



American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



New Jersey Chapter

Supporting New Jersey's Diverse Children and Families:

DEALING WITH ADVERSE CHILDHOOD EXPERIENCES AND RECOVERY POST SANDY



NEW JERSEY DEPARTMENT
OF CHILDREN AND FAMILIES

Outline

Learning Objectives

Putting it into Perspective

- Race and ethnic disparities of NJ's children
- Impact of Hurricane Sandy
 - One Parent's /Family's Experience
- Toxic Stress
- Brain Development
- Study of Adverse Childhood Experiences
- Resilience

Making This Work in Your Practice

- Communicating and Connecting
- Screening
- Self-Care for the Practice
- Linkages to Community Resources
- Continuing Care
- Medical Home

Questions



Learning Objectives

By the end of the session, participants will be able to:

- State some of the racial and ethnic disparities experienced by New Jersey's children that put them at increased risk of harms of trauma and toxic stress.
- Describe the extent of the Super Storm Sandy damage and why it may be very difficult for some children and families to fully recover from it.
- Describe common adjustment reactions in children experiencing toxic stress, including the unique ways that bereavement and specific risk factors make adjustment more difficult.
- Implement strategies for building resilience and protective factors in children and families that can ameliorate impacts of toxic stress.
- Apply communication techniques and screening tools that can assist with recognizing distress in children that may result following a disaster.
- State the rationale for implementing Quality Improvement (QI) initiatives that can assist with identification of children at risk for toxic stress, strengthen medical home practices, and support longer term management of higher risk families.
- Identify community linkages to strengthen practices' capacities to respond to distress in children and their families.



Putting it into Perspective

Impact of Hurricane Sandy



Poverty and New Jersey's Children

- In 2013, in each of NJ's 21 counties, there were children living below poverty – 17% for the state but the range was from 4% in Morris County to 38% in Salem County.
- Also in 2013, about half of the state's total child population was black, Hispanic, Asian, another race or mixture of races.

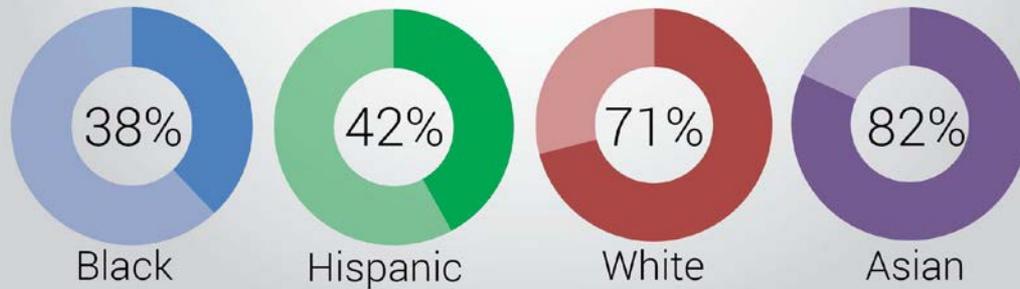


Kids in Poverty by Race



4th Grade State Test Passing Rates by Race

Language Arts, 2013-14 School Year



acnj.org



NJ Children in Foster Care

acnj.org

By Race

Black: 42%

White: 30%

Hispanic: 20%



Black children make up 15 percent of the child population, but are significantly over-represented in foster care.



Infant Mortality

By Race, per 1,000 live births

Black Infants: 11

4 White Infants

4 Hispanic Infants

2 Asian Infants



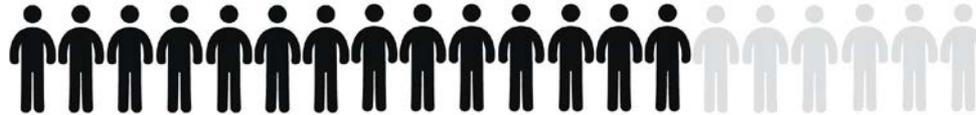
Infant mortality rate is the number of deaths of children less than one year of age per 1000 live births.



2015 NJ Kids Count Data Book

NJ Black Youth Behind Bars

Black teens make up 14% of New Jersey's youth



Black Teens Arrested: 41%

White Teens Arrested: 57%

Black Teens in Juvenile Detention Centers: 65%

14% White Teens in Juvenile Detention Centers



acnj.org



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-
- “New Jersey’s black, Hispanic, and mixed-race children are more likely to live in poverty, experience negative health outcomes, be involved in the state child protection and juvenile justice systems and struggle in school.”

Advocates for Children of New Jersey, April 2015 *Race for Results: Creating a Path of Opportunity for All Children*, p. 1.



Impact of Hurricane Sandy in NJ



- 38 people lost their lives
- 346,000 homes were damaged or destroyed
- 107,300 people lost their jobs
- Lost wages due to the Storm totaled \$833M
- The remaining unmet need is \$28.4 billion

ALICE Households

According to ALICE (Asset-Limited, Income-Restrained, Employed) Study of 2012

- 1/3 of NJ families do not earn enough to afford a basic survival budget. Families are above the poverty line but below financial stability.
- 69% had no home owners insurance, 90% had no flood insurance
- \$2.2B gap between residential damage / income lost and what survivors are able to rebuild / make up

Since many were already living in poor conditions, Sandy was a crisis from which they may never recover.

School of Public Affairs and Administration, Rutgers-Newark

THE IMPACT OF SUPERSTORM SANDY ON NEW JERSEY TOWNS AND HOUSEHOLDS



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One Parent's Story...



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My family, Nicole, Alexis and Jordan



Trauma

- Evolution of trauma in my family
- Survived and endured a Domestic Violent marriage for 11 years
- Had two children born 5 years apart both at 26 weeks gestations. Daughter (Alexix,20) learning disability and mental health diagnosis
- Son (Jordan, 15) mild Cerebral Palsy and neurological cognitive developmental delay
- In October 29, 2012 Hurricane Sandy hit Jersey City



Affects of Hurricane Sandy

- Lived without electricity for 8 long days
- There was no heat and food spoiled
- Had to pack up my children to find places to stay, which at times was difficult
- The trauma from Hurricane Sandy affected me socially and emotionally.
- Needed to keep my children safe, fed and crisis free



After affects

- Emotional affects in connection to electrical blackouts.
- Feel stress when ever there is a rain or snow storm.
- Make sure my children are safe and go over emergency evacuation. Jordan registered on the emergency response county disability registry .



Toxic Stress



Types of Stress, Examples, & Physical Response



- **Positive**
- **Tolerable**
- **Toxic**

http://developingchild.harvard.edu/topics/science_of_early_childhood/toxic_stress_response/

