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# ADVOCATE GUIDE

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Illinois Imagines Project  
December 2018



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# Acknowledgments

Thanks to the Illinois Imagines Team members, who worked creatively and collaboratively to envision and create a new way to serve people with disabilities who experience violence. The Illinois Imagines team includes:

- Self Advocates and The Self-Advocacy Alliance
- Illinois Department of Human Services, Division of Family and Community Services
- Illinois Department of Human Services, Division of Developmental Disabilities
- Illinois Department of Human Services, Division of Mental Health
- Illinois Department of Human Services, Division of Rehabilitation Services
- Illinois Coalition Against Sexual Assault
- Illinois Criminal Justice Information Authority
- Illinois Family Violence Coordinating Council
- Illinois Network of Centers for Independent Living
- Blue Tower Solutions, Inc.

We are grateful to the survivors with disabilities who have shared their experiences and taught us how best to support their healing.

To the rape crisis center advocates who work tirelessly navigating the medical, criminal justice and other systems, we are thankful for your commitment to walking side by side with survivors.

Thank you to the Advocate Guide committee - Sean Black, Mary Hettel, Alice Kieft, Shirley Paceley, Mary Ratliff, Linda Sandman, Teresa Tudor and Susy Woods. Thank you to Carol Corgan and Sean Black for pulling together materials developed by the team.

For more information on Illinois Imagines please visit [www.illinoisimagines.org](http://www.illinoisimagines.org)

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# Introduction

This guide is intended to support counselors in working with survivors with intellectual disabilities and/or autism and others who may have difficulty with abstract language, learning and social interactions. This guide has eight sections:

- 1. Overview** – Foundation information and guidance to assist advocates in supporting survivors with disabilities..
- 2. Communication** – Information to better understand different communication styles and methods to engage clients with different communication styles.
- 3. Guardianship** – Resources to understand guardianship and work with guardians.
- 4. Navigating the Medical System** – Tools and information to assist with supporting survivors with disabilities through the medical process.
- 5. Navigating the Justice System** – Tools and information to assist with supporting survivors with disabilities through civil and criminal justice processes.
- 6. Resources** – Resources to understand and work with survivors.

## **This Guide will help advocates:**

1. Increase their comfort and confidence when working with survivors with disabilities.
2. Understand the barriers that survivors with disabilities may experience when accessing systems' services.
3. Learn strategies for navigating key systems with survivors with disabilities.

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**“Advocates are powerful people. We do many things and fill many roles for survivors. We are the comforting presence in times of crisis, fierce guardians for people/s rights, guides through the aftermath of violence and agents of transformation in our communities.”**

**Strengthening our Practice,  
National Sexual Assault Coalition Sharing Project.**

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# Section 1: Overview

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# SECTION 1: OVERVIEW

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## Key to the Guide

Throughout the guide, you will find a variety of graphic text boxes. These boxes, which can be identified by their graphic, represent different items that can help you in your work to improve services.

### Give Us the Words

As an advocate, you may be in a position to educate allies in the medical and criminal justice systems who may not understand the strengths, abilities and contributions of people with disabilities. They may be influenced by myths or focused upon what someone may not be able to do. Throughout this Guide, sample responses are provided to help you educate and change attitudes about survivors with disabilities.

### Think About It

Throughout this Guide, readers will be encouraged to think about the information presented and its implications for practice. These can also be used as a conversation starter in staff meetings or trainings.



### Problem-Solving

As counselors, you often encounter situations where a number of possible options could help resolve the matter. We have used a Problem-Solving tool throughout this Guide to aid you in thinking through some of those options.



### Resource

Throughout this guide, readers will find links to other resources which will provide new or additional information.



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**“A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.”**

**–Christopher Reeve**

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## Overview

According to the 2016 Bureau of Justice Statistics, people with disabilities experience sexual assault at rates three times higher than those without disabilities. Additionally, VERA

Institute noted that “People with disabilities experience domestic and sexual violence at alarming rates. Yet they are less likely to receive services, supports, and justice that their counterparts without disabilities receive.” Forging New Collaborations, A Guide for Rape Crisis, Domestic Violence, and Disability Organizations, VERA Institute on Justice, April 2011

The occurrence of sexual violence may be more prevalent among people with disabilities because they are often placed in positions in which others have power over them. This power imbalance may cause perpetrators to target people with disabilities and may make it more difficult for people with disabilities to access and receive services after an assault. Additionally, family members, guardians or caregivers may influence the survivors next steps after experiencing a sexual assault. Even when reported, people with disabilities may be denied access to the criminal justice system because they are not seen as viable or credible witnesses.

One way to remedy these problems is to learn more about how to make services more accessible to survivors with disabilities. A first step is to better understand the experiences of people with disabilities and the barriers they may face when accessing the medical and criminal justice systems and rape crisis services. This can best be done by talking with the experts, i.e. people with disabilities. Next, strategize ways to educate these systems and remove barriers (attitudinal, communication, physical).

As advocates and providers of services and support, perhaps our greatest responsibility is to listen to the words of people with disabilities whose lives are affected by our actions. Including people with disabilities in setting policy and rules which affect their access to information and opportunities for full inclusion in a safe and meaningful life is essential to our work in supporting survivors of sexual violence.

### Think About It

If you believe that people with disabilities are less likely to receive support and justice, how will that impact your work?



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When asked what they want everyone to know about them and their sexuality, people with disabilities made these statements.

- I am a human being, just like everyone else.
- I am a sexual being, just like everyone else.
- I am not a child, I am an adult.
- My sexuality is a human right, not a legal one.
- I have the right to information, community participation, private sexual expression, boundaries in personal care and relationships, and a full life.

We must also be willing to look at our own values and assumptions about human sexuality and not place judgments on others just because they may look, think, or sound a little different than we do. Once we have heard the voices of those with disabilities and examined our own values, we are prepared to address the barriers that prevent people with disabilities from accessing systems responding to them after an assault.

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# Value Statements

Illinois Imagines has developed some value statements to guide advocates in their work with survivors who learn and communicate differently than many people who seek counseling. The value statements consider the history of people with disabilities and effective approaches related to equality, access, and inclusion.

This toolkit was written based on the following beliefs and values.

1. All people can learn. When strategies are used that promote access to services for survivors with disabilities, all survivors benefit.
2. All people can communicate.
3. People with disabilities should have equal and quality access to rape crisis center services.
4. All advocates have the capacity to work effectively with survivors who have disabilities.
5. Healing can take many forms and is a person-centered process.
6. Like other survivors, people with disabilities benefit from knowing: You believe them; you are sorry this happened to them, and they are not alone; the violence was not their fault; they are brave to tell what happened; there is hope for healing and that they matter.
7. Many people with disabilities experience multiple forms of trauma over a long period of their lives, resulting in complex trauma. Recovery services need to consider the complexities of the survivor's history and life.
8. Historical trauma is common in the lives of people with disabilities due to the history of oppression, segregation, marginalization, discrimination, mass murders, involuntary sterilizations and more. In some situations, this historical trauma can be addressed along with healing from sexual violence.
9. People with disabilities are part of a minority group, and society needs to change its response and treat people with disabilities as citizens with equal value and equal rights.
10. Each person with a disability can exercise choice and drive their own healing process, with appropriate support.

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# Serving People with Disabilities

## Introduction

The primary goals of intervention with all survivors of sexual violence and trauma are re-empowerment and re-connection. This is true regardless of ability.

Sexual violence takes away a survivor's sense of control and connection to themselves, others, and the world around them. Helping survivors regain a sense of control and re-connect in a positive way is central to recovery. This is done through focusing on each survivor's strengths, providing information, exploring options and resources, supporting the choices the survivor makes and empowering the survivor to help plan their own response and recovery.

## Worker Preparation

People with disabilities have the same needs as survivors without disabilities. They need to be believed, supported, and validated. They need information about their rights and options, and they need to feel safe and empowered. When responding to a person with disabilities, the rape crisis worker needs to:

- become aware of the level of the survivor's knowledge and experience and strive to increase that knowledge;
- inquire respectfully about the particular needs of a person with a disability;
- view the person with a disability holistically and provide victim-centered services;
- acknowledge and address attitudinal barriers in the systems accessed by the survivor; and
- respond positively and creatively to resolve barriers to service delivery (e.g., transportation, communication).

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## People First

**This concept has two primary tenets:**

**“Nothing about us without us”**– This tenet states the obvious, though often overlooked, belief that no decisions about people with disabilities should be made without their input and participation. If we are changing policy or developing service models for people with disabilities, those people must be included in every meeting, as equal members, from the first to the last. They are the experts. Without them, we are missing the most important voice.

**People first language** – The language of disability (as with language used to refer to race, ethnicity and sexual orientation and identity) is continually evolving. Some terms that were once in common use (e.g., retarded) have been or are gradually being replaced by terms that: a) more accurately describe the disability and; b) are positive rather than disparaging. Changes in language occur gradually and the process of replacing one term with another takes time, so continuous self-education is needed to remain current on best practice terminology. See page ## for current terminology.

**Note:** Items that advocates work with may not include people-first language but advocates need to work to educate allies on the importance of people-first language.

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## Recognize and Remove Barriers

People with disabilities often face specific barriers when seeking help.

**Credibility** – People with disabilities are often deemed less credible than others, including medical and law enforcement personnel. It is paramount that the rape crisis worker assures the client that they are believed. By the time the survivor connects with the rape crisis center, they may have already had some negative experiences with the service system. Make it clear that the survivor did the right thing by reaching out for help. Be clear about what you can and cannot do for the survivor.

**Lack of Information** – Another barrier that people with disabilities often face is not having had much education about sex, their bodies or relationships. They may not have the vocabulary that they need to describe what has happened to them. This can make disclosure difficult, particularly with law enforcement and medical personnel who need more specific information. The lack of education might also mean they don't fully understand what has happened. They may need confirmation that what happened to them was wrong, that it was something that should not have happened, and that their thoughts and feelings about the situation are normal and understandable.

**Transportation** – Transportation to and from the hospital, court or the rape crisis center may also be an issue. If the survivor doesn't have their own transportation, explore as many other options with the survivor as possible (e.g. taxi, bus, a friend, an ambulance.) Ask the disability service agency to assist with transportation needs.

**Location** – One adaptation may be the location where the services are provided. As mentioned previously, advocacy sessions may need to be held at the disability service agency the survivor frequents or another site that is accessible and comfortable to the survivor.

## Adapt Communication

Advocates may need to adapt their communication style to meet the needs of the survivor. For example, some individuals do not communicate verbally. Instead, they communicate via pictures, sign language or communication boards (a communication board contains letters or words that the individual points to, spelling out words or forming sentences). Illinois Imagines has produced a Communication guide (page ##) to assist with the process. If a different communication style requires more time, the advocate needs to set aside more time to meet with the client. Consultation with the person and their disability service support person/agency can be helpful with adaptive communication.



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## Initial Contact with Survivors

People with disabilities who face sexual violence need and deserve a survivor-centered response that respects their unique person and empowers them in their healing. Like all survivors of sexual violence, survivors with disabilities need to be believed and supported. The advocate should affirm:

- **what happened to them is not their fault;**
- **it is okay to talk about what happened;**
- **they are not alone; and**
- **others can help.**

Sexual violence is often not reported by the person with the disability, especially if the person has a developmental disability. The individual may not have the language or cognitive ability to do so. The survivor may be dependent on or fearful of a caregiver who is responsible for the abuse. Also, the victim may have experience sexual violence previously and may not realize that it is not typical or that it is a crime.

As with other clients you serve, confidentiality is essential. The person with a disability may not be aware that someone is calling your agency about them, and may not have consented for them to do so. Ask the worker if the person with a disability knows and understands why your agency is being contacted.

Inquire whether the person with a disability has a guardian. If so, you need to know Illinois law and whether you need to contact that person or have the worker do so in order to provide services. If the survivor is their own guardian, get specific written consent to release information to workers or family members. Please consult Section III of this manual for more information on guardians.

Find out what the person's support system is. If the person with the disability agrees, it may be beneficial if you work as a team with the other support system who knows the survivor well.



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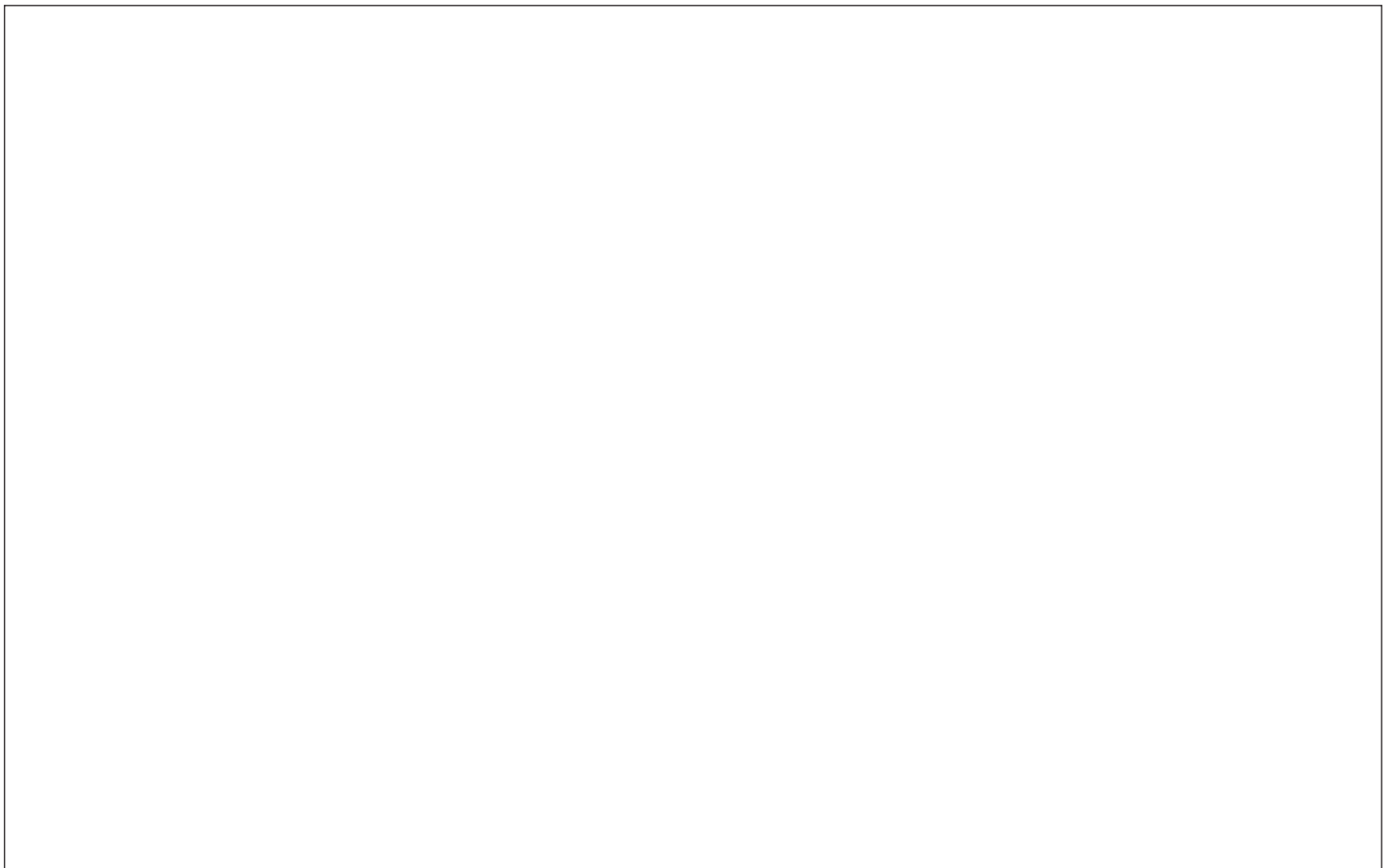
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## Intake and Service Planning

The principles of disability humility should be employed by the worker during intake. Do not make assumptions. Inquire about any disability that may affect service planning and service delivery. The center's intake paperwork should have a place on it for a survivor to indicate what, if any, accommodations would make things easier to receive services.

Not all people with disabilities will be comfortable disclosing that they have a disability. Often, disclosing can lead to a loss of services or a difference in the way the person is treated. While that may not be the case in a rape crisis center, it is important to understand why the person may be reluctant to ask for accommodations. Assure the survivor that having a disability will not negatively affect the kind of help they receive. Rather, it will help rape crisis workers meet the survivor's needs.

When working with a person with a disability, the advocacy service plan should be approached in the same survivor-centered way as a service plan for a survivor without a disability. As with any other survivor, people with disabilities should play a primary role in determining their needs and goals in the advocacy plan.



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## Outreach and Collaboration

Rape crisis centers can also address barriers by conducting outreach to disability service agencies and people with disabilities in a variety of settings. The outreach message should emphasize:

- We know people with disabilities experience sexual violence.
- We are prepared to support you, help you access the medical and legal systems and begin to heal from trauma.

It is also useful to adopt policy about how the agency will serve people with disabilities.

**Connections:** Make connections with agencies or groups serving people with disabilities in your community. These agencies may include:

- Centers for Independent Living
- Agencies Serving Adults with Intellectual and Developmental Disabilities
- National Alliance for the Mentally Ill Support Groups
- Autism Support Groups
- Parent Advocacy Groups
- Self-Advocacy Groups
- Special Olympics

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**Ways to Connect:** There are numerous ways to connect with people with disabilities in your community. Actions your department can take include:

- Set up a meet and greet with entities serving people with disabilities.
- Serve on Human Rights Committee, every agency that works with people with disabilities has a committee that reviews any restrictions that may impinge someone's human rights.
- Serve on the Board of Directors of an agency that serves people with disabilities.
- Meet with autism support groups.
- Work with Psycho-Social Rehabilitation Programs to learn from and educate participants on the best way to interact with law enforcement.
- When working with schools, make sure you are also working with students with disabilities. They may be in separate classrooms or buildings.
- Participate in diversity group events in the community, such as disability expos, etc.
- Connect with your local housing authority about meeting people with disabilities in supportive housing.

Once you have established relationships with community agencies consider a Memorandum of Understanding to further promote community partnerships.

For more information on collaboration, turn to page ##.

### Resource

People with disabilities are three times more likely to experience violent victimization than people without disabilities, and the rates are even higher for women and those with intellectual, psychiatric, or multiple disabilities. Despite these alarming rates of violence, survivors with disabilities are often excluded from the national infrastructure that exists to prevent and respond to this violence.”

**“How Safe are Americans with Disabilities” April 2017 - Nancy Smith, Sandra Harrell and Amy Judy, Center of Victimization and Safety.**



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## Context in Advocacy

Advocacy does not happen in a vacuum. For advocacy to be effective, advocates must have some understanding of the survivor's life. See "Day in their Life of a Survivor" activity on pages 28-30 of this section.

The following experiences or situations are common for people with intellectual or developmental disabilities:

### **Culture of compliance**

Often, caring parents, teachers, staff and others have trained people with disabilities to be compliant. They learn to follow what others tell them to do and not make their own decisions or assert their own wishes or opinions. Of course, this is one of the reasons they experience domestic and sexual violence at a greater rate than others. Too many individuals with intellectual and developmental disabilities have never been encouraged to think for themselves and make decisions about what they want and what they don't want.

It is important for advocates to understand that many people with intellectual or developmental disabilities have had few opportunities to learn about healthy sexuality, healthy relationships and sexual violence. Parents, caregivers, staff, teachers and others may have not seen the importance of this type of education or may have been fearful that teaching people with intellectual or developmental disabilities about sexuality may lead to interest in sexual activity.

### **Think About**

What impact can wanting to please others have on advocacy? How can you respond if you think the survivor is saying what you or others want to hear?



Daily life is not risk free, but compliance and restriction is not the answer.

### **Moving from Over-compliance to Empowerment**

Over-compliance is a challenge for advocates who understand power dynamics and use a survivor-centered approach. Supporting someone to move from over-compliance to self-direction is key to effective advocacy. Advocates who have worked with survivors with disabilities report that this can be a very long process or can happen quickly. As with everything else, it depends on the individual survivor, their support system and the advocates guidance and support.

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When you observe someone who is very careful about:

- their response;
- your reaction to their responses;
- and/or looks to parents or staff before and while responding,

Then you are probably working with someone who is over-compliant.

Here are three strategies that are helpful in letting the survivor know they can speak their truth and to make their own decisions.

1. Intentionally provide the survivor with lots of choices: where they sit; if they want a drink; what activity to do; the time, date, location of the sessions; what makes them comfortable/uncomfortable etc.
2. Engage with the survivor explicitly about their right to be safe; right to make choices; power dynamics, boundaries in sharing their story, and empowering self-statements.
3. If the survivor asks you for advice, ask the survivor: “What do you think?” or “What have you tried?” The key to helping the survivor gain self-confidence is for you to pay attention, be patient, be intentional, and celebrate successes.



### Think About

If a survivor is used to others making decisions for them, what impact might this have on service planning?

These strategies can help survivors to increase their own power and control. It is important to note that information received from others may be influenced by the survivor’s history of over-compliance. For example, the caregiver or staff may assume the survivor will say what the caregiver or staff want them to say. As the survivor feels more empowered, they will be more likely to report their own feelings and perspectives.

### Structured programming/activities

Routine is important for many people with intellectual disabilities and/or autism. Many disability programs or activities are structured, repetitive and consistent. Disruption in routine may be upsetting or produce anxiety. Be aware that if a survivor is upset when meeting with you, it may be related to a change in routine.

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### **Few choices**

A person with a disability may not be allowed to go places alone or do things that they want to do unless approved by someone else. They may not own something of their own; be able to make purchases without consent, have to ask permission to use the phone; be told when lights go out, not be allowed to take food from the refrigerator or have snacks from the pantry. Having to ask permission from others for the simplest of activities, rather than being treated and respected as an adult, is commonplace for many adults with intellectual or developmental disabilities. Using a survivor-driven approach may be more difficult and take more time. Provide support as necessary without “doing for.”

### **Limited opportunities for relationships**

The world for an individual with an intellectual disability and/or autism may be relatively small. Their social interactions may be limited to family members, paid staff, medical providers and other people with disabilities. They may not be allowed to date or even see people outside of structured programming. Information about healthy relationships, boundaries and sexuality may need to be addressed as a part of advocacy, due to limited knowledge and experience.

### **Limited Social experiences**

Similar to or as a result of their small circle of relationships, many people with intellectual or developmental disabilities may not have experienced many of the things that those without disabilities have experienced. Visiting another city, driving, shopping, attending concerts or sporting events may not be activities that the survivor with a disability has experienced. Knowing the individual’s life experiences can help with various aspects of advocacy, such as, building rapport, and developing an advocacy plan. Additionally, this information can be used to enhance understanding of abstract concepts. For example, if someone tells you how they make key chains at work, you may later use this information to explain a concept regarding advocacy.

### **Living Situation**

Some people with disabilities live independently in the community and others may live in a group home or facility. Learn about the survivor’s current living situation. Is safety an ongoing concern? Does the perpetrator have access to the survivor? If a change in living situation is needed to promote safety, what community partners or resources can help make this happen? Knowing the survivor’s living situation will assist in safety planning efforts and in understanding potential risks and triggers.

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### Little “t’s”

People with disabilities may have experienced a lifetime of “little traumas,” in addition to the violence that brought them in for services. The little “t’s” can accumulate over time and create complex trauma. Little “t’s” may include being segregated, bullied, excluded from social events, being called names on a daily basis and enduring stares from strangers.

Advocates may want to explore with the survivor other traumatic events, in addition to the sexual violence in order to understand the full spectrum of advocacy needs, as well as possible trauma triggers. Listen carefully to the survivor’s story without making assumptions about what was most harmful.

#### Think About

What implications might a history of little “t’s” have on the experience of violence? On advocacy needs?



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## Key Concepts

Below are key concepts Illinois Imagines focuses on in improving services to people with disabilities.

### Check Your Assumptions

We all have assumptions. Everything you have heard and experienced about people with disabilities up to this point contributes to your assumptions about people with disabilities and your ability to work with them. The assumption can be about your capacity and/or the person's capacity. You may assume that you don't know how to work with the person and/or assume that the survivor with an intellectual disability can't benefit from advocacy.

It is critically important to know what assumptions you have and the impact of those assumptions. Check with yourself. Assess your assumptions, beliefs and biases about working with a survivor who communicates with movement or pictures.

Assumptions may result from a lack of experience or from one experience with a person which is then generalized to all similar people. Assumptions can cause harm to people if they lead to a survivor not being able to access advocacy services. Assumptions can limit a survivor's potential to benefit from services.

Feel free to discuss your assumptions with co-workers, peers, and/or your supervisor. If your assumption stops you from working with a person, ask yourself: "What would it take to change my assumption?"

### Culture of compliance:

A culture of compliance is one in which people with disabilities are taught to always do what they are told, no matter who tells them and across settings. Compliant behavior is repeatedly reinforced and rewarded and becomes an expectation of the system and culture.



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## Disability Diagnosis

When working with a person who has been diagnosed as having a disability, advocates may notice a tendency for others in the survivor's support network, such as staff from the provider agency or family members, to over-attribute the survivor's behavior to the disability diagnosis. This can lead to misunderstandings about the survivor's ability to work with the medical and criminal justice community. This pattern has been called "diagnostic overshadowing."

**Example 1:** Tayla, age 25, who has been diagnosed with an intellectual disability, may be more withdrawn after an advocacy encounter. Her caregiver may believe Tayla is overwhelmed and confused because of her disability, rather than recognizing her behavior as a response to trauma.

**Example 2:** Sarah, age 12, was diagnosed with autism and had limited verbal skills. She wore a helmet to protect her when she banged her head. She had begun to hit herself more frequently and refused to eat. She had been hospitalized on a psychiatric unit because of her behavior, without improvement. The belief was that Sarah's behavior was a result of her autism. However, it was then discovered that Sarah had an infected molar and it could be life-threatening. Once the pain from her medical condition was addressed, Sarah became calm. The helmet was no longer needed.

It is important for advocates to see past the known disability, look at the whole person and be aware that information received from others may reflect incorrect assumptions.

## Disability Humility

Disability humility is a survivor-centered approach which equalizes power between the advocate and the survivor. This approach reinforces the fact that the survivor is the expert about what happened to them, how they best learn, what they need to feel better, and what makes them most comfortable. Disability humility requires the advocate to be open, respectful, creative and ready to learn.

