

Parent Mentor Program Mentor Training

WESTSIDE REGIONAL CENTER
PARENT MENTOR PROGRAM



This training event is funded by the Mental Health Services Act (MHSA) in partnership with the Department of Developmental Services.

Introductions



- Your name
- Names and ages of your children
- How long have you been a Westside Regional Center parent

Introductions

- How did you learn how to be a parent of a child with a dual diagnosis?
- What is your experience with parent to parent support?
- What you wish you knew when you first learned about your child's disability?



Agenda – Day 1

- Introduction
- Overview of the Parent Mentor Program
- Providing Parent Support/ Basic Parent to Parent Training –Part 1
- Break
- Common Mental Health Conditions
- Lunch
- Parent/Professional Partnerships
- Break
- Cultural Issues
- Finding Quality Information Resources
- Homework/Questions



Overview of Parent Mentor Program

- Part of the Project UNITE
 - 3-year program
 - project funded by the Mental Health Services Act in partnership with the Department of Developmental Services
 - Addresses the needs of **Transition-Age Youth (TAY)** by focusing on early intervention and provision of mental health supports to young adults with co-occurring intellectual and/or developmental disabilities and mental health disorders and their family members.

Overview of the Parent Mentor Program



- Goals
 - Implementation of mental health screening and referral systems
 - Continuation of TAY Collaborative
 - Development of wellness/drop-in center with weekly psycho-educational interventions
 - Development and implementation of educational services for parents and caregivers of young adults with or at risk for dual diagnosis

Providing Parent Support/ Basic Parent to Parent Training –Part 1

What is Parent to Parent Support?

- Parent to Parent is a program that provides information and ***feeling focused emotional support*** to parents of children who have special needs.
- The support is provided by trained and experienced parents of children who also have special needs



Who provides parent to parent support in the Parent Mentor Program?

- Parents who have:
 - Lived experience – they have a child with a dual diagnosis
 - Have navigated at least 2 of the systems that provide support such as:
 - Regional center
 - Department of Mental Health
 - Other Education
 - Department of Rehabilitation
 - And are trained in parent-to-parent support and receive ongoing supervision

What do Parent Mentors in the Parent Mentor Program Provide?

- Feeling Focused Emotional Support
- Systems Navigation
 - Helping families understand the service systems and how to navigate them
- Help accessing resource
 - Helping families get reliable resources, but more importantly, helping them learn how to identify reliable resources.



Benefits of Parent to Parent Support



- Makes a significant difference in the parents' acceptance level of family and disability.
- Makes a significant difference in how much progress parents feel they have made in getting their needs met.
- Appears to help some parents cope better with a disability and their families.
- Helps parents to feel better able to solve problems pertaining to their child.
- There is a strong relationship between the number of contacts a parent has with a supporting parent and how helpful the parents find Parent to Parent to be.
- Over 80% of the parents find Parent to Parent to be helpful.

Parent to Parent National Survey, Beach Center on Families and Disability 1996

What is different about the type of support we will be providing with the Parent Mentor Program ?

- Parents aren't new to intellectual and/or developmental disabilities
- Mental health issues may be new
- New or different service systems
- Adolescence brings its own challenges
- Parents are getting older
- Their children may have different needs than other same age children only with intellectual and/or developmental disabilities
- Their children are bigger and may be harder to manage
- Issues related to independence are more acute.

Role of the Parent Mentor

1) Parent mentors solve problems for families.

False

Role of the Parent Mentor

2. Parent mentors are experts on dual diagnosis and resources

False

Role of the Parent Mentor

3. If I think, I know a better medication for a youth, I shouldn't share that information with the parents.

True

Role of the Parent Mentor

4. I have to be available to a family anytime they want to talk to me.

False

Parent Mentors in Parent Mentor Program will

- Be matched to parents seeking support related to their transition age child with a dual diagnosis
- Contact the parents/caregivers within 24 hours of receiving the referral
- Provide in-person, telephone and/or email support
- Help families understand and navigate systems
- Identify and access resources
- Provide feeling focused emotional support
- Respect confidentiality
- Adhere to Parent Mentor Program program guidelines

Boundaries

- Please don't
 - Give advice
 - Diagnose
 - Prescribe or evaluate treatment
 - Provide therapy
 - Judge
 - Tell people how they should feel or what they should be concerned about
 - Be an “expert”



Providing Support to Adults

- Some differences between the way you support a child and an adult?
 - Adults decide what they need, including:
 - Sympathy
 - Empathy
 - Validation
 - Information/resources
 - Solutions
 - Clarification of their concern



Active Listening

| | Round 1 | Round 2 | Round 3 |
|-------------------------|---------|---------|---------|
| Tallest | A | B | C |
| 2 nd Tallest | B | C | A |
| Shortest | C | A | B |

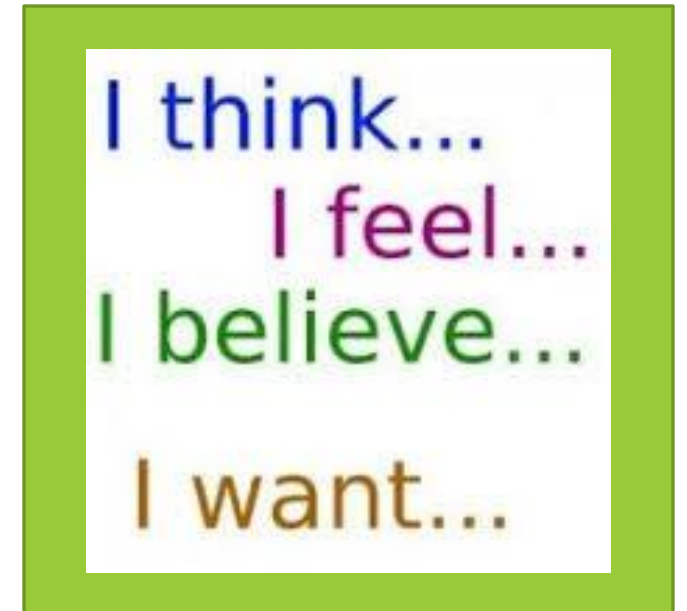
A – Talker

B – Listener

C – Observer

“I” Messages

- I think or I feel
- ⊘ You should or you think
- I think that... = a “you” message



Common Mental Health Conditions

DR. MAYRA MENDEZ

A solid green horizontal bar at the bottom of the slide.

Parent Professional Partnerships

Parent Professional Partnerships

- What is my role on the team?
- What strengths do I bring?
- Who else is on my team?
- What strengths do they bring?
- What do I need from my team members?



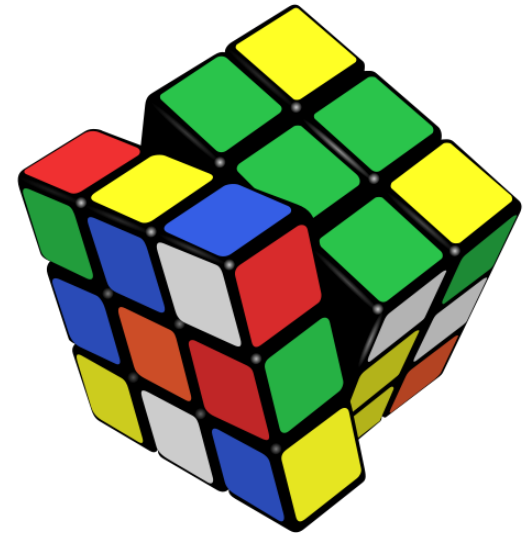
What Is a Parent Professional Partnership?

- What is a partner
 - A partner is a party associated with another or others in some activity of common interest.
 - A partner implies a relationship, in which each has equal status and certain interdependence but also implicit or formal obligations to the other or others.

