

Dear Service Provider,

I am pleased to announce that this year's Manhattan Family and Professional Resource Fair will be held on **Thursday, December 18th** at the **Hotel Penn at 401 Seventh Avenue at West 33<sup>rd</sup> Street (18<sup>th</sup> Floor)** from **9:30AM to 2PM**. All families and professionals are welcome to attend.

If you are interested in hosting a booth at this event, please complete the form below. You may register for a half table at the cost of \$50 or a full table at the cost of \$100. Vendors or for-profit organizations can register for a table for \$150. Please have your agency representative arrive by 9:00 a.m. to register and prepare your booth. Your table must be set up by 9:30 a.m. Attendees will enter the Booth Area just after the keynote. Outlets will be available to those who register by the deadline. Please indicate your need below. If the fee poses a financial hardship and precludes your agency from participating, please call Jennifer at the number below. Due to space considerations, only one table will be allotted per agency. We expect every agency to have a staff person available at their table until 2:00 p.m. to answer questions.

Please use the attached flyer to copy and circulate among families and individuals that may be interested in attending. Please note that the Spanish translation is available on the reverse side. We are preparing a Chinese translation. Please inform us if you need copies. This fair is a good opportunity for service coordinators to become familiar with resources in Manhattan, so please encourage staff to attend as well. MSC credits will be provided. If you have questions regarding the fair, please call Amy Bittinger, at UCP of New York City, 718-859-5420, ext. 234. Questions regarding booth registration should be directed to Jennifer Shaoul at YAI, 212-273-6289.

Hope to see you there!

Sincerely,

Amy Bittinger & Jennifer Shaoul  
Co-Chairpersons, Manhattan Family Support Committee

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Please mail booth registration and payment to: Jennifer Shaoul, YAI/NIPD, 460 W. 34th St., 11th Floor, NY, NY, 10001 by **Monday December 8, 2014**. **No registration will be accepted without the accompanying fee. Space is limited so any registration received after 12/8/14 will not be accommodated.** Checks should be made payable to the Manhattan DD Council.

- HALF TABLE @ \$50
- FULL TABLE @ \$100
- FULL TABLE @ \$150 for vendors / for-profit organizations

NEED ELECTRICAL OUTLET (limited availability)

AGENCY: \_\_\_\_\_

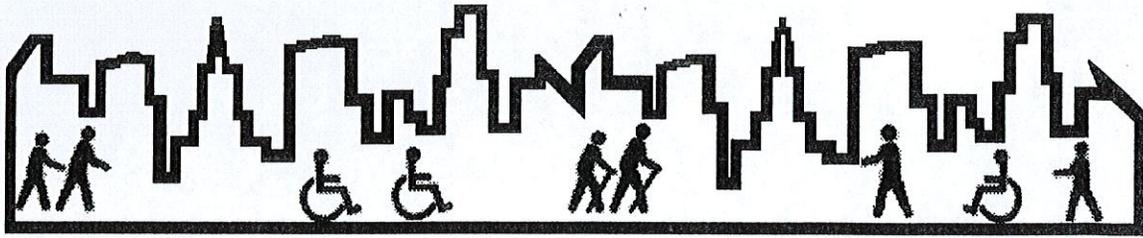
ADDRESS: \_\_\_\_\_ CITY: \_\_\_\_\_ ZIP: \_\_\_\_\_

CONTACT PERSON: \_\_\_\_\_ PHONE NUMBER: \_\_\_\_\_

E-MAIL ADDRESS: \_\_\_\_\_

NAME OF PERSON/PERSONS STAFFING THE BOOTH:

\_\_\_\_\_  
\_\_\_\_\_



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## MANHATTAN DEVELOPMENTAL DISABILITIES COUNCIL

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November 12, 2014

On Thursday, December 18, 2014 the Manhattan Developmental Disabilities Council will host a Family and Professional Resource Fair for parents of children and adults with intellectual/developmental disabilities. Developmental disabilities include: autism, cerebral palsy, neurological impairments, epilepsy, and other related developmental disabilities. We expect 400 parents and 400 professionals to attend. The Resource Fair has come to be an event that parents look forward to attending to learn about services and supports for their family member. We receive small grants to fund the Resource Fair but rely on voluntary agencies to help cover the costs so that no one needs to pay to attend.

The Manhattan Developmental Disabilities Council is a group of parents, professionals and governmental agencies that work together to improve the quality of life for people with developmental disabilities and their families. Please visit our web site:  
[www.manhattanddcouncil.org](http://www.manhattanddcouncil.org).

We are reaching out to your company for a donation to either underwrite the lunch costs for parents or provide a gift for the raffles which are valued at \$100 and above. If you are able to contribute, we will acknowledge your contribution prominently in our program. This is a small way to help our parents know that they are valued and that we understand the challenges and joys in their lives.

Please contact Amy Bittinger at (718) 859-5420, ext. 234 to make a donation.

Thank you for considering this request.

Sincerely,

  
Marco Damiani

Marco Damiani

Chair, Manhattan Developmental Disabilities Council  
[manhattanddcouncilchair@gmail.com](mailto:manhattanddcouncilchair@gmail.com)

cc: Amy Bittinger, Family Support Services Co Chair  
Jennifer Shaoul, Family Support Services Co Chair

The Manhattan Developmental Disabilities Council  
presents

# The Family & Professional RESOURCE FAIR

For parents, family members,  
people with developmental  
disabilities, and professionals



#### DEVELOPMENTAL DISABILITIES INCLUDE:

- Intellectual Disabilities (formerly Mental Retardation) • Autism • Cerebral Palsy
- Neurological Impairment • Epilepsy
- Related Disabilities

#### 8 invaluable workshops

For caregivers: 5 minute massage, gift  
bag, cash raffles

Info on services and supports from over  
90 service providers

## THURSDAY DECEMBER 18 2014

Hotel Penn

401 Seventh Avenue @ West 33rd St.

18th Floor

Hours: 9:30 A.M.-2:00 P.M.

