

DAWN AWAKENINGS

Awaken to Independence

Summer 2009

BARRIERS

By Susan Donald

There are all kinds of barriers. Physical barriers are the easiest to detect. If a person uses a cane, walker, wheelchair, or crutches to get around, barrier free buildings should offer a bit of peace of mind. The problem I have found, however, is that barrier free buildings can be filled with barriers. There are barriers that are harder to see: barriers of attitude. In the past 16 years as I have navigated through life with a daughter who uses a wheelchair, and receives special education services, I have encountered many types of barriers. By and large the most difficult to overcome are the barriers of attitude that are prevalent in society and ourselves.

When Hillary was a newborn, before we knew she had Aicardi Syndrome with its multiple disabilities, we decided to attend a local church. In time, we decided to become members so that our children would have a church "home" as they grew. As we began to learn that Hillary had medical and developmental problems, we marveled at the support of our fellow congregants who prided themselves on having a barrier free building in which to worship and carry out the many activities of a congregation. As Hillary grew, however, something else became evident to me. While all were willing to accept my daughter and her disabilities in concept, the actual acceptance began to disappear as her disabilities became more inconvenient. Once she was large enough to use a wheelchair instead of a stroller, a growing discomfort became evident. The sanctuary was small so in order to stay out of the way, we tried to sit near the back where the pews were staggered and there was a place for Hillary in her wheelchair out of the main aisle. However, when the sanctuary was crowded, ushers set up folding chairs across the back, and Hillary would be blocked in. While I was still taking her back to Sunday school, which started about midway through the service, this caused a commotion as whoever was sitting behind us had to move their chairs in order for us to move Hillary out. Even without the chairs, people were constantly tripping over the wheelchair causing Hillary to be knocked about. Some people didn't even bother to apologize, just kept on walking as if they didn't notice anything, thus in my mind, marginalizing my daughter. Eventually I stopped taking her to Sunday school as the volunteers who were teaching felt that I should stay with Hillary, who made no trouble, while the parents of students who misbehaved were not asked to stay. I explained that it would be no trouble to them if she stayed without me, she had a peer volunteer to help her, and I would be just down the hall in the sanctuary should they need me. I explained that my goal for her in Sunday school was to feel included and be around her peers. I asked for no special treatment or curriculum changes. Even so, they insisted that I stay with her. Defeated, I stopped taking her to Sunday school, opting for the less crowded second service. That was ok, but our fellow worshipers didn't seem to like it when Hillary made noise during the service. Eventually I stopped attending church altogether, feeling unable to surmount the attitudinal barriers I encountered there. It was a disappointment for me as I expected that the one place Hillary would be accepted would be our church. In retrospect, I realize that part of the problem was my inability to accept that other people who were not immersed in the world of the child who has disabilities did not know what to do. My attitude was a barrier, and combined with those of the others, I found it impossible at the time to surmount the problem and so gave up.

My husband belongs to a parade band. It is a nice group of people. They used to have a Christmas party for band members and their families every year at a rescue squad building in town. Eventually the party was moved to a rental hall with a large set of stairs at the entrance. I realized this with some consternation once we arrived. Not to worry, though. Those good people simply gathered a few of the men together and carried Hillary, wheelchair and all, up the stairs and into the party. They did this without being asked. Even though the front of the building was not barrier free, the attitude of the gathered people was without barriers. The next year

the party planning committee made sure that an accessible entrance was available, and that it was cleared of snow. A caring attitude by those in charge of the event was all it took to make sure that everyone who wished to attend was able to do so with safety and dignity.