<http://www.center-school.org/fssr/documents/DevEffColPart.pdf>

Challenges Facing Partners

- Establishing reasonable expectations for themselves and for those with whom they partner
- Challenges to be faced together
 - Respecting differences and acknowledging their importance to producing change
 - Changing attitudes about one another
 - Learning to trust and rely on one another
 - Learning to communicate more effectively
 - Participating together in decision making
 - Being flexible
 - Tracking progress toward improving the partnership



Principles of Family/Professional Collaboration:

- Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
- Promotes a relationship in which family members and professionals work together to ensure the best services for the child and family
- Recognizes and respects the knowledge, skills and experience that families and professionals bring to the relationships

Principles of Family/Professional Collaboration

- Acknowledges that the development of trust is an integral part of a collaborative relationship
- Facilitates open communication so that families and professionals feel free to express themselves
- Recognizes that negotiation is essential in a collaborative relationship; and



Principles of Family/Professional Collaboration:

- Brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health needs and their families



What Works: Partnerships are effective when

- Purpose and goals are clear.
- Each partner's contributions are recognized and valued.
- Each partner receives a return on the investment made.
- Roles and responsibility of each partner are defined.
- Parity exists across partners.
- Differences are respected.
- Partners agree to resolve conflicts.
- Decisions are made by consensus.
- Partners are committed to stay at the table to make the agreement work.
- Each partner helps the other to succeed and not to blame each other for shortfalls.

Challenges for Service Providers

- Changing attitude toward parents ("We know what is best for the family.")
- Responding positively to criticism about the services delivered to families
- Changing agency policies about parental roles
- Decreasing the use of jargon and improving communication
- Participating with families as peers
- Designing new professional development curricula
- Taking the time to involve families instead of making decisions without their input



Challenges for Families

- Contribution being underestimated
- Overcoming fear of negative consequences if you speak up to service providers (such as losing a child to foster care)
- Being uncomfortable or intimidated by jargon, complex procedures, or assuming more pro-active roles
- Skepticism that this partnership approach will be any different than previous methods
- Not sure of the role they want to play on the team (how active a member they want to be)

Team Strengths

- Strengths of the parent
 - Knows their child best
 - Able to see subtleties
 - Sees their child for large portions of the time
 - Sees their child in different environments



Team Strengths

- Strengths of the Professional
 - Wide scope of knowledge
 - Wide range of experience with other children
 - Know of typical child development
 - Know service system and resources



Team Strengths

- Strengths of the team
 - Brings together the two sets of expertise
 - Incorporates the other providers in the child's life
 - Everyone feels they are on the same page
 - Better support for the child
 - More satisfaction for everyone



Helping families participate more effectively on their teams

Mary is the mother of Eddie. Eddie is 17 years old and has Down syndrome and an anxiety disorder. Eddie takes medication for his anxiety. Eddie also has hypothyroid and takes medication for that as well. Eddie lives at home. Eddie is involved in a job training program as part of his IEP. Mary is not sure if Eddie needs to be conserved when he turns 18.

Who are the members of Mary and Eddie's team?

- Mary
- Eddie
- Regional Center
- The School
- Primary Care Provider
- Endocrinologist
- Psychiatrist
- Mental health provider (?)

Lately Mary has noticed that Eddie seems more agitated and is pacing a lot. When she asks him if he is feeling ok and he says that he feels “different”. Mary is worried about Eddie but doesn’t know who to call.

Who are the members of Eddie’s team who should be involved?

- Regional Center
- The School
- Primary Care Provider
- Endocrinologist
- Psychiatrist
- Mental health provider (?)

When Mary calls Eddie's primary care provider and tells her that Eddie is more agitated. The doctor says that Eddie is just stressed and she shouldn't worry about it. Mary doesn't feel comfortable with that answer, but doesn't know what to do.

Think about how you can support Mary in working more effectively with her team so that Eddie's needs are addressed and Mary feels more comfortable with the plan

- What questions you want to ask Mary?
- What are some strategies that Mary can use to work more effectively with her team?

Cultural Issues

Finding Quality Information Resources

Sources of Information

- Books/articles
- Network
- Listservs
- Internet
- Medical libraries
- Family Resource Centers
- Organizations (e.g. NAMI, Autism Society)
- Universities
- Blogs



5 Criteria for Quality Information

- Scope of coverage
- Authority
- Objectivity
- Accuracy
- Currency



Formulating the Question

- Unless you have a clear idea of what you are looking for, you are liable to waste time or find the wrong thing.
- People aren't always sure of what they want, some of the most valuable time is spent helping identify the issues or concerns.



Providers for Individuals with Dual Dx in LA - Search

Dual diagnosis –

8,820,000 hits

Dual diagnosis developmental disability –

299,000 hits

Dual diagnosis developmental disability providers

1,520,000 hits

Mental health services for developmental disabilities

16,200,000 hits

Mental health services for developmental disabilities Los Angeles

2,220,000 hits result



Successful Strategies

- LA DMH Mental Health Client Resource Directory
- LA MHaDDE Resource Directory
- Westside Mental Health Network Directory
- The FRC
- Your Coordinator has access to good resources

(Reachacrossla.org)

Please....

- Check your materials and resources with your coordinator before providing them to parents.
- Remember the best resource person isn't the one who knows everything, it is the one who can find anything.
- Also remember that bad information can come from very good people.
 - if someone gives you unreliable information, they aren't necessarily lying, but may be telling you what they think is true.

Homework



1. Provide Homework Assignment to practice Active Listening and “I Messages” at least 1 x a day and we will be discussing their experience during Day 2 of the training.
2. Do a search for information on autism and using the web information checklist review 3 websites for the likelihood they are providing quality information
3. Review Los Angeles Mental Health and Developmental Disabilities Educational Program Resource Directory

Parent Mentor Program

Day 2

Parent Mentor Program – Day 2

- Homework Review
- Questions



Agenda – Day 2

- Welcome/Check In
- Providing Parent Support/ Basic Parent to Parent Training –Part 2
- Break
- Systems of Care-Regional Center, Department of Mental Health/ Systems of Care- Other Sources of Mental Health Services
- Systems Navigation Principles
- Lunch
- Introduction to Coaching
- Break
- Coaching Practice
- Program Logistics Part 1
- Homework/Questions



Providing Parent Support/ Basic Parent to Parent Training –Part 2

Why do parents want support?

- They want someone to listen to them
- They are facing new symptoms or diagnoses
- They are facing a new stage in their child's development (e.g. transitioning from school-age to adult services)
- They want to talk to someone who has had similar experiences
- They want advice
- They want to vent
- They need information/resources



What is different about the type of support we will be providing with Parent Mentor Program ?

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- Mental health issues may be new
- New or different service systems
- Adolescence brings its own challenges
- Parents are getting older
- Their children are bigger and may be harder to manage
- Their children may have different needs than other same age children with just intellectual and/or developmental disabilities
- Issues related to independence are more acute.



Universal Family Life Cycle

- Couple
- Early childhood
- School Age Children
- Adulthood
- Empty Nest
- Aging Couple



Stressors And Issues In Family Cycle: Early Childhood

- Coping with disability
- Sharing news of disability with family and friends
- Locating services
- Type/place of service delivery – home, school, community
- Transition from Early Start



STRESSORS AND ISSUES IN FAMILY CYCLE: School Age

- Identifying least restrictive environment
- Developing social/recreational activities
- Building child's self-esteem
- Child care
- Transition to adolescence



STRESSORS AND ISSUES IN FAMILY CYCLE: Adolescence

- Social/recreational and sexuality
- After completion of school – college or work
- Preparing as a parent to ‘let go’
- Addressing limitations created by disability
- Transition to Adulthood



STRESSORS AND ISSUES IN FAMILY CYCLE: Adulthood

- Adult services (new system)
- Independent living/supported living
- Reviewing Special Needs Trust
- Review child's Self-Advocacy strengths
- Marriage, own family



Stressors And Issues In Family Cycle: Empty Nesters/Aging Caregiver

- Takes on new meaning
- May have to trust other caregivers
- Siblings have own adult lives



Other Factors

- Severity of Disability
- Perception of the Disability
- Family's Strength and Resources
- Community Resources
- Co-occurring Critical Events in the Family



Coping Strategies

- Internal Strategies
- External Strategies



Family Balance

- Philosophy – not allowing disability to overpower family
- Equality – each family member has equal voice
- Adaptability – doing things different with balance
- Cooperation – family works as team
- Open Communication – make time to discuss issues before they become ‘burning issues’
- Planning – work, play and time alone as couple
- Cohesion – closeness, support and build in ‘family time’



Individual Balance

Relationships

- Spouse
- Children
- Friends
- Co-Workers
- Relatives

Self

- Leisure
- Mental
- Emotional
- Exercise
- Spiritual

Life Work

- House chores
- School
- Volunteering
- Employment
- Career Development



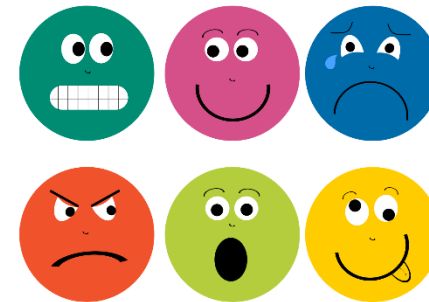
Coping with Loss and Change:

- An individual experience
- Time span is very individualized
- Every person works out his or her own method of coping
 - People turn to friends
 - Like to be alone
 - Seek out support groups
 - Stay at home and cry



Feelings People May Have

- Anger
- Anxiety
- Avoidance
- Anticipation
- Caution
- Challenge
- Concern
- Confusion
- Depression
- Disappointment
- Discouragement
- Dread
- Excitement
- Fear
- Inhibited
- Insecure
- Threatened
- Unbalanced
- Uncomfortable
- Unsettled



Coping Strategies: Anything The Family Does To Reduce Stress

- Internal Strategies (within the family)
 - Setting aside problem
 - Using time to strengthen coping ability (often labeled as denial)
 - Reframing
 - Approaching issues in a positive way and using self or family resources to solve



Coping Strategies:

Anything the family does to reduce stress

- External (outside the family)
 - Spiritual Support
 - Belief system that provides support and understanding
 - Social Support
 - Support from friends, neighbors, relatives, etc.
 - Professional Support
 - Professional help and community resources



Informal Support Systems (Or Stress)

- Parents
- Spouse's parents
- Own relatives
- Spouse's relatives
- Spouse/Partners
- Friends
- Spouse's friends
- Other children
- Neighbors
- Co-workers

Roadblocks to active listening

- Ordering – Stop trying
- Warning – You'd better
- Preaching – You shouldn't
- Suggesting – Why don't you
- Arguing – Yes, but
- Judging – You are not
- Agreeing – I know
- Ridiculing – That's sick
- Diagnosing – In this kind of . . .
- Sympathizing – Don't worry
- Probing – What did you
- Withdrawal – Let's talk about

Characteristics of Empathetic Listeners:

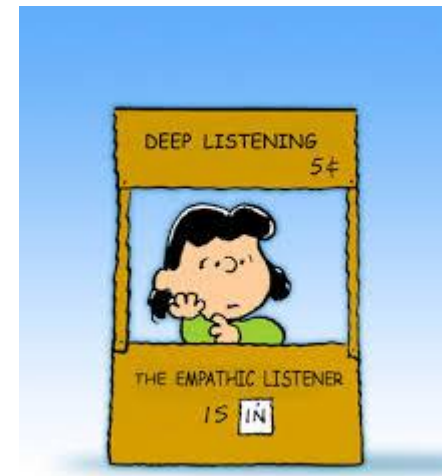
- Desire to be other-directed
 - Rather than to project one's own feelings and ideas on to others.
- Desire to be non-defensive
 - Rather than to protect one's self. When the self is being protected, it is difficult to focus on another person.

Characteristics of Empathetic Listeners:

- Desire to imagine the roles, perspectives, or experiences of the other
 - Rather than assuming they are the same as one's own.
- Desire to listen as a receiver, not as a critic, and desire to understand the other person rather than to achieve either agreement from or change in that person.

Skills for Empathetic Listening

- Restating, paraphrasing
 - Responding to the person's basic verbal message
- Attending, acknowledging
 - Providing verbal or non-verbal awareness of the other, e.g., eye contact, “I see”



Skills for Empathetic Listening

- Reflecting
 - Reflecting feelings or experiences
- Summarizing, synthesizing
 - Bringing together in some way feelings and experiences; providing a focus



Skills for Empathetic Listening

- Supporting
 - Showing warmth and caring in one's own individual way
- Giving feedback
 - Sharing other's ideas or feelings disclosing relevant personal information
- Being quiet
 - Giving the other time to think as well as to talk



Communicating That We are Listening

- Verbal attending: quietly making statements as, "I see," "yes," or "I know."
- Non-verbal attending: eye contact body language use of silence



Sharing Information

- From other sources
- From our experiences
- Based on our beliefs
- Based on our feelings
- Based on our wants



Effective Self-Expression

- Using first-person pronoun--making "I" statements
- Factual self-expression
- Keeping the focus and avoiding "topic jumps"
- Using past-present-future tenses in self expression
- Encouraging others to see themselves with clarity
- Structuring purposeful interaction



What and When to Share

- Sharing is optional.
- Sharing should be invited
- It is important to qualify that your experience (or any experience) isn't universal.
- Your solution may not be the best solution to this parent.
- Sharing should be a way of illustrating a point or situation.
 - It shouldn't divert the attention to you.

Active Listening, Empathic Listening and Selective Sharing

| | Round 1 | Round 2 | Round 3 |
|-----------------------------------|---------|---------|---------|
| 1 st Alphabetically | A | B | C |
| 2 nd Alphabetically | B | C | A |
| Last Alphabetically | C | A | B |

A – Talker
B-
Listener
C –
observer

Systems of Care

Systems Navigation Principles

Introduction to Coaching

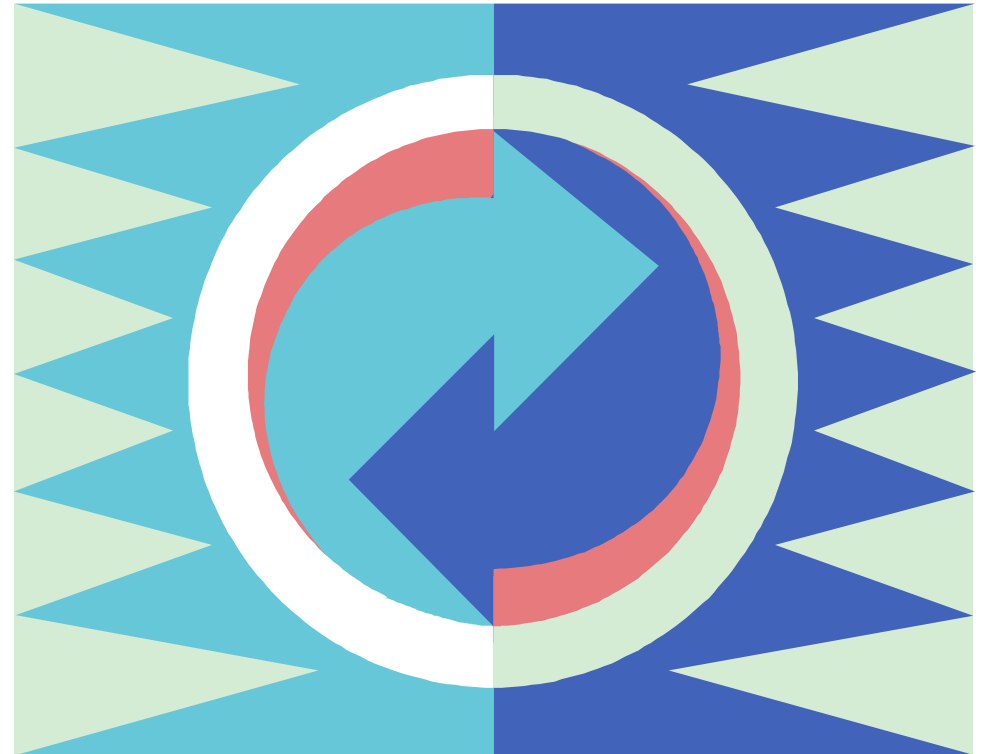
What is the Role of a Coach?