School Groups Must Preregister

## FREE ADMISSION!

(SCHOOL GROUPS MUST PREREGISTER\*)

Free cash raffles for Manhattan  
families!

Receive a free updated  
Manhattan Family Support  
Directory and other valuable  
resource materials.

Sign language interpreters will be available  
at workshops if requested by November  
26th. Spanish and Chinese interpretation  
will be available for workshops.

\*For questions about the fair or school group  
registration, please call:

AMY BITTINGER  
718-859-5420, EXT. 234

abittinger@ucpny.org

For booth registration, call:  
JENNIFER SHAOUL  
212-273-6289

#### TRAVEL DIRECTIONS TO HOTEL PENN

Subway: Take the 1, 2, 3, A, C, E to 34th  
St./Penn Station.

Or take the B, D, F, M, N, Q, R to 34th  
St./Herald Square.

Bus: M34 or M16 crosstown to 34th St./7th  
Avenue

M 7 downtown to 34th St./7th Avenue  
M 7 uptown to 34th St./6th Avenue  
M 20 downtown to 34th St./7th Avenue  
M 20 uptown to 34th St./8th Avenue

#### SPONSORED BY:

The Manhattan Developmental Disabilities  
Council; Metro New York Developmental  
Disabilities Regional Office, OPWDD; NYS  
Department of Health and Mental Hygiene; NYS  
Developmental Disabilities Planning Council; NYS  
Department of Education, District 75

Visit [www.manhattanddcouncil.org](http://www.manhattanddcouncil.org) to  
keep updated on the community's  
activities, or follow us on  
 [facebook/ManhattanDDCouncil](https://www.facebook.com/ManhattanDDCouncil).

### KEYNOTE 9:30 A.M.

Featured Speaker: Morahina Rodriguez, Parent &  
Family Peer Advocate

## WORKSHOPS

### 10:45 A.M.-12:00 NOON

OPWDD's Family Information Session on the  
Service System

(Get credit for mandatory Front Door session to  
access services.) OPWDD staff

The Stress of Caring for a Child with a  
Disability—Strategies for Dealing with Daily  
Stresses

Gary Shulmon, MS Ed, Special Needs Consultant and  
Trainer

#### Creative Arts: Thinking Outside the Box

Representatives from SNACK, CO/LAB Theater  
Group, Keoni Movement Arts, Daniel's Music  
Foundation, and GiGi's Playhouse

Bullying: From the Playground to the  
Internet—the challenges of protecting  
children with special needs

Lauren Lynch, MSE PD, School Psychologist; John  
Aspromonte, MS PD, School Psychologist; Cooke  
Center Grammar School; and Jessie Gardner, MS Ed,  
Special Education, Technology Specialist, Cooke  
Center Academy

### 12:45 P.M.-2:00 P.M.

How to Prevent and Manage Meltdowns,  
Tantrums, and Other Behaviors in the  
Community

Peri Vello, PsyD, BCBA, and Ashley Stahl, MS Ed,  
Community Assistance Resource and Extended  
Services (CARES)

Special Education: What's Out There? What  
Supports and Services Are Appropriate for My  
Child?

Jean Mizutani, Education Program Manager, and Lori  
Podvesker, Program Manager, Resources for Children  
with Special Needs

Resources and Supports: Tips for Navigating  
the System for People with Developmental  
Disabilities

Michelle Lang, LMSW, Supervisor, YAI LINK

Future Planning: Guardianship, Special Needs  
Trusts, Health Care Proxies, Wills, and more

Paola Martinez Boone, MSW, New York Lawyers for  
the Public Interest

Medicaid Service Coordinators will receive training  
credit for participation in these workshops.

VER TRADUCCION EN ESPAÑOL AL REVERSO

El Consejo para Discapacidades del Desarrollo del Condado de Manhattan presenta:

# FERIA DE INFORMACIÓN

Sobre recursos disponibles para individuos con discapacidades del desarrollo, padres, miembros de familia y profesionales



- Las DISCAPACIDADES DEL DESARROLLO INCLUYEN:
- Discapacidad Intelectual (Retraso Mental)
  - Autismo • Parálisis Cerebral
  - Impedimento Neurológico • Epilepsia
  - Otras Discapacidades Relacionadas

8 talleres de vital importancia

Para familiares: masaje de 5 minutos, bolsa de regalos y rifas en efectivo

Información sobre servicios y programas de apoyo de más de 90 proveedores de servicios

## JUEVES 18 DE DICIEMBRE DEL 2014

Hotel Penn

401 Seventh Avenue @ West 33rd St.

Piso 18

Horas: 9:30 A.M.–2:00 P.M.

## ¡ENTRADA GRATUITA!

¡Habrá rifas en efectivo para familias que viven en Manhattan! Recibirá un Directorio de Servicios de Apoyo a la Familia de Manhattan gratis y actualizado y otros materiales informativos

Si requiere interpretación para sordomudos, solicítela antes del 26 de Noviembre. Traducción disponible al Español.

