

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

FALL, 2009

TRYING TO STAY POSITIVE

ADVOCATING FOR BEHAVIORAL SUPPORTS

JON YARD

PHOTO BY
REBECCA SHAVULSKY

OCEAN CITY
18 79
NEW JERSEY



PUBLISHER New Jersey Council on Developmental Disabilities

CHAIR Elaine Buchsbaum

EXECUTIVE DIRECTOR Alison M. Lozano, Ph.D, M.P.A.

EDITOR Norman Reim

DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS

Brenda Considine, Maryann B. Hunsberger, Jonathan Jaffe, Kathi Wolfe

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

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Christopher Miller, Myrta Rosa, Gary Rubin, David Tag, Mary Kay Weber

PARENT, FAMILY MEMBER AND GUARDIAN REPRESENTATIVES

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Frank Caragher, The Arc of Union County

The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building and systemic change that contribute to a coordinated, consumer and family-centered, consumer- and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

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New Jersey Council on Developmental Disabilities, PO Box 700, Trenton, NJ 08625-0700. TELEPHONE: 609.292.3745 TDD 609.777.3238 FAX 609.292.7114 EMAIL njcdd@njcdd.org INTERNET www.njcdd.org

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DR. ALISON LOZANO

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Front Cover: Jon Yard
Photo by Rebecca Shavulsky

