



Options Center of Independent Living Reference Guide to Independence 2013-2014

Options CIL is a not-for-profit, community-based organization that assists persons with disabilities in living independently. Our services include information and referral, advocacy, independent living skills training, peer support, education and awareness about disabilities, personal assistance programs, sign language interpreter referrals, equipment loans, support groups, TTY distribution and volunteer opportunities. Options CIL also offers elderly blind services, children's and youth advocacy and mentoring services, and community reintegration services. For a full listing, visit our website, www.optionscil.org, or contact either of our offices.

Our Mission Statement

Options Center for Independent Living partners with persons with disabilities who want to live independently and participate fully in society.

Options Service Area AND OFFICES

Iroquois County
130 Laird Lane, Suite 103
Watseka IL 60970
815-432-1332 (Voice)
815-432-1361 (TTY)
815-432-1360 (Fax)

Kankakee County
22 Heritage Drive, Suite 107
Bourbonnais IL 60914
815-936-0100 (Voice)
815-936-0132 (TTY)
815-936-0117 (Fax)

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Please contact us for a Membership Application or call Therese Cardosi for more information. www.optionscil.org • 815-936-0132 (TTY) or 815-936-0100, ext. 224 (Voice)

Alternative Treatments For Knee Pain Due To Osteoarthritis

Interview with Dr. Garcia, owner of Finlay Occupational Health

What is Osteoarthritis?

Osteoarthritis (OA) is the degeneration of the articular cartilage, a process of wear and tear.

What is this articular cartilage and why does it degenerate?

Lets take the model of a hardboiled egg. Imagine the yolk being the bone and the white being the articular cartilage covering the bone.

Many theories have been presented as to what initiates the degeneration. Most agree that injuries suffered in the past, including childhood injuries, could start the process. Those injuries do not have to be severe, in fact, most of the time they are trivial.

Can you explain the function of this articular cartilage?

The main function is simply to create a smooth surface in the joint to facilitate movement.

How does the degeneration occur? And how fast does it set in?

The process is rather slow. It takes years. Certain factors can accelerate the degeneration such as obesity, certain

weight bearing activities and chronic debilitating conditions, as well as severe injuries and surgeries that disrupt any area of the articular cartilage.

I use a simple formula to explain this to my patients.

Knee pain= Body weight X Weight bearing activity.

What are the treatments available for this condition?

Let me start by saying that to this date there is no cure for OA. The Gold Standard lately has been joint replacement, but the fact that a person has knees that are “bone on bone” does not mean that this individual is going to have significant knee pain or that he/she will need a joint replacement.

Truly, the only indication for replacement is when other, more conservative methods have been tried and they have not succeeded at improving the pain and the individual’s quality of life.

There are many alternative treatments available nowadays. These are: improved oral anti-inflammatories, targeted physical therapy, special custom braces, Bionicare (electrical impulses), various types of injections, including steroid, Hyaluronic acid (Synvisc, Hyalgan, Euflexa, Orthovisc, Supartz, etc.), PRP, Carticel procedure, ostochondral grafts, etc.

Dr. Garcia, What is your background?

I trained in Cuba as an Orthopedic Surgeon, and in US in Occupational and Environmental Medicine at UIC.

Do you perform surgeries in your office?

No, I only perform minor procedures that could be done with local anesthetics in an office setting. I treat most Orthopedic problems in a conservative manner. If surgery is needed I refer the patients to an Orthopedic Surgeon.

What is your success rate treating OA?

Roughly 80%- 85%. The main thing is avoid creating any false hopes or expectations. I tell my patients that the pain is going to be significantly reduced, but not totally gone, although there are exceptions.

It is important to sit down with the patient in every visit and explain the disease process in every specific case going over the Do’s and Dont’s to prolong the periods of relief.

A Dollar A Day...

That is what most nursing home residents receive. Imagine if you or a loved one suffered some type of extreme health emergency and needed to live in a nursing home until able to recover. Often because of a health emergency and the long term hospitalization required prior to being admitted to a nursing facility, many become delinquent on utilities or are unable to pay their rent or mortgage and lose their home and personal belongings. Now imagine that it’s six months or a year later and you have recovered enough to once again live independently in the community. If you saved every dollar you received while in the nursing home instead of buying yourself toiletries or personal items you would still only have \$365 at the most!

How are you going to pay a security deposit or your first month of rent, pay any outstanding utility balances and purchase furniture or household goods such as pots and pans? Most people would not be able to do so and, if discharged, would be, for all intent and purposes, homeless! What would you do?

Options can help! There is a little known program in Illinois previously entitled Money Follows the Person that has now been more aptly named “Pathways to Community Living.” It is sponsored by HFS (Healthcare and

Family Services) and IDHS (Illinois Department of Human Services) with quality control provided by Master's degreed nurses at University of Illinois at Chicago. This program allows for payments of security deposits, first month's rent, set up of basic utilities, furniture, household furnishings and initial groceries.

Additionally, this program is administered by trained staff called transition coordinators at Centers for Independent Living throughout the state. These trained staff members will meet with people with disabilities living in nursing facilities to determine eligibility for the program. If a person is eligible and also interested in leaving the nursing home to live independently, these same trained staff will then assist them to identify housing and coordinate all aspects of transitioning into the community. This does require a collaborative effort among the physician, nursing home staff, and the person wishing to move.

