

# Understanding Sexual Rights and Sexual Assault in Resident Advocacy



Disability Rights  
WASHINGTON  
Washington's protection and advocacy system



WCSAP  
Washington Coalition of  
Sexual Assault Programs



Washington State Long-Term Care  
OMBUDSMAN PROGRAM

Alliance to End Sexual Violence in Long-Term Care



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## Listen to Me

**“Respect. Listen to me. Get the answer.**

**Get the results I need. Take the time.”**

--Resident (Needs Assessment Report, 2014, p.56)

**“We need an advocate who can speak on our behalf,  
because no one listens to us.”**

-- Survivor (Needs Assessment Report, 2014, p.25)

### What is the Purpose of This Project?



George is a resident in a nursing home facility. In the afternoon, he really enjoys watching his favorite television show in the common area with others. It's the highlight of George's day. Lately though, Jane (another resident) is making it impossible for George to watch his show in peace. Jane makes embarrassing comments about George's body when she comes into the room ("Look at that cute behind! I just want to pinch it!"), and she wants to sit right next to George. George told staff that it makes him uncomfortable when she is there. The aide said, "She probably just thinks you're nice, George! It's so cute that she likes to flirt." George complained to the head nurse, who said, "If it really bothers you, just don't come out of your room--after all, you do have a TV in your room."

People who live in long-term care facilities may experience sexual abuse or other disregard for their rights with regard to sexuality. When this happens, the needs and wishes of the long-term care resident are often overlooked. All too frequently, no one is hearing the individual.

Fortunately, there are those who specialize in listening to people, helping them clarify what they want, connecting them to resources, and ensuring that their voices are heard. They are called advocates, and the purpose of this handbook is to provide basic information to advocates from a variety of fields so that they can assist and support long-term care residents with maintaining rights, including the right to sexual expression.

Three agencies—Disability Rights Washington (DRW), the Washington Coalition of Sexual Assault Programs (WCSAP), and Washington State Long-Term Care Ombudsman Program (LTCOP)—came together as the Alliance to End Sexual Violence in Long-Term Care. Alliance partners created this handbook as a result of their collaboration to develop technical assistance for advocates working with residents of long-term care facilities in Washington State. The vision of the collaboration is:

People living in long-term care settings experience safe, respectful and dignified environments over which they exert control, self-determination and independence. Long-term care environments communicate that residents are entitled to live free from violence, abuse and neglect with support to make choices about their sexuality, healing and justice pursuits. A strong system of advocacy responds to sexual violence in a trauma-informed, survivor-centered manner at every



level. Care providers, organizations and public entities are self-aware of the risks of violence in long-term care settings. All are accountable to the people they serve and promote a model of non-tolerance of sexual violence (DRW, WCSAP, & LTCOP, 2013, p. 5).

This handbook is a basic introduction to what advocates can do to make this vision a reality. Training and technical assistance (consultation) on sexual assault advocacy in long-term care are also part of the project, which is funded by a grant from the Office on Violence Against Women, US Department of Justice.

As this project progressed, it revealed a clear need: residents must have someone dedicated to helping them, to be their “point person,” and to assist in carrying their wishes forward. While services for people living in long-term care facilities have improved and expanded over the years, and there is more attention to abuse issues, there is still a gap. Even if abuse is reported and investigated, victims rarely get individual advocacy. The focus may be on the response of the facility rather than support for the abuse survivor. In addition, there are a wide range of unaddressed resident needs beyond responding to abuse, such as helping to ensure choice and dignity with regard to sexual activities. Washington has strong advocacy programs in the fields of sexual assault, disability rights, and long-term care (ombuds). This handbook celebrates the combined strengths of these fields, made even stronger through cooperation and coordinated services. It encourages all advocates working with long-term care residents to expand their knowledge and become more proficient at supporting survivors facing sexual abuse as well as issues related to healthy relationships and sexual expression.

## Who Developed The Project?

The Alliance to End Sexual Violence in Long-Term Care is comprised of the following three agencies. Each brings a unique perspective and expertise on this subject.

### **Disability Rights Washington**

Disability Rights Washington (DRW) is the protection and advocacy system for Washington, founded as a nonprofit entity in 1977, to address rights-related disability issues, including the right to be free from abuse and neglect. DRW provides extensive disability-rights-related information and technical assistance to the disability advocacy communities, the public, and policy makers at every level of government.

### **Washington Coalition of Sexual Assault Programs**

The Washington Coalition of Sexual Assault Programs (WCSAP), a nonprofit incorporated in 1979, has the mission of uniting agencies engaged in the elimination of sexual violence. WCSAP provides information, training, and expertise to program and individual members who support victims, family and friends, the general public, and all those whose lives have been affected by sexual assault.

### **Washington State Long-Term Care Ombudsman Program**

The Long-Term Care Ombudsman Program (LTCOP) is recognized as the statewide system that ensures the dignity, rights, and well-being of long-term care residents in Washington. Federally mandated to receive and resolve complaints statewide, the LTCOP has served elders; seniors; and people with intellectual disabilities, mental illness, and chronic physical illness in licensed long-term care facilities for 40 years.

## **What Are The Partner Agencies' Shared Values?**

The partner agencies developed a Collaboration Charter in which they agreed on certain shared core values that underlie the entire project, including this handbook. Those values include profound respect for the fundamental dignity and autonomy of each individual. Coming from an empowerment model, partners believe that “no pity” is an important principle, because “pity undermines the ability of people to exercise power and choice” (DRW, LTCOP, & WCSAP, 2013, p. 9). Survivors are the experts on their own lives and experiences, and advocates approach those they serve with humility and openness to learning and understanding.

## **What Types of Advocates Are Involved?**

This handbook focuses on three types of advocates – disability advocates, sexual assault advocates, and long-term care ombuds (a gender-neutral term for “ombudsman”). Advocates share a fervent commitment to provide support and uphold the rights of those they serve. Each type of advocate has a different foundation of training, knowledge, and experience. One goal of this handbook is to help advocates know when and how to reach out to those in other fields to meet a resident’s needs.

## What Are the Key Terms?

It is important to identify a few key terms so that all users of this handbook are on the same page.

### **Long-Term Care**

A long-term care facility provides twenty-four-hour care to meet both medical and nonmedical needs of residents. There are many types of long-term care facilities. For purposes of this handbook, we focus on nursing homes, assisted living, and adult family homes. These will be described in greater detail below. All residents of long-term care experience disability.

### **Disability**

“Disability is a broad term to signify a mental, sensory, cognitive, emotional and/or physical characteristic that, in conjunction with societal values, may limit a person’s physical or emotional well-being or ability. Disability is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which one lives. People may or may not identify with disability. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers” (DRW, WCSAP, & LTCOP, 2013, p. 59). For purposes of this project, it is presumed that all people who receive services in long-term care experience disability. It is important to note, however, not all long-term care residents identify with disability.

Some basic things to remember about working with individuals with disabilities are:

- Always ask a person with a disability if they would like help, before taking action. Offering assistance is respectful, but avoid jumping in and taking over. Special instructions may be involved, or help may not be needed.
- Most people prefer to ask for help if they need it. This approach works well, leaving decision-making up to the individual.
- If the subject of the person's disability comes up, discuss it with the person directly, rather than asking an aide or assistant.
- Speak directly to the person. They can speak for themselves.
- See a person with a disability as a person first.
- Be neither patronizing nor reverential. Understand that the life of a person with a disability can be interesting and normal.
- Treat adults as adults. Call the person by their first name only when extending the familiarity to others.
- Treat people with disabilities as you would like to be treated.
- Appreciate what a person is able to accomplish. Difficulty may stem from society's attitudes and environmental barriers rather than the disability itself.
- Relax and plan for extra time. A calm and reassuring demeanor will benefit all people you serve.

## **Sexual Assault, Sexual Abuse, and Sexual Violence**

Sexual assault or sexual violence are umbrella terms that include a wide range of victimization that occur when a person is forced, coerced, and/or manipulated into unwanted sexual activity. It can include completed or attempted attacks, may or may not involve force and threats, and may or may not be illegal under state or federal law. While “sexual violence” is the broadest term, encompassing the full continuum of behaviors that violate sexual rights and boundaries, it may be a confusing term because people generally equate “violence” with physical harm. Sexual abuse is generally used to describe sexual violence within a relationship, such as sexual violation of any type by a caregiver.

Sexual violence in all its forms is part of a range of behaviors that offenders use to take power from their victims. It can include words, gestures, jokes, intimidation and harassment. It can include coercion, threats and actions that involve unwanted touching or sexual intercourse, and may involve other forms of violence.

It is important to note that most people don't use the terms “sexual violence” or “sexual assault” in everyday language. Embarrassment or a lack of knowledge may lead residents to use vague terms, or they may be more comfortable with slang. Advocates will want to mirror the language used by residents to describe their own experiences, while clarifying what the resident means.



