



NEWSLETTER

ADVOCATES FOR PEOPLE WITH
DEVELOPMENTAL DISABILITIES

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PRESIDENT'S MESSAGE...

The Importance of State Legislators

Most of you probably know who your federal legislators are, and I'm sure you know your local officials. But do you know who your state legislators are, and how important they are to people with developmental disabilities?

Education: Yes, we know that local property taxes pay for the bulk of educational funding. Also, the federal government contributes a small part. In between is state funding. Even more important are the regulations. While the federal government addresses broadly how children with handicapping conditions should be educated, it is the state government that deals with the specifics.

Family Support: Respite, recreation, homemakers, etc. etc. I have been told that the bulk of the funds for these programs come from the state.

Adult Services: Residential, day programs, etc. While many of the funds are federal, with their broad regulations, these funds are enhanced by New York State whose regulations are more specific.

Knowing all of that, GROW journeys annually to Albany to meet with the Commissioner of OMRDD, the budget director of OMRDD, personnel from the governor's office and key legislators for developmental disabilities. A report of this year's meetings is included in this special edition. After reading this report, you will see how much work needs to be done, and how important organizations such as GROW are.

In addition we have been visiting our own legislators locally. So far we have met with Senator Andrea Stewart-Cousins, Assemblyman Mike Spano, and Senator Jeff Klein. GROW members intend to express our concerns to as many members of the Westchester delegation of New York State legislators as possible.

To help you hear where they stand on several issues we invite you to attend our CANDIDATES' MEEETING, SUNDAY MORNING, OCTOBER 19th. Look for more information in an upcoming newsletter.

In the meantime stay informed!!! If you don't know who your state legislators are, call your local League of Women Voters or the Westchester Board of Elections.

Barbara Masur, President of GROW

FROM THE EDITOR...

Every year GROW members visit Albany in order to advocate for services for people with developmental disabilities and to let state officials know about GROW. This special edition of the GROW Newsletter highlights the trip on May 13, 2008. Included are the GROW Position Paper that was presented to each person in Albany, as well as the Albany Report, which describes the issues discussed at the various meetings.

This year GROW focused its Position Paper on residential opportunities. Since we had been informed that there would be only thirty seven opportunities available to persons in the Hudson Valley DDSO area, GROW felt that this needed to be addressed. We were able to express our experiences and voice our concerns, and in return, we received information and clarification. A follow-up meeting at the Hudson Valley DDSO on June 13, 2008 helped answer more questions. What is abundantly clear from these meetings is that open communication is a must. We must be able to get accurate, understandable information, and state and local officials must always be willing to listen to our concerns.

GROW members stay informed by attending various local and state-wide meetings and forums, including a monthly meeting at the Department of Community Mental Health. GROW is committed to passing along this information through its meetings, hotline (914-493-1318), and newsletter. We welcome any comments, viewpoints, or other information. Help us help you to stay informed!

Marilyn Vitale, Editor

POSITION PAPER FOR ALBANY: MAY 13, 2008

In the years since the revelation of the horrors of Willowbrook, New York State has transformed the lives of most people with disabilities. They are an important part of the community, attending schools, eating in restaurants, working and earning money in local businesses. They lead full lives. They must also have the opportunity to live in their own communities. Now at this time of budget constraints, GROW is concerned about how this basic need will continue to be met.

There must be residential opportunities for all who need them. In the past limited residential opportunities resulted in much family stress and often inappropriate living situations.

The registry at the Westchester County Office of Community Mental Health lists a total of 365 people who will need homes: 248 are over age 21, 95 are under age 21, and 22 are aging out of residential schools. Another 90 people are awaiting alternative placement. Westchester is part of the Hudson Valley DDSO, which includes three other counties. Can it be that there will be only 37 residential opportunities this year for all of these people?

We also learn that through restructuring 13 to 15 of these residential opportunities will put vulnerable people into situations with less than 24 hour supervision. There is concern by many people, especially those working in the field and family members, that people with disabilities who lack appropriate training and support for their more independent living arrangements are preyed upon, abused, stolen from and generally living in unsafe situations. To avoid this, we ask that people be carefully chosen, and that they, their families, and their current agencies, agree to a less supervised living situation. We also ask that these individuals receive extensive training, which is only lessened when they have demonstrated that they can thrive in this less supervised environment.

GROW asserts that development of an adequate number of APPROPRIATE residential opportunities must be a top priority in meeting the needs of people with developmental disabilities!

ALBANY REPORT: MAY 13, 2008

Meeting with OMRDD Commissioner Diana Jones Ritter:

At the start of the meeting, GROW members gave a brief history of various experiences with residential opportunities. One member explained how the closing of state institutions created opportunities, including one for his child. Others described how the lack of opportunities in the early and mid '90s caused their children to go into residences that had openings, whether or not they were appropriate (so-called "backfills"). And others described the benefits of NY State Cares in providing homes for their children.

GROW then expressed concern about the fact that only 37 residential opportunities, 37% of which would be for supportive situations (that is, less than 24-hour supervision), are allotted for the Hudson Valley DDSO area. Commissioner Ritter explained that the 37% reflected the wishes of self-advocates and families when asked on a survey what type of residential opportunity they prefer. She emphasized that this was not a mandate, and that no one would be forced out of their present residence. She also pointed out that there are a number of homes presently in development. In response to a report that funding for Family Support Services was increased to help families keep their children home "as long as possible," Commissioner Ritter said that that was not the case, but rather funding was there so that families could keep their children at home "as long as they choose." She emphasized her commitment to personal choice and person centered planning, and at the same time a desire to try new approaches such as having families hire their own residential habilitation support professional.

