



Branching Out

VOLUME VIII

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Breakfast of Champions 2011



Join us to honor

Susan Saladoff and "Hot Coffee"

Tuesday, July 12th 2011

8:00AM - 9:30AM

Empire Ballroom East

Sheraton New York

Each year, at its Breakfast of Champions the Foundation honors one or more Community Champions. Community Champions are consumer advocates who have performed outstanding work on behalf of injured consumers, to prevent injury, and/or to preserve a consumer's access to justice.

Susan will join the distinguished past award recipients: Wendell Potter, Jamie Leigh Jones, Lieutenant Commander Charles Swift, Senator Claire McCaskill, Erin Brockovich, Donald Davis, Helen Haskell, Janette Fennell, Dylan Malone, Carrie Broadus, Father Thomas Patrick Doyle, Paul Sheridan, Bob Fellmeth

Hot Coffee

Not just a CJF grantee, a production like no other!

A letter from Susan Saladoff to the Civil Justice Foundation

I am writing to express my deep and sincere gratitude to you and your board for supporting Hot Coffee. As you know, Hot Coffee was fortunate enough to be selected as 1 of 16 films out of 841 entries for the U.S. Documentary Competition at the 2011 Sundance Film Festival. We premiered to a sold out audience on Monday, January 24th, and in fact all of our screenings were sold out. We were also the only documentary screened for the Patron's Circle of the Sundance Institute, which are the Institute's high donors. The reviews were incredible. Here is a sampling:

"Focusing on another issue entirely, Oregon lawyer and first-time filmmaker Susan Saladoff made a stunning debut with the lively, lucid "Hot Coffee," about the spin behind such notions as tort reform, frivolous lawsuits and "jackpot justice."

*With its energetic pacing, bold visuals and the kind of narrative that sends audiences out of the theater thinking in a brand-new way about something they thought they understood, "Hot Coffee" deserves the kind of release enjoyed by "An Inconvenient Truth" and "Food, Inc." **The Washington Post***

*"An eye-opening indictment of the way big business spins the media and rigs the courts to protect itself from so-called "frivolous lawsuits," Susan Saladoff's "Hot Coffee" is a solid if not especially cinematic public-interest exhibit on how citizens are losing access to America's civil justice system." **Variety***

We were fortunate enough to be acquired by HBO for the U.S. broadcast rights, which means it will be seen by millions of people, probably this summer. In addition, HBO has agreed to allow me to use the film as part of a grassroots effort before it airs. I will be meeting with them in about a week to talk about what that may look like, but I am hoping to plan an event in Washington, DC where we will invite members of Congress and the administration.

I will continue to be showing the film at film festivals and we also hope to have a limited theatrical release in the fall, as well as a tour of law schools and universities. Video on demand will be available from the HBO site this summer, and we will be able to sell DVDs by the fall.

I am thrilled that you were a part of this process, and I can't thank you enough for believing in me and my vision. I truly believe that this film will change the conversation, which we desperately need right now. We all must put our minds together, however, to figure out how to implement change once people are motivated to speak out. Perhaps your group can start thinking of ways that may accomplish.

Susan

Kids In Danger hails progress on children's product safety oversight, launch of public database

Now for the first time, consumers can submit and view reports of problems with products, and incidents and injuries related to consumer products through the US Consumer Product Safety Commission's (CPSC) public database, www.SaferProducts.gov. Launched on March 11, 2011, this important safety tool will help consumers avoid preventable deaths and injuries associated with unsafe products by learning of defects and problems before it's too late. This database will also provide consumers, researchers and CPSC with information about emerging hazards and injury trends.

To this point, the public has had virtually no access to injury and incident reports submitted to CPSC. CPSC has to get manufacturers to agree to a voluntary recall, a process that takes time, and in the interim caregivers continue to unknowingly use products that pose dangerous hazards to children. Now consumers can track and review reports in a timely manner so as to avoid unsafe products and make informed purchasing decisions.

Unsafe children's products abound: Kids In Danger, a nonprofit dedicated to improving children's product safety, released its annual examination of children's product safety, [Moving towards Safety](#), which found that there were recalls for unsafe children's products roughly every two days in 2010. Last year alone, there were 160 recalls for over 44 million individual toys, cribs, sweatshirts, strollers and more – up twelve percent from 2009 in recalls and 110% in units recalled.