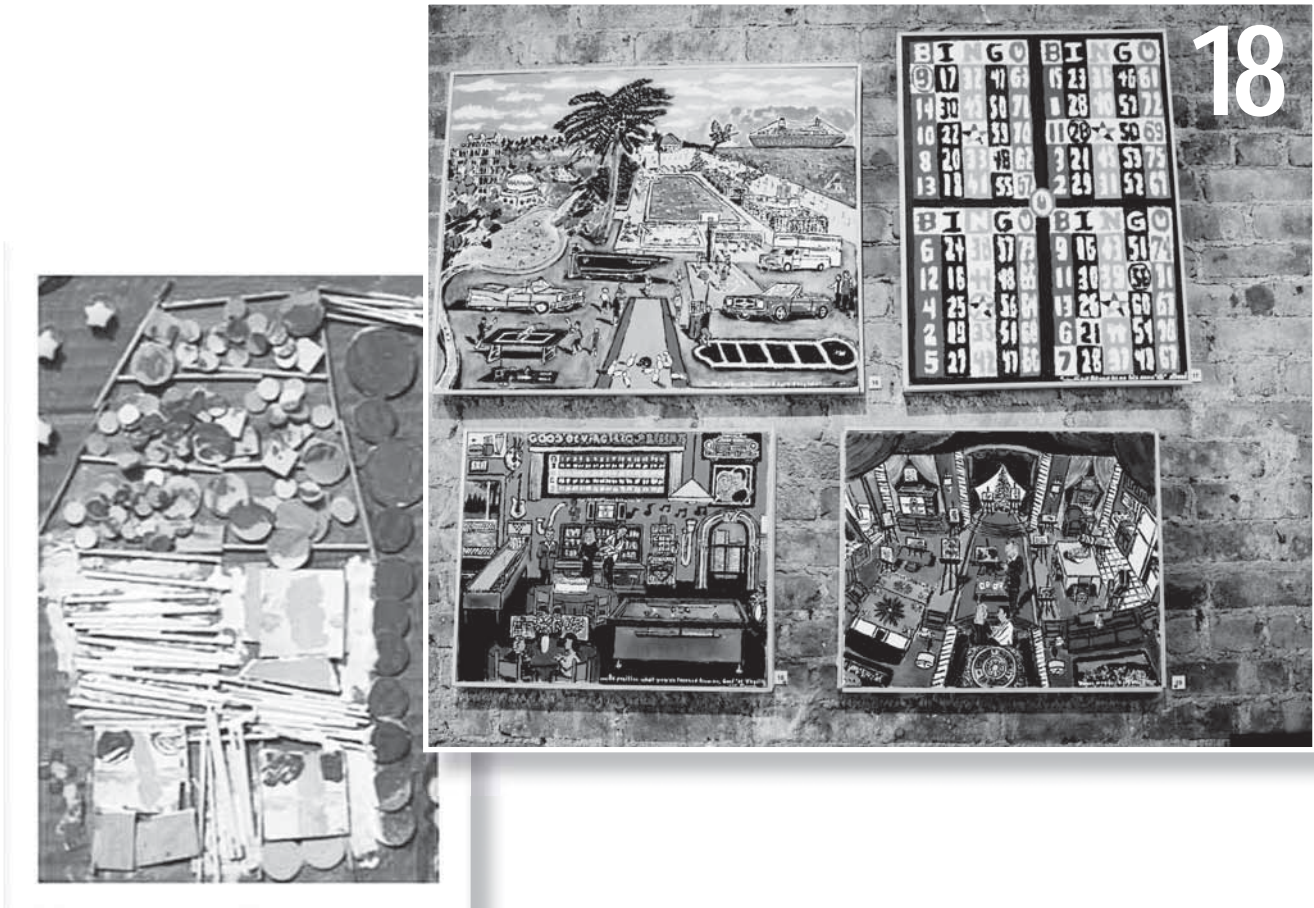


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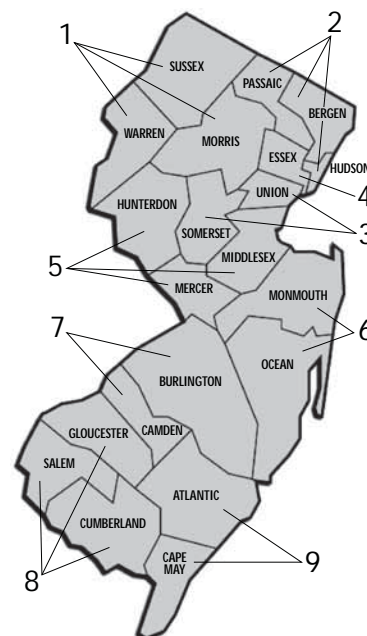


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Comment

Doing the Right Thing, and Saying Something About It

The Council has launched two projects intended to draw attention to public perceptions of people with developmental disabilities. The first one is called “The R Word Campaign.” The goal is to eliminate the use of the words “retard” and “retarded” in all written and spoken language when it is used to refer to people with developmental disabilities.

Recently NPR ran a story on their program “All Things Considered” that discussed the use of the “R” words. The comments after the story were more telling than the article itself. There were several comments to the effect that these are only words. One of the letters suggesting those quoted in the article should get a “thicker skin.”

However, “thicker skin” is not the issue here. It is a matter of respect that motivates individuals with disabilities and their advocates to remove this word from the list of words that have negative connotations.

The “R” words are thrown around in common language with the intention of instilling negative emotions on another person or situation. They also are used to describe an intellectual condition that distinguishes the bearer of the label from others in their lives and communities. The meanings are hurtful in both cases.

In the case of people with developmental disabilities it cuts to the core. It is not just a word intended to have a temporary effect, it is a description of their very lives and self worth.

We might rightly say it is not the words themselves, but the meanings we give the words that are harmful. In fact we could go further and say if we remove these words from our conversations, others may well arise with the same hurtful connotations.

But the bottom line is that people with developmental disabilities want these words removed from our lexicon of abusive language and for this reason alone we must work to make this a reality.

The second project is a natural outgrowth of the “R Word Campaign” and broadens the scope with often a much more pleasant emphasis. The Council has launched a project called “Just Say Something.” The intention of this project is to speak up about things that need to be changed—like the use of the “R” word—but to also draw attention to the good things people in the community are doing to improve the lives of people with developmental disabilities and their families. They may be quite simple activities by quite ordinary people, but worthy of attention.



It is our way of saying thank you to the many people who in the course of their regular activities show insight and kindness to fellow members of our communities; while, also reminding them of things that still need to be improved.

Editor’s Note

Everyone can get involved.

