Communicating With and About People With Disabilities

About 1 in 4, or 61 million, U.S. adults reports having some form of a disability.[1] Disability is part of the human experience, but sometimes people use words or phrases that are insensitive and do not promote understanding, dignity, and respect for people with disabilities. Most often than not, this is not intentional, but is disrespectful just the same.

People-First Language

People-first language is used to communicate appropriately and respectfully with and about an individual with a disability. People-first language emphasizes the person first, not the disability. For example, when referring to a person with a disability, refer to the person first, by using phrases such as, "a person who ...", "a person with ..." or, "person who has ..."

These are some general tips you can follow:

- People-first language is the best place to start when talking to a person with a disability.
- If you are unsure, ask the person how he or she would like to be described.
- It is important to remember that preferences can vary.

Tips	Use	Do not use
Emphasize abilities, not limitations	Person who uses a wheelchair	Confined or restricted to a wheelchair, wheelchair bound
	Person who uses a device to speak	Can't talk, mute
Do not use language that suggests the lack of something	Person with a disability	Disabled, handicapped
	Person of short stature	Midget
	Person with cerebral palsy	Cerebral palsy victim
	Person with epilepsy or seizure disorder	Epileptic
	Person with multiple sclerosis	Afflicted by multiple sclerosis
Emphasize the need for accessibility, not the disability	Accessible parking or bathroom	Handicapped parking or bathroom
Do not use offensive language	Person with a physical disability	Crippled, lame, deformed, invalid, spastic
	Person with an intellectual, cognitive, developmental disability	Slow, simple, moronic, defective, afflicted, special person
	Person with an emotional or behavioral disability, a mental health impairment, or a psychiatric disability	Insane, crazy, psycho, maniac, nuts
Avoid language that implies negative stereotypes	Person without a disability	Normal person, healthy person
Do not portray people with disabilities as inspirational only because of their disability	Person who is successful, productive	Has overcome his/her disability, is courageous

1Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults— United States, 2016. MMWR Morb Mortal Wkly Rep. 2018; 67:882–887. DOI: http://dx.doi.org/10.15585/mmwr.mm6732a3l.

For more resources on disability inclusion, visit: www.cdc.gov/disabilities

Pro-Active Approach

Listed here are twenty common reasons (precursors) why people who are in a position of needing support, experience tension or distress. These were consistently described by various participants across all of the MTC seminars. Each precursor is paired with a brief description of how it may be addressed in a pro-active manner.

PRECURSORS	SUPPORT
1. **Physical Well-being** -Hunger -Fatigue -Thirst -Illness/pain	1. Within your powers as a provider meet the person's needs for food, drink, sleep and medical attention. More challenging aspects of the person's day may have to wait until these basic needs have been met. Guide and educate people toward an understanding on how diet and health can impact on feelings of tension/distress.
2. **Environmental Irritations** -Noise/disruption -Crowds -Lighting -Temperature	2. Pay attention to the environment. Seemingly minor factors such as a humming noise in the background or a blinking light can adversely impact people who have tenuous emotional control. Create or guide people to the environments that are relatively free of "irritants."
3. **Change in Routine** -Major changes -Seemingly minor changes	3. Provide a routine and structured lifestyle to individuals where this is a need. Be aware that some people require high levels of structure. Anticipate changes in routine and help the person prepare for the change (foreshadowing). When to begin foreshadowing depends upon the person. Help the person establish a new routine.
4. **Lack of Control or Choice** -It is common for persons needing assistance to experience loss of autonomy and self direction.	4. Be aware that sometimes we become too controlling in our role as providers. Develop a sensitivity regarding when to provide support and when to promote choice and autonomy. Be creative in how expectations are offered to the person. Use humor, offer choices, give people time, etc.
5. **Transitions** -The time between ending one activity and beginning the next.	5. Foreshadow an upcoming transition. Give the person something to do during the transition. Provide a positive focus for the new activity. Example: "Jimmy, the bus will be here in ten minutes; here is your tape player to take along." "Remember that you are going outside for gym class today."
6. **Ineffective Provider Approach** -Inconsistencies among providers -Improper Training -Lack of program coordination/ communication	6. Training and ongoing education. Provide written protocol for supporting persons who experience tension/distress. Allow all providers to have input in developing the protocol. Develop systems for ongoing communication amongst providers