If you or a loved one would like more information about this opportunity, please contact Options CIL.

I Can Live Independently... With Just A Helping Hand

To truly live life in a full and productive manner, we want to make our own decisions. We want to determine when we go to bed, when we get up, what we eat, and what activities we participate in daily. When a person with a disability desires an independent life at home, he or she should make a plan. This plan should include all that is needed to carry out daily living tasks and to do so safely. In some cases, this may mean having assistance.

Options CIL operates a Personal Assistant (PA) Program that will aid a person with a disability in all the steps from determining whether or not they qualify for this State program, to how to find, hire, and manage their PA. In partnership with the Illinois Division of Rehabilitation Services (DORS), Options CIL will help the person with a disability begin the independent life he desires.

Once a person with a disability has been approved for Home Service Program hours, he can interview, hire and directly manage a personal assistant. Options CIL recruits and provides orientation for people who want to be personal assistants. We also maintain an active referral list of those who want to work as personal assistants. Whenever a person with a disability needs to hire a PA, they call Options for a listing of PAs.

If a person with a disability is not familiar with managing a PA, the PA Specialist at Options CIL will work one-on-one with that person to assist him in learning helpful and effective communication skills, interview skills, and management skills to better manage the hired PA. Learning effective PA management skills could be the difference between a struggle and a blessing when working towards an independent life.

HOW DO YOU FIND OUT ABOUT GETTING and IMPLEMENTING SERVICES?

Call DHS/DORS (815-939-4422) or Options CIL (815-936-0100) for a referral to have your needs assessed in order to be approved for Home Services Program hours.

Call the Options PA Specialist to arrange for a home visit to discuss the hiring of a personal assistant.

Call Options CIL for a current PA list when hiring your PA staff.

Call the names on the list, set up appointments for interviews, and hire your new PA!

IF YOU HAVE ANY TROUBLE AT ALL, CALL OPTIONS CIL FOR ASSISTANCE!

Grumish Chiropractic Patients Share Their Story

“I want a natural way of healing instead of being tied to medications. Dr. Grumish consults my chart with every adjustment. My results are ongoing relief and help with my stress. I think the best thing I can do for a long and healthy life is to continue chiropractic care. Simple!” -Jennifer

“I was golfing and bent down to get the tee and had a shooting pain in my back. Afterwards I was bed ridden for two days, my legs would give out and I had sharp pain. My back is much better, I no longer have hip pain and my golf swing is much more fluid. As a doctor I sit a lot and that was also causing a lot of my hip pain and I no longer experience that either!” -Dr. Jeff

“About a week before my monthly maintenance visit I injured my knee. Instead of seeing an orthopedist I talked to the doctors here to see what could be done. When it comes to the knees I wasn't expecting a lot. I felt relief after the 1st treatment and by the 2nd treatment the pain was completely gone!” -Donna

Grumish Chiropractic has been in practice since 1978. With over 30 years in the community, our clinic is one you can trust. We are proud to be members of the Christian Chiropractors Association and strive to bring our statement of faith and purpose in all aspects of our practice. Grumish Chiropractic specializes in difficult and chronic cases with safe, gentle and effective techniques. The doctors use advanced adjusting tables and have been certified in the Impulse iQ adjusting instrument. Our doctors also advise patients with nutritional and life-style recommendations. Our goal is to get you feeling better and to maintain long term health and wellness. “We care about your health.” Call 815-939-0990 for a free consultation.

Movie Captioning Via Special Eyeglasses

As most of you know, going to the movies is especially challenging when you have a hearing loss. Just the logistics involved in seeing a captioned movie make it difficult to see the movie you want, when you want. According to recent reports, a new Sony product opens up an opportunity for people with hearing loss to view any movie at anytime from anywhere in the theater.

Imagine watching a movie where the captions are not on the screen but wherever you look while wearing special eyeglasses! Sony utilizes its own holographic technology to wirelessly project captions onto the see-through eyewear to provide “a natural, subtitled movie experience.” The captions appear as bright green and can be positioned anywhere on the glasses, eliminating the need to arrange the glasses in ‘the best place’ on the nose for viewing. You can also change the brightness of the captions, how far away they appear to be, and even their angle so that you can get the best view possible. You can turn your head sideways or up or down, and the captions move with you and are clearly visible throughout. Viewers can choose to get captions in one of six languages, depending on which languages are available for the movie. Some people may find that fitting this eyewear over regular eyeglasses is problematic, however, putting some at a disadvantage since they may not be able to watch a movie without their prescription glasses.

The 3-ounce eyewear is also equipped with headphones to provide assistive audio for the hearing-impaired as well as aid blind and visually-impaired individuals via audio description. A lithium ion battery is part of the setup with the headphones. There are conflicting reports as to whether the captioning and audio assist features can be used at the same time.

Movie theaters loan the glasses to movie patrons free of charge. Regal Cinemas is the first to implement use of

this product.

The above article is reprinted from the summer 2012 ALDA (Association of Late-Deafened Adults) Chicago Style Newsletter; their reporter Casey Fronczek looked into this product and reported his findings.

