



# NEWSLETTER

ADVOCATES FOR PEOPLE WITH  
DEVELOPMENTAL DISABILITIES

SEPTEMBER 2011

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P.O. Box 1692

(914) 493-1318

White Plains, NY 10602

## PRESIDENT'S MESSAGE...

### GROW: It's MORE than Traditional Residential Care

As GROW has reached its 30th year I felt it important to reflect on what we do as well as try to dispel a persistent myth about GROW.

Many times when I question parents as to why they haven't become more involved in working with GROW to advocate for services their children need, I hear "Oh GROW is just interested in 24/7 traditional residential services."

As you will note from the enclosed article on GROW's history, it is true that GROW was created in the aftermath of Willowbrook when 24 hour, 7 days a week community supervised settings were considered revolutionary, and the only game in town. And while we feel it is necessary to remind OPWDD and others that there still is and always will be a need for that type of service, GROW advocates for so many more issues, such as:

- Fire Safety in all types of residences; training for first responders
- Appropriate day programs and activities
- Adequate Employment and Supportive Employment opportunities
- Consolidated Supports and Services for those who want it, (see article)
- Early Intervention funding for at risk infants and preschoolers
- Appropriate training for all personnel working with people with developmental disabilities
- Measures to prevent abuse in all settings (including school)
- Full transparency of funding sources and funding expenditures in all types of settings (including school)
- Adequate MSC services

### SAVE THE DATE

Come Meet & Hear  
OPWDD Commissioner  
**COURTNEY BURKE**

Express Your Concerns  
& Help Us Celebrate

GROW's

30th Anniversary

**SUNDAY, October 16, 2011**

**10:30 AM**

**WIHD - Cedarwood Hall  
Westchester Medical Center  
Valhalla, NY**

*Parking vouchers available*

For Information

Call GROW helpline (914) 493-1318

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- Adequate and appropriate residential supports from ICFs to apartment living
- Adequate respite and recreation services
- Maintaining safeguards in the education system
- Parental/Guardian input on all levels of government
- Maintaining appropriate medical services

**WE LOBBY FOR ADEQUATE FUNDING FOR ALL THESE SERVICES!!!!**

Our issues come from YOU, as well from the news. So let us know about issues that concern YOU!! Become more involved in GROW. See you October 16th!

*Barbara Masur, President*



**GROW HISTORY**

GROW was founded in 1981 by a group of six parent advocates whose children resided in group homes: Ann Arcay, Bob Berlin, Leigh and Connie Dimond, Lillian and Hal Poritz. Through the vision and leadership of Nat Mills and Mort Steinberg, two of our early Presidents, GROW grew into the organization we know today. Other early members, some still active today, include: Grace Cosgrove, Hugh Cuthbert, Bob Dorfman, Ray Garofano, Jim Kronenberger, Faye Loyd-Lilly, Ruth Milar, Nat Mills, Murial & Kenneth Plath, Anne & Mort Steinberg, Rosemary Scholl, and Norman & Rochelle Kessler.

While initially the group focused on those residing in group homes, the vision quickly expanded to advocacy for residential opportunities for all those who needed them. To assist in that goal, GROW helped create a registry of people with developmental disabilities. With GROW's influence and advocacy, Westchester County became the first County in N.Y. State to adopt such a registry. While residential opportunities continue to be a major focus for GROW, over the years GROW has advocated for all the necessary programs and services persons with developmental disabilities need to live in and be a part of their community.

*Ray Garofano, Recording Secretary*

**At the next meeting GROW will be presenting its proposed slate of Officers and Board Members for 2011-2012 as follows:**

**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**

**2012**

- Marilyn Hahn
- John Niland\*
- Maryann O'Toole\*
- Jim Pinsley
- Emily Samuels
- Jerrold Shenkman

**2013**

- Judy Frank
- Sheryl Frishman
- Shelley Kessler
- Sharon McDowell
- Leonard Spano\*
- Carol Ullman

**2014**

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

\*New members: Cynthia Ferguson is the mother of Beth age 43 who lives in White Plains and attends Westchester Arc; Cynthia serves on committees at WARC and WWARC where her daughter formerly resided. Maryann O'Toole is the mother of Jamie age 41, who has Norrie Disease causing blindness, deafness and cognitive issues, is doing well with his bilateral implants, and resides in a home in Pound Ridge. John Niland is a fitness trainer and Masters in Social Work student and is the primary caregiver to his 48 year old brother Patrick who has Down Syndrome and attends YAI. Leonard Spano is the Executive Director of the Westchester School for Special Children where he served as an advocate for children since 1996 and continues to maintain a vested interest in the students as they age out.

*Rochelle Kessler, Chairman, Nominating Committee*

# Consumer Directed Services

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What is CDS? With traditional housing options for people with Intellectual and/or Developmental Disabilities (I/DD) limited, individuals and families are increasingly seeking alternative ways to find and fund long term care. One way to do this is via Consumer Directed services (CDS). CDS are much talked about in connection with the 1115 Waiver planning currently underway in New York, but they are not new. People with I/DD who receive SSI or SSDI have always had discretion over how their funds are spent. States have been offering CDS under section 1905 of the Social Security Act since the early 90's. In 2005 the Deficit Reduction Act enshrined the principle that Money should Follow the Person (MFP) and provided funding to states to reduce use of congregate settings.