- Provide direction
- Comment on what looks good or provide strategies to improve performance
- Provide information
- Inspire
- Encourage



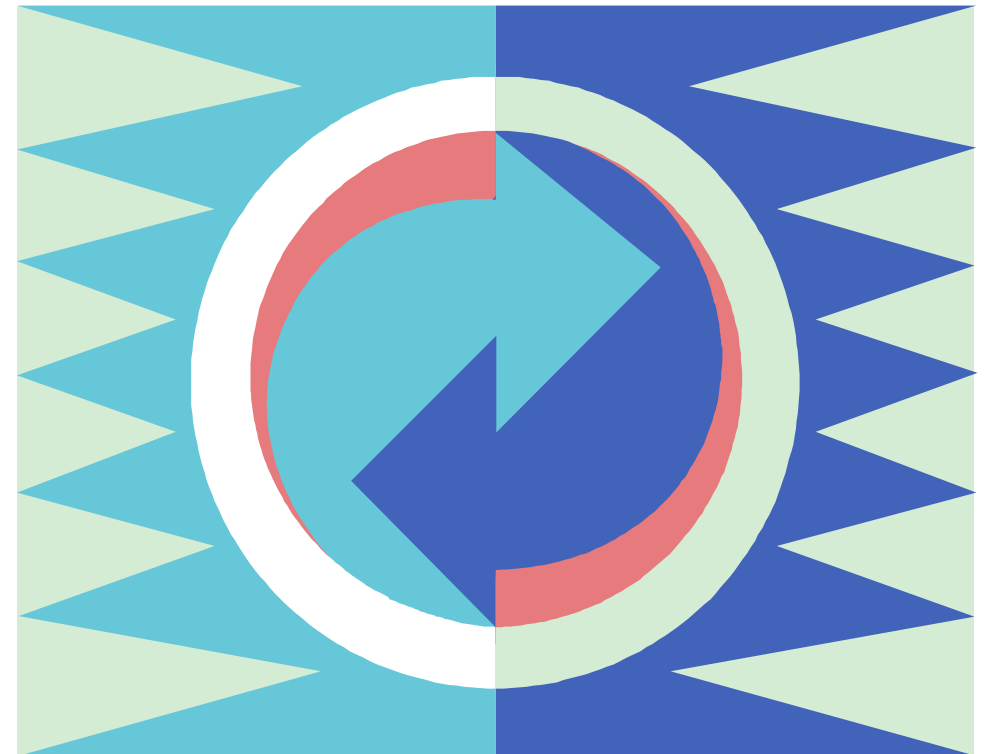
Traditional Model

- Shock
- Denial
- Anger
- Bargaining
- Depression/Sadness
- Acceptance/Objectivity
- Resolution/Maintenance



Limits of the Traditional Model

- Only describes emotions
- May be used to describe behaviors and actions only through the lens of emotion.
 - ex. A parent misses a lot of appointments, so she must be in denial.



Denial Is Just a River in Egypt



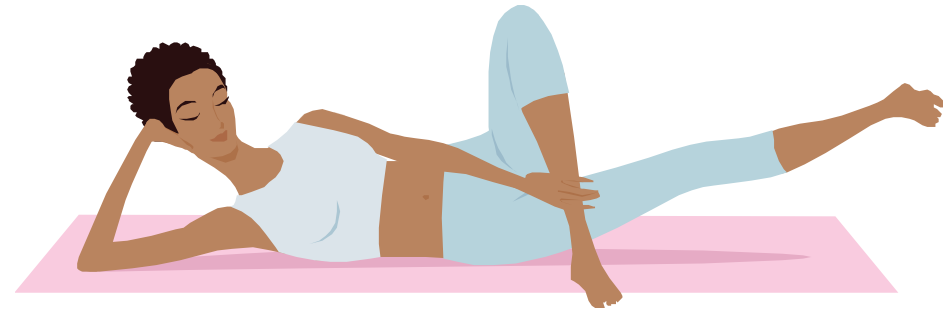
Rethinking Denial: Is Acceptance Enough?

Acceptance: My Keys Are Lost.

Do any of these feelings help you find your keys?



Rethinking Denial: Is Knowledge Enough



Rethinking Denial: Are Skills Enough



Barriers to Coping and Participation

- Knowledge
- Skills
- Time
- Energy
- Complex systems,
- Poverty,
- Transportation,
- Their own challenges
- Fear of criticism
- Stigma

- Needs of Other Children
 - Work
 - Culture
 - Language
 - Philosophy
 - Temperament
 - Capacity
 - Other demands
- and on and on and on and on and on...

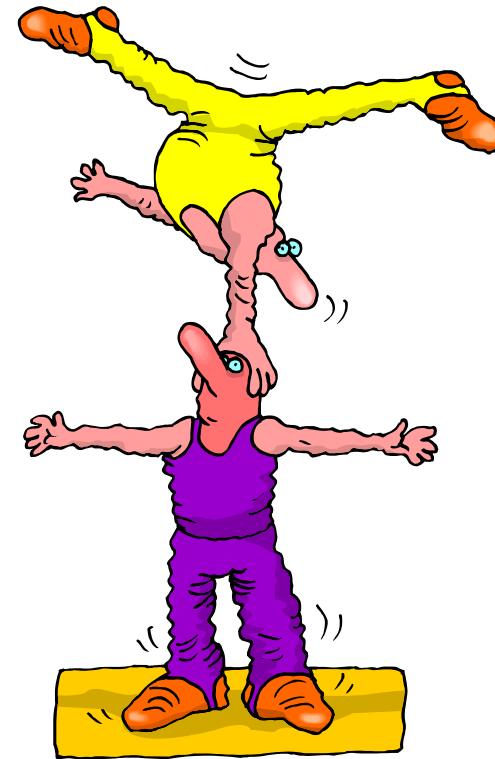
The Terrible Twins

- Denial and Compliance
 - Neither supports confident and competent participation
 - Both convey
 - Judgment
 - Authority



Instead

- Partner with families to
 - Reach mutually acceptable goals and
 - Address barriers to reaching those goals

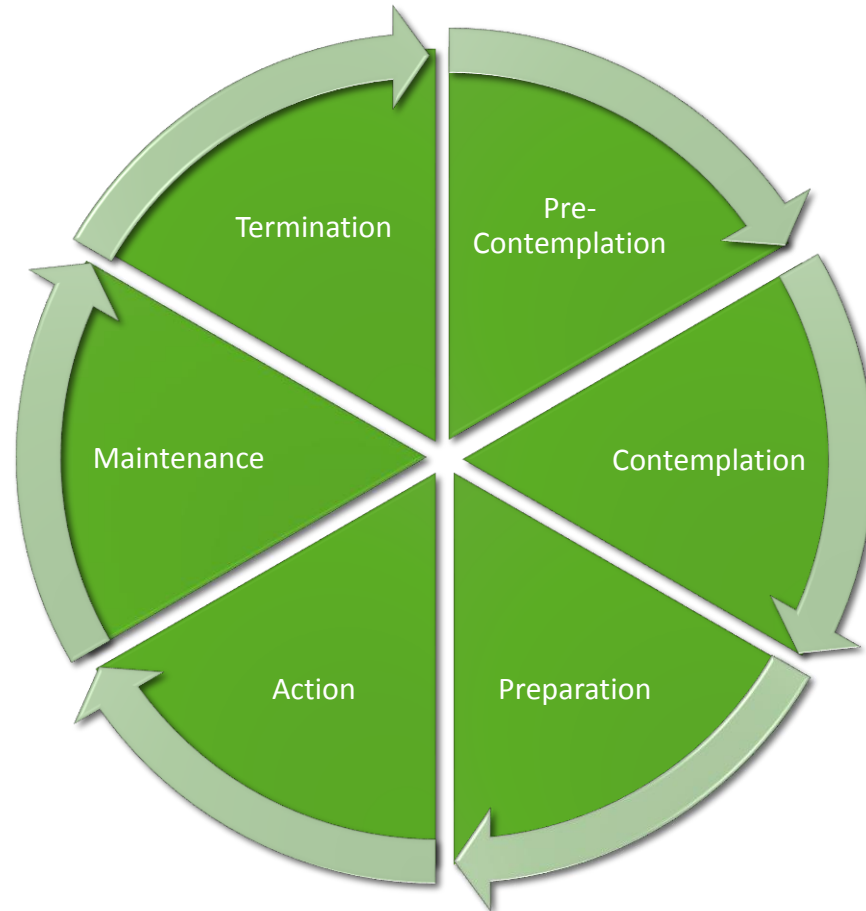


Coaching as a Model

Transtheoretical Model

- Prochaska et al, (1979)
 - Public health model for behavior change
 - Recognizes that barriers to behavior change may be related more to skills acquisition than resistance and
 - Identifies the steps that are necessary for behavior change.
 - Pre-contemplation
 - Contemplation
 - Preparation
 - Action
 - Maintenance
 - Termination

Transtheoretical Model



Applying the Transtheoretical Model

Stage - Pre-contemplation

- Not intending to take action within the next 6 months
- May be at this stage because uninformed or under-informed about the consequences of a given behavior
- May be frustrated because of previous attempts at change

Our Families May

- Feel overwhelmed
- Not accepting of the diagnosis
- Rely on experts
- Not know what they don't know
- Not want to think about it.

