# AAP ZIKA ECHO (EXTENSION FOR COMMUNITY HEALTHCARE OUTCOMES)





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### Communicating with Families Affected by Zika Virus Syndrome

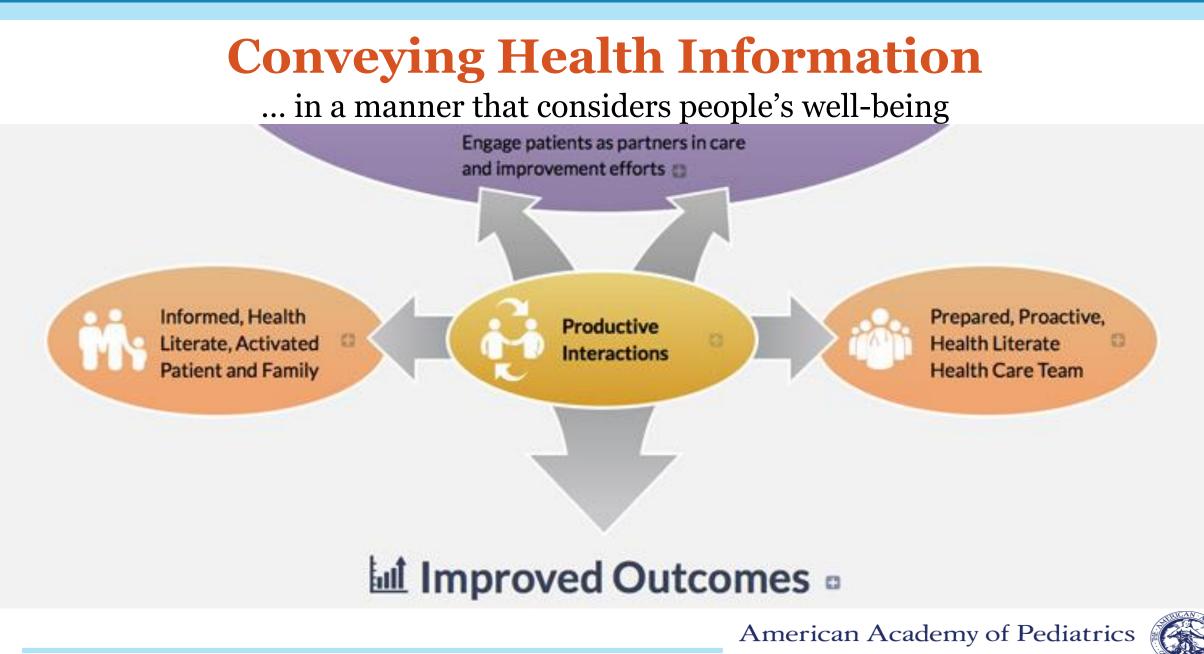
Presented February 27, 2018



### A Provider should....

- Be up to date with the latest information and guidance on Zika virus and its potential consequences.
- Get acquainted with the medical neighborhood of the family
- Get acquainted with available services and support / referral systems for people and their families affected by Zika virus infection during pregnancy and/or microcephaly.





Source: https://health.gov/communication/

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## **Supportive Communication Tips**

Location/Setting:

- Calm and quiet place to talk.
- Minimized outside distractions.
- Private and confidential space.
- Non-hurried atmosphere.



# **Supportive Communication Tips, cont'd.**

- Provide information in a way that people can understand keep it simple.
- Respect the families' culture, age, and gender.
- Honestly address family members' concerns.
  - Ex: "I don't know, but I will try to find out for you and will let you know as new information becomes available"
- Let them know you are listening and make sure you understand what is being said (reiterate/echo what is being said)
- Acknowledge the families' strengths.
- Encourage family members to write information down and/or offer to share resources after the visit.
- Allow for silence.
- Respect the families' right to make their own decisions.



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## **Supportive Communication**

#### Do:

- Allow time for someone's story (i.e. avoid looking at your watch or speaking too rapidly).
- Remember you won't solve all the person's problems.
- Avoid pressuring families for information or their story.
- Avoid blaming the woman for becoming pregnant
- Avoid making things up or giving false promises/reassurances.
- Stay focused on that family (i.e. avoid telling your or someone else's story).
- Remain non-judgmental about actions and feelings.





### **Common Reactions to Difficult News**

- Irritability, anger
- Guilt, shame
- Insomnia, nightmares
- Physical symptoms (shaking, headaches, feeling very tired, loss of appetite, aches and pains) without an organic cause
- Crying, sadness, depressed mood, grief
- Excessive worries, anxiety, fear
- Unhealthy behaviors



"I'm afraid Mr. Bickles has some bad news."



Some Patients will Suffer from Serious Psychological Distress...

Unless you are trained to assess and manage severe symptoms of distress, you should refer people with severe symptoms of distress to specialized care.





# **Other causes of distress**

- Always ask about any other needs or concerns the person may have.
- Do not presume that Zika and its possible consequences are the family's main worry. Other stressors may include:
  - Financial
  - Psychosocial
  - Family
  - Other health problems
- Link families to the relevant services and supports to address these needs and concerns.





