

PROTECTING OUR CHILDREN: WHAT CAREGIVERS AND PROVIDERS NEED TO KNOW ABOUT RISK AND RESILIENCE OF RAISING CHILDREN WITH AUTISM AND OTHER DEVELOPMENTAL DELAYS

Paul M. Shawler, M.S.
paul-shawler@ouhsc.edu



OBJECTIVES

- Increase understanding of the prevalence and risk factors of maltreatment in ASD/DD
- Understand AAP and APA (Division 33) recommendations regarding maltreatment for DD including ASD
- Learn how disability status can impact the placement in child welfare systems and training recommendations for parents and professionals



OUTLINE

- Maltreatment in developmental disabilities
- Autism Spectrum Disorder (ASD)
- Risk factors of maltreatment
- Recommendations from the American Academy of Pediatrics
- Recommendations from the American Psychological Association, Division 33
- Policy & training considerations for caregivers and children
- Question & Answer / Discussion

TYPES OF MALTREATMENT

- Physical Abuse
 - I feel and react to pain
- Emotional Abuse
 - Just because I look like I'm not listening, doesn't mean I can't hear
 - Just because I don't hug, doesn't mean I don't like you around
- Sexual Abuse
 - I don't understand danger
- Neglect
 - I'm trying, but it is hard to communicate and do everyday things other people do. Please care for me.

DEVELOPMENTAL DISABILITY

- 7.3% of child maltreatment cases report a child with developmental disabilities
 - Likely an underestimate of actual rates
- 1 in 6 children have some form of DD
 - Intellectual Disability
 - Global Developmental Delay
 - Learning Disability
 - Physical Disability
 - Medical Problem
 - Speech/Language Delays
 - Autism Spectrum Disorder

MALTREATMENT IN DEVELOPMENTAL DISABILITIES

- Children with DD are 3.4 times more likely to be maltreated compared to typically developing peers (Sullivan & Knutson, 2000)
- Higher levels of disability are associated with increased risk of sexual abuse (Hershkowitz, Lamb, & Horowitz, 2007)
- Physical abuse tends to be underreported (Hershkowitz, 2007)

MALTREATMENT & DD CONT'D

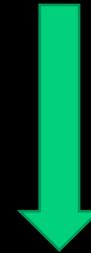
- Out-of-home placements are twice as likely after report of maltreatment (Lightfoot, Hill, & LaLiberte, 2011)
- Parents of children with DD often do not receive maltreatment prevention training (Mahoney & Poling, 2011)

POTENTIAL PATHWAYS OF MALTREATMENT AND DEVELOPMENTAL DISABILITY



Maltreatment

Developmental Disability



Developmental Disability

Maltreatment

AUTISM IS THE FASTEST GROWING DEVELOPMENTAL DISABILITY.

- 1 in 88 births (CDC, 2012); 1 in 68 (CDC, 2014)
- Approximately 50% have a co-occurring intellectual disability
- 30-50% have epilepsy
- 10% have a known genetic cause (e.g., fragile x, rett's disorder)
- Average age at diagnosis is after 4 years of age
- 70% of children are diagnosed with other psychological disorders (e.g., anxiety, behavioral problems)

AUTISM SPECTRUM DISORDER CHARACTERISTICS

Social Communication / Social Interaction

- Deficits in social-emotional reciprocity
 - Talking back and forth, understanding emotions in self and others, approaching others and requesting
- Deficits in nonverbal communication
 - Picking up on social cues like faces and body language
- Deficits in developing, maintaining, and understanding relationships
 - Often wonders on the outside of groups, difficulty sharing, sometimes considered “easy” or “content” babies – may or may not like social contact

ASD CHARACTERISTICS CONT'D

Restricted, Repetitive Patterns of Behavior

- Stereotyped or repetitive motor movements, use of objects, or speech
 - Hand flapping, putting fingers in front or face between light, repeating other words over and over, spinning or lining up objects over and over
- Insistence on sameness, inflexible adherence to routine, ritualized behavior
 - Does the same thing over and over and may have behavior problems if interrupted.
- Highly restricted and fixed interests
 - Highly knowledgeable (more than normal) about a topic, looks at a particular piece of an object (vs. playing with it as normal)
- Hyper- or hyporeactivity to sensory input

