



NEWSLETTER

ADVOCATES FOR PEOPLE WITH
DEVELOPMENTAL DISABILITIES

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PRESIDENT'S MESSAGE...

Our Trip to Albany: Now It's Up to You

As I write this column our State budget still has not passed, and there is always the danger that OMRDD funds can be cut even more. On our recent trip to Albany, GROW told our State legislators that OMRDD should not have to sustain any further cuts. These cuts would involve ALL of their programs. Read our position paper on budget cuts in this issue.

WHAT CAN YOU DO? Keep up the pressure. Call your State legislators and urge them not to reduce funding to OMRDD.

On our recent trip to Albany, GROW voiced our deep concern about the lack of future residential development of ALL types. Read our position paper on residential development in this issue.

WHAT CAN YOU DO? Call your County residential coordinator. In Westchester it's Cindy Lanza, 914-995-5242. Make sure your family member is registered. Make sure that they know your family member's residential needs. Contact your State legislators. Express your concerns to them.

On our recent trip to Albany, GROW sounded the alarm about the dire state of fire safety in residences. Read our position paper on fire safety in this issue.

WHAT CAN YOU DO? If your family member is in a residence, insist on seeing their fire safety plan. If you have concerns about the plan, ask that it be updated and revised. If you have any trouble please call GROW at 914 493-1318. We are currently researching how we can find out more about your rights as a family member or guardian of a person with developmental disabilities.

Throughout this article I have shown you what GROW is currently trying to accomplish, BUT we also know that there is strength in numbers.

WHAT CAN YOU DO? The more of you that become active, the better are our chances of helping our family

members live safe and productive lives. So please become more active in GROW. Come to our Board meetings. They are generally held the 2nd Thursday of the month, from 7:45-9:30PM but contact the help line (914 493-1318) to confirm, AND MAKE THOSE CALLS!!!!

*Barbara Masur
President*

FROM THE EDITOR...

The GROW Board of Directors is seeking new members who will meet with us monthly and help shape the future of our organization. Most of the present Board members have been advocating for many years, beyond their own family's needs, to help ensure services for all individuals with developmental disabilities. Advocacy activities have included speaking to legislators in Albany, meeting regularly with OMRDD and Hudson Valley DDSO directors and others, and arranging for key speakers to present information to families. Now more than ever, it is imperative that new members become involved. The DIRE FINANCIAL SITUATION requires CREATIVE SOLUTIONS to enable services to continue. Residential opportunities, work, day programs are all affected by finances. Those of you whose family member is transitioning from school to adult programs will soon realize how NECESSARY IT IS TO ADVOCATE for the appropriate level of services. WE NEED YOU TO JOIN GROW as ACTIVE MEMBERS!! Call our hotline number: 914-493-1318. One of our Board members will return your call and explain how you can be part of the strategizing and decision-making that will direct the future activities of GROW. Help GROW fulfill its mission of advocating for the full range of support services for persons with developmental disabilities! GROW meets the second Thursday of the month at WIHD at 7:45 pm. Call ahead. GROW HAS A TERRIFIC NEW WEBSITE! Find out what's happening, locate important resources, and take a look at our past and present newsletters. Check it out at <http://www.grow-ny.org>.

Marilyn Vitale, Editor

GROW POSITION PAPERS

POSITION PAPER ON RESIDENTIAL DEVELOPMENT

GROW asserts that continued development of residential opportunities with the appropriate level of supports must be a top priority in meeting the needs of people with developmental disabilities.

GROW, a parent and family advocacy group, has focused on addressing the community based residential needs of people with developmental disabilities for the past 30 years. As parents and family members, we have worked closely with other families, self-advocates and provider agencies to assure that the needs of individuals are met in the communities where they live. When the reality of slow residential development failed to meet the needs of people who were on long waiting lists, Governor Pataki and Commissioner Tom Maul created New York State CARES. For ten years from 1998 to 2008 residential opportunities were created that were more ‘individualized’ than any development had been to date.