Eastcourt Village Apartment Complex for Mature Adults

This stately hi-rise standing at the entrance to Kankakee at exit 312 on I-57 continues to offer apartments, both efficiency and one-bedroom units, to mature adults. In addition to the apartments, there is a beautiful community room along with an array of amenities.

All apartments include wall-to-wall carpeting, vertical blinds, appliances and individually controlled heating and air conditioning. There is a small charge for apartment electricity and cable TV. All other utilities are included in the rent including the heat, which in the past couple of years has been a very expensive utility. There is ample parking for residents and visitors.

Residents have many opportunities for socializing, including weekly church services and various card games. For the convenience of the residents there are several laundry facilities throughout the building. In addition the metro bus service stops at the building every hour between 6 a.m. and 10 p.m. six days a week. There is also a van service exclusively for residents that operates two days a week for local shopping.

There is a full complement of employees including a housekeeper and maintenance personnel to handle apartment maintenance. Apartment maintenance problems are handled as they happen. There is a local fire department within two minutes of the building. Paramedics respond to emergency calls quickly and have access to all apartments at all times.

The management office is open Monday thru Friday from 8 a.m. to 4:30 p.m. for anyone interested in information about our apartments, interested in a tour of the building or wishing to view our model apartments. For those persons who are not available during normal business hours, an appointment may be made to view the building or view an apartment by calling the office at 815-937-4200.

Helping A Loved One With Vision Loss

Reprinted with permission of the National Eye Institute, National Institutes of Health (NEI/NIH).

Vision loss is a major public health concern in the United States. People who have vision loss commonly experience depression, anxiety, and confusion. The consequences of vision loss, however, often extend beyond the person who has low vision. The family members, friends, and caregivers of people experiencing vision loss also are affected.

When a loved one becomes visually impaired, you are likely to feel overwhelmed. You also may experience a range of feelings, from sadness to guilt, and there are many day-to-day adjustments to make. You may find yourself putting aside your feelings and needs to focus on helping your loved one cope. Yet, in many cases, you may feel alone and at a loss about what to do or how to help. It is important to communicate your feelings with

others. By sharing your feelings, you are in a better position to be more accepting of yourself and understand that what you and your loved one are experiencing is not isolated and unique.

Answering the following questions may help you express your thoughts and concerns:

- What feelings have you experienced since your loved one became visually impaired?
- In what ways has your life changed since your loved one's vision loss? Are there things that you've had to give up? How do you feel about these changes?
- What feelings are most difficult for you to accept and deal with?
- What do you do with these feelings? Are you able to share them with your loved one?
- Has your loved one's vision loss brought you closer together in any way? If yes, how?

When sharing your thoughts and concerns with your loved one, it is important to remember that communication involves both verbal and nonverbal expressions. When we think about communication, what usually comes to mind is the verbal aspect of communication. But communication also involves receiving information through listening. And most communication is nonverbal, which poses challenges when talking to people who are visually impaired, as they may not be able to see gestures, nods, facial expressions, and other visual cues.

Here are some strategies that can help you communicate more effectively and deal with difficult situations involving strong emotions and conflict:

- Listen to what the other person is saying as well as the feelings behind the words. This type of listening is hard when you may not want to hear "anger" or "frustration," when you are feeling "attacked" or "criticized," or when you disagree with the other person. At these times, it's helpful to let the person finish what he or she has to say before responding.
- Express your feelings or point of view with the use of the word "I." For example, "I feel upset about" or "I see it differently" rather than "You are being unfair" or "You are wrong."
- After each person has a chance to share his or her feelings and point of view using "I" statements, ask each other: "Are there areas of common ground?" Sometimes, you may have to agree to disagree and come back to the issue at a later time.

Adapted from the Lighthouse International's Program for Partners of People with Impaired Vision.

Is It Legal To Send Kids With Disabilities Home Early?

"In my district, special education kids are sent home from school early - 30 minutes to an hour earlier than 'regular education' students. This doesn't seem right. When I asked about this, I was told, "All special education students are released early - that's the rule." Is this legal?

No. When your district says, "All special education students are released early - that's the rule," they are discriminating against these children and violating the law. What can you do?

File a Complaint with Office for Civil Rights

File a complaint with the Office for Civil Rights (OCR). Download the OCR COMPLAINT:

<http://www2.ed.gov/about/offices/list/ocr/docs/howto.html?src=rt>

This OCR Complaint is a very large (27 page) document in PDF. It might be easier to print it and then fill it out.

Options CIL CrossWalks For Disabilities Cross Disability Peer Support Group

CrossWalks for Disabilities is a peer-driven cross-disability support group that is open to persons with any type of disability. We meet the 2nd Monday of each month from 10:30 a.m. to 12:00 noon.

Find the support of others who provide real-life solutions based on their experiences.

For more information contact Margaret Prosser, Independent Living Specialist, 815-936-0100 – voice, 815-936-0132 – TTY

Tips For Communicating With Health Care Professionals

Information from ElderCareLink.com

Open communication between you and your health care professionals can help improve your outcome. Benefits may include greater satisfaction with your care, reduced stress levels, and improved levels of healthcare.