FAMILY FACTORS WITHIN DEVELOPMENTAL DISABILITIES

HASTINGS, 2002

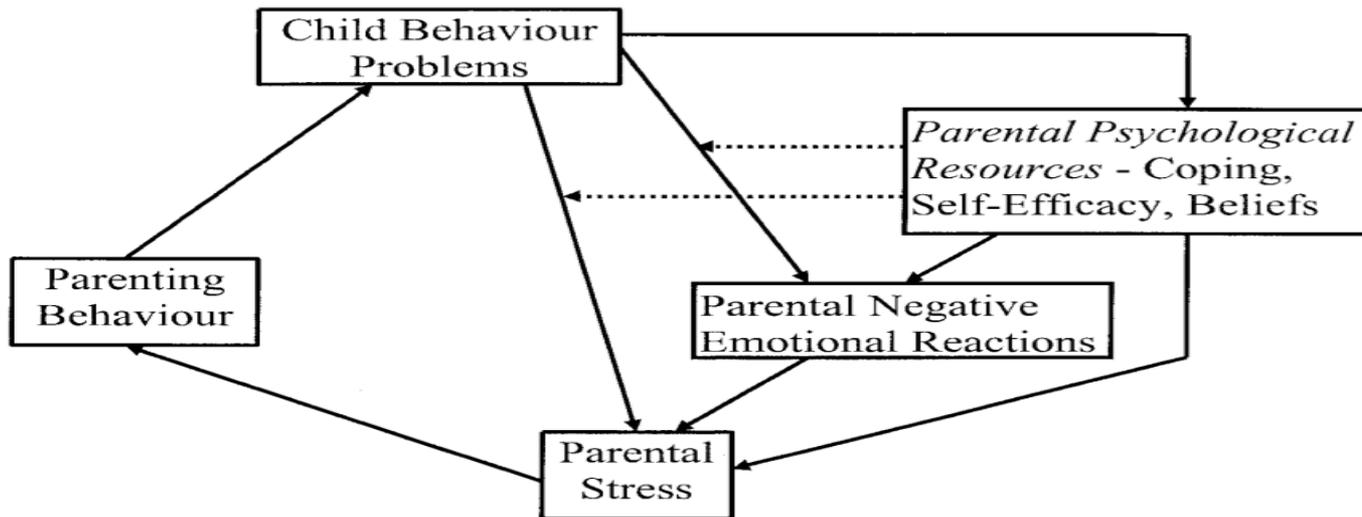


Figure 2.

Expanded model illustrating key variables affecting the relationship between child behaviour problems and parental stress (dotted lines indicate potential moderated effects).

RISK FACTORS OF MALTREATMENT FOR AUTISM

- "He didn't have that natural fear that other children might have had."
- "He also didn't have the reflexes to keep him from getting hurt when he was in those situations. You've got the worst of both worlds."

Court case of child abuse after a
death of a child with autism in Huntington, WV 2013

RISK AND STATISTICS

- Up to half of children with Autism are functionally nonverbal (Edelson, 2010)

HELP ME



**I CAN'T TELL YOU
WHERE IT HURTS!**

RISK AND STATISTICS

- Approximately 50% of children with Autism elope from safe environments (Law & Anderson, 2011)



RISK AND STATISTICS

- Two-thirds of parents report close calls with traffic accidents (Law & Anderson, 2011)



RISK AND STATISTICS

- One-third of parents report a close call with drowning (Law & Anderson, 2011)



RISK AND STATISTICS

- 25% of accidental deaths occur when children are not with their parents (Law & Anderson, 2011)
 - Implications for preventative measures and safety planning (even more extra precautions)



RISK AND SYMPTOMS

TANTAM, 2012

Rigid behavior and difficulty with empathy

- Potentially decreases quality of relationships
- Often results in increased parent stress
- Can appear defiant
- Child may become aggressive when not allowed to perform ritualistic behavior