Now, OMRDD plans to individualize residential supports further, with a major focus on those individuals who may need less than 24 hour supervision. While we support flexible options in principle, GROW has two areas of concern regarding this initiative:

1. For those who truly do not need 24 hour supervision but who are currently living in a 24 hour supervised setting either at home with their families or in an IRA, the transition to a less supervised setting must be well supported with significant education and training, flexible supports that provide a safety net, and some form of supervision or oversight.
2. And for those who need 24 hour supervision throughout their lives, there needs to be continued development of new residential options that provide the level of care to keep them healthy and safe – emotionally and physically – while offering them opportunities to be contributing members of their communities. Relying on existing vacancies cannot be the only option.

GROW supports a full range of residential options for people with developmental disabilities, including more independent choices. Yet, while there is some dignity in being able to take risks, as parents and family members we are painfully aware of the vulnerability of our sons and daughters, brothers and sisters, and we feel strongly that safety must be a primary consideration.

GROW firmly supports OMRDD’s mission of Putting People First. Although we recognize that the current budget crisis has a major impact on the development of services, it should not minimize the needs of those that require the highest levels of support.

GROW POSITION ON CUTBACKS to OMRDD

GROW ASSERTS THAT OMRDD HAS BORNE THE BRUNT OF CUTBACKS FOR THE LAST TWO YEARS AND REQUESTS THAT SOME OF THESE CUTS BE ROLLED BACK

GROW applauds the reinstatement of the trend factor, but requests that the Commissioner mandate that it goes to direct care workers.

While the cuts will affect most of the services that OMRDD provides, it is their impact on residential development and fire safety that most concerns us.

RESIDENTIAL DEVELOPMENT:

There has been no decrease in the number of people on wait lists in the Hudson Valley DDSO area. At last count it was over 400 in Westchester County. As a result of the proposed cuts, OMRDD is planning to move people to less supervised settings, thereby creating vacancies for people on the wait list. While these less supervised settings are less costly, many of the people selected for them are not ready, and do not want to move. The vacancies created are often inappropriate for those awaiting initial placement. Along with less supervised residences we need development of 24 hour supervised residences. However, we fear that with further cuts there will be little if any appropriate residential development.

FIRE SAFETY:

GROW ASSERTS THAT OMRDD ALLOCATE ADEQUATE FUNDING SO THAT RESIDENTS CAN BE SAFELY EVACUATED WITHIN THREE MINUTES. Many of the essential recommendations (adequate staffing, additions to facilities) will require additional funds. Cuts in OMRDD will put additional lives at risk.

SPECIAL NEEDS REGISTRY

Westchester County has a Special Needs Registry for individuals who may need assistance during an emergency situation. The county will share your information with your local municipality so they are aware of your needs. Any individual with special needs who lives independently or in the family home is eligible. Sign up for yourself or your family member either online at www.westchestergov.com/specialneeds or call 211 or the United Way at 800-899-1479.

GROW'S POSITION PAPER ON FIRE SAFETY

GOAL: *All residences should be constructed and staffed to ensure the safe evacuation of all of its residents within three minutes of a fire alarm.*

STAFF/STAFFING:

1. All direct care staff should be required to undergo periodic unannounced random, mandatory alcohol and drug testing.
2. All staff must be trained in the particular fire evacuation plan for each residence before working in said residence.
3. All staff must be trained in uniform fire safety procedures.
4. There should be enough staff to ensure the safe evacuation of all of its residents within 3 minutes.
5. No resident is left unattended either on the inside or outside of the building.
6. Staff should be the last to leave the facility.
7. NO SMOKING on, or anywhere near the facility.

CONSTRUCTION:

1. All new construction should be done under a Uniform Institutional Code under the jurisdiction of OFPC.
2. Existing facilities be upgraded to meet this code.
3. EXITS:

There should be multiple exits to the outside. Where residents sleep on multiple levels there should be direct access to the outside on each level.

Exits need to remain unblocked.

4. SAFE ROOMS:

Where a safe room is warranted that room needs to be completely fire and smoke proof.

Fire department officials need to be aware of the location of such rooms, as well as having ready access to floor and evacuation plans of the residence.

FIRE DRILLS and FIRE EVACUATION PLANS:

1. Fire drills be periodically conducted by the local fire department.
2. Fire drills are unannounced.
3. All staff members know which residents they are responsible for.
4. Family members, legal guardians, service coordinators and any other designated party have full access to the fire evacuation plan and the most recent fire drill report.
5. Alarms are sent directly to the local fire authorities.

