



NEWSLETTER

ADVOCATES FOR PEOPLE WITH
DEVELOPMENTAL DISABILITIES

APRIL 2011

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(914) 493-1318

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The Future is Now!!

It is **TIME** to address these Important Issues:

- Guardianship
- Special Needs Trust
- Advocacy
- Planning for Advanced Health Care

Please Join

Sheryl R. Frishman, Esq.,
President Arc of Westchester,

Lawyer at Littman Krooks, LLP dealing with the entire range of issues involving persons with developmental disabilities.

Parent of three children, one of whom has autism.

GROW Board Member....

and

Ellen Lamonoff, RN, MS,
Director of Nursing Services, WJCS

as they explain **what, when, and how** to take care of these issues...

Come to the GROW General Meeting *Sunday, May 22, 2011*

Brunch: 10:30 a.m. • Meeting 11:00 a.m.

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

Parking vouchers available

PRESIDENT'S MESSAGE...

It Could Always Get Worse???

Our last General meeting dealt with how to manage resources in difficult times. If we hold a similar meeting it would have to be entitled "How to Manage Resources in Even More Difficult Times."!!

We went up to Albany, (see legislative reports inside) with hopes of rolling back, or eliminating the Governor's proposed cuts to OPWDD and Early Intervention Services. Even though a budget has been adopted, providers and consumers are just beginning to learn about its impact. We believe that instead of a 3% cut for OPWDD it was reduced to a 2% cut, and that instead of a 10% reduction in funding for Early Intervention it was reduced to a 5% cut. We think that GROW, along with other advocates, helped lessen the cutbacks. Is the end result good? No, but it could have been worse.

Then it did get worse!! An article in The New York Times (March 13, 2011) described instances of physical abuse inflicted on residents of State –run homes. While one can't put the blame on any one individual or group, certainly a lack of adequate funding for training staff and funding for appropriate monitoring had to play a role (see my Letter to The Editor).

More and more we see the need for us to be involved. It is only by being involved that we, who have a most personal stake, can ensure that our family members lead lives of dignity, free from physical and mental harm in a safe environment. We at GROW have always felt that information is power and that is why we believe that informing you is a most vital role. However we too must be kept informed and that is why we want legislation that will open up the arcane funding mechanisms that drive OPWDD services. In addition we want meaningful input as to how those funds are utilized (see GROW's position

(continued on page 2)

(Presidents Message continued from page 1)

paper inside). We also need more of you to advocate with us. I am continually surprised that at a time when so little of any kind residential development is going on, when day habilitation services are being doled out, and when nearly every service demands a priority status, we haven't heard from more of you. You are welcome at Board meetings. Tell us what you think or need via our hotline or e-mail. There is strength in numbers and ***Remember It COULD Always Get Worse.***

Barbara Masur
President

***Letter to the Editor (NY Times)
Re: "At State-Run Homes, Abuse and
Impunity", March 13, 2011***

As president of GROW, Advocates for the Developmentally Disabled, a voluntary group made up mainly of families of persons with developmental disabilities, I read with dismay, but unfortunately not surprise, about the abuses at state-run homes.

While blame must be placed primarily at OPWDD, and then the arbitrators and the Civil Service Employees Union, I was surprised to find no mention of the effects that budget cuts to OPWDD have had on this sorry state of affairs.

Since 2008, even before the current recession, OPWDD has sustained cutbacks. These cutbacks eliminated nearly any new development. They also affected the quality of existing services for state-run programs as well as those run by not-for profits:

Oversight: Several years ago a program involving Medicaid Service Coordinators (MSC's) was instituted to ensure that people receiving a less costly form of care were guaranteed the services they required. The MSC was to provide monthly contact (in most cases visits) to the person with developmental disabilities. These services were cut back to 3 times a year. Obviously less oversight allows for more abuse.

Training: There are ways to restrain someone without punching them in the eye! OPWDD has never provided enough training to its direct care workers, and there are no minimum state training requirements for the many not-for profits who also service people with developmental disabilities. In addition, MSC's should be trained to spot abuses.

