



## PEOPLE WITH DISABILITIES ORGANIZING FOR FREEDOM AND CHOICE



The *Campaign for Real Choice in Illinois* is a grassroots, citizen action organization consisting of people with disabilities, family members, friends and professionals. We are founded on the premise of participatory democracy and the belief that meaningful reforms in the system of supports for people with disabilities will come only with active involvement of people with disabilities and their families.

The Campaign believes that people with disabilities want to:

- Live in their own place
- Control what happens in their life
- Have flexible supports to live as they choose

To advance these beliefs, the Campaign meets with decision makers, organizes media events, empowers people with disabilities to speak, and engages in actions.

### Campaign Principles

1. **Individuality** - Disability services should be based on the needs and preferences of people with disabilities
2. **Consumer Control** - People with disabilities and their families should have control over their lives
3. **Participatory Democracy** - Citizens should get involved in the political process
4. **Friction** - Meaningful reforms in disability services will only be gained by challenging the status quo
5. **Action** - Improving lives and altering the relations of power will be accomplished through united action

## **ACTIONS AGAINST LINCOLN DEVELOPMENTAL CENTER**

*When the State of Illinois planned to reopen a state institution, the Campaign organized protests and conducted a petition drive to prevent the institution from opening.*

*The Governor of Illinois made a political deal with a politician who exchanged his vote on pension plan reform for the Governor's promise to reopen an institution in Lincoln, Illinois. A task force was appointed in June of 2003 to develop plans to reopen the Lincoln institution.*



On **April 26, 2004**, members of the disability community across Illinois forced their way into the meeting that was held via video-conference between Springfield and Chicago. 40 activists gathered at the Chicago site and 35 assembled in Springfield. At that time the Lincoln Task Force had been meeting behind closed doors since July 2003.

After we forced our way into the meeting that had been cloaked in secrecy for 9 months, the State agreed to open future meetings to the public.

On **May 24, 2004** the *Chicago Tribune* printed a scathing editorial entitled, "The Governor's White Elephant." The piece called Lincoln a "monstrous, money-chomping, isolated" institution.

On **May 27, 2004** Rep. Sara Feigenholtz introduced H.R. 1007 which "strongly urges" Governor Blagojevich and the Illinois Department of Human Services to take "immediate actions" to redirect the funding earmarked to reopen the Lincoln institution to supports for individuals with developmental disabilities. Within 48 hours, the resolution had 28 co-sponsors.

On **June 1, 2004**, the Illinois House of Representatives passed the Feigenholtz Resolution by an overwhelming 75 to 34 vote.



On **June 10, 2004**, members of the Campaign for Real Choice in Illinois converged on the Lincoln Task Force to present Illinois Department of Human Services Secretary Carol Adams with over 1,100 names of individuals from across the State of Illinois who oppose the current plan to reopen the Lincoln institution. The Campaign formally asked the Secretary to rescind her plan to open four 10-bed ICFDDs on the grounds of the former Lincoln institution and redirect the \$7 million dollars earmarked for the project to services and supports tailored to specific needs of individuals with developmental disabilities in Illinois.

On **June 16, 2004**, the Illinois Health Facilities Planning Board reviewed the plan for Lincoln. The Board's staff found the Lincoln plan to be lacking in 4 of the 14 criteria necessary to gain the Board's approval. At the meeting, the Board asked real questions and, if they demand real answers, the State will have a really hard time justifying the Lincoln proposal. At the June meeting, DHS pulled the Lincoln application after several Board members indicated that they would not approve the application at that time. DHS intends to resubmit a more detailed application for consideration at a future IHFPB meeting.

Shortly after the June meeting, the federal Justice Department issued indictments against all of the members of the IHFPB and the Governor fired them. The Governor appointed new members who looked at the Lincoln proposal on **October 20, 2004**. At that meeting, they decided to approve the proposal.

On **November 1, 2004**, DHS disbanded the LDC Task Force.

In **December 2005**, The Governor told members of Chicago ADAPT that his decision to reopen the Lincoln institution was a "mistake."

In **2006**, new buildings were constructed.

As of **Winter 2008**, the State was still deciding what to do with the site. Several options (including an institution for people with disabilities) were on the table.

In **February 2010**, members of the Campaign for Real Choice in Illinois and Community for All Coalition successfully prevented the state from allowing Hope Institute to use the old Lincoln grounds, now known as Lincoln Estates, and expand its residential services for children with developmental disabilities. We sent letters of opposition to Governor Quinn and Hope Institute, which resulted in the withdrawal of their proposal.

