

A Roller Coaster Ride!

Working with people with Hidden/Invisible Disabilities



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Introduction

- Many people with hidden disabilities go undiagnosed and end up marginalized.
- Some people may be unemployed, underemployed or move from job to job.
- While others will develop a dual diagnosis of alcohol and drugs, eating disorders and end up homeless, on welfare or populate our jails and prisons.
- Many people have difficulty getting along with others and authority figures and, as a result, lack friends and support systems.
- Some people if they are lucky will find their way to success.

YOU can make all the difference!

With understanding
and support from
the community
people with these
challenges can get
off the Roller
Coaster Ride or at
least hold on...





Let's Take a Look at Disability

When we think about the word “disability” we may have the following images:

- A person who is deaf
- A person who is blind
- A person who uses a wheelchair or motorize scooter
- Jerry's Kids and the Labor Day Telethon

Disability takes many forms. Statistically, there are approximately 54 million people in the United Stated with a disability today.



Let's Talk Legal!

Disability as defined by Section 504 of 1973 Rehabilitation Act and the 1990 Americans with Disabilities Act:

- A physical or mental impairment that substantially limits one or more life activity.
- A record of such impairment
- Being regarded as a person with a disability even if no limitation exists.



Highlights of the Americans with Disabilities Act:

- A civil rights law that covers employment and higher education.
- The ADA is a federal civil rights statute designed to remove barriers which prevent individuals with disabilities from enjoying the same opportunities available to persons without disabilities.



What is a Major Life Activity?

Anything an average person can do with little or no difficulty. **Major life** activities include, but are not limited to:

- Caring for oneself
- Performing manual tasks
- Walking, seeing, hearing, breathing, learning, working, sitting, standing, lifting, reaching, sleeping and mental/emotional processes such as thinking and interacting with others.



What is a hidden disability?

Essentially, a hidden disability is a disability that cannot be seen. Words to describe what it feels like to have a hidden disability.

- Emotionally lost
- Overwhelm
- Confusion
- A 24 hour a day, 7 day a week, 365 experience
- Exhaustion



Some examples of hidden disabilities:


- Learning Disabilities
- Attention Deficit Disorder (ADD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Chronic Fatigue Syndrome
- Environmental sensitivity
- Psychiatric Disability
- Traumatic Brain Injury (TBI)
- Diabetes
- Lupus
- AIDS
- Cancer
- hypertension

And the list goes on...



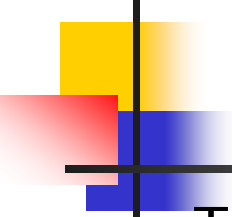
Common Denominators: What do Hidden Disabilities have in common?

- One is unable to “see” the disability.
- There are no “visible” supports to indicate a disability such as canes, wheelchairs, use or sign language used.
- It is a permanent disability that they cope with on a daily basis.
- The disability may be managed through medication or behavior such as in the case of diabetes, asthma, epilepsy or psychiatric disorders.
- It needs to be a documented disability in order to receive reasonable accommodations under the ADA.
- The person is in some kind of physical or emotional pain



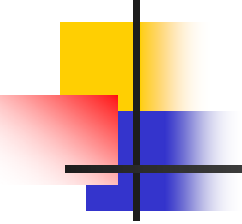
In the case of the following hidden disabilities, there often is an *emotional* component involved.

- Psychiatric Disability
- Learning Disability
- Attention Deficit Disorder (ADD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Traumatic Brain Injury (TBI)
- Diabetes



Daily experiences with a hidden disability is often described as a roller coaster ride:

- There are inconsistencies in behavior or performance levels.
- The person seems fine on one day or with one particular task and not the next.
- There is a lot of stress involved as the person tries to cope on a daily basis.
- The person looks fine on the outside, but feels “out of control” on the inside.
- As a result, the person may appear to be overwhelmed, confused or disorientated on any given day.



**The disability is
unpredictable and
inconsistent and it can also
be “hidden” from the person
with the disability!**



The disability is on the “Inside”

You would not know that the person has a disability unless they disclosed to you or unless you experienced a behavior as in the following events:

- You witness a seizure (epilepsy)
- You see a level of frustration learning a new task (learning disability)
- The person acts unusual or strange (a diabetic who is having a hypoglycemic episode (experiencing low blood sugar))



Challenges for a person with a hidden disability:

- They may not know they have a disability or regard themselves as such.
- They may not have been diagnosed.
- They may not know what they need.
- They may know what they need, but are unable to articulate it.
- They may often feel misunderstood or may feel ignored or feel invalidated
- They may suspect something is wrong, but not know what it is or how to fix it.