Fire Safety: GROW has long advocated for enough staff, and /or appropriate structural changes to ensure the 3 minute evacuation requirement. Obviously in the case Mr. Monsour pointed out, more staff was required. In other cases structural changes are required. However without

appropriate funding neither will occur. We have also requested that OPWDD personnel monitor surprise fire drills at not-for-profit residences, and that some outside agency monitor state-run house fire drills. Once again with cutbacks in OPWDD personnel and cuts in overall funding this is not going to occur.

This is just the tip of the iceberg, and we have been told to expect further cutbacks. This is occurring without any input from individuals with developmental disabilities, family members, provider agencies, and other advocates. We fear that until these cutbacks are stopped there will continue to be these and other abuses.

We also hope that the person Governor Cuomo is nominating for Commissioner of OPWDD has some knowledge and/or experience in the field of developmental disabilities and not someone put in place to make further cutbacks.

Barbara Masur, GROW President

GROW, PO Box 1692, White Plains, NY 10602,
Helpline (914) 493-1318

WHAT'S HAPPENING...

Governor Andrew M. Cuomo has named Courtney Burke as Commissioner of the Office of Persons with Developmental Disabilities (OPWDD) and Roger Bearden as Chair of the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQ-CAPD). The Governor also announced that Clarence J. Sundram will serve as Special Advisor on Vulnerable Persons.

Courtney Burke was director of the Rockefeller Institute's New York State Health Policy Research Center, where she oversaw all health policy research projects at the Institute and was the project director for the Institute's recent research on county variations in Medicaid long-term care. Ms. Burke previously worked as the senior research scientist in the health and Medicaid studies program at the Institute; her research focused primarily on health policy issues related to Medicaid and the Children's Health Insurance Program (CHIP), health reform and private insurance coverage. She also has written about nonprofit organizations' dependence on Medicaid funding and the effects of the state fiscal crises on nonprofits. Prior to joining the Institute, Ms. Burke was employed by the New York State Office of Advocate for Persons with Disabilities for several years, including as the senior policy analyst, and by the New York State Department of Health.

Legislative Report, February 15, 2011

In a season of blizzards, ice storms and floods, the weather was good on February 15 and we were able to make our annual trip to Albany as planned.

We picked up the Orange County Contingent on the way, but parted upon arriving in Albany. The Westchester group met with members of the Assembly from Westchester County. They included: Assemblymen Mike Spano, J. Gary Pretlow, George Latimer, Robert Castelli, Tom Abinanti, along with a representative from Sandra Galef's office. Unfortunately the Senators were at a mandated meeting. While being sympathetic to our requests to rollback the cuts to OPWDD and Early Intervention, they felt that without the extension of



GROW Members with NYS Assemblymen from Westchester. Pictured from left, seated Assemblyman Mike Spano, Assemblyman J. Gary Pretlow; on right, Assemblyman Tom Abinanti.

the millionaire's tax, the cuts were inevitable. Tom Abinanti is on the Assembly Mental Hygiene Committee and said that he would work with us to create legislation ensuring transparency and input for parents, guardians and others concerned with persons with developmental disabilities.

We reunited with members from Orange County and then visited former Acting Commissioner Max Chmura, and Elsie Chun, Director of Human Resources from the Governor's Office. Michael Kirchmer, Director of HVDDSO was also present. We presented our willingness to work with OPWDD to help develop alternative residential settings, and spoke of the reluctance of HVDDSO to be more amenable to this concept. We also spoke of the need for OPWDD to be more proactive in the area of fire safety with the not-for-profits. While no funding for this was forthcoming, Michael Kirchmer did offer training, and said that we should contact him if we felt that regulations were not being met. Regarding our need for input and information nothing was said at that meeting, but former Commissioner Max Chmura did speak about involving parents more in his last e-mail to OPWDD and consumer groups. We drove back to The Legislative Office Building, and met with Felix Ortiz, Chairman of the Assembly Mental Hygiene Committee. He listened to our concerns and expressed a willingness to come to Westchester and work with Tom Abinanti to bring about necessary legislation. Lastly we met with an aide to Roy McDonald, Chairman of the Senate Mental Hygiene Committee. He too expressed a willingness to work in a bipartisan way to bring about desired legislation. Both Senator McDonald

and Assemblyman Ortiz felt that there was a need to keep the millionaire's tax to avert drastic cutbacks. (See the list of all members of the Mental Hygiene Committees and their contact information in this newsletter.)