RISK AND COMMON PROBLEM BEHAVIORS

Self-injurious behavior

- main causes of hospitalization in children with ASD (Mandell 2008)
- Rates vary significantly, but approximately 35% of individuals with ASD exhibit some form of self-injurious behavior (Bishop et al. 2006; Dominick et al. 2007; Richler et al. 2007; South et al. 2005).
- 50% incidence of ASD 18% Down Syndrome, 24% Fragile X (Richards, Oliver, Nelson, & Moss, 2012)
- head banging, hand or arm biting, hair pulling, eye gouging, face or head slapping, skin picking, scratching or pinching, forceful head shaking



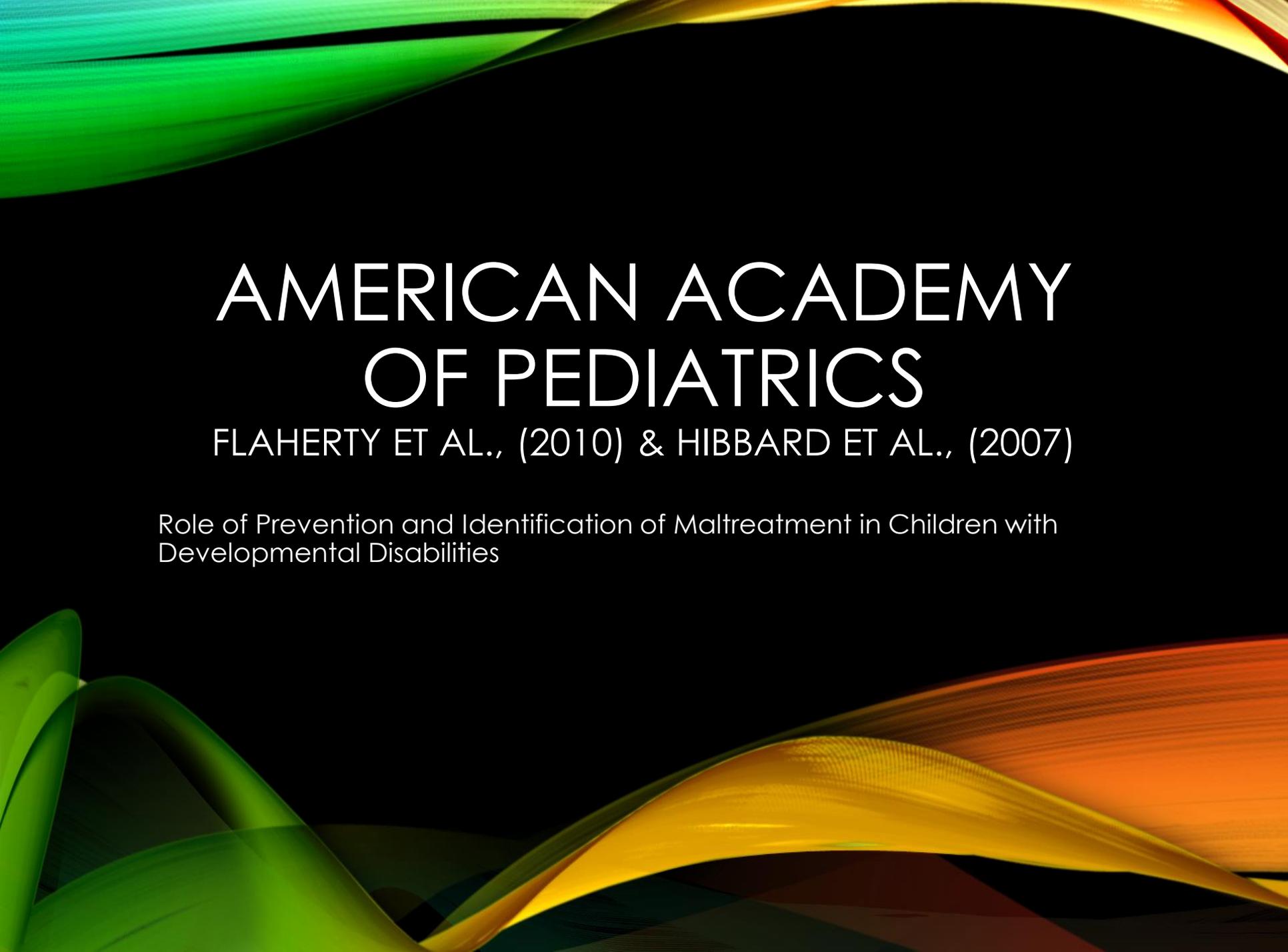
COMMON TREATMENT FOR INDIVIDUALS WITH AUTISM

- Often receive numerous treatments simultaneously
- Most common treatments; special education services, speech therapy, and occupational therapy
- Other forms of treatment can include medications
- Some children also receive alternative therapies that can be harmful



NEWS OF AUTISM AND MALTREATMENT...

