Universal LifeStiles

Enhancing
Family - Provider
Relationships

by

Tom Pomeranz, Ed.D.





Session Goals

Participants of Enhancing Provider-Family Relationships will be able to:

- Adhere to the three core beliefs and principles in working with families.
- Explain the concept of unconditional positive regard and demonstrated the concept of unconditional positive regard.
- · Be aware of and avoid "Family Profiling".
- Explain why and how staff attitude and behavior are the most significant of all influences on families.
- Delineate eight characteristics of exemplary staff and demonstrate them.
- Identify four

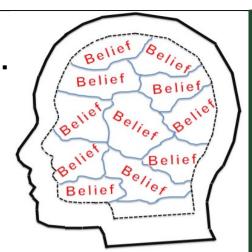
Session Goals (cont'd...)

Participants of Enhancing Provider-Family Relationships will be able to:

- State the "Listener's Code" and demonstrate it.
- Discuss the various components of "Connecting Emotionally" with families and demonstrate it.
- Identify the six potential causes of the appearance of defensiveness, hostility and rejection of agency staff by families.
- Demonstrate in respection regarding their relationship with families.
- Explain to families the difference in the roles of a parent to their adult child, a parent conservator to their adult child and a parent to their minor child.
- Detail four strate them.

Core Beliefs

It is crucial that professionals adhere to the following beliefs in working with families:



-It is not easy for any of us to be a parent; if you have a child (younger or adult) with a disability the task is much more challenging.

"It feels as though I have been thrown off a cliff into deep water and I don't know how to swim. All around me there are people who can help me, or teach me to swim. But I can't get to them and they don't help me, and I know that eventually I will go under"

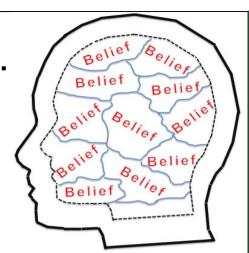
- Family carer

Scary Place Being part of the community can be a scary placefilled with hurt! Why would one want to be there? John O'Brien, Ph.D.



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- -Conflict between professionals and families is not necessarily a bad thing. Interpersonal disputes between families and professionals are an inevitable fact of life and usually can be successfully resolved if professionals respond appropriately.

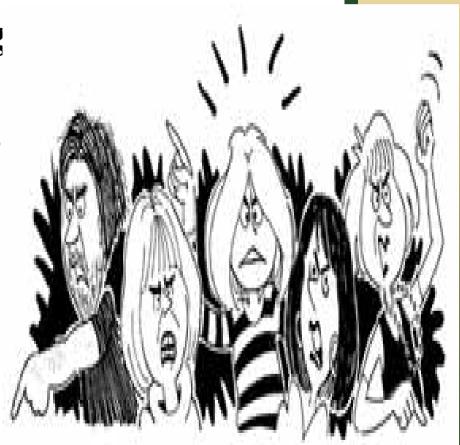


Parent/Guardian Conflict

When parents/guardians:

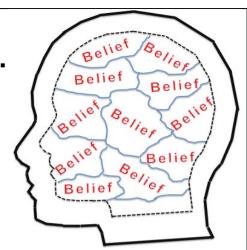
- Refuse to authorize medications
- Refuse to follow BSP protocols
- •Reinforce/incite interfering behavior in their ward
- •Verbally deride staff efforts
 It evokes frustration and
 exasperation in staff!

Management must address the issue!



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- -Conflict between professionals and families is not necessarily a bad thing. Interpersonal disputes between families and professionals are an inevitable fact of life and usually can be successfully resolved if professionals respond appropriately.
- -In the long run, families seem to hold a special respect and never forget the professionals who have hung in there with them faithfully, when the family was really struggling or particularly disagreeable. J. Dale Munro, MSW, RSW, FAAIDD, Regional Support Associates Working

with Families: Essential Skills Every Professional and Manager Should Know!; NADD Bulleting Volume XII Number 3 Article 1

Unconditional Positive Regard

This is an attitude of grace, an attitude that values families even knowing their failings. There is profound relief for a family to drop their pretenses, confess their worst feelings and discover that they are still accepted. In a good marriage, a close family or and intimate friendship, one is free to be spontaneous without fearing the loss of others' esteem. The Psychology Dictionary

To be fully embraced regardless of your demons, faults or failings!



Say, Do, Feel People will forget what you said. People will forget what you did. People will never forget how you made them feel! Maya Angelou



Different Yet The Same

Conflicted and troubled families of children (young and adult) with I/DD are equally distributed among all groups of people

unrelated to:

Nationality

Religion

Age

Gender

Race



Socio-economic status

Education

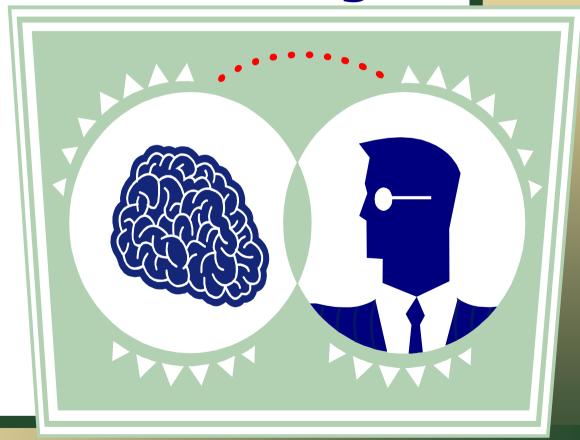
What do they have in common?

Family Profiling

Predetermining a family's abilities, interests and life outcomes without obtaining

insight, input, knowledge and options for (and from) the family.

Sherry J. Lusk, 2009



Core Beliefs (cont'd)

-There is a type of pain, grief, and trauma found in and experienced by families of people with disabilities. Many families have broken spirits and intervention must also focus on spiritual (not necessarily religious) healing. Spiritual approaches include showing compassion and kindness, helping families discover meaning in their suffering, offering hope that current circumstances can improve: and striving to find some degree of peace, joy, harmony and fellowship.

J. Dale Munro, MSW, RSW, FAAIDD, Regional Support Associates Working with Families: Essential Skills Every Professional and Manager Should Know!; NADD Bulleting Volume XII Number 3 Article 1

It May Not Be About You

"Hurting people" hurt people.



John Maxwell

Hurt People

Hurt people hurt people. That's how pain patterns get passed on, generation after generation after generation. Break the chain today. Meet anger with sympathy, contempt with compassion, cruelty with kindness Greet grimaces with smiles. Forgive and forget about finding fault. Love is the weapon of the future.

