

CREATING SAFETY

BY ASKING WHAT MAKES PEOPLE VULNERABLE?



**Developed through Wisconsin's Violence Against Women
with Disabilities and Deaf Women Project:**

**Disability Rights Wisconsin
Wisconsin Coalition Against Domestic Violence
Wisconsin Coalition Against Sexual Assault**

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Violence Against Women with Disabilities & Deaf Women Project of Wisconsin

CREATING SAFETY by *Asking What Makes People Vulnerable?* was developed through the Violence Against Women with Disabilities and Deaf Women Project of Wisconsin. Mark Sweet, Trainer and Consultant at Disability Rights Wisconsin (DRW), authored this guide, and deserves recognition for skillfully articulating the known dangers resulting from a “culture of compliance” for people with disabilities.

Amy Judy, Coordinator of the Violence Against Women with Disabilities and Deaf Women Project, authored the preface and edited the final document into a user friendly format for Wisconsin’s disability, domestic violence and sexual assault programs. We would like to thank C.J. Doxtater, Heather Haberman, Armintie Moore-Hammonds, Kathy Shaw, Pam Malin, Barb Sorensen, Joan Karan and Kim Marble for their insightful and constructive comments to improve this document. We also are grateful for the proofreading assistance provided by Kristine Beck, DRW.

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- Wisconsin Coalition Against Domestic Violence (WCADV);
- Wisconsin Coalition Against Sexual Assault (WCASA).

Through a federal grant funded through the Office on Violence Against Women, U.S. Department of Justice, our three statewide organizations have joined together to promote our collaborative vision:

The objectives and activities of this Project continue to be centered around:

- the distinctive dynamics of domestic violence (DV), sexual assault (SA) and stalking against women with disabilities,
- the paramount importance of victim safety in all of its undertakings,
- the necessity for appropriate and effective services to women victims with disabilities, and
- equal access through compliance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973.

Our activities and efforts have relied on two primary strategies:

1. Elevate collaboration within pilot communities among sexual assault, domestic violence and disability programs; and
2. Enhance the community’s capacity to serve women victims with disabili-

Women with disabilities and deaf/Deaf women who experience sexual assault and/or domestic violence will be supported by people who have actively prepared for access and who think about the meaning of respect one woman at a time.

ities and Deaf women in a manner that is accessible, supportive and culturally affirmative.

These strategies have been employed specifically with three pilot communities: the Ashland/Bayfield area; Brown County; and with a newly emerging statewide Deaf-run/Deaf victim services organization, Deaf Unity, Inc.

Within each of these communities, Disability Rights Wisconsin (DRW), Wisconsin Coalition Against Domestic Violence (WCADV) and Wisconsin Coalition Against Sexual Assault (WCASA) work to foster informal and formal relationships among organizations, tribes and groups located within these communities, while simultaneously integrating knowledge of and enhanced capacity to respond to issues of disability, trauma, violence, abuse and safety.

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Preface

The development of *CREATING SAFETY by Asking What Makes People Vulnerable?* is a ground-breaking culmination of open thought, keen observation and practical understanding of how many, if not most, people with disabilities experience human interactions and relationships designed to provide them support. While people who provide paid support or caregiving to individuals with disabilities are the primary audience for whom this guide was designed, its applicability and relevancy transcends those roles. For domestic and sexual violence advocates, human services workers, social workers or counselors, and even family members, the ideas broached and questions raised throughout this piece are important considerations for any of us who work with, support, advocate or love someone with a disability. As a family member and guardian of a brother with autism, I have found this resource invaluable—comforting and challenging all in one. Here’s a flavor of why this piece is so powerful in its impact.

For those of us without disabilities, throughout our lifespan we develop skills to assert what we want or don’t want in any given interaction, what this guide’s author calls, “wanting energy.” Through communicating our “wanting energy,” we assert ourselves and our choices. We begin to navigate our daily interactions with family, co-workers, neighbors, friends and community members at large.

For individuals who lack opportunities to develop, utilize and assert what they want and do not want (many people with disabilities), they experience less control to navigate their own path within daily interactions. Instead, they are directed to follow someone else’s path or assertions. Many people with disabilities, especially individuals who have an intellectual or cognitive disability, are expected to follow the path of those “in charge.” From more minor decisions about what to have for dinner to life-enhancing decisions about where to live and with whom, it is expected if not demanded that the person with the disability comply with someone else’s wants, needs or demands.

As author Mark Sweet highlights in this guide, this “culture of compliance” that surrounds people with disabilities and those who support them is so ingrained that we fail to grasp the detrimental and sometimes dangerous effects this “culture of compliance” has wrought on the very people we support and love. The danger of this “culture of compliance” is that it gives license to anyone “in charge” to misuse, exploit or abuse those who are expected (and have been trained throughout their lives) to comply—people with disabilities.

Through exploring linkages among assertiveness, vulnerability, compliance

models and imbalances of power in caregiving relationships, we begin to glimpse the often hidden reality of how these linkages make some individuals more vulnerable... more vulnerable to abuse. Whether a paid caregiver, support worker, family member, or domestic violence or sexual assault advocate, each of us individually and as a part of larger service organizations have a stake in creating safety for and with people with disabilities.

By considering the discussion and questions posed throughout this guide, we can and must become aware of and respond differently to our new understanding of what makes people vulnerable. This resource is designed to guide us through this journey, so that the vulnerability inherent in the “culture of compliance” that we inadvertently maintain is replaced with creating and fostering safety in its most basic and impactful form for people with disabilities—through a “culture of assertiveness.” It’s time.

Amy Judy

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Violence Against Women with Disabilities and Deaf Women Project

Disability Rights Wisconsin

Introduction

As a society, we consider some people more vulnerable than others. Children are considered more vulnerable than adults. Older adults with and without disabilities are often considered more vulnerable. People who live with developmental or other disabilities are also considered more vulnerable. It is this last group that we focus on here.

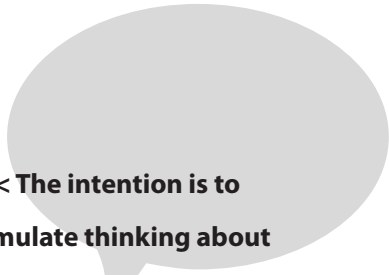
Separation and supervision are two of the planned strategies that have been used to keep vulnerable people with disabilities safe. As used here, separation means apart from people without disabilities unless they are family members or paid caregivers. Many adults with disabilities attended separate schools or classrooms. Many have separate places to work or spend time during the day, live in group-homes with others who have disabilities and participate in separate recreational options. One ongoing assumption that has supported separation has been that harm is perpetrated by unfamiliar or unknown people—strangers. Another assumption has been that family members and paid caregivers would protect those they support from harm by monitoring and supervising them.

Accumulating research is telling a different story. The National Crime Victims Survey of 2007 investigating crimes against people with disabilities found twice the rate of rape or sexual assault than in the general population; and persons with a cognitive disability had a higher risk of violent victimization than those with any other type of disability.

It has been reported that women with disabilities regardless of age, race, ethnicity, sexual orientation or class are assaulted, raped and abused at twice the rate of women without disabilities. An adult with a developmental disability is at 4 -10 times greater risk of being physically assaulted than adults without a developmental disability. Regarding the perpetrators of those crimes: 33% are acquaintances; 33% are natural or foster family members; and 25% are caregivers or service providers (Sobsey, D. 1994). **How is it possible that some of the most closely monitored people in our society are being taken advantage of and abused?**

Even if the findings were half this large, these numbers should shock us. All the degrees of separation and supervision that have been planned and funded to keep vulnerable people safer have been based on the erroneous assumption that family members and other designated caregivers, familiar people, would not harm or take advantage of those they are supposed to keep safe.

If you're reading this as a family member or other caregiver please know that the intention here is not to assume your guilt or frighten you about the well-being of someone you love. The intention is to stimulate thinking about what



<<< **The intention is to stimulate thinking about what increases safety and what decreases vulnerability—whether we/you are doing anything that might be adding to a person's vulnerability.** >>>

LINGER with this thought

increases safety and what decreases vulnerability—whether we/you are doing anything that might be adding to a person’s vulnerability.

Working with this material will not always be comfortable. We have to question our attitudes, goals and methods. Just because we intend to be helpful does not mean that we succeed. We have to examine our underlying thinking about people who receive support. For this, we will need humility. We will also need to be bold because some people will not want to participate in these conversations.

Whether you are a family member, a person who works directly with individuals, a social worker or health care professional, a person in the sexual assault or domestic violence field, or anyone who has a role or interest in the lives of individuals who receive support, **it is our hope that you will consider what you might do to decrease a person’s vulnerability and create more safety.**

Because this Project is federally funded to focus on issues related to violence against adult women with disabilities, we have used female references and examples throughout this guide. Yet, *CREATING SAFETY* is applicable to anyone who has a disability, regardless of gender or age.

The Culture of Compliance

Before jumping to what we should do, let's think about what might be making people with disabilities vulnerable. Consider this: in many disclosures of sexual, physical, emotional and financial abuse the phrase *(someone) told me to* is used. Where and from whom do people with disabilities learn to make the compliant choice—to do what they are told?

What is the role of compliance in the lives of people who receive support?

To better understand the role of compliance in the lives of people who receive support, think about how we learn to be assertive. As young children, there were adults in our lives. Parents, grandparents, foster parents, aunts, uncles, teachers, coaches and others set limits and guided our actions. They told us where we could and could not go; what time to be home; who we could and could not spend time with; what and how much we could eat; how we should interact with others (*leave your sister alone!*); even, which words we could not say.

The people who set limits were trying to teach us to be responsible and to establish social boundaries. They wanted us to be judged positively and to help us fit in. They also wanted us to be safe. At some point, each of you did something you were told not to do. At some point, having been told what we could and could not do, we started to make our own choices.

What are some of your earliest memories of doing what you were told not to do; and, why you did it?

- *I crossed the street because I wanted to get closer to a Lassie dog.*
- *I left the neighborhood with my friend because I didn't want to be called a baby.*
- *I punched my sister because I wanted her to leave me alone.*
- *I wanted another cookie so I took two—one for later.*
- *I wanted to use the words Grandma said only bad girls say; so I yelled them on the way to school.*
- *I left the house without permission and hid behind the barn because I didn't want to see my father after he started yelling at my mother.*
- *I hit a kid with my backpack and then lied about it but I needed to protect my little brother.*

Each of these events represents a particular kind of energy—wanting energy. We want things, experiences, acknowledgment and interactions. We also might want to stop some events from happening. Wanting energy can mobilize

us. The arousal and expression of wanting energy is the beginning of learning to be assertive.