Schools, hospitals, treatment centers, homes... It occurs in all contexts...



AMERICAN ACADEMY OF PEDIATRICS

FLAHERTY ET AL., (2010) & HIBBARD ET AL., (2007)

Role of Prevention and Identification of Maltreatment in Children with
Developmental Disabilities



PREVENTION STRATEGIES

- Locate a medical home
- Provide appropriate treatment for disability as early as possible
- Assess family needs including respite care
- Provide education and training to caregivers and those who are in contact with the child on the disability



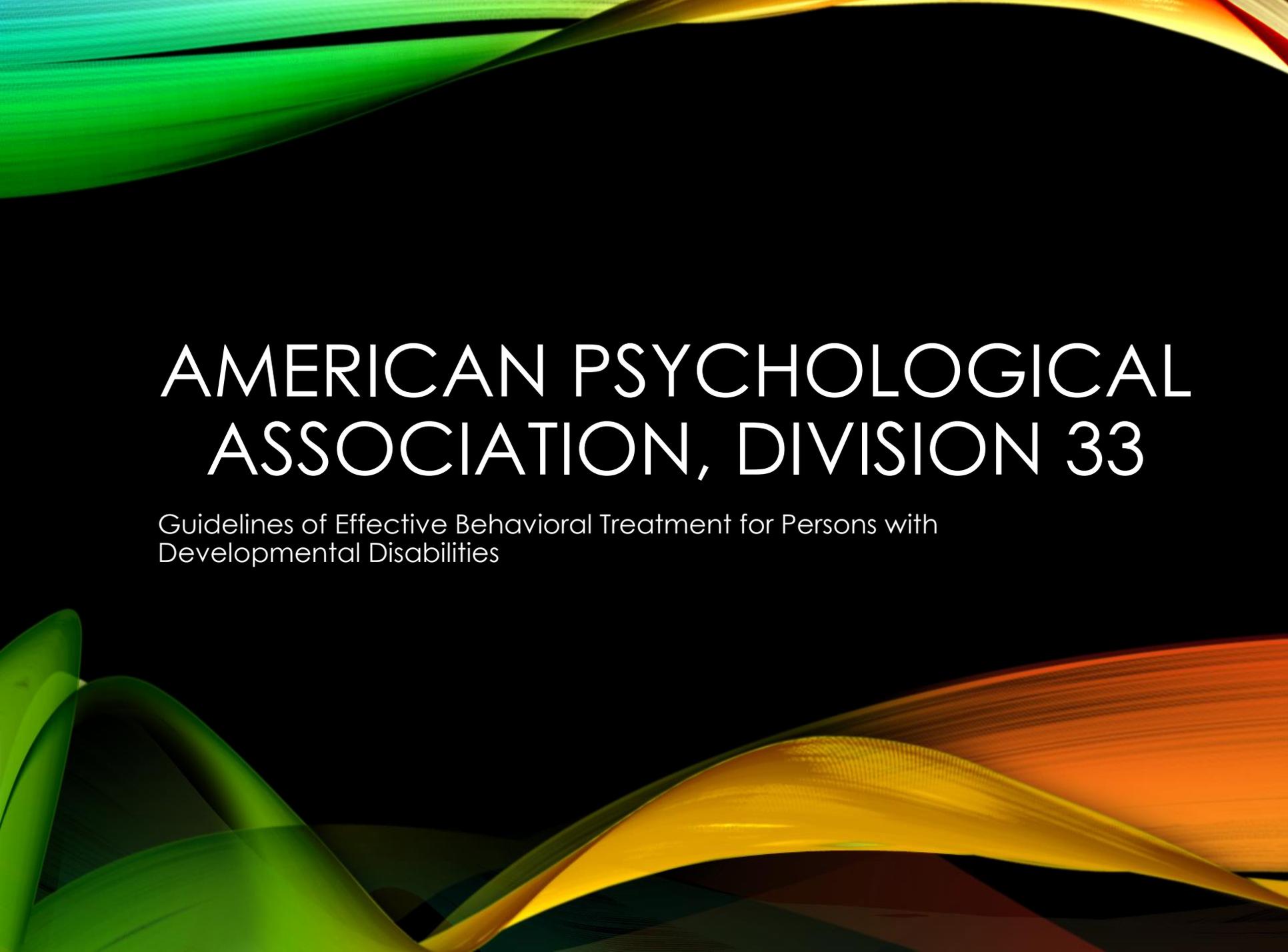
PREVENTION CONT'D

- Advocate for positive behavior supports across all contexts
- Recognize the signs of maltreatment and report suspicion of maltreatment
- Consult with other professionals



WHAT EVERY CAREGIVER AND WORKER SHOULD KNOW & DO

- Know the signs and symptoms of maltreatment
- Be familiar with conditions that pose an increase risk of accidental injury
- Provide ongoing assessment and documentation
- Be actively involved in treatment planning with family and interdisciplinary team (including positive behavior supports)



AMERICAN PSYCHOLOGICAL ASSOCIATION, DIVISION 33

Guidelines of Effective Behavioral Treatment for Persons with
Developmental Disabilities

POSITIVE BEHAVIOR SUPPORTS AND APPLIED BEHAVIOR ANALYSIS

“Highly restrictive procedures (which may entail interventions often referred to as aversive) shall not be instituted without the combined use of procedures that reinforce incompatible, alternative, or other behavior. Highly restrictive procedures shall not be employed until there has been sufficient determination that the use of less restrictive procedures was or would be ineffective or harm would come to the client because of gradual change in the client’s particular problematic behavior.”

ADDITIONAL CONSIDERATIONS

WHAT OPTIONS SHOULD WE CONSIDER?

- What if the child is at risk to him/herself or others?
- What if a medical procedure is necessary?
- Who should be involved in the decision?
- Who can I turn to for questions or concerns?

WHAT ARE THE FACTORS INVOLVED – time, money, people, facilities...

WHAT ARE POSITIVE BEHAVIOR SUPPORTS?

Strategies and Techniques that:

