

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.



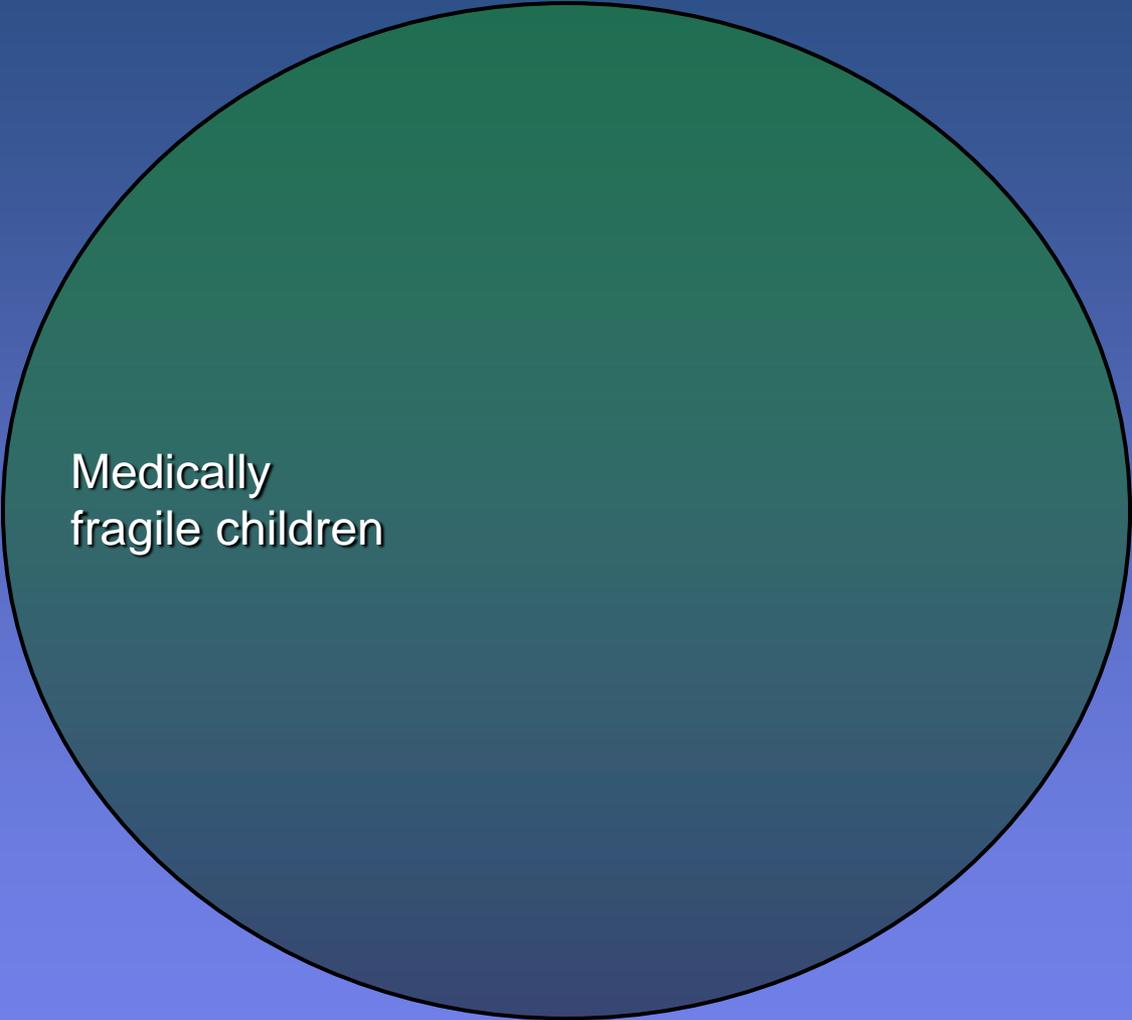
Types of Neglect

Physical