Another example of a barrier free collective attitude we have found at Girl Scout events. Hillary enjoys the company of her fellow scouts. When her troop participates in various community events, along with other area troops, it is a heart-warming experience for us. When Hillary's troop was bridging to Senior Scouts at a collective ceremony of all scouts from kindergarten age through 12th grade, it was held at one of our elementary schools in town. There was a wooden bridge on the stage for the bridging girls to symbolically walk across to get to the next level. When it was time for Hillary's troop, at the request of the woman in charge of the event, some of the fathers in the audience got up, took the bridge, and carried it down onto the floor so that Hillary could go across the bridge with the rest of her troop. These were fathers of the younger scouts, not the fathers of Hillary's troop, so they were not familiar with her; they simply did what needed to be done. Although initially there was a physical barrier to reaching the bridge, a lack of attitudinal barrier made it possible for my daughter to have the same experience as the rest of her troop. Nobody received as much applause upon bridging as Hillary did. Last year the Girl Scouts of our town were asked to participate in a ceremony opening a War Veteran's memorial at our new park. When the Girl Scout leader who was in charge realized that the planned entry point to the route the girls were to walk involved terrain too rough for Hillary's wheelchair, she changed the entry point for a more accessible route. I didn't ask that they do this; they simply saw that it needed to be done and did it. When people have the right attitude, accommodations for those who need them are easy and impact nobody negatively. Teaching children how to accommodate those who need accessibility is the best way to nurture the barrier free attitude that our society must have for future generations. The best way to teach this is to model the behavior, thus passing along the attitude of acceptance.

In our school systems attitudinal barriers run rampant among the administrators and general staff pool, as well as many of the parents of children without disability. Whether it is administrators who make the buildings accessible for wheelchairs only because it is the law and put the accessible parking spots far from the doors; teachers and classroom aides who do not want to deal with the needs of the students who have disabilities; bus drivers who grumble about being forced to deal with the children with disabilities, or parents who believe that having a student who has disabilities in their child's class will somehow negatively affect their child's education, it is a barrier placed in the way of a student's ultimate success. When administrators marginalize students with disabilities, those on lower rungs of the staff ladder feel it is acceptable to do the same. In such an environment it is rare to find a staff member who sees the value to everyone in meeting the needs of every student. When administrators fail to give the staff the supports they need in order to make appropriate accommodations for students who have disabilities, it becomes a traumatic experience for all concerned, again creating attitudinal barriers.

Another place where barriers can be found is in the realm of retail establishments. Although malls and larger stores are generally barrier free, there is frequently a lack of sufficient parking for vehicles with ramps and lifts. Then there is the problem of actually entering the building itself. The best ones have automatic doors that open when someone approaches. Some have electric doors that require pushing a button to open first the outside door, and then another button to open the second, inner door before entering the establishment. Frequently these buttons are placed in an inconspicuous place, and are not well marked. In some instances they are placed so far away from the door that there is little chance a person with mobility problems could push the button and then make it to the door before it begins to close. Frequently, there is no automatic door at all. Then the challenge becomes opening first one door, making it through, then opening the second door and making it through. If one is lucky, a fellow shopper will stop and hold the doors. Sadly, however, it has been my experience that nobody helps. I have had the experience of someone watching me struggling, not offering to help, then smiling at me and nodding their head when I finally get through the doors.

Once parked, and having gained entrance to a store or mall, there are any number of barriers to a successful shopping experience. First, there are the other shoppers. I must be careful to watch for people stopping

suddenly in the middle of the walkway lest I run into them with my daughter's wheelchair. Inside of the bigger stores, it is frequently only possible to traverse the main aisles of merchandise as the displays are set very closely together and I cannot get my daughter in her wheelchair through without damaging merchandise, or having clothing, if that is the merchandise, hitting her in the face. There are some smaller stores that I cannot even go into with my daughter since the aisles are only wide enough for people walking to pass through. My daughter loves going to the mall and looking around at all there is to see there. The law mandates accessibility for buildings, but simply being able to get inside is clearly not good enough. People must begin to realize that once a person who uses a wheelchair is inside a building, there must also be accessibility enough for independent shopping. Thus, it is a combination of both attitudinal and physical barriers that hamper accessibility.

If we do not teach our children by example how to be accepting and accommodating to those who need extra consideration and support, then nothing will change. What society seemingly fails to realize is that one day it could be a child, grandchild, godchild, spouse, parent or oneself who needs an accessibility related accommodation. Will they then rail against others who refuse to or reluctantly make accommodations for them, forgetting how reluctant they were to accommodate someone else? When they are the ones faced with the barrier of attitude, perhaps then they will, if they are in a position to make a change, do so.