FACILITIES WITHIN APARTMENT HOUSE COMPLEXES:

With the move towards more integrated/less supervised settings GROW is particularly concerned about fire safety for those persons with developmental disabilities who reside in apartment complexes, and would like to work with OMMRD and OFPC to ensure their safety.

There should never be an instance where an individual, otherwise suited for a residence, should be excluded from that residence because of an inability to evacuate in a timely fashion. Accommodations for this individual need to be made.

GROW ADVOCACY IN ACTION



GROW members with Executive Deputy Commissioner Max Chmura, in Albany.

GROW's ALBANY TRIP, MARCH 16, 2010

After postponing our trip because of snow, we suffered through a hurricane, but managed to get to Albany as it had just abated.

We met with Executive Deputy Commissioner Max Chmura for nearly two hours! He was joined by Chuck Kearley, director of the Office of Safety and Security Services, and Michael Kirchmer the new director of HVDDSO. GROW presented its positions on residential development along with fire safety. Because there was no budget, Deputy Commissioner Chmura could not address how much money would ultimately be allocated to OMRDD. However he did state that the Governor's proposed cuts to OMRDD were not that drastic. Concerning fire safety, director Kearley explained how new State housing would be utilizing a more stringent code. At that point OMRDD was gathering input on fire regulations for the purpose of developing new guidelines for both not-for-profits and state-run houses.



GROW members with Director of Mental Hygiene Services Michael Seereiter, in Albany.

After that meeting we split into two groups. The majority of the group went with the Orange County members to visit the aide of State Senator Morahan. The rest of us met with Michael Seereiter, head of Mental Health Services from Governor Paterson's Office. He repeated Commissioner Chmura's assertion that the Governor's proposed budget for OMRDD did not contain drastic cuts. Unfortunately Mr. Seereiter is leaving this position, and his successor was unable to attend our meeting.

Several of us visited our State legislators, leaving GROW's position papers with them.

Lastly we met with aides from Assemblyman Sheldon Silver's Office. Unfortunately they were unable to give us the Assemblyman's positions on OMRDD's concerns.

While we would have wanted assurances that there would be adequate funding to address our concerns, given the sorry state of the economy, we didn't achieve that goal. However we know that we were heard, and that what we had to say was met with respectful responses.

Barbara Masur

Albany Report from GROW Members of Orange County

GROW members from Orange County visited NYS Senator Bonacic, Assemblywomen Aileen Gunther and Annie Rabbit, and OMRDD Deputy Commissioner James Moran. We presented GROW position packets to each of them and discussed our desire to enrich lives through personal achievements and to foster independence with strong community and family support systems in place. We emphasized the importance of training first responders in the Hudson Valley Region, fire safety and housing development.

We discussed bill number S6647 with Senator Bonacic. The bill would develop a task force to formulate achievable goals for NY State government to meet the needs of adults with autism. We also discussed the possibility of providing funding to the Center for Discovery for training for parents and self advocates in the Hudson Valley Region on transition from the education system to adult living. This training would provide information on individualized support options.

Assemblywoman Annie Rabbit explained how the state government works and does not work in the budget process. She encouraged us to explore collaborating with "Future Farmers of America" to establish non-profit organic

GROW ADVOCACY IN ACTION: *our Orange County Contingent in Albany*



farming as a meaningful work option for individuals with developmental disabilities in Orange County.

Assemblywoman Aileen Gunther spoke about sponsoring bill number A08906B. The bill proposes development of Autism Assessment Centers that would provide intensive assessment services, residential services, education services, medical services and development of appropriate treatment plans.

Our goal is to continue to advocate with families and organizations in order to develop innovative educational, clinical, social and living experiences. In addition we are part of teams designed to enrich the lives of those with disabilities and assist in helping them to have a good quality of life.

*Natasha Tomlins
Parent Advocate*

Orange County Mental Health Committee Consultant

UPDATE YOUR CONTACT LIST!!!

HUDSON VALLEY DDSO

Michael Kirchmer replaces Jill Gentile as
Director 845-947-6100
Larry Kravitz replaces Diane Lennon as
Coordinator of Quality Assurance 845-947-6050

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.