

Working with People with Disabilities

The **Office of State Guardian** (OSG) works with thousands of individuals (referred to as “**wards**”) from across the state of Illinois who require guardianship services.

These individuals are served by the OSG because it has been determined by a court of law that they are ***unable to make “safe or reasonable decisions”*** concerning their own care.

Working with People with Disabilities

Factors that lead to an individual being unable to make safe or reasonable decisions for themselves may be due to any number of disabilities or conditions including (but certainly not limited to):

- disabilities related to aging,
- persistent mental illnesses, and
- developmental disabilities.

Working with People with Disabilities

It should be noted that the existence of a disability is not enough in itself to warrant guardianship.

It is only when a **disability is severe enough to hinder an individual's ability to make choices for themselves** that guardianship may be appropriate.

Working with People with Disabilities

As a volunteer guardian, you will be working with individuals who have some type of disability or condition that has been determined to be severe enough so as to warrant guardianship.

You are not expected to be an expert on all forms of disability.

However, in order to effectively work with wards, you should at least have some knowledge of the types of disabilities you may encounter.

Working with People with Disabilities

Therefore, we have provided this training module to help familiarize you with a few of the most common types of disabilities you may encounter:

- **Developmental Disabilities**
- **Age-related Disabilities**
- **Chronic Mental Illnesses**
- **Traumatic Brain Injuries**

People with Disabilities in Illinois

Before we begin, here are some quick facts about people with disabilities in Illinois that may provide you with a better understanding of some of the challenges our wards face:

- Almost 1 in 5 people in Illinois ages 16 to 64 have some sort of disability*
- 828, 268 Illinoisans ages 16 to 64 have some form of sensory, physical, or mental disability*

(*2007)

People with Disabilities in Illinois

- Just over 1 in 5 Illinoisans ages 16 to 64 living in the community with a disability are considered to be living in poverty. This is about double the rate for non-disabled Illinoisans (about 1 in 10 in poverty)*
- Only 9.4% of non-disabled, adult age, Illinoisans described their health status as “fair or poor” – compared to 38.1% of disabled, adult-age Illinoisans.**

(*2007 and **2006)

People with Disabilities in Illinois

- Almost 27% of disabled, adult-age Illinoisans report being physically inactive as compared to 16.2% of non-disabled Illinoisans.**
- 35.7% of Illinoisans ages 18 to 64 living with a disability describe having an “independent living disability” – meaning their disability hampers their ability to utilize community resources such as getting groceries, riding the bus, or going to the park.***

(**2006 and ***2008)

Developmental Disabilities

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments.

Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime.

Developmental Disabilities

Depending on severity, **developmental disabilities** can affect a person's ability to learn, to communicate, and to make informed decisions regarding their own care.

Developmental disabilities may ultimately affect a person's ability to be financially self-sufficient and to live independently, which may make them appropriate for guardianship.

Developmental Disabilities

In the following slides, we will discuss three common types of developmental disabilities:

- **Cerebral Palsy**
- **Intellectual Disabilities**
- **Autism Spectrum Disorders**

Developmental Disabilities

Cerebral Palsy:

Cerebral Palsy (CP) is a disability of muscle control and coordination caused by brain damage that occurred before birth.

CP can cause limbs to become very rigid and “lock” into place.

Alternately, it can also cause limbs to be very limp and seemingly move out of control.

CP can affect the entire body, one half of the body, or it can just affect certain limbs.

Developmental Disabilities

Cerebral Palsy:

Depending on severity, CP can cause difficulty in an individual's ability to speak, to walk, to hold objects (such as a phone or a pencil), or to care for themselves physically (such as feeding themselves, bathing, etc.)

Being diagnosed with CP does not necessarily mean that a person's ability to think or reason is also impacted.

Developmental Disabilities

Cerebral Palsy:

Communication can be difficult for those with CP.

They may speak quite slowly and have trouble pronouncing words because CP affects their ability to control the muscles in their face and mouth.

Understanding what a person with CP is trying to say can be especially challenging for a new worker or volunteer.

Although it can be frustrating at first, you will find that you will begin to understand the individual more and more the longer you work with them.