## Know Who I Am

**“We got a call from a parent looking for a supported living setting for her daughter. She wanted a female-only facility, with female-only staff. She wanted birth control for her daughter. An all-female staff and birth control doesn’t mean protection from sexual violence. It’s not about putting a plastic bubble around your daughter. She has sexual desires. It’s about figuring out a way these can be expressed, in a way that is healthy.”**  
--Disability Advocate (Needs Assessment, p. 29)

**“When I was living at another place, I met a gentleman. He and I hit it off just fine. I was seeing a lot of him. We’d occasionally kiss. It made everybody mad! So it ended up I got thrown out.”**  
--Nursing Home Resident (Needs Assessment, p. 32)

People who live in long-term care facilities are just that – a wide range of individuals who are living their day-to-day lives, in places where others have a great deal of control. Contrary to stereotypes, they are not all extremely elderly; in fact, a substantial proportion of this population consists of people in the 18 to 64 age range. Some residents have physical disabilities or medical challenges, and some have cognitive disabilities or communication challenges. About 25 % of the people who live in adult family homes have a developmental disability. Some assisted living facilities

provide services specifically to people with traumatic brain injuries, Alzheimer's or mental health disabilities. Advocates providing services to individuals who live in these facilities will meet people of varied cultures and backgrounds, people of all ages (from late teens to very elderly), people who go to work, people who have friends and romantic relationships, people who have hopes and dreams.

The quality of life in long-term care facilities varies considerably. Regardless of a resident's circumstances, an environment that is violence free and supports competence, choice, dignity, and a personalized approach is critical.

### Where Do People Live?

The different types of long-term care facilities described in this handbook are regulated by the Washington State Department of Social and Health Services (DSHS). Their long-term care web page is <https://www.dshs.wa.gov/altsa/residential-care-services/long-term-care-residential-options>. This page offers links to allow users to search for the facilities in their area and to view inspection reports and ratings.

Individuals may stay in these facilities temporarily, such as while they are recovering from illness or surgery, or on a permanent basis. Facilities have the duty to provide each resident with the necessary care and services to attain or maintain the highest practicable physical, mental and psychosocial well-being, self-care, and independence. The quality of care and the degree of respect for residents' self-determination varies widely. Some of the challenges common to all of these living arrangements are the need to share living space (whether it is with a roommate or in common areas), and the way in which staff exercise their control over residents.



High staff turnover rates are another common challenge that may have an impact on residents' trust levels and willingness to talk to staff about abuse, harassment, or sexuality. The median turnover rate for all direct care staff in nursing facilities in 2012 was 50% (American Health Care Association, 2014).

Note: The descriptions of the long-term care facilities below are taken from the Washington State Department of Social and Health Services (DSHS) website (<https://www.dshs.wa.gov/altsa/residential-care-services/long-term-care-residential-options>). All statistics on residents reflect 2013 numbers (the most current available) provided in response to a request for data to DSHS).

### **Adult Family Homes**

"Adult Family Homes are regular neighborhood homes where staff assumes responsibility for the safety and well-being of the adult. A room, meals, laundry, supervision and varying levels of assistance with care are provided. Some provide occasional nursing care. Some offer specialized care for people with mental health issues, developmental disabilities or dementia. The home can have two to six residents and is licensed by the state."

**In Washington State, there were 2,772 adult family homes licensed in 2013. Some counties have only one of these facilities; there are hundreds in other counties, and more than a thousand in King County. Adult family homes were formerly referred to as "group homes."**

## **Assisted Living Facilities**

“Assisted Living Facilities are facilities in a community setting where staff assumes responsibility for the safety and well-being of the adult. Housing, meals, laundry, supervision, and varying levels of assistance with care are provided. Some provide nursing care. Some offer specialized care for people with mental health issues, developmental disabilities, or dementia. The home can have seven or more residents and is licensed by the state.”

**Washington State has 540 licensed assisted living facilities, housing more than 6,000 residents. Assisted living facilities used to be called “boarding homes.”**

## **Nursing Homes**

“Nursing homes provide 24-hour supervised nursing care, personal care, therapy, nutrition management, organized activities, social services, room, board and laundry.”

**In Washington State, there are 236 licensed nursing homes housing more than 18,000 individuals. Most counties have between one and 10 nursing homes; a handful of counties have 11 to 25 facilities, and there are 67 nursing homes in King County.**

## Washington State Facilities

### Adult Family Homes

7,500 Residents

2,772  
Facilities



4,997	●	65 +
2,500	●	18-65
3	●	0-17

### Assisted Living Facilities

6,000 Residents

540  
Facilities



5,100	●	65 +
900	●	18-65

### Nursing Homes

18,000 Residents

236  
Facilities



13,990	●	65 +
4,000	●	18-65
10	●	0-17

## Residents' Challenges and Strengths

**"We've all worked. We've had families.  
We deserve respect.  
I lived alone for 30 years.  
Now they are treating me like I don't know what's up."  
--Resident, Needs Assessment, p. 43**

Residents of long-term care facilities face significant challenges as they strive to maintain their dignity and independence. Because institutional care often derives from a medical model, residents may be considered to be "patients" and the technical aspects of providing medically adequate care may overshadow the simple fact that these facilities are the residents' homes. Staff may make decisions for residents, telling them what and when to eat or what time to get up in the morning, for example. There may be a clash between institutional efficiency and individual needs and wishes.

According to this project's Needs Assessment, "Residents in long-term care are extremely isolated and accommodations constructed around an individual are often fragile and tentative" (p. 95). Advocates who participated in the project recounted these events, which set the tone for dismissal of individual needs:

- The front entrance and exit of one facility were locked but unstaffed.
- Residents stated they knew not to call for help during the midday shift change because of a staff shortage.
- A resident who fell had to yell and wait 90 minutes for assistance.
- Residents were pushed in a wheelchair, naked except for a bed sheet, to be bathed.
- Staff left doors open while changing residents' incontinence briefs.
- It took months for one resident to get her wheelchair fixed.
- Another resident waited 10 months for an appointment to fix her dentures.
- Residents' belongings were stolen and the facility did not respond.
- Access to blankets, food, visitors, computers, telephones, community, or outside appointments was severely restricted.

While these particular incidents did not take place in every facility, they were only a sampling of the ways in which individuals' needs were ignored.

Some long-term care facilities do take a strengths-based approach to resident care. In a strengths-based approach, the following principles are critical (NY Connects, n.d., p. 1):

**Respect:** recognition of peoples' intrinsic worth, rights, capacities, uniqueness and commonalties, and self-determination;

**Participation:** engagement, empowerment, leadership, decision-making, and choice;

**Collaboration:** teamwork and partnership, consultation, and inclusion;

**Cultural responsiveness:** affirm cultural, racial and linguistic identities, and equity; and

**Community building:** opportunities to contribute, building on informal and formal systems, connections, relationships.

Residents come from all backgrounds and cultures, with a wide variety of life experiences. Advocates can more effectively assist residents when they realize the diversity of this population. The age range is greater than most people think; young and middle-aged adults comprise a significant portion of long-term care residents. Residents of all ages desire intimate relationships and sexual activity. Individual residents' situations and needs may change over time. Some may have positive family involvement and support; others may have family members who override their needs; and still other residents may have little or no contact with family. Social and economic status, family influence, cultural issues, and sexual orientation may have an impact on how residents are treated within a long-term care facility, along with the facility's philosophy and resources.



## Know the Big Picture

### What is the Scope of the Problem?

We know that sexual violence flourishes in an atmosphere of oppression. When people are not seen as individuals, when their voices go unheard, when their concerns are dismissed, and when their perceptions are swept aside, they are more likely to be victimized and less likely to experience justice. Advocates know that cognitive disability does not equal a lack of credibility, that communication barriers can often be overcome through patience and creativity, and that everyone benefits from an environment of respect.

**When people are not seen as individuals, when their voices go unheard, when their concerns are dismissed, and when their perceptions are swept aside, they are more likely to be victimized and less likely to experience justice.**

### Why Does Sexual Assault Happen?

**Sexual assault is about manipulation, exploitation, and exerting power and control over another person. The root cause of sexual violence is oppression.**

Sexual violence affects every person in society, either directly or indirectly. It knows no boundaries and crosses

the lines of every race, class, culture, gender, ability, sexual orientation, gender identity, and sexuality. Sexual violence is deeply embedded in society and is a result of multiple layers of oppression, including ableism, sexism, racism, and heterosexism. It is used as a weapon where perpetrators exert power and control over the victim.

People who live in long-term care may have been abused at any point in their lives, within the facility or elsewhere, once or multiple times. They may describe a recent experience or something that happened in the past. They may want help in being safe from an abuser, information about their options, or simply someone to care about their feelings.

Sexual violence is never the victim's fault. Perpetrators make choices to commit acts of sexual violence, and may base these choices on an individual's real or perceived vulnerability and/or their likelihood of reporting or being believed. When an advocate listens to someone who has survived sexual violence with compassion and concern rather than judgement, and offers support and resources, the healing process can move forward.