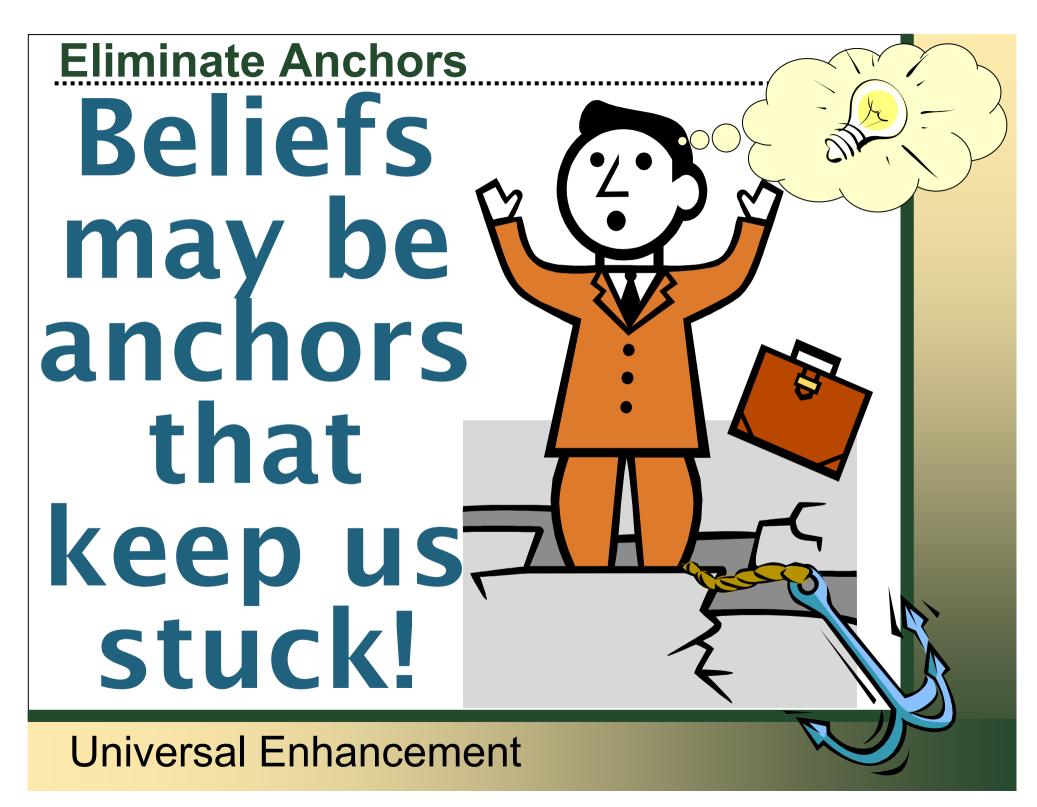
-Yehuda Berg

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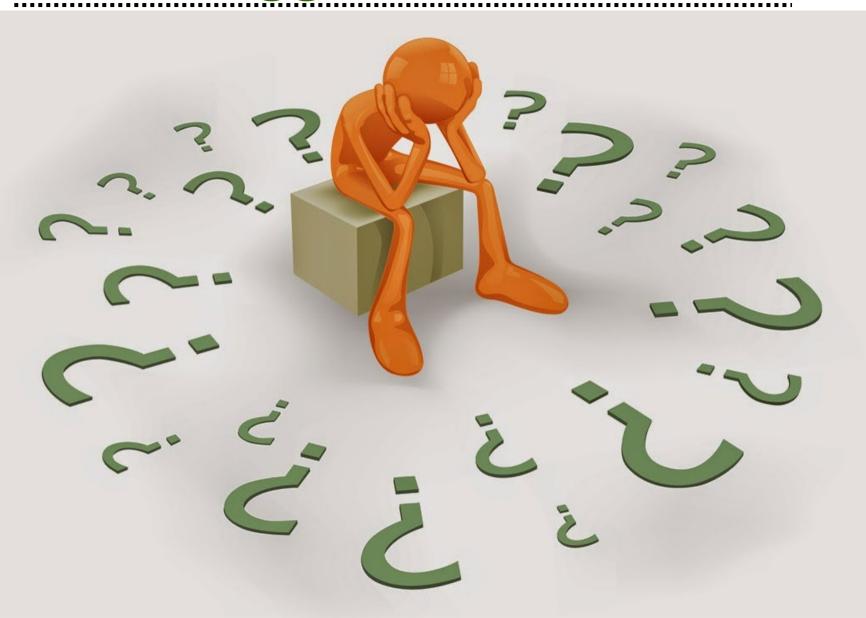
-Having a child with a developmental disability, despite an urban legend to the contrary, does not necessarily destroy the marriage and a family.

J. Dale Munro, MSW, RSW, FAAIDD, Regional Support Associates Working with Families: Essential Skills Every Professional and Manager Should Know!: NADD Bulleting Volume XII Number 3 Article 1





The Struggle Within Us

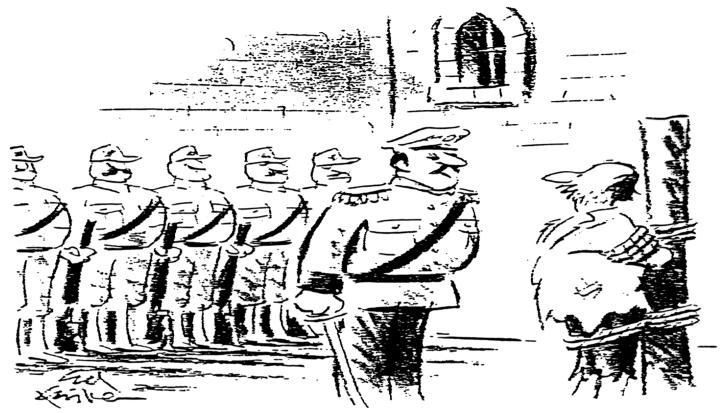


Overcoming Obstacles

Staff who effectively overcome their life's obstacles, are better prepared to assist families in overcoming their challenges.



Preventative



"We want you to know that this is just a preventative execution."

I can and I will control a family's behavior!



Focus Inward Altering the behavior of others necessitates modifying our own.

Our Attitude...

...and behavior are perhaps the most significant of all influences on families.

Do you:

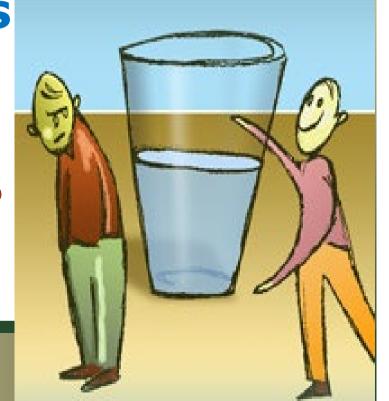
listen engage in humor

smile give options

speak softly have fun

and...

celebrate the efforts of the families!



Exemplary Staff

Sensitive and effective Support Staff, their supervisors and clinical staff who serve as their resources need "fire in their bellies." Check those characteristics depicting how you present yourself to families:

Energetic
Happy
Motivated
Inspired
Excited
Enthusiastic

Fincouraging
Proud
Self Confident
Willing
A leader
Determined





Exemplary Staff (cont'd.)

or...

- □ Tired
 □ Reluctant
- Depressed Inflexible
- Discouraged Angry
- ☐ Indifferent ☐ Passive/Aggressive
- □ Spent
 □ Needy
- Pessimistic Cranky

Which staff would you prefer to interact with?

Lack of Understanding

To refer to a family as uncooperative or undermining is to admit we don't understand them.

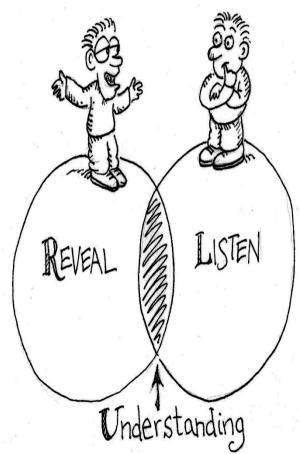
The mom is just plain stubborn. She refused to approve the plan!



Maintain A Positive Relationship

Challenging family members can make maintaining a positive relationship difficult.

• Be proactive; do not let a potential issue develop into a major conflict.



Are You Somebody?

I used to ask "why doesn't somebody do something about that family?" Then I realized that I was somebody!



If It's To Be - It's Up To Me!

Neither Boards of Directors, Executive Directors, Managers, Supervisors or your colleagues can make it happen-

It's up to you!



I Can!

Sources of Conflict...

...develop because of a difference(s) of opinions between families and providers. For example, differences in:

Goals



-- R. Blake and J. Mouton

Goals - Conflict

Interpersonal conflict can ensue between families and providers as a result of conflict over goals: desired by/for the support recipient:

- Seeking employment
- Moving away from family into own home
- •Pursuing an intimate sexual relationship
- •Coming out identifying oneself as a member of the LGBTQ Community
- Converting their religion



Sources of Conflict...

...develop because of a difference(s) of opinions between families and providers. For example, differences in:

Goals Values



-- R. Blake and J. Mouton

Values - Conflict

Interpersonal conflict can ensue between families and providers as a result of conflict over values: desired by/for the support recipient:

- •Adult status seen as a child in an adult body
- •Having friends a community presence
- •A life of purpose giving and doing for others
- The right to risk vs over protective

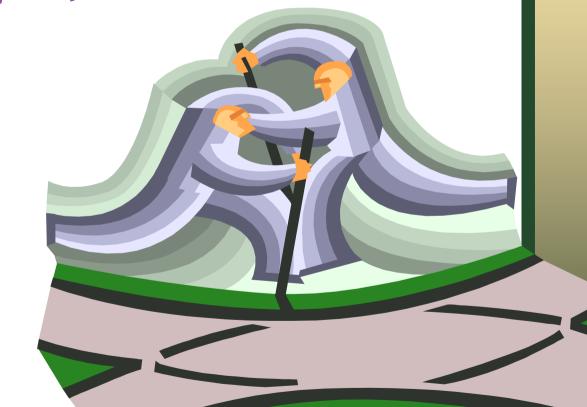




Sources of Conflict...

...develop because of a difference(s) of opinions between families and providers. For example, differences in:

Goals Values Facts



-- R. Blake and J. Mouton

Facts - Conflict

Interpersonal conflict can ensue between families and providers as a result of conflict over facts: desired by/for the support recipient:

- Frequency and intensity of interfering behavior
- Sexual activity
- Diagnosis
- Duration of sleep and awake periods



Sources of Conflict... ...develop because of a difference(s) of opinions between families and providers. For example, differences in:

Goals
Values
Facts
Methods
- R. Blake and J. Mouton



Methods - Conflict

Interpersonal conflict can ensue between families and providers as a result of conflict over methods: desired by/for the support recipient:

- Strategies to address conduct issues in a Behavior Support Plan
- Plan for managing weight, exercise, diet, group meetings, etc.
- Protocols to support actual participation in daily routines i.e. cooking, laundry, house cleaning
- Procedures to gain independence in toileting, facilitate communication i.e. sign language, tablet, pictographs, etc.



Address The Conflict 100 % Anticipation Conscious but unexpressed difference Discussion Open dispute

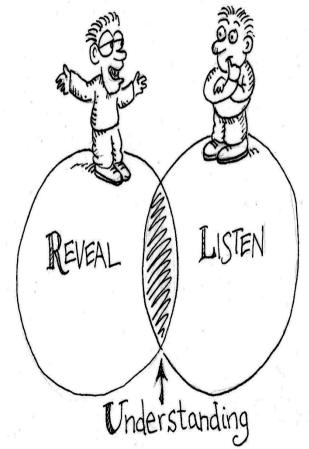
Open conflict

The greatest potential to influence conflict is at the anticipation phase and the least potential to influence conflict is at the open conflict stage.