[Kids In Danger](#) was founded by Linda Ginzel and Boaz Keysar in 1998 after the death of their 16-month-old son, [Danny Keysar](#), when a portable crib at his licensed daycare collapsed, strangling him in the upper rails. At the time, the quality of children's product safety oversight was deplorable: there existed no mandatory testing requirements for children's products and the high numbers of children hurt and killed each year made it clear that safety information was not reaching the public effectively. In Danny's case, the crib had been recalled five years before and Danny was the fifth child to die in this crib, but neither the childcare provider, his parents, nor the state inspector who had visited the facility just eight days before Danny's death knew this deadly item was in their midst.

Everything changed in 2007, when a *Chicago Tribune* [investigation](#) on hazardous children's products ignited a public outcry against deficiencies in children's product safety oversight. This tumultuous period culminated in the passage of the Consumer Product Safety Improvement Act of 2008 (CPSIA), a set of sweeping reforms to our children's product safety system. A key portion of the bill is named in honor of Danny Keysar, requiring mandatory standards and testing for durable infant products, mandating the inclusion of product registration cards with most durable infant and toddler products and banning the sale or lease of unsafe cribs. Already, our children are safer for it:

CPSC and FDA issued a warning on sleep positioners that promoted most retailers to stop selling these unnecessary and [dangerous](#) products.

CPSC issued [alerts](#) on the safe use of baby slings.

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A [strong mandatory standard for cribs](#) was developed and adopted to go into effect June 28, 2010.

Most nursery products must now come with a [product registration card](#) and [website address](#) to assist in alerting consumers in the event of a recall.

This historic law came too late to save Danny Keysar, who would be fourteen this year, but this new database will go far in helping other families. The path to progress has not been [smooth](#). There was strong opposition from manufacturers who have become used to dealing with their problems away from the harsh glare of public scrutiny. A coalition of consumer and safety groups, and victim advocates worked for months to protect the database from being undermined or completely eliminated, prospect that still looms. Many parents of victims stepped forward to [speak out](#) in support of the database; Among them: [Lisa](#), mother of [Ellie](#), who was killed in a Graco play yard, Michelle, mother of [Tyler](#), who died after being entrapped by a drop-side crib and Nicola, mother of [Liam](#), who also died in a drop-side crib.

To address the issues raised by manufacturers and others, CPSC carefully crafted the site to both solicit important safety information from consumers **and** encourage accurate reporting. The database contains an array of protections to ensure that inaccurate information is not published. Anonymous complaints are not permitted, and only safety-related information will be posted. Complaints will not be considered for publication if eight specific minimum fields are not completed. Businesses also get to see every report of harm before its placement in the database and have the opportunity to correct inaccurate information and to provide their own comments. These measures provide an appropriate balance between transparency for consumers and providing protections for manufacturers.

The protections appear to be working. In February CPSC did a soft launch to test the system - that just means it was live, but the information wasn't made public. Nine hundred reports were made during that time and only four were found to be 'materially inaccurate.' And two of those had the wrong manufacturer listed and were easily corrected. One manufacturer/importer said that of the 50 reports they got, 90% agreed to give the manufacturer their contact information, providing a way to verify the information. Some manufacturers told KID they didn't receive any reports during the month, others that they had a few and all were reasonable reports of a consumer's experience.

For consumers ready to access this safety tool: Remember that this is a site to report safety issues, not product reliability or quality, except as they affect safety. So if the infant seat doesn't swing like it shows on the package; that is a quality issue, perhaps to be reported to customer service or an online product rating site. But if the motor that is supposed to run the swing gets so hot it melts its casing and starts a fire, that is a safety issue and should be [reported](#) to CPSC.

In preparing to submit a report, gather as much information about the product as possible

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– including identifying information such as model name or number, date of manufacture, etc. The more complete the report, the more likely it is to be posted and to provide CPSC with the information they need to assess the risk and take action if needed. CPSC has helpful pop-ups on the form to aid in finding the needed information.

Consumers will need to provide their name and contact information for the incident to go into the database, but that information will not be posted and will only be released to the manufacturer with permission. Giving the manufacturer contact information, either through the CPSC form or by reporting directly to the manufacturer will allow them to fully investigate the incident and determine if action is needed. If a consumer chooses to file a report anonymously, CPSC will still get the incident information, but it will not go into the public database.

