



Fighting for the CCA at the White House with ADAPT

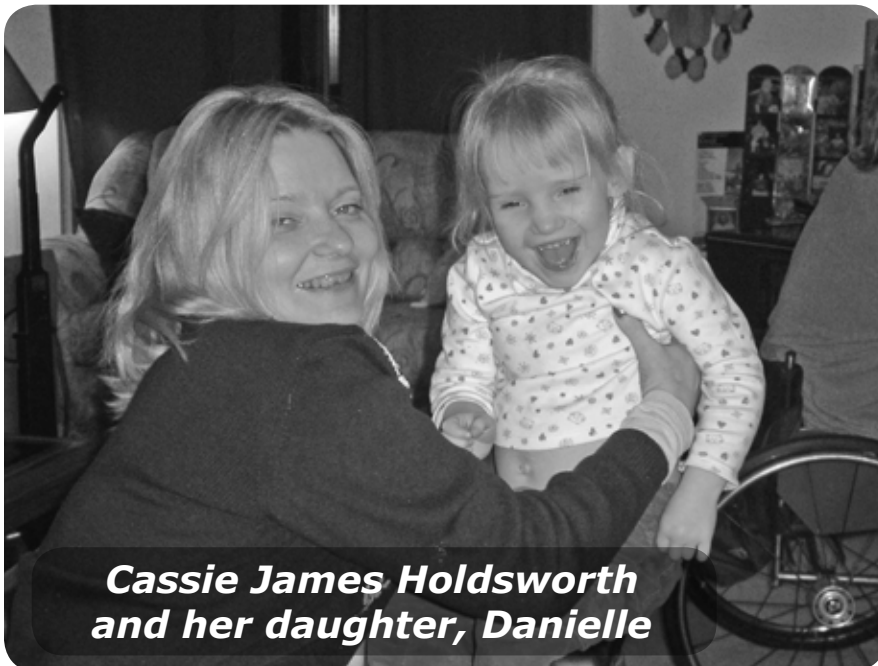
by Madeleine McMahon

I entered the Holiday Inn dragging my rolling suitcase as it twisted with a mind of its own on the casters. My eyes scanned the lobby now filled with guests and a growing number of yellow T-shirts emblazoned with the ADAPT logo.

My role at the ADAPT nationals this year was simple: care for and entertain the young activist named Danielle Catherine Frances Holdsworth, the 9 year-old daughter of activists Cassie James and Alan Holdsworth. The

assignment would bring me into many circles of friends and fellow activists present at the events over these days. All of us would have stories to tell before the week was out. The morning would bring a demonstration at the White House aiming to get President Obama to support the Community Choice Act. For now, I would scan the faces and figures of so many people from all over the United States and beyond.

There was Roxanne, who would soon lead a veteran ADAPT contingent in the blazing sun for two days straight, with her little poodle with



***Cassie James Holdsworth
and her daughter, Danielle***

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his red sunglasses draped behind her scooter seat. They would stay together in jail the second day. On the third day, Roxanne and her dozing pup rode into the Russell Senate Office Building together, only hours after an early morning release from jail. The Capitol Police strategy for the twelve hours of detainment to offer no food, no water, and no access to prescription drugs to most of those detained did nothing to diminish her fire.

There was Jay—kind, smiling Jay—surrounded by the love of his new wife and three children and the others who found their way to his side. Jay and his wife, Lisa, told me they actually were involved in the closing of a state-run nursing home, Beverly Warren Central. “It was pretty easy”, he recalled, “we would go over there and basically, once people found out that we were helping to bring people out into their own housing in the community, we had plenty of takers.”

When I first saw Bob Kafka and Stephanie Thomas, ADAPT’s National organizers, I was star-struck. Watching them shuttle about from group to group, encouraging and remembering together in the hours between a meeting, or a march, or the next action, I reflected on the years and years of love and service to this community and our country. Later, other activists would tell me how much courage they drew from Stephanie or Bob as the mind games began in the lock-up.

Kristin, another ADAPT daughter, easily reached out to Danielle. Each knew without words exchanged, the life of a child in this community. Each were surrounded by parents and good family friends who will work hard together, joke with one another, kiss their children in the morning, and face down the consequences of civil disobedience before lunchtime.

These parents are the children’s heroes, but the children reach to one another for a kind of knowing that does not come from schoolmates or other family and friends. ADAPT children share a bond that is strong.