PRECURSORS	SUPPORT
7. Attention Seeking -Intentionally acting out as a way to attain social attention.	7. Promote or teach appropriate ways to seek attention. Give people positive attention when they are doing well (catch people being good). Respond with a neutral presence when people are acting out to get attention. Avoid anger or excessive attention that may be reinforcing the acting out behavior.
8. Being Told "NO" -Having requests negated by providers in an abrupt manner	8. Try to avoid the word "no." Use redirection techniques. That is, instead of saying what the person cannot do, describe what they can do as an alternative. Example: "Can I go to the movies tonight?" Instead of "no," try something like, "Hey that sounds like fun, why don't we plan for Friday. Let's find the TV guide. I heard there is a holiday special on channel 5."
9. Having to Wait -Inability to understand passage of time -Inability to self-entertain during the wait	9. If possible, reduce long or excessive periods of waiting. Assist people wo can't tell time understand how long the wait will be (e.g., as long as the evening news). Provide ideas for activities during the wait.
10. Boredom/Loneliness -Caused by compromised life situations -lack of resources	10. Help people develop interesting lifestyles and social connections. Provide therapeutic relationships. Help people access the resources they require. Anticipate that this is not an easy task and requires ongoing effort.
11. Communication -Inability in expression of feelings -Limited verbal expression	11. Become skilled in your ability to augment ways for people to communicate needs or feelings. Become a patient listener, use reflective listening skills or be sensitive to non-verbal communication. When appropriate, use manual communication (signing) or picture systems.
12. Weather -Winter: cold/dark -Summer: heat/humidity -Weather changes -Full moon	12. Pay attention to where you are in the seasonal cycle. Typically winter and hot summers require increased attention to emotional support (attention, diversions, empathy). Influence people to dress appropriately for the weather.
13. Mental Health Issues -Affective (mood) disorders -Delusions -Dementia	13. Become educated on when tension/distress is in response to a mental health process. Know when to lower expectations or increase behavioral support. Provide situational counseling. Assure proper psychiatric/medical consultation.
14. Chemical Dependencies -Alcohol -Caffeine -Drugs -Cigarettes	14. Become educated to the signs of specific chemical dependencies. Be prepared to increase support or lower expectations when the person is "under the influence," experiencing adverse effects or withdrawal. Provide guidelines for use, promote education or treatment as indicated.

PRECURSORS	SUPPORT
15. **Psychiatric Medications** **-Lack of appropriate medication** **-Problems with dose** **-Side effects**	15. Develop a basic understand of what medications the person is taking. Know the intended positive effects and possible side effects. Assure that there is effective and ongoing communication with the prescribing physician.
16. **Low Self-Esteem**	16. Become sensitive to this dynamic. Develop ongoing ways that would promote improved self-esteem (compliments, acceptance, providing successful life experiences).
17. **Sexuality** **-Lack of sexual outlet** **-Inappropriate sexual expression**	17. Provide guidelines for appropriate sexual expression. Provide social skills training when appropriate. Offer empathy.
18. **Physical Limitations**	18. Provide empathy. Promote activities that are within skill level. Provide adaptation and accessibility whenever possible.
19. **Peer Conflicts** **-Fairness issues/jealousy** **-Sharing the same resources**	19. Within your powers as a provider, pair people who are compatible. Develop skills in mediation. Promote social skill training when indicated.
20. **Pre-existing Abuse Issues** **-The present situation is associated with a previous incident of physical or sexual abuse.**	20. When appropriate, read social histories that would include this information. Avoid support that would provoke memories of abuse. Refer to counseling or therapy when appropriate. Provide empathy.

Client Rights: Rights When Receiving Services

People receiving services for a developmental disability, mental health, or substance use have rights under Wisconsin law. These include rights related to treatment, records access, communication, and privacy.

Treatment

Every person receiving services has a right to:

- Information about their treatment and care.
- Not receive unnecessary or excessive medicines.
- Participate in treatment planning.
- Prompt and adequate treatment.
- Refuse treatment and medicine (unless it's court-ordered).

Record privacy and access

Every person receiving services has a right to:

- Challenge the accuracy, completeness, timeliness, and relevance of record entries.
- Have their information kept confidential.
- Not have their records released without consent. (This right that may be limited or denied)
- See their records.
- View medicine and treatment records. (This right that may be limited or denied)

Communication

Every person receiving services has a right to:

- Contact public officials, lawyers, or patient advocates.
- See, or refuse to see, visitors. (This right that may be limited or denied)
- Send or receive mail.