Manufacturers have 10 days after they are notified of a report by CPSC to review it for material inaccuracy. The best way to have the full 10 days is to [register](#) now at [SafeProducts.gov](#). The report will then be sent automatically. Then the report, if it has all the necessary information will be posted [online](#). Once the database has injury and incident reports, those will show up here. If there are problems reporting incidents or finding the data, consumers should let CPSC [know](#). ***They already have great tools on the site to help both consumers and businesses navigate the system.***

We've come so far, but the database and CPSIA's other provisions are far from safe. As of this writing, the database is still under [threat](#) as the US Senate is now considering a House-adopted [amendment](#) that would defund the database, and [another](#) that would defund the entire US Consumer Product Safety Commission – a move that would completely cripple product safety oversight in the United States. If accepted, these amendments will undo all our hard-won progress. Consumers can contact their [senators](#) to oppose these assaults on children's safety. For more safety resources and information, please visit www.KidsinDanger.org.

What is the Civil Justice Foundation?

The Civil Justice Foundation is a national charitable organization dedicated to safeguarding justice for all Americans by strengthening the alliance between trial attorneys and consumer advocacy groups. The Foundation is the only national foundation devoted solely to protecting the individual rights, health, and well-being of the injured providing small but significant grants to the tireless efforts of organizations fighting for injury prevention and justice preservation across the country. The Civil Justice Foundation awards grants to progressive grass-roots consumer advocacy groups who share a common vision: consumer injury prevention, public safety protection, and constitutional right-to-trial preservation for all Americans.

2011 Potential Grantees

Birth Defect Research for Children

Overview: To find the causes of birth defects through the use a powerful tool known as the National Birth Defect Registry. This registry, sponsored exclusively by BDRC, can find patterns and clusters of birth defects and potentially find the cause(s) of the birth defects.

Brain Injury Association of Massachusetts

Overview: Our mission is to provide support services to brain injury survivors and their families, offer programs to prevent brain injuries, educate the public on the risks and impact of brain injury, and advocate for legislation and improved services. BIA-MA conducts both prevention programming and advocacy/ awareness activities, serving more than 30,000 people throughout Massachusetts last year alone. BIA-MA's primary constituencies are brain injury survivors and their families, as well as youth and older adults at risk. We also direct programs to healthcare professionals and the general public. BIA-MA has a 19-member Board of Directors, 23 staff members, and 60 educational volunteers.

Community Alliance of Tenants

Overview: Based out of Portland, our mission is to educate and empower Oregon's renters to demand and attain affordable, stable and safe rental homes. We address the impact of Oregon's decreasing supply of decent, affordable housing and absence of meaningful tenant protections. Tenants in Oregon face skyrocketing rents, discrimination, instability, overcrowding and worsening living conditions. In response, we are organizing, educating and developing leadership among low-income tenants – predominately seniors, people of color, people with disabilities, low-wage workers and families with children - to directly improve housing policies and practices and to actively represent Oregon's growing tenant population. CAT is building a strong housing justice movement that is led and directed by those who are most impacted by Oregon's affordable housing crisis - low-income renters.

Colorado Center on Law & Policy

Overview: Our core mission is to advance justice and economic security for all Coloradans and we do that through four core programs:

- Colorado Fiscal Policy Institute, Family Economic Security Program, Health Care Program, Legal/Litigation Department

Center for Economic Integrity

Overview: Established to change corporate practices detrimental to low income workers and consumers.

Childhood Lead Action Project

Overview: The Childhood Lead Action Project is a nonprofit organization founded in 1992 to eliminate childhood lead poisoning in Rhode Island through education, parent support, and advocacy. We coordinate community-based education campaigns and mobilize citizens to organize for environmental justice. Our work has been a major catalyst for a significant decrease in lead poisoning in Rhode Island over the last decade. The Project's advocacy work holds institutions and public officials accountable for conditions that have allowed conditions for lead poisoning to continue.

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Connecticut Center for Patient Safety

Overview: The Connecticut Center for Patient Safety, h c, [hereafter CTCPS] is an organization started after a group of medical malpractice victims was organized to fight tort reform in Connecticut Health care consumers who had experienced serious hospital and other medical related injury defeated the proposal of the Governor of the State of Connecticut to cap injury awards. Successful in that campaign, the founding members decided to start a consumer driven advocacy organization focused on protecting the rights of medical patients in Connecticut.

Drowning Prevention Foundation

Overview: DPF's mission is to prevent the tragedy of drowning through the use of public information, education and policy change. DPF is a non-profit, community-based organization which was established in 1985. It is recognized both locally and nationally as the leading expert in drowning prevention methods, technology, policy and activities.