Wanting energy can be expressed with more or less skill. During the past few weeks, have you raised your voice or been snippy with anyone? Have you stopped talking (thinking *I'll show you*)? Have you gossiped about someone in order to undermine opinions of them? Have you slammed a door, called someone a derogatory name or told a lie? Does someone need to call a behavioral specialist for you or were you asserting something that mattered to you, however unskillfully?

We struggle in our personal and work lives to communicate honestly and skillfully. We want to express what matters and find it difficult. The expression of wanting energy in a skillful manner is a lifetime pursuit.

Asserting wanting energy is not only about breaking rules. Wanting energy can result in trying to accomplish something because you believe in yourself. Wanting energy was behind the report by a Deaf woman who said that as a child she stood back while hearing children ran to the ice cream truck. She assumed the driver was hearing and she didn't talk. After watching other children enjoy their ice cream treats for weeks, wanting energy prompted her to approach the driver. She managed to convey that she wanted a fudge stick. (The pictures on the outside of the truck helped.) Wanting energy prompted her assertiveness and self-confidence.

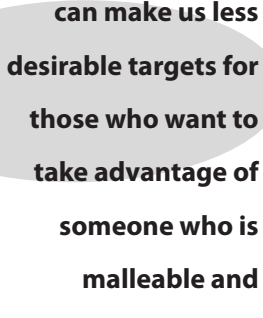
Wanting energy can be aroused as we learn to define our personal boundaries and want something to stop. A woman reported sneaking her brother's backpack into the trash so that he would stop using it to hit her. Expressing wanting energy is the beginning of assertiveness about personal safety. Assertiveness can help us find enriching experiences and it can help us teach others how we want to be treated. Being assertive can make us less desirable targets for those who want to take advantage of someone who is malleable and compliant.

Picture a woman standing in a convenience store. She's listening to someone and appears engaged. Picture a man approaching her from behind. He puts his left hand on her left shoulder and his right hand on her right shoulder. As you see him turning her away from her companion he says something that you can't hear. Now, can you picture the woman's elbow connecting with his ribs?

If you had to write a report about what you saw you might include, at the very least, that the woman seemed startled. She didn't know who was behind her and touching her. She didn't know the person's intentions. You would probably try to imagine her point of view (POV) and report that she appeared to be protecting herself.

What if you found out that the woman who hit the man with her elbow is on the autism spectrum, has a psychiatric diagnosis, a brain injury or an intellectual disability? What if you were told that the person who put his hands on her was her job coach? Is it possible that your report would be different?

In both situations a woman was asserting that she didn't want to be ap-



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proached from behind and touched in this manner. In too many situations, only one of these women will benefit from someone trying to imagine her POV. When a woman is known or even suspected of having a disability, her POV is too often not considered. Her behavior is all that matters as it is judged appropriate or inappropriate.

When we factor in a known or perceived disability, our assessments of people and events too often change. The report about the woman with a disability might say she is unpredictably aggressive, she's violent, and she's a danger in the community. The conclusions might be that she doesn't accept supervision, she needs a more controlled environment, and she needs a behavioral intervention plan. **One of these women is seen as having the right to define how she wants to be treated and the other is not.**

As a caregiver, would you rather support someone who...
...does what she wants to do, or
...does what she is asked or told to do (by you)?

This question is not whether you would rather support someone who does what she wants in the general sense. Most of us would say that we want a person we care about to be happy. The question is also not about who you would rather support on a great day when you and she agree. The question is about who you would rather support when you want her to do one thing at a certain time in a certain way and she wants to do something else. As a caregiver, would you rather support someone who does what she wants to do or someone who does what you want her to do? You might explain your position by noting that you're smarter, more experienced and know things she doesn't know. You might say that the risk for her is too great.

The typical developmental progression in learning to assert ourselves includes being clumsy, awkward, occasionally (or frequently) rude and making mistakes. Think about your adolescence and twenties. Add in your thirties and stop when you can say that you've mastered being assertive in only skillful and risk-free ways to everyone else's satisfaction.

We learn throughout our lives how to be assertive. The adults who tried to guide us and keep us safe had to remember that to learn we needed opportunities and experience. Learning includes not always doing things correctly. Along the way they started to cut us some slack; they made room for us to learn.

In the field of support for people with disabilities new phrases like self-advocacy and self-directed have emerged. When asked what it means to be a self-advocate some individuals with developmental disabilities report that self-advocates stand up for themselves. When asked what that means, too many say *I don't know* or *my staff calls me that*. Some very literal responders stand up. Too often, 'self-advocates' is being used as code for 'people with developmental disabilities.'

People without disabilities don't usually talk about themselves as self-advocates or self-directed. It's more ordinary to think of ourselves as being more or less assertive. When people want to bring experiences and relationships into their lives they assert themselves. When people want to influence the way they are treated or to stop certain events they assert themselves. These acts of assertiveness are sometimes skillful.

When asking people without disabilities how they would describe learning to be assertive and take care of themselves, there were many reports of early rule violations; about sneaking, lying, physical confrontations, taking risks, refusing to do things; and about acts of courage. When asked why they did what they were told not to do knowing they might be punished, they said *because I wanted to, I thought I could, it seemed like a good idea, it was worth the risk.*

People also reported breaking rules to defend themselves or take care of others. They learned over time and through direct experience how to set personal boundaries. Their answers were about wanting energy; wanting to bring something or someone into their lives or wanting something to stop. Learning to be assertive—to stand up for yourself—starts with wanting energy. It requires that others in a person's life understand that everyone has a POV.

When in the lives of people with disabilities are they actively supported to assert themselves? When do caregivers invest more thought and effort into trying to imagine the points of view of those they support than in trying to achieve compliance? Among the things we can do to create more safety in support relationships is to be curious about a person's POV and what she is trying to assert.

You are not alone if you said that you would prefer to support someone who does what she is told to do over someone who does what she wants. It seems to be the universal answer, but—who is easier to take advantage of or abuse?

Every field of work has its own vocabulary. Whether you are a realtor, a contractor or a farmer, there are words and phrases that others might not understand. Consider this partial list of concepts in use today in the field of community support for people considered vulnerable.

- Least Restrictive
- Outcomes
- Empowerment
- Autonomy
- Relationships
- Meaningful
- Reciprocity
- Most Integrated
- Appropriate
- Choice
- Responsible Risk
- Inclusion
- Aging with Dignity
- Self-Directed

This language is often found in mission statements and organizational brochures. It is supposed to refer directly to the relationships caregivers have

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with the individuals they support. Least restrictive and most integrated refer to where people go, what they do and who they are with. How much time is actually devoted to asking whether someone is living or working in the least restrictive and most integrated setting? Do we even have a common understanding of what 'least restrictive' and 'most integrated' mean? The great risk of field talk is that even within the field people often have not talked about what the words mean and how they should guide our interactions.

Consider the word 'choice.' Hetty was recently moved to a group home. She is 59. One of her caregivers said that she and another woman (51) are given choice every day. Her caregiver said at snack time, *I ask my girls if they want water or juice.* (For the moment, we won't talk about how it might influence a caregiver to think about the women she supports as girls.)

What does choice mean when you are at home and hungry? You probably go to your kitchen. You look in cabinets and open the refrigerator. You probably whine a little and think there's nothing good to eat. Then you make a selection from what is available. That's choice.

Having spent much of her life in institutional care, Hetty has never had access to a refrigerator or cabinets. When she walked toward her kitchen in her home she was characterized as defiant, noncompliant and not following house rules. She was told to stop, stay and sit. At a snack time scheduled by someone else she was given choice between water and juice or between an apple and crackers while sitting at a dining room table. If it is not snack time and she approaches the kitchen she is told that she will have to wait. That was one caregiver's (current) understanding of choice.

Before you start defending the caregiver, please understand that this is not an attack. When asked what she understood to be her responsibilities, the caregiver explained that her job was to provide healthy food at scheduled times; and, to keep Hetty safe. When asked about Hetty's safety in the kitchen, the worker reported that there had never been unsafe or dangerous actions in the kitchen because they did not let Hetty enter. This caregiver was doing what she understood to be her job and Hetty was trying to assert her POV. Tension was building.

In every field, a small number of people introduce new words and ideas. For a large number of people, use of these words precedes their understanding of what the words mean. Comprehension requires that we talk about each other's understanding and refine what we do. In order to have healthy and safe support relationships, we have to make the time to understand our field talk.

After reading in their brochure that this group home empowered people to live full lives, staff were asked how they empowered Hetty. They didn't understand the question. They were smart people but no one had asked the organization's director, group home manager or direct support staff what the words in their brochure meant in their daily points of contact with those who receive support.

<<< ... enforcing rather than empowering. Staff wanted to know how to make Hetty behave. Compliance was the unspoken goal and Hetty was starting to resist. >>>

LINGER with this thought

The messages to staff were more along the lines of getting people to do what needed to be done; enforcing rather than empowering. Staff wanted to know how to make Hetty behave. Compliance was the unspoken goal and Hetty was starting to resist. Stated another way, Hetty was starting to assert that she was interested in learning about and using her kitchen.

As we try to appreciate what it means to support people well, from whatever role or point of contact you have, we have to ask what our field talk means. **When we say that we offer choice, autonomy, empowerment, respect, etc.; in relation to what and from whose perspective?** To make any progress, we have to acknowledge the conflict between our field talk in community support and the culture of compliance that influences our caregiving relationships.

For most people with developmental disabilities or differences, the culture of compliance begins early and continues indefinitely. This means that the limitations, restrictions and expectations to be good that are placed on young children often remain in place well into adulthood. It allows us to think of adults with disabilities as children throughout their lives and to treat them as children.

For those who come to need support through age, illness or accident, they are often regressed into the culture of compliance. The expectation that they do what they are told becomes a benchmark of success. *She does what I tell her, she's no problem.* Unraveling the effects and risks of the culture of compliance requires attention and humility.