As an advocate, **YOU DO NOT HAVE TO BE AN EXPERT ON EVERY KIND OF DISABILITY.** The disability is not the most useful or interesting piece of information about the person. Healing is supported by focusing on the whole person. **See "Disability Humility" handout page 8-2.**

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## Intellectual Capacity

Everyone has the capacity to heal. A survivor does not have to verbally express insight about the dynamics of sexual assault to heal. Many survivors of sexual assault who have intellectual/developmental disabilities have participated in counseling and had positive outcomes. It is best to keep an open mind about the person's capacity.

Family members, support staff and disability services personnel may refer to the survivor's mental age. Mental age refers to a person's ability expressed as the age at which a person without disabilities reaches the same ability. Mental age is often included in a psychological evaluation of someone with an intellectual/developmental disability. Yet, it refers to only one aspect of a person's functioning.

There are many types of intelligence. The concept of mental age has led to a false belief that a person with an intellectual disability is an "eternal child." When someone reads that "Sue has a mental age of 6 years," Sue may be treated like a 6-year-old child, instead of her chronological age of 37. It is impossible to live 37 years (or 28 or 65 etc.) and be like a 6-year-old. This false measure causes many problems in the lives of people with intellectual disabilities, including being treated with little value and little respect.

A person's mental age should not be a primary factor in determining the approach to use with an individual. Advocacy may require more direction and it may take more time for survivors with intellectual disabilities and/or autism to process information. Slowing down and allowing time for the individual to take in the information, think about it and respond will support engagement in advocacy and interaction with medical and justice personnel. It's helpful to have a repertoire of action techniques like role playing, or the use of figures to help the client tell their story.

## Presumed Competence

In advocating for any person, it is helpful to see their strengths and competencies as you move through the process. Kathie Snow puts it this way, "When you think about someone with a disability, presume competence. When you see someone with a disability, presume competence. When you are with someone with a disability, presume competence. When we presume competence, we create a community where all are valued and included."

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## Processing Styles

How do I know how a person understands best? People process information in a variety of ways. These are also referenced as learning styles. There are seven distinct styles – visual, auditory, kinesthetic, logical, musical, interpersonal, and intrapersonal. Many people have a dominant style. While people may prefer one style over others, most people understand best when a variety of processing styles are used to reinforce and contrast information. For more information on processing styles, please view Illinois Imagines Guide to Counseling People with Developmental Disabilities and/or Autism.

Paying attention to the words a person uses (for example, I hear, I see, I feel), can be helpful in determining their processing style. When there is an overreliance on one style, people who rely on a variety of processing styles may not fully benefit.

## Staff Capacity

It is in the best interest of survivors and the agency to build the skill set of all staff to meet the diverse needs of survivors. The best method for advocates to become more comfortable and confident in their abilities is by developing relationships with people with disabilities. Advocates who expand their experience and have opportunities to learn new approaches will greatly benefit survivors and the organization.

There is a natural tendency for an agency to identify one person to be the “disability advocate.” This may appear to be an efficient model or align with a particular staff’s interest or skill set. However, there are limitations to this approach.

- Availability of staff
- Loss of capacity to meet the needs of survivors with disabilities when the “disability advocate” staff leave the agency
- Unbalanced caseloads
- Not being responsive to survivor preference
- Restricted opportunities for creativity, resourcefulness, problem-solving and collaboration
- Reduced capacity of other advocates who are less equipped to work with people with disabilities. As with other facets of cultural competence, all advocates need training and experience to respond to the diversity of clients.

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## Terminology/Definitions

**Access and Accessibility** - Individuals with disabilities should be able to utilize the same services as individuals without disabilities. Full access means being able to obtain these services without physical barriers, cultural barriers, communication barriers, attitudinal barriers, and programmatic barriers.

**Adult Protective Services (APS):** The Adult Protective Services Program is locally coordinated through 45 provider agencies, which are designated by the Regional Area Agency on Aging and the Illinois Department on Aging. Case workers from the Adult Protective Services Provider Agencies conduct investigations and work with adults age 60 or older and adults age 18-59 with disabilities in resolving the abuse, neglect or financial exploitation situation.

**Autism Spectrum Disorder (ASD):** ASD is a vast range of neurodevelopmental disorders which impact the person's ability to communicate and interact with others. Challenges, which may include repetitive behaviors, speech, communication, social skills and unique strengths and differences.

**Caregiver** – Individuals who provide support to another person who is ill, has a disability or needs some help. Caregivers provide assistance with daily living activities and support staying in the home. There are several different types of caregivers including parents, siblings, relatives, staff and guardians.

**Center for Independent Living (CIL)** – CILs are non-residential, consumer-controlled, community-based, not-for-profit organizations that provide systems advocacy to create options and choices for independent living. CILs provide services to individuals to help them in increasing skills and abilities for independent living and provide public awareness. Core services provided by all CILs include advocacy, peer counseling, skills training, information and referral.

**Community Integrated Living Arrangement (CILA)** – A CILA is a combination of supports and services individually tailored for an adult with developmental disabilities. The CILA client may live in his or her own home, in a family home, or in a community setting with no more than seven other adults with disabilities. The primary goal of CILAs is to help the individual become more independent in daily living, more involved in his or her own community and more economically self-sufficient.

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**Cultural Humility** – Practice of both being aware of cultural differences and developing partnership between service provider and client that permits respectful exploration of similarities, differences, particular needs of the client and provider capacity to respond to those needs.

**deaf** – This term refers to individuals with severe to profound hearing loss. The lowercase “d” reflects a physical or audiological perspective.

**Deaf** – The term “Deaf” is defined by the individuals who consider themselves a part of Deaf culture. The capital “D” reflects this socio-cultural point of view. Individuals who self identify as Deaf may or may not self identify as a person with a disability.

**Developmental Disability (DD)** – Developmental conditions must be in evidence before the age of 22, be expected to last indefinitely, and result in substantial functional limitations in three or more of six major life activity areas. Developmental disabilities include cerebral palsy, autism, epilepsy and cognitive disabilities.

**Development Training (DT)** – Work skills training for people with development disabilities, generally provided in a central location during weekdays.

**Disability** – The following definition of disability from the World Health Organization is consistent with the collaboration teams’ belief system: “Disability is not something that a person has but, instead, something that occurs outside of the person – the person has a functional limitation. Disability occurs in the interaction between a person, his or her functional ability, and the environment. A person’s environment can be the physical environment, communication environment, information environment, and social and policy environment.”

**Disability Humility:** Disability humility is a model for working with people with disabilities that requires the ‘helper’ to be open, humble, creative and ready to learn. This approach is one of shared and equal power between the advocate and the survivor. It recognizes the person with a disability as the expert on their own experiences and needs.

**Disability Provider Agency** – Local, community-based provider of direct services to people with disabilities, usually focused on developmental disabilities, physical disabilities or mental health.

**Dual Diagnosis** – A person who has two diagnoses, e.g. both a developmental disability and a mental illness or both a mental illness and physical disability.

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**Guardian** – A person appointed by the court when a person with disabilities cannot make or communicate responsible decisions regarding personal care and/or finances. A guardian makes decisions about medical treatment, residential placement, social services and other needs.

**Guardian Ad Litem** – An attorney or lay person appointed by the court to advocate for the best interest of a person with disabilities. The guardian ad litem may interview the person with disabilities, inform the person of his or her rights, and investigate the appropriateness of guardianship.

**Hard of Hearing** – This term refers to individuals who experience hearing loss from a physical or audiological perspective. An individual who is hard of hearing may primarily use spoken language (their residual hearing and speech) to communicate.

**Illinois Department of Human Services (DHS)** – State agency responsible for:  
1) administering funds, establishing standards, and monitoring services to women with developmental disabilities and mental illness through community based providers via the Division of Developmental Disabilities and the Division of Mental Health and  
2) providing direct services to women with disabilities via the Division of Rehabilitative Services.

**Individual Program Plan (IPP)** – A person-centered plan which outlines the services and supports for a person with a developmental disability. May also be called an ISP (Individual Service Plan) or an IHP (Individual Habitation Plan).

**Individual Treatment Plan (ITP)** – A plan that details the services and supports for a person with mental illness.

**Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD)** – People with developmental disabilities who live in the community and have support staff 24 hours a day who help them stay safe while learning new skills.

**Leader** (also referred to as consultant) – Person with a developmental disability that takes part in Network and Statewide Advocacy Council meetings. A leader can also choose to show their skills by speaking in front of a bigger group.



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**Mandated Reporters** – Any individual who suspects, witnesses, or is informed of abuse or neglect and employed by any agency licensed, funded, monitored or otherwise under the authority of the Department of Human Services that provides services to individuals with developmental disabilities or mental illness

**Qualified Intellectual Disability Professional (QIDP)** – A QIDP is an individual with human service or allied health educational training and a minimum of one year of experience working directly with individuals with intellectual disabilities or a related condition. QIDPs are responsible for many tasks including ensuring that the people they serve receive individualized, appropriate and person-centered services. They may function in the role of case manager at the disability provider agency, residential group home supervisor or supervisor at the day rehabilitation program.

**Personal Assistant** – Services provided by individuals who are selected, employed and supervised by the person with a disability. These individuals may assist with or perform household tasks, personal care and, with the permission of a physician, certain health care procedures.

**Psychosocial Rehabilitation (PSR)** – A day program for persons with several mental illnesses.

**Rule 50** – State law (commonly referred to as “Rule 50”) authorizing the Office of the Inspector General to promulgate rules establishing minimum requirements for reporting and conducting investigations into alleged abuse/neglect.

**Self-Advocate** – Person who speaks up for himself or herself and may choose to speak up on behalf of others as well.

**State Operated Developmental Center (Mental Health)** – Residential institution operated by the state for people with disabilities.

**State Operated Facility (Mental Health)** – Residential institution operated by the state for people with disabilities.

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## **ACRONYMS: WHAT IT MEANS**

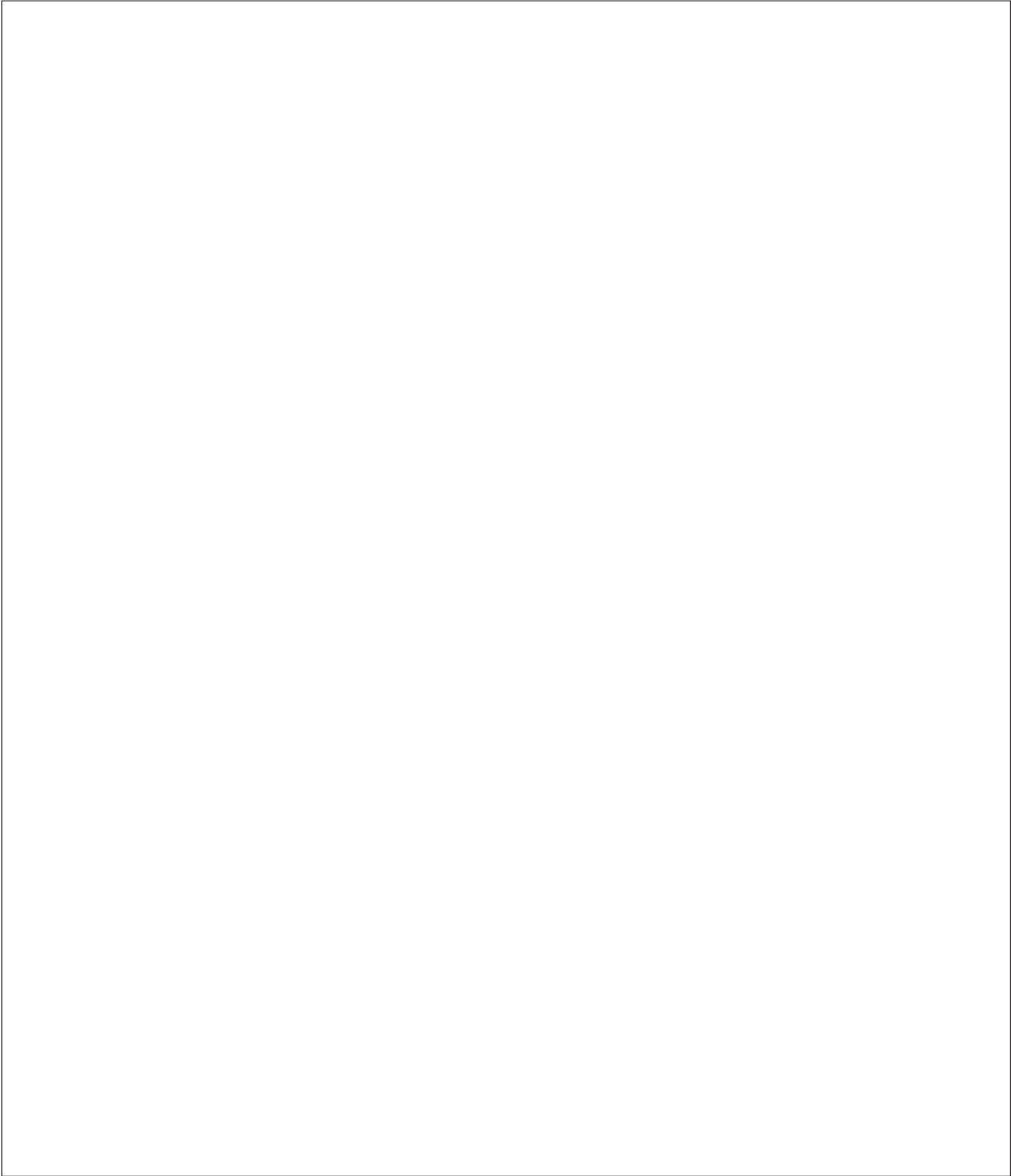
### **Agencies**

|        |   |
|--------|---|
| AG     | Attorney General  |
| APS    | Adult Protective Services   |
| CIL    | Center for Independent Living   |
| DCFS   | Illinois Department of Children and Family Services                   |
| DHS    | Illinois Department of Human Services                                 |
| DOJ    | Department of Justice   |
| ICASA  | Illinois Coalition Against Sexual Assault                             |
| ICF/DD | Independent Care Facility for Persons with Developmental Disabilities |
| IDHS   | Illinois Department of Human Services                                 |
| IDPH   | Illinois Department of Public Health                                  |
| OIG    | Office of Inspector General   |
| OVW    | Office on Violence Against Women                                      |

### **Others**

|        |  |
|--------|--|
| CILA   | Community Integrated Living Arrangement                    |
| CNCO   | Civil No Contact Order                                     |
| DD     | Developmental Disability                                   |
| DT     | Developmental Training                                     |
| GAL    | Guardian Ad Litem  |
| IPP    | Individual Program Plan                                    |
| ITP    | Individual Treatment Plan                                  |
| LGBTIQ | Lesbian, Gay, Bisexual, Transgender, Intersex, Questioning |
| OP     | Order of Protection  |
| PSR    | Psychosocial Rehabilitation                                |
| RCC    | Rape Crisis Center   |
| SANE   | Sexual Assault Nurse Examiner                              |
| SART   | Sexual Assault Response Team                               |
| SASETA | Sexual Assault Survivors Emergency Treatment Act           |
| SOF    | State Operated Facility                                    |
| VAWA   | Violence Against Women Act                                 |
| VOCA   | Victims of Crime Act                                       |





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# THE TOP TEN THINGS ADVOCATES NEED TO KNOW ABOUT PEOPLE WITH DISABILITIES

By Shirley Pacey

**1. We have been hurt.** Sexual violence is a very real part of our lives. We feel shame and guilt and fear and confusion. No one may know that we suffer. It most likely happened many times and by more than one person. For some of us, it has been so common; we think it is just a part of life. We may not report because we fear losing services and independence, not being believed, not being considered a credible witness, not getting victim services. We may not know there is anyone who can help us so...

**2. We need your support to move forward.** Many people with disabilities are denied access to the criminal justice system and even the rape kit following sexual assault. Whether you meet us at the hospital or the courthouse, get to know us. Find out how we communicate and how we can best participate. Help us understand what we can do. It's so confusing and some of us aren't used to standing up for ourselves. When you work with us, it is important to understand that...

**3. We are not all the same.** People with disabilities are a diverse group and there is no one size fits all. Our disability labels include physical disabilities, intellectual disabilities, mental illnesses, developmental disabilities, blind and Deaf. Everyone with a particular label is unique. Designing access requires time, expertise and willingness. Don't worry, you don't have to be the expert on disabilities because we are. Ask if you want to know how to support us. We have learned that this does not happen easily so understand that....

**4. Everyone communicates.** We may not communicate the same way that you do so you might think you can't understand us. Some of us communicate with devices, some of us use pictures, and some of us can show you with gestures and pointing (labeled non-verbal). The hospital and court papers are hard to understand, so we may need your help. Take the time to get to know how we learn things and communicate. Together, we can figure out lots of things. Please don't give up and think that you can't understand. You really can if you....

**5. Listen Carefully.** You can understand us. Through our words or actions, you can know whether we want to have an exam or talk to the police. Consider our wishes as most important instead of family, caregivers or staff. We have the same rights as other victims that you help. You can help us, if you remember that...

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**6. Some of us need accommodations to participate.** Some of us need supports to be able to participate in the medical and legal process. For example, some of us need an American Sign Language Interpreter, some of us need Braille documents, some of us may need pictures to show what happened; many of us need to be spoken with in plain language. Ask what we need so we can best participate. Even though we may need help with some things... As for accommodations at the hospital...

**7. We are experts on how our bodies work.** One woman was told, “we can’t help you because we can’t get your feet in those stirrups.” Although our bodies may work differently, with support from advocates and nurses, we can do it. We can tell you what works best for us and get it done. Partner with us and listen closely. You might be surprised to know that...

**8. We are credible witnesses.** People think that we can’t talk in court and tell our story. We know what happened to us. We know the difference between a truth and a lie. Don’t be fooled by the labels or diagnosis. We are strong and capable. Help me get a chance to share my story with others. If you want to help me, you will need to...

**9. Encourage others to include us.** Some of us are used to others talking for us, doing for us, and deciding for us. When we are sexually assaulted we need information, communication and choice. We are most impacted by the decisions that are made and want to be included. Nothing about us, without us. You can help us remind others to include our voices. And lastly,

**10. THANK YOU.** Thank you for taking the time to get to know me. Thanks for offering me choices and advocating for what I want to happen. Thanks for believing in my value and my desire for equality, justice and healing. Thanks for being with me during these difficult times. Thanks for seeing my strengths and my heart. Thanks for believing in me. Thanks for being you.

## Day in the Life of a Survivor



|  |  |
|--|--|
| <p><b>What happens if you are going to work/school/program?</b></p>  | <p>How do you get to work/school/program?</p> <p>Who is responsible for making the transportation arrangements, if any?</p> <p>How satisfied are you with these arrangements? Are there any challenges that come up?</p>   |
| <p><b>What happens at work/school/program?</b></p>                   | <p>How long have you worked/attended the setting?</p> <p>What is the nature of your relationships with peers, supervisors/teachers and support staff?</p> <p>What do you enjoy at work/school/program?</p> <p>What do you find difficult?</p> <p>What makes you happy and sad at work/school/program?</p> <p>Do you have friends?</p> <p>Are you bullied? Are you called names, laughed at, pointed to or made fun of?</p> <p>Who do you go to for help/support when you need it? How do they respond?</p> |
| <p><b>What happens when it's the weekend or during holidays?</b></p> | <p>How do you spend your time?</p> <p>Do you have any friends? How often do you get to see them? Do you need support to make arrangements to see friends?</p> <p>Do you have the opportunity to leave home independently? For what type of activities?</p> <p>How much choice do you have in setting the schedule over weekends/holidays?</p>  |

## Day in the Life of a Survivor



**What happens at work/school/program?**

How do you get home from work/school/program? What time do you usually get home?

What is the journey home like? Consider opportunities for bullying, etc.

Is there anyone at home when you arrive?

Do you have responsibilities at home in the afternoon or evening?

Do you have any free time in the afternoon or evening? How do you like to spend it?

Do you have any choice about your afternoon or evening activities?

**What happens in the evening?**

When do you usually have your last meal/snack?

What happens if you say you are still hungry?

Do you spend your time watching TV? Do you go out - where and with whom?

What do you do for fun?

What do the other members of the household do in the evening? If there are caregivers/staff, what do they do?

Does anyone talk to you or give you any attention? If not, how do you feel about this? What do you prefer?

## Day in the Life of a Survivor



**What happens at  
bed time?**

Do you have a typical bedtime?

Who decides when you go to bed?

Where do you sleep? Do you have a roommate?

What is your bedtime routine? Do you require any support for bedtime?

Do you have trouble sleeping? If so, what happens?

Who can you go to for help/support if needed? How do they respond?

Who decides when TV or music is turned off?

Who decides when lights are turned off?

Do you have a nightlight in their bedroom or bathroom?  
Would you like one?



## **PEOPLE WITH DISABILITIES ARE PEOPLE FIRST**

- Disabilities can be visual, auditory, physical, communicative, developmental or emotional. Some individuals have a combination of disabilities.
- People with disabilities are a part of a group that cut across racial, ethnic, religious, economic and social lines.
- Disabilities affect a wide range of activities—from small to great.
- Your neighbor, loved one or even you may have a disability.
- Disabilities are not contagious.
- Miracles may sometimes happen, but people with disabilities are not usually waiting for them.
- Not all disabilities can be seen.
- People with disabilities know they have a disability, and tend to know that you know.
- People with disabilities prefer to emphasize what they can do rather than what they cannot.
- Disability is not the sum of an individual's life, any more than having a certain hair color is the sum of your life.
- People with disabilities can and do engage in sex and have intimate relationships.

**DISability is not INability**

## What is Sexual Violence?

Sexual violence has a lot of forms and a lot of names. Some people call it rape, sexual assault, sexual harassment or sexual abuse. It can include:

- Being forced to listen to someone talk sexually to you
- Being forced to look at or participate in sexual pictures or movies, texts or social media
- Being forced to kiss someone
- Being forced to look at or touch someone's private parts
- Being touched when you don't want to be touched, especially in a sexual way
- Being forced, tricked or manipulated to have any kind of sexual activity

Unless you say yes, it is wrong for someone to touch you in a sexual way. If this happens to you, tell someone.

## Healing is Possible

You can heal from sexual violence. Your rape crisis counselor can help you. You may also want to tell some of your friends and family so they can support you.

With support and time, healing is possible!



Insert information about local sexual assault center here

## Sexual Violence and You

If you have experienced sexual violence, please know:

We believe you.

You are not alone.

It was not your fault.

You don't have to keep it a secret.

You can ask for help.

You are so brave to tell.



[www.illinoisimagines.com](http://www.illinoisimagines.com)





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# Section 2: Communication

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# SECTION 2: COMMUNICATION

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### 3. Information on Communication Guide

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# Introduction

This section offers practical information for communicating with survivors with disabilities. Many of the strategies and skills used by advocates to build rapport and interact positively with all survivors and work well with people with disabilities. This section provides additional information and tips. Keep in mind that these are general guidelines and may not be applicable to everyone with a disability. They provide a starting point for understanding and preparing to work with survivors with disabilities. Of course, the best source of guidance is from the survivor. It is most helpful to ask survivors, "How can I best support you?" or "Is there anything that you want me know to know about you, so we can work better together?" Utilizing a direct, honest approach to communication benefits survivors and advocates.

## Give us the Words

**Why can't she understand what I'm saying?  
Is something wrong with her?**

**Response:** Maybe she didn't hear you, or she needs you to explain it differently.

**Response:** She's Deaf/hard of hearing. I can help her to understand you, or we can find an interpreter. Perhaps if you use pictures or writing, that will help.

**Response:** She needs time to process what you're saying. Let her think a minute.

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# Facilitating Positive Interactions with People with Disabilities

○ Intellectual   ○ Autism   ○ Physical   ○ Mental Illnesses

In your role as an advocate, you will interact with people who have a wide range of life experiences, varying levels of support and resources, diverse abilities and different reactions to trauma. Advocates help survivors navigate complicated systems at one of the most stressful times of their lives. Trauma makes it difficult for most survivors to process information, understand choices and take action. Introducing new information by breaking down concepts, slowing down the pace of the conversation and taking frequent breaks, are strategies that you probably already use. Many of techniques that you currently use as an advocate to support survivors, will work also well with people with disabilities that experience sexual violence. Some additional considerations and suggested approaches may be beneficial to facilitate positive interactions with people with disabilities.

Some people are unable to communicate through oral language, yet possess receptive language and other ways of communicating which include: sign language, nodding, or a communication board that has pictures, symbols and words to which the person can point. A communication board may be attached to a wheelchair tray or the person may carry it in a book form. There are also augmentative communication devices, which are usually computerized. The person presses keys or symbols that come out as a synthesized voice. The person may also communicate in writing, drawing, hand or feet movements or by eye-blinking, hand squeezing, etc. The Illinois Imagines Communication Book is an excellent resource for supporting conversation with survivors who communicate best through non-traditional methods.

Communication is a complex process involving speech, language and processing. Different types of disabilities impact communication differently. The following information provides general guidance for communicating and interacting with people with intellectual disabilities, autism, physical disabilities and mental illnesses.

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## General Tips

While some advocates may have limited experience interacting with people with disabilities, it is important to recognize the approaches routinely used with survivors provide a solid foundation to build upon. The following guidelines may help advocates when responding to sexual assault survivors with disabilities:

**Relax.** It's okay if you don't know what to do. The expert is right in front of you. Allow the survivor with a disability to guide you. Ask them what support they need from you. Don't be afraid to make a mistake.

**Reassure.** Affirm that the survivor is not in any trouble and did not do anything wrong. Use kind words and gentle actions. Use simple instructions that are easy to remember.

**Create Safe Space.** Assess the room that the survivor is in. Is it sterile? Is it overstimulating? Does the person have privacy? Have they been asked what would help them calm down? Do they have any self-soothing strategies that you can help them access? Are they being barraged with questions? Maybe they want to wrap in a blanket, rock in a rocking chair, yell, cry, stomp their feet, listen to music, hug a teddy bear, or curl up in a ball. We are not there to judge appropriateness but are there to help that person feel safe.

**Allow time to process.** Being silent for a few moments after your communication will allow the person who needs more time to process your communication to respond. Avoid completing sentences for them or making assumptions

**Assist.** Offer the survivor choices either at the hospital or when discussing legal options. Be aware that some people with disabilities have had limited opportunities to make decisions for themselves and may look to you for the right thing to do. Advocate with others for victim choice and their rights.

**Inquire** - Ask the survivor who they trust and who has helped them in the past when something bad has happened to them. For example, "You say Jaime has always been a help to you. You trust Jaime. It's okay to talk to Jaime about what happened. Do you want to call Jaime before you leave the hospital?"

## Give us the Words

### Why can't this woman give a coherent narrative?

**Response:** Some women with disabilities can't do clocks or calendars very well, but they know their schedules. If you focus on her activities, you will learn a lot.