### **What Do We Know About Sexual Violence in General?**

According to the National Sexual Violence Resource Center (2015, para 1):

- One in five women and one in 71 men will be raped at some point in their lives.
- Nearly one in 10 women has been raped by an intimate partner in her lifetime.
- 91% of the victims of rape and sexual assault are female, and 9% are male.
- In eight out of 10 cases of rape, the victim knew the person who sexually assaulted them.



Though rates vary, studies indicate people with disabilities are sexually victimized more frequently than those without disabilities. Consider the following:

- Among adults with developmental disabilities, as many as 83% of females and 32% of males are victims of sexual assault (Johnson, Sigler, 2000).
- 40% of women with physical disabilities reported being sexually assaulted (Young, Nosek, Howland, Chanpong, Rintala, 1997, p. 534-538).
- Women with disabilities, in a 2001 study, said that their limited ability to perform basic daily tasks was the factor that turned ordinary situations into situations where there was potential for abuse (Gilson, DePoy, Carmer, 2001, p. 220-235).
- Individuals with disabilities often depend on their abuser for daily care or economic needs (Swedlund, Nosek, 2000, p. 57-64).
- 49% of people with developmental disabilities, who are victims of sexual violence, will experience 10 or more abusive incidents (Valenti-Heim, Schwartz, 1995).
- Only 3% of sexual abuse cases involving people with developmental disabilities are ever reported (Valenti-Heim, Schwartz, 1995).
- 33% of abusers of those with disabilities are friends or acquaintances, 33% are natural or foster family members, and 25% are caregivers or service providers (Sobsey, 1988).

In Washington State, Adult Protective Services (APS) is charged with investigating sexual abuse allegations involving vulnerable adults. Per Washington's statutory definition, all vulnerable adults experience disability.

## **What Do We Know About Sexual Violence in Long-Term Care?**

Advocates may find navigating the long-term care system to be tricky. The Alliance to End Sexual Violence in Long-Term Care certainly hopes this handbook will help, and would like to encourage advocates who are not familiar with long-term care to seek technical assistance from any of the three partner organizations within this project, to take advantage of training opportunities that will be offered, and to connect with fellow advocates who are experienced in traveling this road.

Sexual violence is a community-wide problem, and individuals with disabilities are at disproportionate risk, whether in care facilities or living in the community (WCSAP, 2014). In Washington State, the Office of Crime Victims Advocacy collects data from community advocacy agencies. In 2014, of 8,940 survivors of sexual assault who received advocacy services, 1,196 (approximately 13%) self-identified as having one or more disabilities. This information was not collected from every person served (for various reasons, such as not being able to ask during a crisis call). Of the clients who specifically responded to the question about whether or not they had a disability, more than 18% indicated that they did. The breakdown by type of disability (and the approximate percentage of the total number of clients reporting one or more disabilities) was:

- Mental disability – 518 (43%)
- Physical disability – 224 (19%)
- Sensory disability – 71 (6%)
- Other disability – 136 (11%)
- Multiple disabilities – 247 (21%)

According to the National Ombudsman Reporting System data for 2010, seven percent of abuse complaints in nursing homes and seven percent of abuse complaints in adult family homes involve sexual abuse. Abuse in general is vastly underreported. Sexual abuse may be reported at an even lower rate, for a variety of reasons: embarrassment, fear, self-blame, and the belief that the victim will not be believed. Furthermore, sexual abuse complaints may be minimized or ignored.

**Sexual violence perpetrated against residents of long-term care facilities may take one of the following forms:**

- Staff to resident
- Resident to resident
- Family member to resident
- Other visitor to resident

There has not been nearly enough research into the nature and prevalence of sexual abuse in long-term care. One of the most dedicated and prolific researchers, Holly Ramsey-Klawnsnik, conducted a national study of “vulnerable adults” ages 18 to 64 in care facilities. This was a four-year study of all (429) reported cases of sexual abuse in long-term care facilities. She and her colleagues found that “facility employees were the most commonly alleged perpetrators... most of the accused were male... About half [of the abuse victims in the study] required assistance with all activities of daily living, and 64 percent had Alzheimer’s-type dementia... Some said their offenders had threatened them, and some reported repeated assaults. Disclosures ranged from non-contact offenses to vaginal and anal rape” (Ramsey-Klawnsnik & Teaster, 2012, p. 56).

In the study by Ramsey-Klawnsnik, Teaster and colleagues (2007), it was clear that there was not a timely response. Here are some of the findings from the study:

<b>Average Time Between Alleged Abuse &amp; Investigation</b>	10.7 days (range 0-147 days)
<b>Age of Alleged Victims</b>	Mean age 49.5 years old (range 18 to 101)
<b>Percentage of Victims Who Were Female</b>	59%
<b>Most Common Condition Among Victims</b>	Alzheimer's (nearly 25%; 64% of elderly)
<b>Most Common Disabilities Among Victims</b>	Developmental Disability 40% Psychiatric Disability 24%
<b>Alleged Perpetrators</b>	74% male; mean age 42.2 years 45% direct care providers about 25% other residents

In this study, only about half of alleged victims were medically examined, and the vast majority of those exams were by facility staff. While 18 percent of alleged victims were offered mental health counseling, there was no mention of victim advocacy services being offered. There were only five arrests in 429 cases. The most frequent intervention was described as “none.”

**The most frequent intervention was described as “none.”**

The Alliance to End Violence in Long-Term Care recognized that sexual assault advocates, disability advocates, and long-term care ombuds are each direct points of contact to resident survivors of sexual assault, and with technical assistance, could provide greatly needed intervention where there was “none.”

## How Does the System Respond to Abuse in Facilities?

In Washington State, individuals in certain roles and professions are considered mandatory reporters and must report abuse of a vulnerable adult. The relevant statute is:

### **RCW 74.34 – Abuse of Vulnerable Adults**

<http://app.leg.wa.gov/rcw/default.aspx?cite=74.34>

With regard to the types of advocates addressed in this handbook, sexual assault advocates are mandatory reporters, while long-term care ombuds are not and disability advocates may or may not be mandatory reporters depending on their agency or professional role. Advocates who are mandatory reporters should follow their agency's policies and procedures for making mandatory reports. It is important that advocates clearly communicate their mandatory reporting responsibilities at the outset, so that residents are aware of possible outcomes before they disclose any experiences. All staff of long-term care facilities are mandatory reporters.

**The most common disabilities among victims of sexual assault are developmental and psychiatric.**

According to the Department of Health and Social Services (DSHS) (<https://www.dshs.wa.gov/altsa/home-and-community-services/who-vulnerable-adult>):

A vulnerable adult is defined by law as:

- a person 60 years of age or older who lacks the functional, physical, or mental ability to care for him or herself;
- an adult with a developmental disability per 71A.10.020;
- an adult with a legal guardian per 11.88 RCW;
- an adult living in a long-term care facility (an adult family home, boarding home or nursing home);
- an adult living in their own or family's home receiving services from an agency or contracted individual provider; or
- an adult self-directing their care per law (74.39.050 RCW)

When a report is made by or about a resident of a long-term care facility, the aftermath includes investigation of the abuse incident itself and investigation of the facility's responsibility and response. Regardless of who is the alleged perpetrator, the facility has the responsibility to keep residents safe from abuse of all types.

In Washington, Residential Care Services is the licensing and regulatory unit that oversees long-term care facilities, and conducts facility investigations. Adult Protective Services conducts investigations of individuals. There are a variety of other players that may be involved, including the Department of Health, law enforcement, facility staff, family members, guardians, and others.

AGENCY	TYPE OF RESPONSE
<p><b>Adult Protective Services (APS)</b></p>	<p>Investigations of individuals related to allegations of abuse, neglect and exploitation/ financial exploitation under Chapter 74.34 RCW, Abuse of Vulnerable Adults. This includes residents/clients of adult family homes, nursing homes, and assisted living facilities.</p>
<p><b>Residential Care Services (RCS)</b></p>	<p>Systems-based, facility-focused provider practice investigations and regulatory oversight of adult family homes, nursing homes, and assisted living facilities.</p>
<p><b>Department of Health</b></p>	<p>Investigations of licensed or certified providers such as nurses or social workers.</p>
<p><b>Law Enforcement</b></p>	<p>Criminal investigations.</p>

## Agencies involved in sexual abuse investigations

The Investigation Chart (WA State DSHS, 2012; Walters, C. 2014) provides useful information for the advocate to share with a resident who is considering reporting or who would like to know what to expect once a report has been made. It is critical that advocates help residents know where their information may go, and who will have access to it.