Developmental Disabilities

Sometimes, CP can make traditional communication almost impossible for the individual. Fortunately, there are ways people can overcome even this challenge:

- **Eye Rolling** – if unable to speak or use their hands to write or sign, some people communicate by rolling their eyes up (usually meaning “yes”) or down (usually meaning “no”).
- **Switches** – sometimes called “Big Mac” switches, these are big buttons (or a collection of buttons) that the person hits with their hand, leg, or head that triggers a prerecorded message.
- **Dynavoxes** – These are electronic devices that can speak for the individual. Usually, the screen has a series of words or pictures and the individual, using a switch, selects the word they want and then the device says the word.
- **Communication Books** – these are small books that contain pictures of words. These are usually organized by category (eating, emotions, needs, etc.). The person points to what they are trying to say or another person can show them the book and they can then indicate when the person is pointing to the correct picture or word (by rolling their eyes, for instance).



Developmental Disabilities

Intellectual Disabilities:

What is intellectual disability?

Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills.
(Definition from American Association on Developmental Disabilities)

These may be caused by genetic factors, embryonic development, prenatal problems, trauma, organ damage, or environmental influences and unknown causes.

Developmental Disabilities

Intellectual Disabilities:

The severity of the disability is determined by the person's intelligence quotient (IQ) and is divided into the following categories:

- mild (IQ is between 50-70),
- moderate (35-49),
- severe (20-34), and
- profound (below 20).

Developmental Disabilities

Intellectual Disabilities:

Intellectual disabilities manifest differently in every individual, but generally, people will experience difficulties with:

- communication,
- social skills,
- maintaining personal safety,
- interpersonal skills,
- self-care, and
- the ability to handle their own finances.

Developmental Disabilities

Intellectual Disabilities:

Intellectual disabilities do not affect a person's ability to love, to laugh, to create, or to make a positive difference in the world.

When allowed to express themselves and given the space to reach their fullest potential, people with intellectual disabilities can live rich and meaningful lives.

Developmental Disabilities

Autism Spectrum Disorders:

Autism Spectrum Disorders (ASD), also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in:

- thinking,
- feeling,
- language, and
- ability to relate to others.

These disorders range from a severe form, called autistic disorder, to a much milder form, called Asperger syndrome.

Developmental Disabilities

Autism Spectrum Disorders:

Many individuals with ASD:

- avoid eye-contact and physical touch,
- are slower in learning to interpret what others are thinking and feeling (which may make them appear “cold” or “insensitive”), and
- they often have difficulty regulating their emotions or expressing them in a socially acceptable way.

Developmental Disabilities

Autism Spectrum Disorders:

People with ASD may not display feelings of love, sadness, frustration, or affection in a way we understand, but that should never be taken to mean that they do not have those feelings.

It is up to us to try to understand how they express themselves – and that can only be done by spending time with them and keeping an open heart.

Age-Related Disabilities



First, please note that being elderly and having an age-related disability are not the same thing.

Growing older does not mean that developing an age-related disability is a given; most people can live full and rich lives well into their elderly years.

Age-Related Disabilities

A person is characterized as having age-related disabilities when the normal physical changes that occur during the aging process advance to a point where the individual is no longer able to function independently.

In the following slides, we will outline some of the normal changes that can occur as people enter their later years.

We will also look at Dementia and Parkinson's disease, which are not normal symptoms of aging (nor are they exclusive to the elderly), but tend to affect the elderly at greater rates than the general public.

Age-Related Disabilities

- **Physical Changes**

- Aging proceeds at different rates in various parts of the body in the same person.

- In other words, someone might have a healthy heart but poor balance.

- In general, the body of an older person does not function as well as it once did; but barring disease and very stressful situations, it usually continues to function adequately well into old age.

Age-Related Disabilities

- **Physical Changes - Mobility:**

- Changes in joints and decreased bone and muscle mass can result in falls and fractures, misshapen joints, pains, and stiffness.

- Age can also bring a decline in cardiac output, lung volume, and breathing capacity.

- This can cause some older people to tire easily and have limited endurance.

Age-Related Disabilities

- **Physical Changes - Digestion:**

- Digestion slows down and becomes less efficient; reduced production of secretions that aid digestion may account for statements such as,

- “I don’t digest foods as well as I used to.”

- The digestive system is also very sensitive to emotional states; the older person who is depressed or anxious may experience digestive disturbances.

- Diet, lack of exercise, and certain medications can contribute to digestive problems.

Age-Related Disabilities

Sensory Changes - Vision:

Age usually means a decrease in visual sharpness, slower accommodation of the eyes from close range to distance, and loss of peripheral vision.

The older person requires more time to adjust to different light levels and needs more light to see.

Age-Related Disabilities

Sensory Changes - Hearing:

Hearing gradually diminishes, particularly the ability to hear high-pitched sounds (presbycusis).