**Response:** She has difficulty understanding time. Talk about the people involved, herself and what happened, such as "What did John do? What did you do? What did John do then? What did you do?" Focus on the incident itself, not the time-frame.

**Identify** coping strategies. Asking the survivor "When you have been upset in the past, what has worked for you?" "What would make you feel safe right now?" or "What can I do right now to help?" may provide insight into established coping strategies. Many people have worked with counselors at some point in their lives and have a plan for dealing with crisis. Ask the person if they have a crisis plan. If yes, ask the person to share and encourage them to implement any activities or strategies that could be done in the current circumstance. If no plan exists, you can also help them develop a crisis plan to assist them when they are feeling overwhelmed.

**Engage Others.** Help medical or legal professionals and significant others see the strengths and understand the choices of the survivor. Address misconceptions or false assumptions about people with disabilities.

**Follow-up** supportive counseling is recommended as with all survivors, and may need to include family, significant others, and caretakers. Ask survivors the best means of communication for follow up.

**Assess.** Consider needed accommodations and supports. This is best done by asking the survivor with a disability what they need to fully participate in the medical and legal processes. Advocate for needed accommodations within these systems.

**Flexibility is key.** Be willing to adapt the way that you do things. For example, you may need to allow extra time to meet with someone or in some situations schedule shorter, more frequent time together.

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## Survivors with Intellectual Disabilities

For a lot of individuals with disabilities, communication will be no different than with a client without disabilities. The following are some things to keep in mind when interacting with people with intellectual disabilities.

- Try to determine the relationship between the suspected abuser and the survivor. Because many people with disabilities depend on others for their care, you will need to know what the relationship means to the survivor in terms of practical and emotional issues.
- Arrange for a support person to be present if appropriate and possible.
- Let the person tell the story and lead the discussion.
- Use simple words and short sentences. Break down complicated ideas or instructions. Pictures may be helpful.
- Be prepared to go slowly, and take frequent breaks as needed.
- Many individuals with intellectual disabilities may be very concrete in their thinking. Phrase questions and statements in such a way as to avoid ambiguity or confusion. Try to avoid words or phrases with multiple meanings, sarcasm or jargon. Metaphors, analogies and story examples can be very helpful.
- Avoid using leading, or “yes” and “no” questions when communicating. Open-ended, non-leading questions are best. If you are smiling and nodding when you ask a question, you may receive a nod and a smile, but no real information. People with all levels of ability could be led by actions of another person. Remember, people with disabilities are trained to be compliant. They may be easily led and quick to please.
- Realize that you may need to ask the same question in several different ways before you are able to communicate your meaning clearly.
- Look for patterns of misunderstanding.
- Do not ask “Do you understand?” If the person you are talking to is having trouble focusing or staying on track, help them to do so by rephrasing questions and providing structure to the subject you are discussing.



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- If the person does not directly answer questions, they may be associating it with something else of relevance. (“That’s interesting. How does it relate to...?”)
  - You may suggest talking about things irrelevant to the current situation. For example: “First we are going to talk about this, then we’ll talk about that or we’ll take a break.” Redirect the person to the question firmly and politely.
  - Listen to all information. Believe what you are told.
  - Make every effort to get accurate information from the person with a disability before relying on information from others. What they are telling you may seem factually incorrect, but it’s possible they have interpreted the words differently.
  - People with intellectual disabilities may be unable to tell you the exact order of events. They may have limited memory of routine or unimportant details. They may need memory cues. If a person cannot remember the exact time of an event, ask them what they were doing at the time the event happened. For example, ask the person what was happening that day, or if it was warm or cold outside.
  - It is very helpful to use and engage all of the senses: sight, sound, touch, taste and smell. Engaging a variety of senses are often more effective than just talking.

**When you are having difficulty understanding the person, say this:**

- “Can you repeat that?” Repeat the words that you do understand with a questioning tone.
- “I want to understand what you are saying. Can we try again?”
- “I have some pictures with me. Do you want to use the pictures?”
- “Would you like to draw or spell what you want to say?”
- “I know you are trying hard to answer my question. Could you help me by slowing down or trying again?”
- “I hope you will forgive me if I don’t always get what you say the first time. I really want to hear what you have to say. Take your time. I’ll try harder to listen.”
- “Would you like to answer the question now or later?”

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## Survivors with Autism

Following are some interaction tips that may be helpful in communicating with someone who has autism.

- Reduce distractions as much as possible; such as lights and sounds.
- Approach the person in a calm manner. Introduce yourself and extend your hand. Do not be concerned if the person does not extend their hand in return.
- Do not approach the person from behind.
- Speak with a calm voice using direct, concrete terms with one response or concept per question or statement.
- Explain your actions before you do anything. For example, “I am going to stand up.”
- The person may prefer writing notes back and forth, at least until they feel more comfortable with you. Ask if this would be helpful.
- The person may not respond to questions or requests. Be reassuring. Try again.
- Be aware that the person may have difficulty making eye contact or interpreting nonverbal cues. Be clear, direct and specific in your communication.
- The person may not be able to speak and might even appear to be deaf because of lack of response. Determine their primary mode of communication.
- Allow plenty of time for the person to respond. Be patient.
- Ask a family member, teacher or support person if there is a favorite object that makes the person feel safe.
- Avoid using sarcasm, cliques, acronyms or words with multiple meanings. Many people with autism are very literal. If you ask a person “Can you tell me what happened?” They may answer “Yes”, but not answer your question because you started with “Can you.”
- The person might repeat what you say or repeat the same word or phrase over and over or change the subject. This is common and is the person’s sincere attempt to communicate with you. It is not rudeness.
- The person may express themselves with an unusual tone of voice and/or look at you from an odd angle. This is also common and not meant to be disrespectful.

- The person may not understand social norms or the seriousness of the situation. Do not focus on the behavior you feel is unusual; let the person know you want them to be safe. Proceed gently.
- If the person is displaying repetitive behaviors, it may be to help them calm down. Do not try to stop them or take objects away from them unless there is a danger to self or others.
- Be prepared for sudden outbursts or impulsive behavior. If no one is at risk of harm, wait for the behavior to subside and then calmly continue.
- Some people with autism do not express physical pain; The victim may need to be checked for injuries.
- Some people may be sensitive to touch or experience touch as painful.

The Picture guide may be very helpful to many people with autism -- it is logical, repetitive, computer-based and offers an alternative to looking at the person.

## Give us the Words

**Why can't this woman give a coherent narrative?  
It's all jumbled up and out of order.**

**Response:** Some women with disabilities can't do clocks or calendars very well, but they know their schedules. If you focus on her activities, you will learn a lot.

**Response:** She has difficulty understanding time. Talk about the people involved, herself and what happened, such as "What did John do? What did you do? What did John do then? What did you do?" Focus on the incident itself, not the time-frame.

**Response:** She's trying to process a lot right now. Give her time to think/calm down.

**Response:** Focus on her sensory experiences and you will have lots of useful information. You can ask "What she heard, saw, felt, tasted."

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## Survivors with Physical/Sensory Disabilities

People with physical and/or sensory disabilities may also be at greater risk for sexual violence, especially if they depend on others for personal care. When the offender is someone who is supposed to be in a helping relationship, the person with a physical and/or sensory disability may be concerned about a loss of services and independence. Their decisions about medical and legal advocacy may be impacted by their fear of losing services or being placed in a nursing home.

### Survivors with Disabilities that Impact Mobility

Consider the following “disability etiquette” when interacting with a survivor with a physical disability,

- Make sure the meeting place is physically accessible. This includes parking, sidewalks, entry to the building, hallways, doorways, restrooms, and the meeting room. Sidewalks need to be clear of snow and shrubbery. (For more information see [www.ada.org](http://www.ada.org))
- If you normally extend your hand to someone when you meet them, do the same with a victim who has a disability.
- If the person uses a wheelchair, remember that the chair represents personal space and should not be touched or leaned upon without permission.
- Position yourself to be at eye level. If a person uses a wheelchair, sit down.
- Providing assistance, like pushing a wheelchair, should be done only after asking the person if assistance is needed and how it should be provided.
- Some individuals in wheelchairs may choose to transfer from the wheelchair to a different chair (e.g. office chair). Volunteering to assist with this activity is never the wrong thing to do and is almost always appreciated, but always ask first.
- If a person has a service animal to assist them, do not pet or communicate with the animal without the person’s permission.
- Have straws available for people who need a straw to drink.

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- The majority of people with physical disabilities have ‘normal’ or higher intelligence. Speak with them as you would any other victim.
  - Remember that evidence collection on wheelchairs, communication devices and other adaptive equipment can be done and returned to the person prior to discharge from the hospital.

## Survivors with Hearing Loss

- If you suspect or know the person is Deaf or hard of hearing, ask them to let you know if they cannot hear you clearly. Ask about preferred mode of communication. Secure certified interpreters if requested.
- If there is an interpreter present, be sure to talk directly to the person and not to the interpreter.
- When working with someone who is hard of hearing, do not shout. Speak at your normal volume unless the person asks you to speak louder – hearing aids make sound louder not clearer.
- Make sure you gain the attention of the individual who is deaf or hard of hearing before beginning to talk. It is best to approach from the front and to get attention through non-physical strategies.
- Identify who you are and make sure you look directly at the person as you speak.
- To make it easier for the individual to read lips, face the light, speak clearly in a normal tone, keep your hands away from your face, and use short simple sentences.
- Some people with hearing loss, may not consider themselves to have a disability; however, according to the American Disabilities Act, they qualify for protection, i.e. accommodations.
- At the hospital, the survivor may have a choice between an interpreter on-site or an interpreter via Video Relay System (VRS). The survivor’s choice should be honored.

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## When Using an Interpreter

Getting information from a person with a disability or effectively understanding the way they communicate is not possible for you. To ensure that the person is receiving the help they need, it may be beneficial to use an interpreter to assist you. Ask the person with the disability if they have an interpreter they would like you to contact. This should be a certified American Sign Language (ASL) interpreter not a family member, guardian, or friend. If the person with hearing loss agrees, contact the interpreter before you begin the interview.

1. Have the interpreter sign a verification form indicating that for the purpose of assisting the client, all information discussed is confidential.
2. Define what the roles of the interpreter will be in the meeting or interaction.
3. Discuss the questions you wish to ask ahead of time so that the interpreter can best frame them.
4. Never use the interpreter without the survivor present.
5. Always talk to and look directly at the person with a disability, not about them or solely to the interpreter. Avoid saying things like, "Ask her if..."
6. Observe the survivor closely as non-verbal language, i.e. gestures and facial expressions are important aspects of communication by a Deaf person.
7. The interpreter is present for the benefit of the person with hearing loss and should not be used if the person is speaking for themselves and being understood by you. The interpreter's function is to convey what the person with hearing loss is wanting to communicate. Nothing should be added by the interpreter.

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## Working with Survivors Who are Blind or Have Low Vision

- People who are blind or have low vision usually do not need assistance in familiar surroundings but do when they are at the hospital or clinic being examined, the police station filing a report, the rape crisis center receiving advocacy, the state attorney's office or in the courtroom.
- Talk about everything being done around the person and provide verbal orientation to the surroundings including potential obstacles in their path.
- Before you touch the person ask permission then explain that you will be touching them, how and why.
- When moving from one room to another, offer your arm to grasp above the elbow for guidance. Verbally point out obstructions. Always tell them when you are leaving the room. If the survivor has a guide dog, do not be distracted by it or ask about the dog's reaction to the assault; this diverts the blame from where it belongs – with the rapist.
- When working with people who are blind or who have low vision, make sure you speak to the person as you approach: state clearly who you are, and introduce anyone who is with you and speak in a normal tone of voice.
- Ask the person what if any assistance is needed. Follow the instruction of "how to help" from the person. Some people may not want any assistance.
- Be descriptive when giving directions; give verbal information that is visually obvious to someone who can see (e.g. when approaching steps, mention how many steps and in what direction they are).
- Always tell the individual when you are leaving, never leave a person who is blind or has low vision talking to an empty space.
- Assist the person with completing any intake or treatment forms only after you have read the forms aloud in their entirety to her. Have forms and resources available in accessible in alternative communication formats.
- Most people with little or no vision can sign their names. Many people use signature guides and some may ask you to show them the area to sign by guiding their hand.

Remember, an individual who is blind or has low vision can often provide a wealth of information about their assailant. They may be able to identify a voice, particular walk, type of clothing, smells, etc. Law enforcement and legal personnel should be encouraged to accept these types of identifications, as well as visual ones.



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## Survivors with Mental Illnesses

Trauma often leaves the individual feeling helpless or powerless and overwhelms the person's normal sense of control, connection, and meaning in life. The percentages are extremely high for individuals with psychiatric disabilities to be survivors of a variety of past traumatic life events (trauma victimization studies show a prevalence of PTSD between 51-98% among persons with serious mental illness in the public sector). With a prior trauma history complicated by a serious mental illness, a major stressful event like sexual assault will exacerbate symptoms that the person may have otherwise been managing successfully. We have to offer the hope that the survivor can gain back their ability to manage their life and illness.

Interaction tips that may be helpful in communicating with someone who has mental illnesses:

- Do not touch the person or stand too close to the person.
- Do not talk down or raise your voice
- Avoid sudden movements
- Show interest and concern
- Avoid dramatic facial expression
- Approach the person in a calm, nonthreatening and reassuring manner.
- If a person is confused, speak slowly and in a calm, pleasant tone of voice
- If a person seems agitated, offer them a quiet space away from any confusion or shift the conversation to a safer topic
- Avoid multiple instructions and give one piece of information at a time
- Be empathetic. Let the person know you heard them and are there to help.
- If the person is talking non-stop, interrupt with a simple question.
- Do not argue or try to prove a point. If a person is experiencing delusions or hallucinations, understand that these are very real to the person.



- Do not agree or disagree with delusions; empathize with the person's feelings.
- If the person is having difficulty with hallucinations or delusions, ask "What has helped you in the past when you felt this way?"
- Avoid whispering, joking and laughing as this may be misinterpreted by some one with a mental illness.
- Be honest about what you can and can't do.
- Do not take the person's words or actions personally.
- Be aware that individuals experiencing delusions, paranoia or hallucinations may be able to accurately provide information outside of their false system of thoughts, including details related to their sexual victimization.

## Give us the Words

**Why is that woman flapping her arms like that?  
It makes her look really stupid.**

**Response:** She has autism. She does that to calm herself down sometimes.

**Response:** By focusing on the flapping, it helps get her mind off the pain and confusion she's feeling right now. Let her flap, and then let her continue her story.

**Response:** She may be feeling uncomfortable, overloaded, or overwhelmed right now. Let's take a break, or talk about something else for a minute. We can come back.

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Below are some accommodations to facilitate communication that may be used for different types of mental illnesses.

| <b>Behavior/Characteristic</b>                         | <b>Adaptation</b>                             |
|--|---|
| Confusion about what is real                           | Be straightforward and simple                 |
| Difficulty in concentrating                            | Be brief and repeat as necessary              |
| Over stimulated  | Limit input, don't require concentration      |
| Poor judgment  | Don't expect rational discussion              |
| Preoccupation with internal world                      | Get the person's attention                    |
| Agitation<br>transition to a safer/calmer conversation | Recognize the agitation and if possible,      |
| Fluctuating emotions                                   | Do not take words or actions personally       |
| Fluctuating plans                                      | Stick to one plan                             |
| Little empathy for others<br>of a mental illness       | Recognize this as a possible symptom          |
| Withdrawal   | Initiate conversation                         |
| Belief in delusions or hallucinations                  | Don't argue; respond to needs<br>and feelings |
| Fear   | Stay calm                                     |
| Insecurity   | Be caring and accepting                       |

*Chart above taken from West Virginia S.A.F.E. Training and Collaboration Toolkit  
—Serving Sexual Violence Victims with Disabilities.*

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## Communication Guide Information

Advocates play a vital role in shaping the experience of survivors, including survivors with disabilities. Interacting with someone who communicates differently than you do, can be uncomfortable. Experience and relying upon the expertise of the survivor with a disability will increase your comfort and confidence. Don't be afraid to make mistakes. Much of what you already do when you interact with survivors works well with people with disabilities. Illinois Imagines has created several resources to assist you with expanding your knowledge and improving your skills.

### **Who, What, Where, When: A Symbol Book for Victims who use Augmentative and Alternative Communication**

Illinois Imagines produced a symbol book to assist survivors who may communicate best through pictures. It is important to remember that following trauma, many victims (with or without disabilities) may have difficulty communicating their experiences. Many victims are more likely to be able to share their account of what happened by recalling sensory memories rather than a chronological, who, what, where, when approach. Asking questions about what did you see, what did you smell, what did you feel, tell me about any parts of your body that were uncomfortable or hurt, may be easier to recall.

The target audience for the use of this symbol book is people who have communicative disorders, which may include cognitive disabilities, cerebral palsy, autism, traumatic brain injury, speech disorders, learning disabilities, and mental health issues. Although not all people with disabilities have communicative disorders, for purposes of this book, we are referring to people whose disabilities include communicative disorders. Most people with communicative disorders can speak and understand speech, but may not effectively understand certain concepts. Remember to ask the person you are working with what is the best way to communicate. Each person communicates differently.

This symbol book is not intended to replace sign language or deaf interpreters for people who are deaf or hard of hearing. It may be useful as a supplemental visual accommodation, but is not specifically designed for their unique needs.

If you need additional copies of the Symbol Book, please contact ICASA at 217-753-4117.

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# The TEN Commandments:

Etiquette for communicating with people with disabilities and

You may not always be aware that a person has a disability or hearing ten tips below are helpful in communicating with anyone.

1

When talking to a person with a disability or hearing

Speak directly facing that person rather than through a companion or interpreter who might be present. Even if you think that a person cannot or respond to you, it is rude to talk through someone else.

2

When introduced to a person with a disability...

It is appropriate to offer to shake hands. People with limited hand use, wear an artificial limb, can usually shake hands. Using the left hand to hands is also an acceptable greeting.

3

When meeting a person with low vision...

Always identify yourself and others who may be with you. When conversing in a group, remember to identify the person to whom you are speaking as yourself.

4

If offering assistance...

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6

Do not lean or hang...

Leaning or hanging on a person's wheelchair is similar to leaning or hanging on a person's body and is not okay. The chair is a part of the personal body space of the person who uses it. When speaking with a person in a wheelchair or using

7

When talking with a person who has difficulty speaking...

Listen attentively. Be patient and wait for the person to finish, rather than correcting or speaking for the person. If necessary, ask yes or no questions. Never pretend to understand, instead, repeat what you have understood and allow the person to respond. The response will clue you in and guide your understanding. Also keep in mind that a person may use other tools and devices as a way to communicate.

8

When speaking with a person in a wheelchair or using crutches...

Place yourself at eye level in front of the person to help with the conversation.

9

To get the attention of a person who has hearing loss...

Face toward them and wave your hand. Look directly at the person and speak clearly, slowly and expressively to find out if the person can read your lips. Not all people with hearing loss can lip read. For those who do lip read, be sensitive to their needs by placing yourself facing the light source and keeping hands, cigarettes and food away from your mouth while speaking.

10

Relax...

Do not be embarrassed if you happen to use common expressions such as, "See you later," or "Did you hear about this?" that seem related to the person's disability.

\*The Ten Commandments adapted from many sources as a public service by Karen Meyer, ADA National Center for Access Unlimited.

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# Interviewing Tips

## Preparing for the Interview

- Assure the space is physically accessible, including the restroom.
- Recognize what the victim's disability is and provide any possible accommodations. When in doubt...ASK!
- Take time to "listen" to the victim's account. •Schedule extra time for the interview so you do not feel rushed.
- Be aware of the victim's schedule.
- Prepare to tell family members or support persons that you will need to interview the victim alone.

## During the Interview

- Explain to the person that you are here to help.
- Ask the person for their consent to be interviewed.
- Provide facts about who you are, what you are going to do, and what happens next.
- Establish a rapport.
- Communicate with individual like an adult and use a normal tone of voice.
- Speak directly to the person and not a support person or interpreter.
- Make eye contact and get at eye level with the person.
- If the person uses a wheelchair, mobility device or communication tool, ask permission before touching these.
- It is okay to offer assistance, but let the person decide if and what help is needed.

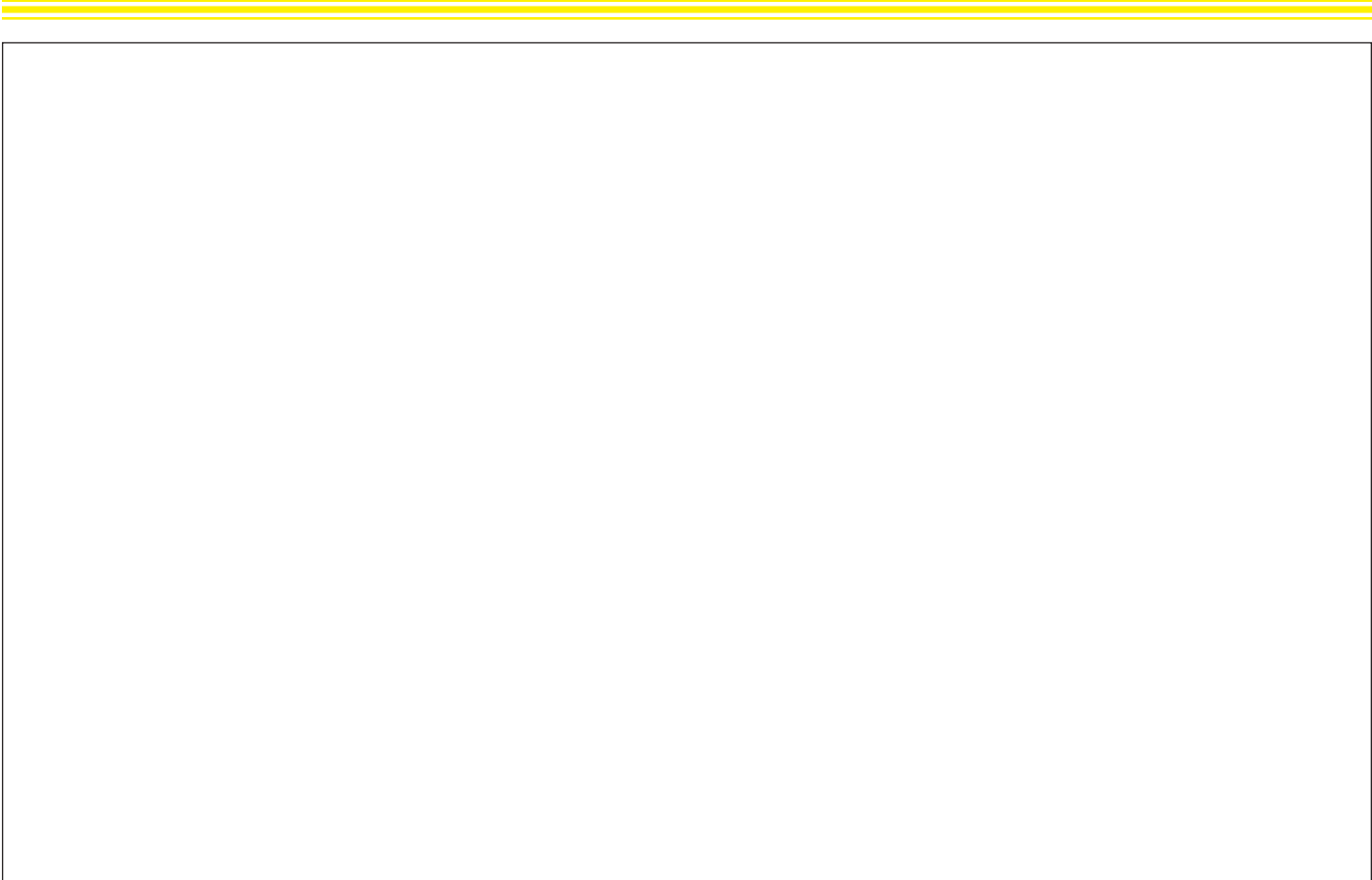


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- Allow time for the person to respond – handshakes, questions.
  - Use plain language, avoid jargon and sarcasm.
  - Use the variety of sensory approaches, i.e. visual, auditory, movement.
  - Let the person know that they are not in trouble and that you believe them.
  - Let the person know that they are brave and they are helping others to be safe.

## **Following the Interview**

- Contact the individual utilizing the preferred method of communication.
- If a follow up interview is needed, provide as much advance notice as possible.
- Check in to see if any additional accommodations are needed for the follow up interview.
- Provide updates on the status of the medical or legal process.

**Following a traumatic experience, all individuals need at least 2 nights of sleep, food and support before being able to provide complete and accurate information.**





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## Communication After Trauma

### Factors that influence communication:

1

Following a trauma, it may be more difficult for a person to follow what is being said and to speak.

5

Some people find it difficult to follow what is said and to speak. This difficulty may be related to the trauma they want to discuss.

2

A person's ability to communicate what happened to them is not necessarily related to cognitive understanding or truth-telling.

6

We all have a right to understand and express our feelings. We all have a right to use our voice to communicate our needs and desires. We all have a right to be heard.

3

It is easier for a victim to communicate what happened to them when speaking with someone they trust.

7

Some people find it difficult to understand how a person's trauma may affect their communication. Some people may be under stress, which may affect their communication. Some people may be misled or misinformed about their own communication.

Some people

It may be

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# Section 3: Parents and Guardians

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# SECTION 3: PARENTS AND GUARDIANS TABLE OF CONTENTS

1. Introduction

2. Overview of Guardianship\_\_\_\_\_ 1-2

3. Ongoing Support\_\_\_\_\_ 1-2

4. Disclosures: What to Do\_\_\_\_\_ 1-2

6. *Fact Sheets*

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## Introduction

Advocating for people with disabilities that have guardians can be one of the most challenging factors for rape crisis center advocates. Many of the challenges come from confusion about the role of guardians and how they interact with providing the best services to people with disabilities. This section will focus on providing information to make that working relationship the best it can be to benefit people with disabilities.

## Overview of Guardianship

### Do all People With Disabilities have Guardians?

The vast majority of people with disabilities, including cognitive disabilities, do not need guardians. An individual may require assistance from others or accommodations based on their disability but still be able to make informed decisions based on their own preferences. Most importantly, the presence of a physical or mental disability or the age of an individual does not indicate the need for guardianship. **Everyone deserves to exercise control over their own life to the extent possible.**

### What is Guardianship?

Guardianship is a legal designation that places the rights, safety, well-being, and legal choices of a person into the hands of another for the purpose of protection from abuse, neglect, or exploitation. Guardianship is conferred on a relative, friend, guardianship program, or private professional guardian by a judge's decision that a person is deemed incapable of making their own decisions.

