# Illinois Citizens for Better Care

### **About ICBC**

Illinois Citizens for Better Care has been the Illinois nursing home residents' advocacy and service organization since 1978. Our mission is to improve the care and quality of life of nursing home residents and other people who need long term care.



Fall 2013

#### What we do:

- Advise families about how to choose a nursing home, about alternatives to nursing home care and how to get good care
- Help establish and sustain family councils in individual nursing homes
- Host workshops for community members on long-term-care issues
- Keep people informed about legislative issues that affect the quality of long-term care
- Advocate for residents with the legislature and state agencies
- Host statewide educational conference calls

To report mistreatment of a nursing home resident, call:

#### 1-800-252-4343

To report mistreatment of an elderly person who does not live in a nursing home, call:

1-866-800-1409

### New Address, Same Mission

We have moved to Suite 1400, 401 South LaSalle Street, Chicago 60605. Our phone number, email and website addresses remain the same. Most importantly, the nature and scope of our work will not change.

## Family Conference Call

Our first family conference call of the year was May 16. Cathy Nelson, Senior Director of Clinical Services at Life Services Network and Nancy Flowers, former Evanston Ombudsman and long-time ICBC board member discussed how to use the care planning conference to improve nursing home care. If you missed the call, you can listen to it and download the notes from our website. www.illlinoiscares.org

### Like Us on Facebook!

We send our Facebook fans legislative alerts, updates on upcoming events and information about long term care. Find us and like us at facebook.com/IllinoisCitizensForBetterCare



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## Community Outreach

ICBC continues to do presentations at hospitals, senior centers and nursing homes for staff, family members of nursing home residents, and other community members. Amber Williams, our family council/outreach coordinator, has been responsible for arranging and planning our presentations. Topics we can do presentations on include:

- 1. How to choose a nursing home in Illinois, and alternatives to nursing home care
- 2. The nursing home care-planning process
- 3. Taking care of long-term care residents with dementia
- 4. What is good dementia care
- 5. End-of-life planning and care
- 6. Legal requirements about privacy and sharing of resident health care information
- 7 Residents' rights
- 8. Advocating for long-term-care residents to your legislator
- 9. How to get good nursing home care



Wendy Meltzer, our Executive Director, at a presentation at MacNeal Hospital about how to get good nursing home care. Best questions came from the 92 year old woman who had visited 13 different continuing care places to do her research. Wish we could hire her!

Nancy Flowers shared her knowledge of what is good dementia care with the family council at Renaissance @ Midway. She is always delighted to help family councils because "once an ombudsman, always an ombudsman."



## **Upcoming Events**

Come join us at one of our community education events

### How to Get Good Nursing Home Care

November 4th 11-12:30 pm West Suburban Medical Center 3 Erie Court Oak Park, IL 60302 Lower Level Classrooms Please call ICBC to RSVP.

### What Families and Friends Should Know About Medicaid Conference Call

November 14th 7-8:30 pm Sign up on our website or give us a call to RSVP and receive the conference call information

## Resources for Families: Our Updated Website

Our website is full of new resources for families. To help families with nursing home selection, we have *How to Choose a Nursing Home In Illinois*. It walks you through the process step by step with pictures of the web pages you need. We also do a community outreach presentation on this topic which has become quite popular. The companion *Nursing Home Checklist* 

reminds you of what to look for and questions to ask when you visiting potential nursing home choices, and helps you track details about each home. The checklist allows you to compare up to three nursing homes at a time.

Our book **SMARTCARE** is no longer available in print. The first half (updated) is on our website, and — as with all our materials — can be downloaded without charge.

SMARTCARE walks you through the process of what families can do for their loved one before and while in the nursing home to have the best chance of getting good care. The book is for people who have already chosen a nursing home. Use our SMARTCARE Checklist as a summary of highlights from the book.

Find the checklist at illinoiscares.org/better\_care

## News from Springfield

This legislative year did not start happily. We had early unpleasantness with a Senate bill from the nursing home industry attempting to stop the Department of Public Health from using nursing home fines to pay for the volunteer abuse prevention teams that review sexual assaults and unnecessary deaths of nursing home residents. Instead, the money was going to be used to "reduce violations and fines," according to a plan to be developed in consultation with an IDPH board dominated by the nursing home industry. As with so many issues, our larger and more powerful friends used ICBC's bill analysis to persuade the sponsor to amend the bill to get transparency about where funds go, without changing current funding priorities. A neat win.

ICBC members helped secure this good outcome. We used our newsletter e-mail lists to alert people about the bill, and that it was going to be heard in committee in only a few days. Through the miracle of Facebook, we were able to share the information even more broadly. People called the sponsor and committee members about the bill; their calls really did contribute to the result. Thank you for your help. Please: "LIKE" US ON FACEBOOK, AND ASK YOUR FRIENDS TO. It makes communication so much more efficient.