TYPE	AGENCY		
<p><b>Staff-to-Resident</b></p> <ul style="list-style-type: none"> <li>• Abuse – Sexual, Physical, Assault with bodily harm</li> <li>• Neglect / Mistreat / Negligent treatment</li> <li>• Financial Exploitation / Misappropriation of Resident Property</li> </ul> <p><i>DOH when allegation involves licensed, certified or registered health care workers</i></p>	DSHS Hotline*	Police 9-1-1	WA State Dept. of Health
<p><b>Non-Staff to Resident</b></p> <ul style="list-style-type: none"> <li>• Abuse/Assault, Neglect</li> <li>• Misappropriation / Exploitation</li> </ul> <p><i>The call to the DSHS hotline will meet the requirement for reporting to APS, but you may still want to contact your local APS office.</i></p>	DSHS Hotline*	Police 9-1-1	APS Adult Protective Services
<p><b>Injuries of Unknown Source</b></p> <p>Substantial injury (not stemming from an incident of abuse or neglect; origin unknown)</p>	DSHS Hotline*		
<p><b>Resident-to-Resident</b></p> <ul style="list-style-type: none"> <li>• Physical abuse with bodily harm or psychological harm</li> <li>• Mental abuse with psychological harm</li> <li>• Sexual abuse/assault</li> <li>• Misappropriation/Financial Exploitation</li> </ul> <p><i>Repeated physical abuse without bodily or psychological harm may become abuse or neglect if measures are not taken to more effectively address the resident's need for care &amp; services.</i></p>	DSHS Hotline*	Police 9-1-1	APS
<p><b>Unexpected Resident Death</b></p> <ul style="list-style-type: none"> <li>• Possibly related to abuse or neglect</li> <li>• Suicide</li> <li>• Not related to abuse or neglect but suspicious</li> </ul> <p><i>See RCW 68.50.010 for certain suspicious circumstances that may need to be reported to police.</i></p>	DSHS Hotline*	Police 9-1-1	Coroner / Medical Examiner

\*DSHS Hotline 1-800-562-6078



## How Much Abuse is Unreported or Unaddressed?

In the community in general, most sexual assaults (65%) are never reported (Langton, Berzofsky, Krebs & Smiley-McDonald, 2012). Another study cites that compared to women without disabilities, women with disabilities were more likely to report more intense experiences of abuse, including the combination of multiple incidents, multiple perpetrators, and longer duration. (Nosek, Young & Howland, 2003).

Long-term care residents may face additional barriers to reporting because of fear of retaliation, a sense that their needs and preferences are discounted in all matters, communication difficulties, or lack of contact with a trusted individual. Given the poor institutional response noted in the research studies described above, it is likely that sexual abuse in long-term care facilities often goes unreported, even when residents voice their concerns.

Even when abuse is reported, the response is often ineffective. For example, Burgess, Hanrahan, and Baker (2005) found that 75% of sexual assault victims in nursing homes sustained physical injury, including vaginal trauma in 45% of the cases, yet only 27% were given a forensic medical exam.

Other factors complicate abuse in facilities. The perpetrator may be staff, someone visiting the facility, or another resident. Each of these instances generates complexity in access to advocacy or abuse response.

An April 2015 news story cited repeated, unreported sexual abuse in a Cashmere, Washington nursing home, where nurses and staff witnessed several instances of a patient abusing other residents. The news report referenced the State's investigative summary, which said the facility failed to recognize the resident's behavior as sexual abuse, and did not take protective measures to prevent abuse to other residents.

Residents or family members may be worried about the consequences of reporting abuse. An ombuds in the Needs Assessment (DRW, WCSAP, & LTCOP, 2014, p. 21) states, "There was an allegation of inappropriate touch, involving a staff person, and the family was afraid the resident was going to be moved to another facility overnight, in retaliation for reporting."

In an article about the range of sexual expression in assisted living, one female resident stated that a male resident named Wally entered her room at night and harassed her in her bed. She reported to the staff, who dismissed her concerns; she finally called the police. The responding officer minimized what had happened and laughed with the nurse. The researchers report:

Rather than supervise Wally, the management faulted Ms. Carson for complaining and publicly airing a grievance. In fact, she said, she felt victimized thrice: once by Wally, once by the nurse and the police officer, and once by the facility (Frankowsky & Clark, 2009).



## Know What is Possible

Advocates uphold individual rights, and they also consider the larger context in which individuals live. Many successful long-term care ombuds have acquired the ability to walk into a long-term care facility and glean, within several minutes, whether the environment is conducive to effective advocacy, or if there will be many barriers to navigate during advocacy processes. Ombuds said they could feel whether an environment was supportive of autonomy or oppressive. In an attempt to understand this skill, and translate it for sexual assault and disability advocates, the Alliance to End Violence in Long-Term Care approached residents of long-term care and asked what makes a welcome and respectful environment, and what this environment looks like when advocacy is effective.

This type of environment helps to promote sexual safety and respect for sexual expression throughout the lifespan. Well-run facilities create welcoming and respectful environments that discourage sexual abuse or other sexual violence. In such a facility, there is attention to and awareness of the entire continuum of sexual violence. Everyone has a voice, everyone has rights, and everyone has access to an advocate.

This description of a welcoming and respectful environment within a long-term care facility came from the project's Resident Advisory Workgroup.

- **Privacy** – Residents' privacy is respected; people recognize and treat the place as the residents' home.
- **Dignity** – Support is readily available, and residents are well-informed of their rights.
- **Focus on People** – There is a clear focus on the needs of residents (not simply administrative convenience for the facility) and a willingness to engage in problem-solving.
- **Advocacy that Works** – People are heard, they know their rights, they have access to impartial advocates, and they know how to engage with the system if there is a problem.
- **Autonomy** – Residents are presumed to be competent, they can express their preferences and have some control over their daily life, and they have choices.
- **"You Know When You Walk In"** – There is laughter, diversity, positive activity, clear communication, a clean, pleasant-smelling and inviting atmosphere, and a connection to the community.
- **Well-Being and an Expectation of Safety** – People feel safe, their property is respected, they are not exploited, and the physical facility is safe and well-maintained.
- **Healthy Relationships** – People are not harassed; LGBTQ (lesbian, gay, bisexual, transgendered and queer) and racial discrimination is not tolerated; residents can set boundaries; they have privacy and support for relationships and intimacy. The facility provides information on healthy relationships.

In a resident-centered facility, there is consistent education about residents' rights. People can't confront the unknown, and they need to know how things should be in order to uphold their rights and to be who they are. Facility staff need ongoing education and support about issues of sexual violence. They need to know the full range of behaviors that qualify as abusive, such as sexual harassment and other non-contact abuse. Sometimes, facility staff don't respond to abuse because they blame the abuse on the disability, or they dismiss the abuse based on disability. Advocates need to recognize these patterns, confront them, and work around them when necessary.



## Remind Me of My Rights

**“Everyone deserves to love and be loved.”**

--Nursing Home Resident (Needs Assessment, 2014, p. 32)

**The more I know, the more I feel supported.”**

--Survivor (Needs Assessment, 2014, p. 52)



John and Mary both live in an adult family home; they have known each other for some time and have recently begun dating. Mary speaks with a communication board and utilizes a power wheelchair. Mary has come to you, the advocate, because she is refused assistance in arranging transportation accommodations for her medical appointment. Her family learned of the appointment, and became suspicious that Mary was seeking birth control. They are insistent that John is taking advantage of Mary. They stress that Mary can't make these sorts of decisions. They demand that staff monitor their interactions more closely. You are also suspicious someone has been hiding her communication board, as it's gone missing during times she regularly sees John. The family is encouraging Mary to break up with John and look for a new residence.

## Human Rights

First and foremost, as human beings, long-term care residents have the same rights as all people to be free from abuse and exploitation. Some important documents that identify these rights are:

### **The United Nations Convention on the Rights of Persons With Disabilities**

[www.un.org/disabilities/convention/conventionfull.shtml](http://www.un.org/disabilities/convention/conventionfull.shtml)

The principles identified by the convention are:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

## **Washington State Allies in Advocacy Proclamation for the Dignity and Rights of All Human Beings**

<http://www.alliesinadvocacy.com/the-proclamation/>

The rights identified in this document include:

- to live free from abuse, neglect, and exploitation
- to live free from oppression
- to lead a meaningful life

One way to demonstrate respect for all people is to use “people first” language. Language can be a powerful way to shape our perceptions. A person may live with a disability, but a person is not a disability. Other language issues make a difference as well – for example, using the phrase “accessible services” rather than “services for the handicapped” helps us to think more broadly about what makes our services accessible to a wide range of individuals.



## **Sexuality**

Because of the widely-held idea that older people or people with disabilities do not have active sexual lives, the sexual needs of long-term care residents have been largely ignored. In their zeal to protect residents from sexual abuse, facilities sometimes overlook the rights of consenting adults to engage in consensual sex, regardless of age or disability. Residents may be scolded or treated like children if they are sexually active. Those who are gay, lesbian, bisexual, or transgender may face additional obstacles (Spring, 2015). Nonetheless,

Qualitative studies have found that sex is an important component of close emotional relationships later in life, and older persons with an active sex life and intimate relationships are more likely to report a higher level of life satisfaction and quality of life. Sexual activity has even been found to have positive physiological consequences... (Rosen, Lachs, & Pillemer, 2010, p. 1075).

While there is increasing recognition that older people can have sexual interests, there is still a widespread misconception that individuals with disabilities (including younger people) are not interested in being sexual. The American Association on Intellectual and Developmental Disabilities 2008 position statement declares "People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected."