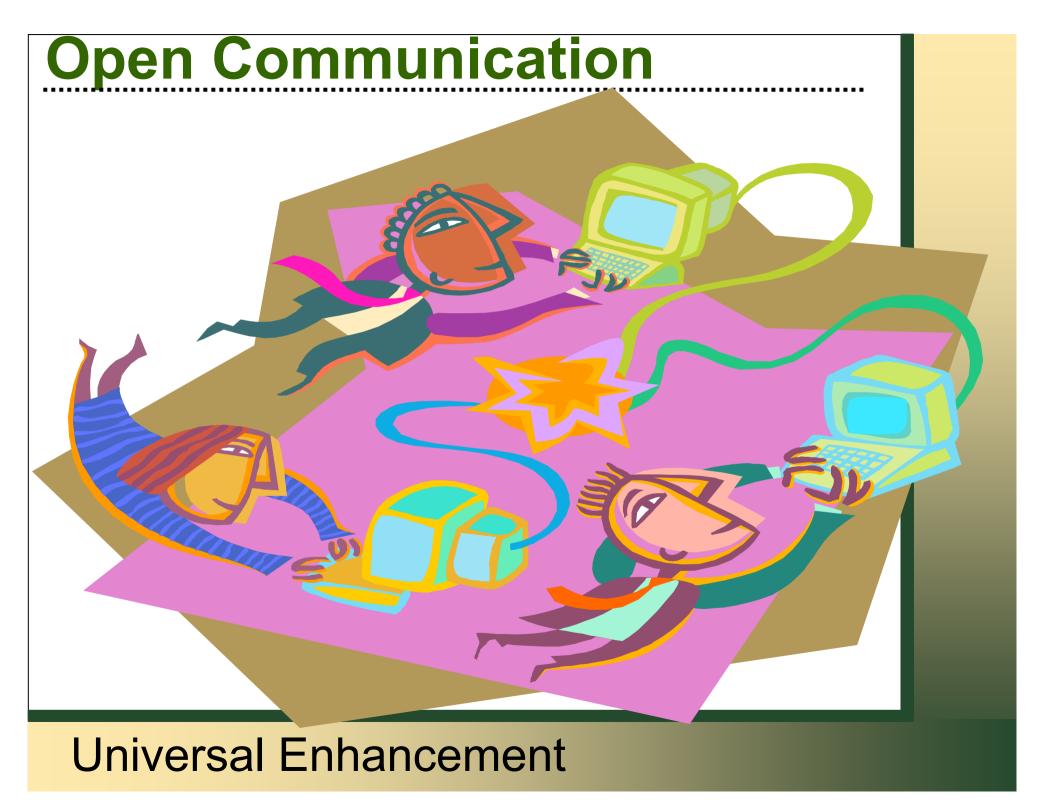
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- Strive to understand the other person's perspective and keep lines of communication open



Good Listener Listener's Code: Never Pass Up The Opportunity To Be Silent **Definition of Listening:** Quiet



Mentor Families...

...help families learn and grow – by listening to what they have to say, identifying emotions which they cannot.



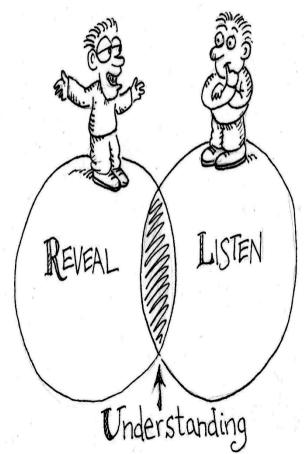
Mentors assist the family in making life choices (without judging), which will enhance their life and the life of their family member with disabilities.

Conflicted Communication I know you believe you understand what you think I said, but I am not sure you realize what you heard is not what I meant. Universal Enhancement

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- Strive to understand the other person's perspective and keep lines of communication open
- Remember that a family member's reluctance or resistance likely has nothing to do with you



Take Care of My Feelings

 You are not responsible for someone else's feelings or behaviors

 Do not expect others to take care of your feelings

 Do not accept blame and don't give it

 Set reasonable limits to protect yourself

You have a right to say "no"

Value Yourself

When you treat yourself kindly it is a good indication that you will treat families kindly as well. It is a statement that you have "water in your well."

Know when to say no
Take time off from work for
renewal

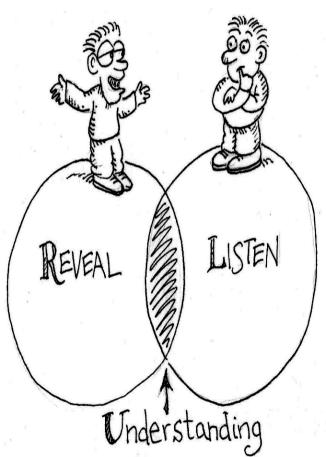
Your personal life must come first

Stay home when ill

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- Be proactive; do not let a potential issue develop into a major conflict.
- Strive to understand the other person's perspective and keep lines of communication open
- Remember that a family member's reluctance or resistance likely has nothing to do with you
- Consistently enforce limits and continue to work on building positive relationships



Saying No says I Care!

When you allow families to place demands on you that are not reasonable, a cycle of mediocrity is nurtured.

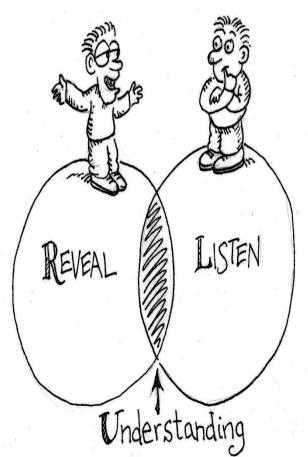
Set boundaries!



Maintain A Positive Relationship

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- Strive to understand the other person's perspective and keep lines of communication open
- Remember that a family member's reluctance or resistance likely has nothing to do with you
- Consistently enforce limits and continue to work on building positive relationships
- Be willing to be flexible in some situations



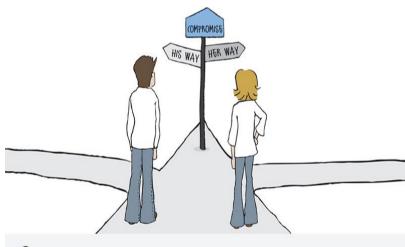
Flexiblity

"Take what you can get closest to what you want."

Compromise

is *not* an act of weakness.

It demonstrates that you care for something or someone beyond yourself.



Relationship-Architecture.com

-- Lee Graber

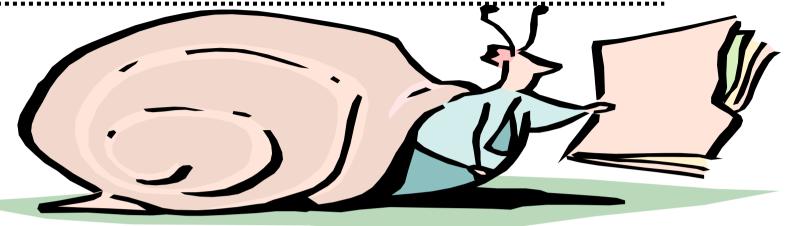
Offer Options When families refuse, don't give ultimatums! Offer Options!



"If You Make It A Struggle - YOU Will Lose." Lee Graber







Move slowly
Be flexible
Praise cooperation
Look at what's right

Potential Staff Barriers

- Staff emotional status
- Unsure of their role with family
- Assume a "one-up" position
- Overwhelmed with tasks at hand
- Feelings of being rejected by family
- Lack of empathy for family

Jan Finch, LCSW, Ph.D. Working with Challenging Families



Don't Be Defensive

Staff in any role (e.g.DSP, clinical, management) may perceive their interactions with a caring dedicated parent as:

Threatening or Demanding

Rejecting or Oppositional

Unrealistic or Unappreciative

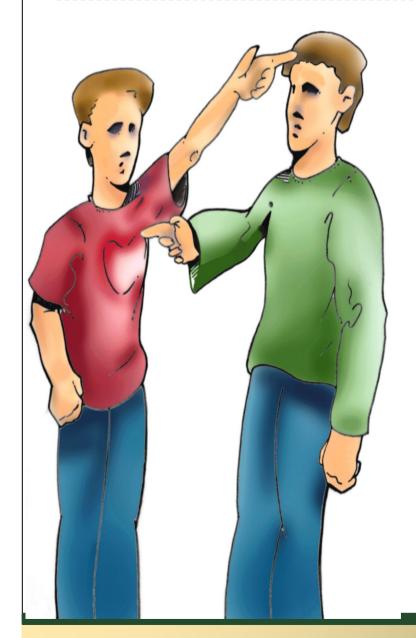
These feelings may be because the parent is:

- disappointed with a particular outcome or condition
- having an expectation requiring a significant effort or sacrifice by staff
- Not acknowledging their appreciation for staff effort expended
- Refusing to approve medication regimes, behavioral interventions, dietary restrictions or clinical referrals
- Struggling with a sense of guilt with their son's/daughter's condition

Don't be defensive or argumentative.

