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# THE ADVOCATES' VOICE

Calling for Justice, Respect and Quality of Life Fall 2016

## ADVOCACY FOR OUR DIRECT SUPPORT PROFESSIONALS (DSPs)

QCDD will be participating in a statewide effort addressing DSP salaries, and the alarming staff vacancy and turnover rates in our industry; both in our OPWDD and education programs.

Not-for-profit OPWDD funded provider agencies deliver approximately 85% of the day-to-day services to the 130,000 people with developmental disabilities in NYS. Stabilization funding is necessary to help these organizations provide a living wage for their tens of thousands of professional direct care staff (DSPs) and other support staff. More than 90 percent of the funding comes from government to pay salaries for staff who care for New Yorkers with intellectual/developmental disabilities. DSP's have the most important jobs at our organizations. The current low wages have led to a crisis in attracting and retaining staff, destabilizing the workforce and threatening the ability to sustain the supports people with disabilities and their families require.

Caring for people with complex needs is a rewarding yet challenging job that requires high levels of responsibility and skill. Years of government funding freezes and sparse increases mean our employees no longer earn a living wage. We were once an employer of choice and now we cannot compete with fast food restaurants and big box stores. New York State has begun to provide funding to transition employees who work with people with developmental disabilities up to the new minimum wage and this phase-in funding must be continued and included in subsequent state budgets, but these are not minimum wage jobs!

To address the high vacancy and turnover rates for professional direct care and other support staff, government not-for-profit provider stabilization funding is needed to transition these staff to an hourly living wage that exceeds the minimum wage over the next six years. When the stabilization funding is fully implemented, average salaries will be \$17.72 in the NYC/ Long Island region and \$15.54 in other parts of NYS. An investment of \$45 million in additional state funding per year, reaching \$270 million in the sixth year, is needed to achieve a living wage. Funds will be matched by an equal amount of federal Medicaid funds. The total investment to achieve the living wage will equate to a 2.3% annual increase each year for the next 6 years for OPWDD services provided by not-for-profit agencies. The Queens Council will be participating in advocacy initiatives to support this proposal.

Similar initiatives will occur for our 4410 Preschool and 853 School age programs. Our schools have even greater staff losses due to limited funding and a tremendous salary gap compared to employee compensation offered by the NYC Department of Education.

Attend QCDD meetings and visit our website for up-to-date details on our advocacy efforts. We need your participation!

Also, a recently published Chalkbeat article addressed the current state of preschool special education in New York City. It asked the question, "Why are preschool students with disabilities struggling to find seats?" Please go to the link below to read the full article: [www.chalkbeat.org/posts/ny/2016/09/30/new-york-city-promised-free-preschool-to-every-family-so-why-do-some-students-with-disabilities-struggle-to-find-seats](http://www.chalkbeat.org/posts/ny/2016/09/30/new-york-city-promised-free-preschool-to-every-family-so-why-do-some-students-with-disabilities-struggle-to-find-seats)

*Note: the above article is based on information and data from publications by the InterAgency Council (IAC)*

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

## 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](http://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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## FIDA-DD Presentation at QCDD Council Meeting

At the Council's April 4th, 2016 meeting we had a special presentation on FIDA—"Fully Integrated Duals Advantage" for individuals who have Intellectual/Developmental Disabilities, a partnership between OPWDD and the NYS Department of Health. It is one health plan centered on the individual that brings together Medicare, Medicaid, and Developmental Disability Services. It provides services through a network of providers contracted with the health plan. Partners Health Plan (PHP) is the only plan selected by CMS to offer the FIDA-DD program. The plan to implement FIDA-DD will involve delivering integrated health and long term care benefits to individuals with Medicare and Medicaid. The goal of this plan is to coordinate services to alleviate stress and confusion among caregivers.