Small groups of women who had been victims of sexual assault or survivors of domestic violence and also had psychiatric illnesses were asked about their experiences when making contact for assistance. Whether in rural or urban parts of Wisconsin, whether they were middle class or poor women, they often commented on the pressure they felt to be compliant. They felt expected to disclose abuse histories on someone else's schedule; to make police reports on someone else's schedule; and to leave their homes, get therapy, find jobs and take medication on someone else's schedule. When they did not comply, they reported that those they contacted for assistance were less willing to help.

The intention to be helpful can dominate our view of ourselves. When we believe that we know what's best for someone, we don't consider her POV. When we see ourselves as smarter or better informed we assume that we should lead. Our brains start to lock. Because our intention is to be helpful, we expect our advice to be taken and our directions to be followed. When a person makes her own choices, we might say *she is noncompliant. She is stubborn. She doesn't want to help herself.*

Humility starts to grow in support relationships when we can acknowledge that our attempts to be helpful are not always experienced as help. Each of us can learn to be more aware of what we say and do. We can try to notice whether someone is responding positively, neutrally or negatively. When you find yourself thinking *I'm just trying to help*, notice the person you are trying to support.

She might not be experiencing you or your attempts as helpful.

In the culture of compliance, we characterize people. We say *she's challenging, she has challenges* or *she needs to make better choices*. While supporting individuals with disabilities to live full lives in the community, we target their challenging behavior for change. We bring in behavioral specialists and create intervention plans. The goal is to change (unskillful) behavior even before considering what she might be trying to assert or accomplish.

In the culture of compliance, we assume the following: I'm fine, the environment (she is in) is fine, the activity is fine and our methods are fine because our intention is to help. The problem is her. She needs to change. We believe that we have the right and the responsibility to change her.

The culture of compliance that begins in childhood and continues into adulthood is reflected in the language of Individualized Education Plans (IEPs) for students with disabilities and in Individual Service Plans (ISPs) for adults.

She... will follow all (adult) directions.

She... will comply with all demands.


She... will not ... (get angry, yell, touch...).

With this logic, the woman in the convenience store who elbowed someone who put his hands on her would be expected to allow hands-on contact. Given these expectations, when she felt herself being moved from behind, she should simply have complied and allowed it, even though she did not know who it was or feel safe. A compliance model requires her to be good even at the expense of feeling safe and respected. It is her responsibility to behave. And who has the authority and power to define what good behavior looks and sounds like?

Among the people most often deemed in need of behavior specialists and intervention plans are those who experience the most difficulty learning and participating in social situations. This includes people experiencing anxiety, instability, impulsivity, mistrust, social confusion, histories of mistreatment and possible trauma. In the culture of compliance, support people try to manage, modify or change behavior as though it is separate from and unrelated to the contexts in which the behavior occurs. This interventionist approach does not acknowledge that the person receiving support has a POV that matters—at least to her.

If our intention is to better understand vulnerability and safety in support relationships, we have to be more honest and balanced in our reporting. Instead of saying *she's challenging*, humility would call upon us to say *I feel challenged or confused because I don't know what the best response might be for this person in this situation from her POV*.

It is not uncommon to hear *she just wants to be in charge*, as though this is unreasonable. **Isn't the desire to be in charge of where you go, what you do, who you do it with and how you want to be treated what is intended by au-**



<<< **A compliance model requires her to be good even at the expense of feeling safe and respected.** >>>

LINGER with this thought

tonomy and self-direction? Isn't the desire to be in charge the developmental path that children and adults without disabilities follow—starting when a child says *you're not the boss of me?*

Those following a different developmental path do not have enough opportunity to learn about being in charge. An adult living in the culture that talks about choice and autonomy is often trying to learn and mature within an array of options that is extremely limited; paper or plastic. And when someone's wanting energy is aroused and she asserts herself—sometimes unskillfully—someone intervenes. What happens to that assertive energy when she is repeatedly ignored, interrupted or even punished?

Note: The phrase trauma informed has come into more general use in recent years. As you continue reading, think about what it would mean to be trauma informed. This concept is discussed in the last section of this guide.

How Do You Think About Behavior?

When compliance goals are questioned, many caregivers say they are needed because of how low functioning, difficult or challenging someone is. The most obvious beliefs that enable and support the compliance model are that it's for her own good; it's in her best interest; she needs to be protected. People emphasize *because we love her and want to keep her from harm*.

Maybe the most paradoxical reason for the culture of compliance is the fear of harm. We want this person to do what she is told because we are afraid that something bad might happen. Implied here is that those who surround this person, including caregivers, would never cause her harm. And so we set goals and systematically teach her to do what she is told. **What if a person masters compliance and non-thinking? How does mastery of compliance decrease her vulnerability and create more safety?**

Please notice while you read that in the depictions of conflict described in caregiving relationships, from the POV of the person receiving support there is often a perceived threat; just as the woman in the convenience store perceived a threat and acted to protect herself. It is also important that examples of physical confrontation do not feed the myth that people with disabilities are inherently dangerous and need to be excluded or feared. The point of sharing stories is to explore how confusion and conflict can arise in caregiving relationships. How do you think about behavior in the context of your support for people with disabilities?


Behavior is a loaded word in our (disability) field talk. It almost always means unwelcome and unwanted actions; behavior means negative. But the word behavior just means action—behavior is what we do. What makes someone's actions good or bad? Most would agree that hitting someone on the head is not skillful. If you draw back for a wider view you might see that the person being hit is punching someone else, maybe someone smaller. With a bigger picture and more information, the same action might be understood differently.

Context matters when trying to understand someone's POV. This is not to suggest that there should be no limits to what actions are encouraged or supported. However, trying to understand someone's POV can greatly enhance a support relationship. With curiosity we might shift from saying *she just wants attention* or *she's dangerously aggressive* to understanding that she might have been trying to accomplish something that matters to her (however unskillfully).

Elopers are not just people running off to get married. In our field talk, elopers are people who leave where someone wants them to be without permission.

LINGER with this thought

<<< When you only see behavior in terms of what you want someone to do as compared to trying to understand what she is trying to accomplish, conflict can arise. >>>



<<< ... the more competent a person is perceived to be, the more degrees of freedom she has. Stated another way, some people are cut more slack. >>>

When you only see behavior in terms of what you want someone to do as compared to trying to understand what she is trying to accomplish, conflict can arise. When support people only value compliance, even under the umbrella of safety, they might conclude that she just needs to stay put and do what she is told. When you add curiosity, you might ask when she gets up—is she going toward something or away from something? Ask because it is respectful to do so. Ask to prevent putting your hands on someone or blocking her way and precipitating more conflict. Ask because her POV matters.

A young eloper named Shay was described as low functioning and having a severe intellectual disability. She was eloping from her work area several times a day. Her support people kept saying *you need to sit. You need to work*. Staff was told to keep her in her designated place. Shay was being taught compliance and passivity.

Shay was no one's favorite person to support. In addition to being an eloper, she was incontinent several times a week. Because she did not want anyone but her mother to assist her with hygiene, she actively resisted while others tried to help her change clothes. Active resistance included pushing, pinching, scratching, and trying to bite those who put their hands on her.

When asked where Shay was trying to go, the answer was that it didn't matter. People said *she just doesn't want to work. She's lazy. She's just trying to get attention*. It was reported that she is not supposed to get up at unscheduled times because she's learning to work. She could get up at scheduled break times or lunch.

Upon request they allowed Shay to leave so that a consultant could help them understand their daily contests. It became clear quickly that she was going toward something—the rest room. When she was done, she returned to her work area. She knew when her bladder was full, how to find the women's room, and how to unfasten and refasten her clothing. It was not known whether she practiced good hygiene. What she did not understand or accept was asking for permission.

Context is important when trying to appreciate someone's POV. Another part of context is how the person doing 'it' is perceived. According to the competence/ deviance hypothesis, the more competent a person is perceived to be, the more degrees of freedom she has. Stated another way, some people are cut more slack. Shay was identified as an eloper, a wetter and low functioning. She was extra work and sometimes smelled. How much curiosity or slack would she receive?

A well perceived woman in a convenience store who elbows the person who put his hands on her is given the benefit of the doubt. Most people would at least try to understand the context of her actions. Identify that woman as having a developmental disability or mental illness—a deviance from the norm—and she is described as aggressive and a risk in the community. These become part of her identity and our characterization of her.

Some people are not given any slack. If you don't feel comfortable with her appearance or hygiene you might not wonder about her POV. If you don't feel comfortable with the way she communicates, including her choice of words, her volume or her attitude you might not wonder about her POV. In fact, you might assume that you know enough about her without wondering anything except how to make her behave or go away. Good people make snap assumptions without even realizing it. Once we become aware of our assumptions, we have a responsibility to notice how they influence our actions as support people and caregivers.

What happens when you perceive someone as smart, accomplished, articulate and fun? What happens when you perceive someone as low functioning, attention-seeking and aggressive as well as an eloper and a wetter? What happens to (your) comfort when someone's communication, movement or responsiveness to questions is different from what you are used to? What happens when her acts of assertiveness are reduced to being called challenging?

When we draw conclusions based only on our own points of view we are missing significant parts of her story. The whole story might include differences in her participation related to culture, family tradition, neurology, opportunities to learn, comprehension, prior experience, trauma history, well being, etc.

We start characterizing people early. It might just be a social shortcut but it has consequences. We talk about babies as good or fussy. As children with disabilities grow into adolescents and adults some of the following words and characterizations are used quite casually.

- manipulative
- noncompliant
- challenging
- distractible
- out of control
- inappropriate
- aggressive
- stubborn
- doesn't care
- just for attention
- disruptive
- inflexible

You could probably add to this list. When we use general words that are considered negative to describe people, it follows that the primary topics of conversation will be about their behavior or their needs (e.g., she's disruptive; she needs one to one support all the time). When behavior is the major topic of conversation about someone, the operating assumption is that you have to get her (behavior) under control first before she can participate in a full life.

When we believe that we are taking these steps for her benefit, the steps we take are justified. "We" is comprised of family and direct as well as indirect support people. Our intention is to help and protect. We intervene.

What if someone was assigned to manage your behavior? Assume that you occasionally eat too much, drink more than you intended and get up without permission. Maybe you sometimes curse or raise your voice. What if you don't clean your room, take a shower (at the time scheduled for you), or clean that

LINGER with this thought

basement of yours? What if the person assigned to manage you decides to intervene?