The funding crisis for people who need Department on Aging programs for services that help them stay home and out of nursing homes, was also resolved satisfactorily for this year. Thanks to the AARP and its network of agencies whose funding ended-because the Legislature had not provided a full year of funding for home—and community-based services, funding was restored. While bills are still being paid very, very late, at least there is the promise of eventual payment, meaning people can still get services such as home-delivered meals, in-home care, and adult day care. ICBC had nothing to do with this: it just made us happy.

There was, of course, bad news. Ironically, the vehicle for the bad news was Senate Bill 26, the much-awaited legislation needed to expand Medicaid coverage to hundreds of thousands of Illinois residents who cannot afford health insurance. (Yes, Obamacare.) The owners of the 24 nursing homes ("IMD's") that house solely people

with a serious mental illness — the guys who used their pocketbooks and their clout in 2011 to get their very own law with their very own rules — struck again. They decided they didn't like the law they wrote two years ago, wrote themselves a new one, and — thanks to the Speaker — got their new law put on as an amendment to the Medicaid expansion bill. The price of passing Medicaid expansion became making these owners happy.

Their new bill expanded the mental health "services" they are authorized to provide, to include services ranging from triage and crisis stabilization to supposedly short-term residential care. Their aim is to replace the customers (and income) lost as people now living in IMD's exercise their court-ordered right to community housing and services.

ICBC joined many community mental health advocates in opposing the IMD expansion. We all know that the newly-funded services are badly needed, but dispute the ability of the IMD's — most of which do not even pretend to provide any meaningful mental health services — to provide quality services, and to do so in a way that would not subvert deinstitutionalization.

The original version of the bill eliminated almost all state regulation of these places, both for new services and old. Thanks to Senator Heather Steans, regulation was put back in. But the owners insisted on trying to eliminate many of the legal rights residents of their facilities now have.

Opponents of the bill didn't even see the bill until the day before the House hearing. The owners refused to negotiate with us. After a contentious hearing at which mental health advocates and ICBC testified, Representative Kelly Cassidy made negotiations, the price of passing the bill out of committee. Fred Friedman (Next Steps) and ICBC's Wendy Meltzer, with Representative Cassidy there for support, got important resident protections restored. These include: no psychotropic drugs without informed consent; residents' right to leave any time; the right of unimpeded access to phones, mail, and visitors, including lawyers and ombudsmen; criminal background checks of residents; protection against arbitrary eviction; whistleblower protections; state Institutional Review Board oversight over any human experimentation.

## From Our Interns:

We were fortunate again this year to have two graduate student interns from the Adler School of Professional Psychology. Here's what they say about their experiences:

#### **Katrina Dotrow:**

I have been looking at records that involve "identified offenders" (convicted felons) living in nursing homes. I spent most of my time reading and collecting data from risk assessments by a forensic psychologist and trained investigators. The investigators interviewed identified offenders in various nursing homes and also reviewed their records. The data I collected may be used for new policies concerning identified offenders.

I thought my criminal justice and psychology background would make me a good fit for this project. I was also interested in learning about individuals after they had been involved in the criminal justice system. To my surprise, I actually began to learn about the injustices that some people suffer from being mentally ill residents.

I learned about people I previously had very little knowledge or understanding of. It was interesting to see the different struggles and issues that this population can go through. Wendy allowed me to ask questions without judgment and also inquired about my opinions and thoughts on what I was reading and understanding. Allowing me to use my critical thought skills gave me the ability to gain confidence in myself. I gained the confidence to trust my own inner compass and that what I am

## How You Can Support ICBC

ICBC exists to protect residents who our parents and grandparents; our neighbors and close friends; our spouses and our children; ourselves. Our mission is to ensure that long-term care residents are provided quality care in humane, compassionate, and dignified settings. More than 100,000 residents in nearly 1,000 long-term care facilities in Illinois depend on ICBC to defend their rights and seek ways to improve the quality of their care.

To make a financial contribution: .

- 1. Visit our website www.illnoiscares.org/content/donate to make a donation.
- 2. Send a check made payable to Illinois Citizens for Better Care
- 3. Make a memorial or tribute gift on behalf of a friend or loved one
- Become a member

#### Illinois Citizens for Better Care

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thinking is not completely ridiculous. I now know I need to stand up for my clients when they are unable to voice their own concerns.

#### Grzegorz Liberadzki:

I visited a number of dementia units in nursing homes. Based on the information that I learned about requirements for proper care of residents, I watched how the staff interacted with the residents. As I watched, I had opportunities to interview residents and staff. I was able to identify discrepancies in care between various nursing homes that were located throughout Chicago. The care provided to residents was not uniform, to say the least. Black residents, and residents who are poor, definitely get worse care.

In addition to visiting different nursing homes, I was able to assess nursing home admission processes. This process is not user-friendly for family members. Based on my experience, I am confident in stating that a family member selecting a nursing home for a loved one would be at a disadvantage without the help of an organization like ICBC. What I learned in my experience is invaluable and will guide me to inform the public about the need for better care of residents who may not have a voice.

#### Membership Categories

- Nursing Home Resident (\$5)
- Individual (\$30)
- Sustaining Member (\$31-99)
- Patron (\$100-250)
- Angel (\$250-499)
- Benefactor (\$500+)

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