Emotional

Educational

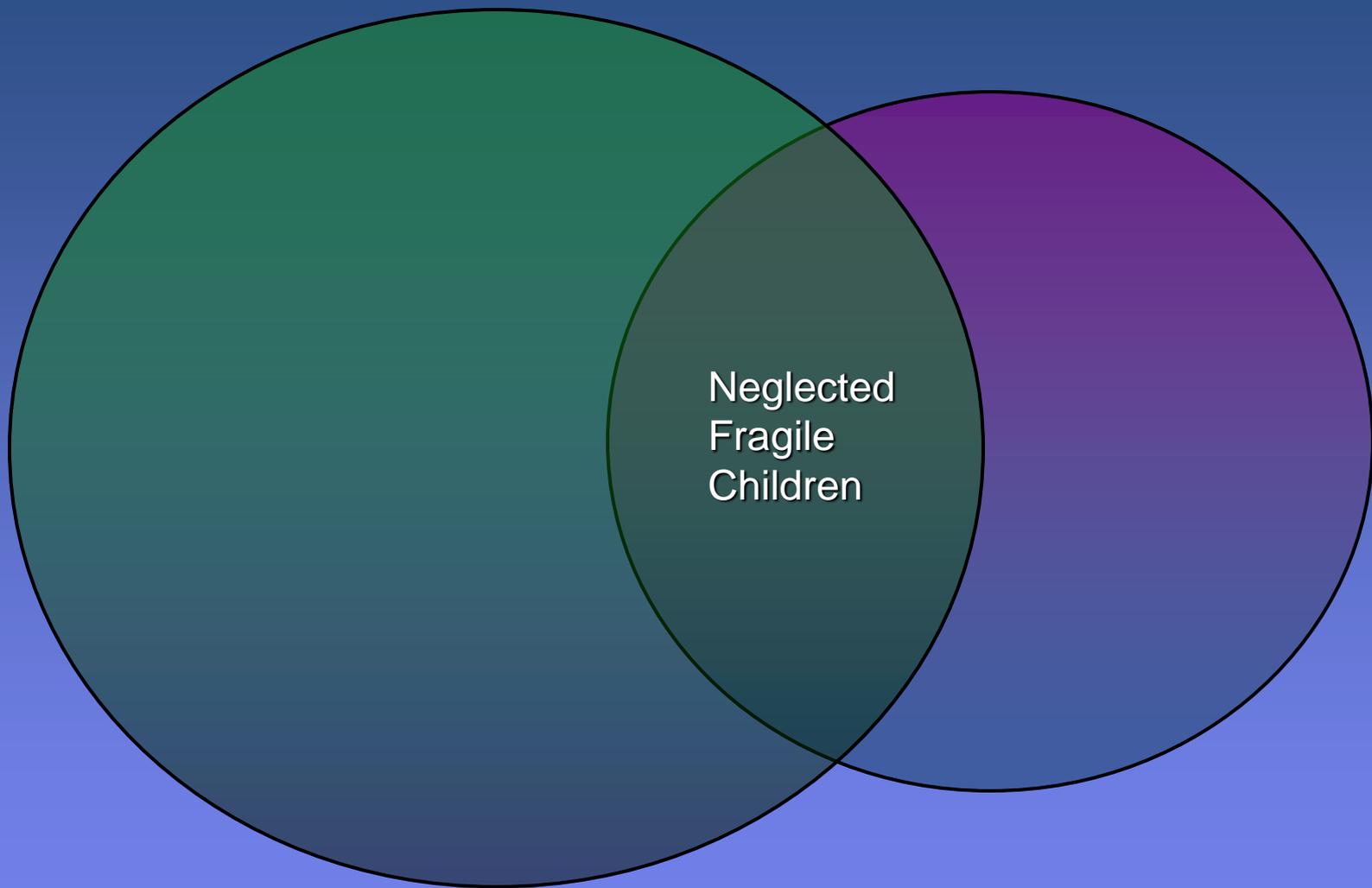
Medical



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!