- Prevent problem behaviors by changing environmental factors
- Assess the function of the problem behavior (functional behavior)
- Target skill development for child with ASD to make problem behavior unnecessary.



PREVENTION STRATEGIES FOR PROBLEM BEHAVIOR

- Rule out medical reasons for problem behavior (e.g., chronic ear infections)
- Make it visual
- Understand the child's "triggers" and intervene with positive techniques before behavior occurs
- Assess environmental factors such as schedule or routines (i.e., reduce transitions and increase positive interactions)



POLICY AND ADVOCACY

- Early Identification
- Treatment
- Training
- Family Systems Perspective
- Informed decision making with expert consultation

POTENTIAL TRAINING NEEDS

- Disability specific training
- Individually tailored trainings to address specific symptoms
- Safety risk management
- Abuse prevention
- Sex education
- Daily routines and schedules of the individual
- Positive behavior support
- Communication training

Worried about a Child?

Ask Now! Advice column to stop child sexual abuse

- Ask your **question**
- Check **Warning Signs**
- Visit the **Online Help Center**
- Call the **Helpline** 1.888.PREVENT



Get Connected

Join with others to make your community safer

Quick Links

- Parents & Caregivers
- People Who Work With Children
- Survivors
- Warning Signs
- FAQs: Child Sexual Abuse Prevention
- FAQs: Sex Offender Registry
- Press Room

Child Sex Abuse Prevention and Protection Center



#12223

Join with us to keep children safe!

Since 1992 Stop It Now![®] has been preventing the sexual abuse of children by helping adults, families and communities take actions that keep kids safe - especially before they are ever harmed.

- Learn **what parents can do to keep kids safe**
- Read responses to real life questions in the advice column, **Ask Now**
- Visit our **Resources page** for links to tip sheets, guidebooks and other specialized prevention resources.

Is my autistic child being sexually abused at school



New Prevention Tip Sheets for Parents of Children With Disabilities



Training and Technical Assistance

Speak Up!
Keep a Child Safe



