

Illinois Citizens for Better Care



About ICBC

Illinois Citizens for Better Care has been the Illinois nursing home residents' advocacy and service organization since 1977. Our mission is to improve the care and quality of life of nursing home residents and other people who need long term care.

What we do:

- Advise families about how to choose a nursing home, and about alternatives to nursing home care
- Advise families about how to get better nursing home care for the people they love
- Help establish and sustain family councils in individual nursing homes
- Connect family councils with other family councils
- 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
- Educate health care providers and other professionals about long-term-care issues

Our New Staff Member

Thanks to generous member support, in 2011 we were able to hire Amber Williams as our Community Outreach Coordinator. Ms Williams is a graduate student in the School of Public Service at DePaul University. Ms. Williams has experience in the nonprofit sector and dedicated to working with underserved populations. She is responsible for coordinating internships, planning volunteer activities, overseeing our family council project, planning outreach events, and upgrading our website. She also helps families with nursing home selection.

"I am excited to advocate on behalf of nursing residents and make an impact on nursing home reform. I have enjoyed interacting with family members and helping them with nursing home selection and family councils. ICBC has given me the opportunity to educate others on the importance of advocacy and enhance my skills in this area as well."



Amber Williams, MHS

Fall 2012

To report mistreatment of a nursing home resident, call the Illinois Department of Public Health:

1-800-252-4343

To report mistreatment of an elderly person who does not live in a nursing home, call the Illinois Department on Aging:

1-866-800-1409

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Interns from Adler School of Professional Psychology Complete Community Placement

Carly Brandess, Leeor Granite, Ryan Ochoa and Rebekah Haenni have just completed six month internships with ICBC. Carly and Leeor worked on our Family Council project. They tried to identify every family council in an Illinois nursing home, and worked with Amber Williams to organize new ones. We will be distributing the family council newsletter they worked on. Given the amount of resistance they encountered, Carly and Leeor did an amazing job.



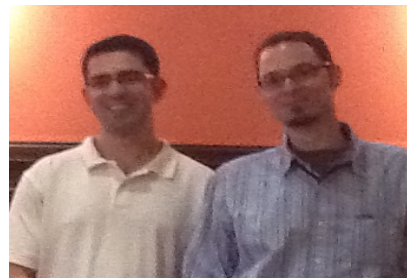
Carly Brandess, Rebekah Haenni

“As a practicing gerontological counselor, understanding what my clients may be experiencing in living in a nursing home facility will be essential to being able to best assist them. I hope to utilize what I have gained here in both being an advocate for older adults as well as in helping clients know how to better advocate for themselves.” - Carly Brandess

“When working with elder clients who live in nursing homes, I will have an appreciation for the environments in which they live, and some of the challenges that they are faced with on a daily basis.” - Leeor Granite

Ryan and Rebekah visited a number of nursing homes with large numbers of residents with a serious mental illness. Before starting grad school, Ryan had worked in a nursing home with residents with a mental illness, and Rebekah had worked with a community mental health agency moving nursing home residents into the community, so they had perfect backgrounds for this project. The two of them interviewed staff and residents, focusing on what kinds of therapeutic services the facilities provide, and what additional services would help residents be able to move to a community setting. We are using and sharing their observations and insights as we participate in the drafting of new

rules for nursing homes that house people with a serious mental illness.



Leeor Granite, Ryan Ochoa

“To me, just the opportunity to understanding the political, legal, and

communal aspects of mental health treatment in nursing homes has influenced me to continue advocating for better approaches to care.”- Ryan Ochoa

If you are interested in becoming an ICBC intern, send your resume to Amber Williams at ambericbc@core.com, or call her at 312-663-5120 to learn more about the projects you could be working on.

Family Council Project

Are you part of a family council? Would you like to get one started in your nursing home? Do you know of a family council that needs advice, information, support?

If you are a friend or relative of a nursing home resident, or work in a nursing home that wants a family council, we can help you start a family council. We provide advice and materials to guide the success of family councils. We also do educational presentations at family council meetings.

Our staff and board members can do presentations on issues that affect a resident's quality of care.

Subjects we can speak on include care planning, requirements for caring for residents with dementia, good dementia care, and end-of-life care. We can also speak on such residents' rights issues as requirements for evicting a resident, and about resident privacy and sharing of health care information. And we would love to help you learn how to advocate with your legislators for better nursing home care for all residents.

Contact Amber Williams at (312) 663-5120 or at ambericbc@core.com if you want to start a family council or for advice or information for an existing family council, including scheduling a presentation.

News from Springfield

This was an odd year for us in Springfield. Implementing nursing home reform went badly; other stuff we worked on went well. However, this year Illinois cut funding for the home care and other services that our clients depend on to keep out of nursing homes. The impact on many people will be grim.