The buildings remained unused, although the state was still allocating funding in the budget each year for basic maintenance, until **Spring 2010** when the Lincoln property was finally zeroed out of the state budget, thus ending this nearly 10 year fight...for now.



### **Freedom Ride '05: A Smashing Success!**

*Thirty-three advocates trekked around the State of Illinois, rallying others to support freedom for people with disabilities.*



The following are excerpts from media coverage of the event:

#### **Disabled advocates rally for independence**

**LINDA N. WELLER , The Telegraph, October 18, 2005**



ALTON--"Freedom Ride," a four-day caravan organized by Campaign for Real Choice in Illinois, is to promote rights of disabled people to live in their homes with whatever support is needed. The group is pushing for passage of the Community First Act, which was introduced in the Illinois General Assembly this spring. If enacted, the law would allow a person with a disability to have the state transfer funds it spends, or would have spent, on the person in an institution to pay for long-term care services in the community.

Judy O'Malley of Godfrey, 64, ceremoniously rolled her wheelchair through black crepe paper jail "bars" at end of the rally. She said she was looking forward to the trip.

## **Freedom Ride supports legislation**

**BILL GRIMES, Effingham Daily News, October 18, 2005**

EFFINGHAM--A tour, billed as "Freedom Ride '05," stopped in Effingham Monday. Freedom Riders illustrated their core issue during a luncheon at the Effingham Knights of Columbus Building. A small group was seated away from the main group of about 30 participants and given choice over their food, when they would eat and other options. But the bulk of the group was treated as Community First Act proponents say nursing home patients are — with little or no choice over any aspect of their lives.

Opportunities for Access/Center for Independent Living (OFA/CIL) sponsored the Effingham stop on the tour. Executive Director Mike Egbert said the goal of the tour was to increase awareness of the disparity between community-based and institutional funding. "We want to raise awareness among communities and legislators so that community-first programs are fairly funded," Egbert said.

State Rep. David Reis, R-Ste. Marie, attended the event to visit with Freedom Ride participants. Reis said he hadn't decided how he would vote on the Community First Act. "I'm here to learn about it," Reis said. "This is the best way. Lobbyists in Springfield are fine, but the best way to find out about an issue is straight from the people who are most affected."

## **Group pushes for end to institutionalization of disabled, seniors**

**JULIE WURTH, The News-Gazette, October 19, 2005**



URBANA--Lois Curtis spent most of her teen and adult years in state-run institutions for people with disabilities. After her repeated requests to live in the community were denied, she and another woman sued the state of Georgia in 1995. They won, the state appealed, and the case wound up in the U.S. Supreme Court. The court's landmark decision declared that unnecessary institutionalization amounts to segregation and violated the Americans with Disabilities Act. The case has had nationwide implications, prompting Illinois and other states to re-evaluate how they support those with disabilities.

Curtis will visit Springfield this week to take part in the Freedom Ride by the Campaign for Real Choice in Illinois, which stopped in Urbana Tuesday morning. About 30 people are on a four-day, 700-mile tour to push for an end to institutionalization of seniors and the disabled. Curtis said it's unfair to force people to live in institutions if "they don't need to be there."

## **"Freedom riders' rally support**

**CINDY WOJDYLA CAIN, Herald News, October 19, 2005**

JOLIET--The "freedom riders" rolled into Memorial Stadium on Tuesday in an effort to drum up support for legislation that would help them live at home, in group homes or on their own. Joliet was the fourth stop. The ride will end Oct. 20 in Springfield at the Capitol Building Rotunda.

As they pulled into the stadium parking lot, freedom riders were cheered by clients from the Will-Grundy Center for Independent Living. Prior to the freedom riders' arrival, center clients gave testimonials about their stays in nursing homes and why they prefer to



be on their own. Many were in wheelchairs. Some were blind. Others limped. But they all had a story to tell and a cause to believe in.

State Sen. A.J. Wilhelmi, D-Joliet; State Rep. Jack McGuire, D-Joliet; County Executive Larry Walsh; and Recorder of Deeds Laurie McPhillips Weglarz attended the event. Dan Campus, the city's deputy liquor commissioner, represented Joliet Mayor Art Schultz.

