

YOUR CONNECTION

A Disability-Connections Newsletter

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Don't ignore Your Needs!



By Marion Trimble

Why is self-advocacy so under used in our society? I think because it gets confused between aggressiveness and assertiveness. This confusion is just as misunderstood by the business you are dealing with (usually more so) than the individual trying to assert their rights. In the process citizens get pushed down, intimidated and managed into silence.

Not all is lost however because there is a weapon you can use and it is the absolute key to your success. That weapon is knowledge of the guidelines, goals and mission of the business or organization that you feel is treating you unfairly and denying you services, programs and respect. You will almost always find the employee who denies you and disrespect you does not represent the business or organization you are trying to access. Government and state programs have employees who are overwhelmed and burn out runs rampant. If you do not learn to advocate you will most likely be shoved to the side and forgotten. Businesses like wise expect employees to do twice the job for the money with no incentive to build the business through customer relations.

However, there are people who care and they are the business owners and the directors of federal and state programs and non-profits. The first group is invested in profits and the rest are vested in the goals through mission statements they agreed to uphold when they took their positions. The "key" to advocacy success is understanding what is important to them. For business it's pretty easy because customer satisfaction and word of mouth marketing equals profits. You already have power here and employees who drive away customer will not last long.

Non-profits, federal and state programs are a little more difficult and intimidating because you don't have a choice weather you do business with them or not. But, it is worth the fight and you can win. First research the organization and find out exactly what they are supposed to be providing and how. If you do not have a computer to research then go to the public library. They will assist you in your research. Letter writing is always the first step to good advocacy but know not only who to send it to but include what happened, how you felt you were treated and where they had not complied with their goals, mission statement or program guidelines. Think of it as verbal litigation. Keep it factual. Emotional letters smack of victimization. Ask them to respond within a certain date. End with thanking them for their consideration and place the ball firmly in their court by stating what outcome you expect in clear and factual words otherwise it is just a complaint letter.

DIAGNOSIS VS PROGNOSIS

by Marion Trimble



Diagnosis and prognosis are very different concepts based on different criteria. Diagnosis refers to identifying the nature or cause of the condition. Prognosis refers to the future of the condition based on previous case histories. People very often get these terms confused and link them together as a predetermined outcome of their injury or their illness. In other words, the prognosis is the likelihood of the person's future with their condition based on other cases. It is a subjective not an objective conclusion but remember there are no two humans exactly alike physically, mentally, with beliefs or inner strength and ability. So really, how much credibility does that really give a prognosis?

In my long career as a disability advocate I've seen hundreds of people come for help as victims and helplessness because some doctor told them that they would never be able to do this or that and their future would be pretty bleak. Negative prognosis is more dangerous than the diagnosis itself because it fosters an attitude of giving up and giving in.

Why do doctors continue to make these negative diagnosis? I think there are two main reasons. One is that they are trained to look at facts based on previous outcomes and not to give patients "false hope" (how I hate those two words). Another reason is they are medically and scientifically trained and are not invested in transitioning their patients into the world after the hospital or diagnosis. In summary, they do not know the almost unlimited options living with disability. They rely on a rehabilitation facility to do that but the rehabilitation staff is bound by doctor's orders and his prognosis. Our whole medical system is based on specialists who are all under the control of the doctors. But guess who has the control over the doctors? **You** and only **you**. That's right, you have the last say, you decide your own prognosis. You empower yourself by digging out the options, learning what is possible. You are a unique human with your own brand of determination and courage. Only you know what you're capable of. Don't let the medical field take away your self-determination by telling you what you can't do.

The life journey is not about the destination but the process of every day and how you live that process is totally up to you. Disability – Connections is a 501c3 nonprofit that was designed with an "each one teach one" platform because we realized experience is the best teacher but a platform was needed to allow people with disabilities and their families to connect with each other. Explore the resources below or share what you know.

Disability-Connections.com **Facebook Page – Disability-Connections Group – "each one teach on disability news"**





Photo Source: www.universaldesignonline.com

UNIVERSAL DESIGN

By Marion Trimble

Universal design is the design of products and environments that is usable by all people without the need for adaptations. Some people use the term “aging in place”. Owning a home is a huge investment but so many reach that goal only to find later it’s not user-friendly as they age and their physical limitations prevent them from using most of the features in the home they originally loved. In addition the need to remodel usually comes at a time when people are on fixed incomes and cannot afford it. Other events such as accidents or illnesses can make it difficult to remodel as money is flowing out to the medical field while on a drastic time limit.

The answer, of course, is to be proactive in design when you buy your home or remodel your existing one. The best time is while you are still working and can afford it a little at a time.

Some areas to consider are –

- **No step entry.** No one needs to use stairs to get into a universal home or into the home's main rooms.
- **One story living.** Places to eat, use the bathroom and sleep are all located on one level, which is barrier free.
- **Wide doorways** that are 32 to 36 inches wide let wheelchairs pass through. They also make it easy to move big items in and out of the house.
- **Wide hallways.** Hallways should be 36 to 42 inches wide. That way, everyone and everything moves more easily from room to room.
- **Open floor designs.** Everyone feels less cramped. And people in wheelchairs have more space to turn as well as people using walkers.
- **Some universal features that could make it safer as you age or incur a disability are-**
- **Floors and bathtubs** with nonstick slip surfaces help everyone stay on their feet. They’re not just for people who are frail. The same goes for handrails on steps and grab bars in the bathrooms.
- **Thresholds** that are flush with the floor that could make it easy for a wheelchair to get through a doorway as well as walkers.
- **Good lighting** helps people with poor vision. And it helps everyone else see better too.

Lever door handles and rocker light switches are great for people with poor hand strength. But others like them too. Try using these devices when your arms are full of packages. You’ll never go back to knobs or standard switches again.

As a society we are proactive in so many other areas like insurance, retirement savings, yearly wellness checks and we also need to be proactive in keeping our independence and freedom to stay comfortable in our own home



Don't ignore YOUR needs!

By William Stork

Don't let your disability dictate your limitations! You are still in charge of both you and your environment. By adjusting to your disability both emotionally and physically, you'll be able to accept that your disability does not define you or restrict your ability to be comfortable or happy. Study your home and locate where you have the need for grab bars. Having grab bars in calculated locations can assist in balance or transferring. Remember the shower, commode, and an area for stretching or exercise. Getting a bed rail to aid in transferring to bed may help.

Emotionally, it can be tempting to want to avoid people and social situations when you're feeling down but doing so will only make you feel worse. Don't use your disability as an excuse to isolate yourself from friends and family or activities you love. Instead, you should be doing the opposite. Take whatever chances you're given to get out and experience new and exciting things. Hang out with friends, go to social gatherings, visit family, try new hobbies. You'll be much happier if you're doing enjoyable things with people you love. Spending time by yourself is different from isolating yourself. Consider having a weekly date with a close friend or family member. That way, you'll always have a reason to get out and see someone you enjoy. Lastly, you should always try to fit in alone time, but don't spend all your time alone!