Try using the following tips offered by the National Family Caregivers Assoc. to improve your communication with your healthcare professionals:

- Write down your questions. Doing so ensures you don't forget the questions.
- Be clear. Don't ramble on about various issues. Instead, be precise and clear about what you want to discuss with the doctor.
- Use consultation appointments. If you need extended time with the doctor, schedule a consultation appointment.
- Get educated. The Internet makes it easier than ever to gather information about your health issues, disabilities or diseases.
- Not all questions have answers. Remember, many questions that start with 'why' often cannot be answered.
- Recognize you're on the same team. It is vital to always remember your physician/health care professional is working for your benefit.

These points apply not only to physicians, but other care providers such as home health nurses, counselors and more.

What Is A Hearing Induction Loop?

An induction loop system transmits sound wirelessly to people who use hearing aids that have telecoils (also called T-coils). Today's new hearing aids must have a T-coil. The loop will also work with a cochlear implant. This system will work for any number of users and requires no receivers.

HOW DOES IT WORK?

- Audio inputs, either from an existing audio system or from dedicated microphone inputs, feed an audio signal into an induction loop amplifier.
- The amplifier drives a current into a hidden loop wire. As the current flows through the wire, it creates a

magnetic field in the listening area.

- Inside the hearing aid a small coil, known as a T-coil, picks up the magnetic field signal, which is then amplified into a high quality audio signal delivered directly to the ear of the hearing aid listener.

Induction loop systems do not require the use of receivers. The best sound is achieved with the use of a hearing aid since the sound is specifically processed for its user. Facilities and consumers are free from the hassles of a multitude of receivers.

People who wear hearing aids or have cochlear implants still have difficulty hearing in large rooms such as churches or places where meetings are held. This might be because of background noise, loud speakers that are placed at a distance, talkers who have accents, a speaker who talks fast, or a woman or child talking. An induction loop greatly reduces the impact of background noise and reverberation.

The “Loop It” application works for places of worship, courtrooms, meeting rooms, classrooms, warning systems, theaters, and lecture halls. It is also appropriate for home use. You could have your sofa or chair looped! The information for this article was provided by the Hearing Induction Loops, Assistive Hearing Systems. www.LoopIT8.com or call 855-LOOP IT-8.

How Can I Support Options Center For Independent Living?

Options CIL is a non-residential, not-for-profit, community-based organization that partners with people with disabilities who want to live independently and participate fully in society. Our primary service area includes Kankakee and Iroquois counties.

Options is guided by the independent living philosophy that people with disabilities have the right to control and direct their own lives, to have choices and options, and to actively participate in all aspects of society.

Options receives the majority of its funding from state and federal grants. In addition, Options utilizes funds raised from several other mission-focused annual events. These grants and the proceeds from our fundraising events enable us to provide much-needed programs and services to people with disabilities in our service area. Below are Options CIL annual fundraising events:

- Options CIL Membership Drive – Membership supports our mission and entitles members to vote for our board of directors. Other benefits are available according to the level of membership. Contribution levels range from \$10 to \$300 and can be made anytime during a calendar year.
- Reference Guide to Independence – This informative booklet is published each year in May. It explains the programs and services that we provide to the community and contains articles that provide tips and tools for people with disabilities. Publication is made possible by advertisements from businesses and organizations in our community that support Options CIL and our mission. Half-page and full-page advertisers are welcome to submit an article about their business. The booklet is distributed throughout the year to all Options’ consumers and at numerous community events in Kankakee and Iroquois counties.
- Wheel-a-thon/Walk-a-thon Events – These are wonderful disability awareness and fundraising events. The Iroquois County Wheel-a-thon will take place on Saturday, September 7, 2013, at Lakeview Park in Watseka. The Kankakee County Wheel-a-thon will take place on Saturday, September 14, 2013, at Perry Farm in Bourbonnais. Form a team of 4 or more people and join us to navigate a 2-mile course using a wheelchair. You can also register as an individual and walk the event route. Raise funds and earn incentive items. A team of 4 people is only \$100; individuals are \$25. There are many levels of

sponsorships from \$100 on up, each with wonderful benefits. Every pre-registered participant receives a goodie bag with their event t-shirt and other free items!

For more information on how you can support Options CIL or for more information on the above events and opportunities, please contact Therese.Cardosi@optionscil.org or call 815-936-0100 (V) or 815-936-0132 (TTY).

United Way Equipment Program

Often adaptive equipment that is prescribed by a physician or can increase a person's independence in the home is not considered to be medically necessary and therefore, not a covered expense through many insurance programs. Thanks to funding from United Way of Kankakee County, Options is able to offer limited assistance in helping people obtain adaptive equipment that can improve quality of life in the home. Because funding is limited, equipment requests are restricted to \$200 per person. Also, it is very important to note that any item(s) covered through an individual's insurance carrier will not be purchased using United Way funds. The purpose of the equipment program is to provide assistance in obtaining items for which an individual's insurance, such as Medicare, Medicaid or any other private medical insurance, will not pay and that may not be able to be purchased through other means. Any individual without insurance is welcomed to contact Options to determine eligibility for the adaptive equipment program. If an individual has insurance, please determine if the item(s) being requested would be considered covered expenses. If the item(s) is not covered, please feel free to contact our office to determine if the item(s) can be provided to you through the United Way equipment program. Any equipment requests/questions can be referred to Sean who is in the office Monday thru Friday from 1:00 to 5:00 p.m.