**Disabled activists rally today**  
**MARNI PYKE, Daily Herald, October 19, 2005**

GLEN ELLYN--This morning, the Freedom Ride '05 van tour rolls into the DuPage Center for Independent Living in Glen Ellyn for a rally in favor of the Community First Act.

Activists say Illinois has lagged in keeping up with a 1999 U.S. Supreme Court decision that concluded states should place people with disabilities in community settings rather than institutions when appropriate. "We all agree the job is not done, there's more work to be done," Illinois Department of Human Services spokesman Tom Green said. But he noted the state had moved 1,000 people out of institutions in recent years. Right now the department is working on plans to meet the goals of the U.S. Supreme Court decision, Green said. "We are in favor of moving people into the least restrictive setting possible," Green said.

**Freedom Riders seek home options: Campaign calls for seniors, disabled to have a choice**  
**JOHN R. PULLIAM, The Register-Mail, October 20, 2005**

GALESBURG - Freedom Riders stopped here Wednesday. Their message? Seniors and the disabled deserve an opportunity to live independently in the home of their choice. Wednesday was the third day of a four-day swing through Illinois.

"We know that some type of segregation is still happening," Gerard Broker, director of the Statewide Council on Independent Living, told the audience comprised of the Freedom Riders, representatives from Stone-Hayes Center for Independent Living and other agencies that deal with the issue, as well as politicians and interested individuals. "It's the ignorance of society that says to these people they can't live among us because they are disabled. ..."

Addressing independent living for seniors and the disabled, state Rep. Don Moffitt, R-Gilson, noted that his association with Stone-Hayes dates back many years. "We all want to live as independently as possible," Moffitt said. "We all want our own home. ... I support your efforts." State Sen. Dale Risinger, R-Peoria, observed, "Better care at less cost, it seems like a no-brainer. ... We need to get into the modern-day century to provide the services to the people who deserve it."

**Freedom Ride comes to town**  
**PAUL SWIECH, The Pantagraph, October 21, 2005**

BLOOMINGTON -- The 90-minute rally marked the final stop of the Freedom Ride, a 700-mile, four-day drive throughout Illinois to drum up support for the legislation. About 65 people with a variety of disabilities and from throughout the state were at the rally, then drove to Springfield for a rally in the state Capitol rotunda.

"The dollars should follow the person," said State Rep. Dan Brady, R-Bloomington, who will be a co-sponsor of the bill. "Why spend tax dollars on things (nursing home services) that they don't need?" Brady asked. "It's a waste."

"Hear our voices, we want choices!" chanted rally-goers wearing matching Freedom Ride shirts that said "Riding for the Choice To Live at Home" on the back.



### **Funding for disabled subject of rally: Attendees request state move away from institutions**

**MARY MASSINGALE, State Journal-Register, October 21, 2005**

SPRINGFIELD--Disabled residents ended a statewide, grass-roots Freedom Ride on Thursday with a rally at the Capitol calling for state government to transfer funding of institutions to community-based settings. The nearly 200 attendees at Thursday's rally urged state officials to break free from the trend of institutionalization in Illinois.

Participants collected more than 5,000 signatures in support of Senate Bill 1324, called the Community First Act and introduced last spring by Sen. Maggie Crotty, D-Oak Forest. The measure calls for state funding that would have been spent to house an individual in an institution to instead be spent on placing that person in a community-based setting.

Rally attendees strung pages of the petition and then encircled the Capitol rotunda with the "chain of bondage." Jennifer Wilson of Springfield cut the symbolic chain. Wilson, 21, is one of nine plaintiffs suing the state for failing to place developmentally disabled residents into community-based settings, thereby forcing them to reside in nursing homes or at home. The advocacy group Equip for Equality is representing the plaintiffs. The armful of petitions were then given to Blagojevich's deputy chief of staff for social services, Louanner Peters, who attended the rally.



## ILLINOIS STATE FAIR 2006

In August 2006, hundreds of people with disabilities showed up at Governor's Day and Republican Day at the Illinois State Fair. We were there to let our leaders know that people with disabilities are an important part of the voting population. Our bright yellow shirts were hard to miss. They stated:

*Life, liberty, and the pursuit of happiness  
It's my right too...*



## LIBERTY LAUNCH 2007



*People with disabilities around the state united in a launch for freedom from the control of others, a launch for freedom from the captivity and confinement of institutions, and a launch for the power to act, speak and live according to choice...a launch for liberty!*

LIBERTY LAUNCH was an opportunity for Illinois residents to join forces with others to create meaningful systemic change in the way Illinois serves its citizens with disabilities.