Toxic Stress: The Facts, Center on the Developing Child at Harvard University

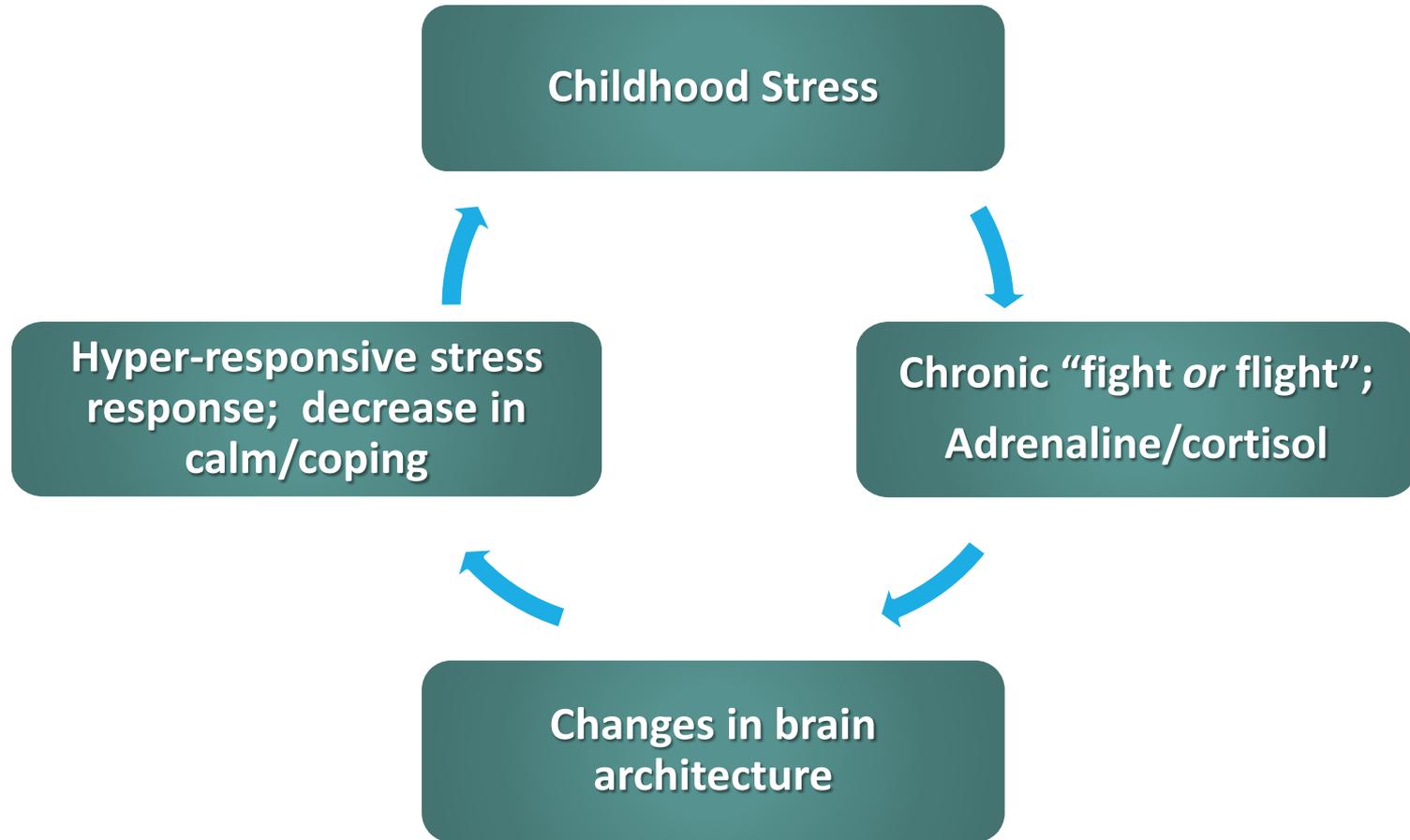
Children's Responses to Stress

<u>AGE:</u>	<u>RESPONSES:</u>
Younger children may. . .	<ul style="list-style-type: none">• Regress behaviorally• Have strong startle responses, nightmares, and outbursts• Process stress through play, drawing, and storytelling• Cling to parents
School-age children may. . .	<ul style="list-style-type: none">• Experience guilt or shame• Constantly retell the stressful situation• Have extreme feelings of fear, sadness or worry• Complain of stomach aches and headaches• Have sleep disturbances, difficulty concentrating/learning• Engage in reckless or aggressive behavior
Adolescents may. . .	<ul style="list-style-type: none">• Feel self-conscious about their emotional responses• Withdraw from family and friends• Experience feelings of fear, shame and guilt• Have a radical shift in the way they think about the world• Engage in self-destructive or accident-prone behaviors

Brain Development



Brain Development and Toxic Stress



[Dr. Collen Kraft "The First 1000 Days: The Importance of Early Brain and Childhood Development"](#)



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**Study of
Adverse Childhood
Experiences**



Critical Concept : Childhood Adversity Has Lifelong Consequences

Significant adversity in childhood is
strongly associated with
unhealthy lifestyles and
poor health **decades** later.



ACE Study

- Analyzed the relationship between multiple categories of ***Adverse Childhood Experiences*** (ACEs), and health and behavioral outcomes later in life
- Data on over 17,000 participants gathered from various sources including outpatient medical records, pharmacy utilization records, and hospital discharge records to track the health outcomes and health care use of ACE Study participants

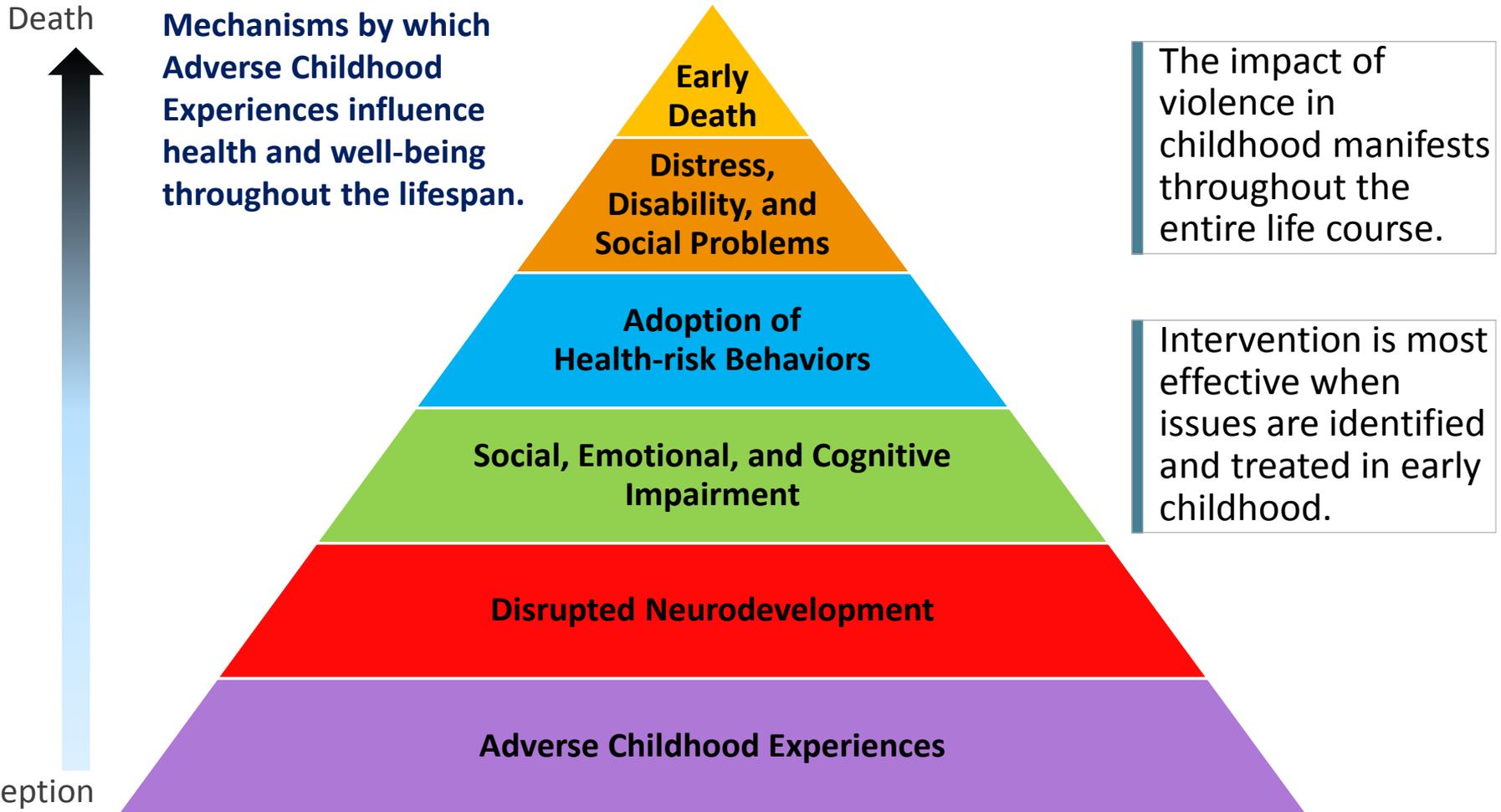


Categories of ACEs

- Physical abuse
- Emotional abuse or neglect
- Sexual abuse
- Substance abuse in the household
- Incarcerated household member
- Household member with mentally illness
- Mother treated violently
- Parental separation or divorce