Disabled Rights Action Committee

Overview: The Disabled Rights Action Committee is a Utah organization committed to expanding and assuring the rights of people with disabilities to boldly go where everyone has gone before.

Funeral Consumer Alliance

Overview: The purposes of this organization are:

1. To promote and protect consumer choice in determining the type of funeral or memorial services desired according to the religious, philosophical and ethical belief of each individual.
2. To promote and encourage the reduction of unjustifiable costs of burial, cremation, and other disposition options.
3. To publish educational materials for the end-of-life concerns and make them available to members and the general public in a variety of media and formats at little or no cost
4. To work with other organizations sharing similar concerns to expand families' choices and control over funeral options,

Florida Consumer Action Network Foundation

Overview: Florida Consumer Action Network Foundation (FCAN Foundation) is a 503 C-3 consumer advocacy organization dedicated to fighting for consumer rights.

Healthcare Patient Safety Investigation

Overview: In December 2008, DK Raymer, Healthcare PSI's founder, launched www.healthcarepsi.com and its companion blog. This was the result of having received permanent nerve damage to her left hand due to a preventable medical error in 2007. Her determined resolve and clear writing ability brought DK to the forefront as she was recognized to be a strong advocate for patient safety. Collaborative relationships were established with such groups as: Kimberly-Clark's "Not on My Watch" campaign; MRSA Survivors Network; Mothers against Medical Error (MAME); the Empowered Patient Coalition; and others. In June 2010, DK filed papers to incorporate Healthcare PSI as a non-profit entity in the state of Missouri; application paperwork for 501(c) (3) status was filed as well.

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Interfaith Workers' Justice

Overview: IWJ was founded in 1996 as a national network that calls upon religious values to improve wages, benefits and working conditions for workers by educating and organizing present and future religious leaders, interfaith coalitions and workers centers. It was born out of a vision of bringing the religious community in America into the worker justice movement, and originally envisioned as a way to support national and local labor campaigns; engage young people in the worker justice movement; educate unions on the importance of the religious community; and to educate the religious community on the importance of unions.

Kids in Danger

Overview: Kids In Danger (KID) is a nonprofit organization dedicated to protecting children by improving children's product safety. KID was founded in 1998 by the parents of sixteen-month-old Danny Keysar who died in his Chicago childcare home when a portable crib collapsed around his neck.

Leadership Center for the Common Good

Overview: Common Good was created to address protection of consumers from environmental hazards.

Louisiana Environmental Action Network

Overview: The Louisiana Environmental Action Network/LEAN is a 501-c-3 non-profit organization that has led Louisiana's environmental movement for 25 years by assisting the citizens of Louisiana with their efforts to keep their communities healthy and safe. During these 25 years LEAN has worked with many small, rural, and coastal communities to address their environmental needs. These communities are generally poor, under-represented, and inhabited by those whose needs are easily ignored.

Legal Forms and Courthouse Services

Overview: The mission of Legal FACS ("Legal Forms and Courthouse Services") is to provide legal assistance and advice to low-income New Mexicans in matters affecting their families, homes, and safety. As Saint Augustine aptly stated, "Peace in society depends upon peace in the family." Yet thousands of low-income New Mexicans have no meaningful access to the court system to resolve family law disputes such as domestic violence, custody, and equitable division of income.

Lead Safe Homes

Overview: Lead Safe Homes, a program of Parks Place Community Resource Center, was founded in 2005 in response to alarming rates of childhood lead poisoning in Bellows Falls. At the onset, Lead Safe Homes worked to assess the local problem of childhood lead poisoning, strengthen enforcement of state housing rules, and mitigate lead hazards for the most at-risk population by working with parents, landlords, health care providers and social service providers. The program also sponsored numerous trainings in lead-safe work practices.

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Many Languages One Voice

Overview: To complement the work of the Coalition, MLOV also organizes LEP/NEP community members to advocate for their language access rights primarily around the areas of education and health services. MLOV runs the S.M.A.R.T. (Student Multiethnic Action Research Teams) program, through which DC public school students grow their leadership, advocacy and communication skills. MLOV also organizes a core group of LEP/NEP community facilitators through the “Health CommUNITY Club,” which gathers stories of barriers to health care services with the purpose of policy advocacy towards greater language access in health care settings in DC. MLOV has started a new initiative on workers’ rights; specifically those of LEP nail salon workers. MLOV has provided “Know Your Rights” trainings to over 2,500 staff and LEP/NEP community members and reached out to over 9,000 people for the US Census 2010.