Danielle, throughout the morning at the White House, would look intently at the large family van that was parked in the President’s driveway and say: “Mrs. Obama will tell her husband at dinner that we were here if he’s too busy to come out and greet us.” Days later I learned from Robert Heim, another one who willingly accepted arrest at the White House fence, that Michelle Obama had in fact taken a long pause parked in her driveway and was seen exiting that van later in the morning.

The promise of the CCA holds the dream of our freedom. ADAPT moved with certainty chaining themselves one by one to the White House fence as word came back from the Administration bureaucrats that priorities in the White House had shifted in recent weeks.

ADAPT members gathered every night in a large room, recapped the day's events, and talked about the personal power that was unleashed during the actions. The plans for the next days' actions were not discussed, simply a time to report to the line again was agreed upon. In pairs and small bands the meeting dissolved into the night, spilling out onto the courtyard and down the sidewalks. Some drank hard liquor, others calculated the cost of a soda from the vending machine. Everyone had something to say, something to hear. The murmurs carried along with lilted giggles and gruff, impatient talk—talk of a revolution and an end to the thought of segregating people with disabilities and aging citizens into nursing homes and other residential facilities that are “beneficently” operated by someone whose own personal freedom is not at stake, and whose stake in the whole affair is profit and plenty of it.

There was talk of the end of a scheme that, for years and years now, has funneled our tax dollars via the Social Security Act into a steady stream of nursing home dollars. Over 80% of the Long Term Care (LTC) money used every year in Pennsylvania is claimed by the Nursing Home Industry. Four out of every five dollars feeds the dragon that extinguishes us. Rebalancing the Long Term Care tax dollars is what the Community Choice Act is all about. The Community Choice Act will make it law that a person

with a nursing home Level of Care Determination can choose to use LTC dollars to remain living in the community or to accept care from a nursing home. The nursing homes know they have a sweet deal that, like campaign promises, can be broken.

On day two, the focus was on Capitol Hill. This Community Choice Act is today in the hands of Senators and Congressional Representatives. ADAPT wanted all of Washington and the watching world to know that this rebalancing of the use of our tax dollars can now be accomplished in this 111th session of Congress. Traffic came to a halt on Independence and New Jersey Streets that morning. The frustration of the Capitol Police began to mount. Another contingent of ADAPTERS had designs on the Capitol Steps. One by one, each crawled, shimmied, or were carried as they mounted the steps enacting the very same action that ADAPTERS deployed the year the ADA passed.

The florid gorgeousness of the Washington springtime was not lost on Danielle and I as we played with a toy ball in the courtyard. The invite to go out for ice cream was irresistible.

When we returned to the Hotel, we found the place noticeably scarcer of our company. Sixty-eight people were arrested and most were still in jail. The party atmosphere was a little subdued under the moonlight, and there was an edge about the whole place. We waited. There was

false information of early releases; pizzas getting colder; people getting annoyed with one another. My outgoing cell phone calls were futile releases of the building anxiety. I hung up when Danielle had quietly come up behind my ear and whispered that she and the others were going to head to the sidewalk and await the release of our people.

People's faces again emerged in relief in the crowd: tired, sunburned, knowing. Knowing how much more it was going to take than this night. Reports of thwarted releases came, sometimes contradicting one another within the same five minutes. Danielle, asleep in her mother's arms, began to stir. The conversation shifted, and heads crane to see: "Is that them?"

Spanning the entire intersection a few blocks away, the returning ADAPters rolled into the moonlit

street. The greetings were personal, like at the airport among friends, and they were all around me. Exhausted but undaunted, they were already joking with one another. "That was an awfully long time to wait for a Bailey's," Pat said as she rolled into my sight from the darkness. Her smile was strong. Pat was arrested not once but twice that same week.

An immediate and sudden end was put to our chatter, upon my spying a large, filthy rat in the courtyard near a trash bin. Pat and I jolted out of the plaza and laughed behind closed glass doors, out of breath. As the elevator doors closed behind me and I quietly walked back to my room for the night, I understood a tiny slice of freedom that is mine and not anyone in a nursing home's: I am free to exit any place I don't want to be..... for now. ★



***Nancy Salandra
handcuffed to the
White House fence***

Housing Advocacy Update:

Welcoming New Director Elvis Solivan

by Miguel Vargas



Some of the housing staff at a HUD Symposium on April 10, 2009: Kenneth Peeples, Robert Mears, Rasheeda Rozier, Antoinette Cottman, Elvis Solivan, & Baker Schaffer.

