



U.S. Department of Health and Human Services
Administration for Children and Families
Office of Family Assistance

Working with Fathers of Special Needs Children

Sept. 23, 2008

2pm – 3:30pm EST

Moderator:

Nigel Vann: NRFC Director of Training & Technical Assistance

Presenters:

Greg Schell - Washington State Fathers Network (WSFN)
W.C. Hoecke - Family Information and Education, Family Connection of South Carolina





Presenters' Stories

Greg Schell, M.Ed.

Director of Washington State Fathers
Network

Kindering, Bellevue, Washington



WC Hoecke, M.Ed. ("Heck-uh")

Director of Family Information
and education at:

FamilyConnection of South
Carolina, Inc





Children with special health care needs (CSHCN)

are defined by the Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as:

“...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

- ♦ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140, 1998.



Number of Children with special health care needs Nationally

21.8 percent of households with children include at least one child with a special health care need.

Survey conducted by Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) in 2005–2006 of prevalence of CSHCN



Common characteristic of CSHCN is their need for access to medical and support services

- ◆ including prescription medications -needed by 86%
- ◆ specialty medical care-52% percent
- ◆ vision care -33%
- ◆ mental health care -25%
- ◆ specialized therapies –23%
- ◆ and medical equipment –11%
- ◆ However, 16% report at least one unmet need for services



Children and Youth with Special Health Care Needs in South Carolina

- ◆ South Carolina has a large population of CYSHCN, based on the definition of HRSA. Over a three-year time period (1999-2001), with an un-duplicated count, **387,653** children and youth were identified as having special health care needs
- ◆ That is approximately 24% of SC children.
- S.C. Budget and Control Board



Unacceptable Health Disparities

- There are sharp disparities between health and well-being indicators for white families, black and “other” families in South Carolina.
- The rates of very low birth weight, early pre-maturity, and infant mortality in black and other minority mothers are over 2.5 times those of whites.
- S.C. Budget and Control Board



Center For Fathers and Families initial round of trainings

- ◆ In the pre-test 18% of fathers self identify.
- ◆ In the post-test we see a 17% increase of fathers self identify.
- ◆ Totaling 35% of their children as having special needs.
- ◆ With additional 7% as unsure needing follow up.



Describing the issues fathers face:

Two tasks for a family with a new diagnosis.

1st- You must make a place for the disability in your family.

2nd- You must put the disability in its place.

Bill Doherty



Describing the issues fathers face:

- ◆ “Fix it” mentality
- ◆ “Saint syndrome”
 - Moms are primary receivers of information- They become the “Super Saint” who knows all about their child and the services received.
 - Fathers typically receive information second hand.
 - Fathers report difficulty having their wives being their teachers.
 - Father report they often feel relegated to being the hunter provider.



Describing the issues fathers face:

- ◆ SC Focus group on stress
 - © Question- “As a father, what about your child causes the greatest amount of stress”?
 - © Answer - “My child has been the best thing that has happened... The stress comes from dealing with the mother of my Child. How do you fix it when she cries for 2 hours or wants to spend more money than we have on the newest therapy”?