Michigan Universal Health Care Access Network

Overview: Michigan Universal Health Care Access Network (MichUHCAN) is a state-wide network that promotes comprehensive health care for all and improved health outcomes by addressing the social determinants of health through education, strategy development and advocacy.

North Carolinians Against Gun Violence Education Fund

Overview: NCGV's mission is to make North Carolina safe from gun violence through the education of the public about preventing gun violence, the enforcement of current gun laws, and the enactment of needed new laws. For over 15 years NCGV has been the only staffed statewide gun violence prevention organization. NCGV sees one of our primary roles as acting as the “resource center” for local populations interested in reducing violence in their communities.

Nevada Foundation for Consumer Education

Overview: The Nevada Foundation for Consumer Education is operated exclusively for charitable and educational purposes. The educational focus wick is to inform the public of their rights as citizens of Nevada and other issues of importance. To accomplish this, the foundation will hold “People’s Law Schools” or seminars which are open to the public. This foundation is supported by voluntary contributions, grants and endowments.

Sunshine State Foundation Inc.

Overview: Established to help the children of Haiti with their social and economical life, following the earthquake.

Treys House SA

Overview: Organized in 2007, the primary purpose of Treys house is to address the feelings of isolation and alienation resulting from acquired and traumatic brain injury. We will do so by following a modified version of the Clubhouse program for the mentally ill. The clubhouse will be a place for the members to go, a place for forge solid relationships, and a place to return. Acquired and traumatic brain injury victims frequently walk a common fence line with the mentally ill. They share challenges and affectations, the same medications, and the same sense of isolation.

Disabled Rights Action Committee Announces the Department of Justice's Investigation against Utah

Since 2000, when the Supreme Court issued the Olmstead decision which noted, in part, that waiting lists for community based disability services should move “at a reasonable pace” Utah’s waiting list has grown by 37%. During this same period the population of the state of Utah has only grown by 25%. In noting that these waiting lists must move at a reasonable pace, the Supreme Court appeared to be directing that unreasonably long waits for services should not drive individuals into otherwise unnecessary institutional settings such as nursing homes. However, since 2000 the State of Utah stated that they have record of at least 196 individuals who have left the state waiting lists to enter nursing homes. In making this statement, the state Division of Services for People with Disabilities also noted that this number excluded individuals currently on the waiting list (persons who entered institutional settings while waiting for services, then went back on the waiting list for community services). This number also excludes individuals who have ever received home and community based services, indicating that the actual number of persons who entered nursing homes while waiting for community services may be much higher. The State of Utah’s Division of Services for Persons with Disabilities has a mandate to serve those individuals with the most critical services first. Thus, individuals who come on to the waiting list with extremely critical needs may wait a very short period for services, while others whose needs are not as critical may have indeterminate waits. The state has noted that there is no way for individuals to work their way up the waiting list. Some individuals have been waiting for over a decade—clearly this is not moving at a reasonable pace. Even given the short waits of those who come on to the waiting lists with extremely critical needs, the average wait for services is 4.1 years for persons with physical or intellectual disabilities and 3.6 years for individuals with acquired brain injuries. Again, we argue that with an average wait of 4.1 years the waiting lists are not moving at a reasonable pace.

Earlier we noted that at least 196 individuals have left the waiting list to enter institutional settings. We believe it is reasonable to assume that these unreasonably long waits forced individuals with serious needs that were perhaps not critical enough to propel them to the top of the waiting list into nursing homes. Several families and individuals have come forward to tell their stories. Rene Bunch has a daughter with a traumatic brain injury who has been on a waiting list for services for seven years—again, an unreasonably long wait. After the mother recently began agitating anew for services a state case manager told her that the only way her daughter could get services in the foreseeable future was to enter a nursing home. She was told that after ninety days, if her daughter then wanted community services she could take advantage of the state’s New Choices Waiver—the state’s version of a federal program called Money Follows the Person. This appears to be a clear admission that the state is advocating unnecessary institutionalization of individuals because of the interminable length of some waiting list waits. Community services are already in place. Moving individuals into these services at a reasonable pace would not represent a fundamental change in the state’s services or approach. The legislature just needs to provide adequate funding.

Karen and Kent Spitler have a child who has a vital need for services, but this need is not yet considered critical as the family is still managing to meet her needs. However, the mother has a progressive, debilitating illness of her own and they are seriously considering placing their daughter in a nursing home as the mother’s strength may give out before the state considers the need to be sufficiently critical.

