

# Who Are The Medically Fragile Children In Our Midst?

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# Outline

- Defining the 'medically fragile child'
- Defining 'neglect'
- Maltreatment and the fragile child
- How we can help
- The role of Child Protective Services (CPS)

# What is a medically fragile child?

- A child who has a
  - Physical disability
  - Chronic disease
  - Developmental disorder
- Numbers have tripled
- 10-15% of children

# What is a medically fragile child?

- A child who
  - Has multiple significant health problems
  - Has a single major, chronic health problem
  - Has one or more manageable conditions that are not managed well
  - Has sustained a debilitating injury

Child with  
chronic disease

Medically  
Fragile  
Child

Environmental  
Factors

Child with  
biological  
problem

Medically  
Fragile  
Child

# Degree of Fragility Depends On...

- Biological problem
- Child's attitudes and behavior
- Environmental factors
  - Family
  - School
  - Medical care

- Family

- Maternal education and age
- Presence of father
- Financial security
- Family stability
- Level of involvement of parent with therapy
- Attitude of parent



How do we identify children at risk?

# What is Neglect?

- Failure to provide necessary care
  - Focus on caregiver
  - Punitive
- Failure to receive necessary care
  - Child's basic needs not met
  - Multiple people, entities, circumstances may be responsible

# Medical Neglect

- Child is not receiving necessary medical/dental care
  - Missed appointments
  - Nonadherence to therapy
  - Delay in seeking medical attention
  - Inadequate primary care/immunizations

# Medical Neglect

- Lack of health care puts child at risk of harm
- Therapy is beneficial
- Gains outweigh risks
- Access to care is available, but not used
- Caregiver understands treatment recommendations

# Ecological Model of Neglect

- Multifactorial etiology
- Characteristics and conditions of
  - Caregiver
  - Child
  - Family
  - Community
  - Culture/society

# Risk Factors for Neglect

- Child
  - Low birth weight
  - Prematurity
  - Chronic disabilities
- Caregiver
  - Substance abuse
  - Mental health
  - Cognitive delay
  - Poor problem solving skills
- Family
  - Problems in parent-child relationship
  - Poor parenting skills
  - Social isolation
  - DV
  - High stress (unemployment, poverty, etc)

# Risk Factors for Neglect

- Community
  - Few resources
  - Poverty
  - Poor access to health care
  - High drug availability and use
- Societal
  - Poverty
  - Limited access to health care
  - Under funded child welfare system
  - Inadequate educational system

# Case Example

- 11 mo female found in suburban home when 911 was called for mother having seizure.