To apply

for an item or assistance through the United Way equipment program:

- The individual for whom the item is being requested must have a disability.
- The individual must qualify through an income-based guideline (Catholic Charity poverty guidelines)
- If the person (and if applicable, family members in the household) is above poverty guidelines, a debit/income ration analysis must be completed.
- A determination guideline application must be completed and proof of income for all people contributing to the person's income must be submitted.
- A prescription for the item requested may be required.
- Each request is capped at \$200 unless approval for additional funding is granted by the Executive Director.
- No item covered by a person's insurance will be purchased using United Way funds.

Hearing And Speech: Presence St. Mary's Hospital Has The Connection To Communication

The National Institute on Deafness and Other Communication Disorders reports that an estimated 43 million Americans have a hearing, speech, voice, or language impairment. Approximately 1.4 million of these individuals are children with moderate to severe communication impairments due to impaired hearing.

“Hearing loss can strike at any age and at any time. It can emerge slowly or come on suddenly. Either way, even

the slightest hearing loss can affect all areas of a person's daily life," explains Lori Ader-Steinhauser, M.S., certified audiologist, Presence St. Mary's Hospital Ear, Head, and Neck Institute and Hearing Center.

Some of the most common indications of hearing loss include frequently asking others to repeat themselves; losing one's place in group conversations; keeping the radio or TV volume at a high level; and having pain or ringing in the ears. The key to addressing hearing loss, she explains, is early detection for babies and children and annual hearing check-ups for adults.

Presence St. Mary's Hospital Ear, Head, and Neck Institute and Hearing Center specializes in preventing, identifying, assessing, and treating disorders of the ear, nose, sinuses, and throat for children and adults. It is under the leadership of Francis L. Hobson, M.D., who is board-certified in otolaryngology.

Speech and language disorders can take many forms, including articulation, stuttering, and aphasia. They may be learning-based, acquired, or the result of injury or illness. For children, proper development of speech and language skills is imperative to ensure their ability to learn, to explore their environments, to interact with others, and to communicate their wants and needs.

The Rehabilitation Department of Presence St. Mary's Hospital provides bilingual speech language therapy for pediatric patients, including the evaluation and treatment of expressive speech/language delays and disorders; articulation and related motor speech disorders; cognitive and oral motor impairments; voice disorders; and swallowing/feeding difficulties.

For more information about Presence St. Mary's Hospital Ear, Head, and Neck Institute and Hearing Center or the Rehabilitation Department, go to www.presencehealth.org/stmarys-kankakee.

CaptionCall - Life is Calling

Do you have difficulty hearing on the phone?

Do you or someone you know have trouble hearing on the telephone? With CaptionCall you can understand every word of every phone call. Its large, easy-to-read screen quickly displays written captions of what your callers say. That means you can get more from your conversations – and from life.

Basic Requirements

To get started with CaptionCall, all you need is:

- A high-speed internet connection
- Standard home phone connection
- Ordinary home electrical outlet

How CaptionCall Works

Similar to captioned television, CaptionCall uses voice recognition technology and a transcription service to quickly provide written captions of what callers say on a large, easy-to-read screen. It works like a regular telephone – simply dial and answer calls as usual – speak and listen using a phone handset like always.

The captioning service is free. Captioning is provided by CaptionCall and paid through a fund administered by the Federal Communications Commission.

View free, nearly instant captions of what your callers are saying on the large, easy-to-read display screen of your CaptionCall Phone. With the CaptionCall Service, you get captioning that's:

- Free—No new bills and no monthly charges; captioning is fully funded by the FCC.
- Automatic—No need to dial through the Captioning Service.
- Secure—Safe, encrypted, FCC-regulated transcription.
- You hear your caller’s voice over a standard phone line.
- The CaptionCall Phone sends their voice to the CaptionCall Service, which quickly converts words to text.
- The text is displayed on the screen of your CaptionCall Phone.

CaptionCall is made available only to individuals who have a medically recognized hearing disability necessitating their use of the service. The CaptionCall service is supported through the federal government’s Interstate Telecommunications Relay Service fund. This fund is established to fulfill the mandate of the Americans with Disabilities Act (ADA) to provide functionally-equivalent communications to people with hearing loss. The CaptionCall service uses communication assistants who convert the calling party’s spoken words into captioned text. All calls made through CaptionCall must include a hearing-impaired person.

Why CaptionCall?

Hearing loss shouldn’t mean losing touch. With the CaptionCall Solution, talking on the phone is stress-free.

This comprehensive solution includes:

- A state-of-the-art, captioning-enabled CaptionCall Phone
- Free, nearly instant captioning with the CaptionCall Service
- CaptionCall Support for friendly, ongoing customer assistance

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The ADA 2+ Decades Later: More Work To Do In Our Community

By Donald R. Mitchell

On July 26, 1990, President George H. W. Bush said “I now lift my pen to sign this Americans with Disabilities Act and say: Let the shameful wall of exclusion finally come tumbling down.” On July 26, 1991, the first regulations were posted to ensure accessibility for people with disabilities under this law. Although we have made great strides in accessibility over the last 21 ½ years, there is still a lot to do in our community to make it accessible for people with disabilities.