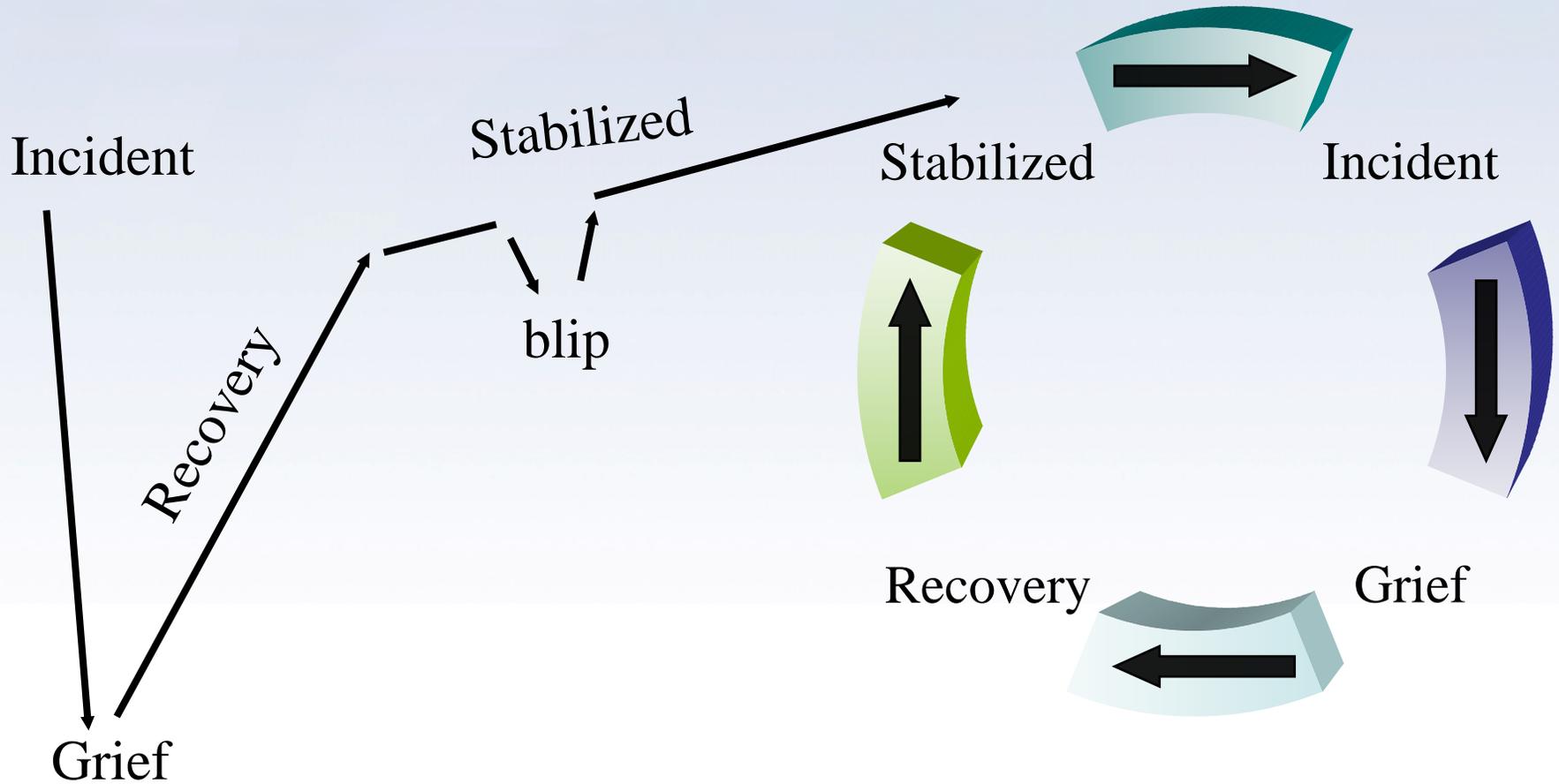
Describing the issues fathers face:

Fathers Prepare Children for Tackling Life

- ◆ **Moms tend to see the rest of the world in relation to their children**
- ◆ **Dads tend to see their children in relation to the rest of the world**
- ◆ **Mom's emphasis: Protect my child from getting hurt by the "Outside world" (strangers, lightning, disease, strange dogs)**
- ◆ **Dad's emphasis: Prepare my child to cope with the harshness of the "Outside world"**

Both are needed

Grief





Describing the issues fathers face:

Summary of findings from
IN FOCUS

The Risk and Prevention of Maltreatment of Children with Disabilities

National Information Clearinghouse
(February 2001)



Describing the issues fathers face:

- ◆ **The Risk of Maltreatment of Children with Disabilities**
 - ◎ (Crosse, Kaye & Rantnofsky, 1993) found 1.7 times more likely than children without disabilities. (They acknowledge that this study may underestimate the incidence of maltreatment)
 - ◎ (Sullivan & Knutson, 1997) found 3.4 times more likely than children without disabilities. (But not a national sampling. Omaha, Nebraska)



What is the Scope of the Problem?

- ◆ Three studies independently found that males with disabilities were more likely to be maltreated (Crosse, Kaye & Rantnofsky), (Sullivan and kutson), and (Wolcott 1997)
- ◆ Should be noted that there are more males diagnosed with disabilities.



What is the Scope of the Problem?

- ◆ Among all family members, mothers are most frequently the perpetrators of maltreatment (note: they most often are the primary caregivers)
- ◆ Sexual abuse is more often committed by males who are not relatives of the victims.



What is the Scope of the Problem?

