



NEWSLETTER

ADVOCATES FOR PEOPLE WITH
DEVELOPMENTAL DISABILITIES

SEPTEMBER 2017

Published by GROW, INC.

VOL. 28 NO. 1

P.O. Box 1692

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White Plains, NY 10602

LOOKING AHEAD

**Many changes
are on the horizon...**

Join **Paul Francis**, Deputy Secretary of the Department of Health and Human Services to discuss important changes ahead such as:

- Development of Care Coordination Organizations
 - Movement towards Managed Care
- Learn how these changes will affect services and programs

and

Join **Denise Miranda**, Executive Director of the Justice Center to discuss its role and responsibilities in:

- supporting and protecting the health, safety, and dignity of all people with special needs
- prevention of mistreatment and investigation of all allegations of abuse and neglect

Bring your thoughts and questions!

**Come to the
GROW
General Meeting**

Sunday, October 22, 2017

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

At WIHD – Cedarwood Hall

Westchester Medical Center, Valhalla, NY

Parking vouchers available

PRESIDENT'S MESSAGE...

Over the past two years, GROW has continued to be an integral participant in seeking positive outcomes for the myriad issues affecting our loved ones. Frequently, that has been as one of the founding group members of SWAN of NYS. Established in 2015, SWAN of NYS, a statewide advocacy network as the name says, has proven to be a force multiplier in reaching decision makers. SWAN of NYS is made up of families from Buffalo, Rochester, Albany, NYC, Westchester and soon to be Long Island. This has enabled us to meet with the Director of Medicaid Jason Helgerson, OPWDD Acting Commissioner Kerry Delaney, Deputy Secretary of Health Paul Francis and their associates to discuss our issues and to request a seat at the table for families with those shaping the future for our community. We have had commitments from each to continue the dialogue, seek broader participation and develop effective solutions as we confront system changes in assessment, care coordination and service delivery.

I sincerely hope that we continue to GROW this collegial relationship towards a better safer future for our loved ones. More is more.

As an overdue homage, I wish to acknowledge a debt of gratitude to Mr. Nathaniel Mills. A longtime former condominium neighbor Mr. Mills (I could never call him by his first name) was a founder and the very first president of GROW. It has been a distinct pleasure to continue the work he and his colleagues started. My stewardship ends in October, so I want to wish the very best for Stacy Osborne and the Board in the years ahead.

William E. Mayerik
GROW President

GROW LEGISLATION REPORT

2016-2017

Paul Francis, Deputy Secretary for Health and Human Services, addressed the GROW membership at the Annual Meeting last October 2016. Most of the entire NYS Westchester Delegation were present. GROW presented position papers on Parent/Guardian Bill of Rights, Guardianship, and Residential Development. Many questions regarding other areas such as self direction and managed care were also raised.

SELF DIRECTION: Mary Dantin is part of a statewide OPWDD group made up of providers and stakeholders. Very little head way is being made to address the concerns of those with more complex needs. Also, the conflicts built into day programming still exist.

GUARDIANSHIP: GROW, along with other advocacy groups, worked to prevent a bill that would make significant changes to Article 17A from being passed in The Assembly. However, the bill and another in the Senate are still there in committees, and GROW must continue to be vigilant.

MANAGED CARE: Alice Stratigos is a member of the OPWDD Joint Advisory Council (JAC) on managed care which is made up of providers and parents throughout the state. The JAC is monitoring the transitioning of services for individuals with I/DD to CCO/HH (care coordination organizations/health homes) and specialized managed care.

FAMILY/GUARDIAN BILL OF RIGHTS: After much discussion with Assemblyman Abinanti's office, a palm card listing guardians' rights was created. However, the card lacks rights that are currently in the law as well as omits several that were proposed in the Assemblyman's bill. Barbara Masur will continue to work with both parties.

FUNDING FOR DIRECT CARE WORKERS: GROW joined with agencies and parents throughout NYS (BeFairTo NYCaregivers) advocating for a statewide minimum wage for direct care workers. Funds for this raise were allocated.

RESIDENTIAL DEVELOPMENT: The enhanced funding stream for those coming out of residential facilities has been eliminated. Now the priority level for

them will be based on need as it is with all individuals. GROW has long sought to end that discrimination against individuals living at home. Also GROW has supported Keeping The Promise, a group of parents urging the Governor to keep the promise of The Willowbrook Consent Decree which guaranteed a life in the community for people with IDD. GROW Past President Barbara Masur was part of the group.

JUSTICE CENTER: While not unanimous, GROW supported 911 legislation related to reporting abuse and neglect. The bill was not enacted but served as a jumping off point to rethink the whole issue of abuse and neglect. We will learn much more about this issue at our annual meeting.

Of course, these issues, and many more, were part of our Spring 2017 meeting in Albany.

Barbara Masur
Legislation Chairperson, GROW

DID YOU KNOW....

Eighteen is the legal age in which an individual is no longer a minor, and as a young adult has the right and responsibility to make legal decisions. This includes health care decisions, right to privacy, educational and residential choices, among others. Families need to consider whether their son or daughter is capable of making these decisions. If they definitely cannot, families should obtain legal guardianship.

In New York, Article 17-A Guardianship, specifically for persons with intellectual and developmental disabilities, is a legal proceeding that takes place in Surrogate's Court. Presently there is a movement to make changes to 17-A, mainly because this type of guardianship grants all decision-making rights to the guardian and therefore is seen as an infringement on the rights of the individual. Two bills in the NYS legislature – A8171 in the Assembly and S5842 in the Senate- make changes to 17A, although they are not the same. Both were in committees at the end of the legislative session (June 2017) and will be active when the legislature is back in session.