- Use a phone. (This right that may be limited or denied)

Individual

Every person receiving services has a right to:

- Be paid for work performed.
- Not be secluded or restrained. (This right that may be limited or denied)
- Reasonable decisions made on their behalf
- Refuse to work. (This right that may be limited or denied)
- Regular and frequent access to the outdoors.
- Regular and frequent chances to exercise.
- The least restrictive environment possible. (This right that may be limited or denied)
- Wear their own clothes and use their own belongings. (This right that may be limited or denied)

Privacy

Every person receiving services has a right to:

- A reasonable amount of storage space for their belongings. (This right that may be limited or denied)
- Not be filmed or taped without consent.
- Receive privacy while using the toilet and bathing. (This right that may be limited or denied)

Miscellaneous

Every person receiving services has a right to:

- Be free from retribution for filing a complaint.
- Be told of costs for their care.
- Be told of their rights.
- Be treated with dignity and respect by staff members.
- File a complaint about a rights violation.

- Refuse drastic treatments.
- Refuse electroconvulsive therapy.

Laws and codes

You can find more information here:

- Wis. Stat. § 51.30—Records(link is external)
- Wis. Stat. § 51.61—Patient Rights(link is external)
- Wis. Admin. Code ch. DHS 92—Confidentiality of Treatment Records(link is external)
- Wis. Admin. Code ch. DHS 94—Patient Rights and Resolution of Patient Grievances(link is external)

Last Revised: July 2. 2022

https://www.dhs.wisconsin.gov/clientrights/intro.htm

Client Rights Office

Department of Health Services
Division of Mental Health & Substance Abuse Services

http://dhs.wisconsin.gov/clientrights/index.htm

Community Programs Training 2012

RESPECTING CLIENT CHOICES

How do we promote, support, or tolerate individuals' lifestyle choices?

Choices may be related to individuals' perceptions of the five basic senses:

Hearing  Sight  Smell  Taste  Touch 

Choices can be influenced by family, cultural, spiritual or regional values. Is there any assessment or documentation of how a client expresses his/her choices?

When / how might staff try to promote (or influence) an individual's choices?

- Assessment of choices, and their function and value to the person
- Consider use of the "Essential Lifestyle Planning" process
- Proactive efforts to "open doors" to new experiences / activities

What might be needed to ensure support for individuals' lifestyle choices?

- Resources from within the system such as staffing, transportation, etc.
- Reasonable access to funds, and items necessary for the activities
- Some degree of compatibility on the part of persons living together

What does *it* mean to tolerate individuals' lifestyle choices?

- Acknowledge the client's right to make a choice / engage in an activity
- Review sources / scope of individual rights (§ 51.61 & DHS 94) [review Chapter 55 "Declaration of Policy" and DHS 94.24(3)]
- Avoid, as much as possible, the societal double standard tendency
- Document and address impediments / obstacles to clients' choices
- Treatment plans: Address choices and reminders of consequences
- Develop an individualized risk management approach for the issue
- Document criteria for, and parameters of, time and place limitations
- Document any "bottom line" health and safety risks, and limits

Other related issues:

- Tolerance and parameters related to "age appropriateness" issues
- Assess if / when a "choice" may be a cue to other issues or emotions
- Guardian should have involvement / input, not unilateral authority
- Goal of team consensus - with county and provider accountability

RECOGNIZING & RESPONDING TO EMERGENCIES

Recognizing Emergencies

Types of emergencies –

- Sudden Illness
- Injury

Your primary role includes –

- Recognizing that an emergency exists.
- Deciding to act.
- Taking action by calling 9-1-1 or local emergency number to activate EMS.
- Giving care until help arrives.

Preparing for Emergencies

- Keep important information about the client in an easily accessible location.
- Keep medical and insurance records.
- Find out if your community is served by 9-1-1 or a local emergency telephone number.
- Keep emergency telephone numbers available.
- Have a first aid kit readily available.
- Learn and stay up to date on first aid and cardiopulmonary resuscitation (CPR) skills.

Responding to Emergencies

Follow the Emergency Action Steps:

- **CHECK**
  - The scene and the victim.
- **CALL**
  - 9-1-1 or local emergency number.
- **CARE**
  - For the victim until EMS arrives.

Adapted from The American Red Cross
6/4/09

Rock County Human Services Department
Department Manual

Section: 0800 Behavioral Health Services No. 0882
Subject:
Title: CLTS Overnight Respite

A respite provider receiving CLTS/Children's COP funding, that is not a licensed foster home, must have a background check completed and approved before providing respite for a participant on Children's Long Term Support Waiver. The proposed provider must also have a face to face meeting with the CLTS Support and Service Coordinator. In addition, a home visit must be conducted by a CLTS service coordinator prior to the participant utilizing respite in that provider's home. Any person living with or staying in the home of the respite provider that is over the age of 18, must also have a background check completed and approved before the participant is able to utilize respite at that home.

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