The Kankakee County Courthouse celebrated its 100-year anniversary in the summer of 2012. On July 2, 2012, there was a public meeting in which the Kankakee County Board reported a not-all-inclusive list of 159 violations of the Americans with Disabilities Act and the Illinois Environmental Barriers Act at the courthouse enumerated in a letter from the Illinois Attorney General’s office. That list included only the issues of accessibility that affect people with disabilities. We also learned that the Courthouse did not meet the Illinois Supreme Court’s Minimum Standards for Courthouses.

In September, Options participated on the Blue Ribbon Commission, which was charged with two tasks. The first task was assembling the list of findings, and then on the basis of those findings, making recommendations

to the Kankakee County Board about the best possible way to bring the Courthouse into compliance. On the first night we took a tour of the Courthouse where we observed many of the listed accessibility issues.

When these violations are viewed through the eyes of a person with a disability, it is easy to see how persons with disabilities have been prevented from accessing and using the Courthouse. The Blue Ribbon Commission would later conclude that the County should keep the current courthouse, and build an addition adjacent to the south entrance of the courthouse that would house at least ten courtrooms, a jury assembly room and all other requirements as set forth by the Illinois Supreme Court. In addition, part of the new building will include unfinished square footage that will be utilized in the future as the county continues to grow, while taking advantage of lower construction costs.

The second task asked of the Blue Ribbon Commission was to make recommendations on how the County would go about paying for the modifications. The finance people for the County shared that there is no money in the budget to pay for what is estimated to be \$45 million dollars in construction and remodeling costs. Furthermore, because of Sales Tax Agreements with the City of Kankakee, the County and City of Kankakee would lose about \$8 million dollars in revenue if the commission were to recommend raising the sales tax by ½ cent. The loss of this money would devastate the current budgets of both the County and City governments. The commission decided that this was not the way to finance the courthouse project.

Various solutions were discussed but they were short-term fixes. Short-term fixes were not the answer to solving the problems but a means to postponing the inevitable. This led the commission to look at raising property taxes as a means of ensuring that a stream of money would be available to address the issues at the courthouse. Many on the committee struggled with the prospect of raising taxes in the current economic climate and so we explored many possible ways to generate revenue. Eventually it was unanimously decided that raising property taxes was the only way to raise the necessary revenue to pay for what needs to be done. The recommended real estate tax increase would cost the homeowner between \$60 and \$66 per year on a \$150,000 home to pay for renovation and construction.

Options CIL wants to encourage you to educate yourself on this subject and keep up with the developments. Most of the documents that the commission had access to can be found on the county website at <http://www.co.kankakee.il.us/>. Take advantage of the opportunity to tour the courthouse to see for yourself the inaccessibility and overcrowded offices. We also encourage you to tour the Kendall County Courthouse to see what a 21st century courthouse is supposed to look like. Many on the commission were able to do this and benefitted from the experience by seeing clearly how far our courthouse has to come. Options hopes that someday Kankakee County will have a courthouse to be proud of that will provide access to everyone.

Community Outreach Program

As an organization, what you don't know could affect your clients!

Have you ever heard or said:

- There has to be something out there to help them.
- I wish I knew of someone or some place that could help you with your dilemma.
- I can't believe someone hasn't come up with a solution for this problem/need.
- That area/town always seems to be left out/forgotten.
- Why is there no help for them?

Many times we need additional assistance in helping our clients and we are frustrated because we don't know

who can help. While there are some gaps, our area is rich in qualified resources - ready to help when needed.

Options' Community Outreach Program is a program designed to assist in reaching as many of the underserved and un-served areas and people as possible. Because people are sometimes unaware of all the community assistance that is available, they suffer needlessly in silence and isolation. Options CIL believes that all people deserve access to whatever community services are offered.

To learn more about what Options Center for Independent Living can do for you or someone you care about, invite us to speak at your business, your church, your social club, etc. Our Community Outreach Specialist will tailor a presentation for your group and share the many and varied programs and services provided by Options CIL. Having this knowledge will enable you to better serve yourself and those you interact with on a business or personal basis.

Options CIL is available to staff a booth or speak at any of your outreach events, informational meetings or forums, or any of your community events that are reaching out to the residents of your community. Call Options today - we welcome opportunities to share the resources in our area!

Managing Your Disability

Let's say that six months ago Jim Smith and John Doe found out that they each have a heart problem. Their doctors tell them that they can live a long, productive life as long as they begin to eat better, exercise and take medication.

Here it is six months later and you run into Jim Smith. He tells you he's thoroughly researched his type of heart disease and understands how he can be affected by weather, stress, other medications and supplements, like St. John's Wort, and other illnesses, like the flu. He tells you that he's started a regular exercise program and is trying hard to eat right even though he's still struggling with that. He tells you he's taking his medication and feels much better. He says he knows that staying with the exercise, eating better and taking medication are now lifelong habits he must follow to feel the best he can, to remain productive, and to live as long as possible.

The next day, you run into John Doe. He hasn't started exercising or eating better and he doesn't take his medication regularly as prescribed. He starts to complain to you about his aches and pains and all the things he can't do because of his heart. He whines that having to eat better, exercise and take medication is too hard and he just can't do it.