Through a drama, individuals experienced the controlled institutional life compared with the freedom and choice of life in the community. Many people shared their experiences in institutions and nursing homes, including:

- Frustration about not being able to get a tattoo
- Feeling a complete loss of control
- The inability to choose what to eat



- The lack of dignity that comes with being seen as a second-class citizen by staff

Thankfully, the day did not end there. Instead, Lester Pritchard inspired us with these words:

"Instead of quietly accepting our plight, we are beginning to stand up and demand real equality. Real equality is founded upon the principle that "all are created equal." Real equality serves as the basis for all other inalienable rights guaranteed to all citizens by the Constitution. Real equality is not achieved, not granted. Real equality does not depend upon the goodwill of others. People with disabilities in Illinois are beginning to assert their real equality. They are beginning to demand something new in Illinois.

That's why the Campaign for Real Choice in Illinois is here today...to give you the opportunity to participate in this movement for something new in our state. We call it our Liberty Launch...

- a launch for freedom from the control of others,
- a launch for freedom from the captivity and confinement of institutions,
- and a launch for the power to act, speak and live according to choice...a launch for liberty!

With those words ringing in our ears, we wrote letters to the Governor, telling him about the lives we wanted to live - lives full of freedom and choice.



## FREEDOM QUEST '09



Freedom Quest '09 was about change...change that will allow people with disabilities in Illinois to get the services they need and live free, independent and inclusive lifestyles. Thousands of people with disabilities and their supporters gathered at rallies across the state, calling on the Illinois government to create a service system that meets people's needs. Freedom Quest '09 included 12 stops around the state, and a closing rally in Springfield.



### Northeast Route:



The Northeast Riders began on the morning of **May 19th** at the Waukegan City Hall to "Pause for the Cause." The organizers, from Northpointe Services, planned a 2 minute pause of silence for Lake County to recognize people with disabilities in Illinois. From here riders went to Northpointe Services in Zion for a rally! The afternoon was spent driving to Joliet for the next event being hosted by Cornerstone Services. The caravan stopped for dinner at White Fence Farms for famous fried chicken and then attended the event at the Joliet airport. Self-advocates spoke and signed a quilt to bring to the Capitol.

## [Freedom Quest's Pause for a Cause in Waukegan ~ May 19, 2009](#)

The North East route began with "Pause for a Cause" at the Waukegan City Hall. About 60 people gathered and at 10:00 am everyone froze for 2 minutes...then we began chants about freedom for people with developmental disabilities in Illinois. The mayor, chief of police and other city staff stopped by to discuss the issues with the riders.

## [Freedom Quest Zion Rally at Northpoint Resources, Inc. ~ May 19, 2009](#)

The Freedom Quest North East Route riders spent a couple hours at NorthPointe Resources, Inc. in Zion, Illinois on **Tuesday, May 19th**. The riders joined many others for a Rally in the parking lot. The speakers included:

Karl Kopp - CEO/President NorthPointe  
Darryl Swank - Chairman Board of Directors NorthPointe  
Patrick Coles - Northpointe Council President  
Brian Dixon - Self Advocate Illinois  
Donna Morask - Family Member  
Lester Pritchard—Founder, Campaign for Real Choice in Illinois

Northpointe graciously provided pizza, salad, cookies and drinks to the riders before we continued our journey across the state.

## [Freedom Quest Joliet Rally ~ May 19, 2009](#)

Mary Tisdale was the speaker from the Center for Independant Living.

Sonia R., self-advocate from Joliet, received the Lighthouse Award for her leadership and teaching of Spanish classes at 2 different locations within the Community Service Department of Cornerstone Services.

Halo Entertainment received the Dream Maker's Award for donating their recording studio, as well as their time and expertise in making a client's dream come true.

After Terry Ber, Vocational Manager presented Halo Entertainment the award she was surprised to be the next recipient of the same award for all the dreams she was instrumental in helping to come true.

Self advocates worked on quilt squares for an advocacy quilt, and made their own "I am a Voter" pin to wear.

Ron R., self-advocate from Joliet, who's dream was to make his own CD had a table to display and sell his dream come true.

Sonia R. headed up a table sharing about the Alliance, a statewide initiative, allowing self advocates to sign up or be added to the mailing list.

