an 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, and governmental entities.

The Queens Council on Developmental Disabilities 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.

We generally meet the first Monday of each month from 9:30-11:30am from September to June at Queens Borough Hall on Queens Boulevard or at 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, and other governmental entities regularly attend and provide much clarity to 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 or providers.

But don't just take my word for it – here are some comments attending parents have to say:

I come to the Queens Council on Developmental Disabilities monthly meetings to get information, find out what's new and what is going on.
-Prudence Robinson, parent

Before coming to the meetings I did not know what was out there to help my daughter. I get a lot of information at the meetings.
-Elizabeth Sahaan, parent

[I attend because] I would like to learn how I can help my son and find different options for him.
-Silvia Giraldo, parent

Learn more about the QCDD by going to our website: www.qcddny.org. Like us on Facebook. 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!



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Beverly Berger *In memorium*

It is with deepest regret that the Queens Council on Developmental Disabilities mourns the passing of Beverly Berger – devoted parent, fearless advocate, and dedicated member of the Council. Ms. Berger, who passed away on February 18th, served on the Council in a variety of capacities throughout the past decades. She was a champion of the achievements and potential of individuals with developmental disabilities, especially the positive impacts they have on their community. She will be greatly missed by all members of the Queens Council and the individuals we serve.



QCDD Sub Committees

See page 7 for meeting dates & calendar

Medicaid Service Coordination Sub-Committee:

Karline Dambreville, AABR (P) 718-321-3800 x229 (E) kdambreville@aabr.org
Toni Cassara Martinez, Heaven's Hands (P) 718-788-5252 x114 (E) amartinez@hhcsny.org
Jessica Paravalos, (P) 347-287-7107 (E) mintjoy@juno.com

Children's Sub-Committee:

Dianne Catrano, Heartshare (P) 718-441-5333 x1401 (E) dianne.catrano@heartshare.org
Jean Steins, St. Mary's Hospital for Children (P) 718-281-8848 (E) jsteins@stmaryskids.org
Nina Roberto, Parent (P) 718-846-6606 (E) nroberto@praderwilli.org

Adult Transition Services Sub-Committee:

Josephine Davide, QCP (P) 718-380-3000 x363 (E) jdavide@queenscp.org
Wendy Schoenfeld, Lifespire (P) 212-741-0100 x4575 (E) wschoenfeld@lifespire.org
Kerbanoo D'Rozario, Parent (P) 917-371-4441 (E) artychef@aol.com

Family & Community Support Sub-Committee:

Gnanendra Sinha, AABR (P) 718-321-3800 x2245 (E) gsinha@aabr.org
Dorothy Wohl, Shield Institute (P) 718-939-8700 x1242 (E) dwohl@shield.org

Public Information / Legislative Sub-Committee:

Jim Karpe, Parent (P) 516-655-2713 (E) karpe.jim@gmail.com
Eric Fenton, Birch Family Services (P) 347-714-0083 (E) eric.fenton@birchfamilyservices.org
Pat Barrientos, QSAC (P) 212-244-5560 x2015 (E) pbarrientos@qsac.com

Residential Sub-Committee:

Brien Cummings, YAI/NIPD (P) 212-273-6100 x2528 (E) brien.cummings@yai.org
Linda Renyi, Life's WORC (P) 516-741-9000 x271 (E) lrenyi@lifesworc.org

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NYC FAIR
Family Advocacy & 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: www.nycfair.org, Facebook Page & Group, and come to our meetings.

FREE Psychological & 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 <https://www.opwdd.ny.gov/> for more information on requirements.**

- General Human Outreach:** (718) 307-6563
- Lifespire** , Kimberly Reynolds: (718) 454-6940 ext. 246
- New York State Institute on Disability:** (718) 494-6457
- PSCH:** (718) 777-5243
- QSAC,** Dr. Kristen DuMoulin: (P) 718-728-8476 ext. 1517;
(E) KDuMoulin@qsac.com



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

**Visit the NYV Mayor’s Office for People with Disabilities
at www.nyc.gov/mopd**

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Important Numbers

Developmental Disabilities Regional Offices (DDROs)