### Is There Only One Kind of Guardian?

No. Although most states provide alternatives for guardianship; in general there are three types of guardians:

- **Guardianship of the person**, which involves decisions about an individual's personal life such as where she/he will live, work, go to school, etc.
- **Guardianship of the estate**, with authority over such decisions as money and property.
- **Limited guardianship**, with authority to make only decisions about one thing or a few things. The probate judge decides which decisions and writes them on a paper called an order of limited guardianship. The order of limited guardianship is very clear about what decisions a limited guardian can make.

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## How do I know if a Person has a Guardian?

If you have concerns or questions about whether someone accessing services may have a guardian, the first place to go for information is that person. During the initial contact or intake process, staff should respectfully ask the individual if he/she has a guardian and how to contact the guardian if he/she does. If you are unable to determine guardianship status by talking with the individual, talk to the court with jurisdiction over guardianship cases in your area. Guardianship proceedings are public record; develop a relationship with the appropriate court and court personnel.

## Can Rape Crisis Centers Work with a Survivor with a Guardian?

A rape crisis center should not be deterred from working with an individual based on the possibility that the person has a guardian. If you have questions about a specific person or situation, you should consult with an attorney, local court personnel, or the office of guardianship and advocacy, depending on the need or question.

Guardianship professionals and attorneys agree that there is not a duty for agency staff to investigate whether or not a person has a guardian. However, any agreement signed by an individual with a guardian may be voidable. The same may be true for an individual under limited guardianship, depending on how that guardianship is structured.

### Give us the Words

#### She says she has a guardian. What does that mean?

**Response:** When someone has a guardian, a judge has decided they need help making decisions. There are different types of guardians. Let's find out what decisions her guardian has the power to make.

**Response:** A guardian is appointed by a judge to make decisions on someone else's behalf. A plenary guardians makes most major life decisions. A limited guardian only makes the decisions the court has determined they can make. Either way, we want the person to express what they think, too.

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## What differences are there for an adult with a disability and a minor child in regards to guardianship and receiving services from a rape crisis center?

There are several important ways that access to services, confidentiality and absolute privilege are different for minor children and adults with a disability who have legal guardians.

1. Most adults with disabilities do not have legal guardians. They may receive support from a caregiver(s) with shelter, education, medical care, employment and food, but unless a court has appointed legal guardianship the survivor still retains the right to consent to services.
2. Adults with disabilities may have designated someone to be their representative payee for social security benefits or to be their “health care agent” under a durable power of attorney. This is not the same as guardianship and does not guarantee access to a survivor’s healthcare record. For more information on guardian access to records see §70/5(b) of the Confidentiality of Statements Made to Rape Crisis Personnel statute, 735 ILCS 5/8-802.1.
3. Current Illinois law allows access to counseling services for minors age 12 - 16 without parent/guardian consent. These survivors can now have up to 8 sessions for 90 minutes each according to 405 ILCS 5/Mental Health & Developmental Disabilities Code. Effective 1/1/18. Minors 17 years and older do not need parent/guardian consent for counseling. Adults with legal guardians can have up to 5 sessions for 45 minutes under current Illinois law 410 ILCS 70/5(b).
4. The best practice standard for a legal guardian or health care agent for a person with a disability is to carry out the survivor’s wishes, even if the guardian or health care agent does not agree with those wishes. This standard is called substituted decision-making. It is not always possible for a guardian to know the survivor’s wishes prior to the determination of “incapacity”. In such cases, the legal standard is for the guardian to act in the best interest of the survivor.
5. Absolute privilege is not waived if an adult survivor with a legal guardian of the person consents to having the guardian inspect their records. 735 Ill. Comp. Stat. 5/8-802.1(c)(2)

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6. An adult with a disability who has a legal guardian retains the right to petition the court to have his or her rights fully restored or to modify the guardianship (i.e., from full guardianship to limited guardianship). The Court will hold a hearing to determine the extent to which guardianship is necessary and if the Court finds it is not necessary, guardianship will be terminated or the Court may choose to modify the guardianship.

7. For more information about Illinois Law on Guardians for Adults with Disabilities, see the Illinois Probate Act (755 ILCS 5/) Probate Act of 1975, Article XIa

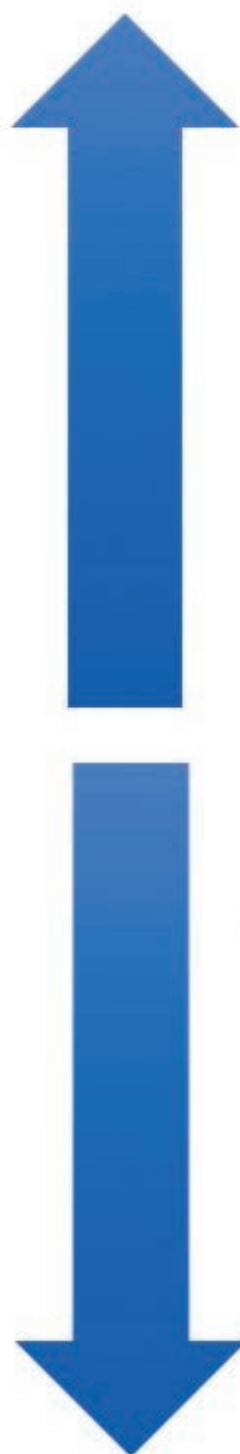
## **How might Advance Directives for a survivor with a disability impact their ability to make decisions in a healthcare setting following a sexual assault?**

Adults with disabilities may have designated a person with power of attorney for health care. This responsibility becomes effective when a person is unable or does not want to make the decision themselves. Having an intellectual disability, autism or communicating differently does not automatically mean the survivor is unable to make health care decisions. It is the responsibility of the physician to assess the individual's capacity to make decisions on their own behalf. If the physician finds the survivor is unable to make decisions about their own healthcare, then the designated healthcare surrogate is authorized to decide on behalf of the survivor.

For survivors with a history of psychiatric treatment, there is an advance directive called the Declaration for Mental Health Treatment which covers both treatment choices and the appointment of an agent. This healthcare surrogate is called an "attorney in fact" under Illinois law and can step in to make mental health treatment decisions if the survivor is unable to do so for themselves. In the Declaration for Mental Health Treatment, the survivor can document choices about medications, treatment and/or psychiatric hospitalization. For more information about this law, see (755 ILCS 43/) Mental Health Treatment Preference Declaration Act.

The advocate can help support the survivor to maintain their rights in the healthcare setting.





## Least Restrictive

- Fewest Restrictions
- Shorter amount of time involved in individual's decision-making
- Tailored to Individual's Capacities & Needs

### **SELF-DETERMINATION**

- Supported Decision-making
- Advanced Directives (i.e., Durable Power of Attorney)
- Substitute Healthcare Decision Making (for those not having a Power of Attorney)
- Representative Payee (Social Security benefits)

## Most Restrictive

- More restrictions
- Increasing up to full involvement in individual's decision-making
- Must act in Best Interest of Ward

### **SURROGATE DECISION-MAKING**

- Temporary Guardianship
- Limited Guardianship
- Full Guardianship (Plenary)

**The National Guardianship Association states that a guardian should only be appointed if alternatives "have proven ineffective or are unavailable."**



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## Give us the Words

**Whom should I be talking to here?**  
**This woman has a guardian and she's incompetent.**

**Response:** Even though she has a guardian, she still has the right to speak for herself..

**Response:** "Incompetent" is a legal term. It doesn't mean she can't express herself.

**Response:** Let's ask her who her guardian is, and what kind of information they want.

**Response:** It is important that the victim have an opportunity to tell what happened to her. Victims with guardians have rights and it is the victim who knows what happened to them.

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## What Should a Parent/Guardian Do

As an advocate working with guardians, remind them of the following items once a victim has disclosed sexual abuse. You may also give them the “Disclosures: What to Do” handout on the following page.

- **Do not push** your loved one to talk about the experience.
- **Restore** your loved one’s sense of control. Allow her to help decide what to do. Provide assurance that you will be there to help.
- **Be honest** with your loved one. Share what you know. Trust is more important than ever at this time.
- **Give** your loved one safety information, but avoid causing more fear of people.
- **Maintain routines** and return to your family’s usual activities as soon as possible. Don’t become too protective. You want to calm any sense of emergency and not escalate the fear and anxiety.

## Supporting a Parent/Guardian After Disclosure of Abuse

As an advocate it is important to understand that the parent/guardian of a survivor needs support as well. Working with parents/guardians of those with a disability, is the same as supporting any other parent/guardian. Be prepared to discuss medical and criminal justice responses, the response of the disability service agency, rape crisis center services. Additionally, remember to inform and reassure the parent/guardian regarding the following key issue areas.

- Emphasize that the child is not to blame for the abuse. Reassure the parent/guardian that they also are not to blame. Remind the parent/guardian that the abuser is the only person responsible for the abuse.
- Explain to the parent/guardian that anger, depression, sexualized behavior, and/or shame are normal reactions to sexual abuse. Talk with them about how to cope with their child’s reactions to the abuse.
- Strategize with the parent/guardian regarding how they can care for themselves. Remind them that their child needs them more than ever. They may feel angry or upset that their child did not tell them sooner or embarrassed that this happened. Tell them these are normal feelings that they may wish to share with a rape crisis center counselor. Remind them that it is important for them to find support in order to support their child.

## Disclosures: What to Do

As a parent or guardian, you are a primary resource of support and aid for your loved one with a disability. It may be that you are the first person she chooses to talk to if she experiences sexual violence.

Here are things for you to remember if your loved one tells you they have been a victim of sexual assault:

### Immediate response:

#### Tune in/Listen:

- Take a deep breath.
  - Be quiet and let them tell the story.
    - Keep breathing.
      - Stay as calm as possible.
        - Believe what they tell you.
          - Do not blame or judge or punish.

#### Say:

- I believe you.
    - I am sorry this happened to you.
      - This was not your fault.
        - You are not alone.
          - You are brave to tell.
            - Thank you for trusting me with this.
- 

**Ask:** How can I help you? What do you need right now?

**Tell:** A crisis center in town can help you – on the phone or in person.

**Help:** Would you like to call them? I can help with that if you want.

**Protect:** What would make you feel safe right now? Let's make a safety plan.

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## Legal Something

The graphic boxes on pages ##-## contain information on the sexual assault evidence collection kit process, counseling records and counseling options available legally to people with disabilities. Pages ##-## are directed toward agency staff and pages ##-## for self-advocates.

### **Access to Health Care and Evidence Collection for Sexual Assault Victims with Disabilities**

Consent of a guardian, health care surrogate or health care power of attorney is not required in order for a victim with a disability to receive health care or release forensic evidence following a sexual assault.

If a victim with a disability is unable to consent to medical forensic services (i.e. health care and evidence collection), the services may be consented to by the persons listed in the Health Care Surrogate Act, in the following order of priority;

1. the patient's guardian of the person;
2. the patient's spouse;
3. any adult son or daughter of the patient;
4. either parent of the person;
5. any adult brother or sister of the patient;
6. any adult grandchild of the patient;
7. a close friend of the patient;
8. the patient's guardian of the estate.

If a victim with a disability is unable to consent to the release of evidence, and the victim's guardian, health care surrogate or health care power of attorney is unavailable or unwilling to release the information, an investigating law enforcement officer may release the evidence.

#### **Decisional Capacity**

A physician (not a team of professionals) decides whether the victim with a disability has "decisional capacity," or the ability to make decisions about her own health care and releasing evidence. The physician makes a decision after having a conversation with the victim and exercising professional judgment.

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## **Right of Adults with Guardians to Control the Privacy of Their Rape Crisis Center Records**

An adult with a guardian can:

- Decide whether their guardian can look at their rape crisis center records; and
- Decide whether or not to waive the rape crisis center privilege.

If a court decides that the adult with a guardian is not capable of making an informed decision about waiving the privilege, the guardian can do so, provided that the guardian's interests are not adverse to the interests of the adult.

## **Rights of Adults with Guardians to Obtain Short-Term Counseling**

An adult with a guardian can attend up to five, 45-minute counseling sessions without the consent of, or notice to, the guardian unless the counselor or therapist believes such disclosure is necessary.

If a counselor or therapist decides to disclose the fact of counseling or psychotherapy to the guardian, the counselor must inform the adult with a guardian.

The guardian is not responsible for the costs of counseling or psychotherapy received by the adult without the consent of the guardian.

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## **You can get Health Care or Release an Evidence Collection Kit after Sexual Assault**

You get to decide if you will go to the hospital to see a doctor after a sexual assault. You do not have to ask your guardian or anyone else if you can go to the hospital.

You can decide whether evidence of the assault is collected at the hospital. Some people call this an evidence collection kit.

You get to decide whether the evidence collection kit is sent for testing. If you consent, the police will take the evidence collection kit to a crime lab to look for evidence. If you want more time to decide whether to send the evidence collection kit for testing, you can have the kit held by police for 10 years and sign the form for testing later.

If you can't give consent, your guardian, health care surrogate or health care power of attorney may be asked. If that person can't be reached or will not release the information, the police officer may release the information.

## **You Can Get Short-Term Counseling**

You do not have to tell your guardian that you want to see a counselor. You can see the counselor up to five times without telling your guardian.

If the counselor thinks there is a need to tell your guardian about the counseling, the counselor must tell you that.

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## **You Decide Who Looks At Your Rape Crisis Center Records**

Your records at a rape crisis center are absolutely private even if you have a guardian. You control who looks at your rape crisis center records. You do not have to tell anyone what you talk about with your counselor.

You can decide if your guardian can look at your rape crisis center records.

You can give up the right to keep your rape crisis center records private if you think it will help you to let someone else (like a lawyer or a social worker) see your records.

If a judge decides you are not able to make this decision, the judge can say it's okay for your guardian to see your records if the judge thinks that is best for you.

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# Section 4: Navigating the Medical System



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# SECTION 4: NAVIGATING THE MEDICAL SYSTEM

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## Introduction

Following a sexual assault, victims may be overwhelmed with the healthcare decisions that need to be made in a relatively short amount of time. Medical advocates play an important role in explaining options, providing support and lending assistance with navigating the medical system. Some people with disabilities may have limited experience making healthcare decisions on their own and will greatly benefit from having an advocate with them throughout the process. It is important that advocates understand the additional barriers and challenges faced by people with disabilities who experience sexual violence and be ready to advocate on behalf of these victims.

Potential factors influencing victims with disabilities' experience with the medical system:

- Not previously having a pelvic exam.
- Being sensitive to sounds, smells, bright lights and fast pace of Emergency Department.
- Emergency Department's not being accessible including attitudinal, physical and communication barriers.
- Medical staff not being comfortable, confident or knowledgeable in supporting victims with disabilities through the exam process.
- Interference of others, i.e. staff, family, guardians
- Mandatory reporting which did not provide choice to the victim
- Limited knowledge of genitals, sexual activities and reproduction
- Limited experience with intimate relationships

**“We know that effective collection of evidence is of paramount importance to successfully prosecuting sex offenders. Just as critical is performing sexual assault forensic exams in a sensitive, dignified, and victim-centered manner. For individuals who experience this horrendous crime, having a positive experience with the criminal justice and health care systems can contribute greatly to their overall healing”**

**A National Protocol for Sexual Assault Medical Forensic Examinations Adults/Adolescents Second Edition U.S. Department of Justice Office on Violence Against Women  
April 2013**

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## Medical Advocacy

Seeking medical care after an assault can be difficult for people with disabilities. Many people with disabilities have guardians who typically make decisions regarding medical care for the survivor. Even people who are their own guardians may be accustomed to asking for input from others before making decisions. They may not be used to making their own decisions about what they want. Therefore, it is important to emphasize that they have the ability and the power to make the decision they think is best, and that there isn't a "wrong" decision if it's what the survivor wants to do. A survivor with a guardian can legally consent to emergency department services, forensic services and follow-up healthcare. They can also consent to release evidence and information about the sexual assault. If the survivor is unable to provide this consent and the guardian is unable or unwilling to do so, law enforcement may authorize the release the evidence kit.

**When working with a survivor in the emergency department it is helpful to keep the 4 C's in mind:**

- Choice
- Communication
- Compliance
- Consent
- Confidentiality

## Choice

Some people with disabilities may not be accustomed to being asked their opinion or being given the opportunity to make choices. They may be used to staff, family members, caregivers or friends speaking on their behalf. The advocate's role in promoting survivor-center choices is crucial.

**Ways to promote choice include:**

- Take the time to explain choices thoroughly
- Avoid overwhelming the victim by presenting options one at a time and checking for understanding
- Offer information in the language best understood by the victim
- Allow adequate time for the victim to process information
- Advocate with medical staff for providing sufficient time for the victim to make own choices

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## Communication

As with any person who has been traumatized, the patient may have problems understanding or processing the information you give her. It is important to communicate with the survivor on their level. Depending on the type of disability they are experiencing and her trauma-response, you may need to explain ideas or procedures multiple times or in different ways. As always, speak to the patient in terms they can understand, not at them, so please be mindful of the language you are using. Words that express complicated ideas may not be understandable to everyone, so be clear and concise when working with someone experiencing this kind of trauma.

### General Communication Tips

- Talk directly to the Patient, not staff or family.
- Use normal tone of voice.
- Be at eye level when possible.
- Use Patient's primary mode of communication.
- Give the patient time to respond.
- Do not interrupt or try to finish the sentence.
- Ask permission before touching person or possessions and/or communication devices.
- Ask sensory questions; e.g., what did you see? What did you feel? etc.

### To understand the patient

- Listen closely.
- Ask the patient to repeat what you do not understand.
- Repeat the words you do understand and pause.
- Use pictures, spelling, writing, 'showing', etc.
- Text when applicable.
- Do not pretend to understand.
- You will get better with practice.

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## To help the patient understand you

- Use plain language; use concrete words.
- Use short sentences; one concept at a time.
- Use pictures and gestures.
- Avoid jargon, technical terms, acronyms, sarcasm, words with multiple meanings.
- Ask patient to repeat what you have said

## Compliance

Some people have life experiences where their value is dependent on being compliant — doing what they are told. Some live in a culture of compliance and get in trouble if they do not ‘cooperate’. It is critically important that the patient is given many choices and given permission to say ‘no’ without judgment or negative consequence. It may take time for the to believe it is ok to say no.

Ways to promote address compliance:

- Be prepared to respond to questions, such as, “What do you think I should do?”
- Be aware that family members, staff, caregivers, etc. may try to influence the victim’s decisions.
- Pay attention of your nonverbal communication. Victims may be looking for signs of what you think is the best choice.
- Ask patient what they want and if they give permission.

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“I waited in the Emergency Room for hours because they couldn’t figure out how to get me on the table.”

**Survivor of sexual assault**

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## Consent

### Ways to promote address consent:

- Become educated about consent and people with disabilities (see SASETA and The HealthCare Surrogate Act – add links)
- Be aware that patient - first choice is the standard regardless of guardianship status, i.e. guardians cannot force a rape kit when a person with a disability has indicated through verbal or nonverbal communication that they do not want one done.
- Advocate for victim choice with medical personnel. The standard for patient ability to consent to a rape kit is much lower than capacity to be one's own guardian. Advocates need to understand the special medical obstacles to services that people with disabilities may encounter after a sexual assault. Advocates must work with medical staff to collect evidence or provide care. Advocates must work to understand the impact the specific disability may have on each victim. Don't be afraid to talk with the person with disability to better understand the obstacles and discover ways to work within the limitations to provide the best victim-centered care.

### Give us the Words

**I don't think I can examine her. She is too disabled.**

**Response:** Let's ask her the best way to examine her.

**Response:** I know some alternative positions that might work. Let's ask her what she prefers.

**Response:** There is a tool that might be helpful in working with the survivor - it is the Picture Guide to Exam Following Sexual Assault. It is helpful with many victims.

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## Confidentiality

Maintaining client confidentiality is paramount to rape crisis services; however, there are some exceptions related to people with disabilities.

The Elder Abuse and Neglect Act was revamped in July 2013 and is now known as the “Adult Protective Services Act.” There were a number of changes, including protection of not only adults who are 60 and older, but also for “adults with disabilities.” The Adult Protective Services Act defines an “adult with disabilities” as “a person aged 18-59 who resides in a domestic living situation and whose disability ... impairs his or her ability to seek or obtain protection from abuse, neglect or exploitation.” As part of the many changes in this area of the law, The Illinois Department on Aging now investigates abuse and neglect against adults with disabilities living in the community. Prior to July 2013, the Office of the Inspector General investigated these cases. There were numerous changes to this area of law, and although they are all important, we need to address the issue of responsibilities of the centers to report abuse, neglect or exploitation for clients falling under this Act.

### **Impact on Rape Crisis Center Advocates**

Although Rape Crisis Centers are not specifically named as mandated reporters in the Abused and Neglected Child Reporting Act (ANCRA), 325 ILCS 5/1, et seq., we believe it was the intent of the legislature to include rape crisis center personnel as mandated reporters because centers provide social services. In the same vein, although centers are not specifically named in the Adult Protective Services Act, it seems the intent is to have those professionals engaged in “social services” to be mandated reporters of abuse, neglect, or exploitation for both elders and adults with disabilities. So, rape crisis center personnel are mandated reporters under ANCRA and the Adult Protective Services Act. Even as a mandated reporter, you must understand under what circumstances you are mandated to report abuse, neglect, or exploitation.

As a mandated reporter of abuse, neglect or exploitation against elders and adults with disabilities, it is imperative to understand when you are mandated to report. The Adult Protective Services Act says that a mandated reporter who has reason to believe that an “eligible adult, who because of a disability or other condition or impairment is unable to seek assistance for himself or herself, has, within the previous 12 months, been subjected to abuse, neglect, or financial exploitation, the mandated reporter shall, within 24 hours after developing such belief, report this suspicion to an agency designated to receive such reports under this Act or to the Department.”

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So, what are the circumstances in which you are mandated to report? You should report when you have reason to believe all three of the following are true:

- 1) The client is an “eligible adult” (adult with disabilities aged 18-59 or a person aged 60 or older who resides in a domestic living situation and is, or is alleged to be, abused, neglected, or financially exploited by another individual or who neglects himself or herself).
- 2) The client is unable to seek assistance for himself or herself. Note, this does not include an eligible adult who is able to seek assistance for himself or herself, but is unwilling to do so.
- 3) The abuse, neglect, or financial exploitation happened within the previous 12 months.

If all of the above criteria are met, as a mandated reporter you SHALL within 24 hours after developing such belief. Contact Adult Protective Services at 1-866-800-1409. For more information, see Illinois Department on Aging (2014) What Professionals Need to Know: Understanding your new responsibilities as a mandated reporter under the recently instituted Adult Protective Services Act.

Although rape crisis center staff are mandated reporters of abuse against adults with disabilities, please remember to take great care in determining whether you should call Adult Protective Services. Other social workers, such as elder abuse investigators may make a mandated report when they determine an adult is not able to self-report out of fear or concern for the abuser. Those social workers do not have an absolute privilege with their clients and follow different agency policies.

Always take a victim-centered approach and decide whether to report on a case-by-case basis. An adult with disabilities may love the abuser, who is likely a family member or friend, and may not recognize what is happening as abuse. The victim may also be dependent on the abuser for physical or financial help. If an adult with disabilities is able to self-report, work with the individual to recognize that she or he is being abused and provide support for the person who decides to report the abuse. Also be prepared to refer the victim to other agencies for assistance, such as finding new housing or a new personal assistant.

Some people with disabilities are not accustomed to their information being kept confidential. They may receive services from a disability service provider and information is shared more freely among staff as confidentiality laws differ from rape crisis center absolute privilege. Additionally, disability providers may be required to share information



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with guardians. If a sexual assault is disclosed, a guardian may need to be notified in addition to mandatory reporting to the appropriate authority (Office of Inspector General, Adult Protective Services, Department of Public Health).

When explaining to victims with disabilities that have a guardian, it is important for advocates to distinguish between the confidentiality requirements for rape crisis center staff and others. If guardians may be notified of sexual violence against the survivor's wishes, advocates can be helpful in preparing the individual for this action.

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## Support During the Exam

The support that advocates provide truly makes a difference in whether victims with disabilities can fully access the healthcare and criminal justice systems. The connection to advocacy services, often begin for the survivor at the hospital soon after the sexual assault. This experience of sexual assault makes it difficult for survivors to navigate the medical system and understand their rights and make decisions. As mentioned previously in this Guide, people with disabilities may come to this experience with little understanding and/or experience with intimate relationships and may limited opportunities to make decisions for themselves.

### Tips for supporting Survivors with disabilities:

- Support the person in expressing her preferences and needs. You may say something like, “It is important for you to let medical staff know how you can best be worked with and any accommodations you may need. You are the expert on your body and your needs, so you can help them.” See [http://www.acog.org/About\\_ACOG/ACOG\\_Departments/Women\\_with\\_Disabilities/Interactive\\_site\\_for\\_clinicians\\_serving\\_women\\_with\\_disabilities](http://www.acog.org/About_ACOG/ACOG_Departments/Women_with_Disabilities/Interactive_site_for_clinicians_serving_women_with_disabilities). Part 2 The GYN Examination, GYN Health Screening, Sexually Transmitted Disease and Skin Examination for detailed information.
- Advocate for victim choice with medical personnel.
- Advocate for necessary accommodations during the exam. See Access to Medical Care for Individuals with Mobility Disabilities. [https://www.ada.gov/medcare\\_ta.htm](https://www.ada.gov/medcare_ta.htm)
- Be attentive to nonverbal and verbal clues that they are not understanding the questions or information. Assist the person in understanding what words mean.
- Provide explanations in language that the individual understands and supply educational materials in preferred communication method, i.e. large print, audio, pictures. See Accessing Safety in Hennepin County, Picture Guide to the Medical Exam after Sexual Assault <https://www.endabusepwd.org/wp-content/uploads/2015/11/ASHC-Picture-Guide-to-the-Medical-Exam-after-Sexual-Assault.pdf> and Illinois Imagines Picture Guide <http://www.icasa.org/docs/illinois%20imagines/safe-self-advocates%20final.pdf> series for self-advocates for picture based, plain language explanations.
- Validate for the survivor that there may be some questions that are difficult to answer and they can take their time to answer.

