



# NEWSLETTER

ADVOCATES FOR PEOPLE WITH  
DEVELOPMENTAL DISABILITIES

AUGUST 2013

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(914) 493-1318

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## COMMUNITY INCLUSION:

### The Olmstead Promise to Provide Services in the Most Integrated Appropriate Setting

- How will the Olmstead decision increase community integration, including school programs?
- How will it affect residential opportunities and daily activities for your family member?
- How will it affect guardianship?

**THIS WILL AFFECT EVERYONE and its  
implementation via the TRANSFORMATION  
FRONT DOOR has already begun!!!**

Join GROW to discuss this important initiative with:

- Joan Volpe, the new Director of the Developmental Disabilities Regional Office 3
- Roger Bearden, NY State Olmstead Decision Implementation

## Come to the GROW General Meeting Sunday, October 20, 2013

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

At WIHD – Cedarwood Hall

Westchester Medical Center, Valhalla, NY

*Parking vouchers available*

### 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.

## PRESIDENT'S MESSAGE...

THANKS IN PART TO GROW'S ADVOCACY the \$120,000,000 cut to OPWDD has been eliminated. THANK YOU to ALL for the e-mails, phone calls, and rallies. (See legislative report for more details.)

### LEAST RESTRICTIVE ENVIRONMENT, COMMUNITY INCLUSION, TRANSFORMATION.....

When my son was diagnosed with autism there was no early intervention, and no guaranteed right to a free appropriate education. State institutions, residential schools and some private school programs were all that was around. Gradually, through much advocacy, things changed, not just for those with autism, but for all persons with developmental disabilities. Institutions started to be emptied out and ICFs were created for people to live in the community. Gradually IRAs, both supervised and supportive, were created with the advent of the first Medicaid waiver. And more recently there is CSS funding. School programs increased in the public sector. Workshops, Day Habilitation and some supportive employment began.

With the Olmstead decision many of these programs and residences are deemed too far removed from true community inclusion.

*While I definitely welcome this movement towards a more fully integrated life for persons with developmental disabilities and feel that we have moved much too slowly in this direction, we must be alert to the hazards that this initiative might bring, if done without careful planning, and family/guardian input and agreement .*

ICFs are now considered institutions, and those with 12 or more people will be forced to reduce the number of

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(Presidents Message continued from page 1)

residents. Four or five is considered the ideal amount. While no one could argue with a smaller amount of residents, our concern is where will the residents go? Who will determine who leaves? What will be the criteria? What will be the quality of the residences?

For those of you who would prefer alternative residential opportunities, CSS funding shows much promise. We must get more involved to see that more CSS funding is allocated: Not just for those just aging out of the educational services into adult services, but for those who are currently awaiting this funding.

The same push is being done in day programming. Here too I personally welcome more people going out into the community, but will that mean less supervision? Students in special education in NYC are already being mandated to go to their local school as opposed to being bused all over the city. As a former NYC teacher I agree that students should go to their neighborhood schools. However what happens if there are no programs there to address their needs?

Even certain types of guardianships are beginning to be thought of as an infringement on the rights of people with developmental disabilities.

It is not enough for a few GROW members to try and have some input into these changes. YOU ALL MUST GET MORE INVOLVED. Start by renewing your membership if you have not already done so. Come to the OCTOBER 20th meeting. Come to Board meetings.

Together we can have a meaningful say in helping people with developmental disabilities lead vital, productive and safe lives.

**Barbara Masur, President**

## **GROW Slate of Officers and Board Members for 2013-2014:**

### **OFFICERS:**

President.....	Barbara Masur
1st Vice President .....	Marilyn Vitale
2nd Vice President .....	Phyllis Smith
Recording Secretary.....	Ray Garofano
Corresponding Secretary.....	Rochelle Kessler
Membership Secretary .....	Cynthia Ferguson
Treasurer .....	Sandy Frank

### **BOARD OF DIRECTORS**

#### **2014**

Sharon Gelfand  
 Mary Green  
 Rita Ross  
 Anne Steinberg  
 Judy Sugar  
 Mary Zingaro