DAWN Wheelchair Softball and Fun Night!



What is Wheelchair Softball? The game is played under the official rules of 16-inch slow pitch softball as approved by the Amateur Softball Association of America, with 15 exceptions that are geared toward the wheelchair user. Teams compete on a hard surface, which affords easier maneuverability than a normal softball field, using a 16-inch softball, which allows players to keep one hand on the wheelchair while catching the softball without a glove.

Wheelchair softball is an exciting and challenging summer sport a fun event for novices, advanced players and spectators alike. Meet new friends or old friends! Come play on the new, hard-surface field complete with painted lines and bases! Sport chairs will be available for those who are interested or in need. Chair changing and gear help will be available upon request..

Find more answers to your questions about wheelchair softball at <http://wheelchairsoftball.org> For additional questions on playing, volunteering or anything else (including directions) please contact Tim Ripley at (973) 723-2074 njwheelchairsoftball@gmail.com . Contact Bob Panzer– rpanzer@dawnCIL.org Location– Off of Kedena Rd. on grounds of Greystone in Parsippany . Setup begins at 5:30pm and the event will end by 9:00pm



<http://wheelchairsoftball.org>

ATTENTION STUDENTS:

Do you have a disability?

Do you want to change the world?

Do you have something you want to say?

Dawn Center for Independent Living in Denville, NJ is trying to organize an advisory council made up of students ages 13-21 who are just like you, who want to make a difference. You'll be given the ability to use valuable advocacy skills as well as being able to meet other kids with disabilities.

Contact Helen Bradfield at 973 625-1940 or email me at hbradfield@dawncil.org for more information.

Family Support Group

Are you the parent, sibling, or grandparent of someone with disabilities?

If so, come join Dawn's Family Support Group. Meet other families: network, and share resources. Group FKen Brucato, Teacher of Special Education, will lead discussions the 4th Thursday of every month while Dawn's Game Night is going on from 6-9. Come and drop in. We look forward to seeing you! RSVPs are appreciated. Drop ins are welcome!!

Contact info: Helen Bradfield, hbradfield@dawncil.org Phone: 973 625-1940

Dawn Center for Independent Living, 30 Broad Street, Denville, NJ 07834

NJ Shares Update

Gov Corzine just expanded funding for NJ Shares. They'll do a one time payment for families for up to \$700 gas and \$1300 heating oil. There are no income requirements. Families just have to show they've been paying bills but are now struggling.

Visit www.njshares.org or call toll free (866) NJSHARES 1-866-657-4273

Web Sites, etc.

www.patientadvocate.org A pain fund is available through PAF's (Patient Advocate Foundation) Co-Pay Relief Program in order to lighten the burden for those experiencing chronic pain due to a multitude of diseases and disorders. To see the list of pain related diseases, disorders, etc; please visit the PAF co-pay relief site www.copays.com. Patients and providers may also call 1-866-512-3861 for more information. It may be in your interest to visit the PAF official website:

Disaboom.com An online disability community full of articles and advice. The site offers a complete list of disability resources and a marketplace to shop online for helpful disability products and services. On disaboom you will be able to meet others, join discussions, post blogs, create a profile and browse or post helpful or just plain fun videos. Disaboom has a user friendly career builder and its own job site.

www.niams.nih.gov The National Institute of Arthritis and Musculoskeletal and Skin Diseases which has published a *Booklet on Arthritis*. To receive this booklet please write to NIAMS/NIH, 1 AMS Circle, Bethesda, Md 20892-3674. Booklet can be obtained from their web-site.

Senior Health Magazine

written by Knight Steel

www.state.nj.us/mvc Now easier to apply for Handicapped Plates and Placards. Download the application and go to any one of the 45-DMV stations statewide that are able to process the application for you. Can also visit your local DMV to obtain the application, placards and plates instantly or you may obtain application by calling 1-(888)-486-3339.

Source: moceanscil.org

dawncil.org

Are you interested in joining our on-line chat room? If so, check the web-site for details on how to sign-on.