Some of you might welcome a person to coach your food and beverage intake as well as your exercise. You might pay for that service. That's a voluntary arrangement. What if you didn't want the service but someone showed up anyway to make you adhere to their program because others agreed it would be good for you? What if they said things you found demeaning and sometimes put their hands on you to keep you on track?

This person might have a key to your house, access to your work place and some control of your money. She might have her own ideas about what words are appropriate for you to say and what time you should go to bed. She might be able to decide whether you have pizza on Friday night based on whether your behavior at work was acceptable. What would you do?

A panel of five individuals was talking about their experiences in the mental health service system. They were asked what they heard others say about them. One woman said she was frequently called manipulative and that she hated it. When asked why she hated being called manipulative, notice how she specified her actions in context. She said *I'm called manipulative because on some days I make a lot of phone calls. On some days I call my therapist 5-6 times. I might call my social worker 5-6 times and I might call some family members 5-6 times. On those days, I'm trying to stay alive. The urge to kill myself is very strong and those phone calls keep me connected.*

If you think of someone as manipulative, it will influence you. You will be on guard. You might try to avoid her. When she says *hello*, you might think *you can't get away with that*. What words and characterizations do you hear used about the people you support? This is not about being language police; our words influence our actions and often shut down our curiosity about her POV.

LINGER with this thought

Social scientists report that we look and listen to confirm what we already think or believe. When you are told that someone is wild and out of control how do you observe her? When you hear that she is inappropriate or demanding, how do you interpret her actions? We like to believe that we are open-minded and accept people one at a time. There is often a difference between what we like to believe about ourselves and what is true. It takes intention, humility and mindfulness to be aware of what we are thinking and feeling in order to counter our quick assumptions and judgments about people.

Many reports generated about Mattie described her as highly distractible with a very short attention span. Then, someone new was overheard talking about her. He said *I met Mattie; she's so curious and interested. No matter what she hears, she wants to find out where the sound came from. When something catches her eye, she wants to see what's happening.*

One word was substituted for another; from distractible to curious. Both are general terms. The difference between them had the power to change rela-


tionships and interactions with Mattie. After years of trying to make her focus on what others thought was important and being met with resistance, efforts were made to learn what interested her. Not surprisingly, people found no resistance. In fact, what had been called her physical aggression, verbal threats and oppositional behavior was actually her wanting energy (expressed unskillfully). She had been asserting herself for years but no one characterized her (actions) that way. She was not seen as asserting herself, she was seen as difficult to handle. The new person assumed that Mattie had a POV.

Most caregivers don't think much about how they are perceived by those they support. They just do what they do and trust that their intention to help is enough. Getting people to do what you want them to do is part of the job. However, working to get those who receive support to master the lessons of compliance can make a person more vulnerable. The person who learns to comply is more likely when someone says *get in the car*—to get in the car. A person who is taught to be compliant is already partially groomed for a perpetrator. When people don't understand healthy relationships they might not recognize mistreatment or abuse. The culture of compliance makes people more vulnerable and less safe.

A very good coach and likable person was observed teaching a young woman to kick a soccer ball. She didn't naturally distribute her weight for this activity. He demonstrated bending at the hips and knees and then extended an open hand toward her left shoulder. He used just his finger tips to suggest that she bend forward. The woman pulled out from under his touch and yelled *that hurt*. He knew his own intention and knew how much pressure he used so he said *no it didn't*.

With one dismissive sentence he gave her two messages that he did not intend. First, he told her that she didn't know what she felt; he would tell her what she felt. Second, he told her that he was not trustworthy. Asking him for assistance in the future would not help her. The coach didn't understand that people are not all neurologically the same and do not all experience physical contact in the same way. His light touch and intention to help was not experienced as either helpful or comfortable. If an incident report is written or comments are shared about working with this young woman, how will she be characterized?

Imagine touching someone you respect, a finger tip on the shoulder, and being told it hurt. An ordinary response might be *I'm sorry. I didn't mean to hurt you*. Maybe even *I won't do that again*. We apologize out of a universal sense of courtesy even if we don't understand how such gentle contact could be experienced as discomfort. **With respect, we would allow the other person to define her own experience. Humility and respect would lead to an adjustment of power and control.**



<<< **A person who is taught to be compliant is already partially groomed for a perpetrator.** >>>

LINGER with this thought

Power & Control in Support Relationships

Caregivers are supposed to do many things from the practical to the recreational and for some the personal. For each person who receives support, there are often many stakeholders. Family members, guardians, social workers, health care workers, therapists, support and service providers, funders, county representatives, state auditors, quality and compliance people, community members, coworkers and employers, supervisors. The person receiving support has a place in there. Who's in charge? Whom do you please? How do you prioritize allegiances among stakeholders?

When groups of support workers and family members were asked to list what they understood to be their essential jobs or roles as caregivers, the following list was generated:

- to help,
- to teach,
- to listen,
- to have fun,
- to teach them to love themselves & others,
- to give choice,
- to empower,
- to provide a schedule,
- to keep them safe,
- to keep them clean,
- to help with money,
- to encourage,
- to structure their time,
- to set & accomplish goals,
- to identify their needs, ...

That is all on a good day. When asked what they understood their roles and responsibilities to be when those who received support did not comply with expectations, there was confusion. The language of choice and autonomy morphed into enforcement; *when can I just draw the line in the sand?*

Support workers often say they took a job because they wanted to have relationships with people while supporting them to live full lives. They learn quickly that they are supposed to get people to do things they might not want to do. They have to get people to follow schedules and engage in activities whether the person is interested or not. They have to tell people when to shower

and eat and go to bed. They have to enforce dietary restrictions. They have to get people out of their homes to a driver who will take them somewhere else. For many, the job of support person becomes that of enforcer, often unwelcome enforcer, rather than supporter.

Relationships are inherently complicated. As soon as there are two points of view, conflict can arise. Ordinary relationship tensions might include decisions about where to go, what to do, when and for how long, who to spend time with, what to eat, how much salt to put in the soup, or the always welcome *are you really going to wear that?*

What are some of the ordinary relationship tensions that arise between caregivers and those who receive support? Include all of the above and then amplify the part about who gets to decide. As a caregiver, maybe you were told that I can only go for a walk after I make my bed. But I don't see the need to make my bed before going for a walk and don't accept that you have any authority over me. What might happen? How close will you come to me? What will you say? Will you put your hands on me? And, what if I resist with my words or the force of my actions? What if the sound of your voice or sight of your hand reminds me of another caregiver who hurt me? Wanting energy rises.

What if you believe that it's your responsibility to make me lose weight? You talk about servings, fat content, calories, how tight my clothes are and then tell me what I won't be allowed to eat. You reach toward my muffin. I haven't learned to be compliant and reach for the muffin too. Sound foolish? Maybe, but these are not uncommon relationship tensions between caregivers and those with developmental disabilities who receive support. Sometimes it's a muffin; sometimes it's coffee or a soft drink. Sometimes someone wants to go out for a walk before making the bed. There is a dynamic of power and control in these moments. Only one person gets to write the report and make recommendations; and that person has more power and control.

What might people who receive support define as relationship tensions? For too many, there is tension about most of their acts of assertiveness every day. Two important questions about how power and control emerges in support relationships are:

- What have caregivers been told they are responsible to do; and
- How are they encouraged to make decisions when conflict arises?

What caregivers understand they are expected to do and why relates directly to perceptions of a person's ability to participate in directing her own life. For example, if the focus has been on a person's developmental age (e.g., she functions like an 8 year old), a diagnostic label or a characterization (severe, profound, low functioning, nonverbal), we might not get around to her interests, humor, preferences or anxieties—her POV.

If you have been told that among your responsibilities are feeding, dressing, toileting and showering it might escape you that there are individuals with per-

sonal histories and preferences who are (supposed to be) participants in those activities. They are not bodies to be acted upon. Would you approach someone differently if you thought your responsibility was to assist her to eat or dress, to use a toilet, or to get washed up? Individuals have a POV about how that assistance is provided.

Maybe you are not a caregiver but an administrator painfully aware of costs. Your screening tool suggests that for a woman of a particular size and physical ability it takes approximately X minutes to shower her. The problem with this calculation is that it does not take into account the whole person who will be assisted in that shower. She might have concerns that are not accounted for in the approved minutes of care for giving a shower. The tools do not necessarily individualize regarding a person's temperament or sense of modesty or history of mistreatment.

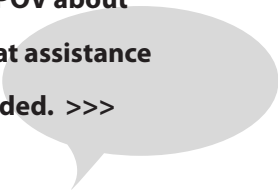
What would you care about if someone was going to assist you in the shower? Would you care about the way they looked at you or the speed with which they took your clothes off? Would it be important if they had interest in your preferred room and water temperature? Would you want them to talk or be silent? If talking is OK, what topics are acceptable? Can your personal care assistant comment about your body? Would you want someone who knows you well and supports you at other times or would you prefer someone who only provides this one service and has no other role in your life? Might you feel afraid that this person will hurt you the way one of the others did?

In a support role, it is not about you or what you would want. How support is provided is about what matters to the person receiving it. We do not need confirmation that someone has experienced harm to be interested in her POV. What might happen if a support worker understands the job is to get her in and get her out? Supporting someone to bathe or shower is not a car wash; it is extremely personal and each person has an important POV about how it is done respectfully and safely.

During the next few weeks, notice situations in which you perceive degrees of enforcement in support relationships. Listen for sentences that begin with some version of *you need to...* Draw from your own experiences and those you observe or hear about. *You need to put that down. You need to leave that alone.*

Here's another version to get you started. A person receiving support wants more coffee. At your house that would probably mean you get up and get it. This person has learned that she has to ask for permission and did. The caregiver said *you've had enough*. If the person asking for more coffee has mastered the lesson of compliance, that will be the end of it. If she has not...what might happen? Ordinary interventions are what caregivers do to achieve compliance. The goal is that someone do something (comply) and not do anything else (be non-compliant).

Many people are included in the decisions about where they live, how they



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how that assistance
is provided. >>>

spend their time and who they spend time with. Many receive thoughtful and individualized support that matches their personal preferences and strengths. Individualization includes attention to the right activities; the right amount of challenge; the right kinds of support; the right amount of support; the right pace of support; and a trusted relationship with a caregiver.