*From left to right:*  
**Aliya Hussein** (Parent, QCDD Chairperson), **Martin Henshaw** (PHP),  
**Janet Zampella** (PHP), **Joanne Lamphere** (OPWDD),  
**Al Kaplan** (AHRC), and **Lisa Veglia** (QSAC, QCDD Chairperson)

## 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  
 Johanna Arteaga, QSAC (P) 718-728-8476 x1317 (E) jarteaga@qsac.com  
 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  
 Beverly Berger, Parent, (718) 224-4066 (E) (sheller@anibic.org)  
 Lisa Severino, Self-Advocacy, NYS (P) 347-613-0808 (E) sevnycadvocate@yahoo.com  
 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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## Medicaid Eligibility for a Disabled Child

Charlie Hope, Revenue/Entitlement Manager at QCP

Navigating the many rules and protocols of Medicaid can make applying for it a daunting experience. How do we acquire Medicaid benefits for disabled children who live with family or guardian? First, if an individual has never had Medicaid or SSI benefits it's time to start. There are specialized services that may not be covered by the caregivers' commercial coverage or Managed Care. Under NYS Directive Spousal/Parental Refusal (89-ADM 47), parents of children with disabilities do not need to disclose their income to apply for benefits.

The **Spousal** portion of the policy allows seniors to separate their income and resources from their spouse's, when that spouse needs to enter a nursing home due chronic health needs that cannot be provided at home. The **Parental** portion allows children with developmental disabilities or traumatic brain injuries to acquire Medicaid Waiver Services. An array of services and supports are funded by Medicaid, including: residential habilitation, day habilitation, prevocational services, supported employment, respite services, environmental modifications, adaptive equipment, in-home services, respite care, plan of care support services, family education and training, and consolidated supports and services.

Many families in Queens—and in NY state—utilize this policy to avoid the high monthly out-of-pocket state fee “Medicaid Spend Down” or “Surplus Income.” For instance, a family of four with a **\$36,000** annual income would be charged **\$1,000/month** in Medicaid Spend Down fees in order for their child to receive benefits. Categories protected from this fee include: Non-Magi Eligibility (ages 65+ or disabled), SSI, Foster Care Spend Down, MBI, and Residents in Adult Homes/OMH facilities. Resources: only if owned by child, even joint bank accounts or trusts, and any possible unearned incomes, like social security benefits or support from other sources, and/or insurance policies.

Caregivers only need to prove that 1) they fully support the child's needs, 2) the child has a disability, by providing human resource documentation forms 486T (Medicaid), 1151 (disability function report), and other relevant documents, such as a support statement (simply states a given individual(s) provide room and board for child; it is not a statement of responsibility/sponsorship). Usually caregivers are required to provide a support statement.

**Citizenship/Immigration Status:** NYS Medicaid coverage is available to all lawfully permanent residents, regardless of the entry date, as well as to all US citizens (provided all other eligibility requirements are met).

**Residency:** One must prove they are residents or demonstrate their plan to become permanent residents (based on intent, residency could be established in one month or less). Proof of residency includes: phone bill, cable bill, any bill, school record, rent receipt, etc.

**Proof of Disability:** There are two required forms: 1) **486T form**, completed by a physician, outlining/describing the individual's disability; 2) **1151 form** completed by caregiver/social worker/clinician, defining activities/level of function of an individual.

The following documentation is also required for the success and completion of a Medicaid Only application: proof of identity/immigration status (birth certificate, green card, social security card).

The State provides a special grant for individuals without Medicaid to get the required evaluations for Medicaid eligibility. Queens programs that will provide evaluations include:

**Lifespire** (718) 454-6940 ext. 246

**PSCH** (718) 777-5243

**QSAC** (718) 728-8476

**General Human Outreach** (718) 307-6563

**New York State Institute on Disability** (718) 231-7711

**YAI Link** (212) 273-5243

Once again, if applying for Medicaid for an individual with a disability, ensure you apply for Community Medicaid **not** Managed Care. An individual with a disability is exempt from Managed Care programs because of the many specialized needs and programs that an individual is enrolled in (care at home programs, OPWDD Waiver, Bridges to Health, foster care, and home and community based services).

