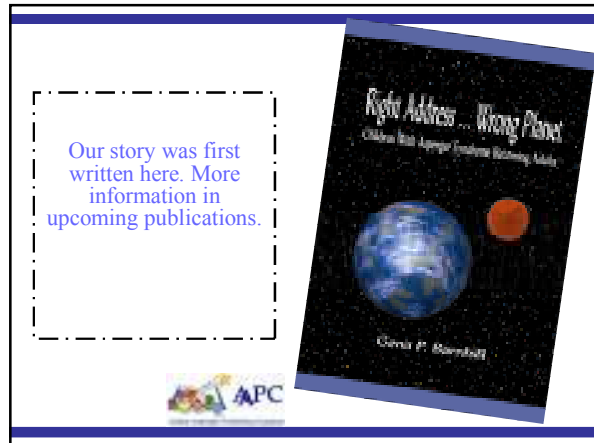


Understanding and Assisting Parents of Children with Autism Spectrum Disorders

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NASP Convention March 3, 2010
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Learning Objectives

- State the importance of gaining knowledge of parents' perspectives
- Gain awareness of parents' perspectives
- Summarize current research on parents' coping skills and list effective coping strategies that may be taught
- Be able to use at least 2 strategies/approaches to assist parents of children with ASD



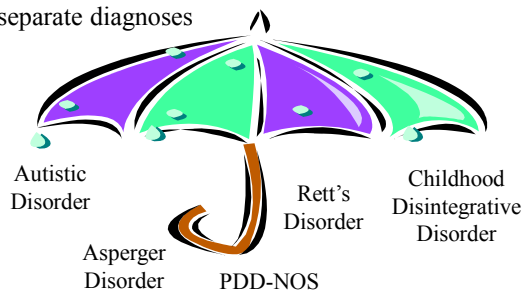
Many parents say they feel like they have stepped onto this ride



Information and research on the effects of autism spectrum disorders on the family has only begun to be explored in the last 8 - 10 years.

The Autism Spectrum "Umbrella" (Pervasive Developmental Disorders)

5 separate diagnoses



Brent's and Our Journey

- Traumatic birth 4/19/76
- Preschool signs of social challenges
- 12/82 Special Ed- Neurologically Impaired
- Neurological Institute 6/83- ADHD, LD
- 5th grade Perceptually Impaired; avid baseball card collector
- Jr. High- Some bullying
- Moved to Fl summer before 9th grade- Did well academically, no special education



Brent's and Our Journey

- 3rd quarter 11th grade moved to MO; best school experience; NHS; perseverative interests very obvious and changing
- 8/94 college 95 miles away for 2 years
- '96 – '97 DeVry; P/T McDonald's; living home
- 5/97 Hospitalization; withdrew from DeVry
- 2/98 KCRC diagnosed with Asperger Syndrome (AS)
- Numerous jobs lasting at most 11 months; several additional diagnoses followed; several relationships with women over next few years

Brent's and Our Journey

- Completed Vatterott College 3.5 GPA
- Lived in St. Joseph 18 months on own
- Engaged briefly
- Numerous employment challenges
- Back home
- Apartment in KC for 1 year
- 2006 moved to VA with parents
- Working almost 3 years P/T at grocery store
- Living separately in a house 1.3 miles from parents

Relationship between Autism and Stress

- Parents of 459 children ages 4-17 compared to parents of children with other health care needs and no health care needs
- 55% of parents of children with autism scored in high aggravation range compared to 44% & 12% of others
- 66% of autism group who recently needed special services had high aggravation scores
- Conclusion: Parenting a child with autism appears to be associated with unique stresses.

» Schieve, Blumberg, Rice, Visser, & Boyle, 2007

Autism's Unique Stressors

- Slow and inconsistent diagnostic process
- Uneven and unusual course of development
- Resulting ebbs and flows of hope and pessimism
- Lack of affection and communication
- Typical physical appearance
- Behavior in public