#### **2015**

Fran Grippo  
 Marilyn Hahn  
 John Niland  
 Maryann O'Toole  
 Diane Shand  
 Jerrold Shenkman

#### **2016**

Judy Frank  
 Sheryl Frishman  
 Shelley Kessler  
 Sharon McDowell  
 Stacy Osborne  
 Leonard Spano

#### **Past Presidents:**

Nat Mills (deceased); Morton Steinberg;  
 Diane Greble; Jackie Fowler; Janet Sugar

There were no new members added to the Board this year. GROW welcomes anyone who is interested to attend our open Board meetings the second Thursday of the month. Appointments to the Board can be made throughout the year.

**Rochelle Kessler, Chairman, Nominating Committee**

## **Administrative Changes at the Office for People with Developmental Disabilities (OPWDD)**

**Courtney Burke** has left the position of Commissioner of OPWDD to become the NY State Deputy Secretary for Health. The new Acting Commissioner of OPWDD is **Laurie Kelley**. The Governor intends to nominate Ms. Kelley to serve as Commissioner of OPWDD during the next legislative session. Her nomination is subject to confirmation by the New York State Senate. Most recently, Ms. Kelley has been the Executive Director for the Ulster-Greene ARC for eleven years, where she led the Taconic region on Portal Initiatives and Individualized Supports and oversaw a \$50 million budget and over 1,000 employees. Before joining ARC, she served as Vice President of Business Development, Professional Services, and General Services at Benedictine Hospital where she worked for 19 years. Ms. Kelley received a Bachelor's Degree in Food and Nutrition from the University of Iowa, as well as a Master's Degree in Business Administration from Union College.

**Michael Kirchmer** has retired from the position of Director of the Developmental Disabilities Regional Office 3. The new Director of the DDRO 3 is **Joan Volpe**. Ms. Volpe has more than 21 years of progressive, broad-based management experience in the nonprofit human services field serving individuals with varying disabilities in a variety of settings. Most recently, she served as Vice President of Services at Ability Beyond Disability in Brookfield, Connecticut, a position she had held since 2008.



**ADVOCATES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES**  
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**GUIDE TO STATE LEGISLATORS**

<b>STATE ASSEMBLY:</b>	<b>District</b>		
<b>J. Gary Pretlow</b>	A87	6 Gramatan Ave., Suite 407 Mount Vernon, NY 10550 (914)-667-0127	pretloj@assembly.state.ny.us
<b>Amy Paulin</b>	A88	700 White Plains Road #252 Scarsdale, NY 10583 (914)-723-1115	paulina@assembly.state.ny.us
<b>David Buchwald</b>	A89	125-131 East Main Street Mt. Kisco, NY 10549 (914)-244-4450	buchwaldD@assembly.state.ny.us
<b>Sandra Galef</b>	A90	2 Church Street Ossining, NY 10562 (914)-941-1111	galefs@assembly.state.ny.us
<b>Steve Otis</b>	A91	933 Mamaroneck Ave., Suite 102 Mamaroneck NY 10543 (914)-777-3832	otiss@assembly.state.ny.us
<b>Thomas Abinanti</b>	A92	303 S. Broadway, Suite 229 Tarrytown, NY 10591 (914)-631-1605	abinantit@assembly.state.ny.us
<b>Shelley Mayer</b>	A93	35 E. Grassy Sprain Road, 406B Yonkers, NY 10710 (914)-779-8805	mayers@assembly.state.ny.us
<b>Steve Katz</b>	A99	824 Route 6 Mahopac, NY 10541 (845)-628-3781	katzs@assembly.state.ny.us
<b>NEW YORK STATE SENATE</b>			
<b>Jeffrey Klein</b>	S34	3612 East Tremont Avenue Bronx, NY 10465 (718)-822-2049	jdklein@nysenate.gov
<b>Andrea Stewart-Cousins</b>	S35	28 Wells Avenue, First Floor Yonkers, NY 10701 (914)-423-4031	scousins@nysenate.gov
<b>Ruth Hassell-Thompson</b>	S36	959 East 233 <sup>rd</sup> Street Bronx, NY 10466 (718)-547-8854	hassellt@nysenate.gov
<b>George Latimer</b>	S37	222 Grace Church Street Port Chester NY 10573 (914)-934-5250	latimer@nysenate.gov
<b>David Carlucci</b>	S38	95 S. Middletown Rd Nanuet, NY 10954 (845)-623-3627	carlucci@nysenate.gov
<b>Greg Ball</b>	S40	1441 Route 22, Suite 205 Brewster, NY 10509 (845)-279-3773	gball@nysenate.gov