It’s easy. Here’s how:

To find out more about the “R Word Campaign” and to link into the Council’s “Just Say Something” blog, visit the Council’s Web Site at www.njcdd.org and scroll down to find the announcements and links. Also see the following pages in this magazine.

—Alison Lozano, *Ph.D., MPA*
Executive Director

THE R-WORD CAMPAIGN

What You Can Do:

1. Stop and Think
2. Stop saying “retard” and “retarded”
3. Ask others not to use “retard” and “retarded”
4. Promote tolerance
5. Become part of a community to promote inclusion
6. Take an Action Pledge
The kindest word in all the world is the unkind word, unsaid.

— *Anonymous*

GO TO www.njcdd.org

If you would like a presentation on the campaign, or if you would like to get materials—buttons, bumper stickers, T-shirts—contact us.

NJ Council on Developmental Disabilities

609-292-3745 or write to
PO Box 700
20 West State Street
Trenton, NJ 08625-0700



T-shirts
full color front,
one color on
back



buttons

DON'T USE IT

The word **RETARD** is Hurtful to
People with Developmental Disabilities

TAKE THE PLEDGE at WWW.NJCDD.ORG



©2009 - Design by NJ Council on
Developmental Disabilities


bumper stickers

“JUST SAY SOMETHING!”

The Most Effective Way To Help Make **POSITIVE CHANGES** Is To Just Say Something About What You Think Is **RIGHT** And What You Think Is **WRONG**

Speech Is Not Only **A RIGHT**, It's A **RESPONSIBILITY**

So Just Say Something The Next Time:

-  You Hear Someone Using Disrespectful Language— Like The “R” Word
-  You Read About Something Really Cool for Students with Disabilities at the Local School
-  A Neighbor Complains That People With Developmental Disabilities Shouldn't Be Living On Our Block
-  The Governor Announces Expanded Health Care Coverage For People With Autism And Other Developmental Disabilities

When You See Something You Like, Or Something You Don't, Just Say Something About It. Face To Face; Through Blogs And Twitter, Email And The Web; Letters To The Editor; Radio Call Ins; Anywhere There's An Opportunity To Set the Record Straight

And Help Us Keep Tabs On What's Going On And What You're Thinking About It All By Visiting Our New Blog:

JustSaySomething.org

“For too many years, people with developmental disabilities have been an afterthought. The “Just Say Something” campaign is aimed at ending that injustice, encouraging thousands of New Jerseyans to speak up.”

— Dr. Alison Lozano,
Executive Director of the Council
on Developmental Disabilities

REV. BILL GAVENTA OF THE BOGGS CENTER

Rev. Bill Gaventa recently appeared in “Creating Room in G-d’s House” on PBS’ Religion and Ethics Newsweekly. The segment featured Rev. Gaventa, MDiv, Associate Professor at the Elizabeth M. Boggs Center; a mosque and synagogue in New Jersey; and a worship program in Pennsylvania called Rejoicing Spirits.

Partners in Policymaking graduate Safiyyah Muhammed, a member of The Boggs Center Consumer Advisory Council, is also featured in the segment. The video and transcript of the segment are available on the PBS website.

The segment has a special feature on *Praying with Lior*, a documentary film about Lior Liebling, a young man with Down syndrome, preparing for, and going through, his Bar Mitzvah (reviewed in the previous issue of *People & Families*).

Rev. Gaventa was an advisor on the award winning film. He is an internationally recognized expert in spirituality and disability, and serves as the Boggs Center’s Director of Community & Congregational Supports. He is editor of the *Journal of Religion, Disability, and Health*. For more information about The Boggs Center’s efforts in Faith Based Supports, please go to their website, rwjms.umdj.edu/boggscenter.

RESTRAINT AND SECLUSION IN SCHOOLS

The National Disability Rights Network, Disability Rights New Jersey’s (DRNJ) national organization, issued a report about the use of restraints and seclusion in schools. DRNJ staff shared information from NJ in the preparation of the report.