Liberty's Housing Advocacy Department is undergoing some exciting changes, including the recent appointment of Director Elvis Solivan. Elvis comes to LRI from the U.S. Department of Housing and Urban Development, where he was appointed Special Assistant to the Regional Director by former Secretary Mel Martinez. As Special Assistant, Mr. Solivan was responsible for the delivery of HUD programs and services while evaluating their effectiveness. Prior to joining HUD, Mr. Solivan was the Community Relations Manager for the Philadelphia Housing Authority. In this position, Mr. Solivan was

responsible for directing, planning, and coordinating programs designed to promote good relations between tenants in the development of group activities such as adult education, job readiness training, good citizenship, and recreation.

Under Mr. Solivan, Housing Advocacy has adopted a fresh Policy and Procedures Manual, allowing counselors and colleagues alike to get a better understanding of what the department does and how its duties are carried out. Mr. Solivan has also created a Strategic Goals Manual in which our fundraising plan is detailed, as is our plan for reaching our target numbers as set forth by the Office of Housing and Community Development.

Recently, we have hosted or have been directly involved in several events, and have given various presentations in order to reach more of Philadelphia's people with disabilities, landlords, and other resources that will help us further Liberty's mission.

In May we partnered with Citizens Bank for a homebuyers' information session here at LRI. The Assistant Branch Manager of the Citizens Bank branch located

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Jean Searle Celebrates 25 Years of Independence

Jean Searle is the Secretary of LRI's Board of Directors, and has served on the Board for several years.

I was born on July 24, 1962. I have three brothers and four sisters; I am the second child. I had been taking care of my brothers and sisters ever since they were little. We were all born with a disability. My Mom and Dad were both heavy smokers and alcoholics. In our system they say we have "mild retardation." I have a brother in an institution that is blind since birth. He only comes home on holidays or on his birthday. He lives in an institution in Quakertown.

I went to special education classes in Philadelphia and then I went to the institution—Allied Services Rehabilitation Hospital in Scranton. They had nowhere else to put me. Then I went to another institution called Still Meadow. They sent me there because I got older and they wanted me to be with older kids.

Living in an institution was like living in prison. You could never leave the grounds and you always had to have at least two week's notice from your Case Manager or your family to come home.

Staff abused people in the institutions. If we did something they



Jean at work at the Disabilities Law Project

didn't like, they would smack us or curse at us, calling us evil names. Sometimes they would throw us up against the wall. It was upsetting to see residents with bruises on their faces and on their bodies. This is why I want to see the institutions closed. People with disabilities don't belong there.

The reason I am writing this story is because I would like to see all of my brothers and sisters out of the institution and in the community where they belong.

Twenty-five years ago, I got out after meeting two people from an agency in Philadelphia. They came to

the institution to interview me, and asked me if I wanted to come out. I said yes, of course.

Two weeks later I was out! I moved to a community Living Arrangement (CLA) in Philadelphia. I went to a sheltered workshop during the day. I worked on the floor and sometimes if they were shorthanded I worked in the office answering phones. I got paid for my work.

I told the job placement person that I wanted a job on the outside. She helped me get a job at Woolworth's in the Neshaminy Mall. I was there for two weeks and then I went to work at the Public Interest Law

Center of Philadelphia (PILCOP). I was a support person for the lawyers. I worked there for three years, and then I found a job working at the Disabilities Law Project. I have been working there almost 10 years. I am one of the secretaries/administrative assistants.

For 13 years, I lived in the CLA. Then I moved to my own apartment, where I lived there for 6½ years. Then I went to live with a family in family living. I like living with a family, but I wish I lived with a family that celebrates holidays. I have been with this family for almost 5 years. ★

LRI Staff Participate in Allentown MS Walk

by Melissa Oscavich



The MS Walk took place on Sunday, May 3rd, 2009 at Coca-Cola Park in Allentown, PA. Several Liberty staff participated in this 3-mile walk to raise money for the Multiple Sclerosis Society.

Proudly wearing their Liberty T-shirts to represent our company from left to right: Nicole Melber, Lisa Williamson, Jaime Yoho, Melissa Oscavich, Susan Weston, Deborah Hume, Susan Schreiner, Stephanie Kuehner, Rebecca Hume, Kristi Breinich, and Yvonne Scharle. ★

"Housing" from p. 5

across the street from LRI at 7th and Market Streets spoke to our Consumers regarding different programs designed to facilitate homeownership.