Our good news was that, working closely with the AARP, (yay Dave Vinkler, their fab lobbyist) the ombudsmen, and sometimes with Public Health, sometimes against them, we killed a number of bills that ranged from bizarre to dangerous. Perhaps the strangest would have let nursing homes screen all visitors, read all materials they intended to show any resident, and refuse entry to visitors such as the ombudsmen and ICBC. Another would have kept Public Health from citing violations where residents died or were seriously hurt until a panel reviewed every similar violation ever cited in the whole state to make sure citations were consistent. Time limits for citing violations would have meant the worst violations could never be cited.

The not-so-good news: We wrote a follow-up nursing home reform bill that got nowhere. And, as part of the 2010 reform follow-up, we and other resident advocates spent countless hours working to get the most responsible allocation of nurse and CNA time in a new Public Health rule. Negotiations with Public Health and the nursing home industry were supposed to decide the outcome. Instead, it was decided in a classic backroom Springfield deal from which all resident advocates were excluded, and the nursing home industry got what it wanted. Senator Jacqueline Collins described what happened.

"They did an end run around the process. It was a disservice to the democratic process. Clout, money and influence determined the outcome."

Before the reform law, residents needing skilled nursing care were entitled to 2.5 hours of direct care daily. Twenty percent -- 30 minutes -- had to be licensed nurse time; the rest could be CNA time. The 2010 law increased staffing in stages: it is now 3 hours direct care every day for skilled care residents. On January 1, 2013 it will be 3.4 hours; on January 1, 2014, it will increase to 3.8 hours.

The fight was over how much of the new total would be registered nurse or other licensed nurse (instead of CNA) time. The old law required no registered nurse care, even though research shows that more registered nurse time means better care.

Now that the dust has settled, Illinois is requiring some registered nurse time for all residents needing skilled and intermediate care, but not as much as we had wanted or the research supports.

A quarter of required staff time must now be done by licensed nurses; 40% of the one-quarter must be registered nurse time. So right now residents are entitled to an average of 45 minutes of licensed nurse time, including 18 minutes registered nurse time. This should mean better care.

The back-room deal will change licensed nurse staffing again when the Medicaid payment system for nursing homes changes. We have no idea what the new standard will look like, or if we will have any meaningful part in creating it.

What's up with Nursing Home Reform? Not Enough.

In 2010, after months of disturbing media stories about the terrible "quality" of many Illinois nursing homes, and about racially discriminatory understaffing, the Illinois Legislature passed major nursing home reform. ICBC was one of the leaders of the efforts that resulted in the reform law. In 2011, again thanks both to awful newspaper stories and to advocate efforts, reforms were extended to nursing homes for people with developmental disabilities.

Some 2010 reforms are in effect. More nursing home surveyors are being hired (although fewer than the law says.) Nursing home fines have been changed, assessments of residents with criminal backgrounds are smarter, and residents who have been sexually assaulted are supposed to be properly treated.

But most of the reforms exist only on paper. Rules to improve the care of residents with serious mental illness are still being drafted. Likewise rules about dangerous residents, and to limit medical experimentation on nursing home residents. And to list and increase punishment of the homes with the worst violation histories. And to implement the 2011 reform law for people with developmental disabilities.

At Public Health's request, we are writing an informed consent form for psychotropic drugs and an informed consent protocol for stronger protection against wrongly drugging residents.

With luck, we will see some of these in 2013.

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ICBC's primary focus is helping individual residents, families and resident and family organizations. We help families choose a nursing home, shorten nursing home stays or avoid nursing home placement altogether by helping them find alternative care. We help them cope with Medicaid and Medicare. We work with individuals and family councils to improve poor nursing home care. Our database helps families make an informed choice telling them about services various nursing homes provide, their violation histories, and the experiences our members have had with them. We charge nothing for these services, and get no government grants to support our work.

ICBC also works as an advocate for nursing home and other long-term care residents with Congress, the Illinois legislature and various government agencies. Our ongoing work with the Chicago Tribune has resulted in several series about nursing home care, including the ones that led to the successful nursing home reform efforts of 2010 and 2011. Many of you know us as one of the leaders of efforts that led to the most significant reforms in Illinois in a generation. We wrote major parts of the reform law, and fought over every word to get the best possible result for residents. The fight over how to implement the law will go on for years. **ICBC must continue to exist to take the residents' part in that fight.**

How You Can Donate Money to ICBC. And Why.

ICBC exists to protect 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.

Your financial support allows us to continue to respond to the needs of long-term care residents and their families, to maintain our ongoing advocacy efforts to ensure that public laws and policies respect the rights and needs of long-term care residents, and to continue our public education programs. People tell us all the time what wonderful work we do; **unless that translates into tangible support, we will not be able to continue that wonderful work.**

You can make a tax-deductible financial contribution in a few ways.

1. Visit our website www.illinoiscares.org to make an online donation using Paypal.
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.
4. Become a member.

Membership Categories

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

You can print the donor form on our website.

Please give us a hand!!!!