Para preguntas en relación a la feria en Español, llame a:  
**MARA HENRIQUEZ**  
212-273-6542

### INDICACIONES PARA LLEGAR AL HOTEL PENN:

Metro: Líneas 1, 2, 3, A, C, E hasta la estación 34th St./Penn Station  
Líneas B, D, F, M, N, Q, R hasta la estación 34th St./Herald Square  
Autobús: M 34 o M 16 hasta 34th St./7th Ave  
M 7 hacia downtown hasta 34th St./7th Ave  
M 7 hacia uptown hasta 34th St./6th Ave  
M 20 hacia downtown hasta 34th St./7th Ave  
Ave  
M 20 hacia uptown hasta 34th St./8th Ave

#### PATROCINADO POR:

The Manhattan Developmental Disabilities Council; Metro New York Developmental Disabilities Regional Office, OPWDD, NYC Department of Health and Mental Hygiene; NYS Developmental Disabilities Planning Council; NYC Department of Education, District 75

Para mantenerse informado visite la

página web:

[www.manhattandevelopmentaldisabilities.org](http://www.manhattandevelopmentaldisabilities.org) o visítanos en facebook/ManhattanDDCouncil

### APERTURA 9:30 A.M.

Oradora Principal: Morahna Rodriguez, Madre y Family Peer Advocate

## TALLERES

10:45 A.M.–12:00 P.M.

**OPWDD—Sesión de Información para Familias sobre el Sistema de Servicios**

(Al atender esta sesión obligatoria del Front Door, obtendrá el crédito necesario para acceder a servicios.)  
OPWDD staff

**El Estrés de Cuidar a un Niño con una Discapacidad—Estrategias para Lidar con el Estrés Diario**

Gary Shulman, MS Ed, Special Needs Consultant and Trainer

**Artes Creativos: Pensando Fuera de lo Tradicional**

Representantes de SNACK, CO/LAB Theater Group, Keoni Movement Arts, Daniel's Music Foundation, y Gigi's Playhouse

**Bullying: Desde el Parque Infantil hasta el Internet—Desafíos para Proteger a los Niños con Necesidades Especiales**

Lauren Lynch, MSE, PD, School Psychologist; John Aspromonte, MS, PD, School Psychologist; Cooke Center Grammar School; y Jessie Gardner, MS Ed, Special Education, Technology Specialist, Cooke Center Academy

12:45 P.M.–2:00 P.M.

**Cómo Prevenir y Manejar Crisis Emocionales, Rabietas, y Otros Comportamientos en la Comunidad**

Peri Vella, PsyD, BCBA, y Ashley Stahl, MS Ed, Community Assistance Resource and Extended Services (CARES)

**Educación Especial: ¿Qué hay Disponible? ¿Qué Apoyos y Servicios son Adecuados para mi Hijo?**

Jean Mizutani, Education Program Manager y Lori Podwiesker, Program Manager, Resources for Children with Special Needs

**Recursos y Apoyo: Tips para Navegar el Sistema para Personas con Discapacidades del Desarrollo**

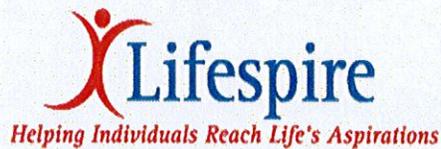
Michelle Long, LMSW, Supervisor, YAI LINK

**Planificación a Futuro: Tutela Legal, Fideicomiso, Representante para Asuntos Médicos, Testamentos, y Más**

Paola Martinez Boone, MSW, New York Lawyers for the Public Interest

Los Coordinadores de Servicios a través del Programa de Medicaid recibirán créditos de entrenamiento por participación en estos talleres.

ENGLISH LANGUAGE ON REVERSE



## **MANHATTAN/QUEENS IN-HOME BEHAVIOR MANAGEMENT**

Lifespire provides in-home behavior management training to families of OPWDD-eligible individuals. Typical areas covered include principles of positive behavior supports, applied behavior analysis, and behavior plan implementation. The service is provided by a master's-level behavioral intervention specialist.

- *The service is free!*
- *Medicaid is not required.*
- *Weekly in-home visits arranged at family's convenience.*
- *No age requirements!*
- *Available in Russian for residents of Queens.*

The individual must be OPWDD-eligible and have a documented live with family in Manhattan. For questions or referrals, please call *Jay Kleinman, L.C.S.W., Director of Family Support*, at 718-454-6940 or e-mail [jkleinman@lifespire.org](mailto:jkleinman@lifespire.org).



## United Cerebral Palsy of New York City Services and Supports 2014

### Children/Education Services

Bronx, Brooklyn, Manhattan and Staten Island

- On-site therapeutic services
- Preschool services
- Integrated programming
- Universal Pre-K
- School-Age Program (Brooklyn Only)
- Early Childhood Direction Center (Brooklyn Only)

### After-School Program

Brooklyn and Manhattan

- Manhattan PS 138@30
- Brooklyn PS 396
- Family Support eligible.
- Transportation is provided to the child's home only.

### Day Habilitation

Opportunities in Day programs available in the Bronx, Brooklyn, Manhattan and Staten Island.

- Persons served must be age 21 or older to apply and have Medicaid or are eligible for Medicaid.

All sites are wheelchair accessible and transportation is available.

### Supported Employment

Employment services for adults with DD. Available for Bronx, Brooklyn, Manhattan, and Staten Island residents. Applicants must go through ACCES-VR orientation and referral process.