Terry Griffin hired a private attorney to sue the state, based on Olmstead non-compliance. The state subsequently got her son into services. She is currently doing the same for a man she has assumed responsibility for whose parents were deported to Mexico.

Cathy Garber has been on the physical disabilities waiting list for ten years, only to be told that her only real hope for getting services is to enter a nursing home for ninety days and then apply to come out under the New Choices Waiver. This appears to be the official stance of the state--that the only gateway to community services is through a nursing home, but we contend that this is a clear violation of the Olmstead Decision, where waiting lists that don't move are forcing individuals into nursing homes.

While a three month stay in a nursing home in order to access community services seems to be a simple solution, we consider this to be a ninety day incarceration and a near total loss of civil rights for during that period in order to

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qualify for community services that are really a right from the outset. Not only is this human costs intolerably high, it doesn't recognize that many individuals will lose housing, be cut off from natural supports and family members and lose skills that they and others have worked years to develop. Conflicts with nursing home staff can develop that lead to labels of being “non-compliant” that can make it difficult to find willing community supports. Accordingly, it can be difficult to impossible to move out once the ninety days are up.

However, all of this is beside the main point, which is that the Olmstead decision clarified that it is illegal to make nursing homes the only available gateway to critically needed community services. We are also asking that if the state's matching money is there for a more expensive nursing home stay now, and if the state's matching money will be there for community services 90 days from now, why can't the state make the money available now for more cost effective community supports now, up front, without requiring a nursing home stay?

In the past year there were 2010 individuals on the waiting list. Anecdotal evidence suggests that this list would actually be much longer, but many individuals and families have become so discouraged that they have failed to maintain eligibility for the waiting list or have simply never applied. Out of these 2010, only 158 came off the waiting list in the past year—a mere 8%. Even as discouraged as individuals have been, the waiting list still grew by 198 individuals—significantly more came on than left, meaning that the list grew even longer.

In their 1999 Olmstead decision the Supreme Court noted that states may not be able to immediately move large numbers of individuals off of waiting lists and out of nursing homes. Accordingly, they said states that would at least develop plans for doing so would have protection from future lawsuits. However, the State of Utah never developed a true “Olmstead Plan” with specific goals for moving unnecessarily institutionalized individuals out of nursing homes. No goals or specific plans were ever made to insure that individuals who were waiting for services could avoid unnecessary institutionalization. The state did produce a document it called an Olmstead Plan that was a description of the services it was currently providing, such as some case management services for individuals on the waiting list. Since that time many of these services have been reduced or eliminated altogether.

Absent an effective plan, with waiting lists that may have no end in sight for many individuals, with many who have left the waiting list for truly unnecessary institutional settings and many more currently on the waiting list who are considering having to enter nursing homes to obtain timely services we strongly believe that the State of Utah is in violation of both the spirit and letter of the Olmstead Decision and therefore the Americans with Disabilities Act.

Accordingly, the Disabled Rights Action Committee drafted a complaint against the state of Utah and submitted it to the Region VIII Office of Civil Rights and the Department of Justice (DOJ). The DOJ subsequently engaged in months of pre-investigative work, including interviewing the individuals whose stories have been related above.

On January 11, 2011, at a press conference in the state's Capitol rotunda The Disabled Rights Action Committee-ADAPT/Utah, in conjunction with several members of the Central Utah Center for Independent Living and the Tri County Independent Living Center, were finally able to announce that the Department of Justice (DOJ), acting on our complaint had formally opened an investigation against the state of Utah. They have focused on the state's Physical Disabilities and traumatic Brain Injuries waiting lists. The DOJ has been very successful in suing several states over Olmstead violations and/or getting settlements from states to begin providing these services. We hope that they will soon add Utah to their list of impressive wins in critical services in obtaining services. In doing so the DOJ should negotiate a settlement that involves getting everyone out of the nursing home who doesn't want and doesn't need to be there. Any settlement should also involve meaningful action to move the waiting lists at a truly reasonable pace such that Utah's with disabilities who need assistance won't have to look to nursing homes as their only resource—an option none of us want, as evidenced by our battle cry—“We'd rather go to jail than to die in a nursing home.”