Consonants become more difficult to hear. Even a slight hearing loss can limit communication and social interaction.

A hearing loss can lead to depression and anxiety in certain people if it becomes severe enough.

Age-Related Disabilities

Sensory Changes - Taste and smell:

Taste sensitivity decreases with age.

The taste receptors that identify sweet and salty stop functioning first.

These changes can affect appetite, causing poor nutritional intake.

Loss of ability to smell occurs with age.

Because two-thirds of taste sensations depend on the ability to smell, decline in the sensory system can further depress an older person's appetite.

Age-Related Disabilities

Sensory Changes - Sensitivity to heat and cold:

Subcutaneous fat (the fat beneath the skin) is an important insulator and it decreases with age. As subcutaneous fat is lost, body heat escapes.

As a result, older people often feel cold when others are comfortable.

In winter, some older people may be the victims of hypothermia, a drop in internal temperature that can be fatal if not treated promptly.

Age-Related Disabilities

Social Changes & Changes to Personal Independence:

Older people face many changes. Retirement can provide an opportunity to pursue personal interests, but it also can mean a loss of a significant life role.

Losses increase with age:

- retirement can bring a fifty percent decrease in income;
- spouses and friends die;
- declining health and mobility cause changes in living arrangements and levels of independence.

Age-Related Disabilities

Social Changes & Changes to Personal Independence:

A person's identity and self-esteem can be threatened by the losses that accompany aging.

Many older people fear dependency - whether physical, financial, emotional, or social.

Throughout their lives, great value has been put on independence and "doing for oneself", so it is difficult for many to seek or accept assistance.

Even when needs are overwhelming, many regard help as charity.

Age-Related Disabilities

Social Changes & Changes to Personal Independence:

Additionally, some older adults can feel as though their “usefulness” has passed.

Some individuals may feel that they are too old to contribute to society or to grow as a person.

These feelings can be exacerbated when they are not encouraged to participate in meaningful activities.

Age-Related Disabilities

Psychological & Emotional Changes:

Most older people are mentally healthy, but certain groups are at high risk for mental health problems.

These include the recently bereaved, the isolated, and the physically and mentally frail older adult.

Mental health is affected by physical conditions, poor nutrition, an overdose or interaction of medications, sensory deficiencies, and multiple social losses.

Signs of depression, dementia, or paranoia are not normal effects of aging despite the fact that they are often portrayed as such in the media and in our culture.

Age-Related Disabilities

Cognitive Changes

Intelligence, memory, and learning ability do not decline with age; limitations are more related to health than age.

An individual's abilities, therefore, should not be underestimated simply because of age.

Most older persons do not have serious memory impairment, but memory does seem to alter with age.

Memory of the past is usually better than of current information. For those older persons who do suffer memory loss, training can help minimize it.

Age-Related Disabilities

- **Abnormal Changes in Elderly Adults - Dementia:**
- Dementia is a word for a group of symptoms caused by disorders that affect the brain.
- *It is not a specific disease*; many different diseases can cause dementia, including Alzheimer's disease and stroke.
- People with dementia may not be able to think well enough to do normal activities, such as getting dressed or eating.

Age-Related Disabilities

- **Abnormal Changes in Elderly Adults - Dementia:**

- They may lose their ability to solve problems or control their emotions.
- Their personalities may change.
- They may become agitated or see things that are not there.