Warning - Deceptive Website

The official HUD (Housing and Urban Development) website is a popular destination online, but some surfers have found themselves in the deceptive grasp of a phishing site posing as HUD. This bogus site has leeches an alarming amount of personal information and is a threat to your identity.

Note - www.hud.gov/recovery. *Is HUD's official website.*

The Phishing site's address is <http://bailout.hud-gov.us>

Never enter a site without checking your address bar. If the address changes *always* investigate that site. Phishing sites sometimes redirect your browser to them even after the official website has been entered. These sites are run by criminals seeking to gain your personal information. Always proceed with caution when a website asks for personal information such as your social security number. Always report a phishing site to help keep online surfing as safe as possible for us all.

Company Crackdown!

The popular travel website hotels.com is now dancing to a different tune when it comes to their accessibility options previously ignored by the company.

The online travel company was sued for its policy of disallowing their bookers to book wheelchair-accessible rooms or even search for them.

“Hotels.com has agreed to improve access for disabled travelers as part of a settlement of a lawsuit that alleged it refused to guarantee reservations for rooms that are wheelchair accessible.”

Sources: <http://www.out-law.com/page-8071>
and www.sfgate.com

Sussex County Team Chosen for National Mobility Institute

Sussex County was chosen to send a team of transportation and disability experts to a national conference on accessible transportation in Washington, DC July 12, 2009 through July 15, 2009.

Only fifteen teams from the entire country were accorded this honor through a national competition to choose participants. Sussex County is one of only two teams from the east coast chosen to attend the conference.

Participants of the Sussex County team are : Freeholder Susan Zellman - Chair of the New Jersey Transportation Planning Authority; Tim Sharpe – Administrator for Local Programs from Board Chair of [DAWN] Division and Tom Drabic - Principal Transportation Planner for Easter Seals, sponsoring the conference, will cover all members to attend the four day working on exploring specific disabilities and develop strategies for meeting those needs. continue to meet to work on implementing these issues and strategies throughout the year .



Musconetcong News
June 2009 , Pg. 7

Personal Assistance Services Program

The Personal Assistance Services Program (PASP) gives adults with physical disabilities opportunities to work, attend school or vocational training and live independently in the community

The NJ Dept. of Human Services, Div of Disability Services, administers the program through provider agencies in each county in New Jersey.

Morris County: 973 285-6865
Warren County; 973 625-1940
Sussex County: 973 948-6000

Services Available Personal assistants help individuals with tasks such as light housekeeping, bathing, dressing, meal preparation, shopping, correspondence, mobility, driving and/or use of public transportation.

Although you may be receiving services from other government programs or have insurance coverage, you may still qualify for the PASP.

You may be eligible for PASP if you are: A New Jersey Resident; physically disabled; between the ages of 18 and 65; living in the community (private home, apartment, boarding or group home); and capable of directing and supervising your own services.

Services are available to individuals who are employed, preparing for employment, attending an educational or training program and/or to support active participation in community –based activities, such as volunteer services or parenting. Individuals may receive up to 40 hours of services per week, depending on need.

Paying for Services Depending on family income, some individuals pay no fee. Others pay a portion of the cost of the service on a sliding fee scale, based on their family income. The remaining cost is covered by the Dept. of Human Services.

Back to Nature with Herbs

Poppies make you sleep, Peppermint energizes, and Lavender is the flower of positive thinking!

It's hard to deny smelling Lavender has a mood enhancing and calming effects on the human body and mind. For more than centuries this flower has been deemed to have medicinal value. There are many different ways to use the flower. Lavender in a pillow may aid you in falling asleep. Lavender in soap soothes the body and mind. Basically this powerful invention of nature can be thrown into endless recipes for consumption. The following recipe will hit the spot on the warmer days to come. Remember that this valuable flower is a gift from the earth as you enjoy. (Recipe created by Iris Lee Underwood and published in "AARP-The Magazine" July/August, 2009 edition).