In order to show our appreciation for the landlords and other resources that have partnered with us, in June we hosted a Landlord Roundtable as well as a roundtable with various community resources that serve low income people.

Housing is now looking into expanding its operations into the Allentown office to assist nursing home

Consumers transition out into the community. We are also looking to take our operations and reach out to those in Lancaster, Delaware, and Lehigh Counties.

The structure of the Housing team has changed slightly, but it is the renewed passion that has forged a hard-working team dedicated to finding new ways to improve service to all of LRI's Consumers. Though we have a new leader and new direction, kudos are due to the staff who adapted to a new system and continue to work together as one cohesive unit. ★

Introducing LRI's HCBS Intake Unit

by Jennifer Barnhart

The Office of Long Term Living (OLTL) Waivers and Programs is seeing a tremendous growth in applications. Word is spreading about the availability of these supports. Due to outreach efforts from LRI, OLTL, Long Term Living in PA, and other community agencies' requests for assessments, demand for Home and Community Based Services (HCBS) Programs is rising quickly.

As an enrollment agency, LRI's HCBS Department is responsible for processing Consumer applications,

assessments, and enrollments for the following programs: Act 150, Attendant Care Waiver, COMMCare Waiver, Philadelphia's Homemaker Program, Independence Waiver, and the OBRA Waiver. In order to best meet the needs of our many Consumers, we have created a specialized Intake Unit.

Our new Intake Unit is a team dedicated to assisting Consumers who are applying for the Home and Community Based Services listed above. Anyone can make a referral by contacting the HCBS Intake Unit hotline number: (267) 765-1513. If you need toll free access, then call 1(888) 634-2155 and request a transfer to extension 577. Requests and questions can be e-mailed to the

intake unit at the following e-mail address:
intakemb@libertyresources.org.

The Intake Unit has been receiving over 200 calls monthly for OLTL Waivers/Programs and the Philadelphia Homemaker Program. Callers may experience a delay in having calls answered immediately on high-volume days, so please leave a message and an Intake Unit

team member will contact you as soon as we are able.

All LRI Center for Independent Living (CIL) referrals for Peer Support, Advocacy, Skills Training, Housing Supports, and Information and Referral should call LRI CIL by contacting (215) 634-2000 or 1 (888) 634-2155 and request to speak with a Specialist from the Independent Living Department. ★

Specialized & Transitioning Services Update

by Norma Robertson-Dabrowski

Recent Transitions

As of July 2009, STS has transitioned 63 Consumers out of nursing homes. In March, the Allentown office transitioned 3 Consumers. This is the highest number of transitions in the Allentown office since the start of the Program.

Employee accomplishments

In November 2007, Tameka Blackwell joined the STS Department. Some people look at Tameka's disability — not her as a person — and ask "how can you be a Supports Coordinator?" Tameka's experience and job performance

speaks for themselves. In one month, Tameka transitioned three Consumers out of nursing homes.

Everyone knows that housing is an issue, especially for persons with low-income who require accessibility features. In July of 2008, Jamie Palagruto transferred from HCBS and joined STS. Jamie has been an asset to the team. On her own, she has been able to identify landlords and apartments for NHT Consumers.

In December 2007, Jessica McInerney, STS Supervisor, joined the department. Jessica works in the Allentown office. An STS Supports Coordinator was hired at the same time. When Jessica was hired, there was no one else on the Allentown team doing nursing home transitions. In the first month of her employment, Jessica had her first transition. A couple months later, the new Supports Coordinator resigned. Jessica's responsibility

increased tremendously in the interim. Essentially, she had to act both as a Supports Coordinator and as a Supervisor. During this time, Jessica, in her role as Supports Coordinator, was able to successfully transition a Consumer from the nursing home to Edinboro University of Pennsylvania.

Later, a new Supports Coordinator was hired to do transitions. Jessica felt much relief and was able to go back to her Supervisory role. Unfortunately, this Supports Coordinator did not stay long.

Jessica was left again in the dual role as a Supports Coordinator and Supervisor.

Through it all, Jessica never gave up. Between January and March of 2009, while waiting to fill the vacant Coordinator position, Jessica successfully transitioned 6 Consumers.

I am happy to announce that Jessica was recently married. She is now Jessica Kemp and has 2 Supports Coordinators doing transitions under her supervision. ★~

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Cassie James Holdsworth's PA Budget Testimony

The following is the testimony given on May 22, 2009 to the House Appropriations Committee of the Pennsylvania State Legislature by Cassie James Holdsworth, LRI's National Advocacy & Policy Director.