How ACEs Impact Health



ACE Scoring

- You get one point for each type of trauma. The higher your ACE score, the higher your risk of health and social problems.
- With an ACE score of 4 or more, things start getting serious. The likelihood of:
 - Chronic Pulmonary Lung Disease Increases 390%
 - Hepatitis 240%
 - Depression 460%
 - Suicide 1,220%

<http://acestoohigh.com/got-your-ace-score/>



ACE Scores

ACE Scores	Prevalence
0	36.4%
1	26.2%
2	15.8%
3	9.5%
4	6.0%
5	3.5%
6	1.6%
7 or more	0.9%

64% reported experiencing one or more

37% reported experiencing two or more

Number of individual adverse childhood experiences were summed.



ACE Study Findings

ACEs in childhood are related to adult disease by two etiological mechanisms:

- Conventional Risk factors – attempts of self help through use of agents like nicotine, alcohol and drugs
- The effect of chronic stress on the developing brain and body systems



Resilience



Protective Factors for Resilience

Safe, cohesive neighborhood

***Basic needs met :
Food, Housing, etc.***

***Access to healthcare
and social services***



***Connection with a
caring, stable adult***

Safe home

National Scientific Council on the Developing Child. *Excessive Stress Disrupts the Architecture of the Developing Brain: Working Paper #3*. Cambridge, MA: National Scientific Council on the Developing Child, Center on the Developing Child at Harvard University; 2005. Available at www.developingchild.harvard.edu. Accessed January 17, 2014.



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The Essential Building Blocks of Resilience

Bottom Line #1:

Young people live up or down to expectations we set for them. They need adults who believe in them unconditionally and hold them to the high expectations of being compassionate, generous, and creative.

Bottom Line #2:

What we do to model healthy resilience strategies for our children is more important than anything we say to them.



Building Resilience

- Address parent needs to increase stability in the home
- Educate parents about children's emerging social-emotional-language skills
- Talk about and encourage adoption of positive parenting techniques
- Ask about and help to strengthen family's social supports
- Link to community resources

AAP Policy Statement "Early Childhood Adversity, Toxic Stress, and the Role of the Pediatrician: Translating Developmental Science Into Lifelong Health "



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Critical Concept :

For young children, **parent/caregiver support is critical**

- Turns off physiologic stress response by addressing physiologic and safety needs
- Turns off the physiologic stress response by promoting healthy relationships and attachment
- Notes and encourages foundational coping skills as they emerge

Pediatricians are ideally placed to:

- Promote this sort of “Purposeful” Parenting
- Advocate for a public health approach to address toxic stress

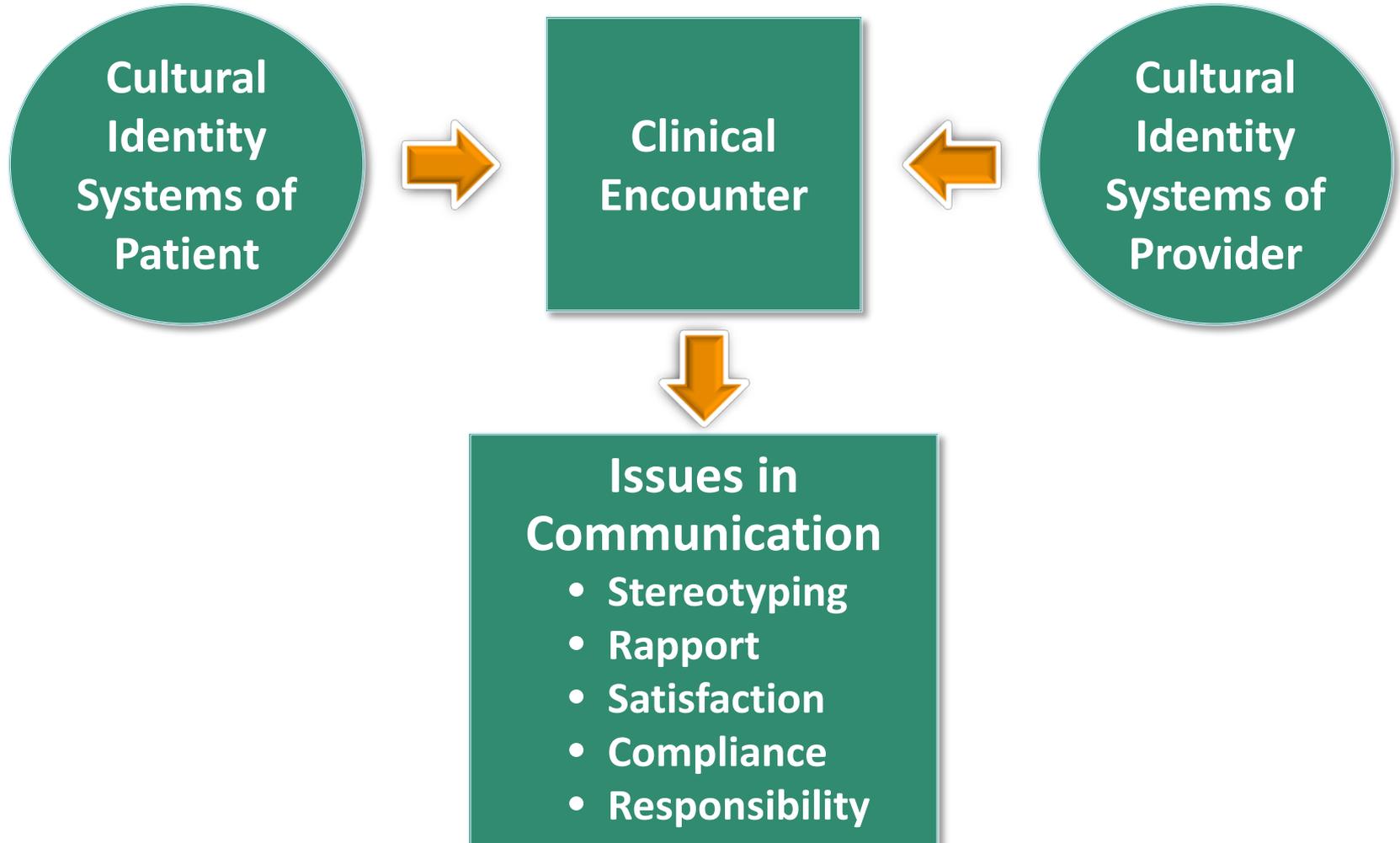


Making this Work in your Practice

*Communicating and
Connecting*



Everyone Brings Their Culture



Factors Impacting Effective Communication

- Culture
- Trust/Mistrust
- Low Health Literacy
- Language Access
- Spiritual and Religious Diversity
- Sexual Orientation/Gender Identity/Gender Expression
- Disabilities and Other Special Needs
- Bias and Stereotyping



The Basics of Creating a Safe Environment

Ask Open-Ended Questions

- Use patient's own words
- Ask questions in a tone that invites openness

Pay Attention to Non-Verbal Communication

- Put patient at ease by considering your eye contact, facial expressions, and your own as well as patient's body language
- Convey respect, interview in a private setting

Convey Care and Empathy

- Acknowledge their feelings
- Use language that is non-judgmental
- Consider things through the family's lens



Common Factors Interventions - H.E.L.P.