For many others, ordinary interventions might be pairing less favored activities with more favored activities to get the desired change in behavior. Stated as a contingency there might be something like *you can go for a walk after you make your bed*. In and of itself, a contingency might not be bad. A person might say to herself, *first I'll clean the basement and then I'll relax and read*. The major difference is that one contingency is voluntary and used to motivate yourself and the other is imposed and perhaps rigidly enforced. Another kind of contingency might be telling someone who is restrained on the floor *when you calm down, then you can get up*.

Other contingencies might include earning or losing privileges. Points, tokens, smiling faces might be amassed for making good choices. The essential message is if you do what I want, you can earn points to do what you want from a limited array of options when I say it's OK. If you don't do what I want you will not be able to do what you want. When you are a person who receives support, making a good choice means doing what others want you to do; anything else is called noncompliance or inappropriate and earns no points.

Another kind of ordinary intervention might be losing favor with a caregiver and being treated badly. An elderly woman identified as noncompliant with regard to medication by her social worker and nurse was upset when describing how her social worker and nurse spoke to her. She was distressed by having aged into needing support but was trying to be grateful. Then, to be lectured and scolded was humiliating. When asked what they wanted her to do, the woman said they were quite angry at her for not taking her diuretic (medication) as prescribed. She wanted to play bridge with her friends and whispered *I can't be getting up every 10 minutes to pee*. She blushed but sounded angry.

The woman laughed when she reported *they come early to catch me being bad. They think I don't know what they're doing? Sometimes, when they come early, I just don't answer the door*. Another area of noncompliance reported by the social worker and nurse was the woman not answering her door when they went for scheduled visits. They didn't report that they arrived early.

The point is not to minimize the concern of the social worker and nurse. Diuretics can be life-saving. The point is that no one considered this woman's POV or tried to help her figure out a way to be medically safer and enjoy spending time with her friends. Instead their actions resulted in her feeling humiliated.

Imagine how your behavior and relationships might be influenced if others had power and control in your life. Would you be frustrated or angry? How do

<<< **When you are a person who receives support, making a good choice means doing what others want you to do; anything else is called noncompliance or inappropriate and earns no points.** >>>

you express frustration and anger? If you just surrendered to the expectations of others would you be more or less vulnerable?

Other ordinary interventions involve our physical presence and contact with those who receive support. Consider proximity factors in support relationships—where and how one person positions him/herself in relation to you. Someone can get close to you, stand behind you, next to you or over you while you are expected to remain seated. The other person can move her arms while saying you need to be still or put your arms down. Imagine how this would affect you? No one is touching you. This caregiver is just trying to be helpful or keep you safe. *You're fine*. That's what will be said if you express fear or try to get her/him to back off.

There are also hands-on supports. Any support person will tell you that time is a huge factor in their lives. Escorting someone who is moving slowly or is resistant might include a hand positioned on the middle of her back to move her forward more quickly. It might be a squeeze at the wrist or elbow to suggest that she needs to speed up. Someone might whisper something so that she will do the right thing and then say *I was just teasing*.

Filane (23) has been called impulsive, aggressive and noncompliant. Transitions have always been difficult. After shooting baskets with a support person, Filane was told to go inside. She walked as far as a bike rack located between the court and the building. She stood with her feet on the lower rail and her hands resting on the upper rail. She looked down and remained silent. Her support person approached from the side and said *you need to make a good choice. I'll count from 10 to zero and you have to be walking or we'll escort you. 10, 9, 8...*

When the support worker got to zero, Filane had not moved. Two people with their arms under hers began to escort her. Filane tried to pull away; they tightened their grip. She dragged her feet; they lifted. She started to yell and then cry; they said she needed to *do what you're told*. Inside, she was still trying to pull away. One support worker held her in a basket hold on the floor while saying *don't be a baby*. This continued for 45 minutes.

What we say, how we position ourselves, what we expect, how we touch others are all part of the formal and informal interventions that are ordinary in the lives of many people who receive support. Use of power and control in support relationships is not an easy topic. People think defensively. The subject is not raised to create defensiveness; it is raised because caregivers sometimes justify strategies that would be seriously questioned in any other context.

Some people take advantage or abuse intentionally. They know what they are doing. There are also people who are designing and implementing behavioral plans without wondering what it's like to be the person receiving support. Some are just doing what they are told to do and trusting that others more experienced than they are would not tell them to do things that are harmful. They are not thinking that every success at achieving compliance makes it easier for

LINGER with this thought

<<< **Anyone who automatically does what she is told whether by training or temperament is potentially more vulnerable and at risk. >>>**

those who want to do harm. **When we ask why people with disabilities are more vulnerable, the culture of compliance has to be implicated. We are inadvertently training people to be easier targets.**

Who else is vulnerable? Much of the focus of this material has been on the culture of compliance in relation to those whose behavior is described as challenging. It is important that we also recognize those who by conditioning or temperament are people pleasers. Many people who are not described as having behavioral problems might have vulnerability problems because they are trusting by temperament. It suits some people to do what they are told. Others welcome the attention that comes with pleasing others. Anyone who automatically does what she is told whether by training or temperament is potentially more vulnerable and at risk.

Our Failure to Imagine

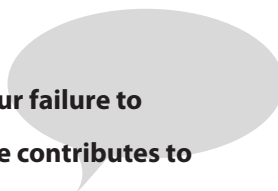
With all of our planned separation and supervision individuals with disabilities are abused and taken advantage of at alarming rates. When stories break and reporters talk to the neighbors and coworkers of alleged perpetrators, a few common statements emerge. The alleged perpetrator was quiet and nice, kept to him or herself and never caused trouble. Coworkers, family members and neighbors often say this person was helpful and kind. And then the statement *I can't imagine.... I can't imagine that (this person) would do that. I just can't imagine.* Our failure to imagine contributes to making those we support more vulnerable.

Please read the next paragraph and then try it. Imagine 4-5 people you have worked with to support someone. Your group could include support people in any role (live-in support, job coach, personal care attendant, advocate, transportation provider, therapist, etc.) as well as family members. Bring their faces to mind and imagine them sitting around a table with you. For each person, call to mind qualities that you have come to know and value. For example, who makes you laugh most easily? Who is the grumpiest? Who is a good listener? If you needed assistance, who would you ask? Then, consider the following possibilities and notice how considering them affects you.

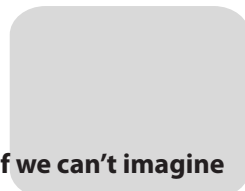
Imagine that one of these people around your caregivers table...

- rescued a puppy from the side of the road.
- has been helping an aging grandparent to stay in her own home.
- takes a person you both support home for holidays.
- was overheard telling someone to sit down or no dinner because she went into the kitchen without permission.
- pretends not to hear calls for assistance during her favorite TV program.
- pinches the inside of a woman's arm to speed her up in the morning.
- takes longer than needed to wash someone's genitals.
- went into the room of a woman not able to give consent and had intercourse with her.

Notice what happened when you tried to imagine someone you know engaging in an act of kindness or an act of abuse. Notice what happened to your thinking, the sensations in your body and your emotions. Many people say that it's difficult to reconcile positive feelings toward someone with reports of negative events; they could not imagine it. So, they override the negative event report. They minimize the significance of the event or tell themselves the report



<<< **Our failure to imagine contributes to making those we support more vulnerable.** >>>



<<< **If we can't imagine that these things are happening, then we can't create more safety.** >>>

was an exaggeration or misunderstanding. They tell themselves that maybe her arm was squeezed *but it probably didn't hurt or she did need to get to her bus or she's just trying to get attention.*

Even if we can't imagine that people we know are violating boundaries and causing harm it does not make it less true. Even if their intentions are to be helpful or to do what they understand to be their jobs, they might be causing harm. If we can't imagine that these things are happening, then we can't create more safety. If we can't imagine it, we are participating in keeping individuals who receive support vulnerable.

Ethics is the branch of philosophy that asks what is the right thing to do. Having an ethical edge might be defined as the difference between reacting and responding. Reacting means acting without thought or with too little information. Responding means acting in consideration of pertinent information. Pertinent information that is often left out of decisions that affect the lives of a person who receives support is her POV.

When we learn about someone's POV, we might notice that we made mistakes in our thinking. We might notice that we are judging or blaming. We might notice that our emotions are overshadowing our best intentions. We might notice that she has a sense of humor and preferences, and that we are using more power and control than we have a right to use. If we slow ourselves down, we might arrive at a different answer to the question *what is the right thing to do.*

We might notice that who we understand someone to be is based on the words that have been used to characterize her. We might also notice that our thinking is skewed toward staying in control rather than empowering her.

When our intention is to be in control we have established a contest. One person wins and by definition the other loses. People feel that dynamic in relationships.

LINGER with this thought

Ethics is about our actions, what we do. If a woman is placed in a group home with five other adults because there was a bed available and she says *I don't want to live with these people*, is that a social justice issue? Do we help or ignore her? What if she starts fighting and hiding her things? Do we implement a behavior intervention plan to target her unwelcome actions? Do we put specialty locks on the door and impose bedtime curfews? It has been said that the most common ethical dilemma faced by people who work in human services is the writing or implementation of a behavioral plan.

An important part of making ethical decisions is considering the POV of the person receiving support. When someone is identified as having a cognitive disability, a mental illness, a brain injury or is losing cognitive functions, assumptions might be made too quickly about her ability to actively participate in making decisions. A live-in caregiver working for a well respected supported living organization said that because the woman she supported needed someone to live with her, she (the paid person) was better equipped to make decisions on

her behalf than she could make for herself. That was her belief. Her actions flowed from that (unexamined) belief.

Reports about Julianne when she was 8 years old said she was nonverbal and functioning at a prenatal level. Born with cerebral palsy, she developed contractures in all of her joints leaving her with very limited movement. She had no symbolic method of communicating. To help her drink and eat, she had to be touched under the chin to stimulate a swallow. In part, this was why she was described as functioning at a prenatal level; babies can suck and swallow. It was also reported that she was blind. Julianne could smile and move her little fingers on both hands.

Those who met Julianne at the beginning of September knew before Halloween that she was indifferent to children's music, cried when she heard traditional country music, fell asleep to classical and was thrilled to hear Aretha Franklin. Her eyes danced up to the right, she wiggled her little fingers and a smile spread across her face.