# LEGISLATIVE REPORT

Early last December 2012 GROW members met with Deputy Secretary for Health Jim Introne. The Deputy Secretary was very busy and our meeting lasted just an hour. We went away with the news that the Governor's proposed budget for OPWDD would remain flat.

With this news, coupled with the chance of snow, we pushed back our annual Albany trip until April. Unfortunately you all know what ensued between December 2012 and April 2013. Because of federal Medicaid overpayments, OPWDD was being hit with at first a \$120,000,000 cut, then reduced to \$90,000,000. Despite all the rallies, phone calls, e-mails etc., only a few members of the Westchester delegation of the State Legislature voted against these cuts. Even though it is now academic, if you want to know who they were call our Hotline, (914-493-1318). GROW members are not shy, and several expressed their displeasure directly to our legislators. The cuts were not supposed to affect direct care services; rather funds would be obtained by routing out fraud, inefficiencies, overpayments, amongst other measures. However thanks to Assembly members' resolutions, Senate cooperation, and Speaker Sheldon Silver, agreement has been reached. If the full \$90,000,000 is not recouped by these measures, the State will give OPWDD the difference. So I guess all our efforts paid off in the long run. Give yourselves a pat on the back and THANK YOU to our Legislators for doing the right thing.

We also met with Roger Bearden who is in charge of implementation of the Olmstead decision. You will hear more about this at our general meeting. While it was unfortunate that Commissioner Burke was unable to attend our meeting, several OPWDD staff members, along with Jim Moran former budget director of OPWDD and Michael Kirchmer former DDRO Region 3 Director were there. They expressed interest in our Family/Guardian Bill of Rights. We are hopeful that eventually something will be enacted. We are currently updating this and plan to have handouts at our general meeting. We also learned that the waiver proposal still has not been approved. However OPWDD has requested letters of intent from organizations wanting to be DISCOs. Also they have initiated a Transformation process with a Front Door procedure to dovetail with

Olmstead implementation. Joan Volpe, new Director of DDRO Region 3 will be at our meeting to answer questions about these initiatives.

Lastly the ongoing saga of curtailment of important early intervention continues. There had been two successive cutbacks in funds for this vital program. As of April counties were no longer responsible for funding these programs, and the Dept. of Health was put in charge. This has led to an incredible amount of paperwork for agencies resulting in a holdback in payments to them. Several have had to close.

As you can see whether your child is young or older much needs to be done. Please refer to the attached list of legislators and use it to express your concerns.

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## FROM THE EDITOR...

In this issue you will see two lists. One is of the State Legislators. We all found out how important it was to contact our legislators during the budget process this past spring when major cuts to the OPWDD budget were proposed. We should keep in touch with our legislators at all times so that we are aware of legislation and financial issues that affect us and our family members. The other list is the GROW Board of Directors. This year we were not able to add any new members so the positions remained the same. However, we can make appointments to the Board throughout the year, and so we welcome you to attend our open Board meetings and become a part of the future of GROW. There are big changes ahead that will affect everyone, but especially those of you with family members aging out of school and entering the adult world of services.

You will also find a GROW 2013 membership letter. We apologize for its lateness, and thank you to those who have already joined. Please renew or join up today.

Consider being part of a group that has always and will continue to advocate for the appropriate services for our family members. GROW meets the second Thursday of the month at WIHD at 7:45 pm. Call ahead at 914-493-1318. All are welcome!

*Marilyn Vitale, Editor*