



FLORIDA INDEPENDENT LIVING COUNCIL, Inc.

“The Room of Pain and Loneliness”

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Activities initiated/hosted by the Florida Independent Living Council are open to the public. For information about these or any other FILC events please contact the FILC office @ (850)488-5624.

Full Council Meeting
November 15-17, 2006

Rosen Center Hotel
9840 International Dr.
Orlando Florida 32819

The following article was written by Ed Hooper, a disability activist from Sarasota and published in the Ragged Edge edited by Darriett Shaw.

“I have a picture of that room. It’s in my head even now. There’s a toilet. There’s an elevated bathtub—the kind that lets them slide you in from a hospital bed. Two frosted windows in there, there in drab green walls. A big heavy door and a cold floor. A cold, cold brown tiled floor.”

At this particular home for “crippled” children in Pennsylvania and in the memory of Tom Zabelsky, it served a very different purpose. It was closet.

The room, the whole institution, had no warmth. It was sterile. Sterile and cold. It was in this room that Tom remembers being confined for hours. For days. Alone.

The very night that Tom arrived at the institution and as he remembers it today, he fell out of bed and broke his hip. He doesn’t remember how he fell because he didn’t have the strength or ability at the time to even move his body. And though X-Rays were taken that confirmed the break, neither he nor his parents were told about the injury for months and then according to Tom’s mother they found out quite by accident.

He was little, he was hurt and he cried. “If you don’t stop crying we are going to put you in the room! By yourself!” Tom recalls the words today, years later. They are memories of the abusive actions and attitudes felt by him at the “Home for Crippled Children”. Tom was sent to the “Room” too many times to count. Perhaps that’s why he remembers the “Room” so clearly. Five year old children do fuss and cry, especially “crippled” children with newly broken bones, rehabilitating from polio. Tom spent what seemed to him like years isolated in that sterile closet. If Tom didn’t obey, if he wasn’t quiet, the casters would be unlocked on his hospital bed and he would be wheeled into the “Room” to contemplate his behavior. He remembers he was always made to feel he had done something bad, but he didn’t know how to meet the Home’s expectations of what being “good” was. “God, when I was in that room how I prayed I could go to sleep so the time would pass faster! But I couldn’t sleep.” He now says, “No one seemed to care that I was lonely or in pain. I’d cry for my mother, but no one ever came.” “What I’ll always remember the most was the loneliness.”

Tom did learn in the two years he spent in the Home how to limit the time spent in the “Room” He learned to obey the “don’t fuss, don’t cry” rules. His body was tended to after a fashion and he was fed, but one could never say he was “cared for”. To this day he cannot remember a smile or even a friendly face, except on weekends during visiting hours when the stern, forbidding faces

(continued on page 2)

October Calendar

Please Note
Call FILC @ 850-488-5624 prior to teleconference for call in num-

Thursday
October 5, 2006

Advocacy Committee 1:30 p.m.

Thursday
October 12, 2006

Planning Committee 1:30 p.m.
Teleconference

Evaluation Committee 2:30 p.m.

Wednesday
October 17, 2006

Point Committee 10:00 a.m.
Teleconference

Thursday
October 18, 2006

Finance Committee 1:30 p.m.
Teleconference

Thursday
October 26, 2006

Executive Committee 2:30 p.m.
Teleconference

Monday
October 30, 2006

Grassroots Forum 2:00 p.m.
Meeting Teleconference



FILC meeting with Ollie Cantos, Associate Director of Domestic Policy at the White House.

(continued from page 1)

turned warm and caring at least until his parents went home.

Why didn't Tom tell his parents about the "Room"? Tom really doesn't know why he never told anyone. Finally after 34 years he came up with the reason—"I guess it was just something I thought I had to endure".