» Marcus, Kunce, & Schopler, 2005

Autism's Unique Stressors

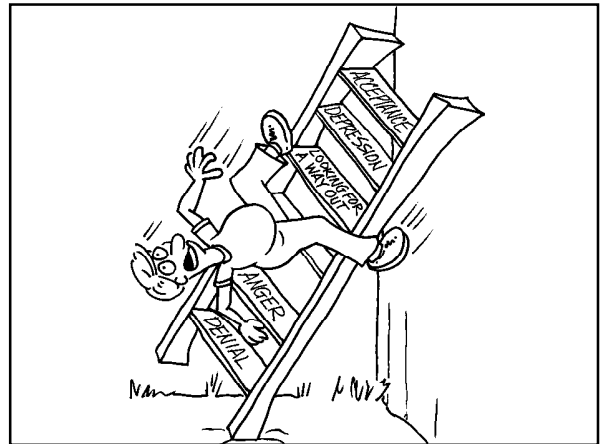
- The "I can't" versus "I won't" dilemma
- Broader autism phenotype
- Professional relationships
- Fads and unproven therapies
- Pressure from others to try more therapies
- Increased parental mental health concerns

» Marcus et al., 2005

Parents' Top Sources of Stress

- Challenging and anti-social behaviors
- Concern for the future
- Attaining support and services
- Understanding their child's needs

» Tehee, Honan, & Hevey, 2009



Parental Concerns

- Poor outcomes associated with autism
- Child's protection and safety
- Aggression and SIB
- Food refusals and poor sleeping habits
- Lack of personal care skills
- Depletion of time available to care for siblings and for themselves

» Gray, 2002; Ivey, 2004; Rogers & Dawson, 2010

Parental Concerns

- Poor language skills
- Disruption and destruction in home
- Inappropriate sexual expressions
- Social rejection and stigma for parents & child
- Anxiety about the future
- Where will my child live when I'm too old or no longer living?

» Gray, 2002

One Parent Commented

“It is very bleak at the moment. There is nothing out there for these children, so it is virtually up to the parents to provide for them. We could cope with [my son] if we had somewhere he could go during the daytime, right? To have an 18-year-old at home who has gone to school from the time he was probably 2 years of age...all of a sudden home.”

» Gray, 2002

Compared to Parents Dealing with ADHD

- Parents of children with autism experienced:
 - Greater level of child care burden
 - Less frequent attendance of religious services
 - Greater likelihood to quit job
 - More school days missed
 - More repeated grades
 - Less participation in activities/events
 - Less involvement in community services

» Lee, Harrington, Louie, & Newschaffer, 2008

Importance of Families/Parents

- Collaboration with parents required by IDEA
- NRC critical component of pre-school programs
- Parents are key providers of therapy in ABA approaches, the Early Start Denver Model, Floortime, Options, etc.
- Research demonstrates benefits of parent training and counseling in early intervention programs.

- “One of the most basic needs of parents and families of children with autism is to secure appropriate direct services.”

» Webber, Simpson, & Bentley, 2000, p. 308

3 Basic Needs of Support

- Information
- Knowledge and skills to deal with their child
- Support from outside the family to assist with coping and problem solving

» Webber et al., 2000, p.310

Information

- Present services
- Future services
- How to teach their child
- Nature of child’s disability
- Experiences of other parents in similar situation
- Handling emotional and time demands of parenthood
- Community resources
- Legal rights

Parents Perceptions During Diagnosis

- Preferred procedure have more coherent structure and content
- Requested greater professional training on ASD
- Wanted better professional interpersonal skills
- Wanted broad information sheets about autism at time of diagnosis to combat negative info from other sources
- Desire knowledge of support groups

» Osborne & Reed, 2008

Parents’ Suggested Improvements

- Receive information right from the start even if cannot take it all in
- Offer counseling and services
- Speed and standardization of process
- Information on organizations and services
- Info on impact of autism and what to expect
- Practical info on how to deal with child

» Osborne & Reed, 2008

Levels of Parental Involvement

- Awareness
- Open Communication
- Advocacy and Participation
- Problem Solving and Procedural Application
- Partnership

» Webber et al., 2000

So what does the *research* have to say about *parenting, marriage and coping strategies* for parents of children with ASD?



Longitudinal Study

- Intense stress in early years until correct diagnosis and educational placement
- School problems, but a relatively good period
- Adolescence worsening of problems
- Adulthood additional problems

» Gray, 2002

Longitudinal Study

- Over ½ parents had significant depression and anxiety and 1/3 of these in therapy
- Career problems, especially mothers
- Most distressed parents had children with aggression and severe obsessions
- Improvement in emotional stress when children developed into less disorderly teens
- Improved relationships with extended families
- Decline in problems with other children

» Gray, 2002

Not Easier with HFA or AS

- Children with high functioning autism and AS have abilities that frequently mask their significant social challenges. This can result in denial of needed supports and require the parents to struggle to obtain services for their child.