Too many people are summarized as nonverbal or low functioning and then dismissed as active decision makers in their own lives. The word nonverbal is often misunderstood as non-communicative, non-thinking or non-feeling – none of which is accurate. It certainly does not mean that a person has no POV. Even someone assessed as having only prenatal skills can have a POV about the music she wants to hear, or how she wants to be touched or spoken to. In the language of ethics it is our duty, our responsibility, our obligation to at least try to understand the POV of each person we support.

Each person communicates in some way how she wants to be treated; or at the very least, how she does not want to be treated. She might push her elbow into your ribs. She might say that your touch hurts. She might hide her belongings and sneak away. She might wave her fist in your face. You have to decide whether you will see her as a behavioral problem or as a person asserting her POV—even if you find her unskillful or inappropriate.

If ethics are about our actions, then what we say – the words we use to describe and characterize a person—is an ethical decision. Ethics includes what we write in log notes and reports, what we say about her and what recommendations we make. Ethical behavior is about what we do on a daily basis. As soon as you describe someone as manipulative, disruptive or uncooperative you are setting the course for how you and others will treat her. How we represent someone is an ethical decision.

While working at the training center of a state institution in 1976, one of my students was sent back to her unit for swearing. (Not my rule.) She was taking medication that resulted in slurred speech and a lumbering walk. Ruth, the director of her unit, did not look at Jo; she just yelled *go upstairs*. This being a controlled setting, the door to the stairway was locked.

After trying to comply, Jo turned to explain that the door was locked. Be-

LINGER with this thought

<<< **You have to decide whether you will see her as a behavioral problem or as a person asserting her POV—even if you find her unskillful or inappropriate.** >>>

cause her speech was slurred, you had to pay close attention. Ruth didn't turn or listen; she yelled again to get upstairs. Jo actually tried the door once more but it was still locked. Amused, with a smile on her face, she walked toward Ruth. As Ruth started to tell her what to do again, Jo laughed and lifted her right hand. It appeared that she wanted to cover Ruth's mouth (presumably to make her stop talking and listen). As Ruth moved, Jo's hand touched her neck rather than her mouth. Ruth called for help; aides came running; Jo was restrained and carried away. Within hours she was moved to an even more restrictive facility.

Ruth was frightened. Jo was confused. The same event was experienced from very different points of view. Ethics are about behaving in a trustworthy manner which demands that we consider situations from more than one POV.

Many people hired to have paid relationships are told about mission and vision statements that include words like empowerment, autonomy and choice. Then, they are left to believe they have both the right and responsibility to control the daily actions of those who receive support—for their own good and to keep them safe. In order to exert that control, some caregivers say and do things that would be questioned in any other context.

Mission and vision statements do not specify that caregivers will use power and control to achieve their goals; but in too many situations, achieving compliance is the goal by default. **In the culture of compliance, the use of power and control is allowed without much awareness that it increases a person's vulnerability.**

LINGER with this thought

Bringing Mindfulness into Support Relationships

Social scientists have found that most of us look and listen to confirm what we already think and believe. We accept our own thoughts and beliefs as fact. This is a form of brain-lock. The words we use to describe or characterize a person become synonymous with the person. Soon, Mary means stubborn and we interact with her accordingly.

To make room in our locked brains, we have to first notice and then adjust our urge to manage or get her under control. What is often called bad or challenging behavior might more accurately be described as her assertiveness. **What if every time someone spoke of challenging or bad behavior, you actively wondered about her POV and invited others to think about that with you?**

LINGER with this thought

If there is an emergency and someone with or without a disability is in imminent danger to herself or someone else, certainly intervene to keep the endangered person safe; but daily interaction is not all about emergencies. While we have whole conferences dedicated to choice and empowerment, so much of what we do is compliance training.

Many people in support roles don't see themselves as having power or control. They see themselves as helpers or family members or friends. People receiving support have no trouble identifying caregivers as having more power.

Think about someone you know who falls under that broad heading of challenging. What does she say or do that is described as challenging? Make a list. (For real – write something down before continuing.)

Now, look at the actions on your list. Which are life threatening or risk imminent danger? Which are annoying or unpleasant? Which are inconvenient? Which are about one person's conception of doing something the right way?

Think about the effects on you when these events occur. What thoughts pop into your mind? Are any of them judgmental or blaming? Any name-calling as in *you little...*? Any competitive thoughts such as *you can't get away with this*? Maybe a dismissive thought such as *she's just doing it for attention*. Or, you might have a thought about your own authority such as *she just wants to be in control (but I am)*. How about thoughts of frustration like *here we go again*?

Maybe your thoughts aren't external judgments but reflect self-doubt. Maybe you're not sure about the right thing to do, but want to be seen as an able and effective caregiver. You want to be the person who can say *she's good for me, I don't have any trouble*.

There is no reason to be embarrassed about thoughts. Thoughts show up uninvited. We are only responsible for what we do after those thoughts arise. It's

important to notice thoughts because they shape our attitudes and influence our actions.

We also experience sensations. When the events you listed occur, what sensations do you feel? Clenched jaw? Headache? Tension in the belly, shoulders, neck? How about heat rising to your face? Sweating? Changes in heart rate or breathing? Some people take big sighs, others switch to shallow breathing and some hold their breath.

While all of this is happening in your mind and body, what happens to your emotions? Any frustration, anger, resentment, fear, disappointment, embarrassment, rage? In these moments, who is trying to understand her POV? Who is being curious, compassionate, thoughtful and creative? Who is thinking about her empowerment, self-direction and choice?

It's hard to be curious and judgmental at the same time; to be curious about what she might be trying to assert while blaming her. These functions are not easy companions in the brain or the body. It doesn't take long to create a new habit. The event—she said no or refused to do what she was asked. The reaction—tightness, heat, you brat, I'm pissed. After this happens a few times, we start having anticipatory reactions; the symptoms begin because it's almost time to see her.

If we don't learn to notice our own thoughts, sensations and emotions, we develop generalized symptoms and walk around tight, irritated and miserable. In western culture, when we talk about how other people effect us we use phrases like *she's driving me crazy*. The trouble with that logic is that she is not holding your jaw in a clenched position or any of the other symptoms that create your discomfort. She did not plant angry and blaming thoughts in your head, they just showed up. With all of this going on in body and mind, the relationship can take a turn for the worse based on trying to be in control and win. Bad things can happen.

If she had just done what she was supposed to do, I would not have had to... In the culture of compliance these kinds of rationalizations and justifications are often accepted (*because she's really challenging*). We create stronger behavior intervention plans and more negative consequences.

These sentiments expressed by caregivers are also the rationalizations and justifications of batterers. It has been described as 'entitled' thinking. More accurately, it's faulty thinking. When such explanations are accepted because the person has a disability, we are accepting what in another context would be called domestic abuse.

To create more safety and decrease vulnerability we can shift from a reaction cycle to a response cycle. This requires mindfulness. Mindfulness means being aware of thoughts, sensations and emotions while they occur. Imagine noticing thoughts of blame and judgment and being able to acknowledge them; that's judgment, that's blame, that's doubt. You can decide in the moment

<<< **It's hard to be curious and judgmental at the same time; to be curious about what she might be trying to assert while blaming her.** >>>

LINGER with this thought

whether the thoughts and emotions are helping or not helping you to support someone well. Are they helping you to appreciate her POV?

When you approach someone with negative thoughts and emotions, a fast beating heart and tight muscles, you are still responsible for what you say and do, and how much force or energy you use. If in that moment you deem it necessary to say something or put your hands on another person, you are responsible for those actions.

When thoughts are not helpful, acknowledging them and naming them begins to diminish their power. When they come back (and they will) you can acknowledge them again and again as often as needed. When you feel tension in your body, you can notice that she is not making you clench your jaw. The risk of not learning to notice or acknowledge your own symptoms of stress is that they influence what you do, sometimes in ways that do not respect the dignity and worth of another person.

It is a mistake to take our thoughts for granted, to move through our days on automatic, being reactive. You can decide what you do in your personal life. When you are a caregiver and accept the responsibility to support a vulnerable person, it means paying special attention to how your thoughts influence your actions.

Stimulating Curiosity about Her POV

Be yourself, you'll be great. This frequently offered tip to just be yourself is not always good advice. We might be using power and control and calling what we do behavioral interventions to achieve our goals rather than to support hers. There's a cartoon in which a child says *every time my Mom wants me to sit down and be quiet she stands up and yells*. Are we trying to teach people to stand up for themselves by training them to be compliant and non-thinking in their relationships?


To support the assertiveness of others we first have to accept that each person has a POV. Her desired outcomes are not about: what you would want; what you like; what you would do; what you think; your preferences or priorities; your risk tolerance; or your values. In order to understand and appreciate the POV of another person, we have to notice when we are assuming that we know more than we actually know.

As caregivers, maybe we tell ourselves what we need to believe about them (people with disabilities) or her. They or she need to be managed and kept safe. They or she need to do as they are told because it is our responsibility to protect them/her. **Two of the most compelling myths that support the culture of compliance are that if we can just achieve compliance she will be safe and healthy. Neither is true.**

When you read reports or hear about a person who receives support, actively read and listen for her POV. When you read diagnoses and characterizations, know that these are not her POV. A list of needs is also not her POV. *She needs constant verbal prompting and attention* might just mean that the reporter talks a lot.

Usable information refers to what helps us understand her POV. Each person is more than what others perceive as her presenting issues. Whether she has an intellectual disability, a mental illness, is on the autism spectrum or has a brain injury, what makes her laugh or smile? What are her interests? When is she stressed? What does she find soothing? This is usable information to support her well.

The characteristic of temperament is often ignored in the culture of compliance. Temperament can be understood as a general energy for life. Researchers often look at temperament on a continuum perhaps from cautious to adventurous or from timid to bold. Some people have a big bold temperament and others are more reserved. People might feel equally engaged but participate differently. Learning about a person's temperament might help you appreciate her POV.



<<< **Are we trying to teach people to stand up for themselves by training them to be compliant and non-thinking in their relationships?** >>>

LINGER with this thought

Most of us spend a lifetime adjusting to our own temperaments. Bold people have to learn that they can't be bold all of the time or others won't like them. Timid people have to learn to assert themselves or the world will pass them by. In the culture of compliance people are expected to accommodate how others want them to behave regardless of their temperaments. They are expected to be just enough – not too much and not too little. What is considered appropriate might change from one caregiver to another. People who receive support cannot simply be expected at all times to operate within someone else's range of what is appropriate.