How many people with a disability in this country are enduring abuses? I know a twenty year old man, who for over a week was not moved, bathed or even allowed toileting. His bowels became so impacted the he required hospitalization. He had been abused by his own mother. This man won't blow the whistle on his mother, nor will countless others come forward to complain. They simply endure. They endure slaps, punches, burns, sexual molestation and more. They endure it. Why? Abused people feel things will only get worse if they complain. Certainly, backlash from an uncaring or violent person is a legitimate fear from someone being abused—and if they complained, where would they go? Or perhaps they internalize the abuse, thinking that it's something they have done. Perhaps being disabled is enough that both victim and abuser just believe that's the way it is when you're disabled. "Shut up and be thankful you're getting anything at all!!" Day after day disabled people like Tom Zabelsky endure. We acknowledge elder and child abuse, but we don't acknowledge abuse of person with disabilities. Not yet. This has to change. We all know the problems exist, but we keep the abuse in the closet. That's the metaphor we use in our society when we do not want to discuss what we are most ashamed of. Yet, Tom Zabelsky lived in that closet metaphor. To him it was no metaphor. It was real. The room of pain and loneliness.

Is the disability community ready to open the closet to confront the reality of abuse? The above is only one story of a child who grew up in an institutional setting. It is for the many people with disabilities that the Florida Independent Living Council is requesting that ACHA submit an application to the Centers for Medicare and Medicaid Services (CMS). CMS is providing an opportunity for funding to assist in implementing systemic changes to better serve individuals with disabilities in the setting of their choosing. The Real Choice Systems Change grants support infrastructure changes that will result in effective and enduring improvements in the community long-term supports systems. Only July 26, 2006, CMS announced the 2007 Money Follows the Person demonstration grants to states. There will be \$250 million available beginning January 1, 2007 and a total \$1.75 billion for five years. We again encourage the Florida Sate Medicaid Office and Governor Bush to use this opportunity to rebalance its Medicaid System. We believe that this opportunity will serve to enhance the current Medicaid Reform efforts in the state.

"Independence Worth Preserving"

Centers for Independent Living

- Suncoast Center for Independent Living** serving Sarasota and Manatee Counties, (941) 351-9545
- Coalition for Independent Living Options** serving Okeechobee, St. Lucie, Martin, and Palm Beach Counties, (561) 966-4288
- Center for Independent Living of Broward** serving Broward County, (954) 722-6400
- Disability Resource Center** serving Holmes, Jackson, Washington, Bay, Calhoun, Gulf, Liberty, and Franklin Counties, (850) 769-6890
- Center for Independent Living of the Florida Keys** serving the Florida Keys, (305) 453-3491
- Center for Independent Living of North Central Florida** serving Hamilton, Suwanee, Columbia, Lafayette, Dixie, Gilchrist, Union, Bradford, Alachua, Levy, Marion, Putnam, Citrus, Sumter, and Hernando Counties, (352) 378-7474
- Self Reliance, Inc.** serving Hillsborough County, (813) 375-3965
- Center for Independent Living of South Florida** serving Dade County, (305) 751-8025
- Independent Living Resource Center of Northeast Florida** serving Baker, Nassau, Duval, Clay, and St. Johns Counties, (904) 399-8484
- Center for Independent Living of Southwest Florida** serving Charlotte, Glades, Lee, Hendry, and Collier Counties, (239) 277-1447
- Center for Independent Living of Northwest Florida** serving Escambia, Santa Rosa, Okaloosa, and Walton Counties, (850) 595-5566
- Caring and Sharing Center for Independent Living** serving Pasco and Pinellas Counties, (727) 577-0065
- Ability 1st** serving Gadsden, Leon, Wakulla, Jefferson, Madison, and Taylor Counties, (850) 575-9621
- Victory Lane Center for Independent Living** serving Flagler and Volusia Counties, (386) 671-1960
- Space Coast Center for Independent Living** serving Brevard and Indian River Counties, (321) 784-9008
- Center for Independent Living of Central Florida** serving Polk, Hardee, DeSoto, Highlands, Lake, Seminole, Orange, and Osceola Counties, (407) 623-1070

Please feel free to distribute this letter to any other persons/organizations that may be interested.

It is the mission of the Florida Independent Living Council to assist and advocate for people with disabilities in achieving equal opportunities. Our vision is to foster change via leadership, collaboration and visibility.