Be introspective - you must appreciate the fact that both you and the parent want what is best for their son or daughter.

Requirements



Intellect and empathy are core requirements for effectively supporting families.

Be Empathetic

Empathy is...

seeing with the eyes of another, listening with the ears of another, and feeling with the heart of another.



Connect Emotionally

Each individual defines what an emotional connection means to him/her. The following are some basic characteristics that are Universal:

•An emotional connection is a bundle of subjective feelings that meld – creating a bond between two people

- •The word emotional means to arouse strong feelings
- •The in-depth feelings may be happiness, disappointment, rejection, sorrow, guilt or any of thousands of emotions that humans experience



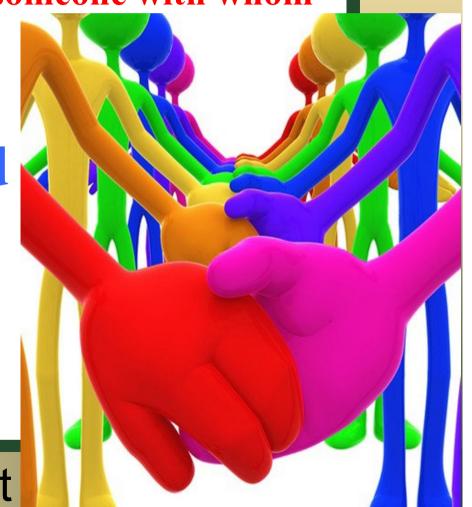
Connect Emotionally (cont'd)

•A connection is a bond, a link or tie to something or someone

•Pair the two words - emotional and connection and it transitions to a bond or tie to someone with whom

a set of emotions are shared

Forge an emotional connection — to build a strong and enduring relationship!

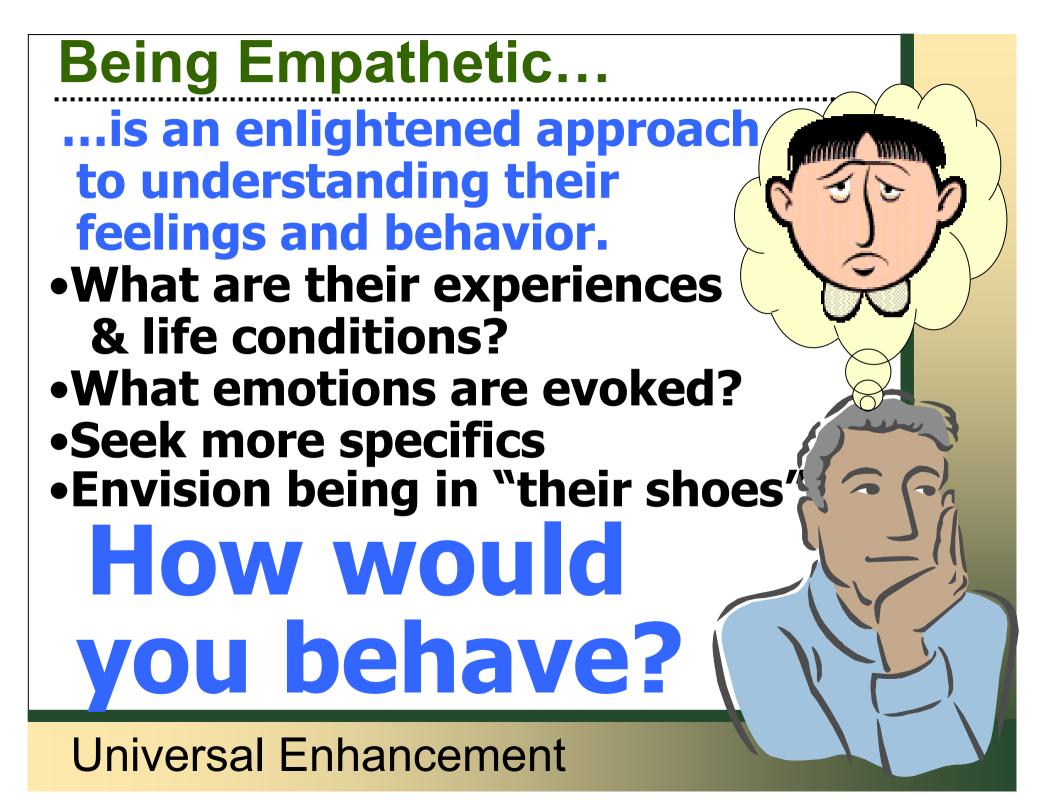


Cognitive vs Affective

Knowing what is sensitive behavior does not assure sensitive behavior!

Sensitivity necessitates that the cognitive process be evoked by emotive (affective) influences.





Kindness

Be kind, for everyone you meet is fighting a hard battle.



Plato

Treating Others Treat everyone as

though they are

who they wish they could be.



Gandhi

Potential Family Barriers

Appearance of defensiveness, hostility and rejection of agency staff may have many

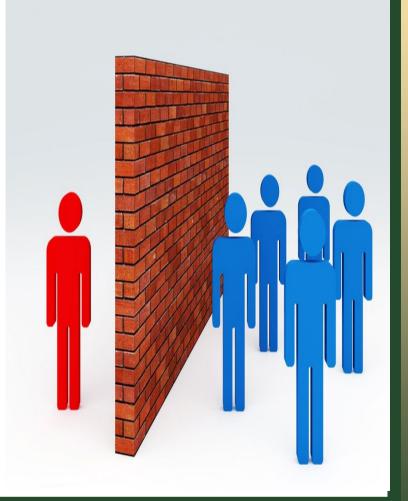
causes:

Feelings of intrusion
Feelings of guilt for family
member's problems
Denial that there is a problem
Pressure from other family
members

Cultural issues

Others just don't understand what they are going through

Jan Finch, LCSW, Ph.D. Working with Challenging Families



Focus On What Matters

Issues
Or
Tasks



Bond With Families

When we bond with families they are less likely to behave in a way to disappoint us. How do we need to behave in order to bond?



Do Something Fun

Doing an activity in which both staff and family can share a common experience of enjoyment may alter the direction of the relationship.

- Go for coffee
- Take a walk together
- Meet at the park
- Work on a project together (e.g. fund raiser)



Be Involved!

If you're not at the table, you're on the menu!

Washington political saying; unknown origin

Snapshots at jasonlove.com



"Ah, man, Stu again?"

Cooperation



Always Remember...

Your ability to work successfully with families depends on you!

You are an important person!
Remember to take care of you!
Take time to relax before you visit with your challenging family!

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Self - Disclose

It is OK to admit to a family that:

- You are tired
- You have other families to serve
- You are having a bad day
- That sometimes you do run a little late, but will call to let them know next time
- You care about their family member
- You want only the very best for them
- You are human too
- You may need to agree to disagree and move on

Taken in part from Jan Finch, LCSW, Ph.D. Working with Challenging Families



Reflect

You must be introspective and realize that you are not alone.

Reflect on the situation -

• What is going right with our conversation with this family?

What is going wrong?

• Is there something about this family that pushes our buttons?



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Button Pushers

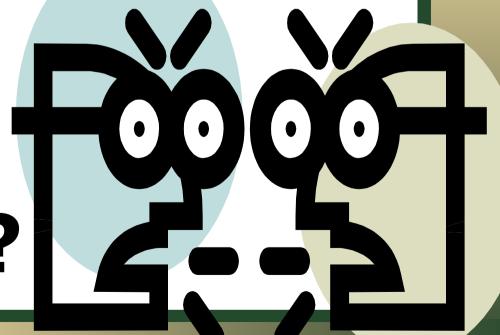
Remember, more often than not, families may have difficulty expressing their primary emotions (fear, frustration, guilt, etc.); thus their behavior may be an expression of those unmet needs!