HOPE

EMPATHY

LANGUAGE and LOYALTY

PERMISSION, PARTNERSHIP and PLAN

Wissow LS, Gadomski A, et al. Improving Child and Parent Mental Health in Primary Care: A Cluster-Randomized Trial of Communication Skills Training. *Pediatrics*. 2008; 121 (2): 266-275.



Psychological First Aid

- Provide broadly to those impacted
- Supportive services to foster normative coping and accelerate natural healing process
- All staff should understand likely reactions and how to help children cope

Anyone who interacts with children can be a potential source of assistance and support – if unprepared, they can be a source of further distress

David J. Schonfeld, MD, FAAP, Director, Nat'l Center for School Crisis and Bereavement



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Psychological First Aid Actions

- Observation or awareness
- Make a connection
- Help people feel comfortable and at ease
- Be kind, calm, & compassionate
- Assist with basic needs

- Listen
- Give realistic reassurance
- Encourage good coping
- Help people connect
- Give accurate and timely information
- Suggest a referral resource
- End the conversation

Source: American Red Cross



Residual Effects of a Crisis – Feelings of Loss

- Future events can lead to temporary resurgence of feelings from past crisis, even if new event is not related – can trigger feelings of Grief, Trauma, Loss
- Children’s general lack of control over their lives means they place a huge importance on feelings of safety and security.
- Loss of a home/neighborhood, parent’s job, change of school, friends – all create a larger feeling of loss of their sense of **SECURITY**.



Screening



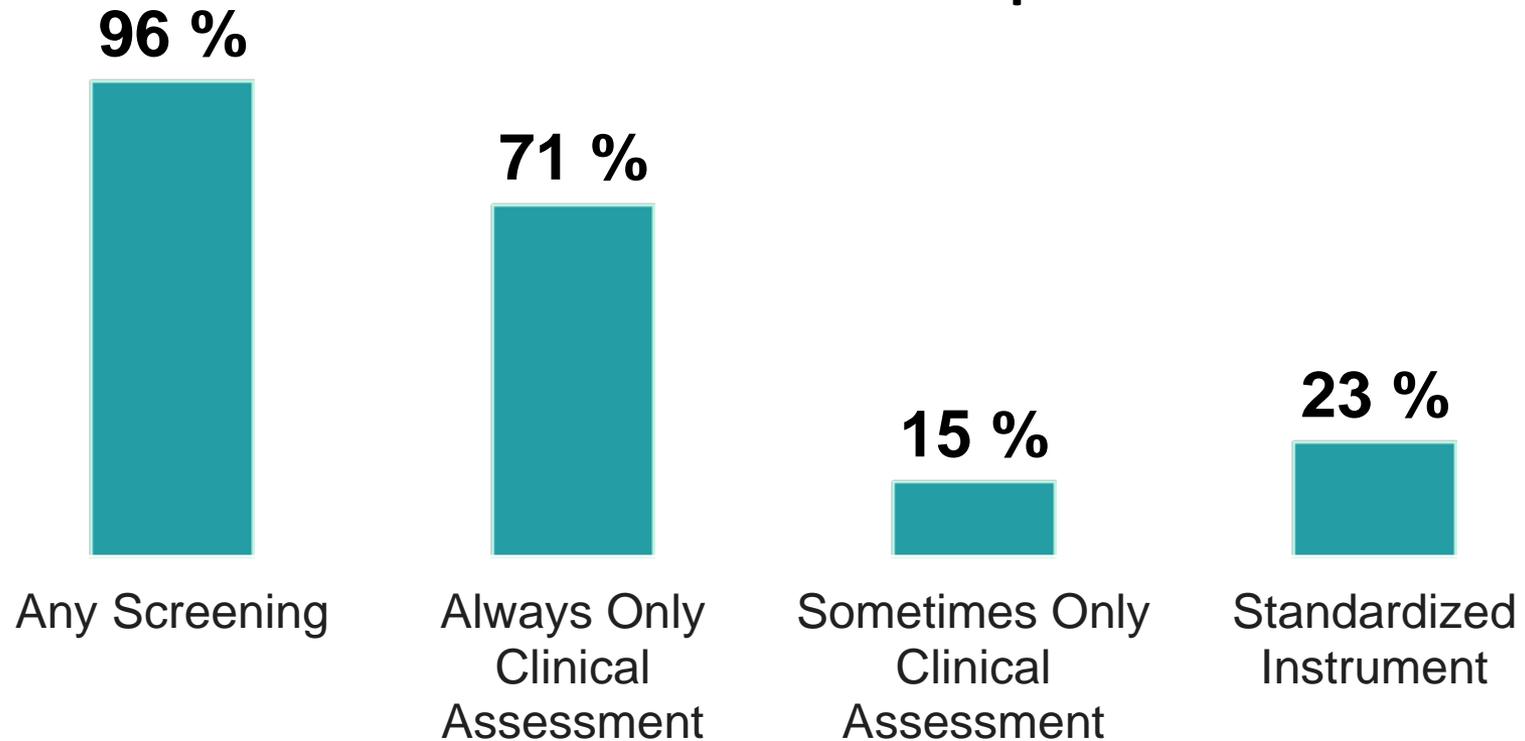
The Importance of Standardized Screening

- Parents Often Underestimate Symptoms:
 - Children may withhold complaints because of concerns they are abnormal, or to protect parents who are upset
 - Parents may not think professionals are interested or assume “normal reactions to abnormal event”
 - Stigma related to mental illness



Developmental Screening

Percent of Pediatricians Screening Young Children for Developmental Problems



AAP Periodic Survey #53, 2002



SWYC



Survey of the Wellbeing of Young Children:

- Comprehensive surveillance or first-level screening instrument for routine use in regular well child care.
- Sections on developmental milestones, social/emotional development
- Combines what is traditionally “developmental” with traditionally “behavioral” screening, and adds screening for autism, parental depression and other family risk factors.
- Freely-available, takes 15 minutes or less to complete, for ages 2 months – 5 years

Tufts University School of Medicine, <http://www.theswyc.org/>



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Ages and Stages Questionnaire



Ages & Stages Questionnaires®,
Third Edition (ASQ-3)

1. Ages and Stages Questionnaire (ASQ)
 - Strictly developmental screen of 5 domains of development: communication, gross motor, fine motor, problem solving, personal-social

2. Ages and Stages Questionnaire: Social-Emotional (ASQ-SE)
 - Taps temperament, behavior, regulations, attention, etc.
 - For children 1 – 66 months
 - Parent completed tool
 - IDs children in need of further assessment



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Pediatric Symptom Checklist

- A psychosocial screen designed to facilitate the recognition of cognitive, emotional, and behavioral problems so that appropriate interventions can be initiated as early as possible
- Can be used for ages 6-18.
- Available in multiple languages and a pictorial version
- Parent version available for young children ages 6 to 11 and self assessment from age 11 and up.

http://www.massgeneral.org/psychiatry/services/psc_scoring.aspx



Linkages
to Community
Resources



Children's System of Care (CSOC)

- Committed to providing services based on the needs of the child and family in a family-centered, community-based environment.
- Serves children and adolescents:
 - in need of behavioral and mental health services
 - in need of substance abuse services up to age 21
 - with intellectual and developmental disabilities up to age 21



PerformCare

- Single point of entry for all children and adolescents entering the New Jersey CSOC to help families and caregivers create a more stable and healing environment for children, and maximize youth and family strengths.
- **Available 24 hours a day, 7 days a week**, families should call if their child's behavior has changed from normal or if they are overwhelmed by challenges at home or in the community.