Subsequent to this meeting we learned that Director Kirchmer helped several GROW members with their individual concerns. He also would like to have more frequent meetings with us.

We also found out that Westchester County has 4 members on the Legislature's Mental Hygiene Committee. In the Senate they are Jeffrey Klein, and Greg Ball. In the Assembly they are Tom Abinanti and Steve Katz.

Submitted by:

GROW Board Members

Rochelle Kessler and Jim Pinsley

Orange County Legislative Report, February 15, 2011

Orange County advocates accompanied the lobby contingent to Albany on February 15, 2011. It was unfortunate that all of the legislators who represent Orange County were in meetings or trainings that day. However, the Orange County group did stop in the offices of Assemblywomen Annie Rabbitt, Aileen Gunther and Nancy Calhoun, presenting the GROW folder with the position papers and verbally outlining the important points to the assemblywomen's staff. The three also dropped off a packet in Senator Bonacic's office and repeated the brief oral outline.

The trip was a wonderful opportunity to express both the fears precipitated by the cuts threatened by Governor Cuomo and the hopes that there will be legislation to create a process for families and self-advocates to have a voice in future planning and decisions regarding OPWDD services in the community.

As always, it was a pleasure to see the GROW board and other Westchester members and learn from them. Thank you for the continued work of GROW that benefits all individuals with developmental disabilities living in New York.

***Anne Klingner, CAPIS Coordinator,
Mental Health Association in Orange County, Inc.
GROW Member, Parent***



GROW Members with NYS Assemblyman Felix Ortiz (seated third from left) Chairman, Assembly Mental Hygiene Committee.

POSITION PAPER ON TRANSPARENCY

GROW is a parent and family run organization whose dedicated members have volunteered their time for nearly thirty years to advocate for a full range of supports and services to enhance the lives of people with developmental disabilities.

During all this time we have experienced limited and inconsistent dialogue with statewide agencies responsible for providing these services. Now during these fiscally challenging times, it is extremely important that groups such as GROW have ongoing input to help determine priorities for services.

We would like to create a transparent environment in which there is the opportunity for open communication between all stakeholders and in particular parents, self advocates and other family members.

We recognize that there are many issues facing OPWDD and believe that a transparent environment coupled with a proactive partnership would be one way to address the full spectrum of planning for the needs of individuals with developmental disabilities.

WESTCHESTER LEGISLATORS ON THE STATE LEGISLATURE'S MENTAL HYGIENE COMMITTEES

Senators Jeffrey Klein (718) 822-2049, jd Klein@nysenate.gov *Northern Bronx, Pelham, Tuckahoe, Scarsdale, Mt. Vernon,(parts) Bronxville
 Senator Greg Ball, (845)279-3773 gball@nysenate.gov * Yorktown Heights, Somers, Katonah, parts of Dutchess and Putnam Counties
 Assemblyman Abinanti, (914) 345-0432 abinant@assembly.state.ny.us * Greenburgh, Tarrytown, Ossining, Elmsford
 Assemblyman Steve Katz, (845) 279-5301 katzs@assembly.state.ny.us *Yorktown Heights, Somers, Katonah, parts of Dutchess and Putnam Counties
 * Areas are not all inclusive.

If any of these legislators represents you, call or e-mail them and ask them to work with GROW to create legislation guaranteeing family, guardian, and self-advocate input, along with measures to ensure transparency.
 Better yet, if you are able to join GROW members to meet with them in their local offices, call the hotline 914-493-1318 and let us know.

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 Ellwood Hall, a short distance from Cedarwood Hall. Route 40 will leave you off at Westchester Hospital, a longer walk.

GROW MEMBERSHIP APPLICATION or RENEWAL (please print)

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____ Email _____

Membership Application Renewal

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

Associate (\$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. The date listed is the last time you joined GROW. If there is no date you have never been a member!! Please accept our apologies for any inaccuracies, and please inform us of them.