

Community Support to People with Intellectual Disabilities and Challenging Behaviors

Paul White, Program Consultant
Community TIES

<https://cow.waisman.wisc.edu/ties/>



Considerations

Support Teams

Attitude Attitude

Attitude

- ▶ **Attitude Is Important**
 - ▶ Interesting and vital aspect of caregiving
 - ▶ Productive attitude - “Support, Care, Safety”
 - ▶ Natural to develop a “bad attitude”
 - ▶ Develop skills in sustaining a productive attitude

Best Practice

- ▶ Proactive plan - evidence based
- ▶ Yields positive behavior
- ▶ Buoyed by positive response
- ▶ Repeated practice
- ▶ Over time
- ▶ People get better

Attitude

- ▶ Paying Attention to Attitude
 - ▶ Person centered
 - ▶ Least restrictive
 - ▶ New ways to think and talk about people
 - ▶ Pro-active vs. reactive

Attitude

- ▶ Behavioral Challenges
 - ▶ Replaces “problem”
 - ▶ Accept as part of disability
 - ▶ Challenge is ours

Support Teams

- ▶ Caregivers Working Together
 - ▶ Team spirit
 - ▶ Systems of communication
 - ▶ Roles and goals
 - ▶ Communicative intent of behavior
 - ▶ “Support Plan”

Considerations

- ▶ Considerations in Providing Support
 - ▶ No quick fixes
 - ▶ Change is slow
 - ▶ Open mind
 - ▶ Identify pressure
 - ▶ Creativity

Considerations

- ▶ How the Disability Affects Behavior
 - ▶ Communication
 - ▶ Sensory organization
 - ▶ Stamina
 - ▶ Mental health issues
 - ▶ Physical limitations
 - ▶ Need for routine / structure
 - ▶ Cognitive / learning style

Considerations

- ▶ Consider the Environment
 - ▶ Create environments that can accommodate challenging behavior
 - ▶ Safety features
 - ▶ Use of restrictive measures

Considerations

- ▶ Sensory Regulation
 - ▶ Sensory Regulation Therapy
 - ▶ Sensory Diet

Considerations

▶ Stress Triggers

- ▶ What events / conditions contribute to challenging behaviors?
- ▶ How can we minimize the negative influence of these triggers?

Stress Triggers

1. Physical Well-being

- Hunger
- Fatigue
- Thirst
- Illness/pain

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 of how diet and health impact feelings of tension/distress.

2. Communication

- Inability to express feelings
- Limited verbal expression

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.

Stress Triggers

3. Change in Routine

- Major Changes
- Seemingly minor changes

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

Be aware that we can 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.

Stress Triggers

5. Transitions

The time between ending one activity and beginning the next

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

Training and ongoing education are important. 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.

Stress Triggers

7. Attention Seeking

Intentionally acting out as a way to attain social attention

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

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 movie 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.”

Stress Triggers

9. Having to Wait

- Inability to understand passage of time
- Inability to self-entertain during the wait

If possible, reduce long or excessive periods of waiting. Help people who 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

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.

Stress Triggers

11. Environmental Irritations

- Noise/disruption
- Crowds
- Lighting
- Temperature

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 environments relatively free of “irritants.”

12. Weather

- Winter: cold/dark
- Summer: heat/humidity
- Weather changes
- Full moon

Pay attention to where you are in the seasonal cycle. Typically, winter and summers require increased attention to emotional support (attention, diversions, empathy). Influence people to dress appropriately for the weather.

Stress Triggers

13. Mental Health Issues

- Affective (mood) disorders
- Delusions
- Dementia

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

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.

Stress Triggers

15. Psychiatric Medications

- Lack of appropriate medication
- Problems with dose
- Side effects

Develop a basic understanding of 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

- Self-deprecating
- Unwilling to try new life experiences

Become sensitive to this dynamic. Develop ongoing ways that would promote improved self-esteem (compliments, acceptance, providing successful life experiences).

Stress Triggers

17. Sexuality

- Lack of sexual outlet
- Inappropriate sexual expression

Provide guidelines for appropriate sexual expression. Provide social skills training when appropriate. Offer empathy.

18. Physical Limitations

- Frustration over limitations
- Self-conscious about limitations

Provide empathy. Promote activities that are within skill level. Provide adaptation and accessibility whenever possible.

Stress Triggers

19. Peer Conflicts

- Fairness issues/jealousy
- Sharing the same resources

Within your powers as a provider, pair people who are compatible. Develop skills in mediation. Promote social skill training when indicated.

20. Preexisting Abuse Issues

The present situation is associated with a previous incident of physical or sexual abuse

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.

Considerations

▶ Relationships

- ▶ Relationships are important
- ▶ Challenging behaviors can preclude good relationships
- ▶ Independence vs. interdependence
- ▶ Adapt counseling / therapy techniques
- ▶ “Situational Counseling”

Considerations

- ▶ Helping People Change - Behavioral plan
 - ▶ Not first consideration - sometimes contra-indicated
 - ▶ Humanistic
 - ▶ Good behavioral approach
 - ▶ Organize caregivers
 - ▶ Emphasis on positive
 - ▶ Thoughtful limits

Considerations

- ▶ Helping People Change - Organized Plan
 - ▶ How is challenging behavior meeting a need?
 - ▶ What behavior could work better?
 - ▶ How do we teach the new behavior
 - ▶ How do we motivate change?
 - ▶ Do we need to set limits? If yes, assure that limits are thoughtful and a form of caring (not punishment).

Considerations

- ▶ Helping People Change, continued
 - ▶ Relationship Guidelines
 - ▶ Catch people being good
 - ▶ Passion vs. Dispassion
 - ▶ Keep it simple

Considerations

- ▶ Expectations of Caregivers
 - ▶ Need to be realistic
 - ▶ Reduce pressure on both individual and caregivers
 - ▶ Sensitivity to amount of support

Considerations

- ▶ Compassion Fatigue - Caregivers
 - ▶ Occupational hazard
 - ▶ Shared care giving
 - ▶ Maintaining personal emotional equilibrium

Considerations

- ▶ Personal Emotional Equilibrium
 - ▶ Separate work and home
 - ▶ Caregivers support one another
 - ▶ Realistic expectations for self and individual
 - ▶ Time off
 - ▶ Humor
 - ▶ Diversions / avocations
 - ▶ Exercise / relaxation / spirituality
 - ▶ Acknowledge success

Considerations

- ▶ Supporting Dangerous Challenging Behaviors
 - ▶ Understand stages of behavior escalation
 - ▶ Know how to present effective support: personal space, body language, when and how to use words
 - ▶ Effectively deal with personal feelings of fear and anxiety
 - ▶ Safe, last resort, physical interventions

Considerations

- ▶ **Psychiatric Medications**
 - ▶ Find psychiatrists / physicians sensitive to the needs of people with intellectual disabilities
 - ▶ Caregivers represent the needs of individuals
 - ▶ Caregivers learn about medications' positive effects and side effects