1-877-652-7624

TTY: 1-866-896-6975



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Resources - State

Help with Basic Needs

- 211 (Available 24/7)
- NJ Help – www.njhelps.org
- NJ Housing Resource Center – 1-877-428-8844
- End Hunger NJ – www.endhungernj.org

Mental Health

- Mental Health Cares Hotline – 1-866-202-4357
- PerformCare – 1-877-652-7624



Resources - State

Abuse Hotlines

- NJ Child Abuse and Neglect
1-877-NJ ABUSE
- Statewide Sexual Assault Hotline
1-800-601-7200
- Statewide Domestic Violence Hotline
1-800-572-SAFE



Disaster Resources - State

- Hurricane Sandy Information Center
- FEMA Disaster Survivor Assistance
- New Jersey Strong



Continuing Care



Building Sustainable Practices and the Utility of the M-CHAT

ROBERT R. KRUSE, MD, MPH

CHIEF RESIDENT, RUTGERS RWJMS

FAMILY MEDICINE RESIDENCY PROGRAM AT CENTRASTATE

Disclosures

I have no actual or potential conflict of interest in relation to to this presentation



What is a Coordinated System of Care

Comprehensive approach to screening for developmental delay

Recognizes that there are many experts in a child's life

Recognizes that care should be delivered in a family-centered approach

Coordinates resources and avoids duplication of services

Helps ensure seamless transition from screening, referral and follow-up

Applies the concepts central to medical home creating a comprehensive developmental screening program



AIM Statement

- Improve and integrate the screening of Autistic Spectrum Disorders with the use of the MCHAT screening tool in the ages of 18 and 24 months in our FMRP with the goal of improving identification of Autism Spectrum Disorders and the outcome by referring to appropriate early interventional services
- Measurable Goal: 50% of well child visits in 18 and 24 month olds will have MCHAT screenings performed
- Measurable period: 8/1/2014 - 2/1/15



Why Screen?

1 out of 6 children are identified with a developmental disorder and/or behavior problem

1 in 88 children are diagnosed with an autism spectrum disorder

Developmental disorders have subtle signs and may be easily missed

Autism Spectrum Disorder is presumably present at birth, with onset of symptoms before 36 months



Importance of Effective Early ID of ASD

CDC determines ASD as a health issue of “critical importance” (CDC 2009)

Early ID provides more intervention opportunities

More intervention = can optimize long term outcome, reduce lifetime cost of services, improve functional independence



M-CHAT

Regular well-child visit

- 18 months
- 24 months

Additional screening might be needed if child is high risk for ASD

- Low birth weight
- Pre-term birth
- Sibling or parent with ASD



The Right Screening Tool

Ages

- What age groups do we serve and what screening tools are made for those ages?

Time

- How much time does it take to use the screening tool?
- Which tool is practical?

Cost

- What is the cost for the screening tool and its ongoing use

Training

- Is there training required to use this screening tool?
- How much training is required?

Languages

- Does the screening tool need to be available in different languages to fit the needs of the families we serve?



M-CHAT

Modified Checklist for Autism in Toddlers

A screening tool used for the early detection of Autism Spectrum Disorder (ASD)

6th-grade reading level

Does not rely on physician's observations of the child

A practical tool for primary care offices

Expanded American version of the Checklist for Autism in Toddlers (CHAT) (Baron- Cohen et al., 1992)



M-CHAT

23 items- Questionnaire completed by parent

Time- parent completion: 5-10 min

Time- provider to score/interpret: 2 min

Validated for screening between 16-30 months

Goal to screen with much wider sensitivity than CHAT, to identify more children with ASD earlier, even though this might mean some false-positives

To account for potential regressions, the M-CHAT should be administered both at 18 & 24 months to increase sensitivity



M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

- | | | |
|--|-----|----|
| 1. Does your child enjoy being swung, bounced on your knee, etc.? | Yes | No |
| 2. Does your child take an interest in other children? | Yes | No |
| 3. Does your child like climbing on things, such as up stairs? | Yes | No |
| 4. Does your child enjoy playing peek-a-boo/hide-and-seek? | Yes | No |
| 5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things? | Yes | No |
| 6. Does your child ever use his/her index finger to point, to ask for something? | Yes | No |
| 7. Does your child ever use his/her index finger to point, to indicate interest in something? | Yes | No |
| 8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them? | Yes | No |
| 9. Does your child ever bring objects over to you (parent) to show you something? | Yes | No |
| 10. Does your child look you in the eye for more than a second or two? | Yes | No |
| 11. Does your child ever seem oversensitive to noise? (e.g., plugging ears) | Yes | No |
| 12. Does your child smile in response to your face or your smile? | Yes | No |
| 13. Does your child imitate you? (e.g., you make a face-will your child imitate it?) | Yes | No |
| 14. Does your child respond to his/her name when you call? | Yes | No |
| 15. If you point at a toy across the room, does your child look at it? | Yes | No |
| 16. Does your child walk? | Yes | No |
| 17. Does your child look at things you are looking at? | Yes | No |
| 18. Does your child make unusual finger movements near his/her face? | Yes | No |
| 19. Does your child try to attract your attention to his/her own activity? | Yes | No |
| 20. Have you ever wondered if your child is deaf? | Yes | No |
| 21. Does your child understand what people say? | Yes | No |
| 22. Does your child sometimes stare at nothing or wander with no purpose? | Yes | No |
| 23. Does your child look at your face to check your reaction when faced with something unfamiliar? | Yes | No |



Por favor conteste acerca de como su niño (a) es **usualmente**. Por favor trata de contestar cada pregunta. Si el comportamiento de su niño no ocurre con frecuencia, conteste como si no lo hiciera.