If you are interested in more information about the NDRN report, please visit the NDRN website at www.ndrn.org

For more coverage on this subject, search the *USA Today* archives under the title —“GAO: Schools restrain, confine disabled children.”

Also, see the related articles in this issue of *People & Families*.

SYNOPSIS FROM THE OFFICE OF THE COMPTROLLER’S PRESS RELEASE AND DHS RESPONSE

An Office of the State Comptroller (OSC) audit released in August found that taxpayer dollars meant for people with developmental disabilities were used to pay for series of inappropriate expenses and for services never received. The audit also points out the potential for millions of dollars in savings at the state’s Department of Human Services.

The audit looked at state-funded programs that, among other things, teach life skills and provide other training to individuals with developmental disabilities. An audit of 10 adult training programs funded by DDD found the state agency wasted approximately \$1.4 million by paying for more individuals than were actually receiving services.

The audit recommends DDD consider an alternate contracting system, the Milestone Payment System, which has decreased costs and improved services in other states by tying payments to predetermined outcomes. In total, nine recommendations for improving contract oversight are included in OSC’s report, each of which DDD has committed to implement. (See the Department of Human Services’ response on the next page.)

The audit also looked in detail at state-funded expenditures of four of the 278 providers that contract with DDD to provide residential and non-residential services for people with developmental disabilities.

Within that sample, OSC uncovered a string of inappropriate expenses paid by DDD to a provider whose CEO is a former DDD director. The expenses included restaurant tabs in Spain and Atlantic City, cruises to the Mediterranean and Caribbean and a GPS navigation device for the CEO’s vehicle. OSC’s audit requires DDD to pursue the recovery of approximately \$160,000 worth of such inappropriate expenses uncovered by the audit.

In addition to cost concerns, the audit found many of the DDD case managers charged with conducting visits to assess the needs of individuals with developmental disabilities in their caseload were either not completing the required quarterly reports or simply copying the same report from quarter to quarter.

Most DDD contracts are renewed each year without a competitive bidding process and without adequate consideration of past provider performance, the audit found. In 2008, DDD reported to OSC the non-competitive renewal of 95 contracts valued at more than \$2 million, including 23 contracts valued at more than \$10 million.

When OSC requested original procurement documents for four of the largest renewal contracts (three of which predated 2002), DDD was unable to provide documentation for any of them, making it impossible to determine if the original contracts were properly awarded.

Costly contract modifications were also approved throughout the audit period without an adequate review. Of 10 providers OSC reviewed, DDD approved modifications totaling \$21 million without adequately determining if the modifications were necessary. For example, modifications for purchasing new vehicles were approved without DDD knowing the number of vehicles the provider has or how they are being used.

DDD officials stated they are taking a number of steps to address issues raised in the audit, including lowering caseloads for case managers, documenting contract modification reviews more thoroughly, performing contract closeouts in a timely manner and eliminating vacant program slots.

DHS Response

According to the Department of Human Services web site, DHS had been working on contract monitoring changes during the time of the audit and will continue that effort.

Those efforts include:

- The expedited close-outs of previous years' contracts—returning approximately \$10.5 million to Treasury by July 2009 and establishing the process for collecting up to an additional \$4.2 million
- Eliminating in excess of 300 day program vacancies
- Reducing case management caseloads by approximately 20 percent through an intra-departmental collaboration
- Monitoring providers noted to be in financial stress or whose performance raises concerns, including follow up on providers' corrective action plans; Contracts have been approved conditionally until corrective action was implemented, and indeed, contracts have been terminated when appropriate
- Initiating a comprehensive review of the entire case management system, including a plan to structurally reduce caseloads and to formalize case managers' training
- Preparing a quarterly performance review "dashboard" comparing each DDD contracted provider agency, which will be posted online later this month with information including providers' licensing status, number of substantiated incidents and other performance standards allowing contract administrators, families of individuals with developmental disabilities and providers themselves to assess provider performance
- Initiating an electronic budget request, approval and tracking system to document any requested contract changes. Contract modifications are now subject to review by case managers, regional administrators, program coordinators, contract administrators and fiscal staff prior to final approval