Lavender Lemonade

Steep one large tea ball filled with lavender in a quart of boiled water until the liquid turns a light pinkish/rose color. Meanwhile, in a gallon jar, mix two large cans of frozen lemonade concentrate with four cans of water. When Lavender "tea" has cooled, add to lemonade. Finally, add ice and garnish with fresh mint, lavender sprigs with foliage, or all three. Sip and sit back for a unique summer treat.

DAWN Members

Do you require this newsletter in an alternate format? Please let us know what your requirements are.
(Example larger print , on tape, etc.,)

The newsletters and other information regarding our upcoming events can be found on our
new and improved Website.

Visit us at:
www.dawncil.org

We did it...together!



dawnCIL.org

Are you interested in joining our on-line chat room? If so, check the web-site for details on how to sign-on.

As you know, New Jersey's state government recently planned to cut \$125,000 from the five state-funded Centers for Independent Living (CILs), including DAWN. This cut would have drastically impaired our ability to help people access the services they need to remain independent, to help people advocate for themselves, to provide programs and services for educational and social programs and more.

DAWN and the other New Jersey CILs reached out to members and other supporters of people with disabilities for help. We needed to show the state that CILs make a difference in people's lives, and that funding cuts would matter to New Jersey citizens. We'd like to take this opportunity to give a big thank you to everyone who participated in these and other ways:

- Signing and circulating petitions.
- Spreading the word and getting others involved.
- Using the "Take Action" tools at gonextstep.org.
- Sending emails, letters, and faxes to state legislators.
- Participating in our call-in day on May 12th.
- Visiting legislators in Trenton.
- Attending the rally in Trenton on May 14th.

Your efforts made a difference! Together, we showed state legislators the importance of this issue. Funding for the 5 State CIL's remains flat for the coming year, however, funding for the following year is uncertain. This success would not have been possible without the participation of everyone who took the time to make their voices heard. We need to keep this issue in the forefront to not only maintain state resources but to expand them in order to build capacity for the CIL's.

Want to do more? For more information about online petitions and other advocacy resources, please visit the new “Current Issues and Advocacy” page at dawnCIL.org. We would also love to hear your ideas for how DAWN can help you get more involved with future efforts like this one. If you have any ideas or would like to be involved in planning or brainstorming advocacy projects for DAWN members, please call our office at (973) 625-1940 or email us at info@dawnCIL.org.

THANK YOU!

LET'S PLAY GAMES



Game Night at the DAWNcil office
4th Thursday of each month from 6pm - 9pm

Board games, parlor and family games, DVD games, even video games!

Contact DAWNcil office at
(888) 383-DAWN
(3296)

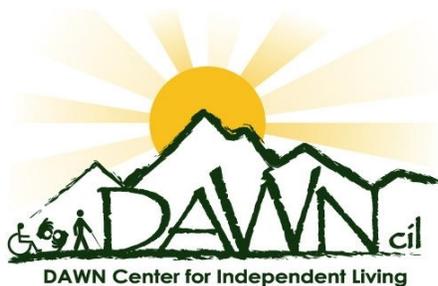
DAWN MISSION STATEMENT

DAWN Center for Independent Living empowers people with disabilities who strive to take control of their own lives by:

- Providing the tools that encourage independence and self-advocacy.
- Promoting public awareness of the rights, needs and desires of individuals living with disabilities.
- Offering community activities that create new experiences and opportunities.
- Creating informed communities that advance the Independent Living Philosophy.

DAWN provides the following services:

- Information and Referral
- Advocacy
- Peer Support
- Independent Living Skills Instruction
- Promoting Self-Advocacy (STEP-Up Student Transition Empowerment Program)
- SAIL (Self-advocacy Institute for Leadership)
- ADRC
- Nursing Home Transition
- Traumatic Brain Injury Program
- Recreation
- Young Adult Recreation
- Membership Meetings
- School Outreach
- IEP Support
- Living Well with a Disability
- Next Chapter Book Club
- Aktion Club (Morris County only)



Phone: 973-625-1940
1-888-383-DAWN
Fax: 973-625-1942
TTY: 973-625-1932
Email: info@dawncil.org

We are on the web!
www.dawncil.org