Age-Related Disabilities

- **Abnormal Changes in Elderly Adults - Dementia:**

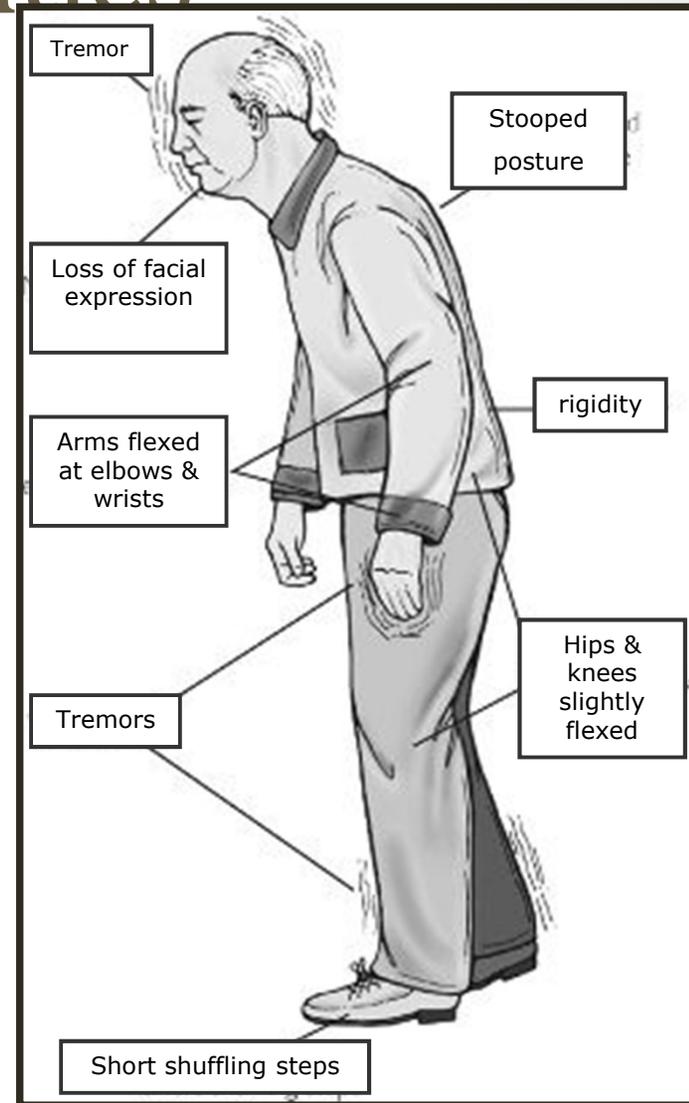
- Because of the complicated symptoms that can occur when someone is experiencing dementia, it is common for those that work with those individuals to feel frustrated or powerless.

- Behaviors often associated with dementia, like wandering or asking questions repeatedly, are uncontrollable behaviors for people with dementia.

- Knowing this, people who interact with individuals with dementia should understand there is nothing they can do to “control” the situation other than to be patient and understanding.

Age-Related Disabilities

Parkinson's Disease (PD) belongs to a group of conditions called motor system disorders, which are the result of the loss of dopamine-producing brain cells.



Age-Related Disabilities

Parkinson's Disease (PD)

The four primary symptoms of PD are:

- rigidity (stiffness of the limbs and trunk),
- bradykinesia (slowness of movement),
- postural instability (impaired balance, and coordination).

As these symptoms become more pronounced, patients may have difficulty walking, talking, or completing other simple tasks.

Age-Related Disabilities

Parkinson's Disease (PD)

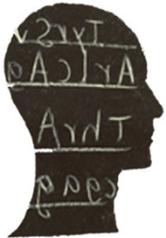
As these symptoms become more pronounced, patients may have difficulty walking, talking, or completing other simple tasks.

Other symptoms may include:

- depression and other emotional changes;
- difficulty in swallowing, chewing, and speaking;
- urinary problems or constipation;
- skin problems; and
- sleep disruptions.

PD usually affects people over the age of 50, but can affect those much younger as well.

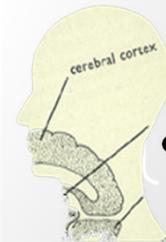
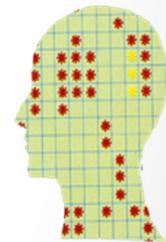
Mental Illness



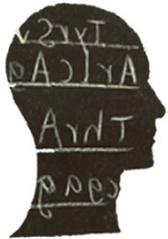
Mental illness is a term used for a group of disorders that can cause severe and persistent disturbances in a person's thinking, feeling, and relationships with others.

The result is substantially diminished capacity for coping with the ordinary demands of life.

Mental illnesses can affect persons of any age, race, religion, or income.



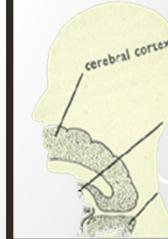
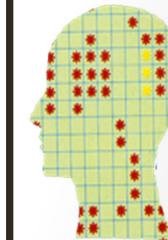
Mental Illness



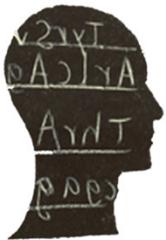
Mental illnesses are not the result of personal weakness, lack of character or poor upbringing.

Mental illnesses are treatable.

Most people diagnosed with a serious mental illness can experience relief from their symptoms by actively participating in an individual treatment plan.

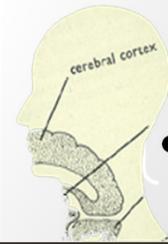
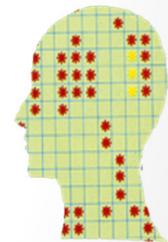


Mental Illness



In the following slides, we will briefly describe a few of the most common types of mental illness that can be found among our wards.