People do not all experience sensory information, i.e., what we hear, see, feel, taste and smell in the same ways. One person's gentle touch might be felt as pain by someone else. One person's dim lighting is blindingly bright to another. In the culture of compliance we expect that what is acceptable for one should be good enough for everyone. So, someone can hear a woman say *that hurt* after he believed that he touched her gently on the shoulder and tell her that she was wrong. We could believe people when they tell us or show us their experience.

When people receive support, their communication is too quickly characterized. Some are labeled nonverbal. Others as having limited speech, echolalic speech, bizarre speech, manipulative speech, disruptive speech, perseverative speech or *she's just doing that for attention*. There are ways that each of us communicates in addition to or instead of speaking. There are ways that people know when we are pleased, annoyed, sad, frustrated or angry without our ever saying a word. Our actions don't even have to be intentional to be communicative. When you learn how someone participates at ease you are more likely to notice when she is experiencing stress (or the other way around).

Approaching a Locked Brain

One way that anyone can invite a locked brain to open is by wondering what it's like to be the person who receives support; to intentionally and actively wonder about her POV. A good question lingers and stimulates thought. Ask questions of yourself and others to invite thinking about this person's POV.

What do you see or hear ...?

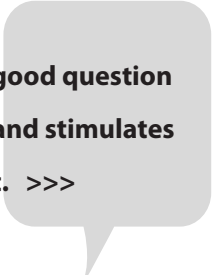
We assume that we know enough when we hear *she's an angry woman*. But when you ask *what do you see or hear that you're describing as angry* you might learn about one person that she cuts herself, and about another that she mutters, and about another that she stops interacting with family and friends, and about yet another that she yells at the dog or slams things around.

No matter which general words are used to describe someone, ask for specific action words. Someone is described as manipulative. Ask *what do you see or hear that you're describing as manipulative?* You might learn that someone is making a lot of phone calls. If someone is described as wild and out of control, or inappropriate or aggressive ask *what do you see or hear that you're describing as... wild and out of control, or inappropriate or aggressive?*

To answer the question what do you see or hear a person has to think. It causes the brain to work a little slower and more specifically. Trying to answer a question that requires thinking about one person in specific situations begins the process of unlocking a brain that has become stuck in generalities. The person has to recall some details.

You can ask for specifics about any general words. A person is described as doing nothing. Ask *what do you see or hear that you're describing as doing nothing*. One person described as doing nothing might be sleeping, another is cleaning her nails or watching TV and yet another is reading magazines. She is not doing what someone wants her to do and in frustration her actions are described as doing nothing.

Ask for detail about positive generalizations as well. She is described as lovely. *What do you see or hear that you're describing as lovely?* One goal is to get accurate and usable information about someone. The primary goal is to help someone unlock her or his thinking. You will know when someone understands the question when you have enough detail that an actor could play the part.



<<< A good question lingers and stimulates thought. >>>

When is she more likely ...?

In the culture of compliance people are used to behavioral language. They are used to being asked about causes, triggers or antecedents to the unwelcome behavior. The point being, maybe we can nip 'it' in the bud. Many believe they need a guaranteed cause and effect to answer the question. If they can't provide a guaranteed answer they might say *it comes out of nowhere*. It can certainly feel like someone else's actions come out of nowhere. The more times a person says it comes out of nowhere the more solid that answer becomes; brain-lock.


Human behavior does not come out of nowhere. Human behavior is a consequence of external conditions that can be observed or internal conditions that are not observable. Asking about context can help someone think about a person's POV. Ask, *when is she more likely to do the things you described as... belligerent (shaking her fist and yelling you can't tell me what to do)?* It doesn't have to be a guarantee. Asking about likelihood of occurrence instead of a guarantee can begin to open a locked brain. The question is worded to invite some evidence based speculation.

Asking someone to think about a week-at-a-glance calendar can also begin to unlock a brain. Are the actions of concern more likely to happen on certain days of the week, in certain places, during certain times of the day, during certain activities, when certain people are around, or when certain interactions occur? These questions require thought to answer and put the thinker further into considering another person's POV.

Minds that have been locked might still have trouble with this line of questioning. The answer that her actions come out of nowhere and the often harsh judgment or blame directed toward the person in question might not be shifting. Try a different angle. Ask *if you wanted to provoke it, what would you do?* Often a very stuck mind can offer ideas about what circumstances might provoke the unwelcome actions. Be clear in your own mind as you ask these questions that the goal is not to stop bad behavior. The goal is to understand what she is trying to assert and not default to using power and control to achieve her compliance.

It's surprising how often when asking how someone might provoke unwelcome behavior that the answers have something to do with uses of power and control. Provocation might be in the form of telling someone what to do or what not to do. A high rate of responses relates to physical proximity and touch—moving in too close or putting hands on another person.

Reports of physical and verbal aggression are often provoked by perceived threats of physical aggression by a caregiver. The paradox is that if you are a caregiver who knows that your intention is to be helpful, you don't think that someone might find you threatening. That is why it is so important to generate curiosity about the POV of the other person; your attempt to be helpful might be experienced as something else.



<<< **The goal is to understand what she is trying to assert and not default to using power and control to achieve her compliance.** >>>

What does she understand ...?

Now that you have a description of the person's actions—how they might look and sound—you can invite someone to respectfully guess about how she might understand the situation. Ask *when she...* (e.g. *elbows you in the ribs, calls you names, refuses to go to her room, tries to enter her kitchen*) *what do you think she understands about the situation? What do you think she understands about your relationship?*

In the culture of compliance we try to manage, modify or change behavior without first trying to understand the person's POV. This does not create more safety or reduce a person's vulnerability. It often precipitates more confusion and risks more confrontation.


What does Anne-Marie at 53 understand about being told when to go to bed, especially by someone she knows is younger than she is? What does she understand about someone blocking her way when she goes to the door so that she can walk to the convenience store? How should she understand it when she is told that she can go to the store two days from now if she does what she is told? When she shakes her fist and says *you can't tell me what to do* what does she understand about the nature of this situation and this relationship?

The goal in asking about a person's probable understanding of situations and relationships is to help someone think about the support relationship from both sides. We can learn to notice how power and control emerges in support relationships and begin to adjust our thinking. This might even lead to conversations about policies, procedures and practices.

What is she probably experiencing (sensations) and feeling (emotions)?

Caregivers talk about their tensions and frustration when someone is non-compliant. It's worth wondering what the person receiving support thinks, feels in the body (i.e., sensations) and feels emotionally. If you notice her shoulders are held higher than usual or her fists are clenched you can speculate that she is feeling tight. If her face is flushed and she is yelling you can speculate that she might be feeling heat. If tears are filling her eyes you can assume this is personally meaningful. If her hands are trembling you can see that her energy is building. If her voice is louder you can guess that she might feel strongly about the matter and maybe adrenaline levels are rising. This is respectful guessing. Use what you see and hear to make respectful guesses about another person's experience. Then ask, what emotional states might accompany the physical conditions you notice?

When trying to help someone achieve her goals (as compared to yours) having a best guess about how she is feeling matters even if it's just to acknowledge her POV. Imagine saying to someone who cares about you *I had a rotten*



<<< The goal in asking about a person's probable understanding of situations and relationships is to help someone think about the support relationship from both sides. >>>

day; and she says *get over it*. Would you experience that as helpful? What if she just acknowledged your POV and said *I'm sorry you had a rotten day*? Basic acknowledgment of what is true from someone else's POV, using her language, is a different experience than being told what to do or what to stop doing.

What is she trying to accomplish?

What assumption does a person have to make to answer this question? It must be assumed that the person has a POV; that she is trying to achieve something. In the culture of compliance people don't have intentions of their own; they have good behavior or challenging behavior. To offer a serious answer to this question requires a shift in thinking and acknowledgment that this person has a POV and intention.

With ease of language, what would she say?

To support vulnerable individuals well and ethically there is a responsibility to respectfully guess about their points of view based on some observable evidence. With ease of language, meaning a symbolic method of communication and the emotional well-being to express what she wants to accomplish, what would she say? What is she trying to assert that she wants, does not want, thinks or feels?

What could you do or not do to support her well?

With a respectful guess about another person's POV, you can actively decide what might be helpful. You can respond rather than react. In the culture of compliance someone often swoops in to intervene after an event. With a more mindful approach, you can think about how you might help a person:

- to understand a situation better;
- to participate more actively;
- to avoid or cope with stress; and
- to communicate more skillfully.

You might find that not doing something, i.e., not saying something, moving closer or touching, are more helpful choices from her POV. You might find that just acknowledging her POV is all that is needed in this moment.

LINGER with this thought

Practices that Might Invite Assertiveness

Provide a large sheet of paper and some color markers. Ask a person who receives support to consider any area of life: home, work, relationship, safety, health, etc. Invite the person to *represent (your life) on paper without words*. Their efforts—stick figures, scribbles or conceptual images—don't have to mean anything to you. It frees some people who have trouble with words to do something that does not initially require them to talk. For others it distracts them from the intensity of being asked a direct question. Here are some questions that might be used to talk about what she put on paper.

What do you want to say about (your life, your home, your safety)?

- Is there something else you *want*?
- What would you *change*?
- What might *make it better*?
- You said, 'I want...'. What *could* you do?
- You said, 'I could...'. With *ideas*, you can make a *plan*. What *will* you do?
- You said, 'I will...'. Do you want *help* with your plan? *Who do you trust*?
- What will you do *first*?

These questions can certainly be asked of someone who does not use paper and markers first when they are ready to talk about their lives. Please realize this is an approach, not a script. This activity is provided to help you think about how we can actively invite and support assertiveness. Consider the following before continuing with this activity.

Neutralize Yourself

Notice how you enter a room and position yourself in relation to the person you want to support. Notice how you establish your presence. Notice how you participate with words; who leads, who sets the pace and who does more of the talking. How could you neutralize yourself so that someone else feels prominent?

Ask Open Questions

Questions that can be answered with one word certainly have a place in our conversations but are more about the questioner's interests. Generally, a question that cannot be answered with one word leaves more room for the other person's POV.

Wait: Avoid Filling the Silence

If you ask an open question such as *what do you want to say about* (e.g., *feeling safe or feeling afraid*), notice how long you would usually wait for someone to reply. Do you wait 10 seconds and then try to help? To be helpful, maybe you ask a different question. *How are things at work?* Another 10 seconds and another question. *Have you been feeling anxious?*

Some people fill the silence to be helpful. Some assume the original question needed refinement. Others believe that enough time has passed and the person should have started to respond. You might try to fill the silence because you're uncomfortable.