## Capacity and Consent

Balancing residents' rights to enjoy sexual intimacy with the facility's mission to protect health and safety can be complicated, and sometimes facilities solve this "problem" by simply discouraging all sexual activity. Often both facility staff and family members assume that simply because a person has some age-related cognitive impairment or an intellectual disability, he or she cannot consent to any sexual activity.

With regard to individuals with disabilities, advocate Theresa Fears of The ARC of Spokane stated in an interview that the definition of consent boils down to:

- We talked about it.
- We understand, to the best of our ability, what it means.
- We are of an equal mind.
- We both said yes.
- We're both old enough to do it.

One addition to this list might be, "We felt free to say no."

Of course, capacity and consent issues are complex. Working at the intersection of disability, sexual assault and long-term care takes dedicated thought, collaboration and communication between ombuds, sexual assault and disability advocates. This is very complex advocacy that requires a high degree of flexibility and coordination. There are legal considerations, such as guardianship, that lie beyond this book's scope.

It is not realistic, and could potentially be harmful, to try to tackle these issues alone. While this book is a stepping stone, it is not meant to provide all the information needed to successfully advocate in this field. The Alliance to End Violence in Long-Term Care fields questions and provides needed technical assistance. Advocates are also encouraged to begin networking with local advocates outside their field to discuss best ways to work together to address issues and co-advocacy strategies to respond to sexual violence in long-term care. While the process is intimidating, there is support, and ongoing technical assistance.

Any resident who experiences sexual assault has a right to an advocate. Not even a guardianship is a stop sign for this. When an advocate recognizes resident sexual violence, the task is to call on available advocacy skills to provide immediate support, discern what the resident wants, and reach out to others, as needed, for assistance to help secure resources and needed advocacy.

## Privacy and Confidentiality

Residents of long-term care facilities certainly have rights of privacy and confidentiality. There are laws that address these rights, particularly with regard to medical records and advance health care directives. Medical information should not be divulged without the appropriate releases of information, and residents should be informed of what may happen to any information they release. The resident has the right to decide with whom to share private information. Advocates often help individuals understand the pros and cons of releasing information, the nature of their privacy and confidentiality rights, and their recourse if those rights are violated.

## Crime Victim Rights

In any Washington State criminal court or juvenile court proceeding, victims, witnesses, and survivors are entitled to rights as outlined in

### **RCW 7.69.030**

<http://apps.leg.wa.gov/rcw/default.aspx?cite=7.69.030>

These rights include the right

...with respect to victims of violent and sex crimes, to have a crime victim advocate from a crime victim/witness program, or any other support person of the victim's choosing, present at any prosecutorial or defense interviews with the victim, and at any judicial proceedings related to criminal acts committed against the victim. This subsection applies if practical and if the presence of the crime victim advocate or support person does not cause any unnecessary delay in the investigation or prosecution of the case. The role of the crime victim advocate is to provide emotional support to the crime victim...

## Resident Rights

Residents in long-term care have the same civil and legal rights as all U.S. citizens, plus a basic set of legally protected Resident Rights, including those under federal law (42CFR483.10). Washington State outlines the legal rights of residents of long-term care facilities, including residents of nursing homes, adult family homes and assisted living facilities, in the following statute:

### **RCW 70.129 - Long-Term Care Resident Rights**

<http://apps.leg.wa.gov/rcw/default.aspx?cite=70.129>

The basic rights (RCW 70.129.005) of residents include:

... the opportunity to exercise reasonable control over life decisions. The legislature finds that choice, participation, privacy, and the opportunity to engage in religious, political, civic, recreational, and other social activities foster a sense of self-worth and enhance the quality of life for long-term care residents.

This statute includes advocacy, access, and visitation rights (RCW 70.129.090), and states clearly that “The resident has the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion” (RCW 70.129.130).

It is the responsibility of any long-term care facility to create a safe and healthy environment. This includes protecting residents from sexual violence (including harassment) by other residents, which can be a difficult task. Tassy, Gorincour, and Leistedt (2013, p. 326), in a Letter to the Editor of the International Journal of Geriatric Psychiatry, state:

...every worker in nursing homes is well aware that the sexual behaviour of some residents is totally inappropriate and might well at times fall within the scope of sexual assault or rape. These are potential crimes in the eyes of the law and could lead to criminal prosecution or civil damages. The victims are other residents and staff members and the effects may be psychologically damaging for the caregivers or residents who still have to deal with the assailant in the home. These problems seem largely ignored by the public, researchers and the criminal justice system alike.

In a 2011 presentation, Lisa Tripp of the John Marshall Law School gives a chilling description of aides laughing as a predatory resident sexually assaulted another highly vulnerable resident. Tripp describes how the entire incident, although eventually reported, was minimized because both residents had some degree of dementia. In this case, however, the facility failed to act to protect the victim, yet it was given only a nominal fine.

The National Consumer Voice organization (2015) recently released a fact sheet on resident-to-resident mistreatment (see Resource section).

Long-term care ombuds are advocates for the rights of residents and can help resolve concerns about safety, accommodations, and quality of life.

## Vulnerable Adult Statute Rights

Washington State provides legal protections to vulnerable adults through this statute:

### **Chapter 74.34 RCW – Abuse of Vulnerable Adults**

<http://apps.leg.wa.gov/rcw/default.aspx?cite=74.34>

When an investigation is opened, the vulnerable adult must receive a statement of these rights (RCW 74.34.305):

You are entitled to be free from abandonment, abuse, financial exploitation, and neglect. If there is a reason to believe that you have experienced abandonment, abuse, financial exploitation, or neglect, you have the right to:

- a. Make a report to the department of social and health services and law enforcement and share any information you believe could be relevant to the investigation, and identify any persons you believe could have relevant information.
- b. Be free from retaliation for reporting or causing a report of abandonment, abuse, financial exploitation, or neglect.
- c. Be treated with dignity and addressed with respectful language.
- d. Reasonable accommodation for your disability when reporting, and during investigations and administrative proceedings.
- e. Request an order that prohibits anyone who has abandoned, abused, financially exploited, or neglected you from remaining in your home, having contact with you, or accessing your money or property.

- f. Receive from the department of social and health services information and appropriate referrals to other agencies that can advocate, investigate, or take action.
- g. Be informed of the status of investigations, proceedings, court actions, and outcomes by the agency that is handling any case in which you are a victim.
- h. Request referrals for advocacy or legal assistance to help with safety planning, investigations, and hearings.
- i. Complain to the department of social and health services, formally or informally, about investigations or proceedings, and receive a prompt response.



## ADA, Federal and State Anti-Discrimination Laws

Other state and federal laws provide legal protections to people with disabilities. Some of these laws include:

**The Americans with Disabilities Act (ADA)** (42 U.S.C. §12132) (<https://www.law.cornell.edu/uscode/text/42/12132>) is the federal law prohibiting discrimination based on disability. The ADA says that physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society. This law ensures equal opportunity to persons with disabilities in employment, State and local government services, public accommodations, commercial facilities and transportation. ([http://www.ada.gov/2010\\_regs.htm](http://www.ada.gov/2010_regs.htm))

In addition, **Section 504 of the Rehabilitation Act of 1973** (29 U.S.C. §701) (<http://www.dol.gov/oasam/regs/statutes/sec504.htm>) provides no individual with a disability in the United States shall, solely by reason of her or his disability, be excluded from participation in, be denied benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance, or under any program or activity conducted by any Executive agency or by the US Postal Service. As many long-term care facilities receive Medicaid and Medicare (Federal funding), the residents who reside in these facilities are protected by Section 504 of the Rehabilitation Act.

**The Washington Law Against Discrimination (WLAD)** (RCW 49.60) (<http://apps.leg.wa.gov/RCW/default.aspx?cite=49.60&full=true>) states that discrimination against people with disabilities threatens both the individual's rights and the democratic principles of freedom. The law prohibits any unfair practice that "directly or indirectly results in any distinction, restriction or discrimination." The law also establishes the Washington Human Rights Commission to oversee complaints of discrimination.

## Guardianship Concerns

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 making decisions and 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.

Most people with disabilities, including cognitive disabilities, do not need guardians. Advocates should not be deterred from working with an individual based on the possibility that a person has a guardian. Each advocate organization should have a protocol on how to work with someone who has a guardian. Advocates should familiarize themselves with their organization's policies on guardianship and consent. (Information in this section was adapted from Illinois Imagines, a statewide project to improve services to women with disabilities who have been victims of sexual violence.)



## Follow My Voice

**“The response should not be to determine if what happened was real.**

**The response should be to support the survivor.”**

--Sexual Assault Advocate (Needs Assessment, 2014, p. 38)

**“You are not being my advocate if you speak to staff without my permission.”**

--Survivor (Needs Assessment, 2014, p. 43)

In any institutional environment, there is a tendency for the needs and wants of the individual to get lost. One of the most powerful lessons from this project has been that the voice of the individual resident often goes unheard. Advocates specialize in amplifying the voices of those they serve.