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- Assure them that it is common for people to forget or have trouble answering questions after experiencing a sexual assault. Let them know that it is okay to add information later during the exam if they forget something.
  - Advocate for the equipment to be swabbed and returned to the victim in a situation in which law enforcement wants to keep the equipment for evidence.
  - Encourage medical staff to allow the survivor to see or touch sample equipment before use.
  - Encourage medical staff to be patient and give survivor time to respond and answer questions.
  - Encourage the survivor to let medical staff know if anything makes them uncomfortable or causes pain. Remind the survivor (and medical staff) that they are the expert on how their body works, i.e. best position for exam, needed supports, transfer tips. Certain positions or smaller instruments may be options that would make the situation more tolerable and less traumatizing for survivors with disabilities.
  - Provide resource information to medical staff if assistance is needed for accommodations, i.e. local Center for Independent Living, ASL interpreters, alternative exams.
  - Discuss follow-up and identify the best means of communication to reach them.
  - Model respect and good communication with the survivor to other medical personnel.
  - Provide reminders that they can refuse any procedure while agreeing to others, and they can stop at any time.

## **Picture Guide to the Exam After Sexual Assault**

Illinois Imagines created a series of tools to support the exam process after sexual assault for people with disabilities. The tools were created for three populations: medical staff, advocates (victim and disability services) and self-advocates. The materials include a picture based powerpoint which can be loaded onto a tablet and brought into the examining room to explain the exam process, related instructional materials and a plain language victim's rights handout. Rape crisis center advocates are encouraged to become familiar with all three sets of materials and to utilize them as a part of direct service with individual clients and in institutional advocacy efforts. In this guide we have the one for advocates and medical staff. The full set of tools can be accessed through [www.illinoisimagines.org](http://www.illinoisimagines.org).

# Picture Guide to the Exam After Sexual Assault for Advocates

## About this Guide

The Picture Guide to the Exam After Sexual Assault for Advocates and the accompanying resources were developed to enhance access to sexual assault forensic examinations for people with disabilities. The tools include:

- Picture Guide to the Exam After Sexual Assault for Advocates who support survivors of sexual assault during sexual assault forensic examinations
- Instructional guidelines for medical advocates and other advocates to accompany the slides and notes
- Victims' Rights Regarding the Exam After Sexual Assault

## Medical Advocacy with People with Disabilities

As with any survivor, a person with a disability needs to know that you are there to help and support them through the process.\* Telling the survivor that you are sorry that the assault happened and that you believe them is extremely important. In some cases, a person with a disability can be seen as having a history of lying or having “behaviors” for attention, so authority figures may not listen as fully. It is important to let them know that their credibility is not in question with you. Also, they need to know you are not part of the investigation, so you do not need to know all of the details about what happened.

When you are providing medical advocacy to a woman with a disability, there are some considerations to keep in mind. She may not have had access to gynecological care in the past, and the pelvic exam provided with the healthcare exam and evidence collection process may be her first. This can add a lot of stress, fear, and additional trauma to an already overwhelming experience. Find out if she has previous experience with gynecological care, but do not assume that this is the case for every survivor with a disability. Listen to the survivor rather than making assumptions about her. If a survivor has not had a previous ‘well woman’ exam, use the slide in the PowerPoint and a speculum to explain what will happen. The medical staff may do this or ask you to assist. Either way is fine as long

as the survivor gets the information she needs. If the survivor seems upset by the picture, ask if she wants you to stop showing it. In that case, explain without the picture. Remember, she is in control of the process.

Please review the PowerPoint slides, notes, and victim rights statement so you are prepared to advocate for survivors with disabilities in the best manner possible.

## **Using the PowerPoint Presentation**

The PowerPoint slides were developed to help you assist survivors with disabilities who are seeking medical treatment and evidence collection after a sexual assault. If you are a rape crisis center advocate, you may be familiar with the evidence collection kit and process, but the one shown here may vary from your personal experience. Please adapt this when necessary to make it useful in the hospitals where you provide services. For other advocates working in the community who are not familiar with the process, we are hopeful that this information will better prepare you when working with a survivor in an emergency room.

## **The Victim Should Not Be Billed for Medical Examinations and Evidence Collection Related to a Sexual Assault**

Please let the survivor know that the medical examination is free. If they do receive a bill for any part of their healthcare, advocate with the provider with the survivor's consent.

## **Privacy of Information and Mandated Reporting**

Medical advocates at rape crisis centers have absolute confidentiality, but other professionals in the community may be mandated reporters. Give the survivor accurate information about who might have to report that a crime occurred. If you are unsure, tell them you will help them to find out.

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## **The Role of the Advocate**

Many survivors describe the medical examination and evidence collection process as overwhelming, scary, and painful. As an advocate, you know you cannot prevent any of these from being true, but you can help a survivor make informed choices, ensure their rights are protected, and understand the process as best as possible. This is the case when working with survivors with disabilities. The role of the advocate is the same no matter who the survivor is, so the goal of this information is to help you meet the survivor's needs.

As with any person who has been traumatized, the survivor you meet with at the hospital may have problems understanding or processing the information you give them. Depending on the type of disability the survivor has and their trauma-response, you may need to explain ideas or procedures multiple times or in different ways. As always, speak to the survivor in terms they can understand, not at or above them, so please be mindful of the language you are using. Words that express complicated ideas may not be understandable to everyone. Be clear and concise when working with someone experiencing this kind of trauma. You may need to find other methods of communication, such as pictures.

## **The Victim's Rights**

A survivor with a disability has the exact same rights as any other survivor when reporting an assault, receiving medical care or going through the evidence collection process following the violence. The advocate's role is to ensure the survivor has the information they need to make decisions around these rights and procedures. Just like anyone else, they can refuse to participate in any part of the process or to any medical procedure. There are no exceptions to the right of refusal. They can say no to an anal or vaginal examination. Our job as advocates is to make sure they have information about their rights when making decisions and to assist them in making these decisions known to the medical staff. When the survivor is asked to sign consent for medical treatment and evidence collection, make sure they understand what they are being asked to sign and what the consequences are if they do not sign.

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## **Advocacy with Family Members, Caregivers and Guardians**

Family members, caregivers, and guardians of people with disabilities sometimes feel entitled to make decisions on their behalf. In the state of Illinois, the survivor is the person who has the right to consent to evidence collection following a sexual assault. If a family member, caregiver, or guardian insists on making decisions, advocate on behalf of the survivor by explaining their rights to this person. Please understand that this person is trying to help as best they know how, so when having this conversation, do not alienate the person you are working with. It may be best to say something such as, "While I understand you are trying to help, only the survivor has the right to make these decisions, and our job is to help support their in these decisions."

## **Advocacy with Medical Staff**

When you provide advocacy and support to a survivor with disabilities, you and the medical staff need to know what accommodations the survivor needs to fully participate in the process. The survivor may need communication accommodations and/or physical accommodations. Communication accommodations might include, but are not limited to, a certified American Sign Language (ASL) Interpreter, Braille consent form, individualized communication device, picture book, or someone who understands the survivor's speech. \*

Physical accommodations typically involve accommodations to lift the survivor onto the examination table and/or alternate positions for the gynecological portion of the examination. The survivor knows what will work best and the advocate can support the survivor in reinforcing her needs and receiving her needed accommodations.

\*The local Center for Independent Living may be a helpful resource for assistance with accommodations. [www.incil.org](http://www.incil.org)



# Picture Guide to the Exam After Sexual Assault for Medical Staff

## About this Guide

The Picture Guide to the Exam After Sexual Assault for Medical Staff and the accompanying resources were developed to enhance access to sexual assault forensic examinations for people with disabilities. The tools include:

- Picture Guide to the Exam After Sexual Assault for Medical Staff and notes for medical staff who conduct sexual assault forensic examinations
- Instructional guidelines for medical staff to accompany the slides and notes
- Sexual Assault Treatment Checklist
- Sexual Assault Evidence Collection Guide
- Victims' Rights Regarding the Exam After Sexual Assault

## Providing Medical Care for a Person With a Disability

As with any survivor, a person with a disability needs to know that you are there to help and support them through the process.\* Telling the patient that you are sorry that the sexual assault happened and that you believe them is extremely important. In some cases, a person with a disability can be seen as having a history of lying or having “behaviors” for attention, so authority figures may not listen as fully. It is important to let them know that their credibility is not in question with you.

Communicate with the patient that the most important reason for her to have an examination is to make sure she is ok and to provide treatment and resources she may need. The evidence collection is only one aspect of the process and the patient can decide later if she wants the samples released to the police.

The fast pace of the emergency department with its many sounds, smells and bright lights can be unnerving for any patient, and for a survivor with a disability it may be extremely confusing and scary. Preparing patients with disabilities for what to expect during the medical and forensic examination will allow for the



opportunity to build rapport, ease fears and consider what assistance may be needed during the examination.

Taking the time to explain examination procedures to patients may reduce potential emotional distress and risk of rape trauma syndrome symptoms following the assault. Remember to contact an advocate from the local rape crisis center to assist you with the process of preparing your patient for the examination. Go to [www.icasa.org](http://www.icasa.org) to find a rape crisis center near you. Services are free and confidential.

As with any person who has been traumatized, the patient may have problems understanding or processing the information you give her. It is important to communicate with the survivor on her level. Depending on the type of disability she is experiencing and her trauma-response, you may need to explain ideas or procedures multiple times or in different ways. As always, speak to the patient in terms she can understand, not at or above her, so please be mindful of the language you are using. Words that express complicated ideas may not be understandable to everyone, so be clear and concise when working with someone experiencing this kind of trauma.

### **Accommodations May Be Needed**

#### **The patient may need communication accommodations.**

Some general tips that might help you communicate with a patient with disabilities include the following: Avoid medical jargon, acronyms, words with multiple meanings and sarcasm; limit sentences to one idea or concept; ask the person to repeat what you have said in their own words; and if you cannot understand what the patient says, ask her to repeat it. Communication accommodations include, but are not limited to, a certified American Sign Language (ASL) Interpreter, Braille consent form, individualized communication device, picture book, or someone who understands the patient's speech. There are a variety of communication strategies in the Illinois law enforcement protocol which can be found at: [www.ifvcc.org](http://www.ifvcc.org).

In obtaining consent(s) for the medical examination and evidence collection, take your time and explain the complicated concepts in plain language. The consent may use complicated language so break it down so it is easier to understand. Also, explain the consequences of not signing the consent so the patient is fully informed. In Illinois, victims with guardians maintain their right to consent to a sexual assault examination. When the patient signs the consent(s), it is still best practice to obtain her permission for each step of the examination and evidence collection process. Explain any applicable mandating reporting that may occur.

### **The patient may need physical accommodations.**

Physical accommodations typically involve accommodations to lift the patient onto the examination table and/or alternate positions for the gynecological portion of the examination. The patient knows best what will work and the medical staff and advocate can support the patient in expressing her needs and receiving accommodations. If another person is needed to provide physical support during the pelvic examination, be sure to introduce the person to the patient as early in the process as possible to establish some rapport and control.

As the examination is taking place, tell the patient everything that is happening. For example: "The special light may cause areas to glow that could be used as evidence. Collecting a sample is the only way we can tell if it is useful." In this example, if there is a spot on the patient's leg that glows, you can ask her if she would like to see it. It is important that the patient knows that she is a partner with you in the examination process. Following a traumatic event, the opportunity to gain a sense of control is critical to the patient's immediate well-being as well as her ongoing journey of healing.

### **Additional Considerations**

The pelvic examination is thought to be the most difficult part of the examination for many patients. Keep in mind that some patients with disabilities may not have had access to gynecological care in the past, and the pelvic exam provided with the healthcare exam and evidence collection process may be her first. This can add a lot of stress, fear, and additional trauma to an already overwhelming experience. Find out if the patient has previous experience with gynecological care, but do not assume that this is the case for every patient with a disability. Listen to the patient rather than making assumptions about her. If a patient has not had a previous 'well woman' exam, use the slide in the PowerPoint and a speculum to ex-

plain what will happen. If the patient seems upset by the picture, ask if she wants you to stop showing it. In that case, explain without the picture. Remember, she is in control of the process.

## **Using the PowerPoint Presentation**

The PowerPoint slides were developed to help adolescent and adult patients with disabilities who have been sexually assaulted to prepare for and better cope with the medical and forensic examination that usually takes place within 7 days following a sexual assault. If you are a Sexual Assault Nurse Examiner, you may not need all of the information in this guide. However, many hospitals do not have SANE nurses available so this guide was written to help in a wide variety of situations. The medical examination and evidence collection procedures at the hospital where you work may vary from the order presented in the slides; please adapt this when necessary to make it useful in the hospitals where you provide services. If you have had no training on the sexual assault examination procedures, please review the Sexual Assault Treatment Checklist and the Sexual Assault Evidence Collection Guide (based on Illinois protocol).

Another consideration to keep in mind is that a caregiver, family member, or support staff may be the offender. This fact makes it even more important that you are able to communicate with the victim alone and do everything possible to empower the victim to make her own decisions about the exam and release of evidence. Some possible resources to assist with this include: rape crisis center medical advocate, Center for Independent Living, or medical social worker.

## **Following are some tips for helping patients to be as comfortable as possible.**

- Provide a private place to talk with the patient, take her history and take the necessary time to utilize the Picture Guide.
- In Illinois, an adult sexual assault patient has the right to decide to have the exam and to have evidence collected or not, even if the patient has a legal guardian.
- All patients have the right to decline any portion of the exam or evidence collection kit.

- Use simple language and the patient's terminology for body parts.
- Ask the patient what position she is the most comfortable in when conducting the examination procedures; if she is not comfortable in one position, try others.
- Allow the patient to assist when possible in activities such as combing through her hair or swabbing inside her cheek or gum line.
- Explain to the patient at each step of the exam what you are about to do and ask if it is ok. Ask the patient after each step if she has any questions about what she just experienced. It is helpful to have the patient repeat what you said or to share what she heard or understood. Asking yes or no to check understanding is often misleading.
- Demonstrate what you are about to do when possible. Provide the patient with a swab to hold, touch a swab to the patient's hand, let her hold a speculum, demonstrate how the speculum works and sounds, demonstrate use of alternate light source on your own arm.

Please review the PowerPoint slides, notes, checklists, and victim rights statement so you are prepared to advocate for patients with disabilities in the best manner possible.

\*\*The local Center for Independent Living may be a helpful resource for assistance with accommodations. [www.incil.org](http://www.incil.org)

Kim Day, RN, SANE-A, SANE-P, SAFETa, Project Director with the IAFN, can be contacted for questions about sexual assault forensic examinations. You may contact Kim at [kimday@ForensicNurses.org](mailto:kimday@ForensicNurses.org).

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## **Victims' Rights Regarding the Exam After Sexual Assault**

A survivor with a disability has the exact same rights as any other survivor when reporting an assault, receiving medical care or going through the evidence collection process after the violence. A rape crisis center advocate can ensure you have the information you need to make decisions around these rights and procedures. You can refuse to participate in any part of the process or to any medical procedure. An advocate can make sure you have the information you need when making decisions and help you make these decisions known to the medical staff.

### **Survivors of sexual assault have the right to:**

1. "free" medical care and evidence collection;
2. accommodations that you need and prefer;
3. a more private space;
4. have a rape crisis center advocate with you during the exam to help you know your rights and communicate your choices;
5. have a support person of your choice with you during the exam;
6. qualified staff who follow standard procedures;
7. request a medical staff member by gender, if available;
8. know what is being done and why;
9. ask questions about the exam and have information provided in a way you can understand;
10. say no to any part of the exam or the entire exam;
11. understand what you are signing;
12. NOT release the kit to anyone;
13. know results of any tests;
14. know what medicines are for;
15. have 'free' follow-up with a doctor of your choice and medications needed;
16. be informed about medications, risks, and options regarding pregnancy; and
17. choose whether or not to talk to the police and to have a support person with you if you choose to talk to the police.



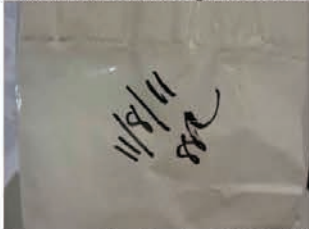
## Illinois Sexual Assault Nurse Examiner (SANE) Training Program

### Sexual Assault Treatment Checklist

#### Overall Considerations:

|  |   |
|--|---|
| * PATIENT MAY DECLINE ANY COMPONENT AT ANY TIME                        | * NEVER LEAVE THE SA KIT UNSECURED/UNATTENDED |
| * USE "DECLINED" NOT "REFUSED"   | * NEVER USE TERM "ALLEGED"                    |
| * LAW ENFORCEMENT IS NEVER IN ROOM DURING EXAM                         | * USE TERM "PATIENT" NOT "VICTIM"             |
| * WITH PATIENT CONSENT THE MEDICAL ADVOCATE MAY BE PRESENT DURING EXAM |   |

\*\*\*Evidence Collection Kit shall be completed if the patient presents himself/herself within **7** days of the sexual assault.

| Actions   | Yes/No | Comments |
|---|--------|----------|
| Registration: General consent for treatment obtained  |        |          |
| Identify patient as sexual assault  |        |          |
| Patient briefly triaged, assigned ESI 2 and placed in a private room  |        |          |
| SANE called and/or primary RN assigned  |        |          |
| Notifications: <ul style="list-style-type: none"> <li>• Call medical advocate</li> <li>• Law enforcement</li> <li>• Other mandated reporting agencies</li> </ul>  |        |          |
| Medical screening exam completed by ED MD <ul style="list-style-type: none"> <li>• Address all emergent medical concerns</li> </ul>   |        |          |
| <b>Prior to starting exam</b> obtain all supplies needed (see recommended supply list)  |        |          |
| Open kit and utilize checklist from Sexual Assault ISPECK kit <ul style="list-style-type: none"> <li>• <b>Obtain patient consents and authorization to release</b></li> </ul>   |        |          |
| Complete patient history including detailed forensic history of the assault <ul style="list-style-type: none"> <li>• Use the medical-forensic documentation form in the ISPECK kit as a guide</li> </ul>  |        |          |
| Collect patient clothing and examine for stains and marks <ul style="list-style-type: none"> <li>• Place in paper bags only</li> <li>• One item per bag</li> <li>• Label and seal each bag (see below for proper seal label – initial and date starting on the container and crossing onto the clear tape)</li> </ul>    |        |          |
| Complete evidence collection as outlined in the ISPECK KIT (see evidence collection guide) <ul style="list-style-type: none"> <li>• All specimens must be dry before packaging</li> </ul>   |        |          |
| Complete head-to-toe physical assessment <ul style="list-style-type: none"> <li>• Document all injury and findings noted on the medical-forensic documentation form (body map + summary of findings)</li> <li>• <b>Note type, location, description (color, shape) and size of all injuries</b></li> <li>• Photograph all injuries and findings (if applicable) – do not place photographs inside the ISPECK, handoff to law enforcement</li> </ul> |        |          |
| Complete detailed ano-genital assessment <ul style="list-style-type: none"> <li>• Conduct external assessment for injury and swab external genitalia first if needed</li> <li>• Place speculum; do not use lubrication per the request of the Illinois State Police Forensic Lab</li> <li>• <b>DO NOT PLACE SPECULUM IN A PRE-PUBESCENT GIRL</b></li> </ul>   |        |          |
| Package, seal and label all evidence <ul style="list-style-type: none"> <li>• <b>Maintain chain-of-custody</b> for the ISPECK kit and other evidence by never leaving the evidence from opening until handoff to law enforcement</li> </ul>   |        |          |
| Collect urine in a clean/dry cup if possible Drug Facilitated Sexual Assault (DFSA) <ul style="list-style-type: none"> <li>• <b>Advise patient that complete drug screen will be done and obtain consent for toxicology screening</b></li> <li>• Do not include urine specimen in ISPECK kit</li> <li>• Package, seal and label and handoff to law enforcement</li> </ul>   |        |          |
| Documentation per policy  |        |          |
| Obtain additional tests ordered by ED MD including pregnancy test   |        |          |
| Administer medication per ED MD order following CDC and/or ACEP guidelines to   |        |          |

|   |  |  |
|---|--|--|
| prevent STIs and pregnancy <ul style="list-style-type: none"> <li>• <b>Ceftriaxone</b> 250 mg IM in a single dose</li> <li>• <b>Metronidazole</b> 2 g orally in a single dose (advise no ETOH prior to and after medication)</li> <li>• <b>Azithromycin</b> 1 g orally in a single dose</li> <li>• HIV Risk Assessment, screening, and prophylaxis per protocol</li> <li>• Emergency Contraception Pill (ECP) per policy</li> </ul> |  |  |
| Provide patient education and discharge material <ul style="list-style-type: none"> <li>• Risk of pregnancy and ECP</li> <li>• Follow-up with referral MD/clinic</li> <li>• Medications/prescriptions</li> <li>• Counseling and advocacy referral</li> </ul>  |  |  |
| Provide an Illinois Sexual Assault Program Voucher <ul style="list-style-type: none"> <li>• Voucher system is activated for all non-Medicaid patients</li> <li>• Verify with registration/billing clerk that chart is coded/registered correctly to ensure the patient does not receive a bill (violates federal and state law to send bill to sexual assault patients for medical-forensic services)</li> </ul>                    |  |  |
| Disposition of specimens to law enforcement: <ul style="list-style-type: none"> <li>• ISPECK Kit</li> <li>• Clothing</li> <li>• Photographs</li> <li>• Drug facilitated sexual assault urine specimen</li> <li>• Other evidence collected</li> </ul>  |  |  |

\*\*\*Patient can decline the release of evidence to law enforcement; the hospital is responsible for storing the evidence in a secure location for up to **14** days.

#### Supply Checklist for Treatment of Sexual Assault Exams

| Supplies  | Yes |
|---|-----|
| Printed hospital labels with the patient name and date of the exam for labeling specimens and forms   |     |
| ISPECK Kit  |     |
| Protective gear, like gloves, gown, mask and hair covering  |     |
| Clear medical or packing tape to seal evidence  |     |
| Scale for photographs and measuring injuries  |     |
| Speculum  |     |
| Light source  |     |
| Wood's Lamp or other alternative light source   |     |
| Digital camera (if available)   |     |
| Patient gown  |     |
| Blanket for patient comfort/privacy   |     |
| Extra sterile swabs   |     |
| Foxtail (large) swabs   |     |
| Urine specimen cup  |     |
| Paper bags for clothing collection and other evidence   |     |
| Black permanent marker for labeling evidence  |     |
| Blood collection supplies   |     |
| Lancet for reference specimen collection (step 12 of the ISPECK kit)                                  |     |
| Culture collection tubes for STI testing if warranted   |     |
| Medical supplies for injury treatment   |     |
| Sterile H2O   |     |
| Styrofoam cups for swab drying  |     |
| Sterile scissors (suture removal kit)   |     |
| Extra small envelopes for additional specimens/swabs  |     |
| Plain copy paper for extra bindles  |     |
| Water for patient to drink after oral specimen collection   |     |
| Disposable scrubs or replacement clothing for patient (advocacy agency may provide)                   |     |
| Sanitary pads   |     |
| Any extra forms, like toxicology screening consent forms for possible drug facilitated sexual assault |     |



# Illinois Sexual Assault Nurse Examiner (SANE) Training Program

## Sexual Assault Evidence Collection Guide

### Overall Considerations:

- Use in conjunction with the Sexual Assault Treatment Checklist Form
- Use in conjunction with the instructions provided in the ISPECK kit
- Per ISPECK instructions, the examiner should wear protective gear during evidence collection, including gloves, gown, mask and hair covering
- Gloves must be changed after each item of evidence is collected
- Thoroughly clean exam room and evidence processing areas
- Package unlike samples separately and in paper bags/envelopes
- Avoid contamination during collection and the drying of samples
- Evidence collection steps can be done in any order; patient comfort is a major factor throughout the exam
- There is only one chance to collect: when in doubt, collect it!