## **Encourage Positive Coping Strategies**

#### **Reiterate the importance of families to:**

- Rest
- Eat regular nutritious meals and drink water
- Talk and spend time with family and friends
- Discuss problems with someone they trust
- Relax (walk, sing, pray)
- Exercise

#### **Discourage families from:**

- Using drugs and alcohol
- Sleeping all day
- Isolation
- Neglecting basic personal hygiene
- Violence

Source: <a href="http://apps.who.int/iris/bitstream/10665/204492/1/WHO\_ZIKV\_MOC\_16.6\_eng.pdf?ua=1">http://apps.who.int/iris/bitstream/10665/204492/1/WHO\_ZIKV\_MOC\_16.6\_eng.pdf?ua=1</a>



### **Advice for Parents**

# For parents of children <u>with</u> both microcephaly and neurological complications (e.g. developmental disorders, epilepsy):

- Help the parents become aware of their child's positive characteristics and build confidence in caring for the child.
- Model a positive and caring attitude towards the child.
- Explain that the child's health problems are not the mother's fault and, if relevant, are not related to sins, witchcraft, or other things.
- Promote child development.
- Remind parents that all children have the ability to learn and develop skills by engaging in everyday activities.



### Advice for Parents, cont'd.

- Refer children for further assessment and management of health complications, as needed
- Provide information on community-based rehabilitation and social services.
- Support the parents to overcome barriers preventing recommended care and services for the infant.
- Promote adult self-care: activities, social development, networking.
- Promote and protect the human rights of the child and family.



### Advice for Parents, cont'd.

# For parents of children with microcephaly <u>without</u> evident neurological complications

- Recognize the baby's positive characteristics.
- Help parents build confidence in caring for the baby.
- Remind the parents that many children with microcephaly can have normal development.
- Model a positive and caring attitude towards the child with microcephaly.
- Counsel on breastfeeding, if necessary.



### Advice for Parents, cont'd.

- Ensure parents are connected to support sources such as family and community.
- Emphasize the importance of play and communication activities for proper development throughout childhood.
- If the mother or primary caregiver presents significant psychological distress:
  - Identify if time off from work is needed
  - Help identify a person who can assist with taking care of the baby.
- Offer further assessment or follow up care, if needed.



#### **Resources**

#### AAP Zika Virus: Psychosocial Support Videos and Handouts

For clinicians: "Zika: Ten Tips for Pediatricians Supporting Families" For families: "Pediatrician Advice for Families: Responding to your Concerns about Zika" (English/Spanish)

www.aap.org/zika

#### World Health Organization (WHO)

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of Zika virus: Interim guidance for health-care providers

http://www.who.int/csr/resources/publications/zika/psychosocialsupport/en/

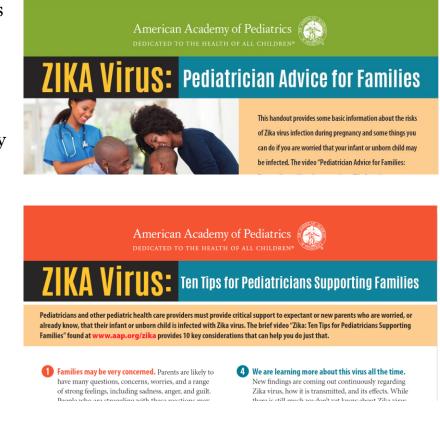
#### Substance Abuse and Mental Health Services Administration (SAMHSA)

Behavioral health resources on Zika virus

www.samhsa.gov/dtac/zika

#### **Psychological First Aid for Parents and Children:**

<u>https://sowkweb.usc.edu/download/about/centers-affiliations/ncscb-psychological-first-aid-parents</u>







### **Resources, continued**

SAMSHA, Behavioral Health Resources on Zika

http://www.samhsa.gov/dtac/zika

#### ASPR, Promoting Stress Management for Pregnant Women during the Zika Virus Disease Outbreak

http://www.phe.gov/Preparedness/planning/abc/Pages/zika-stress.aspx

Family Voices
www.familyvoices.org

**March of Dimes** http://www.marchofdimes.org/complications/zika-virus-and-pregnancy.aspx

#### **Center for Parent Information and Resources**

http://www.parentcenterhub.org/find-your-center/

National Center for Family and Professional Partnerships

http://www.fv-ncfpp.org/activities/zika-resources/



### **Resources, continued**

#### **Puerto Rico Specific**

#### Apoyo a Padres de Ninos con Impedimentos (APNI)

http://www.apnipr.org

#### **Puerto Rico Department of Health**

http://www.salud.gov.pr/Sobre-tu-Salud/Pages/Embarazadas.aspx

#### La Leche League, Puerto Rico

http://www.llli.org/puertorico.html

#### AAP Bright Futures; Spanish

https://brightfutures.aap.org/families/Pages/Resources-for-Families.aspx (note: the Spanish version has not been updated)