Some people just need more time to process the question. To answer a question we have to do many things. We have to understand the question. We have to decide whether we trust the person asking. We have to weigh any risks in answering. We have to think. We have to find our own words to convey our thoughts. We then have to implement the mechanics of speech including positioning our tongues inside our mouths and regulating breath to create sound. There is also the person's experience in the culture of compliance. What has she been conditioned to do when asked a question? What if she fears saying the wrong thing or believes that there is a right answer?

When you ask an open question try waiting 30-40 seconds. This is much longer than most people wait. Remain as neutral as possible to avoid being a distraction; don't fiddle, don't move around, don't stare. Let the expression on your face appear relaxed and interested. This does not guarantee a reply but it sets the opportunity for those who need more time.

Create a Joint Neutral Reference

The eye to eye contact that usually accompanies being asked questions can feel like a lot of pressure. When you're engaging in something more than casual conversation, ask if it's OK to write what she says. Explain that you don't want to forget anything. Have a large piece of paper within full view between you. If she agrees to the paper she should be able to see it whether she reads or not. It becomes her property if she wants it.

As she talks, print her main comments on the paper. Let her express her POV without interruption. Any additional question you ask might change the course of her thought process. Continue to wait longer than usual for her to finish. When she either says that she is finished or her body relaxes from what you observed while she was talking, ask *is there anything else*.

This is not the time to refine her language. It is a safer assumption that she understands the words she used than words you might substitute. If she says something you don't understand, you can certainly ask her to say more about

that word later. Another important reason to use her words is to sustain her trust. When a person sees and hears her own words repeated there can be a feeling of acceptance. The culture of compliance is not big on acceptance and so this is a significant moment for many people who are used to being ignored or corrected.

When she finishes, ask if she wants to read back the notes or if she would like you to do that. In this way, she can tell you if she doesn't read, but doesn't have to. She can just have you read it.

You are not only learning about her POV; you are deliberately adjusting the power and control dynamic in your interaction. The goal is to create an opportunity for her to assert her POV in as safe a situation as possible without feeling interrupted or challenged unnecessarily.

Acknowledge Her Emotion

When a person is given the opportunity to express herself, uninterrupted, you might see or hear things that suggest a level of importance or emotion that is not reflected in her words. Acknowledge non-speech factors with curiosity. *I noticed that your voice got louder when you talked about... I think I saw tears in your eyes when you mentioned... your shoulders got tight when you said... Is there anything else you want to add?*

Listen for Wanting Energy

While listening for her POV, pay close attention for words or non-speech indicators about what she wants or does not want. When reviewing her comments, highlight these in particular. *I heard you say that you wanted ... or do not want ...* Create the opportunity for her to confirm, clarify or elaborate.

Empower Her

As she confirms what she wants or does not want; ask *what could you do about that?* Remember that your goal is to support her thinking and assertiveness, not to implement your plan. Empowering does not mean telling her what she should do. Your attitude and actions are still in neutral. Wait as described before and as she comes up with an I could statement, write it down. Ask, *any other ideas?* Write down as many as she can generate.

For those who are new to thinking about being assertive or advocating for themselves, this process can be valuable. She has reflected on her situation. She is considering what she wants or what she wants to change. Review her I could statements and invite her to consider them.

After she has ideas, ask *what will you do first?* This introduces prioritizing.

You could ask if there is anyone she trusts that she might want to ask for other ideas. When people with intellectual disabilities from around Wisconsin were asked *how do you know when you can trust someone*, a significant number of people said *when they don't tell me what to do*.

The issues she is considering can be about anything. The more practice a person has being assertive on small matters the more prepared she might be for the more significant ones.

Attitudinal Hindrances

You might notice a number of attitudes and understandings by caregivers that keep people who receive support vulnerable. Whether you are hiring, supervising, teaming or just talking with caregivers, notice who is grappling with their own understanding of power and control. **If we fail to notice and then fail to imagine what might happen in those relationships, we are contributing to the ongoing vulnerability of those who receive support.**

They... This population... My people... My girls... The self-advocates... Down's people... Autistics...

How can you get to know someone when your frame of reference is not about an individual but about a group? With respect and appreciation to all who are reading these words, what if I assume that you are all average. (That is meant in the nicest possible way.) Can I then assume that you all laugh at the same jokes; have the same levels of energy and temperaments? Is it reasonable to assume that you all learn in the same ways and at the same speed? Group-think results in missing the individual's POV. Group-think closes the mind around generalities. A relationship is about you and one person. She has a name, a personal history and her own POV.

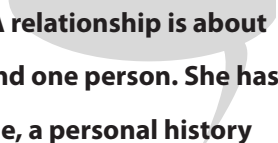
When do we put our foot down?

This question is asked in a variety of ways. It highlights the struggle many caregivers experience. It says *I understand that I have the power to make her do something. When does that kick in?* The question is most often asked in terms of responsibility. It suggests an understanding that I am supposed to make her do certain things, to comply. This understanding is an unfair and risky burden on both caregivers and those who receive support.

You're giving in to her... caving... coddling her. She'll never learn. Life isn't fair. She needs to know who's in charge.

These are not the comments of bad people. These were the comments of people who have a skewed understanding of their roles and responsibilities. When no one helps them refine their understandings, people receiving support are left in vulnerable and unsafe situations. Receiving support should not put a

LINGER with this thought



<<< A relationship is about you and one person. She has a name, a personal history and her own POV. >>>

person in a contest. Caregivers are not supposed to be winning. The person receiving support should not be made to feel like a loser.

Background checks are important but don't reveal a person's attitude. Among the people interviewed for a direct support role was a knowledgeable candidate. She could talk about many aspects of developmental disability and did so with great enthusiasm. When asked about her role as a coach and support person, she talked about motivational strategies and other ordinary interventions.

When given scenarios of actual support situations, she was quick with ideas about what she would do to ensure that *things won't spiral out of control like that again*. She did not indicate in any way that she was curious about the points of view of the individuals receiving support in the scenarios. Her comments reflected her belief that the caregiver should always be in control and that part of her job was to let those she supported know that she was in control. The hiring committee was so impressed (or distracted) by her confidence that they wanted to hire her and make her a supervisor. In relation to power and control dynamics she was a nightmare.

It's for her protection. It's for her own good. She needs to...

Each time you hear someone say, *you need to...* consider whose perspective that really represents. If you try this you might start imagining a lot of people saying back *no, I don't need to. You just want me to. They're not the same*. This is not to suggest dropping people in situations in which they are inexperienced with no instruction, support or accommodations. It is exactly the opposite. Support people well to have the kinds of learning opportunities, experiences and relationships they want.

Trauma Informed Interactions

The phrase trauma informed has come into more general use in recent years. It is most often used in reference to responses: trauma informed care, trauma informed services, trauma informed support and trauma informed therapy. If we are not careful, it will become part of our field talk rather than understood and implemented well. Maybe one way to keep it dynamic in caregiving and support relationships is to think about trauma informed interactions.

One of the questions posed early in this work about the vulnerability of individuals with developmental and other disabilities was, how is it possible that some of the most closely monitored people in our society are being abused? Have you ever thought *if I had known I would not have done that or if I had known maybe I could have been more supportive?* An informed interaction suggests that with awareness we can make different/better choices in our interactions.

With the awareness that someone has been sexually assaulted, I would make different decisions about the way I make contact. With awareness that someone has a history (or present) of emotional/physical abuse, I would make different decisions. With awareness that someone is a member of a group that has experienced discrimination based on culture, ethnicity, race, sexual orientation, ability, etc., I would make different/better decisions.

Every person has a POV. The intention of a caregiver is not more relevant than the POV of a person receiving support. Informed interactions mean that each person is allowed to define her boundaries and ask for respect in ways that help her feel safe. Informed interactions acknowledge that not everyone is able to assert herself skillfully—verbally, politely, quietly, calmly, at the right time... and so with awareness, we can try to understand what she is asserting and help her achieve her desired outcomes. **Informed interactions are about noticing how much control we take in everyday interactions; the forcefulness of our actions.**

A woman in her 40s stood up at a recent training about power and control in support relationships and said *my sister looks at me hard and says 'we're not talking about this any more' even though I haven't said anything yet. It makes me so mad.* If we want to support people well to set their own boundaries as well as to pursue their interests and relationships, we have to be clear with those who are in support and caregiving roles that they are not just enforcers and guards. We have to help each other imagine what it might be like to receive support.

- Think about someone you support or have supported recently. Remember when you wanted her to do something or stop doing something. You wanted

<<< An informed interaction suggests that with awareness we can make different/better choices in our interactions. >>>

LINGER with this thought

certain 'behavior' or 'choices' from her and they were not happening.

- Remember what you did to get what you wanted. What words did you use and how did you use them? Remember your volume and tone. Were there any conditions or implied threats to your words? Wonder how she might have experienced you. Might she have felt demeaned, insulted, threatened?
- Remember how you were positioned. How close were you? Were you standing, sitting, moving? What was her position? Which of you had more physical dominance? Would she have felt acknowledged and empowered or something else?
- Remember your wanting energy during these events. In addition to what you were saying and doing, what were you thinking about her? Were there any judgments or blame? What do you remember feeling (in your body) and how did those thoughts and physical sensations influence your emotion?
- What was your intention? Try not to pretty it up; just be clear. What did you want from her? Did you want her to be compliant or assertive?
- If you spoke to anyone else about this person and the events, how did you characterize her and her actions? What were the exact words you used?
- How did you explain your actions to yourself and maybe to others? What justification did you use for your actions?
- Consider the level of risk in the situation you've been thinking about. In terms of what you wanted and what the other person was trying to assert, what would have happened had you not taken the amount of control you did? Was there imminent danger associated with the situation?
- Now, if you learned that this woman had experienced sexual assault, domestic violence or stalking what might you have done differently?
- What if you don't know her back story but want to participate in the kind of relationship that truly empowers her because you don't want to participate in a culture of compliance that increases the vulnerability of people with disabilities?
- **What could you, will you, do differently in your interactions with this woman and with each of the people you interact with? Who else will you need to talk with in order to adjust what you do? When will you start?**

LINGER with this thought

