



NEWSLETTER

ADVOCATES FOR PEOPLE WITH
DEVELOPMENTAL DISABILITIES

SEPTEMBER 2015

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(914) 493-1318

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THE FUTURE OF OPWDD

Many changes
are on the horizon...
Listen and Learn

Legislators on the NY State Mental
Hygiene Committee will engage in a
panel discussion of topics such as:

- *Managed care*
- *People First Waiver*
- *Front Door*
- *Residential options*
- *Self-direction*
- *Guardianship*
- *Other concerns that you would like addressed*

Come to the
GROW General Meeting
Sunday, October 25, 2015

Brunch & Networking: 10:30 a.m. Meeting 11:00 a.m.

At WIHD – Cedarwood Hall
Westchester Medical Center, Valhalla, NY

Parking vouchers available

(Directions on page 3 of this newsletter)

PRESIDENT'S MESSAGE...

A BITTERSWEET MESSAGE

This has been a very hard message to write. I became President of GROW eight years ago. While I am eager to pass the torch on to a new and qualified team, I sometimes feel like a deserter. People with developmental disabilities and their parents are being buffeted with so many changes and so much still needs to be done. However, as previous GROW presidents have done, I intend to remain active on the Board. Only now I won't have to set the agenda, etc...etc..etc....!!

I recently attended an OPWDD Transformation meeting. Many parents and some advocates spoke. Whether it was the closure of a developmental center without adequate planning for its residents, or a lack of OPWDD transparency, or a lack of appropriate residential opportunities across the board, or managed care, or constant changes in self direction, no one was happy. Since an e-mail sent to me stated that there would not be time for me to speak, I did not prepare a speech. However there was time, and after hearing one sad story after another, I addressed the audience rather than the panel.

In my remarks I was inspired by a book I am currently reading. It is called Neuro Tribes: The Legacy of Autism and the Future of Neuro Diversity by Steve Silberman. The author credits parents for establishing much needed services for people who are on the autism spectrum. He mentions names of people that I knew and in some cases worked with! It dawned on me that without parents all these OPWDD officials and all

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(President's Message continued from page 1)

the people running agencies that support people with developmental disabilities would not have jobs!

It must be remembered that it was the parents of persons with Down syndrome that created what was then called OMR as a distinct agency from the Department of Health. Later the parents of individuals with autism added developmental disabilities to the OMR, making it OMRDD. Now it is called OPWDD. Now, with managed care and commercial insurance companies handling everything, I fear that we are going back to "the bad old days" when there was no special agency for people with developmental disabilities.

I URGE ALL FAMILY MEMBERS TO REASSERT THE POWER THAT YOU POSSESS!!

Contact your legislators; demand transparency of and input in agencies and OPWDD.

Come to GROW meetings. **YOUR VOICE MUST BE HEARD!!!**

Barbara Masur, GROW President

FROM THE EDITOR...

Barbara Masur, President of GROW for eight years is stepping down. She has been a fearless and forceful advocate for individuals with developmental disabilities and their families for many years, starting from when her son Daniel was a baby. Although her advocacy began with her own family situation, it grew to include all families. While maintaining her own career as an educator, Barbara founded the Westchester Chapter of the Autism Society of America and has continued to tirelessly address the issues that affect all individuals with developmental disabilities and their families.

As President of GROW, her dedication and perseverance allowed GROW to be a part of the ongoing conversations with OPWDD and NY State. She has been the voice for the many individuals and families who are confused and concerned about the changes occurring within OPWDD that affect all of us.

On behalf of all the Board members, we thank you Barbara for all your hard work.

Now, take a rest (but not for too long!!).

Marilyn Vitale, Editor

Thoughts from the Incoming President

As one of several members of the GROW Slate of Officers for 2015-16 to be presented to the membership at the Annual Meeting on October 25th, I am honored to be considered for President. I urge everyone to attend and participate. These meetings are always very informative and provide an opportunity for each of us to identify how we may better serve the present and future needs of our loved ones.

By way of introduction, my wife Pam and I, along with his brother Andrew, are blessed to have Gregory in our family. He is a 24 year old with autism who continues to grow as a differently-abled young man. Greg's typical day includes participating in the Devereux Day Hab program followed by a stint at Planet Fitness. Our hope is to have him employed and participating in a meaningful way in our community with a residential setting that will be a safe and nurturing home.

As to GROW, I have been amidst this incredible group for just a few years now and each month I gain a greater respect for their efforts and achievements. The dedication and perseverance that these parents and siblings consistently demonstrate is beyond inspiring and none more so than our Barbara. Mrs. Masur has been a force of nature with GROW in pursuing better outcomes towards the best possible life for our loved ones with developmental disabilities. After these many years as President, Barbara will be shifting gears to become the GROW liaison to our elected representatives and provider agencies. Our thanks Barbara for all your outstanding service and your continuing good work.

William E. Mayerik
1st Vice President

DID YOU KNOW...

As a GROW member you receive minutes of Board meetings as well as the agenda of upcoming Board meetings. In addition, news, programs, hearings, etc. are sent to you. Many of you have not given us your e-mail. If you want to be kept up-to-date, please e-mail us at info@grow-ny.org along with your phone number and address.
Maryann O'Toole, Membership Chairperson.

You can send a contribution to GROW in memory or in honor of an individual. Printed acknowledgements will be sent to the proper individuals. You will also receive an acknowledgement. All contributions are tax deductible. For further information contact Cynthia Ferguson, Treasurer. Checks should be made out to Grow with all the pertinent information and sent to GROW P.O. Box 1692, White Plains NY 10602.

Directions to Cedarwood Hall - WIHD WESTCHESTER INSTITUTE FOR HUMAN DEVELOPMENT

FROM THE SOUTH: Sprain Parkway North to Eastview - 100C - Exit. Go Left.