## How Can Advocates Help?

Advocates can help in these ways:

- **Respond appropriately** if a resident discloses sexual abuse, assault, or harassment.
- **Support residents** who have been sexually abused, assaulted, or harassed by listening to their wishes, staying connected to what they want, and helping them to overcome barriers to obtaining help.
- **Offer accommodations** customized to the individual.
- **Appreciate the value of healthy, consensual sexual interaction** for residents who wish to engage in these activities, and help remove obstacles.
- **Provide resources and participate in cross-training** with other advocates and long-term care staff who want to enhance their response to people who have been victimized and to support opportunities for healthy sexuality.
- **Participate in building a trauma-informed environment** in long-term care facilities, recognizing that many residents may be survivors of sexual violence (or other violence) that happened during childhood, adolescence, or earlier in adulthood, with long-lasting effects. In addition, a wide variety of life experiences can create a trauma history, such as discrimination due to disability, painful or demeaning experiences during illness or hospitalization, or loss and grief.
- **Be a “fierce advocate” when necessary**, refusing to be co-opted by facilities or the system, and continuing to represent residents even when this is challenging.

## **Respond Appropriately**

Advocates without extensive training or experience in the sexual assault field may worry about how to respond to a disclosure of sexual victimization. A compassionate response that acknowledges the difficulty of disclosure will help the survivor. Advocates may choose to say something such as:

- “Thank you for sharing your story (or your experience) with me.”
- “I am sorry this happened to you. I believe you.”
- “This was not your fault in any way.”
- “Do you feel safe and comfortable talking more about this here (or now)?” If not, set up a place and time that feels safe.
- “Do you have anyone you trust that you have been able to talk to about this experience?”

It is important not to ask “why?” questions or to quiz the resident about the specifics of an incident. Be aware that the effects of trauma may make it difficult for a person to give a chronological account of what happened, especially if the incident was recent. Let the person tell as much or as little as they want about the experience.

Sometimes advocates wonder if they should say, “I believe you.” There is no right or wrong answer to this, but the “Start By Believing” Campaign ([www.startbybelieving.org](http://www.startbybelieving.org)) explains:

[You can]...start from an orientation of believing, and that does not necessarily mean saying the exact words, “I believe you.” The same purpose can be accomplished with alternative phrases like, “I’m sorry this happened to you.” The important issue is not the exact words that are used, but that the person is treated with compassion and respect...instead of communicating the message (either explicitly or implicitly) that I don’t believe you. Unfortunately, this is exactly the message that is all too often communicated by friends and family members, as well as responding professionals.

### **Support Residents**

Supporting residents means mobilizing all your advocacy skills to create a customized, personalized response. The individual wants and needs of residents are often overlooked in an institutional setting. You have to be prepared to assist people with a wide range of issues, and to constantly check in to make sure that you are acting to support what the individual truly wants. Bear in mind that:

- A person’s wants and needs may change over time.
- You can return to clarify what the resident wants as the situation evolves and as you build a more trusting relationship.
- You may experience pressure from a variety of sources (the institution, family members, or others) to deviate from the resident’s wishes.
- You can link resident to resources in order to overcome barriers.

- If you are unsure of how to proceed, seek consultation and technical assistance.
- Residents are in control of their own information.

At the beginning of this handbook, we described the predicament of George. He lives in a nursing home, and is uncomfortable with the behavior of a female resident when he wants to watch TV in the common room, which he enjoys. Staff members have dismissed his concerns and told him that he can just watch TV by himself in his own room, which is not his preference.

*How could you help George?*

### **Some Considerations:**

- How can you individualize support to identify what George wants and needs?
- This nursing home is George's home – how does that affect his daily life?
- Does George have the right to be free from unwelcome advances, and to feel safe in his own living environment?
- Is suggesting George stay in his own room the answer? How does this help or hurt the situation?

 **Rights and Choices:**

- The right to be comfortable in one's own home
- The right to safety and the facility's responsibility to promote well-being
- Appropriate use of public spaces
- Freedom from sexual harassment
- Freedom from discrimination and a hostile environment

 **Resources and Next Steps:**

- Use what you know. Call on your advocacy skills.
- Listen to the problem. Help George figure out what he wants.
- Make sure George understands his rights.
- Bring appropriate resources to the table.
- Obtain technical assistance (TA) for more information.
- Develop an action plan based on resources and the specifics of the situation.



## **Offer Accommodations Customized to the Individual**

People who live in nursing homes, adult family homes, and assisted living facilities live there because they need assistance with activities of daily living. These residents may or may not identify as having a disability. Some residents may clearly identify themselves as having a disability such as traumatic brain injury, Alzheimer's, cerebral palsy, developmental disability, mental illness or other disability. Other residents may never say that they have a disability but instead only talk about what they need. "I need some help with a shower", or "They manage my medication here and make my meals."

People are not their disability labels. A label will not tell the advocate who the person is or what the advocate might need to do to accommodate the person. An advocate does not need to learn everything there is to learn about people with disabilities before working with them. People want to be defined by their likes, dislikes, hopes, dreams, accomplishments, and unique personality. While a label might help the advocate understand something about how the person learns or communicates, advocates must always remember that people with disabilities are the experts on themselves. It is best practice for the advocate to ask the person with disabilities how things work best for them. For example, an advocate is meeting with a person who is Deaf. The advocate may assume the person will need an accommodation for hearing but without asking the person will not know exactly what the person needs.

It is important to remember that there is no "one-size-fits-all" approach to providing accommodations. Disability manifests differently in everyone. Using respectful inquiry and humility will go much further than knowing every type of accommodation offered for various disabilities, because each person can describe what works best for them based on

their own experience. It is not necessary for the advocate to understand everything about a given diagnosis or the nature of a specific disability. It is important for advocates to learn about their organization's policies, procedures, and resources for accommodations. It may also be helpful to learn more about a particular disability and the accommodations most commonly provided. Follow your agency protocol for accommodation provision.

### **Disability humility means:**

- Residents (people with disabilities) are viewed as the experts on themselves and their needs.
- Advocates treat each person with a disability as a unique individual.
- People with disabilities are not treated as fitting into generalized categories or a laundry list of symptoms.
- Advocates come with a mindset: "I am open, curious, honest, ready and willing to learn."
- Advocates take into consideration culture, past history, trauma, etc. as a reason for resident "behavior." Others may incorrectly consider the disability as the cause of "behavior."
- Advocates are willing to say, "I don't know, I am still learning."

## **Value Healthy, Consensual Sexual Interaction**

We've talked about the right to sexual expression and some ways in which long-term care facilities can balance residents' freedom with the need to ensure their safety. Advocates can help in a variety of ways:

- Help residents to identify and express what they need, such as a private place for sex.
- Maintain a nonjudgmental, sex-positive attitude.
- Acknowledge the human desire to love and be loved, to be close, and to be physically intimate.

Remember the scenario earlier in this handbook involving John and Mary (page 36), residents of an Adult Family Home. Both residents are interested in a consensual sexual relationship, and Mary may want access to medical care for contraception.

*How would you approach this situation as an advocate?*

### **Some Considerations:**

- Do Mary and John have privacy?
- Does Mary have confidentiality of her medical information?
- Are Mary and John presumed to be competent? To be able to have a consensual relationship?
- Do Mary and John have support for their relationship? Support to advocate for what they want?

## **Rights and Choices:**

- Self-determination
- Autonomy
- Medical privacy

## **Resources and Next Steps:**

- Use what you know. Call on your advocacy skills.
- Listen to the problem. Help each person figure out what that person wants.
- Make sure both John and Mary understand their rights.
- Bring appropriate resources to the table.
- Obtain technical assistance for more information.
- Develop an action plan based on resources and the specifics of the situation.

### **Provide Resources and Participate in Cross-Training**

Each type of advocate has a particular expertise, and together advocates from all three fields can help with a wide variety of resident needs. An excellent way to get to know each other is to develop opportunities for cross-training. In this way, you can learn what each type of advocate is able to do to support residents, and you can develop the personal relationships that allow you to make good referrals if necessary.

## **Participate in Building a Trauma-Informed Environment**

In addition to the risk of sexual abuse within the long-term care setting, residents may very well have been victimized in a variety of ways prior to entering this environment. As mentioned earlier, residents may also have a trauma history unrelated to sexual violence, because of experiences such as oppression and discrimination, severe pain related to medical conditions or treatments, physical violence, or living through war, to name just a few possible traumatic events or conditions.

This is relevant because there may be trauma triggers in the current living situation, ranging from discomfort with the need for personal care to situations in which the resident witnesses abuse. Just living in a facility creates a situation in which other people have considerable power and control over the individual, which can be highly anxiety-provoking for people who cope with the aftermath of trauma.

In an Australian study of more than 21,000 adults aged 60 or older, Draper and colleagues (2008) found that “the effects of childhood abuse appear to last a lifetime” (p. 262). Older adults who had experienced physical and/or sexual abuse during childhood had poorer physical and mental health later in life, including depression and anxiety.