Self-advocates led everyone in an inspiring song "This is America" written to the melody of "God Bless America" with original lyrics by Terry Ber:



**May 20th** began with the caravan loading up all 9 vehicles and driving to Pontiac for an event hosted by Mosaic of Pontiac and other community partners! Mosaic had a rally with a quiz show, speakers, and opportunities for self-advocates to speak up! Riders ended their day at a rally in Central Park in Decatur. Macon Resources organized the event which brought hundreds of self-advocates together to talk about their lives, goals, and dreams!

### **Freedom Quest Pontiac Rally ~ May 20, 2009**

In Pontiac, the riders were provided a nice lunch at a local church and then back outside for a wonderful Rally. The event included:

Opening by Shirley Paceley, Illinois Voices and Freedom Quest '09 Planning Team Member

Original music—"Let's ride to Freedom" written by Karen Donovan (who also played the guitar!) from Futures Unlimited and Nathan played the keyboards with vocals by Michael.

Brian B., self-advocate from Futures Unlimited, read a letter he had written his legislator...ten years ago and the issues are the same today. Brian said that change would come now because the self-advocates are speaking up!

Speeches by Rena, Brenda and Rudy (self-advocates) as well as an Open Mic were all inspiring.

A quiz show about the DD system of services in Illinois was next, then Lester Pritchard, Campaign for Real Choice and Freedom Quest 09 Planning Team Member, gave a speech.

The Ride for Freedom Music happened again, by popular demand

The Balloon Release was the closing activity, capping off an awesome rally!

### **Freedom Quest Decatur Rally ~ May 20, 2009**

At 4:30 pm on **May 20th**, the Freedom Quest North East Route Riders arrived at Central Park in Decatur. We were greeted with cheers from a crowd of people who were waiting for us. We joined them for an out door event under beautiful skies.

Dreux Lewandowski and Molly Chapman from Macon Resources, Inc. welcomed everyone and then Brian D., self-advocate from Zion, opened the Rally with an inspiring speech. Several people spoke from their hearts about their lives and what is important to them.

The riders were then treated with dinner at Macon Ice Cream and More before they left for Springfield.



## Northwest Route:



The Northwest Route began in Moline on the morning of **May 19th**. Riders met at the I-Wireless Center for a rally planned by self-advocates from the ARC of Rock Island. The Mayor of Rock Island spoke as well as self-advocates. From here, the caravan headed to LaSalle-Peru for the event hosted by Horizon House of Peru and a team of community organizations. This event included skits about the difference between community living and institutions and music from the Friendship Choir. The riders left the event and headed to Peoria.

### [Freedom Quest '09 Northwestern Route Rallies a Huge Success!](#)

Rock Island - "What freedom means to me" was the theme of the event in Rock Island. About 150 people with disabilities and their supporters attended the event that included speeches from self-advocates from the Speak Out group, the Rock Island Mayor, Congressman Hare's staff, and area disability services providers. Don Healy, a professor at the local university, ended the event by leading the whole group in a chant of, "Yes We Can!" "Yes They Should!" "Yes They'd Better!" We will take that message with us to Springfield!

LaSalle-Peru - There was a party in Peru yesterday! When the caravan arrived we joined 250 people who were cheering and holding signs with messages about freedom and choice. During the event, there was a skit showing the differences between institutions and the community, speakers, and beautiful songs from the Friendship Choir.

Illinois Mentor hosted a celebration for people with disabilities at the AmericInn in Peoria on the Morning of **May 20th**. Life boards were shared by self-advocates and candles were blown out as a symbol of making wishes for freedom and choice. At the conclusion of the event balloons were let go into the sky. The caravan of 8 vehicles drove from Peoria to Bloomington. MarcFirst hosted a rally in Bloomington where riders could participate in games and various activities. The event was very much like a block party for riders, self-advocates, and their supporters!

## South Route:



The South Route Riders began in Murphysboro on the morning of **May 19th** at a rally hosted by S.T.A.R.T. Self-advocates and their supporters brought signs and listened to speeches on the importance of a better system. From there, the eight vehicles in the caravan headed to Mt. Vernon, where Opportunities for Access Center for Independent Living had planned the next event. Mt. Vernon depicted the difference between institutional restrictions and freedom of choice at lunch. Some people were given choices and an abundance of food, while others were not. At the end of the event, the caravan headed for Mattoon to spend the night.