Neglect was the most common form of maltreatment of children with disabilities



Service Delivery to Fathers

- ◆ Vicki P. Turbiville and Janet G. Marquis University of Kansas
(2001) Father participation in early education programs Topics in Early Childhood Special Education, 21(4),223-231
- ◆ *Survey to determine the preferred forms of participation of fathers, based on a random sample of 318 fathers from six states representing cultural diversity that reflecting the 1990 Census numbers.*



Service Delivery to Fathers

- ◆ Activities in which fathers could participate with their wives or partners were most likely to attract fathers.
- ◆ Outcome – Oriented strategies or activities *Consistent with literature that men are orientated toward action and problem solving.* (Tannen 1990)
- ◆ Responses suggested that decision to participate was based first on what was offered and second on how it was offered.



Fathers Participating in Various Activities

Activity	Part B Ages 3-5	Part C Birth -3
Activities for all family members; holiday parties, Picnics, and camping trips	69%	71%
Learning with men and women about planning your child's future	65%	55%
Learning with men and women about being a better parent	62%	55%
Activities for men and children only; such as "Daddy & Me" days or coaching children's teams	39%	45%
Learning with only men about being a better parent	31%	22%
Learning with only men about planning for your child's future	15%	18%
Going to men-only support groups	14%	20%



Service Deliver to Fathers

- ◆ Deborah J. Lane (2004)

Assessing the Needs of Fathers of Children with Down Syndrome

University of South Carolina School of Medicine
Department of Obstetrics & Gynecology
Division of Genetics, Genetic Counseling Program

*Limitations of the study: Small sample size,
VERY select group of fathers who participated.*



On a scale from 1-5 Preferred Format for Receiving Information

1. Written Materials (4.04)
2. Attending group meetings with fathers (only) who have children with Down syndrome (3.83)
3. Talking with someone in person (3.83)
4. Internet (3.67)



On a scale from 1-5 Preferred Format for Receiving Information

Male Professional



3.50

Female Professional



3.50

Another parent of a child
with Down syndrome



4.17

A couple raising a child
with Down syndrome



4.25



Resources

Fathers Network

fathersnetwork.org

The longest running and one of the most vibrant programs in U.S. and beyond focused on serving dads and families having children with disabilities and special health care needs.



Resources

National Fatherhood Initiative

fatherhood.org

An extensive site for wonderful materials for conducting trainings and current information. Programs include curricula for working with incarcerated dads.



Resources

National Childcare Information and Technical Assistance Center (ACF)

nccic.org/poptopics/fatherinvolvement

An extensive website with long lists of organizations to contact about all kinds of dads. Helpful articles ready to copy and use for lots of different purposes. This site is deep and very useful.



Resources

National Center on Fathers and Families

ncoff.gse.upenn.edu

This is a University of Pennsylvania associated website with a focus on expanding knowledge about dads, strengthening fathering practices, and involving dads in state and national policy discussions.



Resources

National Center for Fathering

fathers.com

A informational website for general information about dads.
Their store has unique items for dads.



Resources

Center for Family Policy & Practice

cfpp.org

This site involves fatherhood practitioners and advocates to work against domestic violence. Useful and informative resources on advocacy and prevention.



Resources

Arc of U.S.

thearc.org

The Arc is in nearly every state in the U.S. and most major cities and counties. It is devoted to promoting and improving supports and services for all people with intellectual and/or developmental disabilities. A valuable tool for brokering of resources and trainings.



Resources

Family Voices

familyvoices.org

This national network aims to achieve family centered care for all children and youth with special health care needs and/or disability.



Resources

National Initiative for Children's Healthcare Quality (NICHQ)

nichq.org

An education and research organization dedicated solely to improving the quality of healthcare provided children. Involving parents so healthcare delivery is family friendly and effective.



Thank You!

WC Hoecke “Heck-uh”

Director of Family Information and Education at FamilyConnection of South Carolina, Inc

For PREP healthy marriage workshops specifically formatted for families with children with special health care needs contact WC and Catherine Hoecke

email: wchoecke@familyconnections.org

phone: 803-252-0914

Contracting with
South Carolina Center for Fathers and Families

2711 Middleburg Drive, Ste. 115

Columbia, SC 29204

803.254.0230



Thank you!

Greg Schell

Director, Washington State Fathers Network

fathersnetwork.org

16120 NE 8th Street

Bellevue, WA 98008

Phone: 425-653-4286

Fax: 425-747-1069

Email: greg.schell@kinding.org

“WSFN is a program of Kinding”



Visit us online: www.fatherhood.gov

If you have questions that were not addressed during this Webinar, please submit them to your Federal Project Officer.

Thank you and have a great afternoon!