### Technology Resource Centers/Techworks to Go Van

Technology Resource Specialists are available to answer your assistive technology questions. Information on various assistive technology products and services, their costs, obtaining them and hands on demonstrations

- Demonstration centers
  - SHARE: Lending Libraries
  - Durable medical equipment program
  - Hands on Assistive Technology trainings
- Free informal evaluations on Assistive Technology devices and softwares  
Bronx, Brooklyn, Manhattan, and Staten Island

### ACTION DAY CAMP

Three week summer day camp experience for young people who reside in Brooklyn, ages 13-21, live with a family member. Must be in OPWDD waiver

### SPIRIT

Saturday Recreation Programs offered in Brooklyn, Manhattan, and Staten Island.

- Individuals between the ages of 13-29, DD eligible and live with a family member who resides in Manhattan, Bronx, Brooklyn and Staten Island
- Transportation is provided

### EXPLORE Club Disco

Friday nights events held in Manhattan and Brooklyn two times per month

- 18 yrs or older, DD eligible and live with a family member who resides in Manhattan, Bronx and Brooklyn
- Wheelchair accessible
- Transportation is not provided
- Light supper served

### Staten Island Club Disco

Friday night once a month

- 18 yrs or older, who have the HCBS waiver and live with a family member who resides in Staten Island
- Wheelchair accessible
- Transportation is not provided
- Light supper served

## PROJECT CONNECT

Information and referral for supports and services offered in Brooklyn, Bronx, Manhattan, Queens and Staten Island.

1-877-827-2666 [projectconnect@ucpnyc.org](mailto:projectconnect@ucpnyc.org)

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



## United Cerebral Palsy of New York City Services and Supports 2014

### Healthcare Services

**Medical Services** in Article 28 clinics located in Brooklyn, Bronx, and Manhattan, serving residents of the five boroughs of New York City. Clinics are wheelchair accessible. Services include Family Medicine, Women's Health, Dental, Audiology Services, Psychiatry, Podiatry, Optometry and Neurology.

### Residential Services

Residential settings are located in Bronx, Brooklyn, Manhattan and Staten Island.

- Information about accessing residential opportunities & NYS Cares registration list
- Must be OPWDD eligible

### Bronx Overnight Respite

Serves all five boroughs.

- Transportation provided in Brooklyn, Manhattan, Queens and Staten Island
- Serves all ages
- Site is fully accessible
- Must be waiver eligible

### In-Home Respite

Bronx, Brooklyn, Manhattan, and Staten Island

- Must be waiver eligible and live with a family member.

### Doorways to Independence

#### Housing Assistance Services

Available in the Bronx, Brooklyn, Manhattan, Staten Island and Queens

- Must be Family Support eligible
- Provides housing case management services, advocacy and referrals

- NYCHA application status checks and assistance processing requests for transfers
- Housing Court Advocacy - South Brooklyn Legal Services contract for Brooklyn and referrals to the Legal Aid Society for the Bronx, Manhattan, Queens and Staten Island

### Home Assessments

Home assessments can be completed providing families with a report on possible modifications and equipment to make their home more accessible for their family member. Bronx, Brooklyn, Manhattan, Queens and Staten Island.

- Must be Family Support eligible

### Family Reimbursement

Funds available in the Bronx, Brooklyn, Manhattan, and Staten Island

\$500.00 limit for Bronx, Brooklyn and Manhattan

Staten Island limit is \$300.00

Special Brooklyn Camp Funds available.

Manhattan Durable Medical Equipment Funds available.

Funding available to assist families in paying for an item Medicaid or other funds will not cover.

Families can apply every 12 months.

### Family Connect

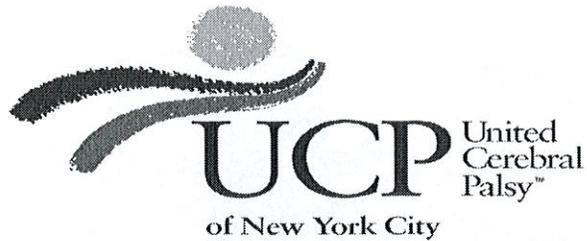
UCP of NYC Family Connect Centers offer free weekly workshops, support services, and educational resources for New York City parents and families of children with disabilities. Through the UCP of NYC Family Connect Centers, families are encouraged to learn, explore resources, and participate in improving outcomes for children with disabilities.

## PROJECT CONNECT

Information and referral for supports and services offered in Brooklyn, Bronx, Manhattan, Queens and Staten Island.

1-877-827-2666 [projectconnect@ucpnyc.org](mailto:projectconnect@ucpnyc.org)

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



*Creating opportunities for people with disabilities*

## United Cerebral Palsy of New York City Family Reimbursement

UCP's Family Reimbursement program provides monies to family support eligible families. These monies cover the cost of items Medicaid does not traditionally cover, such as;

- Clothing
- Summer Camp
- Respite Care
- Children's Furniture
- Nutritional Items
- Supplies
- and More...

Also, Durable Medical Equipment, such as;

- Wheelchair parts/repair
- Shower chair
- Hospital beds/mattress
- Commodes
- Walkers