- | | | |
|---|----|----|
| 1. ¿Disfruta su niño (a) cuando lo balancean o hacen saltar sobre su rodilla? | Sí | No |
| 2. ¿Se interesa su niño (a) en otros niños? | Sí | No |
| 3. ¿Le gusta a su niño (a) subirse a las cosas, por ejemplo subir las escaleras? | Sí | No |
| 4. ¿Disfruta su niño (a) jugando "peek-a-boo" o "hide and seek" (a las escondidas)? | Sí | No |
| 5. ¿Le gusta a su niño (a) jugar a pretendar, como por ejemplo, pretende que habla por teléfono, que cuida sus muñecas, o pretende otras cosas? | Sí | No |
| 6. ¿Utiliza su niño (a) su dedo índice para señalar algo, o para preguntar alguna cosa? | Sí | No |
| 7. ¿Usa su niño (a) su dedo índice para señalar o indicar interés en algo? | Sí | No |
| 8. ¿Puede su niño (a) jugar bien con juguetes pequeños (como carros o cubos) sin llevárselos a la boca, manipularlos o dejarlos caer)? | Sí | No |
| 9. ¿Le trae su niño (a) a usted (padre o madre) objetos o cosas, con el propósito de mostrarle algo alguna vez? | Sí | No |
| 10. ¿Lo mira su niño (a) directamente a los ojos por mas de uno o dos segundos? | Sí | No |
| 11. ¿Parece su niño (a) ser demasiado sensitivo al ruido? (por ejemplo, se tapa los oídos)? | Sí | No |
| 12. ¿Sonríe su niño (a) en respuesta a su cara o a su sonrisa? | Sí | No |
| 13. ¿Lo imita su niño (a)? Por ejemplo, si usted le hace una mueca, su niño (a) trata de imitarlo? | Sí | No |
| 14. ¿Responde su niño (a) a su nombre cuando lo(a) llaman? | Sí | No |
| 15. ¿Si usted señala a un juguete que está al otro lado de la habitación a su niño (a), lo mira? | Sí | No |
| 16. ¿Camina su niño (a)? | Sí | No |
| 17. ¿Presta su niño (a) atención a las cosas que usted está mirando? | Sí | No |
| 18. ¿Hace su niño (a) movimientos raros con los dedos cerca de su cara? | Sí | No |
| 19. ¿Trata su niño (a) de llamar su atención (de sus padres) a las actividades que estada llevando a cabo? | Sí | No |
| 20. ¿Se ha preguntado alguna vez si su niño (a) es sordo (a)? | Sí | No |
| 21. ¿Comprende su niño (a) lo que otras dicen? | Sí | No |
| 22. ¿Ha notado si su niño (a) se queda con una Mirada fija en nada, o si camina algunas veces sin sentido? | Sí | No |
| 23. ¿Su niño le mira a su cara para chequear su reacción cuando esta en una situación diferente? | Sí | No |



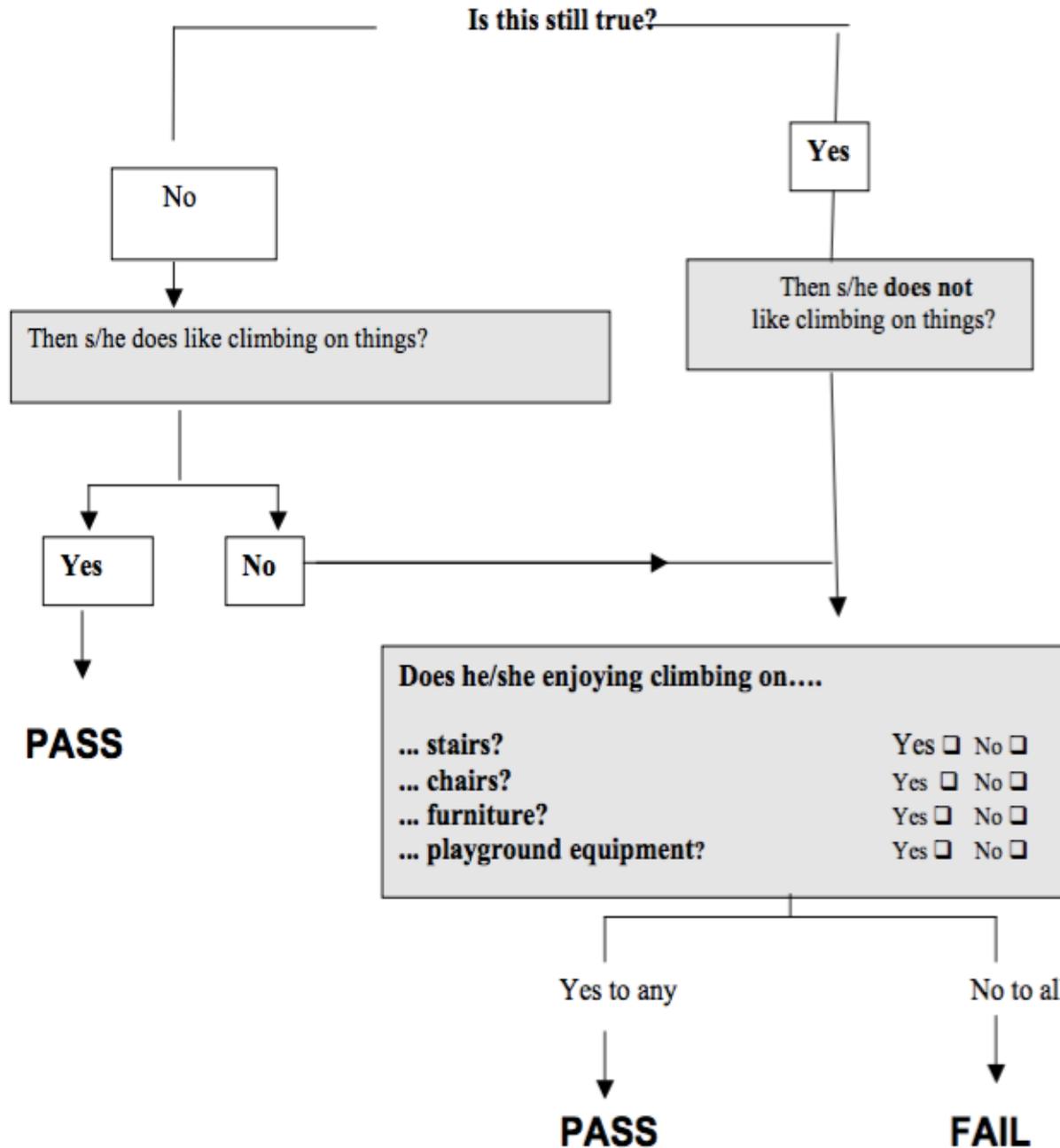
Scoring

A child fails the checklist when 2 or more critical items are failed OR when any three items are failed

M-CHAT follow-up interview: clarifying questions that can be used to increase positive predictive value of a positive screen



3. You reported that _____ does not like climbing on things, such as up stairs.



Does Screening mean becoming an expert in evaluating a child's Development? No...

Screening is looking at the whole population to identify those at risk

Identified children are referred for assessment

Assessment determines the existence of delay or disability, which generates a decision regarding intervention