First of all, I want to thank the Appropriations Committee and Representative Dwight Evans for holding this hearing and giving the taxpayers a chance to respond to this terrible legislation, SB 850, proposing cuts in all the important and human work; the work we can all be proud of.

My focus will be the Home and Community Based Waivers and Act 150. I am here as a taxpayer, mother, disabled person, and user of Act 150. I am representing myself and all the Consumers at Liberty Resources, Inc., an Independent Living Center in Philadelphia.

Because of the State Program Act 150, I receive attendant care. Due to this, I have saved the government loads of money. Attendant Care enables me to work full time, raise my daughter, and enjoy a full life. With Attendant Care services I get assistance in dressing and getting in and out of bed. I have a liver condition and use a wheelchair, so I experience good and bad days.



Cassie James Holdsworth speaks at an ADAPT action last year

On my bad days my attendant helps me with meals, gets my coffee, tea, and water, allows me to have the bed rest I need, and keeps my house and clothes clean.

Presently, I am the Director of National Advocacy and Policy at Liberty Resources. My job demands travel to Harrisburg and Washington on a daily basis. This would not be possible without assistance packing and unpacking, cleaning clothes, and getting the clothes put away. When my liver condition acts up and I need total bed rest, my attendant gives me support by helping me with all of my daily activities so I can regain my strength and get back to work as soon as possible.

God blessed me with a miracle in my forties when I gave birth to a beautiful daughter, Danielle. She is now eight years old. Attendant care allows me to keep the house clean and to afford Danielle a "normal" life and a place to bring her friends.

Without these services I would not be able to hold a full time job. I would not have the support to keep a decent home for my child, and with my auto-immune hepatitis, I might even be at risk of being forced into a nursing home.

I used to spend lots of time in the hospital trying to do everything myself, but with the social supports of attendant care I have remained out of the hospital for years.

I want to thank the Rendell Administration for all the focus on rebalancing long-term care. The goal of moving to 50% funding for home and community-based care and 50% for nursing home care by 2011 is a huge goal to our community.

Many of us were involved in creating Act 150. At one time, Act 150 was the only Attendant Care Program in Pennsylvania. As a disability activist, I have fought for almost thirty years for resources and services that would allow my friends to get out of those hell holes called nursing homes. In the Ridge Administration there were huge waiting lists. Some died waiting to receive services, all in hopes of receiving help so that they wouldn't be forced to remain living in a nursing home or end up in one.

I was one of the fifty activists who slept across the street from the Capitol to get 800 people off the Attendant Care waiting list. During that budget fight, we were offered some money to expand our program, but not enough to get services to those who needed it, so we moved to Governor Ridge's back yard. Eventually, we won and were able to get all of those people services. We were starting to make a dent in Nursing Home Transition with the CSPPPD waiver. This waiver originally was quite 'medical model', but we challenged the State and Centers for Medicare and Medicaid Services to allow Consumers to hire, fire, and direct their own attendant care

services. I have seen people who have been institutionalized almost their entire life come out of those institutions and in two years become contributing members of the community, giving back by becoming peer counselors to help people come out of nursing homes and doing specialized services for people who are in nursing homes.

In fact, one of the Directors at Liberty Resources who is in charge of Nursing Home Transition is herself someone who came out of a nursing home under CSPPPD. She is a young, beautiful, intelligent woman using her tremendous skills to assist others to come out of nursing homes and teaching Supports Coordinators how to do this work. Wouldn't it have been a terrible waste if she had never gotten out of the nursing home?

Every waiver in Pennsylvania is needed. Without these services, people live their lives dependent on others or incarcerated in nursing homes, which are often worse than jail and even harder to get out of.

How can the sponsors of SB 850 say they are being "adults"? Do adults sentence people to cruel and unusual punishment? Look at the lack of care in nursing homes; the bedsores, the malnutrition, the abuse stories. All you have to do is check the CMS website.

Year after year we give them more money and it never seems to trickle

down to change life for the patients there. The patients continue to be neglected. I have friends with Cerebral Palsy who lost the ability to speak in nursing homes because the staff never took the time to talk to them or try to understand what they were saying.

What really makes me angry is that this is not about money. It might be about money that goes into some people's pockets from the nursing home industry, but it is not about saving money. Everyone in Pennsylvania knows by now that it is cheaper in the aggregate to give people support to remain in the community rather than nursing homes. Even people with significant disabilities and frail health whose care may cost more still are better supported in the community and tend to have better health and social outcomes.