The Freedom Quest '09 Rally in Mt. Vernon included participants receiving "money" that represented services in Illinois. Some participants received "money" representing personal choices in a home/community based program while others received "money" representing no choices in an institutional bias program. Participants with choices received a full plate of yummy food served quickly and with a smile while those with no choices got whatever "staff" felt like they should have, regardless of if they wanted it or not or wanted more or not. Some participants even had to go begging to get more food to eat, much to the dismay of the "staff"!

Craig H., self-advocate from Mt. Vernon, won a t-shirt for his guess of 2,400 pennies in the jar!

On the morning of **May 20th**, the caravan headed to the city of Charleston for an event hosted by Charleston Transitional Facility, at the steps of the Charleston Court House. The event started with a proclamation for Freedom Quest from the city. Then there was music, a visit from Abraham Lincoln, and a large rally. After lunch, the riders jumped in the cars and drove to Alton. IMPACT Center for Independent Living hosted the event in Alton. Speakers talked about the importance of choice and freedom and the new Mayor of Alton stopped in to speak!

## [Freedom Quest Alton Rally ~ May 20, 2009](#)

It was a warm and sunny afternoon when the Freedom Quest Southern Route Riders pulled into Impact Center for Independent Living for the Freedom Quest Alton Rally! Banners were waving, signs were displayed, and music played while the Freedom Quest participants greeted old friends and welcomed new ones.

The Rally moved inside for the program which included:

Cathy Contarino, Executive Director of Impact

Sarash Castle, Campaign for Real Choice/Freedom Quest '09 Planning Team  
Lori F., self-advocate from Granite City  
Margie W., self-advocate from Granite City  
Beverly B., self-advocate from Alton  
Barb W., self-advocate from Alton  
Tom Hoechst, Mayor of Alton  
Open Mic where self-advocates shared their stories of dreams and hope

Amy Walker, Illinois Voices Systems Change Activist/Freedom Quest '09 Planning Team member, led the participants in singing "We Are The Champions" by Queen as well as "We Will Rock You" by Queen with original lyrics by Amy:

## **CLOSING HOWE DEVELOPMENTAL CENTER**

**Free people at  
HOWE  
NOW!**

### **Background:**

Howe Developmental Center is a state-operated institution in Tinley Park, Illinois, where 320 people with developmental disabilities live. Howe has repeatedly been cited for poor care. 24 people have died at Howe since September 2005. The federal government has pulled its certification and funding from this institution. In addition, the Department of Justice is investigating Howe for violations of constitutional rights for its residents.

We want those living at Howe to be able to return to their home communities with the support they need. We believe that people deserve to have choices in where they live and the services they receive. We are organizing to bring public attention to the issue and push the state to transition people to the community. Once people are transitioned, we believe Howe should be closed.

### **Press Conference:**





On **May 30, 2008**, the Community for All Coalition released a "report card" about Howe Developmental Center. The State received failing grades for Quality of Service, Ensuring Civil Rights, Maximizing Federal Dollars, and Effective Use of Illinois Taxpayer Dollars. Speakers (pictured above from left to right) included Larry Biondi from Progress Center for Independent Living, Zena Naiditch from Equip for Equality, Amy Walker from Illinois Voices, Derrick Dufresne from The Institute on Public Policy, and Lester Pritchard from the Campaign for Real Choice in Illinois. The Southtown Star and the Chicago Tribune reported on the press conference.

### Rally 21:



Right: A ghost (Tia Nelis) comes to "21" (Amy Walker) in her sleep, telling her how people at Howe have died. Left: Delegates Rena and Jim are interviewed about their experiences.

On **July 29, 2008**, about 100 people rallied in front of the Thompson Center, calling on the Governor to close Howe. Coalition members performed a drama (written by Amy Walker) about the horrible conditions at Howe. Delegates from the Coalition took our demands to representatives from the Governor's office, who promised they would respond quickly. Zena Naiditch, from Equip for Equality, spoke about how they have recently found that three more people have passed away in the last several months. Together, we urged the Governor to "Free our People...Close Howe NOW!!"



Participants laid flowers at the "tombstones" of the 21 people who have died at Howe in the past few years.



State officials announced Friday, **September 5, 2008** that they plan to close Howe Developmental Center within the next year!



Advocates from around Illinois preparing to deliver 1,700 petitions to Governor Quinn, asking him to close Howe Developmental Center.