CentraState Family Medicine Residency Practice

Language barrier

Residency program

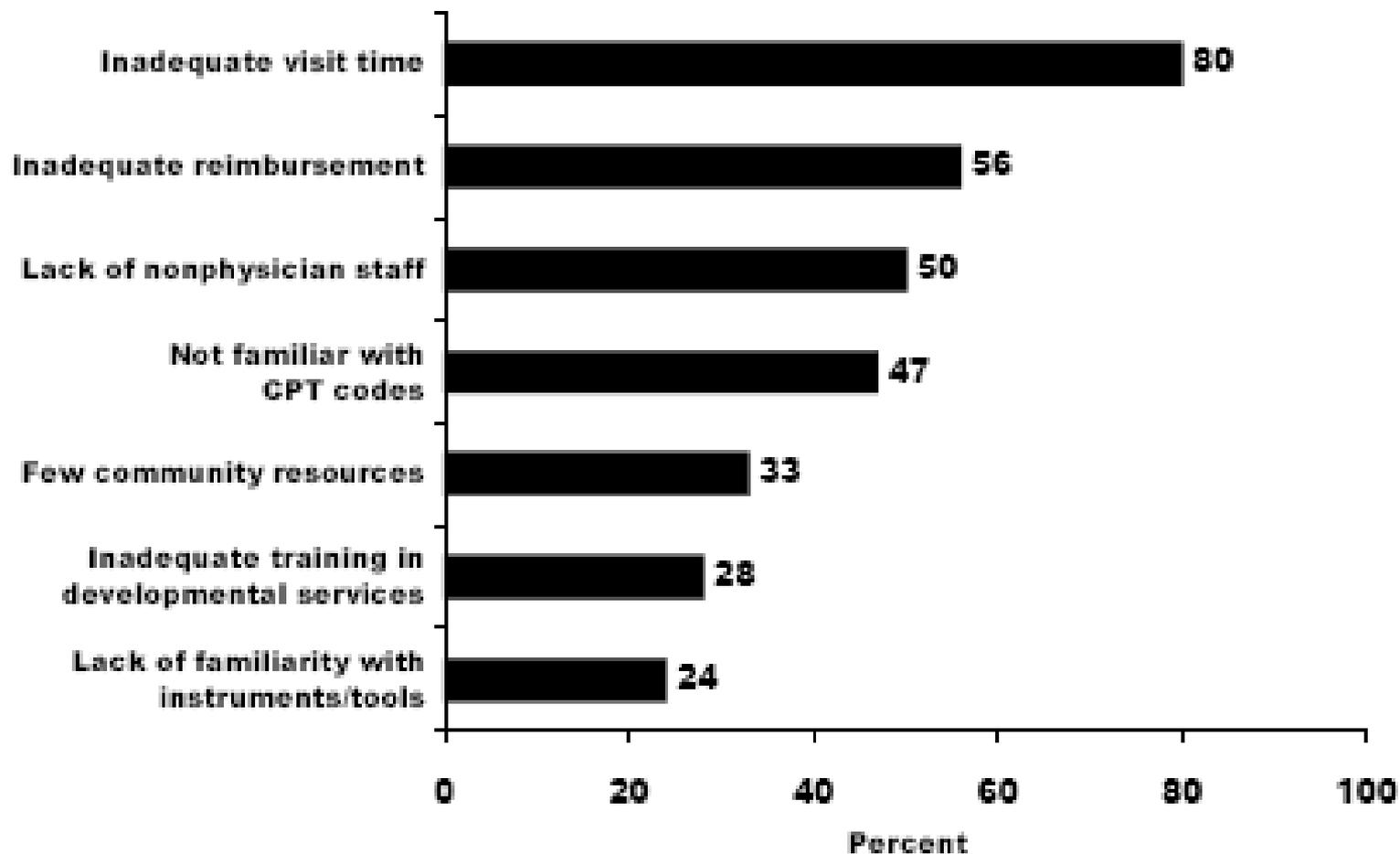
Patient's with illiteracy need to have questions read to them

Barriers

- Lack of time to implement an additional procedure
- M-CHAT may be perceived as replacing clinical judgment



Figure 5. Pediatricians' Reported Barriers to Delivering Developmental Assessments



Source: American Academy of Pediatrics Periodic Survey of Fellows #46, 2000.



How to administer the M-CHAT

Can be given to parents or guardians before a well-child visit while they sit in the waiting room

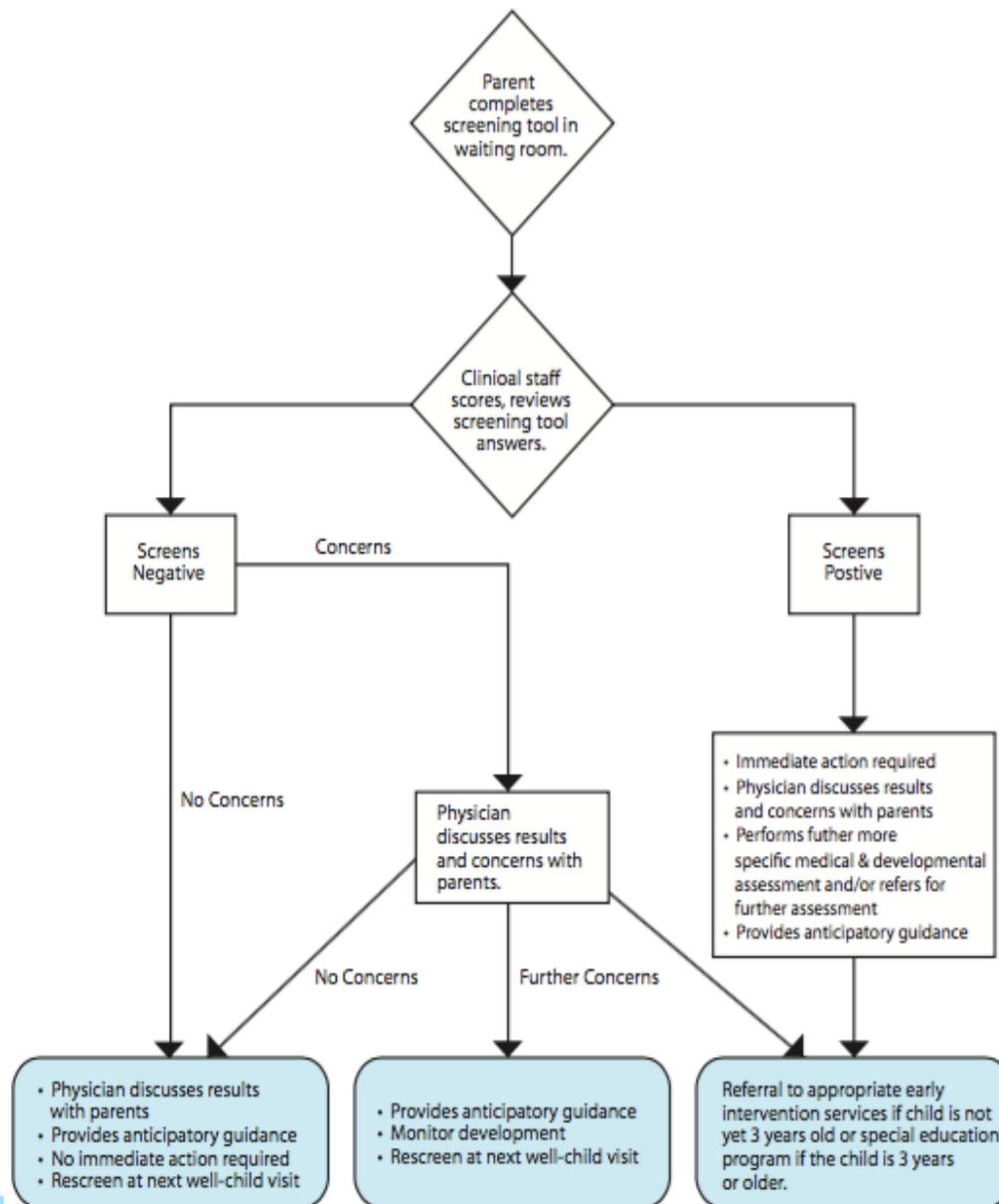
Can be scored by a nurse or physician rapidly for discussion with parents during the visit