Applying the Transtheoretical Model

Stage - Contemplation

- Intending to take action in the next 6 months.
- Characterized by considerable ambivalence

Our Families May

- Think about seeking resources
- Look for formulas or guides

Applying the Transtheoretical Model

Stage - Preparation

- Individual intends to take action in the immediate future
- Generally has a plan of action

Our Families May

- Look for resources
- Contact a FRC or support group
- Go to a conference
- Think about what they need to learn so they can participate in service planning

Applying the Transtheoretical Model

Stage - Action

- Individual has made specific, overt modifications in behavior within the last 6 months.
 - In this model, not all modifications of behavior count as action.

Our Families May

- Actively seek out information specific to their child
- Ask questions at planning meetings
- Bring in concerns and suggestions

Applying the Transtheoretical Model

Stage- Maintenance

- Working to prevent relapse but does not need to apply change processes as frequently as one would in the action stage.
- Less tempted to relapse and increasingly confident in ability to sustain the changes.

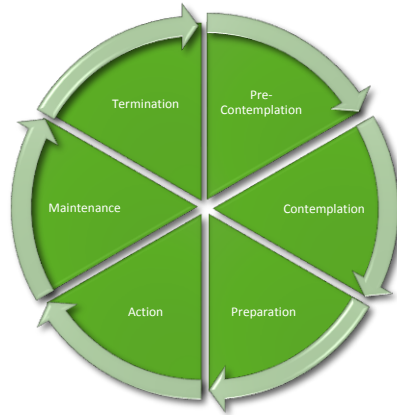
Our Families May

- Feel more comfortable participating in service and support planning
- Feel that they can advocate on behalf of their child
- Provide feedback on the appropriateness of proposed services and supports
- Help provide solutions

Applying the Transtheoretical Model

Stage - Termination

- Zero temptation and 100% self-efficacy regardless of situation



Our Families May

- Know how to find and use resources
- Participate in creative problem solving
- Support other parents

Assumptions

- Families will be on a continuum of knowledge and skill level
- Strategies which are not comfortable will not be utilized.
- Permanent and deep behavior change will be an individual choice.
- Progress is made in steps
 - Not succeeding is not the same as not trying.
 - And not arriving is not the same as not traveling.
 - Progress isn't always visible

Other Contributing Factors

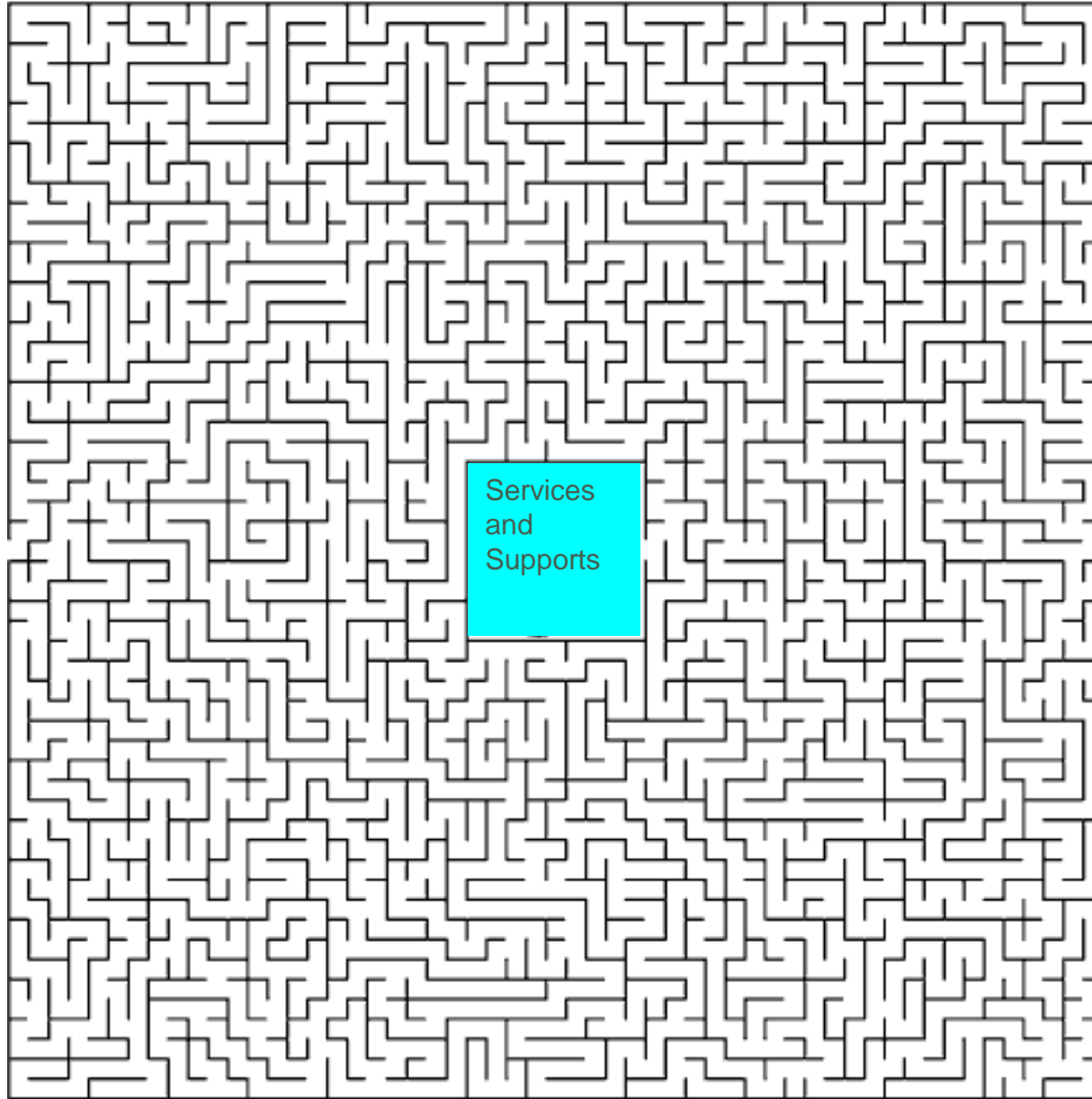
Decisional Balance



Self-Efficacy

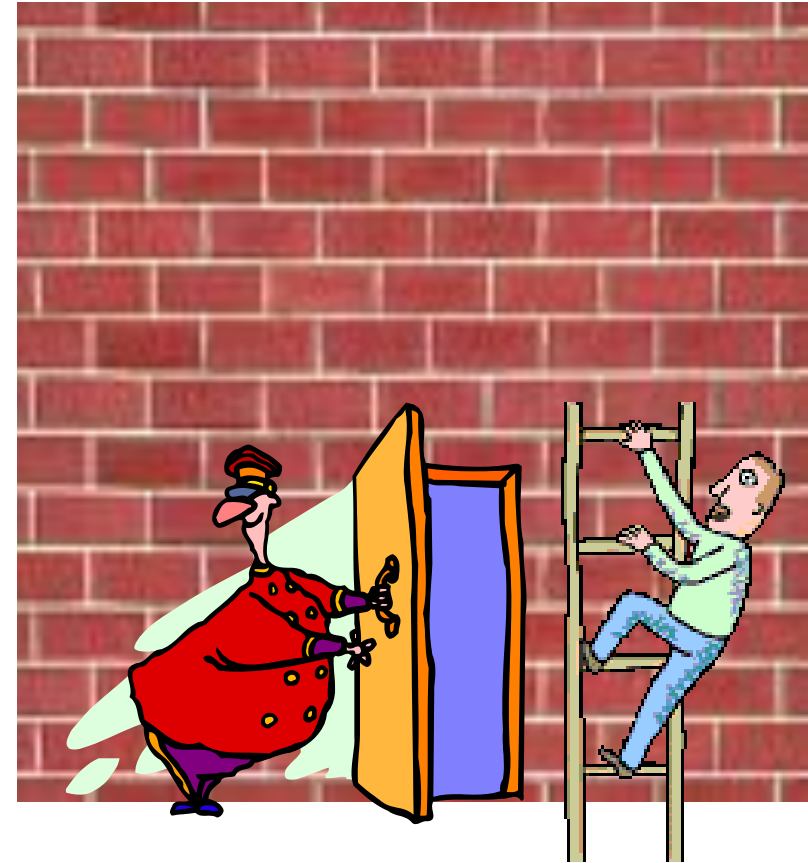


Supporting Knowledge and Skills Acquisition



It isn't help
unless it's
helpful

Provide
Appropriate
Support



Processes of Change - Experiential

- Consciousness-Raising
- Dramatic Relief
- Self-Reevaluation
- Environmental Reevaluation
- Social Liberation