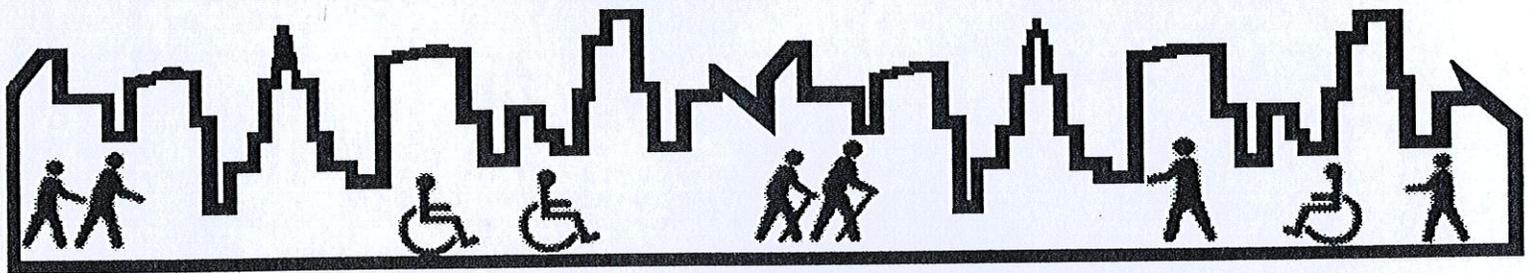
If the request is for medical or adaptive equipment, medical documentation supporting a need for the equipment must be included, such as a letter from the PT, or OT (and must include signature and license #). You must also show proof that Medicaid or your medical insurance does not cover the item.

An updated Level Of Care (LOC) or Psychological evaluation must be included with application. Families can apply every 12 months.

For more information call 718-859-5420 ext 244

UPC of NYC Family Reimbursement  
110 Elmwood Avenue Brooklyn, NY 11230  
projectconnect@ucpnyc.org  
www.ucpnyc.org

## The Manhattan Family Support Services Advisory Council



### For family members of people with developmental disabilities and self-advocates with developmental disabilities!

Join with other family members and individuals from all neighborhoods in Manhattan to build a better life for people with developmental disabilities and their families. **Developmental disabilities** include intellectual disabilities, autism, cerebral palsy, epilepsy, and neurological impairments.

#### Come and Be Empowered:

- Learn about the many services that can help your family
- Help us advise the state and city about needed services
- Meet other family members and people with disabilities
- Advocate with us for more and better services

Spanish or Cantonese interpretation provided if requested by November 21, 2014. Contact Margaret at 212-799-2042 or [margaret.puddington@gmail.com](mailto:margaret.puddington@gmail.com) to request interpretation.

#### Coping with Loss

Much as we wish we could spare our children pain, everyone will at some point be touched by loss—the death of a pet, the loss of a close friend or favorite staff person, the passing of a grandparent or parent. **Mary Donohue**, PhD, Director of Psychology Services, and **Mary Colimon-Pierre**, PhD, Supervising Psychologist, AHRC Adult Day Services, will teach us strategies for helping our children—of all ages and all levels of functioning—cope with their grief. Sooner or later, every one of us will need this advice!

**WEDNESDAY, DECEMBER 3, 2014**

**10:00 AM – 12 NOON**

**RESOURCES FOR CHILDREN WITH SPECIAL NEEDS**

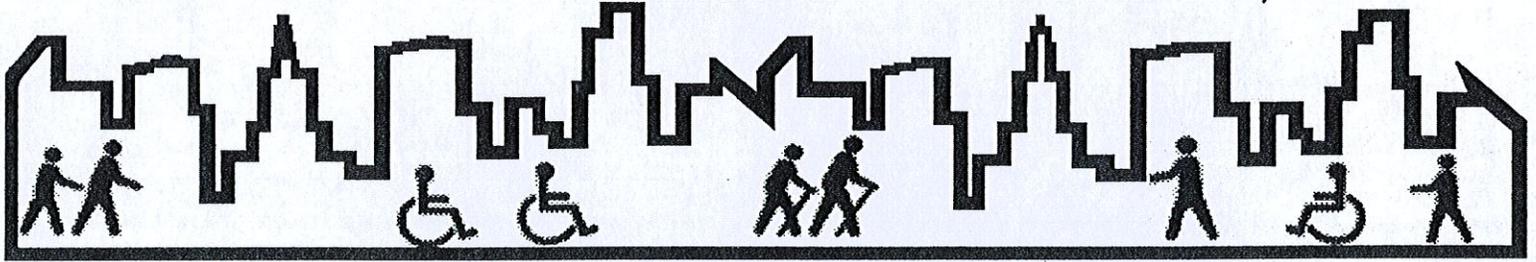
**116 EAST 16<sup>TH</sup> STREET (BETWEEN PARK AVE. SOUTH AND IRVING PLACE), 5<sup>TH</sup> FLOOR\***  
**NEW YORK, N.Y. 10003**

**REFRESHMENTS WILL BE SERVED**

**IN CASE OF VERY BAD WEATHER... we will cancel the meeting ONLY IF THE PUBLIC SCHOOLS ARE CLOSED.**

\*Subway: 4, 5, 6, N, Q, R, W, L To 14<sup>th</sup> St./Union Square. A, C, E, F, V, 1, 2, 3 To 14<sup>th</sup> Street and walk East or take a crosstown bus on 14<sup>th</sup> St. to Park Ave. South. Bus: These buses go to 14<sup>th</sup> Street near Union Square: #1, 2, 3, 5, 6, 7, 9, 14A, 14D, 101, 102, 103. Information: Margaret Puddington, chair, 212-799-2042, [Margaret.puddington@gmail.com](mailto:Margaret.puddington@gmail.com).

## The Manhattan Family Support Services Advisory Council



**Padres de niños con discapacidades de desarrollo: Bienvenidos a la próxima reunión.**

**Si necesita intérprete durante la reunión es necesario avisarle a Margaret al 212-799-2042 antes de 21 de noviembre del 2014.**

Reunase con otras familias y individuos de todos los vecindarios de Manhattan para construir una vida mejor para las personas con discapacidades de desarrollo y sus familiares. **Discapacidades de desarrollo** incluyen: discapacidad intelectual, autismo, parálisis cerebral, epilepsia, incapacidades del aprendizaje, e impedimento neurológico.