Jerry Costley

Disabled Rights Action Committee

Advocacy 101

By Margaret W Griffith, Founder, Trey's House SA

I took three of our members to an advanced leadership and advocacy conference in Austin recently. After attending a rally on the capitol steps we were sitting back at Treys House, musing on what we were going to do next. One of our members looked around at the group and spoke of his little sister. His little sister died when she was in her thirties, but her memory lives on. Regarding his little sister, our member said, "She was retarded. We all knew that. Everyone treated her like she was retarded. But to her, she was just who she was, nothing different or special. And, to me, she was just my sister, someone I loved."

Years ago, a professor of cultural anthropology told us that in the field, anthropologists do not attempt to correct what is wrong (i.e.: bringing vaccinations to primitive cultures) because the end result could in fact be disastrous. Making the population healthier means more than just stopping a sickness...it is a big undertaking. I did not understand the full impact of those words until I started working with individuals with disabilities. Volunteers come and go, and give validity to both those served and the organization they work with. Mostly, they are wonderful people that come in just to help, to be part of our world. But occasionally we see the volunteer become overzealous, and decide they can counsel and solve the problems of the world. These are the volunteers that adopt the title for themselves as "Professional Advocate."

When advocating for individuals with disabilities, we have to remember what the word means. It is a great word. Per dictionary.com it is "the act of pleading for, supporting or recommending." Disabilities are more in the eye of the beholder than anyone else. An adult with disabilities still has much to offer, if we only remember what our member told us. "I am who I am. If you perceive me to be disabled, then you perceive me to be something less than human." Disability is now and always has been part of the human condition."

Fearing a return to the 1970's, a time when many cities had in place "Ugly laws," laws that fined people who were diseased, maimed or deformed in any way if they showed their faces in public, we have seen a phenomenon known as the "professional advocate." For a fee (hourly or per diem), or for mileage and lunch and a few dollars to cover their time, individuals are hanging out their shingles, calling themselves professionals.

At the conference in Austin, the three members I took with me met movers and shakers with more disabilities than they have. Member "Tom" decided to move to Austin and be truly independent. I think this is great...provided he understands fully the consequences of his actions. He is currently in [section 8 housing](#) and has a community support provider who is supposed to take him around to the various appointments he has regarding housing and other issues. The provider system is imperfect at its best, because the individuals working as providers are human, and subject to human

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failings. Service providers are anything but perfect. For the most part, they are poorly educated, minimum wage people who have a specific set of tasks they are allowed to assist with. A provider who does his or her job makes independence more livable. Tom's provider helps him find apartments, helps him fill out the necessary forms, make his deposits, etc. Provider services are limited to the county of residence, and Tom's provider could not help three counties away.

When I explained to him what moving would entail, that it would take time, I suggested he take a greyhound bus to Austin, rent a motel room, and find an apartment...on his own. If he can do that, he will be okay. If anything went awry, he was only an hour away. I could pick him up, and get him home. Tom has lived by himself for ten years...on his own with help of providers and case managers. Moving to another county means his services (not just his section eight voucher) must be transferred or he must make his own way.

Unhappy with my urging him to go slow, with planning, Tom decided instead to enlist the help of a woman he met at the conference, a woman who calls herself a "Professional Advocate." This woman charges \$65 / hour for her services. True advocates are devoted to the health and welfare of the individual, as well as strengthening the individual's ability to be heard. This is done by being committed to empowering individual with reliable information and choices concerning independent living situations, including health and provider services. The focus must be on assessing problems, planning and finally implementing the changes. Additionally, as advocates are not doctors, therapists or lawyers, they must be prepared to seek the necessary referrals when necessary.

I have known Tom for three years. He has been virtually blind since childhood, and could not be taught to read or write, or even use Braille. He has to be read every document verbatim. And, his interpretation of what is being offered is rarely what was intended. In his case, he requires only minimal involvement with a provider. He can and does live independently, caring for himself, meeting his own daily needs. However, choosing to minimize his provider support he has frequently been the target of scammers. He has to be read every document, he has to be told where to sign his name...and he has to sign in good faith that what he was read is what was on the paper before him.

The person he met at the conference, the "professional advocate," could become a positive force. She is encouraging him to move...go for his dream. She truly supports his desire to self advocate...but hasn't given him the skills to manage all of his own business. Without her advice, but based on her encouragement, "Tom transferred his paperwork for housing to Travis County. He changed bank accounts on his own to one that has branches in Austin. But, he thought his SSI check would magically change to the new bank, so he didn't call the Social Security Administration until after the 15th. His check may or may not be there on the first.