Advocates can help by reminding facilities of the prevalence of sexual violence and other adverse experiences and helping them to be sensitive to the needs of survivors. A trauma-informed environment is a setting which takes into account the needs and concerns of trauma survivors, without necessarily identifying who has experienced trauma. For example, upholding residents’ rights to privacy and dignity in caregiving is a trauma-informed strategy that is helpful for all residents, whether or not they are sexual assault survivors. Simple actions such as having aides talk to residents about

what will happen and why (regardless of the resident's cognitive level) can be very helpful: "Mrs. Smith, I need to roll you to the side to take the wet sheets off the bed. I am going to put my hands on your back and the upper part of your legs. It will just take a minute, and we will cover you with a dry sheet while we change the bed."

The use of restraints by care providers may trigger a traumatic reaction. Restraints should never be used simply for staff convenience or because a facility is not sufficiently staffed. There are laws regulating the use of restraints. Compassionate, personalized care can often eliminate the need for restraints, while minimizing trauma triggers for residents. Advocates can inform residents of their right to be free from physical or chemical restraints (as stated in RCW 70.129.120.)

Advocates can also assist when a resident's concern or complaint is dismissed because of cognitive disabilities, and/or the resident is assumed by staff to be talking only about something that happened in the past. While it is possible that a benign action (such as washing the person's private areas) might be interpreted as an assault by someone who experiences dementia, it is critical that residents' concerns not be brushed away without advocate response and support. Neither a past history of abuse nor a current diagnosis of cognitive impairment means that what the resident says should be disregarded. In fact, if a resident reports abuse to the facility, the facility must investigate.

### **Be a "Fierce Advocate" When Necessary**

This kind of advocacy work requires a dedication to justice in the face of systems that may be oppressive or simply dismissive of residents' wishes. Fortunately, there are laws that support a resident-centered approach to care. Nonetheless, in systems set up for caretaking, staff and

administration sometimes overlook the strong human need for autonomy and choice. As an advocate, you want to ensure that you revisit the wishes of the resident as frequently as necessary. You can become a force to help articulate those wishes and to amplify the voice of the resident. In long-term care, as in other systems, there are many who may naturally dismiss or discredit the survivor. There may be times when you are the only one who represents and carries the interest of an individual. As an advocate, you have standing and credibility to navigate the system, even as there is a pull to ignore the wishes of the resident.

Facilities may operate on the principle of administrative convenience, disregarding what individuals want. You may be dealing with compassionate people who truly believe they are doing things for the resident's "own good," but who are mindful of facility regulation and compliance before resident needs or wishes. It is important that advocates remain connected to what the resident wants, and refuse to be co-opted by facility influences.

It is necessary to work with an anti-oppression lens, meaning that you are aware of all the "isms" that diminish the power of the resident, such as racism, sexism, ageism, and able-bodyism. As an advocate, you are trying to level the playing field. Some residents have family members on their side; some have high economic status and access to resources such as attorneys; and some have privilege that bolsters their ability to have their wishes acknowledged. Others face intersecting barriers that make it unlikely that they will be heard without your support. Be prepared to stand your ground in order to support and empower residents.

## What are the Basic Shared Principles for Advocates?

Advocates may feel a bit overwhelmed as they consider providing support to individuals in long-term care facilities. Depending on their background and experience, they may be concerned about how they will communicate with clients, what curveballs the system will throw at them, or whether they will really be able to make a difference.

The first thing to remember is: Call on your core advocacy skills. You may not yet know the specifics or the ins-and-outs of how the various service and response systems work, but you have the basic tools you need just because you are an advocate. All advocates are skilled at and dedicated to listening. They are rich in knowledge about resources, and always willing to learn about additional resources. Advocates help clients to identify their rights and how to improve access to those rights. They are superstars in linking people to resources and helping them develop the confidence to stay safer, heal more quickly, and obtain justice. If systems are oppressive and unfair, advocates speak up to make systemic changes to support survivors. Sometimes they create resources to fill gaps; in other situations, they create bridges between people and existing resources, or among fragmented service systems.



## A Simple Blueprint for Advocacy with Long-Term Care Residents



### **Some Considerations:**

- How can you individualize support to identify what the resident wants and needs?
- What are the various roles that service providers play?
- What are the primary principles and issues involved?
- What barriers does the resident face?



### **Rights and Choices:**

- What rights are involved in this situation?
- How can everyone respect the resident's choices and autonomy?



### **Resources and Next Steps:**

- Use what you know. Call on your advocacy skills.
- Listen to the problem. Help the resident figure out what they want.
- Make sure the resident understands their rights.
- Bring appropriate resources to the table.
- Obtain technical assistance for more information.
- Develop an action plan based on resources and the specifics of the situation.

Advocates may have a tough time when a resident discloses horrific circumstances but does not want the advocate to move forward. Unless the advocate is a mandated reporter and the situation warrants a report, their role is to take direction from the resident—which may be to simply listen. It is important to consider fear of retaliation, whether or not a resident wants intervention. Sometimes the advocate can assist in supporting the resident to diminish that threat, but

ultimately, the resident makes the decision. Residents may just want someone to listen, be a witness, and believe their experiences. The advocate can ask what the resident wants and clarify expectations: “Would you like me to suggest some possible options here, or simply to listen to your experiences? I will do whatever is most helpful to you.” Advocates must follow their agency protocol and may want to seek support from a supervisor or colleague, because this can be a challenging situation.

There are some aspects of advocacy for people in long-term care facilities that may be different from what you ordinarily do. Advocacy needs may range from responding to a recent sexual attack to helping a resident arrange accommodations for a consensual sexual relationship. Some are surprised to discover that sexual and reproductive health concerns as well as healthy sexuality rights are within the scope of sexual assault advocacy in these settings.

Advocates are experts at overcoming barriers and meeting challenges with creativity.

**“...people with communication disabilities who’ve experienced sexual violence can definitely be supported, just like any other survivor, though...it’s going to take some patience and maybe a bit of creativity.”**

--Erica Rich, National Sexual Violence Resource Center webinar on Considerations for Victims with Cognitive and Communication Disabilities, 2011

## What are the Specific Roles of Different Advocates?

### **Disability Advocates**

The disability community encompasses advocates from many cultures, disabilities, and organizations. Disability advocates who work with residents in long-term care may represent an organization, such as the Centers for Independent Living, the Alzheimer's Association, local or national ARC organizations, or others. Or, an individual may advocate on behalf of a specific disability, like traumatic brain injury or spina bifida, and be well connected in a given community.

Some advocates may come from communities that do not identify with disability, though outsiders struggle to understand this. For example, individuals who are blind may not equate blindness with disability. Many in the Deaf culture are very proud of their own language, culture, and systems, and are offended when others try to categorize them as living with disability. Many people do not self-identify as having a disability, even though they experience what others would consider to be a disability. This is often true for people who acquire disability later in life. This makes it offensive when others want to alter their experience to fit inside a conventional idea of what is "normal." Culture and language also affect the disability experience. American Sign Language may (or may not) work for someone from the United States, but not for someone from Mexico, or South Korea.

Disability advocates navigate these complexities to meet individuals where they are, reflecting the individual's experience and providing resources and support, based on an individual's expressed wishes. Disability advocates, depending on the agency, may offer information and referrals, problem-solving strategies for disability issues, community education and training or legal services for

disability discrimination or violation of rights. Some disability advocates focus on individual issues and some include advocacy to improve service systems for people with disabilities. Society and service systems are not always fair or responsive to people with disabilities. Disability advocates often work for change in policies, laws, and systems that promote freedom from abuse and neglect; legal rights and responsibilities; adequately funded supports and services; and communities that involve everyone. Depending on their professional role, disability advocates may or may not be mandated reporters of abuse.

## **Ombuds**

According to the Washington State Long-Term Care Ombudsman Program ([www.waombudsman.org](http://www.waombudsman.org)):

*Long-Term Care Ombudsmen are professionally trained staff and volunteers from the community who advocate for and protect the rights of residents living in Nursing Homes, Adult Family Homes, and Assisted Living Facilities.*

### **Ombudsmen visit residents regularly to:**

**Provide information** about resident rights

**Listen to problems** concerning quality of care and quality of life

**Clarify and respond to questions** raised by residents, families, staff and the community

**Resolve problems** between residents and service providers

**Help people work together** to assure satisfactory service

**The National Long-Term Care Ombudsman Resource Center** (<http://ltcombudsman.org/about/about-ombudsman>) states:

*Ombudsmen provide information about how to find a facility and what to do to get quality care. They are trained to resolve problems. If you want, the ombudsman can assist you with complaints. However, unless you give the ombudsman permission to share your concerns, these matters are kept confidential. Under the federal Older Americans Act, every state is required to have an Ombudsman Program that addresses complaints and advocates for improvements in the long-term care system.*

Long-term care ombuds are not mandated reporters of abuse.