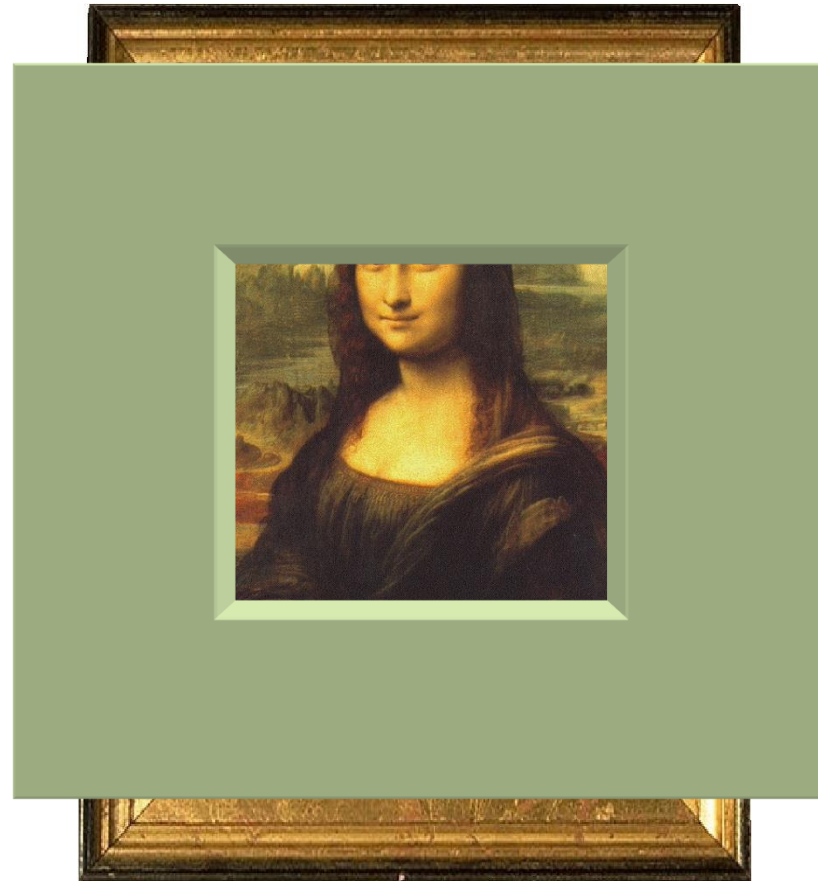
Processes of Change - Behavioral

- Self-Liberation
- Helping Relationship
- Counter-conditioning
- Reinforcement Management
- Stimulus Control



| | Pre-Contemplation | Contemplation | Preparation | Action | Maintenance |
|----------------------------|-------------------|---------------|-------------|--------|-------------|
| Consciousness-Raising | ✓ | ✓ | ✓ | | |
| Dramatic Relief | | ✓ | ✓ | | |
| Self-Reevaluation | | | ✓ | | |
| Environmental Reevaluation | | ✓ | ✓ | | |
| Social Liberation | ✓ | ✓ | ✓ | | |
| Self-Liberation | | | | ✓ | ✓ |
| Helping Relationships | | | | ✓ | ✓ |
| Counter-conditioning | | | | ✓ | ✓ |
| Reinforcement Management | | | | ✓ | ✓ |
| Stimulus Control | | | | | |

Re-Framing the Parent Experience



Scenario 1 – The T's and Ruthie

Mr. and Ms. T. are at their wit's ends. Their daughter Ruthie is 19 years old, has Down syndrome and was just diagnosed with depression. Ruthie cries a lot and is very reluctant to go out of the house. Mr. and Ms. T are very anxious about Ruthie's mental health. Ruthie's primary care provider wants to give Ruthie an anti-depressant and refer her to a therapist. The T's agree to everything the doctor recommends, but don't do everything they are told to do. Mr. and Ms. T. find being parents very hard. Ruthie's doctor suggested the T's call Parent Mentor Program so they can learn more about Down syndrome and depression. The T's call, but don't really have any questions.

Questions

- Using the Transtheoretical Model, how would you describe Mr. and Ms. T ?
- What are some of their barriers to confident and competent participation?
- What would you like Ruthie's doctor to know?
- Who can help Mr. and Ms. T?



Scenrio 2 – Hector's Tantrums

Grace and Carlos has 3 children; Sophie (21), Sam (19 years), Hector (16) Grace works in a fast food restaurant and Carlos works full time as a certified plumber's assistant. Neither of their jobs provides benefits. Hector was diagnosed with autism and is receiving services from regional center and special education.

Hector has had a lot of tantrums and the school calls Grace about 3 days a week and tells her to pick up Hector. Hector also has a lot of tantrums at home. Hector has gotten big and Grace and Carlos can't handle him easily. They are very tired and don't know what to do. They say that things have to change.

Grace and Carlos call Parent Mentor Program to find out where to get help.

Questions

- Using the Transtheoretical Model, how would you describe Grace and Carlos
- What are some of their barriers to confident and competent participation?
- What would you like Hector's school to know?
- Who can help Grace and Carlos?



Coaching Practice

| | Talker | Coach | Observer |
|----------------|---------------|--------------|-----------------|
| Round 1 | Flower | Star | Heart |
| Round 2 | Heart | Flower | Star |
| Round 3 | Star | Heart | Flower |

Program Logistics – Part 1

Parent Mentor Program Structure

- Your contacts at the FRC are:
 - Pat Ball – Parent Mentor Program Coordinator
 - Liz Spencer- Director, Westside Family Resource and Empowerment Center
- Additionally you have contacts in the Project UNITE Program
 - Aga Spatzier, Wellness Manager
 - Jonae Perez Project Coordinator



WESTSIDE
REGIONAL CENTER

Matches

- Matches are made by trying to match up as many characteristics as possible, e.g. age of child, diagnoses, concern. Therefore we are asking you to provide some in-depth information to help make the match.
- As parent mentors, you will not be responsible for recruiting your parents.
- You will be given some preliminary information about
 - 👉 the parent
 - 👉 his/her child
 - 👉 his/her concern
- Contact will be by email

Your Responsibilities

- Let the FRC know if you are not available for referrals
 - If you are contacted about a referral and can't take it, send an email to Pat (with a cc to Liz and Aga) immediately or at least within 24 hours of their contact with you.
- Contact the parent within 48 hours
 - If you can't reach the parent and are able to leave a message; try a total of 3 times -leaving a message each time (record dates/times) and then send an email to Pat (with a cc to Liz and Aga) letting her know that you were unable to contact the parent.
 - If you aren't able to leave a message ((disconnected phone, wrong number) send an email to Pat (with a cc to Liz and Aga) within 24 hours.

Your Responsibilities

- Do not be afraid to ask for a parent/caregiver to be matched with another mentor if after contacting the new referral, you feel you cannot relate to them.
 - It is better to switch mentors than to fail to give the support needed.
 - Occasionally two mentors may be assigned. You will be notified if this is the case

Your Responsibilities

- Schedule a time to meet by phone or in-person
- Send an email to Pat (with a cc to Liz and Aga) within 24 hours to let them know that you have made contact with the parent
- Follow through on your appointment
- Fill out your report form and submit electronically. Forms are submitted once a month to Pat (with an cc to Liz and Aga).
- Maintain confidentiality
- Listen to the parent
 - Make sure you are responding to their concerns rather than what you think their concerns should be

Your Responsibilities

- Follow through on what you say you are going to do.
- Follow Parent Mentor Program values and protocols
- Attend monthly supervision/continuing education session
- Do not do too much for the parent.
 - You help people by helping them learn to do things rather than do it for them

Homework/Questions



Homework

1. Active Listening/I Messages – continue practice everyday
2. Review Transtheoretical Models of Change
3. Explore resources for systems of care

