

Delivering Difficult News to Families

Sarojini Budden M.D. FRCP (C) FAAP
Oregon Health and Sciences University

&

Pediatric Development Program
Neonatal Follow up Clinic
Legacy Emanuel Children' Hospital
Portland, Oregon

Define Children with Special Health Needs

“Children who have or are at risk for chronic physical, developmental, behavioral and emotional conditions which require health and related services in type and amount not usually required by children”

Continuum of specialized services these children may need

- ❖ Medical and Nursing
- ❖ Therapeutic
- ❖ Educational
- ❖ Family support and social services
- ❖ Child care
- ❖ Early intervention
- ❖ Special Education
- ❖ Medical equipment
- ❖ Transportation
- ❖ Financial

Diagnostic considerations before delivering difficult news

- ❖ Is this a progressive condition
- ❖ Is this a genetic problem
- ❖ Is this a static condition
- ❖ Is there therapy /treatment
- ❖ Is this a developmental norm which might improve

Delivering Difficult News

“There is no one way”

- ❖ Family may be prepared for bad news
- ❖ Family may have come to be reassured
- ❖ Diagnosis may come as a shock
- ❖ Family may need information as to why they should be concerned
- ❖ Parents may be under pressure from family or the legal system but are not interested
- ❖ Family may have developmental disabilities and may not comprehend

Effective communication

Verbal and non-verbal

- ❖ Develop a trusting relationship
- ❖ Remember to introduce yourself with a hand shake and address parents by name
- ❖ Avoid professional distance
- ❖ Make eye contact
- ❖ Do not appear distracted or rushed and speak slowly
- ❖ Ensure privacy

Delivering difficult news

- ❖ Show that you care and be authentic
- ❖ Recognize how giving difficult diagnosis affects you as a health professional
- ❖ Parents often relate that the direct approach was jarring
- ❖ Its best to discuss their concerns review your findings and any tests and how you came to the conclusion

Delivering difficult news

- ❖ LISTEN TO PARENTAL CONCERNS
- ❖ Become familiar with concerns
- ❖ Review and clarify all information provided
- ❖ Be thorough and **GET THE WHOLE PICTURE**
- ❖ Bring both parents and care giver into the evaluation.
- ❖ If possible include grand parents or older siblings
- ❖ If spouse not present send notes, contact person by phone or let family record on tape
- ❖ Include person when appropriate

Delivering Difficult News (continued)

- ❖ Translate medical jargon
- ❖ Be clear, concise and avoid confusing information
- ❖ Be specific and use appropriate terms
- ❖ Be aware of what the diagnosis means to this family
- ❖ Offer hopeful discussions
- ❖ Identify family support systems, (grandparents , family, church, social systems friends etc) and coping mechanisms

Delivering Difficult News (continued)

- ❖ Be sensitive to the family's response
- ❖ Reach out to parent or child with a touch
- ❖ Allow quiet time for parents to confirm what has been said; when people are in crisis they do not hear after the initial diagnosis.
- ❖ Acknowledge parents emotional response
- ❖ Acknowledge what you do not know but would be willing to find out

Delivering Difficult News (continued)

- ❖ Be open and non-judgmental
- ❖ Express empathy and concern and be supportive
- ❖ Discuss choices and options
- ❖ Respect family values strengths and competence
- ❖ Be aware of cultural differences and religious beliefs
- ❖ Give families time to accept , deny, grieve and be angry

Delivering Difficult News (continued)

- ❖ Share complete information
- ❖ Send your report
- ❖ Be honest. Consult if necessary
- ❖ Offer to follow up on medical investigations and contact family
- ❖ Incorporate developmental needs
- ❖ Discuss plan of action and who are the contact people, provide phone numbers

Delivering Difficult News (continued)

- ❖ If possible have a nurse or social worker so that follow up can be provided and help access resources and answer financial questions
- ❖ Offer to call as a follow up either to discuss with spouse or answer questions
- ❖ Provide handouts or contact number on how you can help
- ❖ Parents need to leave with some hopeful information and a feeling that you care.

Support Strategies

- ❖ Help family identify child's strengths and abilities
- ❖ Acknowledge their courage and competence
- ❖ Build a team relationship
- ❖ Build confidence ,courage and comfort
- ❖ Assist family in taking control and face challenges
- ❖ Be caring and compassionate
- ❖ Assist in making a plan.
- ❖ Acknowledge family's grief

Coping mechanisms and family strengths

- ❖ Financial
- ❖ Intact family
- ❖ Support systems, spiritual and religious beliefs
- ❖ Acknowledge cultural diversity
- ❖ Advocacy
- ❖ Accessibility to services

What does the family expect

- ❖ Understanding child's problem
- ❖ Plan of action short and long term goals
- ❖ Help them maintain control
- ❖ Assistance with finances and insurances
- ❖ Respect , honesty, integrity, compassion confidence and competence

Remember each Child has a Name PERSON FIRST! Disability Second

- ❖ Attitude
- ❖ Acceptance
- ❖ Awareness
- ❖ Avoid anger
- ❖ Avoid judgment
- ❖ Avoid pity

Provide a medical home for the child

- ❖ Follow up in a few days - a week should always be planned
- ❖ If parents request a second opinion try to identify another consultant for them and be open for them to pursue this
- ❖ Assist them with community resources / other parent groups/ and financial services as needed.

Team up with parents and other professionals involved in the child's care