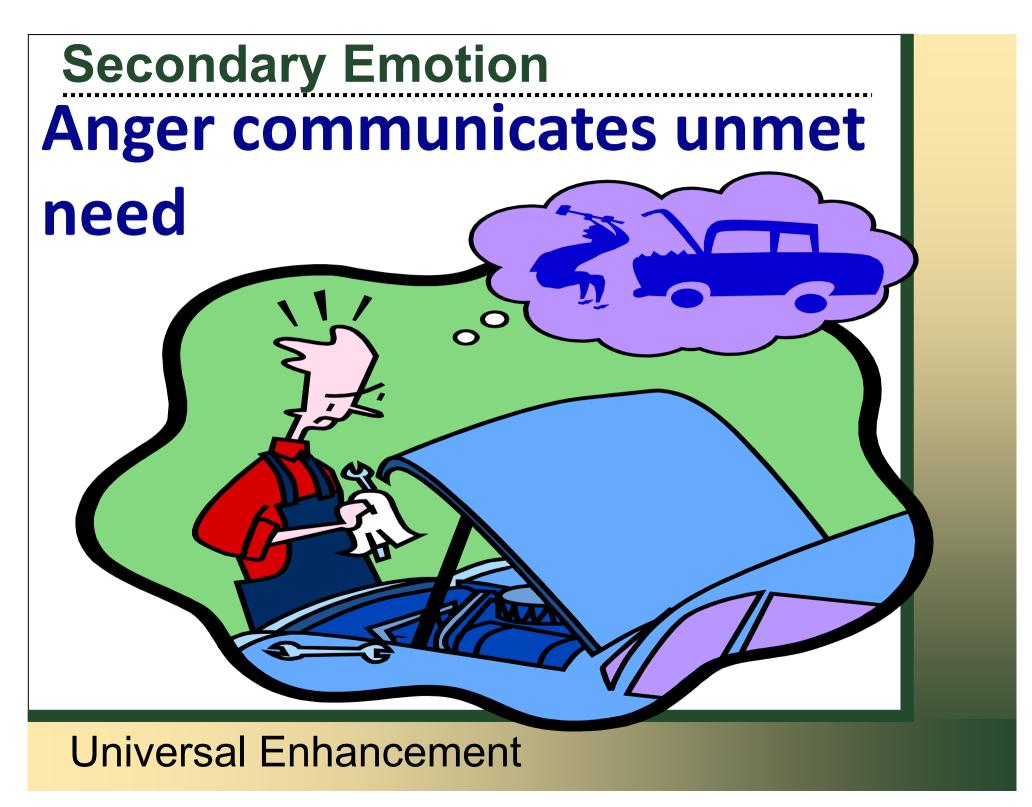
Have you made my son's doctor appointments yet?

The Worst In Us

Obstinate, malcontent and aversive people bring out the worst

Can you bond with them?





Secondary Emotion

Anger is a secondary emotion to:

Fear

Frustration

Grief

Anxiety

Disappointment

Paranoia

Inferiority

Confusion

Suppression

Repression

Depression

Panic

Loneliness

Hysteria

Aggravation

Secondary Emotion (cont'd)

Disillusionment
Subjugation
Impatience
Rejection
Hopelessness
Remorse

A family's inability to manage these emotions may result in anger.

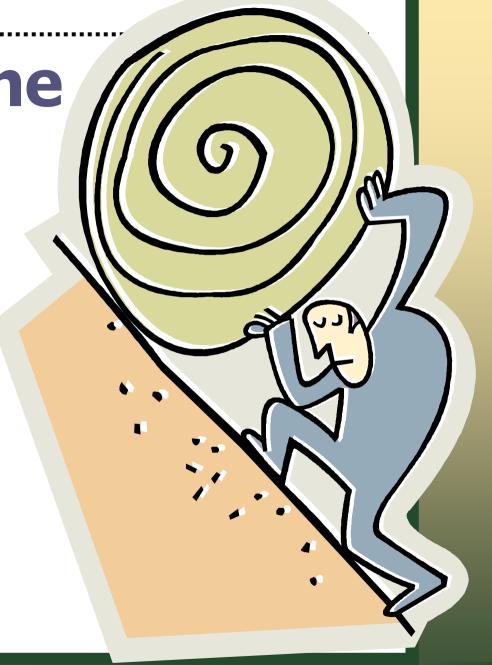
Overwhelmed Jealousy Ineptness Sadness Deprivation

Exhaustion



The Challenge

Identifying the family's unmet needs does not assure that one is either able or willing to



Universal Enhancement

meet them.

Don't Inflame When families are resistive to support approaches for their family member.... frustrating alienating angering provoking or denigrating families, will not resolve the issue.

Reflect

You must be introspective and realize that you are not alone.

Reflect on the situation -

- What is going right with our conversation with this family?
- What is going wrong?
- Is there something about this family that pushes our buttons?
- Is there a way to reframe the situation to improve the relationship?

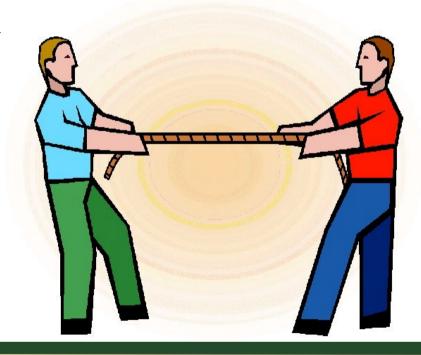
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What Are My Options?

When the relationship is not going well:

- · Speak with your supervisor early on
- Check with others on the team
- Reflect with your supervisor and/or peers about what you might do differently
- Don't be afraid to ask for the family to be reassigned to another staff we can't be expected to "click" with all families.



Jan Finch, LCSW, Ph.D. Working with Challenging Families

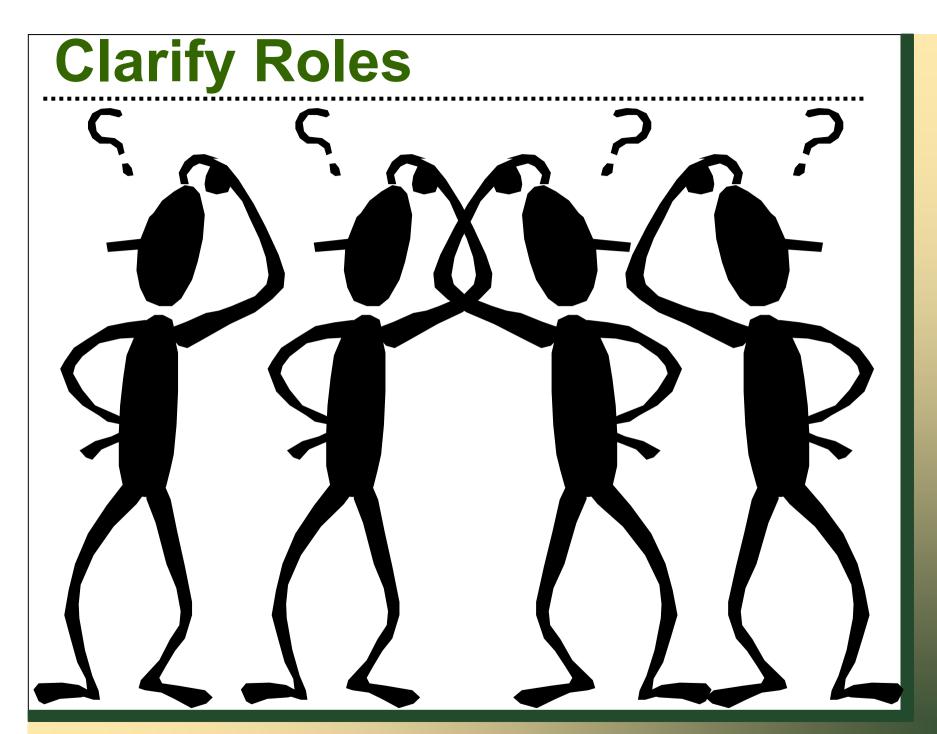
Strategies

We must develop strategies to assure that we can

"emotionally connect" with the family. Remember, they <u>in fact</u> need our help and support.

Explain your role



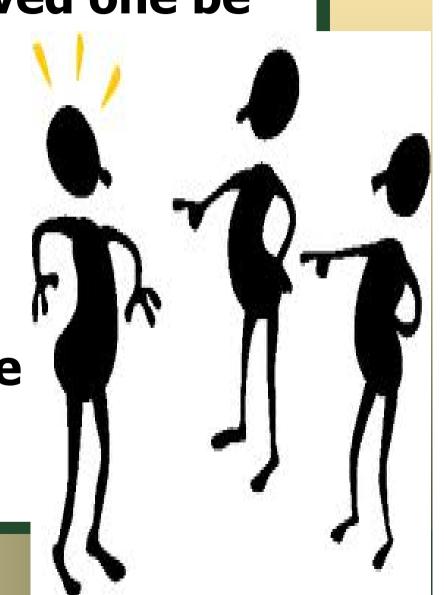


Establish Expectations

Families commonly expect (if not demand) that their loved one be cared for; served versus supported!

Don't blame the families!

Our services system has done a remarkable job in nurturing these expectations.



Strategies

We must develop strategies to assure that we can

"emotionally connect" with the family. Remember, they <u>in fact</u> need our help and support.

- Explain your role
- Explain what we expect of them



My Entitlement

A concept meant to encapsulate the social or economic beliefs that a government should provide access to goods or services.



The connotation of the phrase often implies that the recipients of government entitlements are individuals that do not deserve to receive such benefits or entitlements. Wikipedia

Communicate

I think I'm a mushroom 'cause they keep me in the dark and feed me manure.



Guardian's Confusion Many guardians and providers are confused--guardian's are not bestowed unlimited rights by the court. They are delegated duties and responsibilities!

Confusing Roles

It may be confusing to some parents — the role of a parent to a minor vs. a guardian to an adult ward.

Wearing makeup

Engaging in masturbation

Decorating your room

Choosing clothing

style

Choosing a hairstyle

Expressing religious

preference

This is the domain of the parent to a minor; not the guardian of an adult ward.

Guardian's Expectations...

...can serve as a self-fulfilling prophecy either negative or positive!

Their expectations should not be determined by a diagnosis!

It is essential that guardians dream about opportunities for their family members enhanced quality of life.



It's A Choice

Destiny is not a matter of chance, it is a matter of choice.