### **VENGA Y SIENTASE PODEROSA:**

- Aprenda sobre muchos servicios que le pueden ayudar a su familia.
- Ayúdenos a aconsejar al estado y la ciudad sobre los servicios necesarios.
- Forme una red de comunicación con otras familias y individuos.
- Abogar con nosotros para más y mejores servicios.

### **Lidiando con la Pérdida**

Tanto como nos gustaría evitarles el dolor a nuestros hijos, todos en algún momento estaremos tocados por la pérdida—la muerte de una mascota, la pérdida de un amigo cercano o persona favorita del personal, la muerte de un abuelo o padre. **Mary Donohue**, PhD, Directora de los Servicios de Psicología, y **Mary Colimon-Pierre**, PhD, Psicóloga Supervisora, Servicios Diurnos para Adultos de AHRC, nos enseñarán estrategias para ayudar a los niños—de todas las edades y niveles de funcionamiento—lidiar con el dolor. ¡Tarde o temprano, cada uno de nosotros necesitará este consejo!

**MIÉRCOLES, 3 DE DICIEMBRE DEL 2014**

**10:00 AM - 12:00 PM**

**RESOURCES FOR CHILDREN WITH SPECIAL NEEDS**

**116 EAST 16<sup>TH</sup> STREET (BETWEEN PARK AVE. SOUTH AND IRVING PLACE), 5<sup>TH</sup> FLOOR\***

**NEW YORK, N.Y. 10003**

**SE SERVIRÁ BOCADILLOS**

**EN CASO DE MUY MAL TIEMPO SOLAMENTE...canceláremos la reunión SI LAS ESCUELAS PÚBLICAS SUSPENDEN SUS CLASES.**

\*Metro: Líneas 4, 5, 6, N, Q, R, W, L hasta la estación 14<sup>th</sup> St./Union Square. A, C, E, F, V, 1, 2, 3 hasta 14<sup>th</sup> Street; camine hacia el este o tome el autobús hacia Park Ave. South. Autobus: : #1, 2, 3, 5, 6, 7, 9, 14A, 14D, 101, 102, 103 hasta 14<sup>th</sup> St. cerca de Union Square. . Para más información llame a Margaret Puddington, 212-799-2042 o [Margaret.puddington@gmail.com](mailto:Margaret.puddington@gmail.com).

## DEVELOPMENTAL DISABILITIES ADVOCACY SURVEY

The purpose of this survey is to enable families and self-advocates to help set the advocacy agenda for the coming year. Results of the survey will be used to identify the top advocacy priorities across New York State. Professionals should complete this survey only if they are a family member or self-advocate.

Please do not complete more than one survey.

**What are the 3 MOST IMPORTANT unmet needs in your region? Keep in mind that they may or may not be your own family's most important needs. Please mark your top priority "1"; your second priority "2"; and your third priority "3."**

- Out-of-home residential services with 24-hour staffing
- Out-of-home residential services with part-time staffing
- Employment services
- Pre-employment services
- Center-based adult day services (day habilitation)
- Community-based adult day services (day habilitation without walls)
- In-home caregiving (respite)
- In-home skills building/caregiving (community habilitation)
- Help managing challenging behaviors
- Afterschool programs for children
- After-program recreation for adults
- Weekend recreation
- Caregiving during a family emergency (emergency respite)
- Other – please specify

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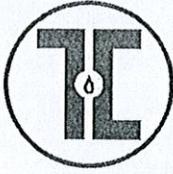
In the next few years, people with developmental disabilities will be required to join a managed care organization.

over  
↓

- The managed care organization will have a network of service providers, and people will have to get their services from network providers.
  - The managed care organization will get a monthly payment for all its clients.
  - The goals of managed care are to improve care coordination and to save money.
- 

**What are your 3 MOST IMPORTANT concerns about managed care? Please mark your top priority "1"; your second priority "2"; and your third priority "3."**

- If managed care organizations do not receive sufficient funding:
  - needed services may be limited or denied
  - people with intense (and costly) needs may not receive all the services they need
  - staffing, training, and supervision may be inadequate, causing the quality of services to decline
- Managed care organizations may not provide people with enough choices of providers and may not allow individuals to keep their current providers
- Managed care organizations try to keep costs down and may be unwilling to provide much needed higher salaries for direct support staff
- Managed care organizations are expensive to run. Costs for running these organizations should not be deducted from the money available for services
- Other — please specify



**TOURO COLLEGE**

**SCHOOL OF HEALTH SCIENCES**

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27-33 West 23<sup>rd</sup> Street, New York 10010 • (212) 463-0400 Ext. 5606 • Fax (212) 989-2054

## **Physical Therapy Department**

Dear Parent/Guardian:

Thank you for participating in our research. These forms and questionnaires are part of a research study which will improve our knowledge and understanding about level of participation in leisure and recreational activities of families and their children with cerebral palsy. The forms and questionnaires will take about 20 minutes to complete. Upon completion of the enclosed documents, you will be compensated with a \$25.00 gift card. The documents must be completed in their entirety and returned to us in order to receive the \$25.00 gift card (first 30 participants only). Your participation is voluntary and the information you provide will be confidential as there will be no identifying information. Please answer every question in this packet to the best of your ability and without worry that you will be judged in any way.

Included in this packet you will find:

- Letter of informed consent
- Demographic survey
- Instructions on how to fill out the Child Participation Questionnaire (CPQ)
- Child Participation Questionnaire (CPQ)

If you have any questions, please do not hesitate to contact me.