Disability organizations from around Illinois gathered at the Capitol in Springfield on **February 10, 2009** to urge Governor Pat Quinn to continue the process of closing Howe Developmental Center. Equip for Equality announced that five more people have died at Howe since closure was announced in September 2008. More than seventy advocates took part in the press conference and in delivering petitions to Gov. Quinn. The event was one more step towards getting the shameful, wasteful institution closed.

On **April 28, 2009** the Commission on Government Forecasting and Accountability voted to close Howe Developmental Center by a vote of 9-3!

On **August 28, 2009**, after months of delay, Governor Quinn announced that he will close Howe Developmental Center. "It is with the utmost consideration for the well-being of the residents and staff at Howe Developmental Center that I make this decision," Quinn said in a news release. Congratulations to all the advocates who have fought so hard for the freedom of Howe residents!

On **June 21, 2010** the last of the 257 residents of Howe were moved out and the institution was finally empty, ending the months long process of shutting down the 36 year old facility.

## **ACTIONS AGAINST MEDICAID MANAGED CARE**

In the **Fall of 2009** the Campaign for Real Choice started hearing rumors that all Medicaid eligible seniors and people with disabilities living in the Chicago area would be required to enroll in a Managed Care pilot program. The pilot was to be divided into 3 phases, beginning with medical services in Phase 1, and then moving into long-term care and community services in Phases 2 & 3.

Like many people, we believed this was a horrible idea that had the potential to disrupt or eliminate services, particularly specialist services, limit access to providers, and severely impact already beleaguered community services. We had grave concerns and unanswered questions, with no real opportunity to voice our objections. For the most part, the state was shutting out advocates and consumers from the planning process and violating our basic principle, “nothing about us without us!”

Along with members from the Community for All Coalition, we testified at several legislative hearings and press conferences throughout the **Spring of 2010**, to express our opposition and demand access to information and involvement in the process.

We participated in the first Managed Care Stakeholders meeting on **March 13, 2010** at INCIL in Springfield, which was facilitated by the Department of Health and Family Services but organized by advocates. Half of the 20 people in attendance were members of the Community for All Coalition. These meetings are still held regularly today and have grown to close to 100 attendants with two meeting sites in Springfield and Chicago.



On **August 12, 2010**, the Community for All Coalition held a march and rally in downtown Chicago to protest the pilot, including stops at several of the Managed Care Organizations bidding to participate in the pilot as well as the Thompson Center and Daley Plaza. The rally resulted in a meeting between the Coalition and HFS Director Julie Hamos.

During the **Fall 2010**, the Campaign for Real Choice and Community for All Coalition met with the two participating MCOs, Aetna and Illinicare, as well as a follow up meeting with Director Hamos to continue to express our concerns and opposition and demand that if this pilot continues it must have consumer control at its core. A major victory from these meetings was the development of an independent evaluation of the pilot to be conducted by the UIC Institute on Disability and Human Development, with an evaluation committee that consists of advocates and consumers from the Community for All Coalition, including the Campaign for Real Choice.

During the **Spring of 2011**, we worked to organize the 6 Centers for Independent Living in the pilot area, which includes suburban Cook, Kane, DuPage, Lake, Will, and Kankakee Counties. Several of these CILs have become enrollment facilitators to support and advocate for consumers as they go through the mandatory enrollment throughout the Summer of 2011.

## **SAVE THE SAFETY NET RALLY 2011**



On **May 16, 2011**, the Campaign for Real Choice and Community for All Coalition held a rally at the Capitol Building in Springfield calling on Governor Quinn and the legislature to ensure the State Budget funds programs that support people with disabilities living at home, or in small community-based settings, rather than institutions. The rally was unique in that it fought to “Save the Safety Net” for all people with disabilities, including seniors, people with physical and developmental disabilities, and people with mental illnesses.

The day began with a press conference in the Capitol Blue Room with Rep. Esther Golar, chair of the House Disability Services Committee, as well as speakers from the Coalition and organizations representing each disability population. More than 100 advocates and consumers had the opportunity to meet with their legislators prior to the rally in the Capitol Rotunda.



With the media watching and legislators forced to pass through the Rotunda on their way to their offices or chambers, speakers, advocates, and consumers from across the state and across disability populations demanded respect and freedom from institutions. The day ended with a public demonstration in front of the Lincoln Statue in which advocates came together to Save the Safety Net.