William Jennings Bryan



Preferred Future

Identifying and seeking a preferred future is the essence of a quality life.



The greatest obstacle to discovering the shape of the earth, the continents and the ocean was not ignorance, but the illusion of knowledge.

Daniel J. Boorstein

Avoid Blaming Families Be a support and role model for parents and other family members:

•Do parents observe staff interacting with their son or daughter as an adult?

 Do staff provide parents with a list of suggested gift items that are appropriate?



 Do staff share with parents accomplishments of their son or daughter he made the bed, earned a pay check, participated in cooking?

Strategies

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"emotionally connect" with the family. Remember, they <u>in fact</u> need our help and support.

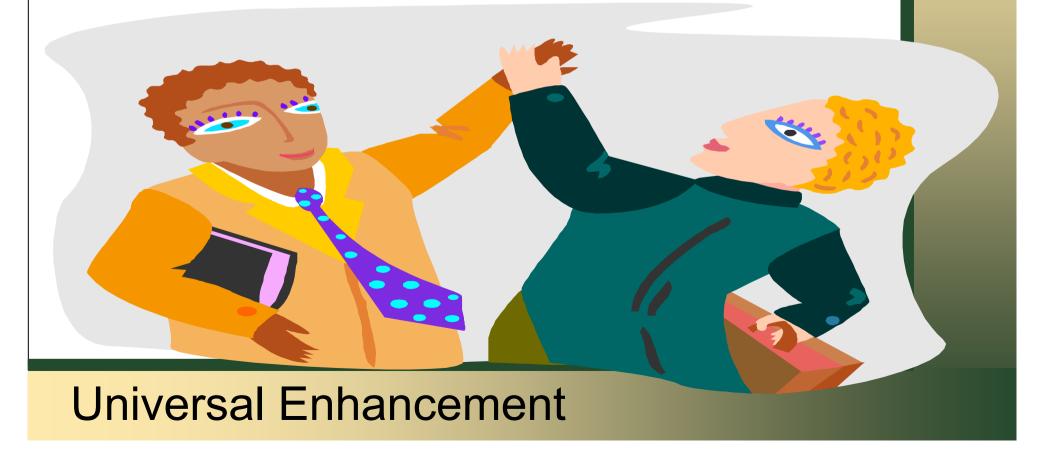
- Explain your role
- Explain what we expect of them
- Start where the family is
- Listen to their concerns before starting
- Notice something positive and comment



Jan Finch, LCSW, Ph.D. Working with Families

Positive Focus

Celebrate the family's successes and accomplishments in supporting their family member, instead of just looking for problems. Then they will be more willing to listen and accept change.



Strategies

We must develop strategies to assure that we can

"emotionally connect" with the family. Remember, they <u>in fact</u> need our help and support.

- Explain your role
- Explain what we expect of them
- Start where the family is
- Listen to their concerns before starting
- Notice something positive and comment
- Ask what their greatest success and greatest frustration were

Jan Finch, LCSW, Ph.D. Working with Families



Be Celebratory If you don't have You can't give it! Universal Enhancement

Strategies (cont'd)

- Acknowledge how difficult it can be for that parent
- Change the location of the visit (away from your office or at least sitting beside them not behind a desk)
- Find out what the parents' goals are for themselves



Unreasonable Requests

When families ask for things that are not available, "professionals" may determine the request inappropriate.



Strategies (cont'd)

- Acknowledge how difficult it must be for that parent
- Change the location of the visit (away from your office or at least sitting beside them not behind a desk)
- Find out what the parents' goals are for their family member
- Find resources for what they want
- Work on something together tasks of cooperation

Jan Finch, LCSW, Ph.D. Working with Families



Family Intervention



An intervention is a deliberate process by which change is introduced into peoples' thoughts,

feelings and behaviors. The overall objective of an intervention is to confront a person in a non-threatening way and allow them to see their self-destructive behavior and how it affects themselves, his or her family, friends, coworkers, etc.

Family Intervention (cont'd)

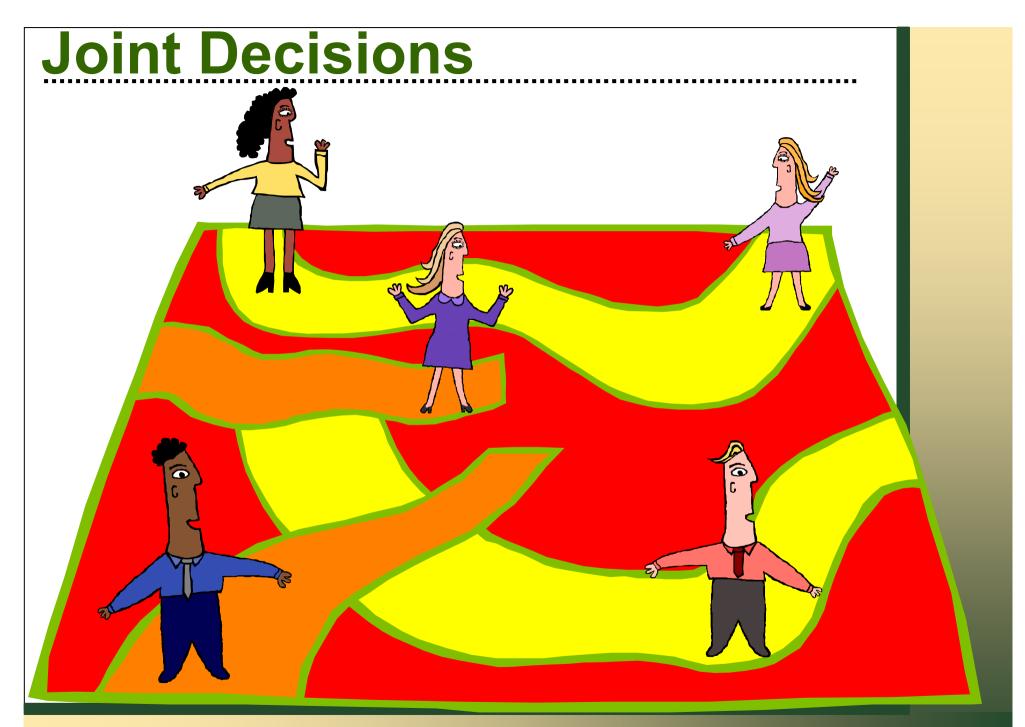
- Consider having someone skilled to facilitate the intervention and keep it focused.
- Prepare for and anticipate a hostile or emotionally confronting response from the Focus Person.
- Though the intervention may not be successful at the time it is conducted, the Focus Person may process the discussion later on and modify their self-defeating behavior.
- It is critically important that the right people are invited to and attend the intervention.
- Selecting a venue for the intervention must be carefully considered.



Family Intervention (cont'd)

- The stronger the emotional connection with the Focus Person the more effective the intervention.
- The purpose of the intervention is to breakthrough the Focus Person's denial of their conduct so that he or she can experience a moment of clarity, admit the depth of the problem and agree to alter their behavior and/or accept support and guidance to do so.
- When possible, Intervention Members should share how the Focus Person's conduct has effected them personally – the negative consequences.
- In preparation, the Intervention Members should identify and discuss ahead of the meeting the defensive statement which may be posed by the Focus Person.





Maldistribution of Time We must address and y is it very limpolitant 0%-80% tress the issue? Rule! What are the implications if the stribution of staff time is n 20% of the families

Resolving Differences **Resolving differences of** opinion is achieved through active listening: Ask questions Repeat what you understand of their position Use "I" statements Stick to the initial issue

Resolving Differences (cont'd)

Find points of agreement:

- Agree with the goal
- Agree with basic values
- Agree with the stated need
- Agree with the process
- Agree with some specifics of the resolution



Resolving Differences (cont'd)

Negotiate toward resolution:

- Be prepared to give up something in order to gain something
- Validate the other person's good

points

- Stay non-defensive
- Don't take it personally
- Focus on the immediate issue



Resolving Differences (cont'd) Positive internal messages: Put anger on hold Say 'Stop! I'm not going to get angry.' Give benefit of doubt Think — 'I'm OK. I have skills.' Give yourself an affirmation Think — 'I need to learn more about this.' Think — 'They have a right to their opinion.' **Universal Enhancement**

Resolving Differences (cont'd)

Body language:

Good eye contact

Hands at side –

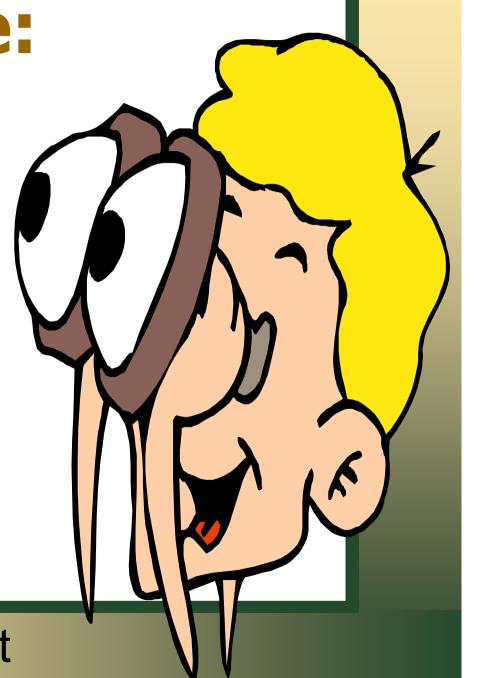
comfortable

Respect personal

space

Stand calmly -

better yet – sit!