**\*\*\*Evidence Collection Kit shall be completed if the patient presents himself/herself within **7** days of the sexual assault.**

| Type of Evidence Specimen                              | Reason to Collect  | Collection Equipment   | Method/Instructions  |
|--|--|--|--|
| Miscellaneous/debris collection<br>Clothing collection | If patient has not changed clothes post assault; to collect trace evidence that may be present on clothing                                       | Cloth sheet/exam mat provided in ISPECK kit  | <ol style="list-style-type: none"> <li>1. Place clean hospital sheet on the floor</li> <li>2. Place cloth sheet/exam mat directly over the clean hospital sheet</li> <li>3. Patient stands on cloth sheet/exam mat</li> <li>4. Patient removes one article of clothing at a time</li> <li>5. Place each article of clothing in a separate paper bag</li> <li>6. Create a privacy wall for the patient during the process using a blanket</li> <li>7. Collect the cloth sheet/exam mat by placing in paper bag provided in ISPECK kit</li> <li>8. Always collect the patient's underwear even if not same as worn during the assault</li> <li>9. Document stains/tears in clothing</li> </ol> |
| Other debris collection                                | To collect trace evidence or other findings on the patient's body  | Paper bindle; will need to add to ISPECK kit using new printer/copy paper; fold paper the same as bindle found in Step 10 (head hair combings) | <ol style="list-style-type: none"> <li>1. Collect any debris found on patient's body using a newly gloved finger or a swab; do not use forceps/tweezers</li> <li>2. Place each item collected in a separate bindle and place in envelope</li> <li>3. May need extra small envelopes</li> <li>4. Document debris/other findings</li> </ol>  |
| Oral specimens   | Oral penetration with or without ejaculation   | Sterile swabs  | <ol style="list-style-type: none"> <li>1. Use dry 2 swabs at a time; collect a total of 4 swabs</li> <li>2. Swab oral cavity of patient; concentrate on area between lower cheek and gums</li> <li>3. Air dry swabs</li> <li>4. Place in corresponding envelope</li> </ol>   |
| Miscellaneous stains/bitemark evidence                 | Oral contact by assailant, i.e. anywhere the assailant touched the patient with his mouth (kissing, biting, etc...); to collect assailant saliva | Sterile swabs<br>Sterile water   | <ol style="list-style-type: none"> <li>1. Moisten one swab with sterile water</li> <li>2. Swab the entire area/stain</li> <li>3. Air dry swab</li> <li>4. Place in corresponding</li> </ol>  |



|                            |  |  |  |
|----------------------------|--|--|--|
|                            | <p>To collect any area that fluoresces under a Wood's Lamp or other alternative light source</p> <p>To collect any dried secretions/stains noted</p> <p>Direct skin contact by assailant, i.e. anywhere the assailant grabbed the patient; to collect assailant skin cells/sweat</p> |  | envelope   |
| Fingernail specimens       | If the patient scratched the assailant during the assault; to collect assailant skin/blood cells   | Fingernail wood scraper and bindle; one per hand; provided in ISPECK kit | <ol style="list-style-type: none"> <li>1. Remove 2 specimen envelopes (right hand, left hand)</li> <li>2. Place bindle under patient's hand on flat surface</li> <li>3. Scrap nails while holding nails over bindle so that debris falls into bindle</li> <li>4. Refold bindle and place scraper and bindle in corresponding envelope</li> <li>5. Repeat steps for other hand</li> </ol>                                   |
| Head hair combings         | To collect trace evidence in patient's hair  | Comb and bindle; provided in ISPECK kit                                  | <ol style="list-style-type: none"> <li>1. Remove paper bindle and comb</li> <li>2. Unfold paper bindle</li> <li>3. Comb head hair so that any loose hair/debris falls into bindle</li> <li>4. Refold bindle and place comb and bindle in corresponding envelope</li> </ol>   |
| Pubic hair combings        | To collect trace evidence in patient's pubic hair  | Comb and bindle; provided in ISPECK kit                                  | <ol style="list-style-type: none"> <li>1. Remove paper bindle and comb</li> <li>2. Unfold paper bindle</li> <li>3. Place under patient's buttocks</li> <li>4. Comb pubic hair in a downward motion so that any loose hair/debris falls into bindle</li> <li>5. Refold bindle and place comb and bindle in corresponding envelope</li> <li>6. If no pubic hair present, document "patient groomed" and skip step</li> </ol> |
| Penile specimens           | Oral, anal, digital or other contact   | Sterile swabs<br>Sterile water   | <ol style="list-style-type: none"> <li>1. Moisten 2 swabs with sterile water</li> <li>2. Swab shaft of penis and foreskin if present</li> <li>3. Moisten 2 more swabs with sterile water</li> <li>4. Swab glans (head of penis)</li> <li>5. Do not swab urethra</li> <li>6. Air dry swabs</li> <li>7. Place in corresponding envelope</li> </ol>   |
| Vaginal/cervical specimens | Penile, digital, oral or other penetration with or without ejaculation; genital-to-genital contact   | Sterile swabs  | <ol style="list-style-type: none"> <li>1. Conduct external assessment for injury and swab external genitalia first if needed</li> <li>2. Place speculum; do not use lubrication per the request of the Illinois State Police Forensic Lab</li> <li>3. <b>DO NOT PLACE SPECULUM IN A PRE-</b></li> </ol>  |

|   |  |                                |  |
|---|--|--------------------------------|--|
|   |  |                                | <b>PUBSCENT GIRL</b><br>4. Using 2 dry swabs, swab posterior fornix of the high vaginal vault (area directly under the cervix)<br>5. Using 2 dry swabs, one at a time, swab the face of the cervix<br>6. Air dry swabs<br>7. Place in corresponding envelope   |
| Anal specimens  | Penile, digital, oral or other penetration or contact with or without ejaculation      | Sterile swabs<br>Sterile water | 1. Moisten 2 swabs with sterile water<br>2. Gently place inside anus so that entire cotton tip is within<br>3. Move in circular motion and withdraw<br>4. Then repeat with 2 more moisten swabs<br>5. Air dry swabs<br>6. Place in corresponding envelope  |
| Blood on filter paper   | Reference specimen to obtain patient DNA   | Filter paper<br>Lancet         | 1. Write patient's name and date on filter paper; can also use a patient label<br>2. Only touch bottom of filter paper with newly gloved hands<br>3. Don't allow to lay on the counter; place on a clean paper towel or the envelope<br>4. Finger stick patient with lancet; can use blood obtained for medical purposes/blood draw<br>5. Fill 5 circles with drops of patient's blood<br>6. Allow filter paper to air dry<br>7. Place in corresponding envelope |
| Urine specimen  | Possible drug facilitated sexual assault (DFSA) based on signs and symptoms of patient | Urine specimen cup             | 1. Collect earliest urine specimen possible<br>2. Advise the patient to urinate directly into cup<br>3. Do not place inside the ISPECK kit   |
| 1. Place all appropriate evidence specimens/envelopes inside the ISPECK kit<br>2. Date and initial the red evidence tape provided in the ISPECK kit<br>3. Place in the appropriate space to seal ISPECK kit<br>4. Label ISPECK kit with requested information<br>5. Maintain chain-of-custody until hand off to law enforcement or placed in a secure area for storage; document when either action is performed on the outside of the ISPECK kit |  |                                |  |

\*\*\*Patient can decline the release of evidence to law enforcement; the hospital is responsible for storing the evidence in a secure location for up to **14** days.

## Give us the Words

**Why can't this woman understand the paperwork  
I'm trying to get her to sign?**

**Response:** She uses pictures to communicate instead of written words. Why don't you explain to her what the paperwork says in everyday language, without big words?

**Response:** She doesn't understand all the legal jargon. Could you please explain it?

**Response:** The print is too tiny for her to read. Do you have a large-print format?

## Advocating for Change

As a part of institutional advocacy, rape crisis center advocates are encouraged to work with the medical system and disability service providers to enhance supports for people with disabilities who experience sexual violence. Activities may include:

- Arranging for or delivering training on sexual violence and people with disabilities.
- Coordinating a sexual assault response team which addresses the needs of victims with disabilities.
- Encouraging medical facilities to assess accessibility of services. See Project Safe SANE Center Accessibility Audit Tool.
- Facilitating transportation options with disability service providers and mass transit districts.
- Encouraging medical facilities to develop policies and plans to meet the needs of survivors with disabilities.

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"I told the doctor my legs can't go in those things and  
he sent me home and said I refused the exam."

**Survivor of sexual assault**

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# Section 5: Navigating Criminal Justice System

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# SECTION 5: NAVIGATING THE CRIMINAL JUSTICE SYSTEM TABLE OF CONTENTS

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## Introduction

The heart of the advocate's role is providing compassionate crisis intervention and ongoing support to survivors. Advocating for a person with a disability involves preventing or addressing any unfair treatment or abuse a person with disabilities may face. Legal advocates act as allies and guides by helping survivors explore options, understand their rights, find answers to questions, and connect with resources to build a network of support. When the victim is a person with a disability, advocates need to educate the victim about the criminal justice program as well as educate the criminal justice system, family and caregivers about the victim, their disability and their rights. Most importantly, advocates empower victims with information and support so that they are able to make informed decisions and begin a process of healing.

## Victim's Rights and Options

Victims with disabilities need to understand about their rights and options following a sexual assault just as victims without disabilities need this information. The difference in providing this advocacy service to victims with disabilities may be how this information is communicated. Some people with disabilities may need to have Rights of Crime Victims and the Victim's Compensation Act presented in easy to understand, plain language. It may be helpful to break it down into smaller bite size chunks of information and augment with pictures or concrete examples. Some people with disabilities may need the materials in large print, Braille or audio. It is important for advocates to be prepared ahead of time with this information in alternate formats and protocols for explanation. See "Checklist for Handouts" for additional guidance on page XXX.

Depending upon the nature of the relationship with the perpetrator, the victim with a disability may be eligible for a Civil No Contact Order or an Order of Protection. If the perpetrator is responsible for providing assistance with daily living tasks and the legal remedy prohibits contact, advocates can help the victim think through options for care. Asking the victim about back-up plans and how they arranged for care in the past may assist with determining next steps. Centers for Independent Living (CILs) may be of assistance in providing a list of individuals ready to provide immediate, short-term care. See [www.incil.org](http://www.incil.org) for the CIL closest to your area. If a change in guardian is needed, see Section 4 for information on the guardianship process and available resources. Another factor potentially impacting the advocate's experience in explaining rights and options with a victim with a disability is the culture of compliance which is common in the disability world. The victim may not know how to respond to being given the freedom to make their own choices without direction or agreement from others. Consequently, it is important for advocates to present information and options without implying a preferred or best course of action. See Advocacy in Context on pages XXX for more information.

## Give us the Words

**“She was smiling as she told me about her attack.  
It couldn’t have happened.”**

**Response:** A lot of people smile when they are nervous. That doesn’t mean it didn’t happen.

**Response:** A lot of women with disabilities have been over-trained to be pleasant – that is what you are seeing. She is really very scared.

**Response:** Some disabilities make it hard for the face to match the real feeling. It doesn’t mean she isn’t upset by what happened.

People with disabilities can access rape crisis center services regardless of guardianship status. If a person does not have a legal guardian or there is limited guardianship, they are entitled to the same service choices as victims without disabilities. If the person has a guardian (full/plenary), the individual may receive Five, 45-minute sessions (405 ILCS 5/2-101.1). Offering a connection to counseling services is one of the core legal advocacy services and should be extended to all victims.

Although guardian consent for services may not be required, it may be beneficial to educate family members and guardians about trauma, criminal justice procedures and victim’s rights.

## Reporting

People with disabilities who have little experience exercising their rights or are accustomed to others making decisions for them, may have difficulty understanding they are the one to choose what role to play in the investigative and judicial processes. It is important for advocates to stress that they do not have to speak to the police. (725 ILCS 203/20 No law enforcement office will require a victim of sexual assault or sexual abuse to submit to an interview). Well meaning family members, guardians, staff, etc. may try to pressure them to seek justice or to influence them to not participate in the court process. In some circumstances, it may be best for the advocate to provide time and space for victims to process the information and make decisions away from others. It is important for advocates to understand that sexual assault against some adults with disabilities may be subject to mandatory reporting. Making sure that the person with a disability understands that some decisions are prescribed through Illinois law. As an advocate, you may be working with someone who does not want others to know what



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happened or does not want action to be taken; however, others such as staff at a disability service agency working with the victim may be required to report the assault. See Adult Protective Services Act (320 ILCS 20/), Office of Inspector General Rule 50 (Title 59 Part 50 Section 50) and IL Dept of Public Health (210 ILCS 30) for detailed information about mandatory reporting and authoritative agencies. The handout “Who to Call” on page XXX provides an abbreviated guide to mandatory reporting. Additionally, ICASA guidance for rape crisis center staff regarding mandatory reporting can be found on page XXX.

If a victim with a disability wants to speak to law enforcement about what happened to them, a report must be taken. Law enforcement cannot refuse to complete a report because of the victim’s disability (725 ILCS 203/15).

Some people with disabilities are afraid they will get in trouble for what happened to them due to previous experiences and power dynamics in their relationships. It is helpful for advocates to explain to victims with disabilities that once a report is taken, the decision of whether to prosecute a crime is up to the state’s attorney’s office not the victim. A victim may want to go to court, but the prosecutor may elect not to bring the issue to court. Likewise the victim may not want to go further with the criminal justice process, but the prosecutor determines it is in the best interest of the state to pursue a conviction.

## **Liaison to police and state’s attorney’s office**

Investing time in explaining the court process, can help victims gain a realistic picture of the time it takes from the sexual assault incident to the conclusion of a trial and sentencing. Many victims feel forgotten or falsely assume that the case has been dropped if extended amount of time elapses without updates. The role of liaison between the criminal justice system and the victim is crucial in keeping victims engaged in the process.

Communication with victims regarding the status of their case and keeping them apprised of upcoming court dates supports them in participating in the criminal justice process as well as assists with healing. Strategies for follow up communication with victims with disabilities needs to take into account their access to private communications. It is recommended that advocates inquire about privacy and communications. “Do you have access to a telephone?” Do you need to seek permission to use a phone?” When making phone calls, are others close by?” A similar line of questioning for email communication is helpful in determining the best mode of communication. Be mindful of how the lack of privacy noted above may affect storage of court related documents. Help victims think through where to keep important information that they



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want to be kept confidential yet need access to. Shared living spaces and absence of secure places are challenges to confidential communications.

For some people with disabilities, it may be difficult to keep track of important appointments. Brainstorming with the client and being creative may result in an effective reminder system for meetings with law enforcement or prosecutors, court appearances and other important activities. If appropriate, enlist the assistance of others.

## **Accompanying victim through court process**

Boundaries imposed by absolute confidentiality may interfere with an advocate's direct participation in meetings with law enforcement personnel; however, there is much that an advocate can do outside of meetings to provide victim support. Support activities for victims with disabilities regarding law enforcement interviews may include advocating for meetings that:

- Align with best time of day for meetings due medication use or health conditions
- Allow for advance notice to arrange accessible public transportation (typically 48 hours)
- Are held at an accessible location or meeting in the victim's home or disability service provider
- Provide for needed communication, i.e. ASL interpreters, large print, braille, picture-based aids
- Include support personnel, if needed and appropriate
- Offer flexibility in scheduling for individuals who may need to maintain their routine or may need breaks during meetings
- Are conducted by a Forensic Interviewing Specialist or utilize the Forensic Experiential Trauma Interview. See <https://www.bwjp.org/resource-center/resource-results/the-forensic-experiential-trauma-interview-feti.html>

Behind the scenes support activities as well as being outside of the meeting room, can improve the experience of victims with disabilities. Additionally, proactive steps with law enforcement, i.e. institutional advocacy, can improve outcomes for victims with disabilities. Advocates are encouraged to utilize the "Protocols for Law Enforcement: Responding to Victims with Disabilities and Older Adults Who Experience Sexual As-

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sault, Domestic Violence, Abuse, Neglect or Exploitation” as a resource for training law enforcement personnel. Topics include model response and investigative procedures, quick reference guide for enhanced penalties, interview/communication tips, joint investigations, command staff resources and sample materials.

Advocates can promote accessible meetings and best practices for engaging people with disabilities in the court process as they work with prosecutors. The support activities mentioned above are appropriate accommodations for prosecutorial meetings. Meet with prosecutors, victim witness coordinators and court personnel to assess and discuss access issues and advocate for needed supports or accommodations to allow the victim with a disability to fully participate. When present in meetings, advocates can provide additional support for victims with disabilities. For example, by paying attention to the victim’s verbal and nonverbal responses you may notice that the victim is becoming anxious and suggest a break. You may provide a copy of the “Who, What, Where, When Communication Book to help someone who does not appear to have the vocabulary for sexual activity or is struggling to comprehend information.

Although most rape crisis center advocates are not attorney’s, they can suggest resources that are available to familiarize prosecutors with legal strategies for enhanced penalties, case law, pre-trial motions and overall court preparation for victims with disabilities. resources such as, “Protocols for Prosecutors: Responding to Victims with Disabilities and Older Adults Who Experience Sexual Assault, Domestic Violence, Abuse, Neglect or Exploitation” and “The Prosecutors’ Resource; Elder Abuse – AE-quitas.

## **Court Preparation**

Many victims are unprepared for the court experience, including victims with disabilities. They may unrealistic expectations regarding time, outcomes, evidence analysis and other components of the criminal justice system. The terminology that is used throughout the court process can be overwhelming and confusing for many victims. The “What Happens in Court” handout on page XX can be used by advocates to explain key terms and concepts to victims. This resource can be shared with local prosecutors as a part of institutional advocacy efforts.

## **Court Disability Coordinators**

It is important for advocates to know the Court Disability Coordinator at each courthouse. The Attorney General’s Office trains network of court disability coordinators who receive and disseminate information regarding accommodating people with disabilities in a judicial setting.

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Court Disability Coordinators are persons who have been appointed by the Chief Judge of their circuit court. They are professionals who currently have various duties and specific expertise in some aspect of the judicial process. Court Disability Coordinators have access to a vast array of people and agencies that can help ensure program accessibility for people with disabilities as well as the statute regarding sign language interpreters.

Coordinators have been given guidelines for determining who is a protected person with a disability, what constitutes program accessibility and how it can be achieved. To obtain the name of the Court Disability Coordinator in your area, contact the Disability Rights Bureau in Springfield at 1-217-524-2660 and 1-877-844-5461 (TTY) or in Chicago at 312-814-5684 and 1-800-964-3013 (TTY).

## **Confidentiality**

Cannot sit with them during interview with law enforcement due to confidentiality. Important to explain. They may view advocates as their support person and feel abandoned when not present.

Explaining releases of information – your information, is your property. You get to decide who gets that information. RCC record law. New concept for many people with disabilities. Dealing with guardians and confidentiality. Similar to how advocates navigate interference of parents/guardians of minor children, these skills will come in handy with adults. Explaining confidentiality to guardians. See guardian section.

## **Victim Concerns**

Corresponding with the victim or criminal justice personnel regarding specific concerns about the victim's case.

People with intellectual disabilities experience a greater rate of sexual violence than individuals with any other type of disability. Perpetrators may target them because of their lack of sex education, limited experience with relationships, perception of not being a credible witness and/or easily influenced. These factors may also have a negative influence on their participation in the court process. In your role as an advocate, it is important to understand how these disability related issues may impact your advocacy efforts.

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**The following excerpt from “Capacity, Consent and Undue Influence” provides insight for advocates on these issues.**

## **Capacity, Consent, and Undue Influence**

In working with victims with disabilities it is important that law enforcement personnel understand the issues of credibility, consent, and undue influence. Many people with disabilities are capable of making all of their life decisions and it is important to presume competence. Some people with disabilities, however, do not have the capacity to consent to sexual activity. Others may not meet the criteria to testify in a court hearing. Some individuals can be considered credible witnesses without having the capacity to consent to sexual activity.

## **Credible witness issues**

The general criteria for a credible witness includes understanding the difference between truth and lie, remembering what happened, and being able to communicate what happened. The majority of people with disabilities are credible witnesses. To assess ‘understanding the difference between truth and lie’ in a person with an intellectual disability, it is best to use several concrete questions. For example: “There is an elephant in the room. Is that the truth or a lie?” or “My shirt is red (when your shirt is green). Is that truth or lie?” After a few of these questions, ask the person, “Is it better to tell a lie or the truth?” and “What happens if someone tells a lie?” This concrete approach can give you a wealth of information.

Keep in mind that the person may need some accommodations to be able to explain what happened to them in a way that is easy for others to understand. Common accommodations for someone with an intellectual disability include allowing extended time to respond to questions, use of concrete words to communicate with the individual, and allowing the person to point to pictures or use a communication device or book.

A victim’s ability to sequence events is not required. In this situation, it is helpful to establish understanding of the victim’s routine. The victim may be able to reference events surrounding the assault(s) by their activities when they are unable to use a clock or calendar.

## **Capacity to consent to sexual activity**

Consent for sexual activity is when someone can voluntarily make a decision whether or not to participate in sexual activity. If a person is not able to make that decision, legal charges can be filed against the person who engages in sexual activity with the person who lacks capacity to consent. Therefore, it is important that

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law enforcement and prosecutors understand what this diminished capacity means. This capacity is evaluated by a professional (usually a psychologist) who has specific training and understands the professional guidelines for making such determinations. The determination is then decided through adjudication. It is best for law enforcement to work with prosecutors in determining what needs to be investigated in this regard.

Consent for sexual activity has three components: knowledge, reasoning, and voluntariness. Knowledge includes facts needed to make a decision and risks such as diseases, pregnancy. Reasoning is the ability to understand and weigh different options in making an informed choice. Voluntariness is the ability to protect oneself against coercion in making sexual decisions.

One study of more than 300 psychologists (Kennedy and Niederbuhl, 2001), revealed that important elements of consent include

- Being able to say or demonstrate “no.”
- Knowing that having intercourse can result in pregnancy.
- Being able to make an informed choice when given options.
- Knowing that having intercourse or other sexual relations can result in obtaining a disease.
- Being able to differentiate between appropriate and inappropriate times and places to engage in intimate relations.
- Being able to differentiate between males and females.
- Being able to recognize individuals or situations which might be a threat to him/her.
- Being able to stop a behavior if another person tells him/her “no”.

This list may be helpful to prosecutors in determining if someone needs an evaluation of their capacity to give consent for sexual activity.

Just as someone who is under the influence of alcohol or illegal drugs may lack the capacity to give consent for sexual activity, a person with mental illness who is adjusting to new medications may lack consent for sexual activity.

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## Capacity

Another inherent problem in discussing capacity is that mental status is usually measured through mental status examinations. These tests measure categories of mental functioning including cognition and memory. It is not always clear how these measurements apply to the performance of specific legal functions. A variety of other issues further complicate assessments of capacity. Additionally, some severely impaired individuals have periods of lucidity. For this reason, abusers who are charged with exploiting an older person's incapacity can always claim that a victim was "lucid for a moment" (e.g. when he/she signed a contract or gave a gift). Consequently, financial exploitation investigators must consider how often a person is affected and how long the impairment lasts. Additionally, a mental impairment in and of itself does not render a person incompetent to make decisions or testify. The seriousness or gravity of a situation also affects the degree of competency that is needed.

## Consent

Determining whether financial exploitation has occurred may involve assessing if an individual consented to make purchases, accept assistance, or transact business. To exercise consent, an individual must have knowledge of the true nature of an actor transaction. He/she must also act freely and voluntarily and not under the influence of threats, force, or duress. He/she must further possess sufficient mental capacity to make intelligent choices about whether or not to do something that is proposed by another individual. Mere passivity does not amount to consent.

*Adapted from the following resources:*

*Delaware Office of the Attorney General's Financial Exploitation Investigative Check list; Financial Abuse of the Elderly by Lisa Nerenberg, produced by the San Francisco Consortium for Elder Abuse Prevention for National Center on Elder Abuse, 1996.*

## Give us the Words

**She's not a credible witness.**

**Response:** What is it that you need that you don't have?

**Response:** Many women with disabilities are credible witnesses. Tell me what you need, and I'll try and help.



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# Criminal Justice Advocacy

## Working with Law Enforcement

1. Tell the survivor that the emergency room is required to contact the police to let them know that a crime has been committed. Even though the police are required to come to the emergency room, the survivor does not have to speak with an officer if she chooses not to do so.
2. Let the survivor know that the police officer may want to ask some questions in order to best respond to what has happened. Tell the survivor that some of these questions may make her uncomfortable, or be difficult to answer.
3. Reassure her that the purpose of giving information to the police is to help in stopping this from happening to anyone else and to keep her and others safe.
4. Let the survivor know that she is not in any trouble and that she was right to let others know what has happened.
5. Reinforce that the survivor never has to talk to a police officer if she does not want to do so. She has the right to refuse to speak to an officer at all, or to stop talking to the officer if she feels too uncomfortable.
6. Let the survivor know that she can have someone she trusts with her when she speaks with the officer. She also has a right to speak to the officer in private, and to go slowly and take breaks as often as she needs.
7. Work with the law enforcement officer to help guide him/her in working slowly with the survivor and in understanding any communication barriers.

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## Before going to court

1. Provide an opportunity to visit the courtroom and meet the personnel.
2. Explain who sits where.
3. Use simple language and explain what will happen.
4. Practice looking at the attorney and answering questions.
5. Role-play giving testimony.
6. Identify visual cues for calming down or taking your time.
7. Stress that it is okay to say “I don’t remember.”
8. Practice saying “Can you say that another way?”
9. Remind the survivor how brave she is and that an advocate will be with her.
10. Anticipate the court day and prepare a personal safety plan for getting through the testimony and returning home.

## Remember

Every client has different needs, and sometimes those needs are not what advocates typically perceive or address. The message here is to keep an open mind, be creative, be flexible and give every effort to making any accommodation that may be needed. Work together with the survivor to provide the best services possible.



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## Advocating for Change

As a part of institutional advocacy, rape crisis center advocates are encouraged to work with the medical system and disability service providers to enhance supports for people with disabilities who experience sexual violence. Activities may include:

- Arranging for or delivering training on sexual violence and people with disabilities.
- Coordinating a sexual assault response team which addresses the needs of victims with disabilities.
- Encouraging law enforcement to assess accessibility of services. See [http://www.icjia.state.il.us/assets/ifvcc/Model%20Protocols/LE\\_Review\\_2015.pdf](http://www.icjia.state.il.us/assets/ifvcc/Model%20Protocols/LE_Review_2015.pdf). For a Law Enforcement Accessibility Review Tool.
- Facilitating transportation options with disability service providers and mass transit districts.
- Encouraging law enforcement to develop General Orders to meet the needs of survivors with disabilities. See sample General Order Law Enforcement at [http://www.icjia.state.il.us/assets/ifvcc/Model%20Protocols/General\\_Order-9-16.pdf](http://www.icjia.state.il.us/assets/ifvcc/Model%20Protocols/General_Order-9-16.pdf)
- Educating law enforcement and prosecutors on working with people with disabilities who experience sexual assault.
- Invite people with disabilities to be a part of SART or other community efforts addressing sexual violence.

### Give us the Words

**This doesn't have to go to court.  
It'll never get a conviction if this case does go to trial.**

**Response:** All people have a right to due process and protection under the law.

**Response:** We need to do what's right for the survivor, even if it means going to court.

**Response:** The perpetrator needs to be held accountable, conviction or no conviction.

**Response:** Many people with disabilities can and do testify in court and these cases are winnable.

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# Checklist for Documents

| <u>Topic</u>   | <u>Yes</u>               | <u>No</u>                |
|--|--------------------------|--------------------------|
| <b>Organization and Content</b>                                      |                          |                          |
| ○ Is the most important information first?                           | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Is the information limited to what readers need to know?           | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Is the content arranged in an order that makes sense?              | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Language</b>  |                          |                          |
| ○ Are most words limited to 1-2 syllables?                           | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are terms used consistently?                                       | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are unfamiliar words, abbreviations or acronyms explained?         | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are sentences short and concise (about 15-20 words)?               | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Does it use active voice most of the time?                         | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Does the document use “you” and “we” where possible?               | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are abstract words avoided?  | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are pictures used to augment communication?                        | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Format</b>  |                          |                          |
| ○ Is text accessible (14 point sans-serif font – Arial, Tahoma)?     | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are italics and bold point used sparingly?                         | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Is there plenty of white space (at least 1” margins, uncluttered)? | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are headers used to make it easier for readers?                    | <input type="checkbox"/> | <input type="checkbox"/> |
| ○ Are lists and tables used for complicated information?             | <input type="checkbox"/> | <input type="checkbox"/> |

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# Who Do You Call?

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Reporting abuse of a person is an important role, but it isn't always clear who you should call to report abuse. The following chart can help identify where to report abuse.

**Remember:** All crimes may be reported to the police. If the victim would like to contact law enforcement, assist them with this process.

| Who was abused?  |                 | Where did the Abuse Happen?      |                    | Report To  |
|--|-----------------|----------------------------------|--------------------|--|
| Person 60 years or Older   | <b>If Yes</b> → | Community or Domestic Setting    | <b>Then Call</b> → | Adult Protective Services<br>1-866-800-1409            |
| Person with a disability 18-59 years old                               | <b>If Yes</b> → | Community or Domestic Setting    | <b>Then Call</b> → | Adult Protective Services<br>1-866-800-1409            |
| Person 60 years or older or a person with a disability 18-59 years old | <b>If Yes</b> → | Licensed Long Term Care Facility | <b>Then Call</b> → | Illinois Department of Public Health<br>1-800-252-4343 |
| Person with a disability 18-59 years old                               | <b>If Yes</b> → | Licensed Facility                | <b>Then Call</b> → | Office of Inspector General<br>1-800-368-1463          |

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Rape crisis centers assist victims of sexual violence. Services at rape crisis centers are free and confidential. You can reach your local center by visiting [www.icasa.org](http://www.icasa.org) or call 800-656-4673

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Domestic violence centers assist victims of domestic violence. Services at domestic violence centers are free and confidential. You can reach your local center by visiting [www.ilcadv.org](http://www.ilcadv.org) or call 877-863-6338.