Ralph K. Garcia, MPT, PhD  
Research Coordinator  
Associate Professor  
Department of Physical Therapy  
% Touro College  
27-33 West 23rd street  
Room 600  
New York, NY 10010

We look forward to your response and will be following up shortly.

For Researchers Use Only:

Family/Child ID# \_\_\_\_\_

### Informed Consent

Title: Participation in extracurricular activities of children ages 4-18 years with cerebral palsy across various cultures.

Researcheers: Ralph K. Garcia, MPT, PhD, Sarit German, SPT, Celina Schoenblum, SPT, and Bari Sloves, SPT.

You have been invited to take part in a study to describe out of school participation of children ages 4-18 with cerebral palsy (CP) from different family cultural backgrounds. This study will be conducted by Ralph K. Garcia, Sarit German, Celina Schoenblum, and Bari Sloves as part of a degree requirement for the Touro College DPT program. The faculty sponsor is Ralph K. Garcia, MPT, PhD.

Participation in this study will include filling out a one-time survey about out of school participation of children ages 4-18 with CP and about family background. There are no risks or hazards associated with participation in this study.

This research may result in a better understanding of the connection between out of school involvement in children 4-18 years of age with CP and their family cultural backgrounds. Information obtained during this research is confidential, and will be used for the purpose of this study only. Your name or other identifying information will not be disclosed to anyone but the researcher. You will sign this consent form and complete this survey on behalf of your children. All records will be kept locked and available only to the researcher, and will be destroyed 3 years after the study is completed.

Your participation in this study is voluntary and you can withdraw your consent to participate at any time without any negative consequences. Participation or nonparticipation in no way impacts your current employment or any services that you receive. You can request a summary of the research findings from the researchers named above.

If there is anything about the study or your participation you do not understand, you have questions or concerns, or if you wish to report a research related problem, you can contact the researcher/faculty sponsor Dr. Ralph K. Garcia 212-463-0400 ext 5257 or [ralph.garcia@touro.edu](mailto:ralph.garcia@touro.edu).

For questions about your rights as a research participant, you can contact Touro College Health Sciences Institutional Review Board for the Protection of Human Subjects at 1700 Union Blvd, Bay Shore, NY 11706. Tel: 631-665-1600 ext 6219, or email: [touroirb@gmail.com](mailto:touroirb@gmail.com).

You will receive a copy of this consent form to keep.

Participant Consent

Name of Participant \_\_\_\_\_

Signature of Participant \_\_\_\_\_ Date \_\_\_\_\_

For Researchers Use Only:

Family/Child ID# \_\_\_\_\_

**Demographics Form**

**Caregiver Information: Age:** \_\_\_\_ years

<p><b>Gender:</b>  <input type="checkbox"/> Male  <input type="checkbox"/> Female  <input type="checkbox"/> Prefer not to say  <input type="checkbox"/> Other                  (please specify _____)</p>	<p><b>Race:</b>  <input type="checkbox"/> Caucasian  <input type="checkbox"/> African American  <input type="checkbox"/> American Indian  <input type="checkbox"/> Alaska Native  <input type="checkbox"/> Asian  <input type="checkbox"/> Pacific Islander  <input type="checkbox"/> Other                  (please specify _____)</p>	<p><b>Religion:</b>  <input type="checkbox"/> Christian  <input type="checkbox"/> Muslim  <input type="checkbox"/> Hindu  <input type="checkbox"/> Jewish  <input type="checkbox"/> Buddhist  <input type="checkbox"/> Roman Catholic  <input type="checkbox"/> Other                  (please specify _____)</p>
<p><b>Primary Language:</b>  <input type="checkbox"/> English    <input type="checkbox"/> Chinese  <input type="checkbox"/> Spanish    <input type="checkbox"/> Arabic  <input type="checkbox"/> French    <input type="checkbox"/> Hebrew  <input type="checkbox"/> Italian    <input type="checkbox"/> Korean  <input type="checkbox"/> German    <input type="checkbox"/> Persian  <input type="checkbox"/> Portuguese    <input type="checkbox"/> Japanese  <input type="checkbox"/> Russian    <input type="checkbox"/> Polish  <input type="checkbox"/> Vietnamese  <input type="checkbox"/> Other (please specify _____)</p>	<p><b>Family Income:</b>  <input type="checkbox"/> &lt;\$20,000  <input type="checkbox"/> \$20,000-\$40,000  <input type="checkbox"/> \$40,000-\$60,000  <input type="checkbox"/> \$60,000-\$80,000  <input type="checkbox"/> \$80,000-\$100,000  <input type="checkbox"/> &gt;\$100,000</p>	<p><b>Highest attained Education:</b>  <input type="checkbox"/> 7th-8th grade  <input type="checkbox"/> High school, no degree  <input type="checkbox"/> High school graduate  <input type="checkbox"/> Some college, no degree  <input type="checkbox"/> Associates degree  <input type="checkbox"/> Bachelor's degree  <input type="checkbox"/> Master's degree  <input type="checkbox"/> Professional degree  <input type="checkbox"/> Doctoral degree  <input type="checkbox"/> Other                  (please specify _____)</p>