» Klin, Volkmar & Sparrow, 2000

Asperger Syndrome (AS)

- “The challenges of parenting a child with AS should not be underestimated”
- Often those with AS do not get a diagnosis prior to age 4

» Epstein, Saltzman-Benaiah, O’Hare, Goll & Tuck, 2008, p. 503- 504

Ambiguous Loss

- Cause, symptoms, treatment and outcomes of autism are ambiguous and lead to perceptions of stress and inadequate functioning.
- Conflicting reports on cures
- Although child is physically present, s/he is not entirely psychologically present.
- When child diagnosed with ASD, the identities of the parent and child become unclear.

» O'Brien, 2007, p. 136

Ambiguous Loss

- Higher levels of identity ambiguity in mothers was linked to higher levels of depressive symptoms and perceived stress independent of the severity of the diagnosis.
- Identity ambiguity linked to immobilization, feeling overwhelmed and unable to change the situation, and difficulty adapting to change
- “The inconsistency in the child’s performance levels can keep family members off-balance” and never sure if child is not able or unwilling.

» O'Brien, 2007

Impact of External Circumstances

- Family income
- Extent disabilities are accepted
- Preexisting problems in family
- Spirituality and participation in religious activities
- Extent parents seek support and assistance

» Brobst, Clopton, & Hendrick, 2009

Impact on Family Life

- Major impact on finances:
 - Lost employment and income
 - Lost leisure time
 - Out of pocket expenses
- Sleep problems of the child with ASD disturbed the sleep of other family members
- Parents’ support needs are different at different life stages.

» Gray, 2006; Jarbrink, Fombonne, & Knapp, 2003; Patzold, Richdale, & Tonge, 1998; Tehee et al. 2009

Common Themes

- Increased risk of divorce
- Decrease in father’s involvement
- Greater parenting and psychological stress
- Often mothers reported > stress than fathers
- Higher levels of depression in parents
- Men tend to engage in problem focused coping and women in emotion focused coping.

– Brobst et al., 2009; Gray, 2003; Little, 2002; Pottie & Ingram, 2008; Tobing & Glenwick, 2006

Common Themes

- Compared to parents of children with other disabilities, parents of children with HFA & AS:
 - Reported higher levels of anxiety
 - Experienced worse physical health and health-related problems
 - Had less adaptive coping skills
 - Had more strain on the family system
 - Were less active in getting informal social support and in using reframing to deal with stress

» Hastings, 2003; Lee, 2009; Pakenham, Sofronoff, & Samios, 2004; Sivberg, 2002

Common Themes Compared to Control Groups

- Did mobilize family more to get help
 - More active in seeking professional help
 - On coping measures appeared:
 - Less optimistic
 - Less engaging in informal social support
 - Less use of reframing
- » Lee, 2009

Quality of Life (QOL) Comparisons

- Parents of children with HFASDs compared to parents of children with no disabilities:
 - More reported stress
 - Physical and mental health lower
 - Lower levels of adaptive coping and resources
- » Lee et al., 2009

QOL Study

- Higher stress predicted lower mental and physical health.
 - Higher income associated with better physical and mental health
 - More children predicted higher physical health
 - Coping did not contribute to QOL.
 - Intrapersonal factors may have mediated QOL (self-esteem, self-efficacy, optimism).
- » Lee et al., 2009

Mothers versus Fathers

- Mothers used wider varieties of coping (formal and informal support, spirituality and positive appraisal).
 - Mothers had higher depressive and anxiety symptoms.
 - Mothers assumed more care giving responsibility.
- » Hastings, 2003; Lee, 2009

Behavior Problems and Couple's Relationship

- Those with children with ASD and behavior problems experienced more parenting stress and lower relationship satisfaction than couples who did not have children with ASD.
 - Mothers of children with the most intensive behavior problems reported lower levels of support from spouse, respect for spouse, and commitment to their marriages.
- » Brobst et al., 2009.