Parent Mentor Program

Day 3

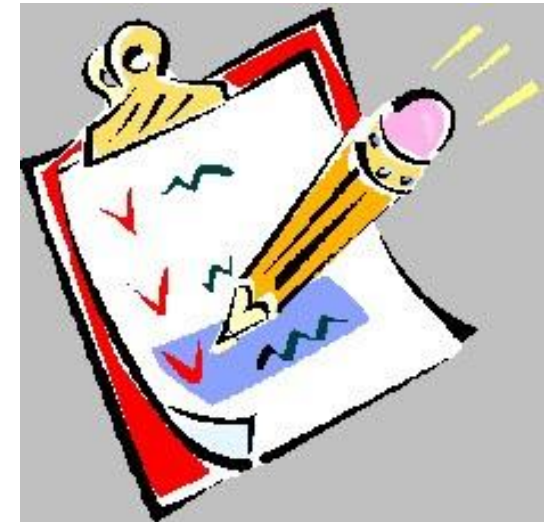
Parent Mentor Program – Day 3

- Homework Review
- Questions



Agenda – Day 3

- Rights and Responsibilities for Mental Health
- Program Logistics Part 2
- Break
- Identifying When a Parent Needs More Help
- Managing Stress- Taking Care of the Parent and Yourself
- Lunch
- Vocabulary and Person First Language
- What Do I Do If...
- Break
- Questions
- Graduation



Program Logistics Part 2

Parent Meetings

- Meetings can be:
 - By phone
 - In the person's home
 - In a neutral location (e.g. Starbucks, park, at the FRC)
 - Depending on mutual agreement and your comfort
- Meetings can be a single conversations or several sessions
 - In general, parents find multiple sessions feel more supportive than one session
 - There may be many contacts with the new family in the beginning; however, they should decrease as the family becomes connected with information, services and supports.
- Follow up with the family approximately 2 weeks after the meeting.

Identifying When a Parent Needs More Help

Identifying When a Parent Needs More Help

- Expression of suicidal intent
- A pattern of alcohol abuse/dependence
- Inability to care for self or their child (not getting sleep, not eating)
- Extreme anger, sadness or anxiety
- Expressing Concern (s)he may harm the child
- Physical harm to self or others
- Feeling stuck – telling the same stories or bringing up the same problem over and over
- Medical issues that should be evaluated by a doctor.
- Over dependence on the mentor

Identifying When a Parent Needs More Help

- Indicators the child needs more help
 - Changes in behavior/health status
 - Violent or unsafe behavior
 - Expression of suicidal intent
 - Extreme anger, sadness or anxiety
 - Lack of progress in IPP/IEP goals
 - Medication issues/concerns

Managing Stress- Taking Care of the Parent and Yourself

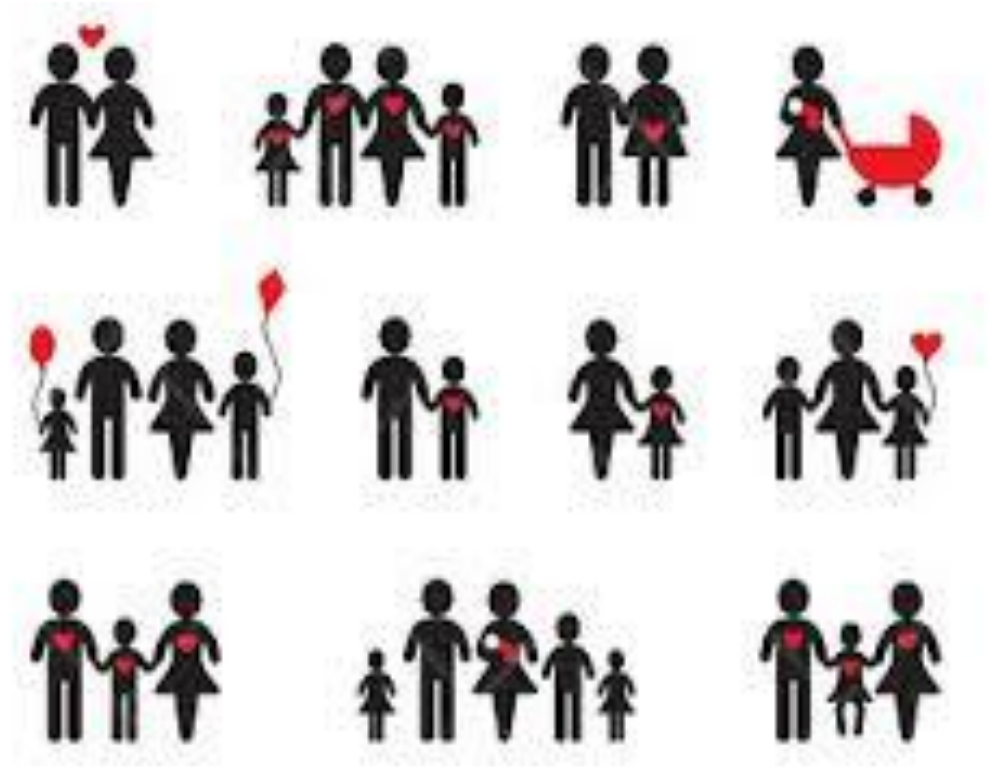
We want the best for our kids so
we are committed taking care of
them at any cost.



YOU ✓

But sometimes we forget
that our child with a
disability isn't the only
person in the family...

It is important to take care
of everyone,
Especially you



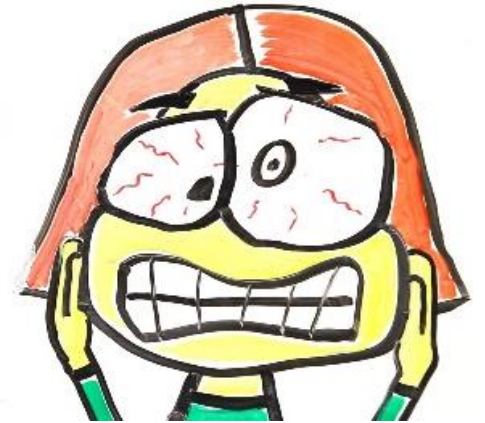
The Facility of the Airplane Analogy





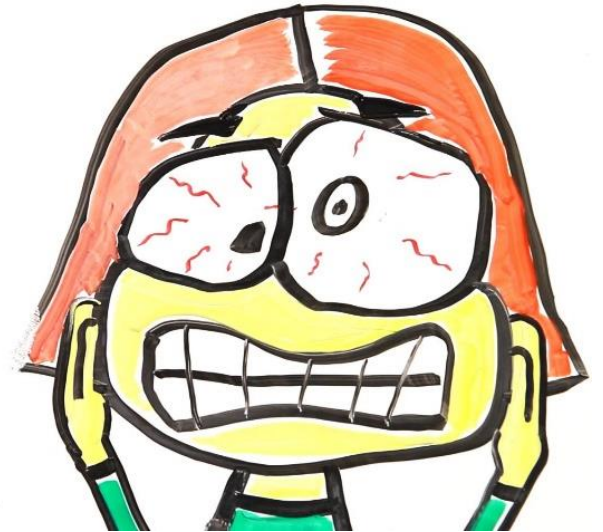
Caregivers Need to Take Care of Themselves

- Family caregivers are less likely than non-caregivers to practice preventive healthcare and self-care behavior.
- Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing care-giving responsibilities.



Caregivers Need to Take Care of Themselves

- They report:
 - Sleep deprivation
 - Poor eating habits
 - Failure to exercise
 - Failure to stay in bed when ill
 - Postponement of or failure to make medical appointments.



Feeling stress doesn't
mean we are not doing a
good job.



Strategies for the Ride



Caregiver Self Care

- Put yourself first,
- Manage stress,
- Socialize
- Get help

Caring to the End – Princess Margaret Hospital



Tips

- Be a “good enough” parent



Tips

- Use respite



Tips

- Be a team



Tips

- Watch out for signs of depression



Tips

- Accept help



Tips

- Learn the difference between caring and doing.