*At Hospital entrance (Second light) go right. Go 4/10 of a mile (passing the county jail) and go left following the sign for All Other Facilities. When you get to the T intersection bear right until the Stop sign. Turn left around oval.

FROM THE NORTH: Sprain Parkway South to Eastview 100C exit. Go right. Follow directions from ** above.

FOR PARKING: Go around circle, pass through parking ticket dispenser and park in lot opposite Cedarwood Hall. Ask for parking voucher at reception desk.

BUS DIRECTIONS: Routes 1, 15, and 14 will leave you off at Elmwood Hall, a short distance from Cedarwood Hall. Route 40 will leave you off at Westchester Hospital, a longer walk.

NEW PROCEDURE FOR RESIDENTIAL REQUESTS

The process for residential placement in an OPWDD certified home is now called the Certified Residential Opportunities (CRO) protocol. It is essentially a vacancy management program that will keep a database of individuals' needs and residential vacancies available. Each DDRO has a CRO team; Region 3 (Capital District and Hudson Valley) is headed by Vicki Tobar. An individual's service coordinator or other referral source completes a residential request form, along with a full packet of information, and sends it to the CRO team. The packet includes a statement signed by families that their service coordinator discussed other residential options with them. The CRO team reviews the information and assigns a placement priority designation. Agencies then receive the information from the CRO team in order to match it with their current openings.

Since there will be a limited number of openings in existing certified houses, GROW understands that the CRO team will be looking to place the highest priority individuals. In addition agencies are under financial pressure to fill these vacancies as soon as possible. GROW is concerned that this situation sometimes results in individuals being placed in residences that are not appropriate for them or for the residents who currently reside there.

OPWDD is in the process of calling families of individuals presently on the Residential Request List, formerly known as the NY State Cares List, to assess their needs more thoroughly. They will be asked if they still need certified residential services, what services they currently have and what other services may be helpful.

OPWDD will be presenting the findings of this survey to the State legislature by February 2016 and will use the information for its future residential planning.

If you have not been called and feel that you would like your needs to be known, you can call 1-844-679-3369 to complete the survey. For further information and to see a copy of the survey questions go to the OPWDD website at http://www.opwdd.ny.gov/opwdd_about/commissioners_page/rrl/home or the Parent to Parent website at

http://parenttoparentnys.org/news/headline-news/opwdd_to_conduct_survey_of_those_on_the_residential_request_list/#sthash.QuDq79KQ.dpuf.

For those who are not interested in a certified home, OPWDD has made a commitment to assist families with self-directed housing supports. Speak to your service coordinator about self-direction, or if you are in the Hudson Valley DDRO, you can contact Michele Altenrath at 845-947-6236.

***GROW State of Officers
and Board Members for 2015-2016:***

OFFICERS:

President.....William Mayerlik
 1st Vice President.....Daniel Maillet
 2nd Vice PresidentPhyllis Smith
 Recording Secretary.....Ray Garofano
 Corresponding Secretary.....Rochelle Kessler
 Membership SecretaryMaryann O'Toole
 TreasurerCynthia Ferguson

BOARD OF DIRECTORS

2016	2017
Judy Frank	Mary Green
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2018
 Mary Dantin*
 Sharon Gelfand
 Marilyn Hahn
 Edie Shumansky*
 Nortrud Wolf Spero*
 Alice Stratigos*

Past Presidents:

Nat Mills (deceased), Morton Steinberg (deceased),
 Kenneth Plath, Diane Greble; Jackie Fowler; Janet Sugar,
 Barbara Masur

***New Members:**

Mary Dantin is the parent of Michele Masi who is 23 and has Down syndrome and autism. Michele is pursuing the option of self-direction for his day programs and eventually for residential. Mary was on the Board of the Arc of Westchester for some years, and in 2014 Mary became a Board member of Pendennis, an advocacy group whose mission is to support individuals with developmental disabilities. **Edie Shumansky** is the parent of Lauren, who is 29 years old. Lauren lives in a Richmond Community Services group residence and she attends the Richmond Day Program in Mount Kisco. Edie is a retired administrator from Columbia University Medical Center, and she presently volunteers on a number of committees at Richmond where she also started a parent/family group. She is a Board member of The Home Program, which provides behavior therapy services. **Alice Stratigos, M.D.** and her husband Peter are the parents of Kristine, who is 37 years old and lives in a YAI residence. Kristine has cerebral palsy with cognitive disability, and she attends YAI's day program in Tarrytown. Alice is a retired pediatrician with a specialty in adolescent medicine and caring for children with disabilities. She moved to Hartsdale, NY in 2011 after practicing in the Chicago area for almost 40 years. Alice presently volunteers at YAI Premier Health Care doing quality assurance work with the staff. **Nortrud Wolf Spero** is the mother of Tanya who is 46 years old and lives in a YAI residence. Tanya attends a Jawonio day program. Nortrud was an original parent member of the Yonkers Committee on Special Education and the Yonkers Special Ed PTA. She is treasurer of The Untermyer Conservancy, on the Board of Yonkers Historical Society, and runs her own real estate agency.

Rochelle Kessler, Chairman, Nominating Committee

GROW MEMBERSHIP APPLICATION or RENEWAL

(please print)

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____ Email _____

Membership Application Renewal

Family (\$20) _____ Single Parent/Guardian (\$15) _____

Contribution beyond dues _____

GROW, Box 1692, White Plains, N.Y. 10602
 GROW is a not-for-profit, tax exempt organization

To check your membership status, look at the mailing label. If there is a "15" next to your name, you are up to date with your membership, and need not renew. Please accept our apologies for any inaccuracies, and please inform us of them.