Behavior Problems and Couple's Relationship

- Researchers concluded that support groups need to emphasize sustaining relationships at times of stress rather than having couple focus on parenting roles.
 - Important link between respect and relationship satisfaction suggested couples need to be helped to be explicit about their appreciation and respect.
 - One limitation of study was couples were highly educated and mostly Caucasian.
- » Brobst et al., 2009

Coping Responses

- Seeking support: Social Support
- Escaping or avoiding
- Doing problem solving: Problem Focused
- Seeking distraction
- Blaming or directing anger at someone
- Focusing on the positive or accepting:
Reframing

» Pottie & Ingram, 2008

Coping Responses

- Worrying a lot
- Expressing or controlling emotions:
Emotional Regulation
- Withdrawing socially
- Compromising or negotiating
- Feeling helpless/letting go

» Pottie & Ingram, 2008

Daily Stress and Coping

- Study done in VA with 93 parents
- 5 coping responses predicted increased positive mood
 - Problem Focused
 - Social Support
 - Positive Reframing
 - Emotional Regulation
 - Compromise

» Pottie & Ingram, 2008

Daily Stress and Coping

- 4 factors decreased positive mood
 - Escape
 - Blaming
 - Withdrawal
 - Helplessness
- ASD symptoms and time since diagnosis did **not** predict daily parental mood.

» Pottie & Ingram, 2008

Daily Stress and Coping

- Lower levels of daily negative mood predicted by Distraction and Emotional Regulation coping
- Higher levels of daily negative mood predicted by Problem-Focused, Blaming, Worrying, and Withdrawal coping
- Problem-Focused coping predicted increases in positive and negative mood; therefore, it may not always be an adaptive approach.

» Pottie & Ingram, 2008

Daily Stress and Coping

- Social Support moderated parenting stress in unexpected ways.
- When Social Support used on more stressful days, more daily negative mood reported.
- Gender did not moderate any of the daily coping-mood relationships.

» Pottie & Ingram, 2008

Psychological Stress in Mothers

- Mothers who had children with greater functional impairment reported higher parenting stress.
- Mothers of children with AS reported higher levels of parenting stress than did those with autism or PDD-NOS.
- Greater satisfaction with social support, but not number of supports, was associated with lower levels of stress.

» Tobing & Glenwick, 2006

Gray's Study on HFA

- Fathers recognized effect on family, but reported it did not effect them personally.
- Stress experienced by wife was described as disturbing by husbands.
- Fathers saw themselves as the reserve source of support for wives.
- Most fathers less involved in child rearing.

» Gray, 2003

Gray's 2003 Study

- Mothers' careers were more frequently affected than father's careers.
- Mothers had responsibility for medical appointments and crises at school.
- Mothers perceived failure of health care professionals to diagnose quickly as having negative effects on them.
- Mothers reported grieving the diagnosis and their husbands as having trouble accepting it.

Gray's 2003 Study

- Mothers tended to express feelings and emotions; fathers tended to suppress them.
- Mothers more likely to rely on talking to friends and family to deal with their emotions.
- Both mothers and fathers reported the following coping strategies: planned and reasonable response & taking 1 day at a time
- Dads: kept child busy at home & went to work
- Mothers: worked with child in therapy & separated child from siblings

A Few Words of Caution

- Most research consisted of families from middle and upper middle socio-economic classes so they most likely had more financial supports and resources than those from lower SES groups.

Enmeshment Found To Be Helpful

- Those who rated their family as enmeshed used more positive coping strategies than those who did not.
- Enmeshment may be more adaptive than originally thought for families that encounter extreme challenges.

» Altieri & von Kluge, 2009a

Also, there were many positive experiences expressed by parents as a result of having a child on the autism spectrum.

Mothers Redefined Fulfillment

- Placed less emphasis on career and more on parenting role
 - Engaged in more leisure activities with extended family
 - Placed less emphasis on others' opinions about child's behavior
 - Placed more emphasis on spousal support
 - Showed greater tolerance for ambiguity
- » Tunali & Power, 2002

Mothers

- Despite significantly higher stress level of mothers with children with ASD compared to mothers of typically developing children, these mothers reported close relationships with their children.
 - Researchers recommended interventions to reduce parental stress.
- » Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009

Resiliency Was Observed

- Adaptive coping demonstrated by parents of children with AS when they found benefits to their situation and when they developed sense-making explanations for adversity
 - Almost every parent of a child with autism described significant, positive experiences despite the challenges.
- » Altieri & von Kluge, 2009b; Packenham et al., 2004; Tway, Connolly, & Novak, 2007

Coping Strategies

- Higher coping scores for reframing in Asian Americans compared to Caucasians
 - Parents with English as second language scored higher on spiritual support than English speakers.
 - English speakers scored higher on passive appraisal than non English speakers.
- Tway et al. 2007

Benefits

- Positive personality change
 - Greater understanding of children with disabilities
 - Increased knowledge of ASD
 - Change in priorities and goals
 - New opportunities
 - Strengthening of relationships
 - Growth in faith/spirituality
- » Packenham et al., 2004

Comments from Parents

- “Appreciate life more in general”
- “No longer take things for granted”
- “We learned that all people are different.”
- “Having a child with this kind of problem (autism) changes your priorities.”
- “We learned more about ourselves when solving the challenges that we faced.”
- “We got rid of friends who shied away from autism or responded badly to it.”