For additional information and your local resource center call the Human Resources Info line at 1-718-557-1399 or 1-888-699-6116. You can also contact the Bernard Fineson DDRO at 718-217-4242; representatives will be able to direct you to a program with Non-Medicaid Service Coordination. This program informs caregivers of different services available for their child, as well as information and services for caregivers.

## 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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## 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](http://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](mailto:KDuMoulin@qsac.com)

**YAI-LINK:** (212) 273-6182



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](http://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](http://www.addwarehouse.com)

#### **American Association on ID/DD**

[www.aamr.org](http://www.aamr.org)

#### **American Foundation for the Blind**

[www.afb.org](http://www.afb.org)

#### **American Speech Language Hearing Association**

[www.asha.org](http://www.asha.org)

#### **The Arc**

[www.thearc.org](http://www.thearc.org)

#### **Attention Deficit Disorder Association**

[www.add.org](http://www.add.org)

#### **Augmentative Communication Centers**

[www.aac.unl.edu](http://www.aac.unl.edu)

#### **Autism Resources**

[www.autism-resources.com](http://www.autism-resources.com)

#### **Autism Society of America**

[www.autism-society.com](http://www.autism-society.com)

#### **Autism Speaks**

[www.autismspeaks.org](http://www.autismspeaks.org)

#### **Best Buddies**

[www.bestbuddies.org](http://www.bestbuddies.org)

#### **Developmental Disabilities Resources**

[www.ddhealthinfo.org](http://www.ddhealthinfo.org)

#### **Down Syndrome: Health Issues**

[www.ds-heath.com](http://www.ds-heath.com)

#### **Brain Injury Association of America**

[www.biausa.org](http://www.biausa.org)

#### **Cerebral Palsy Guidance**

[www.cerebralpalsyguidance.com](http://www.cerebralpalsyguidance.com)

#### **Cerebral Palsy Guide**

[www.cerebralpalsyguide.com](http://www.cerebralpalsyguide.com)

#### **Epilepsy Foundation of America**

[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

#### **Helen Keller Center for Deaf-Blind**

[www.hknc.org](http://www.hknc.org)

#### **International Dyslexia Association**

[www.interdys.org](http://www.interdys.org)

#### **LD Online**

[www.ldonline.org](http://www.ldonline.org)

#### **Lighthouse International**

[www.lighthouse.org](http://www.lighthouse.org)

#### **National Association of the Deaf**

[www.nad.org](http://www.nad.org)

#### **National Center on Birth Defects & DD**

[www.cdc.gov/ncbddd/autism/actearly](http://www.cdc.gov/ncbddd/autism/actearly)

#### **National Down Syndrome Society**

[www.ndss.org](http://www.ndss.org)

#### **NIH—Rare Diseases**

[www.rarediseases.info.nih.gov](http://www.rarediseases.info.nih.gov)

#### **National Resource Center on AD/HD**

[www.help4adhd.org](http://www.help4adhd.org)

#### **Prader-Willi California Foundation**

[www.pwcf.org](http://www.pwcf.org)

#### **Presidents Committee for People with ID**

[www.acf.hhs.gov/programs/pcpid](http://www.acf.hhs.gov/programs/pcpid)

#### **Special Olympics**

[www.specialolympics.org](http://www.specialolympics.org)

#### **Spina Bifida Association of America**

[www.spinabifida.org](http://www.spinabifida.org)

#### **Tourette Syndrome Association**

[www.tsa-usa.org](http://www.tsa-usa.org)

## Useful Websites

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

## 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 TBD  
 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 TBD

## 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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**Save the Date!**

**Queens Council on Developmental Disabilities  
Annual Legislative Breakfast**

**Friday March 3, 2017  
Queens College  
Student Union  
4<sup>th</sup> Floor Ballroom  
65-30 Kissena Blvd.  
Flushing, NY 11367  
8:30-11:00am**

**Meet Local Legislators, Hear Speakers Discuss Issues,  
and Have Your Voice Be Heard!**

*This event is offered free of charge as a public service event of the Queens Council on  
Developmental Disabilities*

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