Finally, Commissioner Ritter expressed concern about the federal regulations that would dramatically hurt New York State Medicaid funding. Considering state budget constraints, she felt that OMRDD received more funding than other agencies.

Commissioner Ritter introduced Associate Commissioner Stephen Smits who agreed to schedule a follow-up meeting.

*Meetings with Governor David Paterson's Staff
and Legislators:*

GROW members met with Michael Seereiter, Program Director of Mental Hygiene Services who reiterated the budget constraints and concern over the federal regulations concerning Medicaid funding.

Unfortunately, neither Senator Morahan nor Assemblyman Rivera was available. However, GROW did speak with Bill Egger who is a senior analyst on the Mental Health Committee and works for Speaker Sheldon Silver. Mr. Egger discussed the fact that community opposition to residences is still strong in many places, and that there even was a bill submitted to Assemblyman Rivera to put a cap on

(continued on page 3)

(“Albany Report” continued from page 2)

development. Fortunately, that bill did not make it out of committee.

Meeting with staff from Division of the Budget:

GROW members met with Lou Raffaeli and four members of his staff, all of whom work on Mental Hygiene and Developmental Disabilities funding. GROW addressed the proposed slow down in residential development in relation to the growing number of people on the waiting list. Mr. Raffaeli explained that they are waiting for the spending plan from Commissioner Ritter at which point they will have a better idea about the amount of money being requested for the various program areas, including residential. The spending plan will reflect the governor’s directive to his commissioners to reduce their budgets by 3+ %.



GROW members with Michael Seereiter (front center), Program Director of Mental Hygiene Services.

GROW also discussed our concerns about the proposed increase in the development of less than 24 hour supervised residential opportunities. While this is a less expensive option for those who may want/need less supervision, the transition period requires intensive training and flexible supports so that our sons and daughters are not put at significant risk.

Lastly, the Medicaid funding issue was discussed again. Change on the federal level could have quite an impact on OMRDD. In any case, the current economic climate does not bode well for continued growth in services; rather we are going to be asked to look at how the dollars that we have are being spent. All of the staff who met with us from the Division of the Budget were very receptive and clearly stated that it was important for them to hear from us.

Follow-up Meeting with Stephen Smits, Associate Commissioner: June 13, 2008:

Associate Commissioner Smits met with GROW to further clarify some of the issues raised in Albany. In attendance were Janet Wheeler, Sareh Arya, and Ira Rothenstein from the Hudson Valley DDSO, along with GROW members. In reference to GROW’s concern about limited residential opportunities, Commissioner Smits explained that there are 37 opportunities for the next three years in the Hudson Valley area, 600 opportunities for the entire state, and 400 more to be allocated. Once the 37 opportunities are satisfied, there may be more supported opportunities available. He reiterated that the amount of 37 opportunities is a goal, not a mandate. In addition, there are approximately 90 opportunities presently in development in the Hudson Valley DDSO area. In some cases development has been delayed due to local opposition.

GROW members touched on other issues, which will be discussed at a later time. GROW asked that these meetings with the DDSO convene on a regular basis. Therefore, another meeting is set for September 12, 2008.



GROW members with OMRDD Budget Director Lou Raffaeli (seated left) and his staff.



GROW members with OMRDD Commissioner Diane Ritter-Jones (6th from the right, standing).

WHAT'S HAPPENING...

- Every year GROW has presented the Tony Luccaro Award to an individual who works directly with people with developmental disabilities. Past recipients include a nurse, medical assistant, direct care worker, and a psychologist. The person nominated should show extraordinary dedication. The award will be presented at the October meeting. If you know such an individual please contact Mary Zingaro at the GROW Helpline, 914-493-1318.
- OMRDD is looking for advocates for persons living in residences who have no family or others in this role. The advocate would share birthdays and other events with the person as well as sit in on meetings and reviews. For more details call Janet Sugar at the GROW Helpline, 914-493-1318.
- The next meeting of the Subcommittee on Mental Retardation and Developmental Disabilities at the Department of Community Mental Health, 112 East Post Road, White Plains, is on September 3, 2008 at 10:30 a.m. It is open to family members. For further details, call 914-995-5256.

GROW HelpLine (914) 493-1318

GROW

is an organization primarily of parents of individuals with developmental disabilities. Its purpose is to advocate for a full spectrum of opportunities to enable their family members to achieve their greatest potential. GROW is an all-volunteer organization, independent of any provider agency. GROW has been successful in its advocacy efforts because it has only one item on its agenda, the best possible lives for their family members with developmental disabilities.

Join together, Join GROW

**It's There for YOU.
You can get us through e-mail
Info@grow-ny.org
Find out about us through the web
www.grow-ny.org
and there is always the phone
(914) 493-1318**

GROW MEMBERSHIP APPLICATION or RENEWAL

(please print)

Name _____

Address _____ City _____ State _____ Zip _____

Phone _____

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

If there is a particular subject you would like to have presented at a GROW meeting please let us know.