### **Sexual Assault Advocates**

Sexual assault advocates generally work for victim advocacy organizations, either as employees or as trained volunteers. In Washington State, most of these agencies are nonprofits, but some are government-based, and many operate under the accreditation system of the Office of Crime Victims Advocacy. Accredited agencies must provide a full range of services: information, referral, and awareness; crisis intervention (including 24/7 response); general, medical, and legal advocacy; system coordination to enhance community response to survivors; and prevention activities. There are also tribal advocacy agencies and other culturally-specific organizations, such as those serving the Deaf community or focusing on Latino survivors.

In Washington State, sexual assault advocates are mandated reporters of child abuse and vulnerable adult abuse. They are held to a high standard of confidentiality and are trained to offer survivor-centered services. Sexual assault advocacy programs also work in the community to counteract the conditions that lead to sexual violence.



## Know My Resources

**“Not everyone can deal with sexual assault and that’s fine; but know when you can’t do this and find someone else to help me.”**

--Survivor (Needs Assessment, 2014, p. 39)

**“The information may be there; but if you don’t know it is there, you don’t know what to ask for.”**

- Resident (Needs Assessment, 2014, p. 51)

Yes, it is true that this handbook encourages advocates to expand their comfort zone. However, individual advocates do not have to be all things to all people. Learning about the other types of advocates involved in this work can help the advocate to direct people to the appropriate services. Every advocate needs to be able to have basic conversations with people who live in long-term care facilities about sexual needs and rights, sexual safety, and sexual assault. Each advocate will want to be able to pursue these conversations at least long enough to help individuals identify their needs and concerns, and to affirm their perceptions and experiences. Just knowing about the other fields of advocacy will be useful to advocates as they seek information and resources to help long-term care residents.

When it comes down to the specific advocacy expertise needed, a specific advocate may be the right person to help, or may need to make what is called a “supported referral.” A supported referral is more than just advice to call another agency. To make a supported referral, an advocate must take the time to really learn about the services offered by another program, the procedure for getting help, and perhaps even some of the individual advocates at other agencies. A supported referral might even include accompanying the person when they meet the other advocate.

**For example, an ombuds might say, “Ms. Jones, I really appreciate everything you have shared with me today. We have talked about some of the things I can do to help and support you. Because of everything you have been through, I think that an advocate at the ABC Program could really be of help as well. Their services are free and confidential, and they can help you through [whatever the situation may be]. If you’d like, we can call one of the advocates I know and ask her to come talk to you here. I would be happy to stay with you when you meet her if you would like me to.”**

As advocates very well know, service systems can be complicated. Each advocate has the opportunity to learn the “who, how, where, and when” of getting help, and then to help others navigate the system. People who face multiple challenges, such as recent trauma, communication barriers, and societal stigma, can really benefit from advocates’ knowledge and support as they try to exercise their rights, stay safe, or recover from abuse.



As an advocate, you receive a call from Sue, a friend of Olivia. Olivia lives in an assisted living facility and needs assistance with bathing. Sue calls your office upset after just having visited with Olivia. Olivia told Sue that she hated having to bathe every day because it makes her tired and sore. Sue asked if the washing was just too frequent and if that was making it exhausting (all the getting up and moving). Olivia said, "Yes, and it is too much soap and it makes my vagina itchy." Sue thought the way Olivia answered her was weird, and was concerned because Olivia avoided eye contact with her. Feeling that something wasn't right, Sue asked Olivia if she's being hurt. Olivia said no, but Sue believes she is hiding something. Sue is requesting inquiry into bathing practices and demands you go talk to her friend about suspected abuse.

*How would you handle this situation?*

 **Some Considerations:**

- What is your advocacy role in this situation?
- Is the Ombuds a resource?
- How would you know if Olivia wanted the services that Sue is requesting?
- How can you individualize support to identify what Olivia wants or needs?
- Can you give Sue information to share with Olivia?
- What kind of resources and supports would you consider for Sue?



## **Rights and Choices:**

- Residents' rights to control their information
- Choices about how care is administered
- Right to freedom from abuse, if that is in fact what is happening

## **Resources and Next Steps:**

- Use what you know. Call on your advocacy skills.
- Listen to the problem. Help each person figure out what she wants.
- Make sure Olivia understands her rights, if she is willing to talk to you.
- Bring appropriate resources to the table (for example, the ombuds if you are not an ombuds yourself).
- Obtain technical assistance for more information.
- Develop an action plan based on resources and the specifics of the situation.

### **It Takes A Village**

**One advocate can't do it all.  
These are tips for using resources effectively.**

- Have a good map of the system.
- Know your own limitations.
- Know who to call.
- Make supported referrals.
- Connect residents with self-advocacy groups.



## Take Care of Yourself

**“We are in this work together, all of us.  
Our best hope is to understand that it is a long journey.  
We need to take care of ourselves and each other”**

(Conte, 2009, p. xiii).

Advocates are generally compassionate people, and with this trait can come what is called “compassion fatigue,” defined by the American Institute of Stress (n.d.) as

...the emotional residue or strain of exposure to working with those suffering from the consequences of traumatic events. It differs from burn-out, but can co-exist. Compassion Fatigue can occur due to exposure on one case or can be due to a “cumulative” level of trauma.

The American Institute of Stress identifies three strategies for preventing and dealing with compassion fatigue:

**Awareness  
Balance  
Connection**

It is helpful to be **aware** of your own feelings and recognize this work can be challenging. As advocates, we hear very difficult stories and encounter substantial obstacles.

We have to **balance** our lives so that we have the opportunity for play, joy, humor, and activities unrelated to our work.

We can also protect ourselves through **connection** – connecting with colleagues and supervisors for support at work, and with family, friends, and even pets for stress relief outside of work. Understanding the scope and limits of our role and knowing that we can turn to those in other disciplines for help (as noted in the “Know Your Resources” section) can reduce the stress we feel.

**I am only one, but still I am one.  
I cannot do everything, but still I can do something;  
and because I cannot do everything,  
I will not refuse to do something that I can do.**

--Helen Keller



## Find Out More Information

### Links to Partner Organizations for this Project

Disability Rights Washington  
[www.disabilityrightswa.org](http://www.disabilityrightswa.org)

Washington Coalition of Sexual Assault Programs  
[www.wcsap.org](http://www.wcsap.org)

Washington State Long-Term Care Ombudsman Program  
[www.waombudsman.org](http://www.waombudsman.org)

### Additional Resources

#### Accessing Safety

*Understanding Disability*

[http://www.accessingsafety.org/index.php/main/main\\_menu/understanding\\_disability](http://www.accessingsafety.org/index.php/main/main_menu/understanding_disability)

*Addressing Accessibility*

[http://www.accessingsafety.org/index.php/main/main\\_menu/addressing\\_accessibility](http://www.accessingsafety.org/index.php/main/main_menu/addressing_accessibility)

#### Alzheimer's Society (U.K.)

*Communicating*

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=130](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=130)

## **The Arc**

(for people with intellectual and developmental disabilities)

National Center on Criminal Justice and Disability  
[www.thearc.org/nccjd](http://www.thearc.org/nccjd)

## **The National Consumer Voice for Quality Long-Term Care**

[www.theconsumervoice.org](http://www.theconsumervoice.org)

Residents' Rights: An Overview  
<http://theconsumervoice.org/uploads/files/advocate/resident-rights-an-overview.pdf>

Resident to Resident Mistreatment  
Brochure: <http://theconsumervoice.org/uploads/files/actions-and-news-updates/rrm-brochure-508-compliant.pdf>

Fact Sheet: <http://theconsumervoice.org/uploads/files/actions-and-news-updates/rrm-factsheet-large-font-508-compliant.pdf>

## **National Long-Term Care Ombudsman Resource Center**

[www.ltombudsman.org](http://www.ltombudsman.org)

*Sexuality and Intimacy in Long-Term Care Facilities*  
(resource collection)  
<http://www.ltombudsman.org/issues/sexuality-and-intimacy-in-long-term-care-facilities>

## **National Sexual Violence Resource Center**

[www.nsvrc.org](http://www.nsvrc.org)

*Sexual Violence in Later Life: A Technical Assistance Guide for Advocates*

[www.nsvrc.org/publications/nsvrc-publications/sexual-violence-later-life-technical-assistance-guide-advocates](http://www.nsvrc.org/publications/nsvrc-publications/sexual-violence-later-life-technical-assistance-guide-advocates)

*The Sexual Violence in Later Life Information Packet*

<http://nsvrc.org/publications/sexual-violence-later-life-information-packet>

*Considerations for Victims with Cognitive and Communication Difficulties (webinar)*

<http://nsvrc.org/elearning/20871>

## **Nursing Home Ombudsman Agency of the Bluegrass, Inc. and Bluegrass Rape Crisis Center**

*The Prevention and Detection of Sexual Assault of Nursing Home Residents*

<http://ltcombudsman.org/uploads/files/support/sexual-assault-manual-2014.pdf>

## **Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders**

<http://www.sageusa.org>

## **Washington State Department of Social and Health Services**

*Adult Family Home Guidebook: Partners in Protection*

<https://www.dshs.wa.gov/sites/default/files/AL TSA/rcs/documents/AFH%20Guidebook.pdf>



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