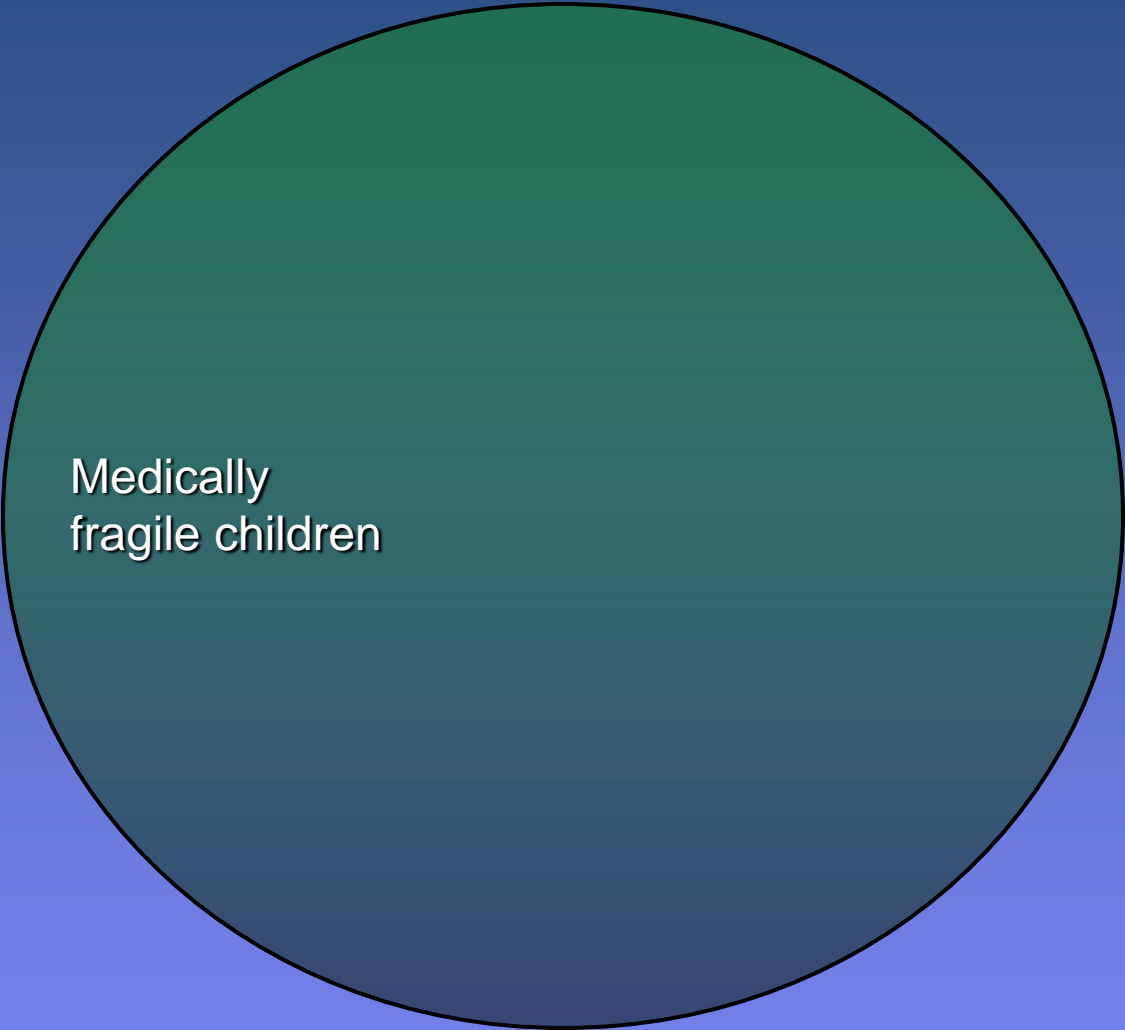
# Types of Neglect

Physical

Emotional

Educational

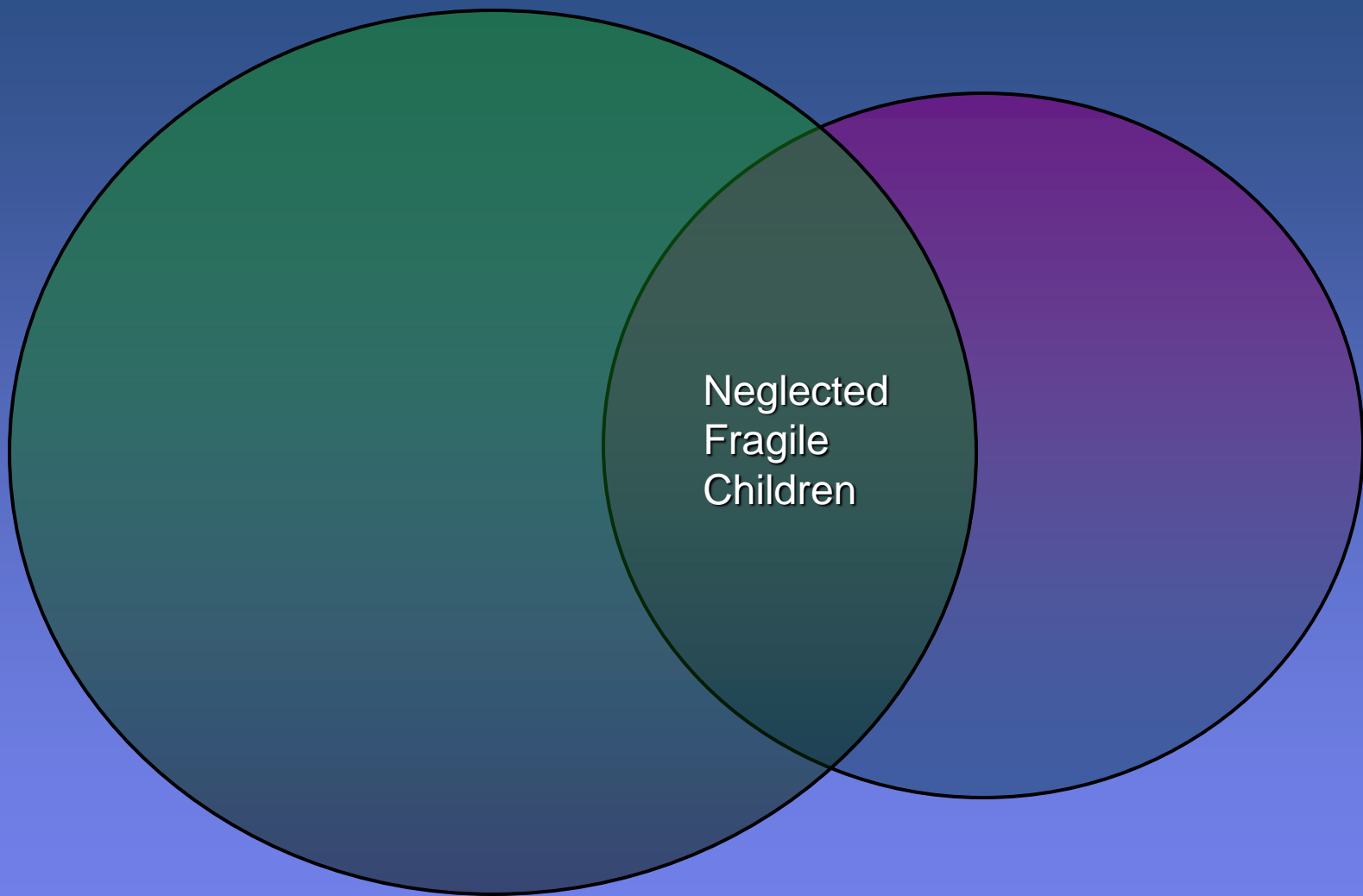
Medical



Medically  
fragile children



Neglected Children



Neglected  
Fragile  
Children

# Maltreatment and the Medically Fragile Child

- Fragile child is at risk for
  - Neglect
    - Demanding medical needs
    - Same risk factors contributing to fragility
      - Caregiver AODA
      - Poor access to health care/prenatal care
      - Trauma (from DV, abuse)
      - Poverty
  - Abuse
- A neglected child is at risk for becoming fragile
  - Poor caregiver compliance
  - Poor caregiver supervision

# How Can We Help These Fragile Children?

- Screen for risk factors of neglect
- Search for the underlying cause
- Communicate with medical provider(s)
- Help parent obtain additional resources
  - Educate parent
  - Provide community referrals
  - Connect with other parents

# How does Child Protective Service fit in?

- A means to an end
- A “last resort”
- Should NOT be avoided if necessary
- Should be helpful, not punitive
- Provides many resources
- Refer at any time if child not safe

Consider all potential neglect cases as possible CPS referrals.



# Documentation is the key

- Painful now, but it pays off later
- If it isn't documented, it didn't happen
- Written notes are far better than memory

# What's Causing The Noncompliance?

# Lack of Knowledge

- Discuss and (document) the problem:
  - The illness (in lay terms)
  - The noncompliance issues (be specific)
  - Why compliance is important

# Lack of Knowledge

- Discuss and (document) the risks and harm
  - Past and future
  - Be very specific