Questions or concerns can be resolved during follow-up interview

Integrate into EMR



Pediatric Developmental Screening Flowchart



Activity	Staff	Pediatrician	Head Nurses	Office Manager	Other Nurses	Office Staff
Establish the developmental screening and referral system within the practice – agree on screening protocol and encourage support from office staff.						
Participate in training on the importance of early childhood development, early intervention, screening tools, appropriate referrals, and billing information.						
Train other staff members (e.g., nurses) in the practice who will be scoring screening tools.						
Screen children at designated well-child visit, or if there is a concern.		primary responsibility of the pediatrician				
Score screening tools.*		primary responsibility of the pediatrician				
Evaluate children's developmental status. Identify children with and at risk for developmental problems.		primary responsibility of the pediatrician				
Provide feedback to parents on the results of the screening.		primary responsibility of the pediatrician				
Advise parents on their child's development and behavior.		primary responsibility of the pediatrician				
Initiate appropriate further assessment, referrals/interventions.		primary responsibility of the pediatrician				
Recognize the manifestations of parenting stress, evaluate the risks involved and determine necessary referrals/interventions.		primary responsibility of the pediatrician				
Distribute patient materials.						
Maintain and update referral lists.						
Enter data into the chart/electronic health record and also the web-based special needs registry system, if available.						
Medical records staff: maintain record keeping system.						
Secretarial staff: copy or order tools, maintain inventory of all necessary supplies.						
Receptionists: serve as a resource for parents (e.g., explain tool, ask if the parent needs assistance in filling it						



Concerning Scores on M-CHAT

Refer for a developmental/ASD evaluation

Refer to Early Intervention

Refer for audiology evaluation (even if newborn hearing screen was normal)

If a child has an older sibling with an ASD consider referral for evaluation early



Adapting an Autism Screening Tool for Use in Refugee Patients at the Pediatric Refugee Clinic of DeKalb County, Georgia

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INTRODUCTION

- Little knowledge exists about the prevalence of Autism Spectrum Disorder (ASD) within the US immigrant and refugee population
- To screen for ASD in the refugee population, culturally appropriate ASD screening tools are needed
- The Modified Checklist for Autism in Toddlers, Revised with Follow-up (M-CHAT-R/F) is a valid and reliable tool for ASD screening that was unavailable in Nepali, a primary language spoken at the DeKalb County Pediatric Refugee Clinic in Decatur, Georgia

OBJECTIVES

- To create a culturally appropriate Nepali translation of the M-CHAT-R/F that can be used for clinical and epidemiologic purposes
- To measure caregiver understanding of concepts related to child development and ASD

METHODS

- Forward Translation: translation of original English M-CHAT-R/F into Nepali by a certified Nepali translator, followed by an independent revision of the initial version by a certified medical interpreter
- Pilot Study: 13 Nepali patients & caregivers
 - Nepali M-CHAT-R/F administered to Nepali-speaking caregivers by certified medical interpreter (n=13 caregivers)
 - 2) Caregiver understanding of each M-CHAT-R/F item elicited via standardized questions during a qualitative interview (n=10 caregivers)
- Mid-point & Final Revisions: Nepali M-CHAT-R/F underwent two revisions, based upon medical interpreter expertise and consensus among caregivers regarding clarity of translation
- Transcription Analysis: Qualitative interviews identified and subsequently reviewed by ASD expert to determine extent of caregiver 'understanding' of each M-CHAT-R/F item

TABLE 1: Characteristics of refugee children and caregivers in the study population

Characteristic	%
Age (months)	
Mean (Range)	21.9 (17 – 26)
Sex	
Male (5)	38.5%
Female (8)	61.53%
Time Lived in US (months)	
0 – 10 months (3)	23.0%
11 – 20 months (5)	38.5%
21 – 30 months (5)	38.5%
CAREGIVER EDUCATION LEVEL	
Up to 10 th grade (7)	58.3%
11 th – 12 th grade (4)	25.0%
Graduate School (2)	16.7%
Administration Method	
Read aloud by interpreter (9)	69.2%
Parent read (4)	30.8%
CAREGIVER UNDERSTANDING OF M-CHAT-R/F	
"Poor understanding" of at least one M-CHAT-R/F item (8)	80%
CAREGIVER UNDERSTANDING OF SPECIFIC TERMINOLOGY	
"Child Development" (10)	77.0%
"Autism" (3)	23.0%

Table 2: Caregiver responses to M-CHAT-R/F items (concerning for ASD, unconcerning for ASD) and Caregiver understanding of M-CHAT-R/F item (n=10 caregivers, 190 item responses)

	%
M-CHAT-R item understood by Caregiver (173)	91%
Among M-CHAT-R items NOT understood by Caregivers (17):	
Concerning responses (3)	18%
Unconcerning response (14)	82%
Among concerning responses (7):	
Caregiver understood item (4)	57%
Caregiver did NOT understand (3)	43%
After follow-up of concerning responses, positive M-CHAT-R/F (0)	0%

Table 3: Revisions to Nepali M-CHAT-R/F

Original	Reason for Change(s)
Introduction: Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no.	The term "behavior" may not be understood by caregivers with low literacy level. The word was changed so that the sentence reads: "If you have seen your child do the things below a few times, but he or she does not usually do it, then please answer no."
Question 1: If you point to something across the room, does your child look at it?	The Nepali word for "something" may be interpreted by those from rural regions as "cattle." The word was changed to a more generic word for "thing" that will be more universally understood
Question 5: Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?)	The word "unusual" was found to be an unfamiliar word for many Nepali caregivers. The word was changed to mean "strange" or "odd."
Question 17: Does your child try to get you to watch him or her? (For example, does your child look at you for praise, or say "look" or "watch me"?)	The translation of this question (including the example) was found to be quite long, and was shortened for ease of translation.

SUMMARY AND CONCLUSIONS

- The translation process is time-intensive, requiring multiple revisions; however, this process is necessary to produce a culturally appropriate & version, and to improve caregiver's understanding (see Table 3)
- Almost all caregivers (80%) had poor understanding of at least one M-CHAT-R/F item
- Two of the most frequently poorly understood M-CHAT-R/F items (Q1 & Q5) required revisions to produce a more easily understood version of the M-CHAT-R/F
- Given the % of responses in which a caregiver lacked understanding of the question, all positive responses should prompt a translated M-CHAT-R/F Follow Up questionnaire, and negative responses should be interpreted with caution in the context of the child

IMPLICATIONS

- The Nepali M-CHAT-R/F will facilitate ASD screening in Nepali refugee children; the Nepali follow-up screener is key for improving specificity
- Providers caring for refugee families should educate caregivers on typical child development, as well as ASD & other developmental conditions
- We recommend that providers identify community & clinical resources for refugee children that screen positive for ASD or other developmental delays



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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

National Center on Birth Defects and Developmental Disabilities



What is your Role

Developing community partnerships

Building a strong foundation

Carrying out well defined and organized physician outreach

Clearly defining the referral and follow-up processes

Making parent education a priority

Organizing community training efforts



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What We've Learned Through Evaluation

- Through pre- and post- training evaluations and 3-month follow-up findings, the PPI training worked.
- Participating providers are now...
 - ...more comfortable introducing small changes in their practices;
 - ...doing standardized screening;
 - ...using more open-ended, probing questions & learning more of patient's/families needs;
 - ...are more familiar with community resources available ; and
 - ...are referring patients to these resources more often – all things emphasized during the training.



Highlights and Other
Enduring PPI
Materials

*New Jersey Pediatrics Special Edition
(Fall 2014)*

<http://mazdigital.com/webreader/16537>

New Jersey Pediatrics Special Edition II

<http://mazdigital.com/webreader/29535>



QUESTIONS?



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Acknowledgements



This training is made possible by a grant from the State of New Jersey Department of Children and Families Dr. Allison Blake, Commissioner

The New Jersey Chapter, American Academy of Pediatrics would like to thank the following for contributing their expertise and time in developing this training materials:

Colleen Kraft, MD, FAAP
Manuel Jimenez, MD, MS
Steven Kairys, MD, MPH, FAAP
Elizabeth "Sooze" Hodgson, MD

Suzanne Sawyer, MSN
David J Schonfeld, MD, FAAP
Robert Like, MD, MS
AAP, Illinois Chapter