The Centers for Medicare and Medicaid Services (CMS) the federal administrator of Medicaid, support CDS. They now require that Consumer Directed Medicaid services be Person Centered, have an Individualized Budget and that States should provide assistance and support for CDS.

## Why CDS?

While the system of care that emerged post Willowbrook was a vast improvement, and was hard won, it is unsustainable. A growing population of people with I/DD, a shrinking workforce, and reduced public funding coupled with reluctance of many people to enter a congregate system compel us to find alternatives. There is a growing body of research that shows that people who choose to employ CDS report an increased quality of life and greater freedom and independence. There is evidence that CDS reduce costs to the taxpayer. There is also a shift in how Disability is perceived, away from the medical definition and assumption of helplessness, and towards supporting people with a disability so that they achieve their highest level of functioning and quality of life.

## The 1115 Medicaid Waiver:

### Where is NY State Headed?

The prospectus for the 1115 is very clear that CDS is at the core of how services will be shaped for the future: "A transformed long term care delivery system that places person centered planning, individual responsibility and self determination at the forefront (which will) enhance care and individual satisfaction and lower Medicaid costs." That will "prioritize services that adapt to the individual rather than asking individuals to adapt to the service" and that "financial support will be directed to individuals not to programs or institutions."

## How does CDS apply to Housing?

CDS and Consolidated Supports and Services (CSS), the mechanism through which CDS is expressed in NY

State's Waiver, are not programs. They are a way to channel a payment stream. In traditional services, funding is directed from the State to a provider agency, which then funds a day or residential program. People in need of services can choose from the list of programs but their choice is limited by the provider agency's design. Under CDS/CSS, the individual's support needs are assessed, an individualized budget through which they can purchase the support is created, and the individual or their advocate then purchases those services. The individual can choose to buy services from an existing provider for all or part of their needs, but they control which provider and they can purchase different services from different providers. People who want greater control have the option to purchase services from non-traditional providers or to hire their own support staff or buy assistive technology. In the case of housing this might permit someone to stay in their family home and purchase habilitation support, or to rent a home by themselves or with others, hiring staff directly or through a provider agency. In either case they will have a greater degree of control over where they live, who they live with, and who supports them than they do through a traditional model.

## How does CSS work in NY?

If an individual who is eligible for OPWDD services and has Medicaid decides that they want to create their own service environment as an alternative to traditional services they must first contact the DDSO liaison to obtain approval to proceed with a CSS or CSS-like plan. If they receive approval the DDSO liaison will provide them with a listing of Start Up and Support brokers and Financial Management Services (FMS) from which they can select a Start Up broker. The Start Up broker will work with the individual, their circle of support and the DDSO liaison to develop their individual plan, which will include their habilitative needs and an individualized budget. The DDSO liaison will review the plan and work with the Budget Office to obtain approval. Once approved, the role of the Start Up broker fades and the Support broker helps to implement the plan, ensure compliance with Medicaid rules, help maintain and revise the plan and implementation as necessary. Throughout this process the FMS has been an advisor and is the "Employer of Record" If the individual's plan includes contracting directly for support. The individual may also choose to purchase their services from an agency, - in some states the experience has been that most people do, - in which case most of the billing is done by the agency at their usual rate directly to the state.

The MSC is a required member of the Circle of Support, but does not perform the role of Start Up or Support broker. Best practice is for all of the brokers and the MSC to be independent of any agency providing direct service.

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### How does CSS work in our region?

While CSS has had a slow start in our region compared to some neighboring regions, the Hudson Valley DDSO has affirmed their commitment to supporting people who seek the option of self directed services and the flexibility and reduced cost to the taxpayers that is the “win-win” that thoughtfully planned and supported CDS can provide. If you are interested in CSS please contact Michael Kirchmer at 845-947-6014.

**John Maltby, M.S.W.**, 914-493-5718  
*Director, Community Support Network*  
*Westchester Institute for Human Development*  
*GROW Member*

**BY-LAW CHANGE:**

**• Quorum**

Ten (10) members in good standing or **five (5) members of the Executive Board shall constitute a quorum. The Executive Board consists of the duly elected Officers Slate and all active Past Presidents.** Bold letters constitute this proposed change. Members in good standing will vote on the change at the annual meeting.

## WHAT'S HAPPENING...

### *The DCMH Residential Subcommittee*

In November, 2010, a small group of family members along with county, state and voluntary providers began to meet in order to address the current issues around residential development. These issues include the use of openings in existing residences (vacancies) and the possible reconfiguration of some existing residences, limited new residential development using less than 24 hour supports, and information dissemination for families and agencies alike.

We are currently working on creating a guide to provide families with information about accessing residential services. Since there are some significant changes regarding new services, families and people with developmental disabilities need to be aware of these initiatives and choices. Given the current economic constraints, it is important that individuals, families and providers work together to maximize resources and identify possible solutions so that we continue to move forward!

**Jackie Fowler**  
*Chair, Residential Subcommittee*  
*Department of Community Mental Health*  
*GROW Past President,*  
*Current Executive Board Member*

### 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.

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.