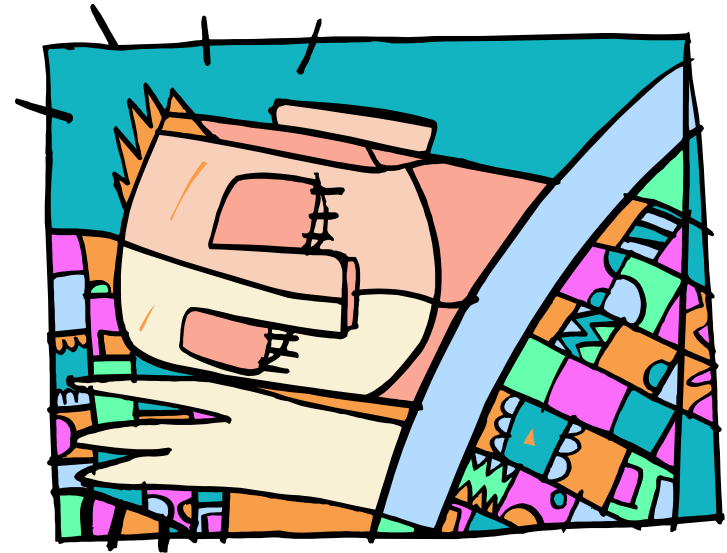
Tips

- Trust your instincts. Most of the time they will lead you in the right direction.



Tips

- Grieve for your losses, and then allow yourself to dream new dreams.



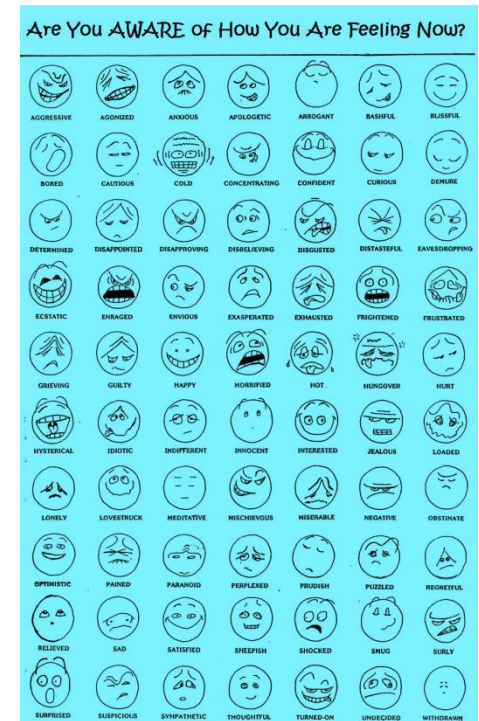
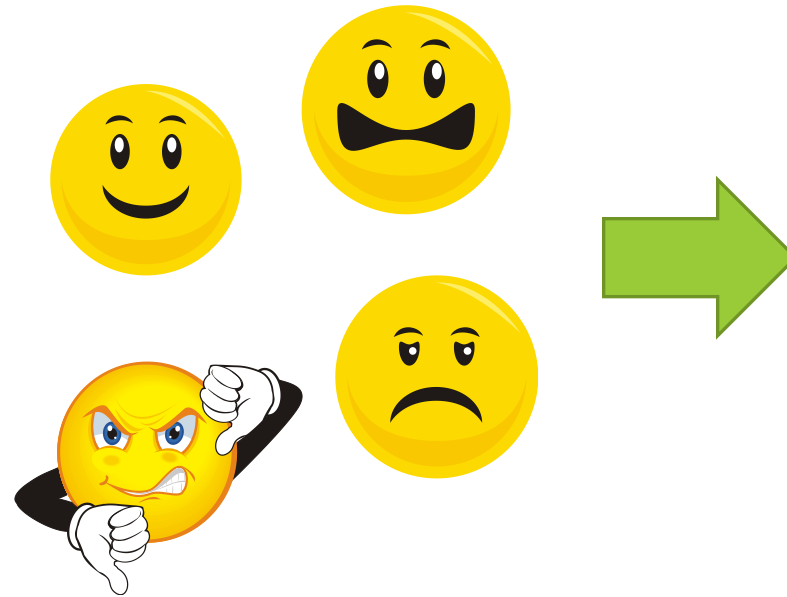
Tips

- Seek support



Tips

- Have a Expanded Vocabulary of Emotions



Tips

- Bag Full of Marbles or Basket of Kittens?



How Do You Gather a Basket of Kittens?



One Kitten at
a Time

What's On Your Plate



Priorities

- 1.
- 1.
- 1.
- 1.
- 1.
- 1.
- 1.



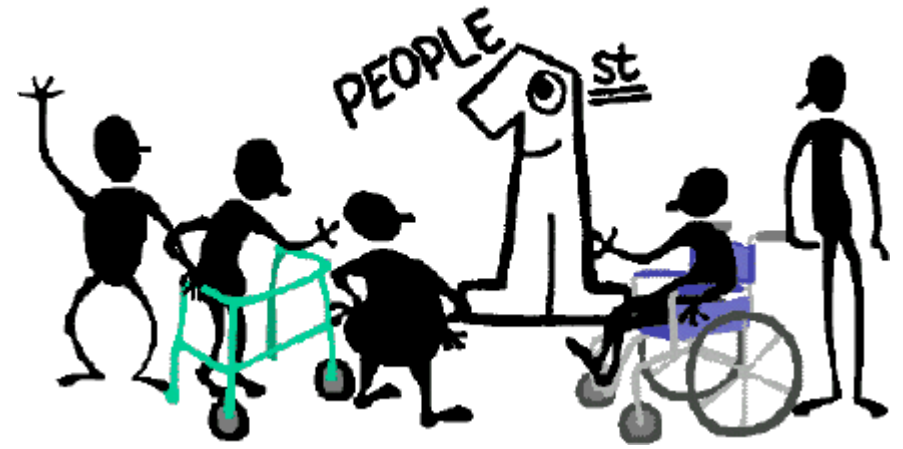
Resources

- ARCH – National Respite Network and Resource Center <http://archrespite.org/home>
- Disability.gov
[http://www.disability.gov/health/caregiver & provider resources/caregivers](http://www.disability.gov/health/caregiver%20&%20provider%20resources/caregivers)
- Family Caregiver Alliance <http://www.caregiver.org/caregiver/jsp/home.jsp>
- National Alliance for Caregivers <http://www.caregiving.org/>
- National Family Caregivers Association (NFCA) <http://nfcacares.org/index.cfm>
- The Unplanned Journey <http://www.parentcenterhub.org/repository/journey/>
- Sibling Leadership Network www.siblingleadership.org
- Sibling Support Project <http://www.siblingsupport.org/>

Person First Language

Person-First Language

- Puts the person before the disability
- Describes what a person has not what a person is
- Is inclusive rather than exclusive



Person-First Language

- Places people with significant disabilities on the same level as people without disabilities or those with minor disabilities
 - Wears glasses as opposed to *myopic person*
- De-sensationalizes language
 - Suffers, victim, heroic

**DISABILITY
≠ PATHETIC**

Examples

- Use
 - Boy with an intellectual disability
- Instead of
 - *Mentally Retarded*
 - *Retarded boy*



Examples

- Use
 - Uses a wheelchair
- Instead of
 - *wheelchair bound* or
 - *in a wheelchair*



Examples

- Use
 - Psychiatric or emotional disability
 - Mental health needs
- Instead of
 - Crazy
 - Mentally Disturbed



What Do I Do If...

Logistical Issues

- No one is home
- You get sick or can't make the meeting
- You get the parent's voicemail
- Someone has an accident
- You don't feel comfortable going to the person's home
- You are having a crisis or are under a lot of stress



Mentoring Issues

- A parent asks you a question you don't know the answer to.
- A parent asks you to tell them what they should do in a situation
- A parent talks and talks but doesn't get to the point
- A parent doesn't talk
- A parent cries
- A parent is very angry
- A parent disagrees with you or has different values and/or beliefs
- A parent rejects every suggestion you make - the "yes, but" phenomenon
- A parent appears to have problems that are more than you can handle .
- A parent who calls you all the time or is very needy
- You don't like the parent

Remember...

- We can't insist that only people we like attend our groups.
- People under stress are never at their best.
- People may say things or discuss situations that trigger memories and feelings from a stressful time in your life



Assertive Caring

Assertive Caring

- Show that you understand the member's position or dilemma
- Set limits: Gently but firmly correct the behavior.
- Suggest an alternative
- Get the person's agreement on the alternative



Mentoring Practice

| | Talker | Coach | Observer |
|----------------|------------------------------|------------------------------|------------------------------|
| Round 1 | Oldest Child | 2 nd Oldest Child | Youngest Child |
| Round 2 | 2 nd Oldest Child | Youngest Child | Oldest Child |
| Round 3 | Youngest Child | Oldest Child | 2 nd Oldest Child |

Questions/Review