  - Short and long term consequences

# Other Potential Causes

- Caretaker does not believe there is a problem
- Cultural and/or religious issues
- Insurance, transportation, etc.
- Learning disability of caretaker
- Mental health issues
- Distrust of health system

# The Practical Approach

- Be creative in working with family
- Assume parent wants to comply
- Ask the parent what would be needed to have compliance?
- Listen to the family objections
- Consider the larger community for support

# Intervention

- Keep track of how you've tried to intervene:
  - Accommodated scheduling restrictions
  - Provided insurance assistance
  - Educated parent (repeatedly)
  - Public health nurse visits
  - Collaboration with school or BCW
- Contract

# Why is it so hard for us?

- Explain a complicated process
- Lack physical findings of harm
- Communicate urgency about a chronic process



There is no clear definition of  
neglect.

“I don’t know what it is, but I know it  
when I see it.”

Justice Potter Stewart, defining pornography for Supreme Court

But why is it REALLY so  
hard?

It takes so much TIME!!!

# Making a CPS referral

- Describe the illness
- Discuss the noncompliance issues (be specific)
- Describe why compliance is important
- Describe harm that has occurred from parental action/inaction

# Making a CPS referral

- Describe future risk/harm if noncompliance continues
- Describe the cause (if known), or what ISN'T the cause
- Describe what you've done to try to help
- Discuss results of your interventions

# Stay Involved...

- Continue to monitor situation
- Advocate for child
- Strengthen relationship with parent
- Keep documenting your findings!