Would the sponsors of this bill like to go live in a nursing home, if this is the "adult" thing to do? I talk to people everyday who are so glad to be free. They take nothing for granted: the right to choose when you go to bed; the right to have the TV on until one in the morning; the right to choose your own friends, have relationships, and fall in love. These things don't happen in a nursing home very often because they are just not allowed.

Supporting people in the community is the right thing to do. It is also the cost-effective thing to do. The

problem in Pennsylvania is that for everyone we get out, someone else goes in.

Aging and disability are not tragic—it is what choices our states make that can be tragic. Are disabled people expected to run for their lives and live in another state to remain living in the community? Are families expected to starve their other children, quit their jobs, live in poverty to take care of elderly and disabled family? Is that what you consider “adult” behavior?

Getting rid of the Medicaid bias and allowing more and more people attendant care and supports in the community will not only save money, but it will bring in more federal dollars and create more jobs in these difficult economic times.

Would the Republicans give up the stimulus money that comes in for Medicaid this year and force us to live in nursing homes to make some political statement? Don't use us in this political game. We are real people with real lives. We could be your child, your mother, your neighbor, or your friend.

Do you really believe we don't need these services? Do you really believe we can live without them, or do you just want to use us as cash cows and get the nursing home industry to pay for your next campaign? There are other options. We can create jobs in the community. We can offer the elderly and disabled real lives. We

can allow them the right to manage their services.

Meanwhile, we can close beds, change the nature of what these facilities do, and still bring money into Pennsylvania. I know that Act 150, the program that supports me, is most at risk because it is all State dollars. But even talking about stopping the expansion of the waivers makes my skin crawl.

We know right now 200 names of people trying to get out of nursing homes. We are getting extra enhancements because of Money Follows the Person. I could write a book about the lives of the people I know who have come out of nursing homes and lived to tell the tales. If any of these cuts take place for Home and Community Based Services, I will move right across the street again and we will fight. We will let the taxpayers know that we get nothing for what we pay in our taxes.

The Rendell Administration has worked hard to start the rebalancing process and I am sure some of it has been to save money. This is not a Democrat or Republican issue; this is a bipartisan issue if ever there was one. Any of us, regardless of income, race, or religion can become disabled and need these supports. If we are lucky, we will get old.

Most of us love the bits of life that we get to control: going to the movies, or staying up late eating our favorite ice cream. These simple

choices are choices that I will never take for granted because I have met many people who have had these choices stripped from them in the name of “care”.

This is from the heart of a person who has gone in and out of nursing homes all of her life. None of them have any resemblance to any proper home I have ever lived in. And even if you might believe in these places, let’s face it—they will only become easier to manage when they become the last resort.

Rendell’s Administration is finally getting to a point where they know how to rebalance the system, and they are creating lots of options and choices. Don’t threaten this progress for political gain or games.

The Baby Boomers certainly are not going to want to exist in a nursing homes. Disabled people want to work, pay taxes, and give back to our society like everyone else. This can only happen if we offer services and supports to people when they need them. We have come so far in our civil rights movement. Don’t hurt the poorest of the poor with a system where you have to become impoverished to get services.

A lot of the elderly and disabled people I know are not as lucky as I am as far as well-paying employment. They live on very minimal money, below poverty levels. Elderly

people often live on very little even though they have worked most of their lives. Despite this, they are so happy to be able to direct and manage their own support. They value each day. Young disabled people are volunteering and going to school and trying to gain skills. They dream of getting a job and because of these supports they just might.

Please keep going forward in rebalancing. Let’s all do our best to get to the 50/50 goal. And if there are any cuts to Act 150 or the waivers, you’ll be seeing a lot of disabled people around these halls. Some of us might just be moving into this neighborhood. Right across the street looks like a great place to pitch a tent.

Thank you for this opportunity to tell you about people who have been neglected and locked behind walls, out of sight, out of mind. Nursing homes have become our poor houses. I dream of a day when you will have to get a waiver to get *into* the nursing home! I dream of a day when services and supports are just another Consumer resource, like going to the market or renting an apartment. We can all be included and free.

Thank you very much for this opportunity to speak my mind and advocate for the community that I am so lucky to be a part of. ★

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LIBERTY WORKS is published quarterly by Liberty Resources Inc. All contents © 2009, Liberty Resources, Inc.

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A Publication of Liberty Resources, Inc.