Region 4 NYC & Metropolitan Area

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

Government Numbers

Medicaid Choice	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

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

Queens Front Door

718-217-6485

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

- 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

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QCDD 2016-2017 Committee Meetings

SEPTEMBER

9/19/2016 9:30 AM QCDD Full Council Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428

OCTOBER

10/5/2016 9:30 AM Adult Transition Committee Lifespire, 87-21 121st St., Richmond Hill, NY
 10/13/2016 9:30 AM Children's Committee Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428
 10/20/2016 10:00 AM MSC Committee Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428
 10/28/2016 8:30 AM QCDD Family Support Conference Flushing Sheraton Hotel, 135-20 39th Ave., Flushing, NY 11354

NOVEMBER

11/7/2016 9:30 AM QCDD Full Council Queens Borough Hall—Rm. 200, 120-55 Queens Blvd., Kew Gardens, NY 11424
 11/10/2016 10:00 AM Family & Community Support BF DDRO—Rm. 2014A, 80-45 Winchester Blvd. Queens Village, NY 11428
 11/16/2016 9:30 AM Adult Transition Committee Heaven's Hands, 69-21 164th St., Suite 10, Flushing, NY 11365
 11/16/2016 9:30 AM Residential Committee YAI Hollis Hills IRA, 82-24 209th St., Hollis, NY 11427

DECEMBER

12/5/2016 9:30 AM QCDD Full Council Queens Borough Hall - Rm. 200, 120-55 Queens Blvd., Kew Gardens, NY 11424
 12/8/2016 10:00 AM MSC Committee Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428

JANUARY

1/9/2017 9:30 AM QCDD Full Council Queens Borough Hall - Rm. 200, 120-55 Queens Blvd., Kew Gardens, NY 11424
 1/18/2017 9:30 AM Adult Transition Committee YAI, 211-11 Northern Blvd., Bayside, NY 11361
 1/19/2017 9:30 AM Children's Committee QCP, 81-15 164th St., Jamaica, NY 11432

FEBRUARY

2/6/2017 9:30 AM QCDD Full Council Queens Borough Hall - Rm. 200, 120-55 Queens Blvd., Kew Gardens, NY 11424
 2/9/2017 10:00 AM Family & Community Support Bernard Fineson DDRO, 80-45 Winchester Blvd., Queens, NY 11428
 2/15/2017 9:30 AM Residential Committee YAI Hollis Hills IRA, 82-24 209th St., Hollis, NY 11427
 2/16/2017 10:00 AM MSC Committee Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428

MARCH

3/3/2017 8:30 AM Legislative Breakfast Queens College, 65-30 Kissena Blvd., Flushing, NY 11367
 3/6/2017 9:30 AM QCDD Full Council Queens Borough Hall - Rm. 200, 120-55 Queens Blvd., Kew Gardens, NY 11424
 3/15/2017 9:30 AM Adult Transition Committee PS 752 Q, 142-10 Linden Blvd., Jamaica, NY 11758
 3/16/2017 9:30 AM Children's Committee QSAC Preschool., 245-37 60th Ave., Douglaston, NY 11362

APRIL

4/3/2017 9:30AM QCDD Full Council Queens Borough Hall - Rm. 200, 120-55 Queens Blvd., Kew Gardens, NY 11424
 4/19/2017 9:30 AM MSC & Adult Transition Joint Mtg QCP, 81-15 164th St., Jamaica, NY 11432
 4/21/2017 9:30 AM Children's Committee Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428
 4/25/2017 6:00 PM Celebrating Success QCP, 81-15 164th St., Jamaica, NY 11432
 4/26/2017 9:30 AM Residential Committee YAI Hollis Hills IRA, 82-24 209th St., Hollis, NY 11427

MAY

5/1/2017 9:30 AM QCDD Full Council Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428
 5/11/2017 10:00 AM Family & Community Support TBD
 5/17/2017 9:30 AM Adult Transition Committee QCP - Bellerose, 249-16 Grand Central Pkwy, Bellerose, NY 11426
 5/18/2017 9:30 AM Children's Committee Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428

JUNE

6/5/2017 9:30 AM QCDD Full Council Bernard Fineson DDRO, 80-45 Winchester Blvd. Queens Village, NY 11428
 6/14/2017 9:30 AM Adult Transition Committee Luncheon TBD

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