» Altire & von Kluge, 2009b

Positives Shared from Others

- Parenting a child with ASD humbled them
- Gave them courage beyond words
- Gained patience
- Valued things ignored in the past
- Became less selfish
- Learned the true meaning of love
- Learned nothing was impossible with God

» Stillman, 2008

Recommendations Based on Research



General Recommendations

- School Psychologists need information on:
 - characteristics of ASDs
 - diagnostic procedures
 - research on outcomes for persons with ASD
 - knowledge of the research on parents coping
 - available resources in the community
 - knowledge of family systems
 - levels of family involvement
 - evidence-based or established treatments for ASD
 -

Established Treatments

- Antecedent Package
- Behavioral Package
- Comprehensive Behavioral Treatment for Children
- Joint Action Intervention
- Modeling

» National Autism Center, 2009

Established Treatments

- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package

» National Autism Center, 2009

Goals of Parent Training

- Decrease inappropriate behavior and increase appropriate child behavior
- Improve quality of family relationships
- Increase adaptive family functioning
- Enlist family members in change process

» Marcus et al., 2005

Parent Skills Training and Counseling

- Increased mental health and adjustment for parents of young, newly diagnosed as a result of:
 - 20-week parent education and counseling
 - 20-week parent education and behavior management
- No statistical evidence to support one treatment over the other.

» Tonge, Brereton, Kiomall, MacKinnon, King, & Rhinehart, 2009

Eight Family Approaches

- Education
- Parents as (co)therapists
- Behavioral approach
- Relationship enhancement
- Cognitive approach
- Emotional support
- Instrumental support
- Advocacy training

– Marcus et al., 2005

TEACCH Principles

- Understand autism as a developmental disorder
- Individuation and flexibility
- Importance of structure
- Parent-Professional collaboration
- Competencies and coping
- Consideration of total family needs
- Developmental continuum (family life cycle)

» Marcus et al., 2005

Parent Training Increased Self-Efficacy

- Education on AS
- Comic Strip Conversations
- Social Stories
- Management of behavior problems
- Management of rigid behaviors, routines, and special interests
- Anxiety management

» Sofronoff & Farbotko, 2002

Program Recommendations

- Clinical interventions to address *direct* and *indirect* consequences of ASD on families
- Programs need to provide respite and other supportive services to parents.
- Include programs based on positive behavior support to reduce child's behavioral difficulties.

» Benson, 2006

Program Recommendations

- Design programs to help parents make more effective use of existing supports from:
 - Family members
 - Friends
 - Other parents with ASD
 - » Benson, 2006

School Psychologists need to

- Recognize amount of knowledge parents have already gathered regarding cause and treatments.
- Not become a barrier by immediately challenging parents' beliefs but rather support parents and earn their trust.
- Realize that parents may or may not be experts on autism, but they *are* experts on their child.

School Psychologists need to remember

- Impact of ASD on families *changes* over time
- Importance of a family's culture and values
- Trusting relationships involve openness, acceptance, honesty and a willingness to stand in the shoes of the parents.
- Collaboration and good communication skills with parents and other professionals are critical.

Nonverbal Communication Skills

- Pace of speech
- Interpersonal distance and touch
- Gestures and postures
- Facial expressions
- Paralanguage
- Clothing and grooming

Verbal Communication Skills

- Furthering responses
- Paraphrasing
- Response to affect
- Questioning
- Summarization

Influencing Skills

- Providing information
- Providing support (social and affirming)
- Focusing attention
- Offering assistance (options not directives)

Difficult Situations

- If family in crisis may need to use:
 - assertiveness
 - conflict resolution
 - negotiation
 - ways to diffuse anger

Final Thoughts

- ASD can be considered a gift.
- It's just the way some people are
- It is a difference, not a disability.
- It is a marvelous occurrence of nature.
- It's not something to suffer from; we don't say that others suffer from being normal.
- ASD does not manifest itself in same way twice.

» Adapted from Hall, 2001 & O'Neill, 1999