It is important for families to be aware of these bills, and GROW will continue to monitor them.

IMPORTANT PHONE NUMBERS

September 2017

WESTCHESTER COUNTY DEPT. OF COMMUNITY MENTAL HEALTH

112 East Post Road, White Plains, NY 10601

Main Number 914-995-5242

Michael Orth, Acting Commissioner	914-995-5235
Ashley Ward, Executive Assistant	914-995-5242
Michelle Armisto, Program Coordinator DD Services	914-995-3009
Matthew Faulkner, OPWDD Eligibility & Transitional Students	914-995-5253
Angelique Clavell, Case Manager	914-995-5276

HUDSON VALLEY DDRO Region 3

9 Wilbur Road, Thiells, New York 10984-0470

Joan Volpe, Director.....	914-332-8945
Mary Newhard, Deputy Director of Community Supports	845-947-6060
Debbie Newman, Coordinator of Community Supports.....	845-947-6060
Lewis Prescott, Coordinator of Community Funding and Development	845-947-6060
Michelle Neustadt, Team Leader, Community Supports, Westchester	914-332-8957
Amy Coccodrilli, Front Door Coordinator	914-332-8958
Vicki Tobar, Coordinator, CRO Team and Eligibility	845-947-6011
Janis Levitt, CRO Team	845-947-6037
Michele Altenrath, Self-Direction Liaison.....	845-947-6236
Elizabeth Dunnigan, Administrative Support	914-332-8930
Jill Lipson, Community Support, Orange & Sullivan.....	845-695-7366
Vivian Street, Community Support, Rockland	845-947-6333

FRONT DOOR 914-332-8960

HUDSON VALLEY DDRO, WESTCHESTER OFFICE

220 White Plains Road, Suite 675, Tarrytown, NY 10591

Main Number 914-332-8989

**GROW Slate of Officers and Board Members
for 2017-2018**

Officers:

President	Stacy Osborne
1st Vice President	Alice Stratigos
2nd Vice President	Mary Dantin
Recording Secretary	Ray Garofano
Corresponding Secretary	Rita Ross
Membership Secretary	Barbara Masur
Treasurer	Edie Shumansky

Board of Directors:

2018

- Cynthia Ferguson
- Sharon Gelfand
- Marilyn Hahn
- Daqueen Monroe*
- Maryann O'Toole
- Nortrud Wolf Spero

2019

- Judy Frank
- Shelley Kessler
- Sharon McDowell
- Phyllis Smith
- Mary Zingaro

2020

- Lirio Covey
- Rochelle Kessler
- Cristina Hui Chun Lee*
- Leonard Spano
- Ann Steinberg
- Marilyn Vitale

Past Presidents:

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

***New Members:**

Cristina Lee is the mother of three children; one of them is Martin, a young man who will be 18 next March 2018. Martin has autism as well as physical and visual impairments and resides at the Center for Discovery. Cristina worked for 7 years in International Business, and the last 7 years as a Mandarin teacher. She is fluent in Mandarin and Spanish.

Daqueen Monroe is the mother of Shaquan who is 26 years old and is on the autism spectrum. Shaquan attends the Opengate day habilitation program and lives in an Opengate residence. He was the inspiration for Daqueen to start a nonprofit 501c3 organization entitled The Autism Project-F.L.O.S. (For the Love of Shaquan) Inc. As President and CEO, Daqueen is leading this organization to help bring awareness and the message of inclusion and support for families to Yonkers and lower Westchester county cities. Daqueen has a BBA in Health Service Administration and an MBA from Monroe College. She is presently a student at the CUNY School of Professional Studies pursuing an MA in Disability Studies.

Rochelle Kessler, Chairman, Nominating Committee

**Please RENEW your membership or JOIN GROW now.
We need your membership and we need you to be an ACTIVE MEMBER!
It is our MEMBERS who set GROW's agenda.**

Some of GROW's past accomplishments include:

- Helped to create a Registry for services for persons with developmental disabilities that became a tool for statewide planning.
- Developed information packets for parents and sponsored transition guides for residential services.
- Advocated and continue to urge the State legislators to fund appropriate adult day and residential services. Along with other groups we were responsible for reinstating a \$120 million cut to OPWDD.
- Succeeded in putting the burden of proof back on local school districts when there is disagreement with the CSE.

GROW monitors system changes such as the move to Coordinated Care Organizations and eventually Managed Care. We continue to press for an adequate number of appropriate residential opportunities. We make trips to Albany every year. We also host meetings with our local legislators, and attend County Mental Health meetings as well as regional OPWDD meetings. We are currently working with legislators to create a "Guardian Bill of Rights" to ensure transparency in all aspects concerning persons with intellectual and developmental disabilities. We helped create SWAN of NYS, a statewide coalition of independent parent groups, and have joined forces with other groups to better enable us to advocate on a statewide basis.

Whether it is trips to Albany, the GROW website, the GROW Newsletter, the Helpline, or membership meetings, they all cost money. Please RENEW your membership or join GROW NOW.

Will Mayerik, President

IF you include your e-mail you will receive GROW board minutes, agendas of future meetings, as well as other important info. Please write clearly! GROW DUES ARE TAX DEDUCTIBLE.

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 "18" 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.