- **Schizophrenia**
- **Bipolar disorder**
- **Schizoaffective disorder**
- **Major Depression**
- **Dual diagnosis**



Mental Illness

- **Before we begin looking at specific mental illnesses, here are some facts about mental illnesses in general:**
 - Mental illnesses are serious medical illnesses. They cannot be overcome through "will power" and are not related to a person's "character" or intelligence.
 - Mental illness falls along a continuum of severity.
 - 1 in 17 Americans live with a serious mental illness.

Mental Illness

- **Facts about Mental Illness:**
- One in four adults - approximately 57.7 million Americans - experience a mental health disorder in a given year
- The World Health Organization has reported that four of the 10 leading causes of disability in the US and other developed countries are mental disorders.

Mental Illness

- **Facts about Mental Illness:**

- Mental illness usually strikes individuals in the prime of their lives, often during adolescence and young adulthood.

All ages are susceptible, but the young and the old are especially vulnerable.

Mental Illness

- **Facts about Mental Illness:**

Without treatment, the consequences of mental illness are staggering:

- unnecessary disability,
- unemployment,
- substance abuse,
- homelessness,
- inappropriate incarceration,
- suicide, and
- wasted lives.

Mental Illness

- **Facts about Mental Illness:**
 - The best treatments for serious mental illnesses today are highly effective.
 - Between 70 and 90 percent of individuals have significant reduction of symptoms and improved quality of life with treatment.

Mental Illness

- **Schizophrenia:**

- Schizophrenia profoundly distorts an individual's sense of external and internal reality.

- Schizophrenia typically appears in a person's late teens or early 20s – right when they are on the brink of discovering their possibilities as adults.

- Schizophrenia can forever change the course of people's lives and the lives of their families and loved ones.

Mental Illness

- **Schizophrenia Symptoms include:**

- *hallucinations* - sensing things that are not there, such as seeing bugs that are not there or hearing voices.
- *delusions* - believing in things that are not real or true, such as the belief that the government is trying to kill them.
- *disorganized talking* - rambling, switching topics suddenly, making up words
- *flat affect* - no facial expressions, monotone speaking
- *disorganized behavior* - “strange” behaviors such as constantly clearing their throat, bobbing their head, or standing in odd positions.

Mental Illness

- **Bipolar Disorder:**

- Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in mood, energy, activity levels, and the ability to carry out day-to-day tasks.

- Symptoms of bipolar disorder are severe; they are different from the normal ups and downs that everyone goes through from time to time.

- Bipolar disorder symptoms can result in damaged relationships, poor job or school performance, and even suicide.

- But bipolar disorder can be treated, and people with this illness can lead full and productive lives.

Mental Illness

- **Schizoaffective Disorder:**

- Schizoaffective disorder is one of the more common, chronic, and disabling mental illnesses.

- As the name implies, it is characterized by a combination of symptoms of schizophrenia and an affective (mood) disorder.

- Schizoaffective disorder may account for 1/4 or even 1/3 of all persons with schizophrenia.

- To diagnose schizoaffective disorder, a person needs to have primary symptoms of schizophrenia along with a period of time when he or she also has symptoms of major depression or a manic episode.

Mental Illness

- **Major Depression:**

- Unlike normal emotional experiences of sadness, loss or passing mood states, major depression is persistent and can significantly interfere with an individual's thoughts, behavior, mood, activity and physical health.

- Among all medical illnesses, major depression is the leading cause of disability in the United States and many other developed countries.

Mental Illness

- **Dual Diagnosis:**

- When we speak of dual diagnosis, we are actually speaking of the type of services individuals receive – not an actual diagnosis (such as “biopolar disorder”).
- Dual diagnosis services are treatments for people who suffer from co-occurring disorders - mental illness and substance abuse.
- For many individuals dealing with severe mental health disorders, abusing drugs and alcohol can be a way of self-medicating.