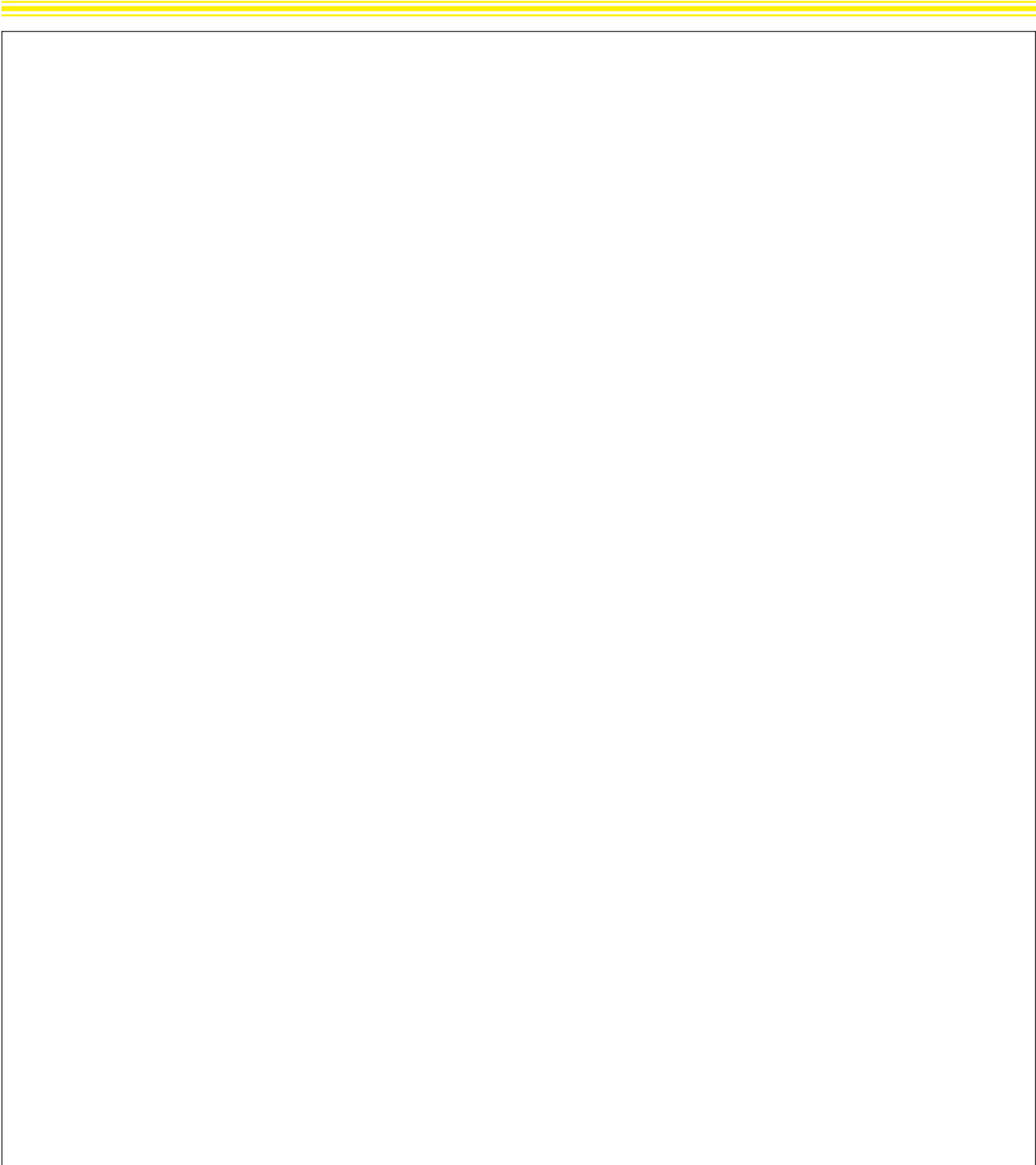
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## Tips for working with survivors

Below are good tips for working with any survivor of sexual violence, but may be especially important for survivors with disabilities:

1. Talk with the person in a quiet, private place that is free of distractions or excitement. Make sure the person feels safe.
2. Speak directly to the person. Put yourself at eye level and make eye contact.
3. Interact in an adult manner and use adult language; avoid condescending language or behavior.
4. Be respectful and patient. It may take more time than for other survivors of sexual violence with whom you work. Allow time for the survivor to respond. You may also need to take frequent breaks.
5. Use first names and plain language. Avoid bureaucratic language or jargon.
6. Establish rapport. It may be helpful to “chit chat” first until a connection is made between you and the survivor.
7. Ask about any assistance needs and what they would be.
8. Do not make assumptions about abilities or guesses about needs. For example, a person with slow or difficult speech may not be cognitively impaired.
9. Identify and accommodate the person’s needs to the best of your ability. Be open to communicating in new and creative ways. Acknowledge and take responsibility for limitations.
10. Always use people first language. For example, say “People with disabilities,” not “disabled people.”
11. Offer choices as often as possible.
12. Respect boundaries. Remember, chairs and other support aids are part of a person’s being, so don’t touch or move support aids without permission.
13. Reflect and normalize feelings.
14. Provide facts and options.
15. Remember that certain disabilities may impact emotional affect. For example, just because a person is smiling doesn’t necessarily mean she is happy, or a seemingly angry grimace may not mean the person is mad. Be calm and do not fear possible appearance.



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# Section 6: Resources

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# SECTION 6: RESOURCES

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## Introduction

“Sexual Violence doesn’t just affect one part of a survivor’s life. It deeply affects all areas of our lives: health, spirituality, mind, emotions, sexuality, and relationships. Strong advocates serve the whole survivor. We may focus our efforts on medical and legal needs, but we must attend to other concerns of the survivor.”

*Strengthening Our Practice: The Ten Essential Strengths  
of Sexual Violence Victim Advocates in Dual/Multi-Service Advocacy Agencies.  
Resource Sharing Project Rural Sexual Assault Services*

People with disabilities are people first. Survivors are people first. Sexual violence is experienced through the lens of who they are as a person. As noted above, sexual violence impacts all areas of living. A person with a disability who has lived independently in the community without the support of disability services, may need assistance after the assault. Health conditions may be complicated as a result of the violence. The offender may have been their primary caregiver, so another person needs to be secured. Victims in recovery may desire stronger supports as the trauma of sexual assault has compounded past traumas.

Victims with disabilities may benefit from advocacy efforts, such as case coordination, with their established service providers and/or connection to new services. To be most effective, it is helpful for advocates to have a working knowledge of the disability service system. This section will provide an overview of disability services, strategies for collaboration with the disability service system, and a reference list for ancillary or basic needs services.



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## Collaboration with Disability Service Agencies

In addition to conducting the Disability Responsiveness Assessment, it is useful to work with your local disability service agencies. The goal of this outreach is to make women with disabilities and their service providers, family/friends and support workers aware of your services. They need to know:

- that a rape crisis center exists in their local area;
- the services the center provides;
- that your services are disability responsive; and
- how to collaborate with you to serve women with disabilities who experience sexual violence.

The statewide needs assessment conducted by the Illinois Imagines team showed that women with disabilities would be more comfortable working with a rape crisis counselor at their disability service center than they would be meeting with someone at the rape crisis center. There are two important reasons for this: familiarity and comfort with the disability service agency, and ease with which they can access the agency.

The disability service agency is a familiar place for the survivor. They already know and trust the people there. By having a rape crisis worker come to them, they are able to talk and get help in a safe and comfortable environment, and they don't have to worry about how to get there. Transportation is a huge barrier that women with disabilities must negotiate, and disability service agencies usually have accessible transportation options that their clients are already quite familiar with.

Outreach or marketing efforts to reach women with disabilities will be most successful if they are conducted at or through the disability service agencies or self-advocacy groups. Therefore, the disability service agency is your greatest ally in reaching out to women with disabilities who experience sexual violence.

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The following are some strategies to conduct outreach with local disability service agencies and others who work with women with disabilities.

1. Arrange to have a rape crisis counselor go to the disability service agency each week to meet with people who wish to access services.
2. Work with the disability service provider to establish a way for clients to call the center's hotline confidentially.
3. Set up a support group for abuse survivors at the disability service agency.
4. Arrange for educators to go to the disability agency to talk with clients about issues like healthy relationships or sexual violence.
5. Provide the disability service agencies with posters, pamphlets or business cards with rape crisis center hotline information and staff contacts.
6. Contact self-advocacy groups and ask if you can be a guest speaker on sexual violence and the right to be free from sexual violence.
7. Contact disability organizations (see #9 below) and self-advocacy groups when recruiting for new employees and board members.
8. When working in the schools, make sure you are also working with students with disabilities. They may be in separate classrooms or buildings.
9. Contact the local Center for Independent Living (CIL), local Mental Health/ Behavioral Health Center(s), the local organization(s) that support people with developmental disabilities and Office of Rehabilitation Services. Schedule a meeting with each agency to discuss collaboration, including:
  - negotiating a working agreement;
  - discussing cross-training opportunities;
  - scheduling an in service for staff;
  - presenting an in service for ongoing groups;
  - attending special events/fundraising activities;
  - agreeing to create links to each other's websites;
  - sharing prevention education ideas, materials;
  - inviting them to assist with your center's 40-hour training.

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10. Review educational and outreach materials to make sure they are accessible and inviting to women with disabilities. Provide information about rape crisis services that is written in simple, easily understandable language and/or provide posters with large print and/or pictures.
  11. Partner with women with disabilities to design your outreach efforts and materials. Conduct a focus group, establish a committee, and engage women with disabilities as co-presenters.
  12. Participate in diversity group events in the community, such as disability expos, etc.
  13. Plan a “field trip” for all staff to a local disability organization.
  14. Ask the Illinois Assistive Technology Project (<http://www.iltech.org>) to conduct a presentation on assistive technology.
  15. Provide privacy tear-off materials accessible to persons with disabilities.
  16. Serve on the regional Human Rights Authority Board (part of the Illinois Guardianship and Advocacy Commission).
  17. Recruit women with disabilities to be board members, staff, and/or participants in ad hoc committees (e.g., training, policy and procedures and program reviews).

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# Disability Service Systems

## Department of Human Services (DHS) Developmental Disabilities Services

### Eligibility

A person with an intellectual and/or developmental disability (I/DD) may be receiving services through their local educational system until the day before their 22nd birthday. An adult with I/DD may be eligible to receive services through the Illinois Department of Human Services, Division of Developmental Disabilities and/or the Illinois Department of Rehabilitation Services.

### To Begin Services

If the person with I/DD is not currently receiving any state-funded waiver services and may qualify, the first step is to contact the local Independent Service Coordination (ISC) Agency. The Illinois Department of Human Services Office Locator can help you locate the ISC Agency closest to you. See this link:

<http://www.dhs.state.il.us/page.aspx?module=12&officetype=&county>

If the person with I/DD is currently receiving waiver services at a disability service provider agency funded by the Department of Human Services, Division of Developmental Disabilities, they may be receiving community day services (i.e., day program or sheltered workshop) and/or residential services, which may also be called CILA (Community Integrated Living Arrangement) services. CILA services can be received in a group home setting, family home, Host Family Setting, or an apartment setting on a full-time or intermittent basis. More information is available about DHS services for people with I/DD at <http://www.dhs.state.il.us/page.aspx?item=81789>.

The Division of Developmental Disabilities Hotline 1-888-DD-PLANS (1-888-337-5267) (TTY: 1-866-376-8446) is available to persons and the family of people with developmental disabilities to answer questions on community programs, respite care, and other state services available to persons with a disability. More information is also available visit the Developmental Disabilities Web site

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## Department of Human Services (DHS) Mental Health Services

The Division of Mental Health (DMH) is responsible for assuring that children, adolescents and adults, throughout Illinois, have the availability of and access to public-funded mental health services. Services are available through 162 community mental health centers/agencies, 27 community hospitals with psychiatric units and nine state-operated hospitals. Community services help individuals maximize their potential and independence through an array of services which are designed to maintain an individual with mental illness in his home and community and sustain an enhanced quality of life. Information about access to these services may be obtained by contacting the DHS Help Line at 1-800-843-6154 (TTY: 1-800-447-6404) or visit the Division of Mental Health Web site.

### To Begin Services

If the person with a disability is looking for Mental Health services, the Illinois Department of Human Services Locator can help find resources for information, assessment & referral regarding mental health and mental illnesses.

<http://www.dhs.state.il.us/page.aspx?module=12&officetype=&county>

If healthcare – including Medicaid plans or other insurance programs - are not in place for the individual with a disability, please go to: <https://www.illinois.gov/hfs/Medical-Clients/health/Pages/disability.aspx>

Information on specific programs will be up to date at that website, and will include information on health benefits for disabled workers, rehabilitation services, and how to sign up for services.

### Statewide Coordinator for Deaf and Hard of Hearing Services

The Statewide Coordinator for Deaf & Hard of Hearing Services provides training programs and additional materials in the area of mental health and deafness/hearing loss. The program serves individuals who are deaf or hard of hearing and who also have mental health needs. For more information contact the DHS Help Line at 1-800-843-6154 (TTY 1-800-447-6404) or visit the Services for People Who Are Deaf or Hard of Hearing site Web site.

### Screening, Assessment and Support Services (SASS) Program

The Screening, Assessment and Support Services (SASS) Program, provides mental health screening, assessment, planning, crisis intervention and treatment services for youth who are at risk of psychiatric hospitalization and who are without resources other than the State's Office of Mental Health. SASS helps prevent unnecessary hospitaliza-

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tions of children and adolescents, and provides increased access to more appropriate community treatment alternatives. For more information on SASS services contact the DHS Help Line 1-800-843-6154 (TTY 1-800-447-6404) or visit the SASS Program Web site.

## **Department of Human Services (DHS)**

### **Division of Rehabilitation Services**

The Department of Human Services Division of Rehabilitation Services (DRS) is the state's lead agency for providing services to individuals with disabilities. DRS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities. Visit the Division of Rehabilitation Services Web page <http://www.dhs.state.il.us/page.aspx?item=29727> or call the DRS Hotline at 1-800-843-6154 (TTY: 1-800-447-6404).

#### **Home Services Program**

The Home Services Program (HSP) provides services to individuals with severe disabilities so they can remain in their homes and remain as independent as possible. Services include: Personal Assistants, Homemaker Services, Maintenance Home Health, Electronic Home Response, Home delivered meals, Adult Day Care, Assistive Equipment, Environmental Modification, Respite Services and Specialized Services for people with HIV/AIDS and/or Traumatic Brain Injuries (TBI).  
Vocational Rehabilitation Program

#### **Eligibility**

Individuals with disabilities of working age (16-64 years old) who have a significant physical or mental disability that makes it difficult to go to work.

#### **To Begin Services**

Apply online at <https://wr.dhs.illinois.gov/wrpublic/wr/dynamic/referral.jsf> or visit a local DRS Office. See DHS Office Locator for DRS Office near you.  
<http://www.dhs.state.il.us/page.aspx?item=27893>

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## **Healthcare and Family Services (HFS) Health Insurance Programs for Individuals with Disabilities**

### **Eligibility**

HFS Medical Benefits may be available for individuals who are age 65 or older, blind or have a permanent disability. To qualify for HFS Medical, persons must live in Illinois and meet income and asset limits. Persons must also be U.S. citizens or qualified immigrants. You can review the HFS Medical Benefits Information to find out if you qualify.

### **Health Benefits for Workers with Disabilities (HBWD)**

Health Benefits for Workers with Disabilities (HBWD) allows working individuals with a disability to pay a low monthly premium and receive full medical benefits. To find out if you're eligible visit our Web site the HBWD Web site or call the Illinois Health Benefits Hotline at 1-800-226-0768 (TTY: 1-866-675-8440).

### **Social Security**

Social Security is a program administered by the Federal Government. For those who are eligible to receive benefits from Social Security, it can provide the following cash benefits for 1) Retirement Benefits, 2) Disability Benefits, 3) Widow and Survivor Benefits, 4) Additional Benefits known as Supplemental Security Benefits for those whose income is low and 5) Medicare. To find out more about who qualifies for benefits and how you can sign up for those benefits, visit the Social Security Administration's Web site or by telephone call 1-800-772-1213 (TTY: 1-800-325-0778).



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## Other Allied Systems

In addition to working with the disability service systems, advocates can offer guidance for getting connected to needed supports and services beyond those offered at the rape crisis center.

### **ADDICTION TREATMENT/COUNSELING SERVICES/MENTAL HEALTH:**

1. NAMI Illinois: phone: 217-522-1403  
Website: <https://namiillinois.org>
2. Alcoholics Anonymous: Website: <https://aa-meetings.com/Illinois>
3. State of Illinois Department of Mental Health: Website: [www.dhs.state.il.us](http://www.dhs.state.il.us)
4. Community Mental Health Centers: Website: [www.dph.illinois.gov/topics-services/health-care-regulation/facilities/](http://www.dph.illinois.gov/topics-services/health-care-regulation/facilities/)
5. Illinois Addiction treatment Centers:  
Phone: 844-768-1241  
Website: [www.addiction.com/region/illinois](http://www.addiction.com/region/illinois)
6. Community Behavioral Healthcare Association of Illinois: Website: [www.cbha.net/](http://www.cbha.net/)
7. Depression and Bipolar Support Alliance: Website:  
<https://secure2.convio.net/dabsa/site/spageserver/p?pagename=home>
8. County/city resources: \_\_\_\_\_

### **BLIND/VISUALLY IMPAIRED SERVICES:**

1. Illinois Council for the Blind: Website: [www.icbonline.org](http://www.icbonline.org)
2. Audio books for the Blind: Website: <https://loc.gov/program/national-library-service-for-the-blind-and-physically-handicapped/>
3. Illinois State Library Talking Books/Braille Services: Phone: 800-426-0709  
Website: <http://www.ilphg.org>
4. Illinois School for the Visually Impaired: Phone: 217-479-4400  
Website: [www.dhs.state.il.us/page.asp?item=87728](http://www.dhs.state.il.us/page.asp?item=87728)
5. County/city resources: \_\_\_\_\_



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## **CHILD CARE:**

1. Single Parents Assistance for Childcare: Website: <https://www.spaoa.org>
2. DHS Child Care Assistance Program (CCAP): Phone: 877-202-4453  
Website: [www.dhs.state.il.us/page.aspx?item=30355](http://www.dhs.state.il.us/page.aspx?item=30355)
3. Illinois head Start Association: Phone: 217-241-3511  
Website: [www.ilheadstart.org](http://www.ilheadstart.org)
4. Voices for Illinois Children: Phone: 312-456-0600  
Website: [www.voices4kids.org](http://www.voices4kids.org)
5. Child Care Association of Illinois: Website: <http://cca-il.org/>
6. County/city resources: \_\_\_\_\_

## **CLOTHING AND FURNITURE:**

1. American Red Cross: Website: [www.redcross.org](http://www.redcross.org)
2. Crisis Assistance Program and Expedited Services for SNAP:  
Phone: 800-843-6154  
Website: [www.dhs.state.il.us/page.aspx?item=32273](http://www.dhs.state.il.us/page.aspx?item=32273)
3. County/City resources: \_\_\_\_\_

## **DENTAL ASSISTANCE:**

1. Illinois State Dental Society: Phone: 217-525-1406  
Website: [www.isds.org/](http://www.isds.org/)
2. Illinois Dental: Phone: 888-286-2447  
Website: [www.illinois.gov/hfs](http://www.illinois.gov/hfs)
3. Dental Lifeline Network: Phone: 888-235-5826  
Website: <https://dentallifeline.org/illinois/>
4. Free Dental Care: Website: [www.freedentalcare.us/st/illinois](http://www.freedentalcare.us/st/illinois)
5. County/City Resources: \_\_\_\_\_

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## **DISABILITY SERVICES (not other where listed):**

1. Illinois Assistive Technology Program: Phone: 800-852-5110  
Website: [www.iltech.org](http://www.iltech.org)
2. Disability Determination Services: Phone: 800-843-6154  
Website: [www.dhs.state.il.us/page.aspx?item=29979](http://www.dhs.state.il.us/page.aspx?item=29979)
3. Centers for Independent Living: Phone: 217-525-1308  
Website: [www.incil.org/](http://www.incil.org/)
4. The Arc of Illinois: Phone: 815-464-1832  
Website: [www.thearc.org/](http://www.thearc.org/)
5. The Autism program: Phone: 217-585-5178  
Website: [www.tap-illinois.org/](http://www.tap-illinois.org/)
6. The State Board of Education/Special Education:  
Phone: 866-262-6663  
Website: [www.isbe.net/pages/search-results.aspx?k=special%20eucation](http://www.isbe.net/pages/search-results.aspx?k=special%20eucation)
7. Life Span: Website: <http://www.illinoislifespan.org>
8. Illinois Spina Bifida Association: Website: <https://www.isba.org/>
9. National Association for Down Syndrome: Phone: 630-325-9112  
Website: [www.nads.org](http://www.nads.org)
10. United Cerebral Palsy of Illinois: Phone: 815-744-3500
11. County/City Resources: \_\_\_\_\_

## **DOMESTIC VIOLENCE:**

1. Illinois Coalition Against Domestic Violence: Phone: 217-789-2830  
Website: [www.ilcadv.org](http://www.ilcadv.org)
2. DHS Domestic Violence Victims Services: Phone: 877-863-6338  
Website: [www.dhs.state.il.us/page.aspx?item=30275](http://www.dhs.state.il.us/page.aspx?item=30275)
3. County/City Resources: \_\_\_\_\_

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## **EDUCATION:**

1. Illinois State Board of Education: Phone: 866-262-6663  
Website: [www.isbe.net](http://www.isbe.net)
2. Family Matters: Phone: 866-436-7842  
Website: <http://www.fmptic.org>
3. Community Residential Services Authority: Phone: 877-541-2772  
Website: <https://www2.illinois/agencies/crsa>
4. Illinois Branch of International Dyslexia Association: Phone: 630-469-6900  
Website: <http://www.readbida.org>
5. Adult Education and Literacy: Website: [https://www.iccb.org/adult\\_ed/](https://www.iccb.org/adult_ed/)
6. County/City Resources: \_\_\_\_\_

## **ELECTED OFFICIALS:**

3. Illinois Governor: Phone: 217-782-0244  
Website: <https://www.2.illinois.gov/contactus/pages/default.aspx>
4. Illinois Attorney General: Phone 1-800-243-0618  
Website: [www.illinoisattorneygeneral.gov/about/email-ag.jsp](http://www.illinoisattorneygeneral.gov/about/email-ag.jsp)
5. County/City Resources: \_\_\_\_\_

## **EYE EXAMS/GLASSES ASSISTANCE:**

1. Vision USA: Phone: 800-365-2219 Ext. 4200
2. Lions Clubs of Illinois: Phone: 217-632-7775  
Website: [www.illinoislionsmd1.org/](http://www.illinoislionsmd1.org/)
3. County/City Resources: \_\_\_\_\_

## **FAN PROGRAMS (FOR SUMMER):**

1. Keep Cool Illinois: Website: <https://www2.illinoisgov/sites/keepcool/pages/default.aspx>
2. County/City Resources: \_\_\_\_\_

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## **FOOD PROGRAMS:**

1. Food Connections/DHS: Website: [www.dhs.state.il.us/pages.aspx?item=31245](http://www.dhs.state.il.us/pages.aspx?item=31245)
2. Feed America: Website: [www.feedingamerica.org/find-your-local-foodbank/](http://www.feedingamerica.org/find-your-local-foodbank/)
3. Salvation Army: Website: <https://centralusa.salvationarmy.org>
4. County/City Resources: \_\_\_\_\_

## **FRATERNAL ORGANIZATIONS:**

1. Knights of Columbus: Phone: 815-935-2262  
Website: [www.illinoisknights.org/mary/](http://www.illinoisknights.org/mary/)
2. Lions Clubs of Illinois: Phone: 217-632-7775  
Website: [www.illinoislionsmd1.org/](http://www.illinoislionsmd1.org/)
3. Veterans of Foreign Wars: Phone: 217-529-6688  
Website: [www.vfwil.org](http://www.vfwil.org)
4. Ansar Shrine: Phone: 217-525-1771  
Website: [www.answarshrine.com/](http://www.answarshrine.com/)
5. County/City Resources: \_\_\_\_\_

## **HOMELESS SHELTERS/HOUSING:**

- 1, Homeless Shelters: <https://www.homelessshelterdirectory.org>
- 2 Midwest Center for Homeless Veterans: Phone: 630-871-8387  
Website: [www.helpveterans.org](http://www.helpveterans.org)
3. DHS: Emergency and Transitional Housing: Phone: 1-800-843-6154  
Website: [www.dhs.state.il.us/page.aspx?item=30362](http://www.dhs.state.il.us/page.aspx?item=30362)
4. Coalition for the Homeless: Website: [www.coalitionforthehomeless.org/](http://www.coalitionforthehomeless.org/)
5. Habitat for Humanity: Phone: 800-422-4828  
Website: [www.habitat.org/](http://www.habitat.org/)
6. U.S. Department of Housing and Urban Development:  
Website: <https://www.hud.gov/states/illinois/homeless/hsghelp>

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7. DHS Homeless Prevention: Phone: 800-843-6154  
Website: [www.dhs.state.il.us/page.aspx?item=30360](http://www.dhs.state.il.us/page.aspx?item=30360)
  8. 24-Hour Shelter Hotline: Website: <http://owpi.dc.gov/service/24-hour-shelter-hotline>
  9. Housing Action Illinois: Website: <http://www.housingactionill.org>
  10. County/City Resources: \_\_\_\_\_