Which one of these men is managing his heart disease and which is letting the heart disease manage him? Are you managing your disability? Are you as knowledgeable about it as you can be? Are you aware of any foods that help or hurt your disability? Are you exercising to the extent you can? Are you taking medication as prescribed? Do you know what other medications and supplements affect the medication you take? Do you know what affects your disability, i.e., other illnesses, stress etc.? Are you aware of any new treatments for your disability?

Many of us with a disability don't think in terms of managing it but that is the responsible thing to do. It is not only being responsible to others but more importantly, being responsible to ourselves.

About 5 years ago, an 18-year old young man was diagnosed with bipolar disorder. He was encouraged to research his disability, to know what affected this disability, such as a weight gain or loss, and to have a plan in place for the bad times. He was urged to stay informed about his disability to know if there were clinical tri-

als he could participate in, if there were support groups he could join, periodicals he could read, or websites he could visit to stay on top of the latest developments.

He learned from his research that many individuals who have bipolar disorder sometimes feel so wonderful that they don't think they need to take their medication any longer and stop. As a result, they start feeling not so wonderful and then fight taking the medication. He also learned that when taking medication is then resumed, it takes awhile to get the positive affects of the medication back as it has to be re-established in the body.

As a result, he chose someone that he trusts completely and gave his medication to that person. Now, no matter how he feels, when this trusted person hands him his medication, he doesn't let his 'urgings' overtake his common sense and trust and he takes it without question or argument because he knows this is the right thing to do. As a result, he experiences fairly minor bad times because he knows what triggers them, he knows how he feels when they are coming on, and he has a plan for what to do. He is employed, has kept the job for over three years, is in a stable relationship, and has dreams for his future.

Regardless of whether a disability is physical, mental, or emotional, it's in your best interests to manage it. Just like Jim Smith, knowing the potential triggers that your disability may react to will help you to be prepared to ride the storm. It is better to be proactive then reactive.

To effectively manage your life as a person with disability, know yourself well enough to know what you can do by yourself and what you can control and accomplish with the proper medication, the support of a personal assistant, an accommodation, an independent living aid, assistive technology, etc. No one can do it all without some type of support or assistance. Don't focus on what you cannot do. Focus instead on the positive and take control of your life. Determine what you need to live the life you want to live...and let that positive focus rejuvenate you! If you need assistance in developing an independent living plan, or in identifying and acquiring supports for independent living, call Options at either office.

Remember The Ham!

by Kathie Snow

Have you heard the story about the young husband who tried to learn the family secrets of cooking a ham? Shortly after the wedding, the young man's new bride proudly cooked a big ham. Before putting it in the baking dish, she sliced the ends off the ham. Her husband asked—with a genuine desire to understand—why she did that. She was slightly hurt that her hubby seemed to be questioning her culinary skills, and her hurt came out as irritation. She first gave him the look—the one that says, “Don't you know anything?”—and with a tinge of exasperation in her voice, she replied, “That's the way you cook a ham!” The husband scratched his head in bewilderment; he couldn't figure out the need to cut off two perfectly good pieces of ham, but what did he know?

A few months later, the young couple enjoyed a sumptuous Sunday dinner with the bride's family. When the mother-in-law was preparing to cook the ham, she also cut the ends off the ham before putting it in the baking pan, and once again—a little timidly this time—the young husband asked why. Like her daughter before her, she scoffed gently, came close to rolling her eyes, and said, “That's the way you cook a ham!” Again, he wondered about it, but figured his no-nonsense mother-in-law wouldn't do something if she didn't have a good reason for it. And he also decided not to press his luck if he wanted to maintain a harmonious relationship with his in-laws.

More time passed, and one day, the young couple attended a big family event at his wife's grandmother's home.

Husbands, sons, aunts, uncles, wives, daughters, cousins—lots of folks of all ages—filled the kitchen, the den, and other rooms. The young husband happened to be nearby when the grandmother prepared to cook the ham and—you guessed it—she cut off the ends of the very large ham before placing it in her ancient-looking, slightly dented, metal baking pan. He wondered if he should risk questioning the matriarch of the family. But his wife’s grandmother was a spritely, kind, and patient soul, so he took a chance. He edged closer to her, kept his voice close to a whisper (he wanted to make sure his 87-year-old grandmother-in-law could hear him, and hoped no one else would), and respectfully inquired, “Mee-Maw, I noticed you cut off the ends of the ham, and my wife did that, too, and so did her mother. Why is it important to cut the ends off the ham?” With a look of surprise, a little giggle, and a gentle pat on his arm, she replied, “Well, honey, I don’t know about my daughter and granddaughter, but as you can see, the pan isn’t quite long enough—and it’s the biggest pan I have—so if I didn’t cut the ends off, it wouldn’t fit, would it?” Badda-bing, badda-boom.

The young man was curious; he wanted to learn and understand. His wife and mother-in-law, however, were not so curious. They actually didn’t need to cut the ends off their hams, and never—over many years—did they ask Mee-Maw why she did. They just assumed there must be a good reason for doing so, and they mindlessly followed suit.

How many times have we done things the way they’ve always been done, with no idea of the “why”? How many of us lack intellectual curiosity, are afraid to question others, and/or think others must know best, and so we simply “follow the leader”?