Mental Illness

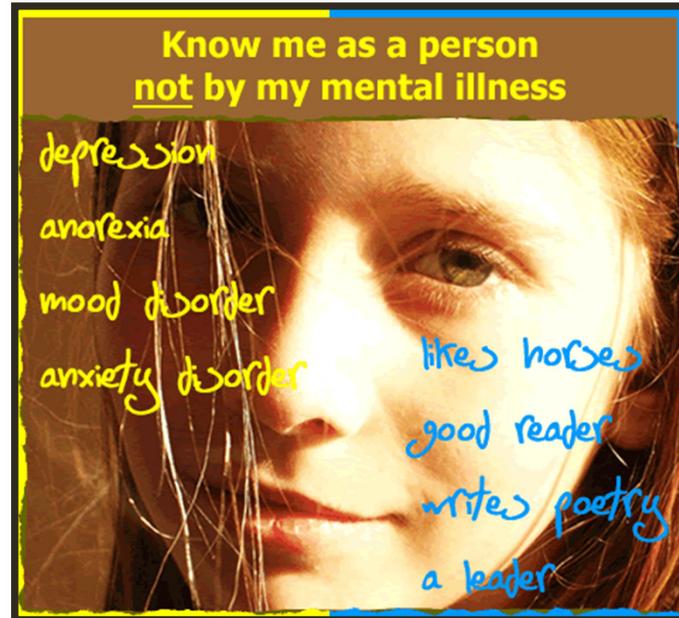
- **Dual Diagnosis:**

- As a group, individuals with severe mental illnesses are at much greater risk for developing substance abuse problems.

- In fact, people with schizophrenia are 4x as likely as the general population to develop substance abuse problems.

- It is estimated that 61% of individuals with a bipolar disorder also develop a substance abuse problem.

Mental Illness



- Many of the barriers people with mental illnesses face (finding housing, employment, social inclusion) are caused by the stigma associated with having a mental illness.
- Much of this is caused by a lack of knowledge concerning mental illnesses by the general public.

Mental Illness

- There are many medications, therapies, and treatment programs that aim to help those with mental illnesses put their lives together.
- What is often missing for these individuals is the feeling that they are accepted, that they have something to contribute, and that they have a real place in society.
- As volunteer guardians, you can help do this by simply being a friend and allowing people to have moments in their lives that do not revolve around their having an mental illness.

Traumatic Brain Injuries

Nationwide, an estimated 500,000 people sustain Traumatic Brain Injury (TBI) every year.

TBI is caused by a blow to the head which results in a complex set of impairments affecting any one or more of the following:

- memory,
- ability to concentrate,
- control of emotions and behavior,
- caring for oneself,
- balancing and walking,
- seeing,
- hearing and
- speaking, among others.

Traumatic Brain Injuries

Mild TBI can be personally devastating and more serious brain injury often results in the need for life-long medical or nursing home care.

Survivors of brain injury can be faced with lingering difficulties with:

- memory,
- judgment,
- ability to adapt to changes in the world around them,
- ability to solve novel problems and
- ability to interact socially.

Traumatic Brain Injuries

Survivors of traumatic brain injury may also have problems of:

- muscle strength,
- physical coordination,
- vision,
- hearing, and/or
- speech.

These persisting difficulties can interfere with an individual's ability to live independently, work, go to school and form relationships with others.

Traumatic Brain Injuries

Persons with TBI are part of a growing population of brain injury survivors that did not exist 20 years ago.

Due to improvements in medical treatment, many people who would have died from their injuries in years past now have a life expectancy close to that of non-brain injured people.

Because of this, the need for individuals to “step up” and help work with persons with TBI has increased as well.

Working with People with Disabilities

Conclusion (rewrite??)

The **Office of State Guardian** (OSG) works with thousands of individuals (referred to as “**wards**”) from across the state of Illinois who require guardianship services.

These individuals are served by the OSG because it has been determined by a court of law that they are *unable to make “safe or reasonable decisions”*

concerning their own care.

Thank you!

Working with People with Disabilities

Acknowledgements & Links:

In addition to crediting the sources used in this training module, this section has been included to give you further resources should you want to learn more about what you've read.

- Facts on slides #6-8 from: the [Annual Disability Statistics Compendium](#) (available for free from their website) and the [U.S. Census Bureau](#).
- Photo on slide #23 from: [The Queens Health Coalition](#)
- Image on slide #40 from: [The Free Medical Dictionary](#).
- Information & various text for slides #12-57 from: [The National Institute of Mental Health](#), the [CDC](#), the [National Alliance on Mental Illness \(NAMI\)](#), and the book "[Caring for the Mind](#)" by Dianne Hales & Robert Hales, M.D.
- Image on slide #58 from: the [Washington County Mental Health Authority](#)
- Text on slides #60-63 from: the [Volunteer Guardianship One-on-One, Inc.](#) volunteer manual (available for free from their website).