The person often feels *emotionally lost or overwhelmed!*



- The person may feel emotionally lost or overwhelmed by information overload.
- Feeling overwhelmed they are unable to convey how they feel and what help they need in order to cope better.
- They may feel like they are drowning and there is no one there to help!
- The person may feel fatigue or in physical pain due to chronic illness.



The person may be in a state of *confusion!*

- They may describe their situation as being in a stupor or a maze and they can't get out!
- They have hit "the invisible brick wall" (Underestimated how long it takes to complete a particular task. They then begin to panic and become agitated.)
- They may not have taken their medication.



Let's talk about the two D's: Documentation and Disclosure

Documentation:

Written documentation that a disability exists is needed in order for reasonable accommodations to be provided.



What is documentation and why is it important?

Documentation is a written statement by a professional that verifies the person has a legitimate disability. Documentation is usually done by a licensed neuropsychologist or a clinical psychologist. A medical doctor would diagnose diabetes, lupus, cancer or other illness, while a psychiatrist would diagnose a psychiatric disability.

Written documentation is important because without it a person with a disability will have no legal standing. The person will not receive financial benefits or social services. In addition, accommodations will likely not be provided.



What happens when a person goes undiagnosed?

- May become marginalized on the fringes of society
- May develop a dual diagnosis (drugs & alcohol) in order to cope
- May be unemployed, underemployed or move from job to job
- May become incarcerated because they are unable to support themselves
- May become homeless, alone and on the street



To disclose or not to disclose?

Reasons people do not disclose and consequences:

- Do not regard themselves as having a disability
- Does not get close to people for fear of personal questions or people finding out.
- Fear of reprisal (discrimination)
- Shame or embarrassment associated with having a disability
- Fear people will not understand and treat them differently or isolate them.
- Stigma associated with having a disability
- If one does not disclose; one does not receive the accommodation(s) and are not covered under the ADA
- Stress of keeping a secret



To disclose or not to disclose?

Reasons to disclose:

- They will probably receive the help they need to function better.
- They will receive accommodations for their disability.
- Revealing a “secret” will lessen their stress level.
- There will be an element of trust developed with coworkers, bosses, friends and others.



Four Things to Remember about Disclosure:

1. It's up to the individual to disclose a disability. You should never insist that a person accept a particular accommodation.
2. The amount of information provided about the disability is up to the individual.
3. If an individual discloses a disability, that information must be maintained confidentially and cannot be disclosed to others.
4. All medical and/or disability-related information is kept in locked files separate from personnel records, with limited access by only selected personnel.



Accommodations

Is any change in the environment or in the way things are customarily done that enable an individual with a disability to enjoy equal opportunities.



Examples of FREE or low cost accommodations:

- A flexible schedule
- Work at home
- Change in work schedule to accommodate energy levels
- Use of a tape recorder
- Small group activities, rather than larger ones
- Provide a meeting agenda to organize information
- Allow the person to have food nearby in the case of diabetes
- Provide written and verbal instructions
- Additional preparation time to complete a task
- Color coding filing system
- Check list system
- Provide information in LARGE print

Invisible Illness

Come Along for the Ride

*Living with invisible
illness is a
roller coaster*



Help a friend hold on!

**National Invisible Chronic
Illness Awareness Week**

www.invisibleillness.com



What you can do to help!

- Believe the person when they disclose a disability!
- Listen and validate what the person is telling you.
- Please do not speak louder or slower when responding.
- Ask HOW you can help, rather than say you don't know how to help.
- Offer to assist with completing forms
- Give both oral and written instructions
- Just show them ONE way to learn for the time being.



What you can do to help!

- Please understand that when the person is frustrated, confused or agitated, it may not be a “teachable” moment.
- Remain calm since your agitation will likely make a challenging situation worse.
- Allow the person with the disability to learn their own way.
- Allow them to show you what they know.
- Ask them to repeat back your instructions.
- Be patient and non-judgmental!
- Help them get diagnosed by making a referral
- If at all possible, help them develop a plan of action



Use the K.I.S.S. Method

Keep It Simple Sweetie