**Child Information: Age:** \_\_\_\_ years

<p><b>Gender:</b>  <input type="checkbox"/> Male  <input type="checkbox"/> Female  <input type="checkbox"/> Prefer not to say  <input type="checkbox"/> Other                  (please specify _____)</p>	<p><b>Race:</b>  <input type="checkbox"/> Caucasian  <input type="checkbox"/> African American  <input type="checkbox"/> American Indian  <input type="checkbox"/> Alaska Native  <input type="checkbox"/> Asian  <input type="checkbox"/> Pacific Islander  <input type="checkbox"/> Other _____</p>	<p><b>Religion:</b>  <input type="checkbox"/> Christian  <input type="checkbox"/> Muslim  <input type="checkbox"/> Hindu  <input type="checkbox"/> Jewish  <input type="checkbox"/> Buddhist  <input type="checkbox"/> Roman Catholic  <input type="checkbox"/> Other _____</p>	<p><b>Primary Language:</b>  <input type="checkbox"/> English    <input type="checkbox"/> Chinese  <input type="checkbox"/> Spanish    <input type="checkbox"/> Arabic  <input type="checkbox"/> French    <input type="checkbox"/> Hebrew  <input type="checkbox"/> Italian    <input type="checkbox"/> Korean  <input type="checkbox"/> German    <input type="checkbox"/> Persian  <input type="checkbox"/> Portuguese    <input type="checkbox"/> Japanese  <input type="checkbox"/> Russian    <input type="checkbox"/> Polish  <input type="checkbox"/> Vietnamese  <input type="checkbox"/> Other                  (please specify _____)</p>
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## CHILDREN PARTICIPATION QUESTIONNAIRE (CPQ) INSTRUCTIONS

Date of Birth (CHILD) \_\_\_\_\_  
Current Date \_\_\_\_\_

Dear Parent,

This questionnaire is intended to learn the participation habits of your child in different day-to-day occupations, typical for children aged 4-18 years. Please answer in accordance to what your child actually does, and not what your child is capable of doing. Your responses will assist in determining the intervention goals, and in assessing progress in the future.

Regarding the last three months, mark the following for every activity:

1: Place an X in the box representing on a scale of 0-5 how frequently your child participates in a certain activity, according to the key at the top of the column (for example: showers -everyday, visits a friend -twice a week, etc.) In the event that your child does not participate in a certain activity at all, mark the 0 box and move on to the next question.

2: The degree of help/assistance/encouragement/escorting, your child requires in participating in the activity at hand (for example: help dressing, guidance in playing a game, parental presence at a friend's birthday party).

3: In your opinion, the degree of enjoyment your child obtains from the activity (pleasure, motivation, will to carry out).

4: The degree of satisfaction you have as a parent from the frequency of participation and from your child's independence in the activity in general.

- In the event that an activity your child participates in is not mentioned in the questionnaire, please add it to the questionnaire in the designated spot (under 'other activity').
- Refer to the activities your child performs in outside the preschool.

Example: The child dresses herself every day, so an X is placed in box #5. She is able to do most of the dressing by herself with a minimum of assistance from the parent (about a 5 on a scale of 1 to 6), but she does fuss about it some days (about a 4 on the enjoyment scale). This is somewhat satisfactory to the parent, but there's room for improvement (a 5 on the satisfaction scale).

CHILDREN PARTICIPATION QUESTIONNAIRE (CPQ)		Frequency of Participation	Degree of Assistance	Child's enjoyment in participation	Parental satisfaction from child's participation
	The Activity	0 1 2 3 4 5 <small>Never</small> <small>Once in 3 months</small> <small>2-3 months</small> <small>Once a week</small> <small>Twice a week</small> <small>Every day</small>	1 2 3 4 5 6 <small>Needs more assistance</small> <div style="text-align: center;">←-----→</div> <small>Independent</small>	1 2 3 4 5 6 <small>Does not take pleasure</small> <div style="text-align: center;">←-----→</div> <small>Takes much pleasure</small>	1 2 3 4 5 6 <small>Not at all satisfied</small> <div style="text-align: center;">←-----→</div> <small>Very satisfied</small>
1. Dressing	ADL	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6

# CHILDREN PARTICIPATION QUESTIONNAIRE (CPQ)

## The Activity

ADL	Frequency of Participation	Degree of Assistance	Child's enjoyment in participation	Parental satisfaction from child's participation		
					0	1
1. Dressing	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
2. Showering/Bathing	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
3. Brushing Teeth	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
4. Toileting	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
5. Eating with cutlery	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
6. Other activity: _____	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
ADL	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
1. Taking part in organizing room/house	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
2. Taking part in meal preparation/setting the table	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
3. Operating electronic device (TV, DVD, phone)	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
4. Shopping in grocery store	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
5. Taking care of pet	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
6. Other activity: _____	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
IA/DL	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
1. Choosing a game	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
2. Playing with construction toys (building blocks, puzzles)	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
3. Playing games with rules (cards, board games)	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
4. Playing computer games	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
5. Taking part in pretend or make believe play	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
Leisure	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
1. Choosing a leisure activity (occupy oneself)	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
2. Playing on playground equipment	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
3. Riding a bike	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
4. Playing ball games	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
5. Listening to a story	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
6. Watching TV	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
7. Doing arts and crafts at home	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
8. Using art and craft materials	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
9. Going for a day trip, picnic, camping	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
10. Going to a live event (eg. Movie, theatre)	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
11. Other activity: _____	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
Social Participation	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
1. Playing with a friend	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
2. Visiting at a friend's house	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
3. Inviting and hosting a friend	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
4. Attending friends' birthday parties	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
5. Going to family events	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
6. Sleeping over at family house	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
7. Sleeping over at a friend's house	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
8. Talking on the phone	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		
9. Other activity: _____	0 1 2 3 4 5	1 2 3 4 5 6	1 2 3 4 5 6	1 2 3 4 5 6		