On the other hand, how many who have been asked “why” feel irritated or threatened by the question, and believe the one asking the question is rude, arrogant, or ignorant? How many respond, “That’s just the way we do it!” How many, when questioned, stop in their tracks and say, “Gosh, I don’t know—maybe we’d better find out.”

I first heard the Ham Story many years ago (I can’t even remember from whom or where I heard it) and it stuck with me. Having the image of a ham tucked into one corner of my brain has been a helpful reminder to ponder my own practices and habits, as well as those of others.

In the frequently nonsensical domain of Disability World, being intellectually curious, wanting to learn and understand, and trying to get to the bottom of “why things are done the way they are” goes beyond mere interest; it can be of paramount importance. Uncovering a false, irrational, erroneous, or antiquated justification of a particular practice in disability services, special education, etc., might lead to significant, positive change. It might also mean the difference between a life of exclusion, dependence, and hopelessness, or one of inclusion, interdependence, and confidence for a person with a disability. At the same time, and as an example, if a parent’s curiosity—her “inquiring mind”—leads to the recognition that a service/program makes no sense for her child, she may decide to let her good judgment and common sense trump the recommendations of experts and say, “No!”

Do you know why your human service agency, disability organization, public school, or other entity does this or that? Does anyone know? The origins of some practices are so old they have hair on them and may have made sense at one time, but don’t any longer; others are lost to obscurity; and some never made sense to begin with, but they’re still operational.

Putting a young child with a disability who’s not talking into a special, segregated class with other children who may also be delayed in speech doesn’t make any sense. If we want a child to learn to talk, he needs to be surrounded by children who talk! Similarly, why do we congregate students with emotional/mental health diagnoses in the same classroom? Is it any wonder they learn more “inappropriate behaviors” from one another? Why do we do this? Why, in the 21st Century, do we follow the antiquated, institutional practice of congregating

people based on their diagnoses, perhaps in the erroneous belief that they have the same needs. This practice has never been what's best or what makes sense for people on the receiving end of services—we know it results in negative outcomes for people with disabilities—but it has always seemed convenient or “good” for those who provide services!

Again, learning the “why” (and then making changes when the practice doesn't make any sense) can be crucially important. But as the young husband in the Ham Story realized, how we attempt to learn is just as important. Simply blurting out, “Why,” may cause the other person to feel attacked, criticized, etc., which can result in communication breakdown, ruffled feathers, and worse! There are better strategies to use—like following the wisdom of Wendell Johnson, a great linguist, who wrote, “In the meaningful use of language it is a cardinal rule that the terminology of the question determines the terminology of the answer.”

Let's say a mother doesn't understand why teachers do such-and-such regarding her child's education. Instead of asking, “why,” she could ask, “Is this a school policy?” Amazingly, some educators don't know if a practice is part of special ed law, an official school board policy, or simply the whim of a principal, special ed director, etc. The mother could then ask, “May I please have a copy of that written policy?” There are many other ways to ask “why” without saying the word, and without igniting angry responses. Put your thinking cap on, get creative, and come up with more.

The process of sincerely asking respectful questions in order to learn—not to attack, argue, or be disagreeable—has the potential to create positive change. What if, in the example above, we learned that a particular practice was never a written policy, but was simply a procedure instituted 20 years ago, by an administrator who's now dead and buried, and the procedure seemed to make sense at the time for some students, and over time it became unofficial policy for all students. But no one ever cared to wonder about it until that courageous, inquisitive parent came along.

Remember the ham! Pump up your intellectual curiosity; wonder why; and ask sincere questions in a respectful manner. Your actions just might change a practice, a policy, the life of a person with a disability, or even the world. Oink-oink!

A prudent question is one half of wisdom. Francis Bacon

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Disability Etiquette - The Basics

ASK BEFORE YOU HELP.

Just because someone has a disability, don't assume she needs help. If the setting is accessible, people with disabilities can usually get around fine. Adults with disabilities want to be treated as independent people. Offer assistance only if the person appears to need it. And if she does want to help, ask how before you act.

BE SENSITIVE ABOUT PHYSICAL CONTACT.

Some people with disabilities depend on their arms for balance. Grabbing them—even if your intention is to assist—could knock them off balance. Avoid patting a person on the head or touching his wheelchair, scooter or cane. People with disabilities consider their equipment part of their personal space.

THINK BEFORE YOU SPEAK

Always speak directly to the person with a disability, not to his companion, aide or sign language interpreter. Making small talk with a person who had a disability is great; just talk to him as you would with anyone else. Respect his privacy. If you ask about his disability, he may feel like you are treating him as a disability, not as a human being. (However, many people with disabilities are comfortable with children's natural curiosity and do not mind if a child asks them questions.)

DON'T MAKE ASSUMPTIONS.

People with disabilities are the best judge of what they can or cannot do. Don't make decisions for them about participating in any activity. Depending on the situation, it could be a violation of the ADA to exclude people because of a presumption about their limitations.

RESPOND GRACIOUSLY TO REQUESTS.

When people who have a disability ask for an accommodation at your business, it is not a complaint. It shows they feel comfortable enough in your establishment to ask of what they need. And if they get a positive response, they will probably come back again and tell their friends about the good service they received.

Article taken from the 60th Anniversary edition of the United Spinal Association Disability Etiquette Booklet.

To download or order publications of the entire booklet go to www.unitedspinal.org

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