### **LEGAL SERVICES:**

1. Equip for Equality: Phone: 800-53702632  
Website: <https://equipforequality.org>
2. Prairie State Legal Services: Website: <http://www.pslegal.org>
3. Land of Lincoln Legal Assistance: Website: <http://www.freelegalaid.com>
4. Illinois Attorney General: Attorney General Lisa Madigan: Phone 1-800-243-0618  
Website: [www.illinoisattorneygeneral.gov/about/email-ag.jsp](http://www.illinoisattorneygeneral.gov/about/email-ag.jsp)
5. Illinois Legal Aid Online: Website: <https://www.illinoislegalaid.org>
6. Human Rights Authority: Phone 866-274-8023
7. Legal Advocacy Service: Phone: 866-274-8023  
Website: <http://gac.state.il.us>
8. County/City Resources: \_\_\_\_\_

### **MEDICAL ASSISTANCE**

1. DHS Medical Assistance Program: Phone: 800-843-6154  
Website: [www.dhs.state.il.us/page.aspx?items](http://www.dhs.state.il.us/page.aspx?items)
2. State Hemophilia Program: Phone: 877-782-5565
3. HFS Healthcare and Family Services: Website: <https://www.illinois.gov/hfs/medical-clients/pages/medicalprograms.aspx>
4. County/City Resources: \_\_\_\_\_

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## **MORTGAGE ASSISTANCE**

1. Illinois Housing Development Authority: Phone: 312-836-5200  
Website: <https://www.ihda.org/my-home/saving-my-home/>
2. Illinois Hardest Hit: Phone: 855-873-7405  
Website: [www.illinoishardesthit.org](http://www.illinoishardesthit.org)
3. County/City Resources: \_\_\_\_\_

## **PRESCRIPTION ASSISTANCE**

1. Illinois State Pharmacy Assistance Program: Website: <https://q1medicare.com>
2. Prescription Management Group: Phone: 888-314-1939  
Website: <http://prescriptionmanagement.com>
3. Illinois RX Card: Website: <https://www.illinoisrxcard.com>
4. County/City Resources: \_\_\_\_\_

## **RENTAL ASSISTANCE**

1. Single Parent Alliance of America: Website: <https://www.spaoa.org>
2. Rent Assistance Illinois: Website: <https://rentassistance.org/Illinois-programs.html>
3. Housing Assistance: Website:  
<https://www.illinois.gov/dceo/communityservices/housingassistance/page/default.aspx>
4. County/City Resources: \_\_\_\_\_

## **SENIOR SERVICES**

1. Illinois Department on Aging: Website:  
<https://www2illinois.gov/aging/pages/default.aspx>
2. Illinois Senior Services Caregivers: Website: [www.caregiverlist.com/Illinois/seniorresources.aspx](http://www.caregiverlist.com/Illinois/seniorresources.aspx)
3. Illinois Senior Services: Phone: 773-336-7632  
Website: [www.illinoiseniorservices.org/](http://www.illinoiseniorservices.org/)
4. County/City Resources: \_\_\_\_\_

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## SUICIDE PREVENTION

1. Suicide Prevention: Phone: 800-273-8155(Talk)  
Website: [www.dph.illinois.gov/topics-services/prevention-wellness/suicide-prevention](http://www.dph.illinois.gov/topics-services/prevention-wellness/suicide-prevention)
2. NAMI Illinois: Phone: 217-522-1403  
Website: [www.namiillinois.org](http://www.namiillinois.org)
3. American Foundation for Suicide Prevention: Website: <https://afsp.org/chapter/afsp->
4. Illinois Suicide Hotlines: Website: [www.suicide.org/hotlines/illinois-suicide-hotlines.html](http://www.suicide.org/hotlines/illinois-suicide-hotlines.html)
5. County/City Resources: \_\_\_\_\_

## TRANSLATORS

1. Illinois Interpreter Services and Language Translator Services: Phone: 800-726-8891  
Website: <https://interpretersunlimited.com/illinois-interpreter-tranlation/>
2. Illinois Language Services: Phone: 888-522-5527  
Website: <https://illinoislanguageservices.com/>
3. Illinois Deaf and Hard of Hearing Commission: Phone: 217-557-4495  
Website: <https://ww2illinois.gov/dhhc/pages/default.aspx>
4. Deaf Interpreter Services Inc.: Website: <https://www.deaf-interpreter.com>
5. County/City Resources: \_\_\_\_\_

## TRANSPORTATION\*

1. Illinois Senior Transportation: Website: <https://www.care.co/senior-transportation/il>
2. Transportation Services Aging:  
Website: <https://www2.aging.communtyervices/pages/transportation.aspx>
3. Transportation Adults with Developmental Disabilities:  
Website: [tps://www.illinois.gov/hfs/medicalclients/hcbs/pages/dd.aspx](https://www.illinois.gov/hfs/medicalclients/hcbs/pages/dd.aspx)
4. National Care Planning Council:  
Website: <https://www.longtermcare/link.net/a8profiles.html>
5. County/City Resources: \_\_\_\_\_

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## UTILITY ASSISTANCE

1. Illinois LiHeap Application: Website: <https://www.benefitsapplication.com/>
2. Utility Bill Assistance: Phone: 877-411-9276  
Website: <https://www.illinois.gov/dceo/communityservices/utilitybill/assistance/pages/default.aspx>
3. Illinois Low Income Energy Assistance Program:  
Website: <http://www.benefits.gov/benefits/benefit-details/1556>
4. County/City Resources: \_\_\_\_\_

## VETERANS

1. Illinois Warrior Assistance Program: Phone: 866-554-4927 (IWAP)  
Website: [www.illinoiswarrior.com/](http://www.illinoiswarrior.com/)
2. Veteran Homes: Website: <https://www2.illinois.gov/veterans/homes/pages/default.aspx>
3. State Benefits for Veterans: Website:  
<http://www2.illinois.gov/veterans/benefits/pages/default.aspx>
4. County/City Resources: \_\_\_\_\_



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## WORK/EMPLOYMENT ASSISTANCE

1. Workforce Development: Phone: 217-785-6006  
Website: <https://www.illinois.gov/deco/workforcedevelopment/pages/default.aspx>
2. WIPA (Work Incentives Planning and Assistance: Phone: 800-852-5110  
Website: <https://www.iltech.org/repository/wipa>
3. Supported Employment DHS: Website: [www.dhs.state.il.us/page.aspx?item=47494](http://www.dhs.state.il.us/page.aspx?item=47494)
4. Illinois Job Link: Website: <https://Illinoisjoblink.illinois.gov/ada/r/>
5. Resources for People with Disabilities: Website: [www.ides.illinois.gov/pages/resources-for-people-with-disabilities.aspx](http://www.ides.illinois.gov/pages/resources-for-people-with-disabilities.aspx)
6. Help for Felons: Breaking through the Past: Website: <http://helpforfelons.org/jobs-for-felons-in-illinois/>
7. National Hire Network: Website: [www.hirenetwork.org/content/illinois](http://www.hirenetwork.org/content/illinois)
8. Salvation Army: Website: <https://www.salvationarmy.us.org/usn/assist-the-unemployed/>
9. County/City Resources: \_\_\_\_\_

### Other

1. County/City Resources: \_\_\_\_\_

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# What Happens at Court

When someone has hurt you and that person has been arrested there may come a time when you are asked to give information to help put the person in jail, this is called a trial. This paper will tell you some of the things that may happen during the trial. this time, explain some of the different people you may work with and places you will be.

## THE PEOPLE YOU MAY MEET

**Prosecutors/State's Attorney** - The prosecutor works for the county or the state where the illegal thing that happened to you took place.

**Judge** - The judge is the person who sits in front of the courtroom. Sometimes the judge wears a black robe. The judge is the boss in the courtroom and listens to what the witnesses say. Not all witnesses have seen something, sometimes they may be an expert police officer's, medical examiner's etc. The judge may ask you or other witnesses questions. The judge always wants to hear the truth. If there is no jury, the judge decides what will happen to the defendant.

**Jury** - Sometimes the jury decides if the person is guilty or not guilty The jury is a group of 12 people. Their job is to listen carefully to everything that the witnesses, the lawyers and the judge have to say.

**Bailiff** - The Bailiff is a deputy sheriff, the bailiff wears a uniform. The bailiff's job is to keep the courtroom a safe place. The bailiff is there to protect the judge and everyone else in the courtroom. Sometimes the bailiff brings witnesses into the courthouse.

**Court Clerk** - The Court Clerk helps the judge in court. The court clerk writes or types notes for the judge. Either the court clerk or judge will ask you to raise your right hand and promise to tell the truth.

**Defendant** - The defendant is the person who is accused of doing something wrong. Accused means that others say that they have done something wrong. The defendant will be in the courtroom while the witnesses, including you, answer questions.

**Defense Attorney** - The Defense Attorney is the lawyer for the defendant. The defense attorney will ask you and the other witnesses questions. The questions may be about yourself, what you saw and know.

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## THE PLACES YOU MAY GO

**Courtroom** - This is a special room where witnesses go to tell what they know.

**States Attorney's Office** - This is where the Prosecutor works. You may go to this office for meetings before the trial.

## TERMS YOU MAY HEAR IN COURT

**Acquittal** - This means that the judge or the jury has decided that there is not enough evidence to prove that the defendant has committed the crime they have been charged with.

**Admissible** - A term used to describe evidence that a jury or judge can think about when deciding whether someone is guilty or not.

**Arraignment** - When a person is brought into court and told what they are being charged with, they are asked to plead guilty or not guilty. This is called an arraignment.

**Bail** - To get out of jail, a person must make bail. Bail is the amount of money the judge decides a person must pay to get out of jail. This is done to make sure that the person shows up to court. Sometimes the judge decides that a person does not have to pay money but can get out of jail.

**Conviction** - When the person who is on trial is found guilty it is called a conviction.

**Evidence** - Information presented in testimony or in documents that is used to persuade the judge or jury to decide the case in favor of one side or the other.

**Felony Crime** - A serious crime, that if a person is convicted can mean they may go to prison for at least one year.

**Misdemeanor Crime** - A crime that a person commits that, if they are convicted, will have them put in or jail for one year or less. See also felony.

**Motion** - A request by either the prosecutor or a defense attorney to a judge for a decision on an issue relating to the case.

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**Plea** - In a criminal case, the defendant's statement pleading "guilty" or "not guilty" in answer to the charges.

**Sentence** - The punishment ordered by a court for a defendant found guilty of a crime. The judge has the defendant come back to court another time to tell them what their sentence will be.

**Subpeona** - An order from the court that tells a person they have to come to court and tell the court what they saw or heard.

**Testimony** - When witnesses tell the judge and/or jury what they saw or heard or sometimes witnesses testify as experts.

**Verdict** - When the judge or the jury decides the guilt or innocence of a criminal defendant.

**Voir Dire or Jury Selection** - Jury selection is when the prosecutor and defense attorney ask questions of the people who may be on the jury to find out if they would be good jurors.

**Guilty** - The word guilty means that the judge or jury has decided that the defendant did what they are accused of.

**Not Guilty** - When someone is found "Not Guilty" it means that the judge or jury do not believe they have enough evidence to say for sure the defendant committed the crime.

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## **WHAT HAPPENS BEFORE THE TRIAL**

You may have one meeting or many meetings with the prosecutor, to help them know about what happened to you. They might ask you many times what happened to you. They may practice with you to tell what happened to you in the courtroom. You may take a tour of the courtroom to get you ready for when it is your turn to talk. You will see where everyone sits: the jury, judge, defense attorney, prosecutor and defendant.

## **WHAT HAPPENS DURING THE TRIAL**

A trial may have a jury to decide in the case or a judge may make the decision in the case. Sometimes a trial is long and sometimes a trial is short. You may or may not be able to be in the courtroom during the trial. If you are going to talk to the judge and the jury about what happened to you, you will not be able to be in the courtroom. You and the prosecutor will decide whether you can attend. During the trial you may tell the judge or the jury what happened to you.

At the end of the trial, the judge or jury decides what will happen to the defendant. If you have questions about what is happening during the trial or after the trial, you can ask the prosecutor or the victim advocate.

You have done a very important job in court.

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## **NOTICE TO PERSON MAKING A DECLARATION FOR MENTAL HEALTH TREATMENT**

This is an important legal document. It creates a declaration for mental health treatment. Before signing this document, you should know these important facts:

This document allows you to make decisions in advance about three types of mental health treatment: psychotropic medication, electroconvulsive therapy, and short-term (up to 17 days) admission to a treatment facility. The instructions that you include in this declaration will be followed only if two physicians or a judge believes that you are incapable of making treatment decisions. Otherwise, you will be considered capable to give or withhold consent for the treatments.

You may also appoint a person as your attorney-in-fact to make these treatment decisions for you if you become incapable. The person you appoint has a duty to act consistent with your desires as stated in this document or, if your desires are not stated or otherwise made known to the attorney-in-fact, to act in a manner consistent with what the person in good faith believes to be in your best interest. For the appointment to be effective, the person you appoint must accept the appointment in writing. The person also has the right to withdraw from acting as your attorney-in-fact at any time.

This declaration will not be valid unless it is signed by you and by two qualified witnesses who are personally known to you and who are present when you sign or acknowledge your signature.

This document will continue in effect for a period of three years unless you become incapable of participating in mental health treatment decisions. If this occurs, the directive will continue in effect until you are no longer incapable.

You have the right to revoke this document in whole or in part at any time you have been determined by a physician to be capable of giving or withholding informed consent for mental health treatment. A revocation is effective when it is communicated to your attending physician in writing and is signed by you and a physician.

If there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

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## DECLARATION FOR MENTAL HEALTH TREATMENT

I, \_\_\_\_\_, being an adult of sound mind, willfully and voluntarily make this declaration for mental health treatment to be followed if it is determined by two physicians or the court that my ability to receive and evaluate information effectively or communicate decisions is impaired to such an extent that I lack the capacity to refuse or consent to mental health treatment. "Mental health treatment" means electroconvulsive therapy, psychotropic medication, and admission to and retention in a health care facility for up to 17 days for treatment of a mental illness. I understand that I may become incapable of giving or withholding informed consent for mental health treatment due to the symptoms of a diagnosed mental disorder. These symptoms may include:

\_\_\_\_\_

### PSYCHOTROPIC MEDICATIONS

If I become incapable of giving or withholding informed consent for mental health treatment, my wishes regarding psychotropic medications are as follows (check the option that applies):

\_\_\_\_\_ I consent to the administration of psychotropic medications.

\_\_\_\_\_ I consent to the administration of psychotropic medications except the following:

\_\_\_\_\_

\_\_\_\_\_ I consent to the administration of only the following psychotropic medications:

\_\_\_\_\_

\_\_\_\_\_ I do not consent to the administration of any psychotropic medications.

Conditions or limitations:

\_\_\_\_\_

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## ELECTROCONVULSIVE TREATMENT

If I become incapable of giving or withholding informed consent for mental health treatment, my wishes regarding electroconvulsive treatment are as follows (check the option that applies):

\_\_\_\_\_ I consent to the administration of electroconvulsive treatment.

\_\_\_\_\_ I do not consent to the administration of electroconvulsive treatment.

Conditions or limitations:

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## ADMISSION TO AND RETENTION IN FACILITY

If I become incapable of giving or withholding informed consent for mental health treatment, my wishes regarding admission to and retention in a health care facility for mental health treatment are as follows (check the option that applies):

\_\_\_\_\_ I consent to being admitted to a health care facility for mental health treatment.

(This directive cannot, by law, provide consent to retain me in a facility for more than 17 days. )

\_\_\_\_\_ I do not consent to being admitted to a health care facility for mental health treatment.

Conditions or limitations:

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## APPOINTMENT OF ATTORNEY-IN-FACT

I appoint the person named below to act as my attorney-in-fact to make decisions regarding my mental health treatment if I become incapable of giving or withholding informed consent for that treatment. My attorney-in-fact is authorized to make decisions that are consistent with the wishes I have expressed in this declaration or, if not expressed, as are otherwise known to my attorney-in-fact. If my wishes are not expressed and are not otherwise known by my attorney-in-fact, my attorney-in-fact is to act in what he or she believes to be my best interest.

Name \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

If this person refuses or is unable to act on my behalf, or if I revoke that person's authority to act as my attorney-in-fact, I authorize the following person to act as my attorney-in-fact:

Name \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

## ACCEPTANCE OF APPOINTMENT AS ATTORNEY-IN-FACT

I accept this appointment and agree to serve as attorney-in-fact to make decisions about mental health treatment for the principal. I understand that I have a duty to act consistent with the desires of the principal as expressed in this appointment. I understand that this document gives me authority to make decisions about mental health treatment not only while the principal is incapable as determined by a court or two physicians. I understand that the principal may revoke this declaration in whole or in part at any time and in any manner when the principal is not incapable.

\_\_\_\_\_  
(Signature of Attorney-in-fact/Date) (Printed Name)

\_\_\_\_\_  
(Signature of Alternate Attorney-in-fact/Date) (Printed Name)

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## SELECTION OF PHYSICIAN

If it becomes necessary to determine if I have become incapable of giving or withholding informed consent for mental health treatment, I choose the doctor named below to be one of the two physicians who will determine whether I am incapable. If that physician is unavailable, that physician's designee shall determine whether I am incapable.

Name \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

## ADDITIONAL INSTRUCTIONS OR CONDITIONS

\_\_\_\_\_  
\_\_\_\_\_

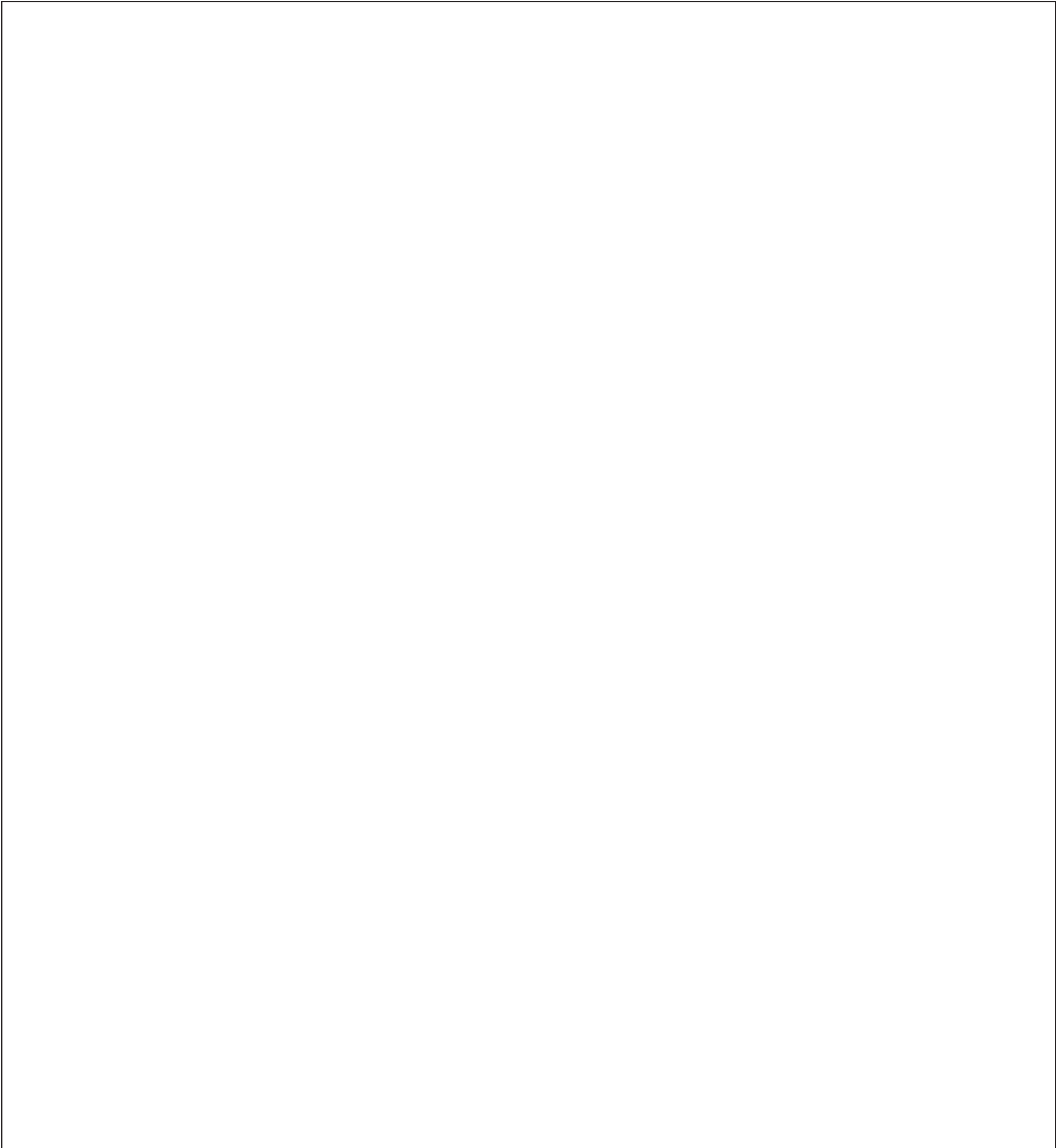
(Signature of Principal/Date) (Printed Name of Principal)

## AFFIRMATION OF WITNESSES

We affirm that the principal is personally known to us, that the principal signed or acknowledged the principal's signature on this declaration for mental health treatment in our presence, that the principal appears to be of sound mind and not under duress, fraud or undue influence, that neither of us is a person appointed as an attorney-in-fact by this document; the principal's attending physician or mental health service provider or a relative of the physician or provider; the owner, operator, or relative of an owner or operator of a facility in which the principal is a patient or resident; or person related to the principal by blood, marriage or adoption.

\_\_\_\_\_  
(Signature of Witness/Date) (Printed Name of Witness)

\_\_\_\_\_  
(Signature of Witness/Date) (Printed Name of Witness)



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## Give Us the Words

**Responses to questions that advocates may receive from allies when working with people with disabilities.**

**Where does she live? (or any question directed to you and not the person)**

**Response:** Please ask her that question.

**Response:** She can tell you.

---

**Do you know her mental age?**

**Response:** The only age that counts is her age of 36.

**Response:** She has 36 years of life experience.

**Response:** The truth is that no one can live 45 years and be like a three-year old. That is a myth that some people don't understand.

**Response:** That only refers to one aspect of a person, and she is still an adult.

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**Her staff said that she has a history of lying.**

**Response:** We need to treat every allegation report with respect and dignity. Actually, people with a history of lying are at greater risk of sexual violence because the offender is hoping that no one will believe the survivor.

**Response:** Most people have lied at one time or another. We need to proceed with her statement and follow up accordingly.

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**I don't know how to communicate with this person.**

**Response:** Let's ask her how we can best communicate with her.

**Response:** Everybody communicates in some way. How does she communicate with others?

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### What's wrong with her? Is she retarded or something?

**Response:** She's a person, just like you and me, and she has a disability.

**Response:** Nothing is "wrong" with her — she just thinks differently than we do.

**Response:** The word 'retarded' is not used anymore and is considered disrespectful. Let's focus on what she can do, not what she can't do.

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### Why can't she understand what I'm saying? Is something wrong with her?

**Response:** Maybe she didn't hear you, or she needs you to explain it differently.

**Response:** She's Deaf/hard of hearing. I can help her to understand you, or we can find an interpreter. Perhaps if you use pictures or writing, that will help.

**Response:** She needs time to process what you're saying. Let her think a minute.

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### Why can't this woman give a coherent narrative? It's all jumbled up and out of order.

**Response:** Some women with disabilities can't do clocks or calendars very well, but they know their schedules. If you focus on her activities, you will learn a lot.

**Response:** She has difficulty understanding time. Talk about the people involved, herself and what happened, such as "What did John do? What did you do? What did John do then? What did you do?" Focus on the incident itself, not the timeframe.

**Response:** She's trying to process a lot right now. Give her time to think/calm down.

**Response:** Focus on her sensory experiences and you will have lots of useful information. What did she hear, see, feel, taste, etc.?

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**Help! I said something that made the woman upset, and I didn't mean to! Let's ask her who her guardian is and what kind of information they want.**

**Response:** Tell her you're sorry, and see if you can figure out what it is that upset her.

**Response:** Let's all take a break for a minute and talk things through. You may have brought up some part of the incident she may not have remembered before.

**Response:** After you apologize, maybe you and I can talk to her together about it.

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**Why is that woman flapping her arms like that? It makes her look really stupid.**

**Response:** She has autism. She does that to calm herself down sometimes.

**Response:** By focusing on the flapping, it helps get her mind off the pain and confusion she's feeling right now. Let her flap, and then let her continue her story.

**Response:** She may be feeling uncomfortable, overloaded, or overwhelmed right now. Let's take a break, or talk about something else for a minute. We can come back.

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**Whom should I be talking to here?  
This woman has a guardian and she's incompetent.**

**Response:** Even though she has a guardian, she still has the right to speak for herself.

**Response:** "Incompetent" is a legal term. It doesn't mean she can't express herself.

**Response:** Let's ask her who her guardian is, and what kind of information they want.

**Response:** It is important that the victim have an opportunity to tell what happened to her. Victims with guardians have rights and it is the victim who knows what happened to them.

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**This woman's guardian won't release the information/rape kit/evidence, etc.**

**Response:** Illinois law states that the survivor or law enforcement can release the kit.

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**She says she has a guardian. What does that mean?**

**Response:** When someone has a guardian, a judge has decided they need help making decisions. There are different types of guardians. Let's find out what decisions her guardian has the power to make.

**Response:** A guardian is appointed by a judge to make decisions on someone else's behalf. A plenary guardian makes most major life decisions. A limited guardian only makes the decisions the court has determined they can make. Either way, we want the person to express what they think, too.

**Response:** In Illinois, adults with disabilities who have guardians have the legal right to:

- a. access 5 counseling sessions without guardian consent/knowledge;
- b. consent to the sexual assault exam and release of records;
- c. restrict access to rape crisis center counseling records.

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**I don't think I can examine her. She is too disabled.**

**Response:** Let's ask her the best way to examine her.

**Response:** I know some alternative positions that might work. Let's ask her what she prefers.

**Response:** There is a tool that might be helpful in working with her-it is the Picture Guide to the Exam Following Sexual Assault. It is helpful with many victims. minute.

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**Why can't this woman understand the paperwork I'm trying to get her to sign?**

**Response:** She uses pictures to communicate instead of written words. Why don't you explain to her what the paperwork says in everyday language, without big words?

**Response:** She doesn't understand all the legal jargon. Could you please explain it?

**Response:** The print is too tiny for her to read. Do you have a large-print format?

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**This person is drunk. We can't help her?**

**Response:** Perhaps there are other reasons for her behavior. Have you asked if she has cerebral palsy or is diabetic. Sometimes trauma impacts blood sugar levels, which can make a person appear intoxicated.

**Response:** Ask the survivor what she would like to be moved. It's always important to ask the survivor and not the caregivers how best to care for them.