He will not get a new provider until he has an address in Travis County. He won't get an address until someone takes him to Austin and tours the available apartments. I believe that if someone makes the effort to encourage change, they have to also be prepared to do the work involved.

Moving him from one apartment to another wasn't included in their job description, so the last three times he moved, we helped him as a friend would...we borrowed a truck, got two of my sons and a member or two, and we moved him. This always took the better part of a day. Moving to another town is more difficult...more time consuming and more costly and I cannot help this time. When I asked him how he was going to do all this, he suggested "we" go to Austin next week. I told him he I couldn't. So, he contacted a [transitional housing](#) person from Austin Housing Authority, and she told him that she could help with the papers he submits, but that she cannot help with anything else. If he cannot find someone to help him move, help him set up his services, help him get it together, he will stay here, and possibly end up in a group home. The woman acting in good faith as his advocate has created a true "no-win" situation.

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Advocacy does not mean getting what you want at all costs. Reality has to play a significant role. While it is our right to live where we want, the reality is that there are limitations. To believe otherwise will just lead to poor outcomes. Sophomoric understanding of Advocacy is dangerous, and we need Rules of Conduct as well as accountability for these individuals

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Prioritizing goals and identifying the needed services will also identify which resources and services that will be needed. Where Tom is concerned, a goal of his moving to another town is great. He would be in a place that offers more resources than we have here; he would be able to connect with people who are doing what he wants to do which is affecting policy and acting as a disabled rights activist. He has great confidence and both speak and presents well in public. Goals with a clear plan of action, including contingency plans, are far more critical to his success.

Volunteers and Advocates alike should adhere to a basic code of ethics...Rules to play by so to speak. The rules should be simple and direct:

Advocates are devoted to the health and welfare of their clients, collaborating with providers to provide the greatest independence.

Advocates are not counselors or doctors. The commitment is to empower individuals with reliable information and choices concerning care and options, not with problem solving or medical decisions.

Advocates must maintain confidentiality in all communications, sharing only what their client allows.

There are other rules that must come into play, but without even minimal rules in place, there can be no consequences for those who overstep their boundaries.

Hospitals employ patient advocates for a reason. There is an equally great need for social service advocates as well. Like the medical advocates though, there must be in place a system of checks and balances, of rules and sanctions.

From the director: A letter to Connecticut legislators
A patient perspective on liability PROTECTION

What do I want for you as a health care consumer? Perhaps the best way to answer that question is by telling you what I do not want.

I do not want you to go into the hospital and get an infection you did not have when you went in. The Centers for Disease Control and Prevention (CDC) estimates that 100,000 people die each year from preventable health care - acquired infections (HAIs). A Pennsylvania study indicates a 9.4% mortality rate for patients with health care - acquired infections, compared to 1.89% mortality rate for patients without infection. This same study finds the average hospital stay for a patient with an infection is 21.9 days, compared to 4.9 days without infection. Decreasing the rate of HAIs in our state's hospitals will not only reduce the number of patient injuries suffered by our citizens, it will also reduce our state's healthcare costs.

I do not want you to suffer preventable harm while hospitalized. According to the Office of the Inspector General's (OIG) 2010 report, one out of seven patients suffers preventable harm while hospitalized. A 2011 report by HealthGrades finds 500,000 preventable hospital deaths in the last ten years.

I do not want you to unknowingly seek medical care from a repeat offender - a doctor WHO REPEATEDLY injures patients, yet is not disciplined and continues to (MAL) practice. State medical boards collectively failed to discipline 55% of the nation's doctors who had their clinical privileges revoked or restricted by the hospitals where they worked. Our state's Medical Examining Board ranks 47th in the nation in taking action against doctors who injure their patients.

I do not want you to experience a medication error. The Institute of Medicine (IOM) reports that there is one medication error per patient per hospital day.

I do not want you to receive medical care that is influenced by conflicts of interest. ProPublica has initiated Dollars for Docs, a campaign for consumer transparency to disclose financial ties between doctors and the pharmaceutical industry they too often seem to serve.

What I do want for you, when inevitably you or your loved one becomes a patient, is access to justice should you suffer a preventable medical injury caused by negligence.

What I do want for you are doctors who are concerned MORE about patient safety and less about litigation.

If the goal of healthcare is to protect and improve the health of our citizens, then legislation must be guided by a patient-centric moral compass. Patient injuries are, after all, non-partisan. Considering the number of adverse events that occur, I would expect far more litigation arising from these health care errors.

Please put patients first.

Jean Rexford

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