Resolving Differences (cont'd)

State your opinion clearly:

- Use "I" statements
- Focus on the immediate issue
- Admit your mistakes
- Accept responsibility for correction
- Ask for what you need

Resolving Differences (cont'd) When negotiations fail: Listen more – longer Repeat validations & points of agreement **Have patience** If there is too much anger to continue - then leave Set boundaries on behavior be willing to follow through

Resolving Differences (cont'd)

Backlash:

- A change in your behavior may not change someone else
- Change is a difficult & slow process – have patience
- Some people may become angrier when you refuse to fight Consistency over time will pay off!

Remember, you will be treating everyone with dignity and respect!

Dysfunctional Family...

...a family whose interrelationships serve to detract from, rather than promote, the emotional and physical health and well being of its members.

Although this term is used casually in popular culture, health care professionals define dysfunctional family as one where the relationships among family members are not conducive to emotional and physical health. Sexual or physical abuse, alcohol and substance addictions, delinquency and behavior problems, eating disorders and extreme aggression are some conditions commonly associated with dysfunctional family relationships.



Fatalism...

... a doctrine that events are fixed in advance so that human beings are powerless to fix them (Webster Dictionary)

Some families believe that their family member with a significant disability cannot have a quality life!

Dysfunctional Family (cont'd)

Some of the characteristics of dysfunctional family systems:

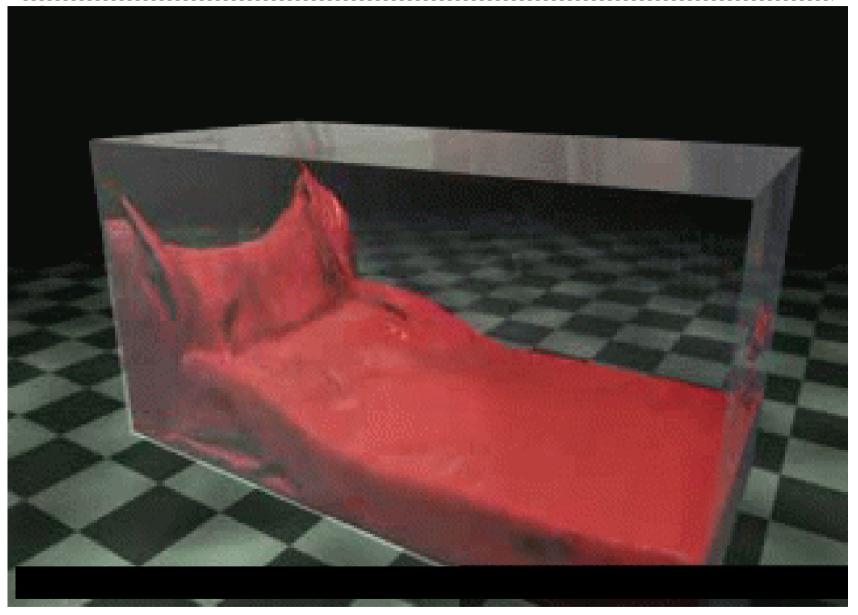
- Blaming; failure to take responsibility for personal actions and feelings; and invalidation of other family members' feelings
- Boundaries between family members that are either too loose or too rigid. For example, the parent may depend excessively on the child for emotional support (loose boundaries) or prevent the child from developing autonomy by making all the decisions for the child (rigid boundaries)

Psychology.jrank.org

Enmeshment

This often happens on an emotional level in which two people "feel" each other's emotions or when one person becomes emotionally escalated and the other family member does as well.

Enmeshment (cont'd)



Consequences of Enmeshment

Enmeshment becomes a problem when:

- the individual starts to lose their emotional identity
- they lack the required autonomy to grow emotionally and relationally
- they become too afraid to venture to increased autonomy- becoming independent of parents
- they become reactive to the enmeshment and run too far in the other direction.

Glenview Counseling Group Glory Jordan L.C.S.W.

Disengagement

The opposite of enmeshment is disengagement, in which personal and relational boundaries are overly rigid and family members come and go without any apparent knowledge of what each other is going through.

Glenview Counseling Group Glory Jordan L.C.S.W

Disengagement (cont'd)

Disengagement may manifest itself by:

- Failing to return phone calls of staff
- Not participating than ning meetings
- Responding with indifference when concerns are shared regarding the welfare, health and/or safety of their family member with disabilities with

Dysfunctional Family

Some of the characteristics of dysfunctional family systems:

- Blaming; failure to take responsibility for personal actions and feelings; and invalidation of other family members' feelings
- Boundaries between family members that are either to loose or too rigid. For example, the parent may depend excessively on the child for emotional support (loose boundaries) or prevent the child from developing autonomy by making all the decisions for the child (rigid boundaries)
- Boundaries between the family as a whole and the outside world may also be too loose or too rigid



Dysfunctional Families (cont'd)

 A tendency for family members to enact set roles (e.g. caregiver, hero, scapegoat, saint, bad girl or boy, little prince or princess) that serve to restrict feelings, experience, and self-expression

• A tendency to have an "identified patient" – one family member who is recognized as mentally unhealthy, who may or may not be in treatment, but whose symptoms are a sign

of the inner family conflict.

Dysfunctional families require family therapy. Family therapists, like other therapists, take many different treatment approaches – psychodynamic, behavioral, cognitive or a combination of these therapies.

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All Alone

The reality is that most families are not receiving counseling to promote their emotional well being and address their intra/inter personal conflicts.

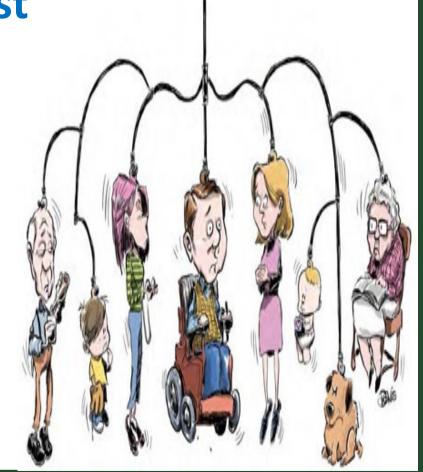
- The role of support staff may need to extend beyond the individual they support by providing emotional encouragement and sustenance to family members.
- When needed and available families should be encouraged to seek professional counseling to address their emotional pain and suffering.

Many families are emotionally

Source of Frustration

A severely dysfunctional family is defined as a group of two or more blood relatives, at least

one of whom is permanently disabled, that behave in an extremely self-destructive or resistant manner.



Source of Frustration (cont'd)

These families pose one of the greatest dangers to the emotional growth of their "disabled member" and are a constant source of frustration for direct support professionals and agency executives.

J. Dale Munro Counseling Severely Dysfunctional Families of Mentally and Physically Disabled Persons

Family Enablers Codependence: A relationship in which one person, the Rescuer/Victim is a partner in codependency the rescuer/victim is psychologically dependent in an unhealthy way on someone who struggles with issues of addiction or disability.

Family Enablers (cont'd)

In a codependent relationship:

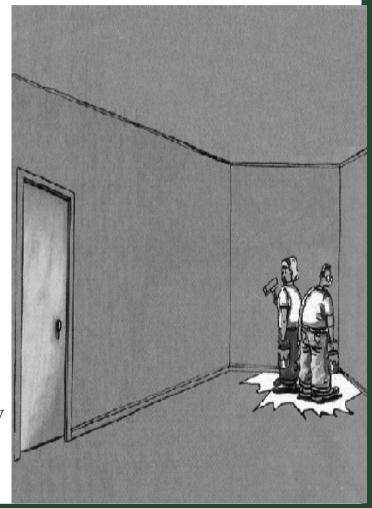
The person with the disability is tricked, or taken advantage of, thus harmed by or made to suffer from an act or circumstance of the rescuer/victim "doing for." Doing for" people with disabilities fulfills the needs of the rescuer/victim. **How does this codependency** "enable" people with disabilities to maintain a life of dependency?

At An Impasse

When we come to an impasse with families; when it seems like there is no resolution to

the impasse:

- We blame ourselves
- We blame the family
- We feel inadequate
- We are perplexed
- We don't feel we are effective in our profession
- We are not doing what we set out to do – help others
- We are frustrated
- We want to give up on this family



Jan Finch, LCSW, Ph.D. Working with Challenging Families

Against Medical Advice...

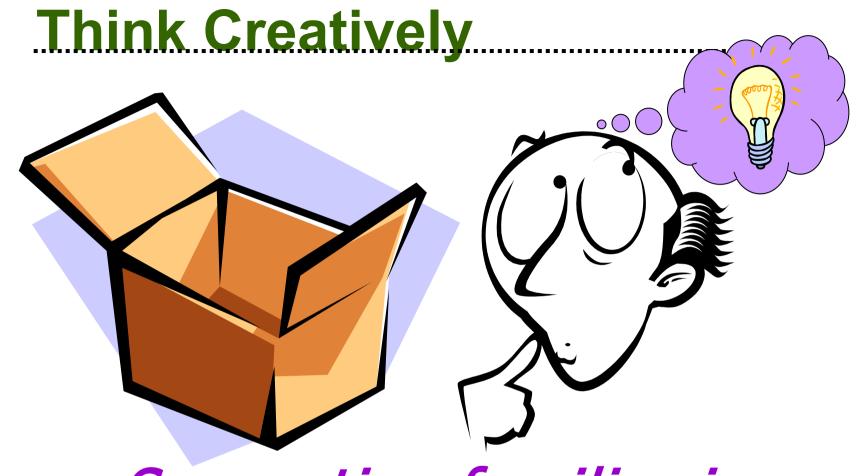
...includes a discussion disclosing the risks, benefits, and alternatives to hospitalization (aka supports, services, interventions), as well as the patient's (aka support recipient's) understanding. This should be documented in the patient's (aka support recipient's) chart (aka record). (This is applicable in our work to the support recipient's family and/or legal guardian or conservator).

Taken in part from Wikipedia

Against Medical Advice (cont'd)

Though AMA commonly connotes a situation in which a patient chooses to leave the hospital against medical advice, it has valued applicability in addressing a family's and/or guardian/conservator's refusal to:

- authorize prescribed medications
- follow behavioral support plan guidelines
- respect the privacy of their "ward"
- interact with their "ward" with dignity and respect
- follow through with recommended therapies/counseling
- allow certain recommended services



Supporting families in realizing their goals is a creative process

Limiting Influences

Supporting families in realizing their goals requires creativity.

Limiting factors:

Stress
Self doubt
Routines
Fear
Ego
Beliefs



Don't give up—we must persist! Use creative approaches to support families in being focused and proactive.

Essential Family-Work Skills

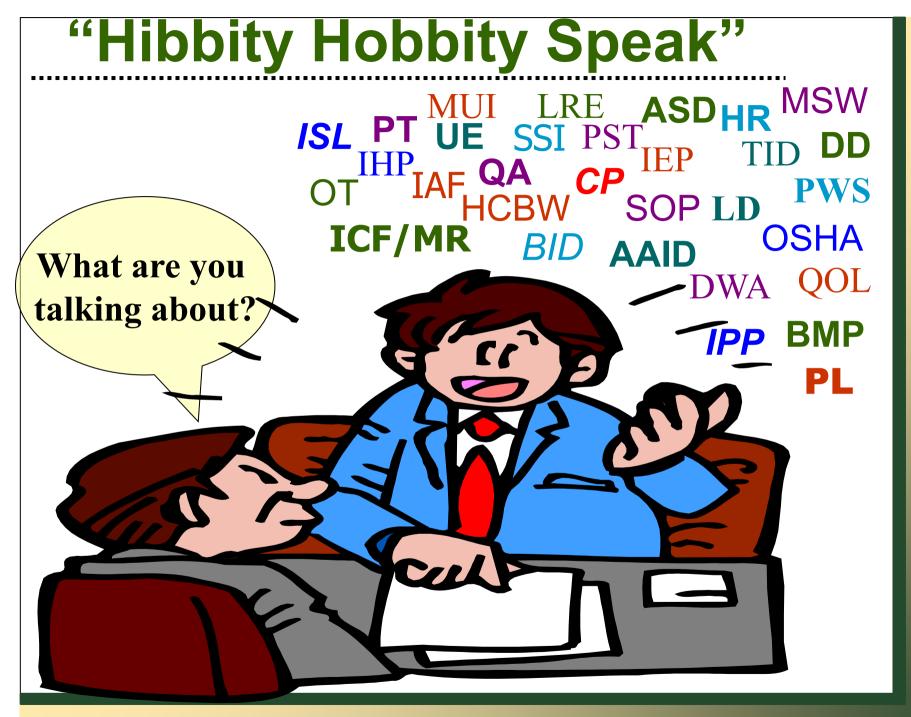
- <u>History:</u> It is vitally important to help professionals who may be overly critical of families, to gain a level of historical perspective. The need to know that almost every significant service advance for people with I/DD has come because of hard-fought advocacy by dedicated family members. It is also important to know that there have been tragic times in human services' history when professionals recklessly blamed parents for their children's disabilities, told parents to place them in state institutions and never see them again, etc. We must vigorously guard against seeing families as "the enemy."
- Recognize Healthy Families: Professionals are often too quick to criticize the relatives of people with disabilities and may tend to "pathologize" family behavior that is essentially normal (e.g. appropriate assertive expression of concerns). Even healthy families can become negative at times if they are exhausted or not comfortable with

Universal Enhancement

how services are provided.

• Building Positive Relationships:

Professionals may need to be reminded that collaborative relationships with families frequently begin in simple ways, by casual small talk, practicing empathic listening and sharing a coffee. Rapport with families can be enhanced by professionals who focus on "here and now" issues; avoid jargon; celebrate (even small) successes; suggest helpful reading about families taking care of themselves; frankness and cheerleading.



• Building Positive Relationships (cont'd):

-When dealing with people who have pervasive, coexisting disabilities, families often are desperate for, and appreciate staff suggestions about calming activities that allow visits with the individuals to go better (e.g. going for walks in nearby parks, car rides, trips to the beach, or preparing a favorite food together). This advice can contribute to a growing sense of family-agency teamwork and cooperation. -Family - professional relationships can improve through the use of regular planning or support circle meetings that may include the individual, family members, friends, volunteers, and key professionals. These meetings help to reduce family isolation, improve planning and create strong family-

Universal Enhancement

system networks.

Really Understanding Why Families Challenge Us: Many professionals need to better understand why families sometimes give us such a rough time. They need to become more insightful about how unresolved grief can affect family behavior and emotions (e.g. following the diagnosis of a disability, when there is a death in the family); how intellectual and communication deficits, language and cultural differences, powerful personality dynamics, caregiver exhaustion or how relatively healthy families can be labeled difficult, when the real problem may rest with exhausted professionals or impersonal, unresponsive or nonexistent human services.

• Becoming Aware of Unspoken Family Questions:
To ensure family cooperation, agency staff need to become more skilled at reassuring families. This reassurance (requiring examples from individual's typical week) must address questions that are seldom stated openly.

Family members often "test" professionals and organizations to reassuringly answer four unspoken (but vitally important) questions:

- 1. Do you really care (about my relative/me)?;
- 2. Is my child/relative really safe?;
- 3. Is my child/relative happy?;
- 4. Am I a good parent/sibling/grandparent?



Ponder This

What does it mean when a parent says "If I'm happy, then they're happy!?



• Clarifying Roles:

One of the greatest sources of acrimony and confusion between service providers and families, result from unclear roles and expectations.

- -Families and professionals can improve their relationships and reduce distress by deciding who does what, how and when.
- -In particularly complicated situations, a written service agreement is useful in outlining the responsibilities of agencies, professionals, families and the individual, to enhance the possibility of the individual's successes.
- -It is often wise to designate one contact person (usually a supervisor or middle manager) through whom families can raise serious concerns with an agency.

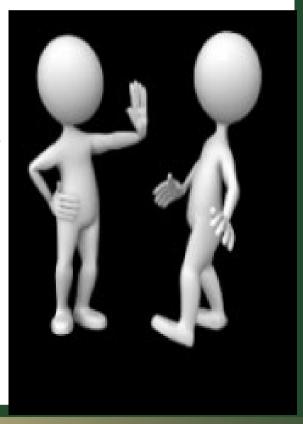
• Clarifying Roles (cont'd):

Some families prefer to approach many different (often parttime or weekend) staff with complaints or deep concerns, but this usually results in miscommunication and emotional upset. A brief written script can be created and rehearsed by staff to be used if family members approach them with complaints ["I know you are concerned and I will ask Joe (the designated contact person) to get back to you as soon as he can about it."] Likewise, staff should feel empowered to suggest positive ideas or raise concerns about the family's behavior with the designated contact person. Staff ideas or concerns can be addressed with the family at regularly scheduled planning or support circle meetings. Please remember, constructive complaining should always be a two-way street!

• Setting Proper Boundaries: Professionals who learn to set appropriate work-related boundaries, tend to manage stress better, and families inadvertently benefit from dealing with healthier, more confident professionals.

Examples of setting boundaries may include:

- > reducing excessive overtime
- > politely ending acrimonious meetings
- ➤ demonstrating team solidarity in not disclosing certain personal information with families
- > showing caution about receiving gifts or giving hugs
- > not giving out home phone numbers



Conclusion:

Most professionals involved in the I/DD field receive limited or no training in effective family-work methods, yet often interact with families on a regular basis. It is important that professionals develop specific skills for improving communication and ensuring a strong foundation of professional-family cooperation. This will make the difference between tremendous progress, or failure, in appropriately supporting a family member with

Essential Family – Work Skills slide series based on J. Dale Munro, MSW, RSW, FAAIDD, Regional Support Associates; NADD Bulleting Volume XII Number 3 Article 1

a developmental disability!